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What works and what needs to change: Women's perspectives on pregnancy-related epilepsy care and service improvements in the United Kingdom

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ABSTRACT

Background: Despite clinical guidelines emphasising coordinated, person-centred care for pregnant women with epilepsy, preventable maternal deaths and suboptimal care continue.
Purpose: To explore the perspectives of women with epilepsy on pregnancy-related care and their views on how to improve it.
Methods: We conducted semi-structured interviews with eleven women aged 27–39 years who were currently pregnant or had given birth within the last two years. We recruited participants from across the UK. Data were analysed using reflexive thematic analysis.
Results: Three main themes were identified. *Enabling and supportive care* was characterised by supportive healthcare professionals as anchors, proactive preconception counselling, collaboration between providers, a single coordinator of care, and access to specialist expertise. *Fragmented and inadequate care* included absence of informed decision-making, poor coordination, women being left to correct errors in their own care, encounters lacking empathy, limited epilepsy knowledge among non-specialist staff, and over-reliance on remote contact. *Priorities for service improvement* included early and direct conversations about risks (including SUDEP), respectful and balanced communication, partnership-based adult-to-adult dialogue, in-person consultations, and coordinated, holistic care that includes mental health support.
Conclusion: Despite longstanding guidelines, women with epilepsy continue to experience significant gaps between recommended standards of pregnancy care and service realities. Women describe deficits in early, proactive discussions about medication and risks, informed decision-making, and joined-up care, leaving some to perform unsupported "safety work", correcting errors and mediating between neurology, obstetric and midwifery teams. Improving care requires a commitment to holistic, person-centred support that embeds clear, respectful, two-way communication with women and across services as a core safety practice.

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1. Introduction

Epilepsy is a common chronic neurological condition in women of reproductive age, and approximately 0.3–0.8% of pregnancies occur in women with epilepsy [1]. Pregnancies in women with epilepsy are associated with higher risks for both mother and baby, including miscarriage, stillbirth, preterm birth, congenital malformations, and a five-to ten-fold increased risk of maternal mortality [2–4]. Despite these well-recognised risks, pregnant women with epilepsy frequently receive suboptimal medical care [5]. In the UK, only 4% of pregnant women experiencing severe morbidity related to epilepsy in 2013–15 received care consistent with recommended standards [6].

Optimising pregnancy outcomes for women with epilepsy depends on well-organised care across the preconception, antenatal, and postnatal periods [2,7]. Enquiries continue to report preventable epilepsy-related maternal deaths, commonly linked to gaps in assessment, communication and access to timely specialist input [4,8]. Although, guidelines emphasise appropriate preconception counselling, careful review of antiseizure medication regimens, and coherent care throughout the maternity pathway [2,9–11], a national survey of UK healthcare professionals found wide variation in timing, format and delivery of care for pregnant women with epilepsy [7].

Women with epilepsy remain poorly informed about the effects of antiseizure medications, importance of an agreed treatment plan, risk of sudden unexpected death in epilepsy (SUDEP), and other pregnancy-related complications [12–16]. They must navigate these knowledge gaps and service shortcomings in their everyday lives [17–20]. Women's experiences of epilepsy during their reproductive journey consistently reveal ongoing challenges in care, including inadequate information provision, fragmented support, and poor continuity [21,22]. They describe difficulties accessing specialist preconception counselling, and report that reproductive health discussions with neurologists and other healthcare practitioners are often absent, cursory or narrowly focused on avoiding unplanned pregnancy [22–26]. During pregnancy, women encounter inconsistent or conflicting advice and must mediate between services themselves when communication breaks down [22,27,28]. After giving birth, they feel particularly vulnerable as they continue to balance seizure management, sleep deprivation and infant care, often with limited guidance and support [17,19,22,29,30]. Alongside these service-related challenges, women may also experience a moral burden, as they balance expectations of protecting their baby and being a 'good mother' with the demands of managing their epilepsy and being a 'good patient' [17].

Research on women's experiences of epilepsy, pregnancy and reproductive health has broadly explored risk, information needs, and healthcare interactions, but few have directly focused on women's views of how to improve pregnancy-related care [22]. A recent national investigation into maternity and neonatal services in England reported several system level challenges in maternity care and concluded that listening to women matters, as they are too often "disregarded" during pregnancy and labour [31]. The NHSE's recent Maternal Care Bundle sets care standards for epilepsy in pregnancy, to be implemented across all Trusts by 2027 [32]. As services work towards implementing these standards, women's voices and lived experiences offer critical insight into where current care falls short and what changes they prioritise. This study, therefore, aims to provide a timely exploration of the views of women with epilepsy on pregnancy care and how to improve it.

2. Methods

2.1. Design

This study is part of the EpiSafe programme,[1] which aims to improve the safety and care of pregnant women with epilepsy. We adopted a qualitative approach [33,34] to explore the perspectives of women with epilepsy on pregnancy care and how to improve it. Semi-structured interviews were conducted to ensure key topics were covered across all interviews while also allowing participants to raise issues important to them.

We obtained ethical approval from Birmingham City University (ERN: 12093) and the Health Research Authority's Edgbaston Research Ethics Committee (REC reference: 24/WM/0061; IRAS ID: 333607). A patient advisory group of women with epilepsy informed the study's development and reviewed participant-facing materials. Participants were recruited from across the UK; we adopted a purposive sampling strategy to ensure inclusion of those with direct experience of epilepsy and pregnancy care [35]. Healthcare professionals (HCPs) and relevant community groups, charities, and organisations, shared the study advert in their networks. Inclusion criteria were age 18 years or over, self-reported diagnosis of epilepsy, taken antiseizure medications prior, during and/after their pregnancy, current pregnancy or pregnancy within the previous 24 months, willingness to give informed consent, and use of NHS maternity services during that pregnancy. Women who did not meet these inclusion criteria were excluded. Participants contacted the research team directly to express interest, after which they were provided with a participant information sheet. Our recruitment efforts ultimately resulted in 11 participants. Consistent with reflexive thematic analysis, the adequacy of the sample was assessed in relation to its interpretive potential in addressing the study aims [36,37].

2.2. Interviews

Based on participant preferences, interviews were conducted online via Microsoft Teams or Zoom (with just one face-to-face). Informed consent was obtained before each interview and verbally reconfirmed at the start. An interview guide with open-ended questions was used; the guide was informed by our literature review [22] and patient advisory group. Interviews were conducted between June 2024 and September 2025 by AW, a female senior researcher with extensive experience in pregnancy and epilepsy qualitative research. Interviews lasted 45–60 min, were transcribed verbatim, and imported in NVivo 12 Plus for analysis. AW assigned participant pseudonyms and redacted any potentially identifiable information.

2.3. Analysis

AC and AW completed analysis of the data using a reflexive thematic approach (RTA) [38,39], progressing through six recursive phases: familiarisation with the data, generating initial codes, organising codes into initial themes, iteratively reviewing and refining themes, and producing the final report emphasising patterns of shared meaning. Throughout the analysis, AC and AW engaged in ongoing reflection and discussion to co-construct interpretations of participant perspectives.

3. Results

3.1. Participant Characteristics

We interviewed 11 women, aged 27 to 39 years, who self-reported a range of different epilepsy or seizure types and who had lived with epilepsy from 7 to 30 years. At the time of interview, most (n = 8) were in their second or third trimester of pregnancy, and three had given birth within the past year (n = 2) or two years (n = 1). Further details of self-reported socio-demographic characteristics are summarised in Table 1 and broken down by participant in Table 2.

3.2. Themes

The analysis resulted in three main themes and 16 subthemes

[1] For more details of EpiSafe, see https://www.episafe.org.

(Table 3) relating to the perspectives of women with epilepsy on pregnancy care and their views on how to improve it. Each are presented in turn, with subthemes presented in bold.

3.2.1. Enabling and supportive care

Participants identified key elements of care they experienced as enabling and supportive across their reproductive journey. A consistent feature was the presence of **supportive healthcare professionals as anchors**. Most identified at least one HCP who provided meaningful support and guidance. Enabling care was not tied to a single professional group; participants described receiving valuable guidance from specialist consultants, midwives, and nurses. The main emphasis was on personalised support:

> *"Some [HCPs] are better at bringing things up [like pregnancy] than others. And it was only when I got a new nurse, who then was the first person to say, 'Well, okay, if this is something you want to look at then let's, we'll work that out together.'"* (Daria)
>
> *"I feel very lucky to have this specific midwife. Throughout the pregnancy, she's been great and supportive. They wrote two letters to the council to support our cause [to change to a house without stairs] …"* (Laura)

Proactive preconception counselling and clear signposting enabled women to feel prepared. Participants noted the benefits of explicit guidance on what to do once pregnant.

> "*The epilepsy team gave me a lot of advice…[T]hey told me to make sure I was registered as high-risk with the maternity unit. As soon as I did that, I got an appointment straight away, quite early in the pregnancy*." (Sarah)

Visible **collaboration between providers** contributed to women's perceptions of coherent and reliable care. Participants highlighted examples of joined–up care with effective communication between departments, where their views were respected and they were kept consistently informed.

> "*I was referred [to a specialist team] and received extra input from consultant obstetricians… They contacted [my neurologist] to make sure everything was okay…[I]t felt like a three-way conversation…*" (Claire)

Participants also valued having a **single coordinator of care**, who liaised with midwives, provided information, and remained present throughout the pregnancy journey, emphasising the importance of continuity of care.

> *"This time round, the midwives are more than aware, because [my epilepsy specialist nurse] has been in contact with them, so that's just been really brilliant."* (Kate)

Access to specialist expertise and proactive monitoring increased women's perception of safety. Being consultant-led, and having more frequent check-ins or scans, was seen for some as reassuring and evidence of being well cared for.

> *"I've seen a consultant who says at the moment we aim for a normal vaginal birth but we're going to get extra scans to see how the baby grows… It's reassuring, they know best and it means I get to see the baby more and I know everything's okay.*" (Rebecca)

For the women we spoke to, good care meant being supported to understand that looking after their own health and keeping seizures under control was central to protecting the baby.

> "*Obviously when you're pregnant your first concern is your baby, but in my mind, by looking after the mother you're also looking after the baby*." (Lucy)

Enabling and supportive care was characterised by supportive HCPs, proactive communication, anticipatory guidance for pregnancy, care coordination, and specialist expertise throughout the reproductive journey. These elements, from participants' perspectives, enhanced their confidence in managing pregnancy–related concerns alongside epilepsy and contributed to feelings of reassurance and safety.

3.2.2. Fragmented and inadequate care

Participants also described experiences of fragmented and inadequate care across their reproductive journey. A recurring concern was the **absence of informed, shared decision–making**, with women describing changes to their care, such as dose increases, being communicated as instructions rather than discussed or explained. These instances reduced women's confidence in medication safety and reinforced their need to verify clinical advice.

> *"I got a text message [from] my midwife that '[the obstetrician] would like to increase your dose by X amount.' But there wasn't like a 'are you happy with this, do you want to do this?' anything like that. That's why I phoned my neurologist to check if this a safe dose."* (Sarah)

One participant reflected that she believed power imbalances underly how she came to feel excluded from involvement in decisions about her care:

> *"I think the dynamic of power in the medical-patient relationship is very difficult…[A] conversation that was very, like, 'you are likely, you will be heavily encouraged to have a C-section' sounded to me like 'you will.' You can be very sensitive to it…"* (Sophie)

Care was often experienced as **fragmented with limited coordination** between providers leading to emotional strain on women. Some participants described how they were left to navigate multiple providers, and shoulder the burden of deciding whom to contact, whose advice to prioritise, and how to align care to maintain continuity.

> *"…[M]y experience is, it's all been quite disjointed. There doesn't seem to be a connection between the teams. They're not really talking to each other… And the midwives didn't really have that knowledge for the birth… when you're going through your birth plan what needs to be in place if you've got epilepsy."* (Hannah)
>
> *"[T]here's just so many different practitioners involved. At the moment, I'm chasing my GP to increase my medication because my epilepsy nurse has asked for it to be increased… They've not got the letter, so they're refusing to prescribe it."* (Emma)

Disjointed care created a hidden administrative workload, illustrated by this participant's describing the logistics as emotionally draining.

Table 1
Summary of Participant Socio-Demographic Characteristics.

Demographic	Years
Age	
Range	27–39
Mean	33.6
	Number of Participants (Total = 11)
Employment	
Employed	9
Full-time parent	2
Ethnicity	
White	11
Years with Epilepsy	
Range	7–30
Mean	16
Stage in Pregnancy	
2nd Trimester	3
3rd Trimester	5
Given birth < 1 years	2
Given birth < 2 years	1
Self-reported Epilepsy or Seizure Type	
Temporal lobe	3
Idiopathic	2
Generalised	1
Focal	1
Photo-sensitive	1
Unknown	1
Tonic-clonic seizures	2

Table 2
Self-Reported Socio-Demographic Characteristics by Participant.

Participant Pseudonym	Age	Stage in Pregnancy	Self-Reported Epilepsy or Seizure Type	International League Against Epilepsy Terms	Years with Epilepsy	Type of Antiseizure Medication in Pregnancy	Resides with	Occupation Group	Ethnicity	Region and Country
1 Sarah	37	3rd trimester	Temporal lobe	Focal	21	Levetiracetam & Lacosamide	Husband	Professional/ managerial	White British	London, England
2 Emma	27	2nd trimester	Idiopathic	Unknown whether focal or generalised	17	Levetiracetam & Lamotrigine	Husband & child	Fulltime Parent	White British	Northwest England
3 Claire	37	Gave birth < 1 year	Idiopathic	Unknown whether focal or generalised	16	Levetiracetam	Partner & two children	Professional/ managerial	White British	Southeast England
4 Laura	31	2nd trimester	Generalised	Generalised	15	None	Partner	Administrative/ clerical	White British	Highlands, Scotland
5 Rebecca	27	2nd trimester	Tonic clonic seizures	Unknown whether focal or generalised	7	Lamotrigine	Partner	Education/ childcare	White Scottish	Highlands, Scotland
6 Hannah	35	3rd trimester	Tonic clonic seizures	Unknown whether focal or generalised	10	Lamotrigine	Husband & child	Education/ childcare	White British	East of England
7 Rachel	39	Gave birth < 2 years	Temporal lobe	Focal	20	Levetiracetam	Husband & two children	Professional/ managerial	White British	North of England
8 Sophie	33	3rd trimester	Temporal lobe	Focal	10	Levetiracetam	Husband	Public sector	White British	London, England
9 Kate	31	3rd trimester	Unknown	Unknown	16	Lamotrigine	Husband & child	Professional/ managerial	White British	West Midlands, England
10 Daria	36	3rd trimester	Focal	Focal	15	Levetiracetam & Lamotrigine	Husband & child	Professional/ technical	White European	Southeast of Scotland
11 Lucy	37	Gave birth < 1 year	Photosensitive	Unknown whether focal or generalised	30	Levetiracetam	Husband & two children	Fulltime Parent	White British	West Midlands, England

Table 3
Themes and Subthemes.

Themes	Sub-Themes
1. Enabling and supportive care	*1.1. Supportive healthcare professionals (HCPs) as anchors* *1.2. Proactive preconception counselling and clear signposting* *1.3. Collaboration between providers* *1.4. A single coordinator of care* *1.5. Access to specialist expertise and proactive monitoring*
2. Fragmented and inadequate care	*2.1. Absence of informed, shared decision-making* *2.2. Fragmented care with limited coordination* *2.3. Women left to correct errors in their own care* *2.4. Encounters lacking empathy* *2.5. Limited knowledge about epilepsy amongst non-specialist HCPs* *2.6. Over–reliance on remote contact and lack of proactive follow–up*
3. Priorities for service improvement	*3.1. Early, direct conversations about concerns and risks* *3.2. Respectful, balanced, and non-judgmental communication* *3.3. Partnership and adult-to-adult dialogue* *3.4. In-person consultations for clarity and trust* *3.5. Coordinated, holistic care that includes mental health*

> *"The almost administrative burden of arranging the extra appointments… [S]ometimes it has felt like having a kind of, mini part-time…job…the sheer boringness and emotional toll of the logistics… [F]or me the most frustrating thing is just the time and energy spent…"* (Sophie)

Participants reported experiences of **being left to correct errors in their own care**. Despite assurances that issues had been resolved, mistakes sometimes recurred, eroding trust and leaving women feeling unheard.

> *"We'd changed some of my medications and they didn't read the letter properly, so they gave me the wrong dosage. I rang…and they said they'd fix it, but the next time it was still wrong, and again after that. You just think, listen to me." (Daria)*

Some HCP encounters were described as **lacking empathy**. A participant described an interaction in which the practitioner appeared distracted while discussing her child's unconfirmed additional health needs. She stated the experience was "*traumatising*" and felt it contributed to her feelings of distress and "*guilt*" (Claire).

Additionally, **limited knowledge about epilepsy among non–specialist HCPs** contributed to feelings that the care was inadequate. One participant described the non-specialists HCPs as being a "*bit petrified*" when learning about her epilepsy and that:

> *"[W]hen I was having seizures in hospital, I remember the look of sheer horror on the midwife's face – she hadn't got a clue of what to do."* (Rachel)

Finally, an **over–reliance on remote contact and lack of proactive follow–up** left some participants unsure about their care, highlighting poor communication and insufficient information.

> "*I haven't seen a neurologist face-to-face for quite a long time. He called asking…the same questions as before, then said, 'we'll keep an eye on you.' I thought, how, because all you do is a phone consultation once in a blue moon.*" (Laura)

These accounts demonstrate that women with epilepsy experience pregnancy-related care as fragmented, poorly coordinated, insufficiently collaborative, and, for some, at times lacking in empathy. Participants described having to assume responsibility for coordinating communication between providers, verifying treatment decisions, and monitoring the accuracy of their care. This transfer of responsibility from HCPs to women created practical and subsequently emotional burdens, impacting women's perceptions of safety and trust in their care.

3.2.3. Priorities for service improvement

Participants' reflections highlighted clear priorities for improving pregnancy-related epilepsy care. This theme sets out women's recommendations for how care could be delivered more effectively and compassionately.

Participants reported wanting HCPs to have **early, direct conversations about** their antiseizure medications use, while also addressing any **concerns and risks**.

> *"I think personally I'd rather them just ask me [if I'm taking my medication] up front. That's just me, I wouldn't be offended…it is just the way that they ask."* (Sarah)

Participants emphasised that **respectful, balanced, and non–judgmental communication** was important in these conversations. They valued balanced discussions that presented "*both sides of the coin*" and wanted information about risks to be delivered in a "*non-judgmental*" way, avoiding language that implied blame or that they might "*damage*" their baby (Hannah).

This preference also reflected a **desire for partnership and adult–to–adult dialogue**. Participants wanted honest, straightforward communication in which risk information was made explicit and plans for addressing were mutually decided. For example, regarding receiving information about SUDEP, one participant stated:

> "*It's like an adult-to-adult conversation. I think we are adults and we should just embrace certain information…[I]n my head, it's better to try to find the solution instead of sitting and crying about it.*" (Laura)

However, some felt overly direct questioning around medication adherence in pregnancy could potentially be experienced as "*patronising*":

> "*[A] direct question [about taking medication] for me, I think I would probably find that a bit patronising, but that might just be me.*" (Rachel)

There was a clear preference for **in-person consultations for clarity and trust**, which allowed opportunities for clarification and follow–up questions.

> "*I would have preferred in person [consultations] because I feel like she could have just shoved it [information] in an envelope and that was it.*" (Rebecca)

Finally, participants discussed the need for **coordinated, holistic care that includes attention to mental health**. Women report that psychological wellbeing may too often be sidelined within epilepsy and maternity care, despite the significant emotional demands of navigating pregnancy with a chronic condition.

> *"I think that [mental health] gets discounted quite a lot. So, I think that should be somehow integrated into a care plan for women and should be especially flagged."* (Emma)

This priority reflects a desire for care that addresses the whole person, rather than treating epilepsy and pregnancy as separate clinical concerns. Participants described good care during pregnancy as involving communication that was timely, direct but respectful, and balanced. They emphasized the importance of coordinated care that positions women as partners in decision making rather than as passive recipients of risk information.

4. Discussion

This study explored the views of women with epilepsy on pregnancy-related care and how to improve it. Collectively, findings highlight a continuing gap between clinical guidelines in the UK for coordinated, person-centred epilepsy care in pregnancy [2,11,40] and the realities of women's experiences with health services. Across themes, women's accounts suggest that good pregnancy-related epilepsy care is achievable and is characterised by early and proactive conversations about reproductive concerns, access to specialist expertise, respectful and balanced communication, informed decision making and coordinated, holistic care. In contrast, fragmented and inadequate care frequently transfers responsibility for treatment coordination and safety monitoring onto women themselves. These findings highlight how the organisation and coordination of care can shape women's safety and confidence in managing pregnancy alongside epilepsy. They suggest that current care may continue to fall short of the recent standards set by NHSE's new dedicated Maternal Care Bundle [32], with women reporting fragmented care, delayed specialist input, and lack of coordinated follow-up. However, these findings should be interpreted within the context of the UK National Health Service, which is funded primarily through general taxation and is largely free at the point of use. Women's experiences may vary in healthcare systems with different funding, access, and service delivery arrangements.

Women's descriptions of good care closely reflect existing national guidance in the UK, particularly recommendations for early specialist involvement, proactive preconception counselling and coordinated multidisciplinary care [2,11,32,40]. They also align with previous work on preconception and pregnancy experiences of women with epilepsy, emphasising the importance of specialist advice, continuity of care, informed decision-making around antiseizure medication, and the provision of timely, accessible information across the reproductive pathway [18–20,23,24,26,29]. Despite this long-standing guidance, our findings suggest a persistent inertia in translating policy into consistent, positive care experiences. Gaps in communication, coordination, and access to specialist care continue to shape women's care experiences in ways that remain similar to those found a decade ago [21,22]. Recent work also suggests that women's experiences of care can affect whether they trust the health information they receive [26]. In the context of the UK, our findings contribute up-to-date, nuanced evidence that women continue to experience avoidable gaps in care despite the publication of updated clinical guidelines.

The priorities for care identified by women align with barriers reported in a recent systematic review of HCPs providing care for pregnant women with epilepsy [41]. The review found that while HCPs recognised the importance of communicating key information, barriers included knowledge not being shared between specialties, discomfort discussing sensitive reproductive issues, and limited time and access to guidelines [41]. Furthermore, only a third of UK hospitals have joint obstetric-neurology clinics [7]. HCP-reported barriers to providing coordinated care correlate with women's descriptions of the lived consequences, including navigating multiple care providers, having to correct errors in their care, and bearing the practical and emotional toll of disjointed services. Our study contributes to evidence that pregnant women with long-term conditions experience a "substantial burden of responsibility to maintain communication with their care team, often feeling vulnerable, and patronised" [42]: p.1. In the context of epilepsy, our study suggests this burden can also be understood as a form of 'safety work,' particularly in relation to the labour involved with correcting errors or miscommunication in relation to medication.

A key finding from women's accounts concerns the relationship between professional care and self-management. Women wanted specialist expertise and to be partners in their care; they valued expert guidance and proactive monitoring delivered respectfully. They preferred in-person consultations for dialogue, clarification and trust building, which facilitate complex, sensitive discussions of seizure risk and antiseizure medication in pregnancy. For women with epilepsy, good care is not a choice between clinical oversight and patient autonomy; it requires time, skilled communication, and genuine informed decision-making. Findings demonstrate that communication is not merely one component of good care, it is both a key deficit in current practice and the central solution.

A limitation of this study is the absence of voices of women from ethnic minoritised communities. We proactively made targeted efforts to recruit participants from a range of ethnic backgrounds through

collaborations with HCPs and community groups working with pregnant women from minoritised communities. However, these HCPs and community groups did not identify any women with epilepsy. Additionally, we did not capture the experiences of those under 18, where care is already often complicated by the transition between paediatric and adult services, and this group may be further disadvantaged.

A strength of this study is that it recruited participants from a wide geographical area across the United Kingdom. Although the sample was small, in RTA sample adequacy is determined by the richness and relevance of the data (information power) rather than a pre-determined number of participant numbers or data saturation [36,43]. This focused interview approach generated sufficiently dense material for deep interpretive analysis. Another key strength is the focused design, in which women were explicitly invited to reflect on what constituted good care versus inadequate care, and to offer recommendations for how maternity services can better support women with epilepsy. These findings are internationally relevant, as women with epilepsy face similar care needs across health systems [19,27,30].

Based on findings, we tentatively suggest several recommendations for consideration in future service development. NHS England's Maternal Care Bundle may address some gaps identified in this study by requiring access to local epilepsy in pregnancy teams and referral to maternal medicine network multidisciplinary teams for women with more complex needs [32]. However, as our findings show, policy initiatives and guideline recommendations do not always translate into practice. Furthermore, our findings highlight coordination and communication-related gaps that will require additional attention in service development. For instance, services could explore assigning a named coordinator for pregnant women with epilepsy to liaise between neurology, obstetrics, and midwifery teams. Treatment decisions, including dose changes before, during and immediately after pregnancy, should ideally be agreed upon through collaborative discussions rather than be communicated via text messages that do not provide opportunity for dialogue. Continued barriers to providing routine, proactive preconception counselling, that include vital discussions about SUDEP risk, warrant further exploration [4]. Ensuring midwives feel adequately knowledgeable and confident to support pregnant women with epilepsy, including what to do in the event of a seizure is important. And finally, exploring how mental health support could be integrated into epilepsy and maternity care pathways is warranted. With all these potential approaches, further evaluation is needed to assess feasibility and effectiveness.

Future research should focus on co-designing interventions with women with epilepsy and with HCPs involved in maternity and epilepsy care. These interventions should address the specific issues highlighted by women: clear and consistent communication, access to specialist input, and a coordinated, joined-up care pathway. Further research is needed to include the perspectives of women with epilepsy from ethnic minoritised communities to explore whether they feel informed, listened to and safe when using maternity services.

5. Conclusion

This study explored women with epilepsy's perspectives on pregnancy-related care and how to improve it. Three main themes emerged: enabling and supportive care, fragmented and inadequate care, and priorities for service improvement. While some women receive supportive care with access to specialist expertise, many continue to experience fragmented services, exclusion from decisions, and the burden of coordinating their own care. Epilepsy care remains inadequately prioritised: despite longstanding guidelines, the policy-practice gap persists. Women's views highlight that communication is not merely one component of good care but rather a primary deficit and a central solution. Moving beyond ongoing inertia requires a commitment to services that both manage clinical risk and provide coordinated, holistic, person-centred support before, during and after pregnancy..

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Declaration of competing interest

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