



Review



Barriers and facilitators to healthcare practitioners providing care for pregnant women with epilepsy: A systematic review and narrative synthesis

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1. Introduction

Epilepsy is one of the most common long term conditions affecting women of child-bearing age, impacting approximately 1 in 200 (0.5%) pregnancies in the UK [1]. Global figures of the prevalence of epilepsy in pregnancy are difficult to estimate, however it is suggested that between 0.3 and 0.8% of all gestations are impacted [2]. Neurological conditions are the fourth highest cause of all maternal deaths in the UK and epilepsy related deaths show no significant sign of decreasing [3]. The risk of mortality and morbidity to women with epilepsy and their babies are greater than for women without epilepsy [3]. For the pregnant woman these risks include miscarriage, stillbirth, preterm birth and maternal death [4]. For babies born to women with epilepsy these include an increased risk of congenital conditions, admission to hospital and neonatal or infant death [4]. Some risk is directly due to seizures, which may increase in frequency for some women with epilepsy when they become pregnant [5]. This can result in accidents causing injuries [5,6] and hypoxia of the fetus [7]. Additional risk of harm relates to the use of anti-epilepsy drugs (AEDs), prescribed to 80% of pregnant women with epilepsy [4]. There is further risk when women with epilepsy are concerned about taking AEDs in pregnancy and stop taking them [8–10]. Uncontrolled seizures and sudden unexpected death in epilepsy (SUDEP) are real concerns.

There are clear guidelines for caring for pregnant women with epilepsy to best mitigate and address risks of harm [11,12]. These include: referral to an epilepsy specialist team, shared information between epilepsy, obstetric and primary care teams, counselling about the risks versus the benefits of medication [13], regular risk assessment

(including factors such as sleep deprivation, stress, medicine adherence, seizure type and frequency), postpartum safety advice (e.g., breastfeeding, seizure deterioration) [11], access to care within two weeks, urgent referral for nocturnal seizures, action where women discontinue medication, folic acid prescription [14] and ensuring risk awareness, assessment and minimisation of failure to take AEDs [1].

Despite the risks and clear guidelines to minimise these, a national surveillance system in the UK, “Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries” (MBRRACE) [3], examining the cause of maternal deaths, stillbirths and infant deaths in the UK, found many care failures. This included lack of specialist neurologist or epilepsy care, an absence of pre-pregnancy counselling, or, when pregnancy counselling did take place, it did not always include information about SUDEP or the importance of medicine adherence and inconsistent AED blood monitoring [15]. Evidence of suboptimal care suggests that any efforts to reduce maternal and perinatal mortality and morbidity requires improvement in services and care offered to pregnant women with epilepsy [16,17]. To establish the reasons for non-adherence with epilepsy care guidelines, we conducted a systematic search and narrative synthesis of the literature.

1.1. Aim

Identify barriers and facilitators to healthcare practitioners providing recommended care to pregnant women with epilepsy.

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2. Methods

Following Preferred Reporting System for Systematic Reviews and Meta-Analyses (PRISMA) reporting framework [18], we conducted a systematic search and a narrative synthesis [19]. After a scoping review to identify subject headings and relevant search terms, and with the support of a subject specialist librarian, we conducted database searches of ASSIA, CINAHL complete, MEDLINE, SCOPUS and the Cochrane library of systematic reviews. We completed forward and backwards citation searches of all included papers by using the google scholar function “cited” and by reviewing reference lists within papers. Our search terms were:

Barrier* OR obstacle* OR challenge* OR difficult* OR issue* OR problem* OR facilitator* OR enabler* OR lever* OR determinant*
 AND
 Epilep* OR convulsion* OR seizure* OR fit*
 AND
 Pregnan* OR prenatal OR antenatal OR perinatal or maternal
 AND
 “health* worker” OR “healthcare practitioner” or midwi* or obstetric* or neurology* or doctor or nurse

Our inclusion criteria were empirical, peer reviewed research from any country relating to barriers and facilitators of practitioners managing pregnant women with epilepsy. We captured papers published between 2013 to November 2023, in the English language. We included all practitioner groups as barriers to one group may be transferrable to another. We also included papers that reported pre-pregnancy care as this significantly impacts risks during pregnancy. Our inclusion criteria were broad and within the last ten years to achieve a comprehensive yet contemporary understanding. Two reviewers (AH and JD) independently screened titles, abstracts and full texts. Selection was discussed

with a third reviewer (AW). A summary of the study process is presented in Fig. 1.

Data were extracted using a bespoke spreadsheet which captured aim, participants, methods and results. Table 1 summarises all included papers. Included studies underwent critical appraisal for methodological quality using CASP (Critical Appraisal Skills Programme) Checklists [20] for the qualitative studies and Centre for Evidence-Based Management (CEBma) [21] for surveys. Score (number of items on the checklist reported) and exceptions to quality are presented in Table 1. For comprehensiveness, all studies were included, irrespective of quality.

2.1. Analysis

Due to methodological heterogeneity, quantitative synthesis was not possible across all papers. However, eight included papers were surveys which sought to test knowledge. We therefore synthesised mean percentage of correct responses for survey papers [Table 2]. We then combined all data through a narrative synthesis, an iterative process comprising extraction and visualisation, description and interpretation [19].

3. Results

3.1. Characteristics of included studies

There were 16 included studies, of which three were conducted in the USA [22–24], two in Palestine [25,26], two in the UK [27,28] and one each in Saudi Arabia [29], Japan [30], Sudan [31], Israel [32], Estonia [33], Poland [34], Italy [35], Canada [36] and China [37]. There were three interview studies [22,26,27] with the remainder being

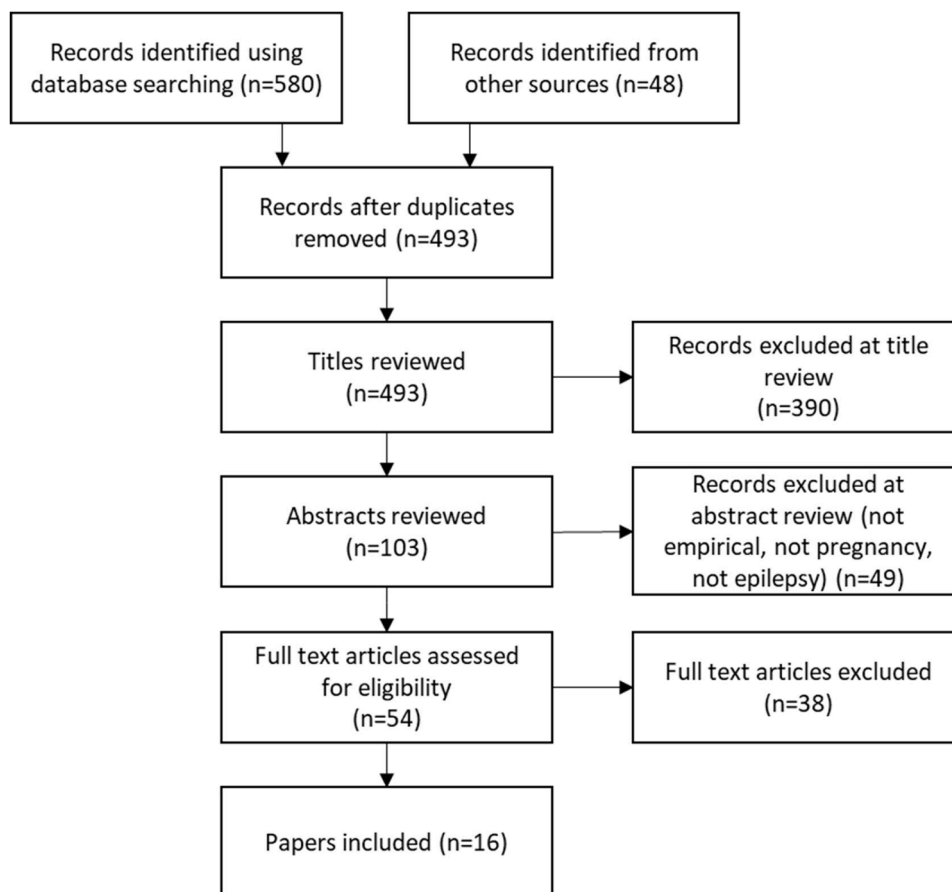


Fig. 1. Prisma flow diagram.

Table 1
Summary of included studies.

First Author Year Country	Participants	Study Aim	Methods	Findings	Quality Appraisal (score and exceptions)
Al Anazi 2022 Saudi Arabia	General practitioners ($n = 42$) and obstetricians ($n = 66$)	Assess knowledge of general practitioners and about relevant topics and concerns of women with epilepsy	Questionnaire survey	Varied levels of knowledge ranging from 71.3% correct about Anti-Epileptic Drugs (AEDs) to 11.5% correct about risk of children with birth defects. Obstetricians scored higher than general practitioners; senior doctors higher than juniors	10/12: No report of response rate or confounding factors reported
Egawa 2020 Japan	Epileptologists ($n = 115$) and Obstetricians ($n = 187$)	Investigate attitudes of epileptologists and obstetricians regarding preconception counselling and perinatal care for women with epilepsy	Questionnaire survey	Obstetricians need information from epileptologist about seizure management for their patients. Half of epileptologists did not consider communication with obstetricians pre-pregnancy necessary	9/12: No report of representative sample, response rate, confounding factors
Elnaeim 2018 Sudan	Doctors (various specialities and grades) ($n = 154$)	Assess the knowledge about women's health issues related to epilepsy	Questionnaire survey	Insufficient knowledge identified in multiple areas including choice of AEDs during pregnancy and breastfeeding.	9/12: No report of representative sample, response rate, confounding factors
Fantaneanu 2023 Canada	Doctors, registered nurses, trainees and pharmacists ($n = 156$) (identifying as epilepsy specialists $n = 107$)	To identify potential gaps in knowledge and care for pregnant women with epilepsy	Questionnaire survey	Self-reported concordance with guidelines was good. Patient preference, cost, drug monitoring tests were not always available and there were differences in prescribing practices according to location.	9/12 No report of representative sample, response rate, confounding factors
Giuliano 2019 Italy	Epileptologists ($n = 169$)	Assess prescribing attitudes of epileptologists about valproate use in female patients	Questionnaire survey	Good knowledge, wide range of attitudes/responses to prescribing. Scenarios causing the greatest challenges were i) little girl who VPA would probably be the most effective and ii) women with juvenile myoclonic epilepsy, 2 years seizure free, on valproate, planning pregnancy failed on other drugs. Shared decision making preferred.	9/12: No report of response rate, confounding factors or degree of sample representativeness
Jasnos 2018 Poland	Neurologists ($n = 141$) and gynaecologists ($n = 72$)	Determine knowledge about reproductive and maternity health issues for women with epilepsy	Questionnaire survey	Gynaecologists and (to a lesser extent) neurologist need more knowledge on reproductive and maternity health issues and closer collaboration between the two specialities is needed.	9/12: Small sample size, no report of response rate or confounding factors
Kirkpatrick 2020 USA	Paediatric neurologists ($n = 6$) and epileptologists ($n = 10$)	Explore the attitudes and practices relating to sexual and reproductive healthcare of adolescents and young adult women with epilepsy	Semi-structured interviews	Practice is variable, many systemic and interpersonal barriers to delivering care including time, provider, patient or family discomfort, lack of knowledge or expertise.	8/10: Recruitment strategy unclear, relationship between researcher and participants not reported
Kirkpatrick 2021 USA	Child neurologists ($n = 108$)	Evaluate knowledge, attitudes and practices regarding sexual reproductive health care for adolescents and young women with epilepsy	Questionnaire survey	Gaps in care delivered (especially for those with mild intellectual disability). Knowledge good at 87%. Confidence in counselling was limited with 65% confident to discuss drug interactions and contraception <64%. Barriers included time, presence of parents or partners, patient discomfort and poor rapport with the patient. Facilitators were additional time, guidelines and co-management.	10/12: No report of response rate or confounding factors
Kirkpatrick 2022 USA	Physicians and advanced practitioners ($n = 329$)	To evaluate knowledge, attitudes, and practices about sexual and reproductive health for adolescent and young adult women with epilepsy	Questionnaire survey	Barriers included time and lack of knowledge and facilitators included guidelines, algorithms education and electronic health record alerts for managing sexual and reproductive health.	11/12: No report of response rate
Morley 2020 UK	Community midwives ($n = 4$)	To explore the experiences of midwives using a maternity epilepsy toolkit	In-depth, semi-structured interviews	Participants said the toolkit supported their knowledge, confidence and reduced fear. It motivated them to learn more and encouraged timely referral.	9/10: No report of relationship between researcher and participants
Roth 2016 Israel	Pharmacists ($n = 121$)	To evaluate pharmacists' knowledge of pharmacological treatment of epilepsy.	Questionnaire survey	Pharmacists were knowledgeable in some areas of care including the need to continue AED treatment and the need to call the physician for loss of seizure control however, only 12%	10/12: No report of sample size or response rate

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Table 1 (continued)

First Author Year Country	Participants	Study Aim	Methods	Findings	Quality Appraisal (score and exceptions)
Shawahna 2017 Palestine	Community pharmacists (n = 30)	To develop and achieve consensus knowledge that community pharmacists should have on women's health issues in epilepsy	Questionnaire survey	identified all three situations in which clinicians should be contacted urgently and 27% did not identify any of them. Key areas of knowledge that pharmacists need to know were identified as teratogenicity of AEDs, effects of pregnancy on epilepsy and preconception counselling.	9/12, no report of sample size, response rate, confounding factors
Shawahna 2022 Palestine	Neurologists (n = 6), gynaecologists (n = 5), psychiatrists (n = 3), clinical pharmacists (n = 5) and internist (n = 1)	To explore the status of caring for women with epilepsy in the Palestinian healthcare system	Semi structured Interviews	Barriers to optimal care included lack of protocols, lack of specialist care pathway and woman specific issues such as lack of adherence to AEDs and experience of side effects.	9/10: No report of relationship between researcher and participants
Taylor 2022 UK	Obstetricians (n = 65), neurologists (n = 13), epilepsy specialist nurses and midwives (n = 49) and general midwives (n = 17)	Undertake a nationwide survey of healthcare professionals to map the care provided to pregnant women with epilepsy in UK maternity units	Questionnaire survey	Participants from 65% of hospitals reported a care pathway for pre-conception counselling, 11% did not have a protocol for managing pregnant women with epilepsy, 31% had joint obstetric and neurologist clinics. Only 20% of respondents used risk calculators. 19% of all respondents reported "not confident" communicating risk of seizures in pregnancy to women.	11/12: No report of response rate
Teesaar 2023 Estonia	Gynaecologists-obstetricians (n = 14), neurologists (n = 28) and general practitioners (n = 65)	To assess healthcare specialists' awareness of management of epilepsy in women during pre and perinatal period.	Questionnaire survey	Median correctly answered questions was 4.5/10 with gynaecologists-obstetricians and neurologists scoring higher than general practitioners. Only 30% of general practitioners were aware of the high teratogenic potential of valproate.	10/12: No report of representative nature of the sample or response rate
Xu 2022 China	Neurologists, neurosurgeons and paediatricians (n = 62)	To evaluate the knowledge of specialist doctors	Questionnaire survey	Average knowledge score was 71% with knowledge about risk of caesarean section, preterm delivery, appropriate analgesic drugs during delivery and post-partum blood monitoring being poorest.	9/12: No report of sample representativeness, sample size or confounding factors

questionnaire survey design. There was a total of 2045 participants across all studies comprising obstetricians/gynaecologists (n = 447) and neurologists (n = 765) but also included midwives/nurses (n = 70), general practitioners (n = 107) and pharmacists (n = 156) with the others being mixed groups of physicians, advanced practitioners or unspecified. Four studies considered only care during pregnancy [27,28,36,37], five considered only pre-pregnancy care [22-24,29,31] and seven considered both [25,26,30,32-35]. All studies were of good quality. Exceptions in quality in qualitative studies tended to be failure to state the relationship between the researcher and participants and/or the recruitment strategy. Survey studies often did not report response rate or representativeness of the sample.

3.2. Categories

We identified five categories with nine sub-categories relating to practitioners' barriers or facilitators in providing care for pregnant women with epilepsy [Fig. 2]. Each are presented in turn and where there were differences between professional groups, these are described in the narrative.

3.3. Theme 1: knowledge

Knowledge was tested in nine studies [23,24,29,31-34,36,37] and reported as a determinant of practice in a further five [22,23,25,26,35]. Where it was possible to synthesise responses to knowledge test questions, that is, questions were asked about a common area of care, these are presented in Table 2 as percentage of participants offering correct responses. Where there were variations in the way questions were asked

this is indicated in foot notes. Although the same questionnaire was used in several studies, for example "Knowledge of Women's Issues and Epilepsy" (KOWIE II) [38], was used in three studies [24,29,31], the way questions were asked varied. For example, in one study participants were offered "the majority of women with epilepsy have healthy children" with true/false/don't know options [31] compared with "what percent of children born to a WWE is at risk for major birth defects?" with a numerical response required in another [29].

Knowledge was generally good among practitioners, with the mean score, across all questions and papers of 60.1% correct answers [Table 2]. However, when participants were asked for exact answers (e. g., dose of folic acid [29]), rather than to agree or disagree, scores were lower. There were variations in knowledge across areas of care, with areas of poor knowledge including relation to sexual dysfunction [24,29,31], whether women should get pregnant when taking AEDs [29,31,34] and the impact of progesterone and oestrogen on seizures [24,29,31]. Participants scored higher when asked, for example, about taking AEDs with contraception [23,24,29,31,32] or when pregnant [24,32], risk of birth defects [23,24,31,32,34,36] and taking folic acid [24,31].

Papers reported differences between participant groups. For example, in two studies, knowledge of health issues was significantly lower in GPs than in obstetricians [29], gynaecologists or neurologists [33]. Other differences were not statistically significant and appeared to be linked to the nature of the questions (whether more epilepsy or pregnancy focused) with one paper reporting higher scores in neurologists compared with gynaecologists [34] and another higher in gynaecologists-obstetricians compared with neurologists [33]. Where comparisons were made in studies, knowledge was (generally) greater in practitioners who were more senior and experienced [24,29,32,34],

Table 2
Responses to knowledge test questions.

Knowledge tested (% correct responses)	Al Anazi	Elnaeim	Fantaneanu	Janos	Kirkpatrick 2022			Roth	Teesaar			Xu	Mean
	GPs, Obstetricians	Doctors	Doctors, nurses, pharmacists	Neurologist, gynaecologists	Paediatrics	Adolescent Medicine	Paediatric Gynaecologists	Pharmacists	GPs	Gynaecologists-obstetricians	Neurologists	Neurologists, Paediatricians	
Relationship between seizures and hormonal cycle	61.1	62	–	–	–	–	–	–	–	–	–	–	61.6
WWE higher rate of sexual dysfunction	30.8	20.1	–	–	19.5	16.9	20.4	–	–	–	–	–	38
AEDs interfering with oral contraceptives	34.6 ¹	72.1	–	–	66.1	92.9	100	72	–	–	–	–	81.1
Oestrogen has proconvulsant and progesterone anticonvulsant properties	22.2	15.6	–	–	16.8	57.8	72.5	–	–	–	–	–	31.1
WWE should not get pregnant while taking AEDs	44.2	18.2	–	15.0	–	–	–	–	–	–	–	–	25.8
WWE should stop taking AEDs when they get pregnant	–	–	–	–	75.3	73.8	100	92	–	–	–	–	91.2
Children born to WWE have a higher risk of birth defect than women without	11.5 ²	68.2	–	91.5	90.8	92.9	98	52	–	–	–	–	72.1
AEDs cause cognitive development delay in child	–	–	81	–	–	–	–	–	20 ²	50 ³	67.9 ³	53.2	54.4
Folic acid during pregnancy may reduce teratogenesis in children born to WWE taking AEDs	25 ⁴	89	–	–	90.2	89.3	100	–	–	–	–	–	86
Mean% correct answers	–	–	–	–	–	–	–	–	–	–	–	–	60.1

¹Participants asked to list “which” rather than “yes/no” or multi-choice option offered in other studies.

²Participants asked to record a percentage rather than respond “yes/no” or multi-choice option.

³Participants asked to list the specific AEDs compared with “yes/no” or multi-choice option.

⁴Participants were asked to specify an amount rather than agree or disagree folic acid is beneficial.

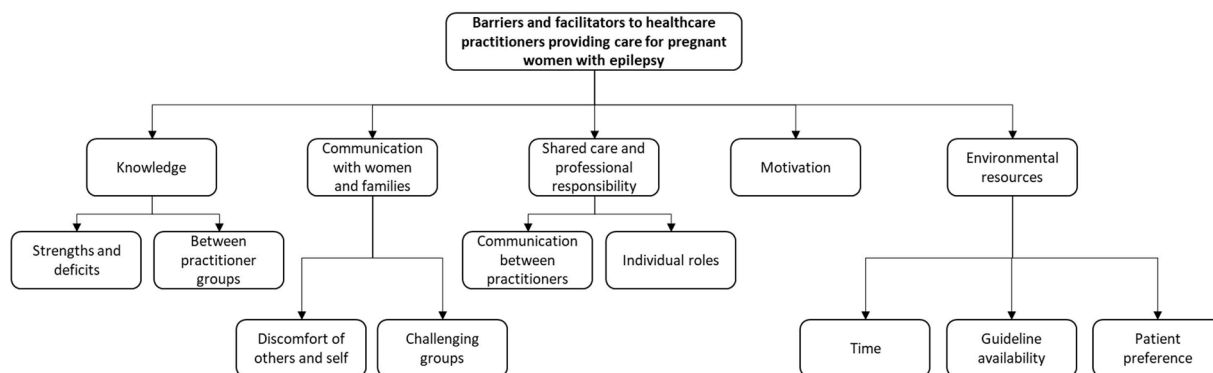


Fig. 2. Summary of barriers and facilitators to healthcare practitioners assessing the risk when supporting pregnant women with epilepsy.

with the only exception being in one study where consultants had slightly lower scores than registrar grade doctors [31].

Sometimes, even if knowledge was good, applying it in practice in complex cases was challenging to practitioners, for example, in one survey, 64% of participants found difficulties in implementing valproate prescribing guidelines into clinical practice [35]. In another neurologists were concerned reproductive health was out with the scope of their speciality [22]. Similarly, in interviews, practitioners stressed the challenges of balancing the benefits versus the risks of taking AEDs, the consensus being that seizures would be riskier for the fetus than AEDs [26]. Practitioners were generally aware when they had knowledge deficits. For example, in one study between 11 and 75% recorded “unsure” to one or more questions [29], in a second study, 8% responded “I don’t know” to one or more questions [32] and in a third study, 54.1% reported a lack of personal knowledge about epilepsy [24].

To address knowledge deficits participants suggested the provision of training or provider education, [22–24,32], electronic health records and alerts and guidelines [24]. Some participants suggested risk algorithms to support application of knowledge in practice [24], however, when these were available, they were poorly implemented, with only 20% of practitioners adopting them [28]. A Delphi study to develop consensus on a core list of important knowledge items concluded 13 key categories that pharmacists need to know: teratogenicity, effect of pregnancy on epilepsy, preconception counselling, bone health, catamenial epilepsy, menopause and hormonal replacement therapy, contraception, menstrual disorders and infertility, eclampsia, breastfeeding, folic acid and vitamin K, counselling on general issues, and sexuality [25]. One study tested an educational toolkit on four community midwives who reported previous epilepsy education as a “distant memory” [27]. In addition to improving their knowledge, participants said the toolkit helped them understand the boundaries of their knowledge and gave them confidence to refer to other colleagues in the wider team.

3.4. Theme 2: communication with women and their families

Impact of epilepsy medication and seizures on the unborn baby was identified by practitioners as key concerns for women [28] and self-reported communication about these issues was relatively high, with 98% of participants in one study reporting discussions about teratogenic risks [35] and 65% in another study reporting conversations about seizure risk [28]. This was not the case for all, and it was not without challenges. In a study of neurologists and epileptologists caring for the sexual and reproductive health of adolescents and young women, although most had experience of their patients becoming pregnant, they rarely asked patients about their current or future reproductive intentions [22]. When they did, most suggested they avoid becoming pregnant; a neurologist in one study said, “I usually tell them, ‘please don’t get pregnant until you’re like 30’” [22]. Reasons for lack of questioning

given by neurologists in a survey, included the presence of partners or parents during clinic visits (44%), concern that the patient will become uncomfortable (24%), an inadequate rapport with the patient (20%), lack of educational resources for patients (33.1%) and, in fewer cases, personal discomfort (13%) [23]. Practitioners reported challenges at addressing women’s beliefs about AEDs and concerns about adherence [26]. Some participants perceived this was attributable to the health literacy of some women or their being in denial about having epilepsy. They found it difficult when having failed to comply with recommended treatment, their health deteriorated and women became angry with physicians [26]. Communicating with patients with a learning disability or their carers was a particular challenge for some physicians and advanced practitioners, as was communicating with those reported to have poor health literacy [24].

Strategies suggested to address these challenges include: guidelines specifying what content and how often to counsel patients on sexual and reproductive health, better undergraduate and provider training and educational materials, with one physician stating “most [women] don’t recall ever having conversations about [sexual and reproductive health] with their docs, so if you only do it once, nobody’s ever gonna remember it, so you gotta do it over and over again, and you gotta provide written education about it as well” [22]. Participants in one study (38%) [28] reported using a “shared care” toolkit [39] a document to support shared knowledge and awareness of risks and care responsibilities.

3.5. Theme 3: shared care and professional responsibility

The need for communication between obstetricians and neurologists about pregnant women with epilepsy was identified by both obstetricians and neurologists [22–24,30]. In one study most obstetricians said they needed information relating to seizure frequency, seizure-free period, risk of different AEDs and risk of patients taking AEDs when breastfeeding. However, only 51% of neurologists suggested a need for prior communication between the professional groups [30]. In another study, although neurologists believed sexual and reproductive health-care should be shared responsibility, they were concerned this would complicate matters relating to ultimate responsibility for the patient; their “medical home” [22]. They were also concerned women’s health providers lacked epilepsy-specific expertise to deliver appropriate care. One participant said around 60% of women’s health providers “don’t . . . understand how the meds interact. . . how pregnancy can change their metabolism”. This participant went on to report women being told by non-neurologists they should not have children [22].

When specifically asked about their role in sexual health with adolescents and young women, most neurologists considered this involved counselling about teratogenic effects of AEDs (99%), contraception and AEDs (96%) and epilepsy and pregnancy (95%) [23]. Fewer considered folic acid supplementation part of their role (70%) and fewer still believed they were responsible for contraception counselling (10%) or

counselling about planning to become pregnant or have children (25%) [23]. Gynaecologists-obstetricians for adolescents and young women indicated they should be primarily responsible for counselling tasks, with the exception of folic acid and teratogenic effects of antiseizure medications which they believed to be part of the role of a neurologist [24]. One study identified joint obstetric-neurology clinics, in only 31% of hospitals in the UK with another 52% led by an obstetrics or neurology specialist but with remote contact with the other speciality [28]. Several participants in other studies recommended joint clinics and other ways of effectively sharing care including, co-management plans (63.2%), use of a templated notes (45.6%), integrated electronic health record systems (42.9%) and electronic messaging between specialities (40.7%) [24]. Fewer suggested dedicated time for communication between groups (23.1%) or joint e-consultations (19.8%) [24].

3.6. Theme 4: motivation

Motivation of practitioners appeared to be a facilitator to practitioners providing pre-pregnancy or sexual and reproductive healthcare for women with epilepsy. When asked the overwhelming majority 98.8% said such care was important or very important (98.8%) [24]. In an interview study neurologists and epileptologists for adolescents and young women were clear that sexual and reproductive healthcare was essential and, in the words of one participant, “*should be addressed with any woman of childbearing age . . . at a developmentally appropriate level*” [22]. A multi-disciplinary group of neurologists, gynaecologists-obstetricians, psychiatrists and pharmacists “stressed” preconception consultations were of great importance in particular to discuss the risk of teratogenicity of AEDs, and importance of folic acid calcium and B vitamin supplementation [26].

3.7. Theme 5: environmental resources

Time was frequently expressed as a barrier to delivering pregnancy or pre-pregnancy care to women with epilepsy in up to 80% of appointments [22–24]. One participant in an interview study said: “*there is a million and one things you have to discuss with your epilepsy patients*” [22]. Other barriers included a lack of educational resources for patients identified in one study (33.1%) [24] and, for a minority of participants in another study, no access to drug monitoring tests (4.5%) [36]. However, facilitators were also reported, for example, availability of a pathways of care as reported in two studies by 86.5% [36] and 65% [28] of respondents.

Guidelines for various elements of optimal practice were not always available, with 11% of respondents in one survey [28] and 17% in another [24] reporting no protocol for managing pregnant women with epilepsy. Participants in a qualitative study identified a need for additional guidelines to support content and frequency of pre-pregnancy counselling and communication [24]. Where guidelines existed, they were not always effective. For example, in one study, despite a common guideline, there was significant variation in prescribing between different areas of the country (Canada) [36]. Participants attributed deviation from guidelines as down to patient preferences, (defined as “patient-based rationale”, the patient’s evaluation of expected outcomes) with medication choice and the impact not only on health but also on cost (insurance cover or lack thereof within the healthcare system) [36]. In Palestine participants reported multiple, differing protocols or guidelines with practitioners tending to adopt those they first became familiar with at their place of training [26].

4. Discussion

This systematic literature review examined the barriers and facilitators to healthcare practitioners delivering optimal care for pregnant women with epilepsy. We identified 16 papers following our search and study selection processes and identified five themes: i) knowledge,

which included areas of strength and deficit and differences between practitioner groups, ii) communication with women and their families, including feelings of discomfort and particular difficulties when communicating with some groups of women (for example, those with a learning disability), iii) shared care and professional responsibility, which identified challenges in communicating between practitioners and differences in perceptions of each individual’s role, iv) motivation as a facilitator for care, with practitioners agreeing the importance of supporting pregnant women with epilepsy and v) variations in environmental resources, including time, availability of guidelines and patient preferences.

The strengths of this review include the fastidious, meticulous searching of the literature and the inclusive approach. Of studies that were available, all but three were surveys, limiting the detail and nuance of data extracted. Although several studies tested knowledge, with some using the same survey tool, adaptations made by individual authors meant synthesising these data was challenging and limited. There were only 16 studies that addressed our research question and studies were conducted in a range of countries, with disparate health care systems, where models of care vary. Despite these limitations and a clear need for more research, there were repeating and shared barriers and facilitators across studies, allowing us to present themes. Below we consider each theme in turn, presenting our findings within the context of the wider literature relating to women’s care experiences, challenges with of delivery maternity care more generally and existing guidelines. From this we tentatively offer recommendations for practice.

The most frequently investigated and reported barrier in included studies was **knowledge**. Knowledge, whilst a clear prerequisite, is just one of many other potential determinants of optimal practice [40]. Although some of the included survey papers used a valid and reliable tool to assess knowledge [24,29,31], authors changed questions thus significantly limiting the quality of our results. However, it was clear that knowledge was specific to, but not shared between specialists. For example, neurologists were more likely to know about AEDs and cognitive development delay in a child [33] whereas obstetricians were more likely to correctly answer questions relating to pregnancy hormones [41]. Applying knowledge in this complex field of practice was challenging. This suggests a risk score, algorithm or decision-making tool might be useful. Although these exist [42,43], there appears to be a lack of awareness and uptake of these [28]. When they are used, they are well evaluated [27] but there are no data relating to comparative outcomes. In some studies, women reported receiving inadequate information, and when information or advice was given they said it was too late in the pregnancy [44,45]. Guidelines suggest pathways of care involving either epilepsy specialist midwife or joint neurologist and obstetrician clinics [11] which would address these problems. This links with our theme **shared care and professional responsibility**, where communication between specialists was problematic for both neurologists and obstetricians [22–24,30]. In qualitative studies, women expressed similar concerns about poor care coordination [41,46] and said that obstetricians and neurologists sometimes gave them contradictory advice [41].

Communication with women and their families was a challenge for practitioners, with reports of discomfort in communicating about sensitive topics for both themselves and the pregnant woman with epilepsy [23]. Women concur they feel uncomfortable engaging in these conversations [47]. Practitioner discomfort at discussing sensitive matters with pregnant women is reported in relation to a wide range of topics including alcohol [48], smoking [49], mental health care needs [50] and weight gain [51]. This suggests interventions to support practitioners have difficult conversations with pregnant women more generally may be of benefit. However, it is worth noting, although women wanted clearer information from practitioners, for support they were more likely to expressed a need for *peer* support from other women living with epilepsy [52].

Despite the dearth of literature, **motivation** was a clear facilitator for

practitioners [22,24,26]. But this was limited by the lack of **environmental resources** including time [22-24] and available guidelines [24, 26,28]. Whilst the absence of guidelines may be a relatively simple challenge to fix, with the availability of a common and accessible practice guideline [24,26,36], resolving a lack of time is a challenge facing practitioners globally, in many fields of care, and few solutions have been suggested. One strategy with an early indication of success in focusing finite practitioner time to maximum benefit is the provision of care pathways [53], already part of guidelines for care for pregnant women with epilepsy [11].

As we have discussed the results of this review, we have integrated some potential recommendations for practice. However, we do so tentatively, as although this paper offers the range of published barriers, these will differ according to local context, resources and culture, as will the suitability of suggested strategies to improve care.

Recommendations for research include in-depth explorations of the barriers and facilitators for practitioners in offering recommended care to pregnant women with epilepsy.

5. Conclusion

Despite successive reports identifying poor outcomes for pregnant women with epilepsy, very little research has sought to explore *why* guidelines and recommendations have not been adopted. This review presents the published challenges faced by practitioners in providing care for pregnant women with epilepsy. Identification of the barriers and facilitators reported here could guide local assessment of barriers and development of strategies and resources to aid appropriate, timely responses to the needs of pregnant women with epilepsy.

Declaration of competing interest

The authors have no competing interests.

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Registration of the review

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References

- [1] Knight M, Kenyon S, Brocklehurst P, Neilson J, Shakespeare J, Kurinczuk J. Saving lives, improving mothers' care: lessons learned to inform future maternity care from the UK and Ireland confidential enquiries into maternal deaths and morbidity 2009-2012. *MBRRACE-UK: saving Lives. Improv Mothers' Care* 2017.
- [2] Li Y, Meador KJ. Epilepsy and pregnancy. *Continuum (Minneapolis, Minn)* 2022;28(1):34.
- [3] Knight M., Bunch, K., Felker, A., Patel, R., Kotnis, R., Kenyon, S., Kurinczuk, J., . Saving lives, improving mothers' care, maternal, newborn and infant clinical outcome review programme 2023.
- [4] Mazzone PP, Hogg KM, Weir CJ, Stephen J, Bhattacharya S, Chin RF. Comparison of perinatal outcomes for women with and without epilepsy: a systematic review and meta-analysis. *JAMA Neurol* 2023.
- [5] Tomson T, Battino D, Bromley R, Kochen S, Meador K, Pennell P, et al. Management of epilepsy in pregnancy: a report from the international league against epilepsy task force on women and pregnancy. *Epileptic Disord* 2019;21(6): 497–517.
- [6] Kapoor D, Wallace S. Trends in maternal deaths from epilepsy in the United Kingdom: a 30-year retrospective review. *Obstet Med* 2014;7(4):160–4.
- [7] Chen YH, Chiou HY, Lin HC, Lin HL. Affect of seizures during gestation on pregnancy outcomes in women with epilepsy. *Arch Neurol* 2009;66(8):979–84.
- [8] McAuley JW, Patankar C, Lang C, Prasad M. Evaluating the concerns of pregnant women with epilepsy: a focus group approach. *Epilepsy Behav* 2012;24(2):246–8.
- [9] Thangaratnam S, Marlin N, Newton S, Weckesser A, Bagary M, Greenhill L, et al. AntiEpileptic drug Monitoring in PREGnancy (EMPIRE): a double-blind randomised trial on effectiveness and acceptability of monitoring strategies. *Health Technol Assess (Rockv)* 2018;22(23):1–152.
- [10] Weckesser A, Denny E. Re-working biographies: women's narratives of pregnancy whilst living with epilepsy. *Soc Sci Med* 2017;185:110–7.
- [11] Royal College of Obstetricians and Gynaecologists. Epilepsy Pregn. guideline no. 68 2016 [Available from: https://www.rcog.org.uk/media/rzldnacf/gtg68_epilepsy.pdf].
- [12] National Institute for Health and Care Excellence. Epilepsies: diagnosis and management [CG137] 2012 [Available from: www.nice.org.uk/guidance/cg137].
- [13] National Institute for Health and Care Excellence. Epilepsies in children, young people and adults 2022 [Available from: <https://www.nice.org.uk/guidance/ng217>].
- [14] Royal college of obstetricians and gynaecologists. Epilepsy in pregnancy, green-top guideline No.68 2016 [Available from: <https://www.rcog.org.uk/guidance/brows-e-all-guidance/green-top-guidelines/epilepsy-in-pregnancy-green-top-guideline-no-68/>].
- [15] Knight M. The findings of the MBRRACE-UK confidential enquiry into maternal deaths and morbidity. *Obstet Gynaecol Reprod Med* 2019;29(1):21–3.
- [16] Leach J, Smith P, Craig J, Bagary M, Cavanagh D, Duncan S, et al. Epilepsy and Pregnancy: for healthy pregnancies and happy outcomes. Suggestions for service improvements from the Multispecialty UK Epilepsy Mortality Group. *Seizure* 2017; 50:67–72.
- [17] Kinney M, Craig J. Pregnancy and epilepsy: meeting the challenges over the last 25 years: the rise of the pregnancy registries. *Seizure* 2017;44:162–8.
- [18] Page M, McKenzie J, Bossuyt P, Boutron I, Hoffmann T, Mulrow C. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *MetaArXiv* 2020:2020.
- [19] Ferrari R. Writing narrative style literature reviews. *Med Writing* 2015;24(4): 230–5.
- [20] Centre for Evidence-Based Medicine Critical Appraisal tools. Critical Appraisal Sills Programme (CASP) [Available from: <https://casp-uk.net/casp-tools-checklists/>].
- [21] Center for Evidence-Based Management. Critical appraisal of a cross-sectional study (survey) [Available from: <https://cebma.org/assets/Uploads/Critical-Appraisal-Questions-for-a-Cross-Sectional-Study-July-2014-1-v2.pdf>].
- [22] Kirkpatrick L, Collins A, Sogawa Y, Talabi MB, Harrison E, Kazmerski TM. Sexual and reproductive healthcare for adolescent and young adult women with epilepsy: a qualitative study of pediatric neurologists and epileptologists. *Epilepsy Behav* 2020;104:106911.
- [23] Kirkpatrick L, Harrison E, Khalil S, Miller E, Patterson C, Sogawa Y, et al. A survey of child neurologists about reproductive healthcare for adolescent women with epilepsy. *Epilepsy Behav* 2021;120:108001.
- [24] Kirkpatrick L, Liu H, Bhatnagar S, Bravender T, Harrison E, Kazmerski TM, et al. A survey of healthcare providers about reproductive healthcare for adolescent women with epilepsy. *J Pediatr Adolesc Gynecol* 2022;35(1):39–47. e1.
- [25] Shawahna R. Which information on women's issues in epilepsy does a community pharmacist need to know? A Delphi consensus study. *Epilepsy Behav* 2017;77: 79–89.
- [26] Shawahna R, Zaid L. Caring for women with epilepsy in Palestine: a qualitative study of the current status. *Epilepsy Behav* 2022;130:108689.
- [27] Morley K. Reducing risks for pregnant women with epilepsy: a qualitative study exploring experiences of using a toolkit at the antenatal booking appointment. *Epilepsy Behav* 2020;103:106418.
- [28] Taylor E, Junaid F, Khattak H, Sheikh J, Ghosh J, Kemah BL, et al. Care of pregnant women with epilepsy in the United Kingdom: a national survey of healthcare professionals. *Eur J Obstet Gynecol Reprod Biol* 2022;276:47–55.
- [29] Al Anazi RF, Atef GM, Alhafaan KM, Al Sharif RA, Al-Attas AA. Knowledge of obstetrician and family medicine doctors in Saudi Arabia about women with epilepsy. *Egyptian J Neurol Psychiatry Neurosurg* 2022;58(1):115.
- [30] Egawa M, Hara K, Ikeda M, Yoshida M. Questionnaire dataset: attitude of epileptologists and obstetricians to pregnancy among women with epilepsy. *Data Brief* 2020;31:105948.
- [31] Elnaeim AK, Elnaeim MK, Babiker IB. Knowledge of women issues and epilepsy among doctors in Sudan. *Epilepsy Behav* 2018;84:79–82.
- [32] Roth Y, Neufeld MY, Blatt I, Guy-Alfandary S, Rasaby S, Ekstein D, et al. An evaluation of pharmacist knowledge on treatment with antiepileptic drugs. *Seizure* 2016;34:60–5.
- [33] Teesaar RL, Taba N, Rakitin A. Competency in the management of women of childbearing age with epilepsy among primary care and specialist doctors in Estonia. *Epilepsy Behav Rep* 2023;22:100599.
- [34] Jasno I, Cieslik A, Wanot J, Sejboth J, Szurlej D, Gurowiec P. Knowledge of neurologists and gynaecologists regarding reproductive and maternity issues in women with epilepsy. *Med Sci Pulse* 2018;12(3).
- [35] Giuliano L, La Neve A, Galimberti CA, Aguglia U, Bilo L, Ermio C, et al. Valproate and female patients: prescribing attitudes of Italian epileptologists. *Epilepsy Behav* 2019;97:182–6.
- [36] Fantaneanu TA, Thornton HF, Zhang T, Bercovici E, Hrazdil C, Ikeda KM, et al. Real-world practices for the care of women with epilepsy during pregnancy: a Canadian perspective. *Epilepsy Behav* 2023;148:109468.

- [37] Xu ZYR, Qian P, Cai MT, Ding MP, Guo Y. Management of epilepsy in pregnancy in eastern China: a survey from the Zhejiang association against epilepsy. *Front Neurol* 2022;13:1001918.
- [38] Long L, Montouris G. Knowledge of women's issues and epilepsy (KOWIE-II): a survey of health care professionals. *Epilepsy Behav* 2005;6(1):90–3.
- [39] Morley K. **Pregnancy toolkit: a resource for women and health professionals 2021** [Available from: <https://www.womenwithepilepsy.co.uk/pregnancy-toolkit/>].
- [40] Michie S, Johnston M, Abraham C, Lawton R, Parker D, Walker A. Making psychological theory useful for implementing evidence based practice: a consensus approach. *BMJ Qual Saf* 2005;14(1):26–33.
- [41] Kirkpatrick L, Harrison E, Borrero S, Davis AR, Miller E, Sogawa Y, et al. Preferences and experiences of women with epilepsy regarding sexual and reproductive healthcare provision. *Epilepsy Behav* 2022;129:108631.
- [42] Allotey J, Fernandez-Felix BM, Zamora J, Moss N, Bagary M, Kelso A, et al. Predicting seizures in pregnant women with epilepsy: development and external validation of a prognostic model. *PLoS Med*. 2019;16(5):e1002802.
- [43] SUDEP action. SUDEP Seizure Saf Checklist [Available from: <https://sudep.org/ch/ecklist>].
- [44] Viale L, Allotey J, Cheong-See F, Arroyo-Manzano D, Mccorry D, Bagary M, et al. Epilepsy in pregnancy and reproductive outcomes: a systematic review and meta-analysis. *The Lancet* 2015;386(10006):1845–52.
- [45] Dupont S, Vercueil L. Epilepsy and pregnancy: what should the neurologists do? *Rev Neurol (Paris)* 2021;177(3):168–79.
- [46] Lawther L, Dolk H, Sinclair M, Morrow J. The preconception care experiences of women with epilepsy on sodium valproate. *Seizure* 2018;59:82–9.
- [47] Srikanth P, Vranda MN, Thomas PT, Raghvendra K. Quality of life and stigma among women with epilepsy during their reproductive years. *J Epilepsy Res* 2021; 11(1):63.
- [48] Dyson J, Onukwugha F, Howlett H, Combe K, Catterick M, Smith L. Midwives and service users' perspectives on implementing a dialogue about alcohol use in antenatal care: a qualitative study. *J Adv Nurs* 2023.
- [49] Kalamkarian A, Hoon E, Chittleborough CR, Dekker G, Lynch JW, Smithers LG. Smoking cessation care during pregnancy: a qualitative exploration of midwives' challenging role. *Women Birth* 2023;36(1):89–98.
- [50] Bayrampour H, McNeil DA, Benzie K, Salmon C, Gelb K, Tough S. A qualitative inquiry on pregnant women's preferences for mental health screening. *BMC Pregn Childbirth* 2017;17:1–11.
- [51] Christenson A, Johansson E, Reynisdottir S, Torgerson J, Hemmingsson E. Shame and avoidance as barriers in midwives' communication about body weight with pregnant women: a qualitative interview study. *Midwifery* 2018;63:1–7.
- [52] Qiang Y, Zhang S, Xu S, Li W. Experimental and theoretical studies on the corrosion inhibition of copper by two indazole derivatives in 3.0% NaCl solution. *J Colloid Interface Sci* 2016;472:52–9.
- [53] Macke LB, Sieja A, Suresh K, Schilling LM. EHR-integrated clinical pathways promote education, confidence, and save time for primary care providers. *Am J Med Qual* 2022;37(6):528–34.