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Pregnancy-Related Anxiety Among Women Living With Epilepsy in Southeastern Türkiye: An Exploratory Qualitative Focus Group Study

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Abstract

Background

Pregnancy-related concerns among women with epilepsy are well described, including fear of seizures, antiseizure medication (ASM) exposure, fetal harm, childbirth, stigma, and parenting. Less is known about how these concerns interact within specific sociocultural and healthcare contexts and how they shape coping and treatment behavior. This study explored how women with epilepsy in southeastern Türkiye experienced pregnancy-related anxiety, how clinical and social concerns intersected, and how women responded to these concerns.

Methods

This qualitative descriptive study was conducted at a university hospital in southeastern Türkiye. The neurology outpatient clinic records for the predefined screening period included 561 women with epilepsy. Record screening identified 20 women who had experienced at least one pregnancy while living with epilepsy and met the study eligibility criteria. All 20 eligible women were invited to participate; 10 agreed to participate and took part in two focus groups, whereas the remaining 10 declined. Discussions were audio-recorded, transcribed verbatim, and analyzed using inductive thematic content analysis supported by MAXQDA 2020. Reporting was developed with reference to COREQ. Given the small sample and the use of only two focus groups, the findings are presented as exploratory and context-bound rather than representative, and full thematic saturation cannot be assured.

Results

Sixty-two codes were organized into seven interconnected themes: epilepsy as bodily unpredictability; seizure-related anxiety; concerns about fetal health; childbirth-related anxiety; concerns about the child's future health and safety; social pressure and stigma; and coping strategies. Within this small sample, women described a recurring tension between preventing seizures and protecting the fetus from perceived medication-related harm. Family involvement could be protective or distressing, and some participants reported skipping medication because of fetal-harm concerns.

Conclusions

The study does not identify wholly new categories of concern; rather, it provides context-specific evidence on how established concerns may cluster and interact in women's accounts in southeastern Türkiye. The findings highlight areas for further investigation, including repeated risk communication, medication-adherence discussions, family-sensitive support, and psychological assessment. These

implications should be evaluated in larger and more diverse samples before broad practice recommendations are made.

Background

Epilepsy is a common chronic brain disorder affecting more than 50 million people worldwide [1]. Women and girls of reproductive potential face additional concerns related to contraception, pregnancy planning, antiseizure medication (ASM) exposure, seizure control, breastfeeding, and parenting [2–5]. Pregnancy therefore represents not only a clinical transition but also a period in which risk, responsibility, and uncertainty become closely intertwined.

Most women with epilepsy can have successful pregnancies, but treatment decisions require a careful balance between preventing maternal seizures and minimizing fetal exposure to medications with known or uncertain reproductive risks. Contemporary guidance emphasizes avoiding valproate when clinically feasible, selecting a lower-risk effective monotherapy where possible, maintaining seizure control, and providing folic acid before conception and during pregnancy [6–10]. Pregnancy-associated pharmacokinetic changes can substantially lower serum concentrations of several ASMs, making early therapeutic drug monitoring and individualized dose adjustment clinically relevant [11]. These recommendations are clinically important, yet risk information itself can become a source of distress when it is delayed, inconsistent, or not individualized.

Existing qualitative literature has already documented many concerns experienced by women with epilepsy during pregnancy and motherhood, including medication changes, congenital anomalies, hereditary transmission, seizure recurrence, labor, infant safety, stigma, and doubts about motherhood [3, 5, 12–15]. Prospective evidence also indicates increased anxiety symptoms during pregnancy and postpartum among women with epilepsy compared with control groups [16]. Accordingly, the gap addressed by the present study is not whether these concerns exist, but how they are experienced together within a particular sociocultural setting and how they may influence coping and treatment behavior.

Evidence from Türkiye, particularly southeastern Türkiye, remains limited. Family involvement, social expectations surrounding motherhood, illness-related stigma, and patterns of support may shape how women interpret and manage pregnancy-related risk. The present study therefore offers an exploratory, context-specific account rather than a claim of broadly novel themes. Particular attention is given to the way seizure unpredictability, perceived medication-related fetal risk, family and community responses, and coping behaviors intersect in women’s narratives.

This study aimed to explore how women who had experienced pregnancy while living with epilepsy described pregnancy-related anxiety, the clinical and social factors that shaped those experiences, and the coping responses they used.

Methods

Study design and reporting

This qualitative descriptive study used focus group discussions and inductive thematic content analysis. A qualitative approach was selected to capture how participants interpreted pregnancy-related anxiety in the context of epilepsy. Reporting was developed with reference to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [17].

Setting and participants

The study was conducted at Gaziantep University Şahinbey Research and Practice Hospital in southeastern Türkiye between 16 June 2019 and 16 June 2020. Participants were eligible if they were 18–40 years old, had a diagnosis of epilepsy, had experienced at least one pregnancy while living with epilepsy, were able to communicate in Turkish, had attended the hospital for pregnancy or epilepsy care, and provided written informed consent. Women who declined participation or chose to withdraw were excluded.

Homogeneous purposive sampling was used. The neurology outpatient clinic records for the predefined screening period (2013 through August 2019) included 561 women with epilepsy. The records were screened to identify women who had experienced at least one pregnancy while living with epilepsy and met the study eligibility criteria. Twenty eligible women were identified and invited to participate between September 2019 and January 2020. Ten women agreed to participate and attended the scheduled focus groups, whereas the remaining 10 declined participation. Thus, 50% (10/20) of the eligible women participated in the study. All women who enrolled completed the focus group discussions. The two groups generated recurrent and sufficiently detailed accounts to support an exploratory analysis of the focused research question; however, with 10 participants and two focus groups, full thematic saturation cannot be assured and is not claimed.

Data collection

A 17-item participant information form collected data on age, education, employment, income, epilepsy history, ASM use, and obstetric history. A semi-structured discussion guide was developed from the literature and reviewed by experts. Core questions asked: “What did you experience during pregnancy while living with epilepsy?”, “Which issues caused anxiety during pregnancy?”, and “How did you cope with these anxieties?” Probes explored seizures, medication, fetal health, birth, infant care, social responses, and support.

Focus groups were held on 2 February and 22 February 2020 in a quiet private room at the hospital. Chairs were arranged in a U-shaped configuration to support interaction. The researcher explained the purpose and procedures, obtained written consent, and assigned participant identifiers (P1-P10). With

permission, discussions were audio- and video-recorded; field notes were taken. The sessions lasted 51 and 46 minutes.

Data analysis

Audio recordings were transcribed verbatim by the researcher and checked against the recordings. Analysis proceeded iteratively through repeated reading, identification of meaning units, open coding, comparison of codes, and grouping into categories and themes. MAXQDA 2020 supported data organization. Sixty-two initial codes were generated and subsequently organized into seven themes. Interpretations were checked against transcripts and field notes, and representative quotations were selected to preserve participants' language and contextual meaning. Quotations were translated into English for publication and reviewed for conceptual equivalence.

Rigor

Credibility was supported by the interactive focus group format, audio-recording, verbatim transcription, repeated engagement with the data, and the presentation of participant quotations. Transcripts were checked against the audio recordings, and interpretations were repeatedly compared with transcripts, field notes, and selected quotations. Dependability was strengthened by documenting recruitment, data collection, transcription, coding, and theme-development procedures. Confirmability was supported through participant identifiers, a traceable code-to-theme structure, and quotations demonstrating the relationship between interpretations and the original data. Transferability was addressed through description of the setting, sampling strategy, participant characteristics, and data-collection context. Nevertheless, the small, highly selected sample and two-group design constrain the breadth of perspectives represented. Independent double coding and participant checking were not documented in the available study records; these limitations were considered when interpreting the findings.

Ethical considerations

Ethical approval

was obtained from the Hasan Kalyoncu University Ethics Committee (Approval No. 2019/86; 14 June 2019), and institutional permission was obtained from Gaziantep University Şahinbey Research and Practice Hospital. All participants provided written informed consent and were informed that participation was voluntary, withdrawal was possible at any time, and data would remain confidential. Identifying information was replaced with participant codes.

Results

Participant characteristics

Ten women aged 25–40 years participated. Five completed primary education, two high school, and three university. Eight were not employed. Nine were using ASMs at the time represented in study data. Six reported at least one miscarriage, seven had experienced at least one seizure during pregnancy, and four reported a seizure during childbirth. Six had delivered by cesarean birth and four vaginally. Participant characteristics are summarized in Table 1.

Table 1
Participant characteristics

ID	Age	Education	Employed	Year of epilepsy diagnosis	Pregnancies, n	Seizures during pregnancy, n
P1	27	Primary	No	1998	4	1
P2	25	High school	No	2005	3	0
P3	36	University	Yes	2014	2	1
P4	33	Primary	No	2011	4	0
P5	39	Primary	No	1990	6	2
P6	33	High school	No	1997	2	1
P7	31	Primary	No	2000	4	≥ 4
P8	36	University	Yes	2000	3	1
P9	31	University	No	1999	3	0
P10	40	Primary	No	1998	5	3

Miscarriage history: P1 Yes; P2 Yes; P3 No; P4 Yes; P5 Yes; P6 No; P7 Yes; P8 No; P9 Yes; P10 Yes. “Number of seizures during pregnancy” refers to the total number of seizures experienced by each participant during pregnancy.

Qualitative findings

The analysis yielded seven interconnected themes. Because the sample was small and highly selected, these themes are presented as patterns within participants’ accounts rather than as exhaustive categories for women with epilepsy more broadly. The themes and illustrative quotations are summarized in Table 2 and described below.

Table 2
Themes, central meanings, and illustrative evidence

Theme	Central meaning	Illustrative quotation
Epilepsy as bodily unpredictability	Illness was understood through frightening physical manifestations and loss of control.	“Before, there was bruising, shaking, and my jaw would lock.” (P1)
Seizure-related anxiety	Fear of recurrence, severity, being alone, injury, and death.	“Would my seizures change? Would they become more severe?” (P3)
Fetal health	Tension between seizure prevention and perceived medication-related fetal harm.	“Would the medicines harm the baby? Would there be a developmental problem?” (P4)
Childbirth	Fear of seizures and emergency intervention during labor.	Participants linked prior difficult births and intrapartum seizures to anxiety in later pregnancies.
Child’s future health and safety	Hereditary transmission, later disability, and injury during maternal seizures.	Women worried that epilepsy could “pass to the baby” and that a seizure might harm the infant.
Social pressure and stigma	Pity, monitoring, judgment, and repeated reminders of illness.	“Sometimes I wish I had not listened to anyone.” (P5)
Coping strategies	Support and social connection were protective; medication skipping was hazardous.	“Their love and support were enough to help me cope.” (P1)

Theme 1. Epilepsy as an unpredictable bodily experience

Participants commonly defined epilepsy through visible and embodied manifestations loss of consciousness, shaking, cyanosis, jaw locking, limb contractions, falling, and injury rather than biomedical terminology. These descriptions conveyed unpredictability and loss of bodily control. One participant explained: “It was like suddenly falling. Before, there was bruising, shaking, and my jaw would lock” (P1). Another described repeated falls and limb contractions after childbirth (P4). The illness image that women carried into pregnancy was therefore shaped by frightening past events and anticipated recurrence.

Theme 2: Seizure-related anxiety

Fear of a seizure was one of the strongest and most persistent forms of anxiety. Medication changes, previous severe seizures, being alone, sleep disturbance, and uncertainty about whether pregnancy would alter seizure patterns intensified concern. A participant stated: “Would my seizures change? Would they become more severe? Would my child be disabled? Would the medicine affect my child?” (P3). For some, anxiety disrupted sleep and family relationships: “I was afraid of having a seizure at any moment… I would wake at night and could not sleep until morning… I kept saying I was going to die” (P5). Even women who did not have seizures during pregnancy arranged frequent contact with relatives because they feared what might happen if a seizure occurred while they were alone.

Theme 3: Concerns about fetal health

Participants described a difficult balance between fear of uncontrolled seizures and fear that ASMs might harm the fetus. Concerns included miscarriage, congenital anomalies, impaired growth, and developmental problems. P4 recalled asking whether medication could cause disability or interfere with fetal development. Previous miscarriages made these fears especially salient. Several women interpreted medication exposure as a direct threat and attempted to reduce that perceived threat by skipping doses, despite recognizing that this could increase seizure risk.

Theme 4: Childbirth-related anxiety

Labor and birth were imagined as moments of heightened vulnerability. Women feared having a seizure during labor, being unable to cooperate, requiring emergency cesarean birth, or harming the infant. Prior difficult births and seizures during childbirth reinforced anxiety in later pregnancies. These concerns were not restricted to the physical event; they also reflected uncertainty about whether healthcare teams would understand epilepsy and respond rapidly.

Theme 5: Concerns about the child's future health and safety

Anxiety continued beyond pregnancy and birth. Participants worried that epilepsy might be inherited, that prenatal medication exposure could cause later developmental or cognitive problems, or that a maternal seizure during infant care or breastfeeding might cause injury. Eight participants expressed concern about hereditary transmission, while six raised the possibility of harming the baby during a seizure. These accounts framed motherhood as an ongoing safety responsibility rather than a concern ending with delivery.

Theme 6: Social pressure and stigma

Relatives and social networks were both sources of support and sources of distress. Participants reported sadness when others pitied them, repeatedly reminded them that they were ill, monitored medication use, or questioned reproductive decisions. For women who were not employed and spent more time at home, repeated illness-focused interactions within the family appeared particularly burdensome. One participant described regret about acting according to others' expectations and the emotional cost of sustained pressure (P5). Such responses reinforced the sense that pregnancy with epilepsy was socially scrutinized.

Theme 7: Coping strategies-protection and risk

The most frequently reported coping strategies were not being alone and receiving support. Mothers, spouses, siblings, and friends provided reassurance and practical safety. P1 stated: "My loved ones were with me and always supported me. Their love and support were enough to help me cope." Socializing, prayer and gratitude, positive self-talk, reading, knitting, and psychological support were also described. However, coping was not uniformly protective. Some women skipped medication because they believed

this would protect the fetus. P2 said: “Because I was afraid something would happen to my children, sometimes I took the medicine and sometimes I did not.” In this sample, these accounts suggest that anxiety and perceived treatment risk can contribute to self-directed medication changes.

Discussion

The themes identified in this study largely align with concerns already described in the qualitative literature, including seizure unpredictability, ASM-related fetal risk, childbirth, hereditary concerns, stigma, and social support [3, 12–15]. The contribution of this small exploratory study is therefore not the identification of wholly new thematic domains. Rather, it provides context-specific evidence from southeastern Türkiye on how established concerns were experienced together and how they intersected with family relationships and treatment behavior. In participants’ accounts, women simultaneously felt responsible for preventing seizures and protecting the fetus from perceived medication-related harm, creating a form of double responsibility that could sustain vigilance and anxiety.

Seizure-related anxiety was central. Participants feared recurrence, increasing severity, being alone, injury, and death. Similar studies have described pregnancy and childbirth as periods marked by uncertainty, fear, concern for fetal well-being, and heightened responsibility for seizure control [3, 12–15]. Recent qualitative evidence also indicates that treatment changes and inconsistent communication can intensify fear, particularly when women lack information needed for shared decision-making [14, 15]. The present findings are consistent with that literature and suggest that repeated, individualized counseling may be important to explore further in maternity and epilepsy services.

Medication-related anxiety was closely linked to nonadherence in some participants. Several women reported skipping ASM doses in an attempt to protect the fetus, even while recognizing that missed doses could increase seizure risk. Prospective electronic-diary research has likewise documented clinically relevant missed doses among women with epilepsy planning pregnancy [18]. This pattern is therefore not unique to the present study, but its appearance in these women’s narratives illustrates how perceived fetal risk can influence self-management. Current guidance prioritizes both seizure control and fetal safety. The 2024 AAN/AES/SMFM guideline recommends minimizing convulsive seizures, avoiding valproate when clinically feasible, considering lamotrigine, levetiracetam, or oxcarbazepine when appropriate, and prescribing at least 0.4 mg folic acid daily before conception and during pregnancy for patients treated with ASMs [6]. WHO guidance likewise favors lamotrigine or levetiracetam as first-line monotherapy for women and girls of childbearing potential in relevant seizure types [7]. These recommendations support clear, comparative risk communication and caution against unsupervised treatment changes.

Participants’ concerns about congenital anomalies, miscarriage, neurodevelopment, and hereditary transmission were consistent with previous reproductive health research among women with epilepsy [2–5, 13–15]. Contemporary cohort findings can support more balanced counseling: newer-ASM exposure in the MONEAD cohort was not associated with lower overall cognitive outcomes at age 2

years, and early neonatal outcomes were broadly similar between infants of women with epilepsy and healthy comparison participants, although medication-specific risks still require individualized assessment [19, 20]. Generic reassurance may be insufficient where women are weighing competing fears. Individualized discussion of seizure history, current ASM and dose, comorbidities, reproductive plans, and personal values may help women understand risk more accurately.

Anxiety also extended into childbirth and motherhood. Women worried about seizures during labor and about harming an infant during breastfeeding or routine care. These concerns are consistent with earlier qualitative work [12–15]. Practical safety planning including sleep protection, medication routines, safe infant-care practices, and emergency plans-may be useful topics for individualized counseling, but the present small sample cannot establish the effectiveness of such interventions. Qualitative work on structured maternity epilepsy tools suggests that systematic risk assessment can strengthen early antenatal planning [21].

Social responses had an ambivalent role. Family presence reduced fear of being alone, yet pity, surveillance, and repeated reminders of illness contributed to distress. Epilepsy remains associated with psychosocial burden and discrimination globally [1, 22], and recent qualitative research continues to identify family and community misconceptions as barriers to safe and dignified maternity care [14, 15]. In this study, the same family network could function as both practical support and a source of pressure. This context-dependent duality may be particularly relevant when clinicians consider involving relatives in counseling, because support should preserve the woman’s autonomy and preferences.

Spirituality, socializing, crafts, reading, positive self-talk, and psychological support were described as adaptive coping strategies. Psychological help was sometimes sought only after distress became severe. Population-based and prospective cohort studies have demonstrated elevated depression and anxiety symptoms during pregnancy and after delivery among women with epilepsy, particularly in the presence of frequent seizures, polytherapy, unplanned pregnancy, socioeconomic adversity, or previous psychiatric illness [16, 23]. These data support continued research on feasible approaches to psychological assessment and support within epilepsy and maternity pathways.

Implications for practice and research

Given the small and highly selected sample, the present findings should not be used to justify broad practice recommendations on their own. Instead, they identify clinically plausible areas for assessment and future evaluation. These include asking women directly about medication fears and intentional dose changes; providing repeated and individualized risk communication; assessing anxiety, sleep disruption, stigma, and perceived social pressure; discussing practical seizure and infant-safety planning; and, where the woman wishes, including chosen family members in education. Larger qualitative studies across diverse regions of Türkiye and mixed-method or prospective studies are needed to determine how common these concerns are, whether they differ by ASM regimen or seizure history, and which support strategies are acceptable and effective.

Strengths and limitations

The study provides a detailed exploratory account of pregnancy-related anxiety among women with epilepsy in a southeastern Turkish setting and includes verbatim quotations linking interpretations to participants' accounts. The focus group format also allowed participants to respond to and build on one another's experiences. However, several limitations constrain interpretation. First, the neurology outpatient clinic records for the predefined screening period included 561 women with epilepsy, of whom 20 met the study eligibility criteria based on pregnancy experience and the other inclusion criteria. Ten of the 20 eligible women participated and 10 declined, corresponding to a participation rate of 50% among eligible women. Nevertheless, self-selection bias remains possible because women who agreed to attend a hospital-based focus group may have differed systematically from those who declined. The findings therefore cannot be considered representative of all women with epilepsy in the region or in Türkiye. Second, only two focus groups involving 10 participants were conducted. Although recurrent patterns were observed, full thematic saturation cannot be assured and is not claimed. Third, the study was conducted at a single university hospital, limiting transferability across different healthcare, socioeconomic, and cultural settings. Fourth, pregnancy experiences were retrospective and may have been influenced by recall. Fifth, because sensitive issues were discussed in groups, some experiences may have remained undisclosed. Finally, independent double coding and participant checking were not documented in the available study records. For these reasons, the findings should be regarded as context-bound and hypothesis-generating and should be examined in larger, more diverse samples.

Conclusions

In this small exploratory sample, women with epilepsy described pregnancy-related anxiety as an interrelated set of concerns involving seizure unpredictability, treatment decisions, fetal and child health, childbirth, social judgment, and caregiving responsibility. These themes are broadly consistent with previous qualitative literature. The study's contribution lies in showing how these concerns were experienced together within a southeastern Turkish context, including the dual role of family involvement and reports of medication skipping in response to perceived fetal risk. Because participation was highly selective and limited to 10 women in two focus groups, the findings should not be generalized or used as stand-alone evidence for broad clinical recommendations. They instead highlight questions for further research and potential areas for individualized discussion in preconception, antenatal, neurological, and psychosocial care.

Abbreviations

ASM
antiseizure medication
COREQ
Consolidated Criteria for Reporting Qualitative Research.

Declarations

Ethics approval and consent to participate

Approval was obtained from the Hasan Kalyoncu University Ethics Committee (Approval No. 2019/86; 14 June 2019) and institutional permission from Gaziantep University Şahinbey Research and Practice Hospital. Written informed consent was obtained from all participants.

Consent for publication

Not applicable. The manuscript presents anonymized participant quotations and no identifiable personal information.

Competing interests

The authors declare that they have no competing interests.

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Author Contribution

H.A. contributed to investigation, data curation, formal analysis, and writing the original draft. F.Y. contributed to conceptualization, methodology, supervision, validation, writing-review and editing, and project administration. Both authors read and approved the final manuscript.

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Data Availability

The qualitative data generated and analyzed during the current study are not publicly available because the transcripts contain sensitive and potentially identifiable participant information. The data may be available from the corresponding author on reasonable request, subject to ethical approval and institutional requirements.

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