Asian Nursing Research 13 (2019) 122–129

Contents lists available at ScienceDirect

Asian Nursing Research

journal homepage: www.asian-nursingresearch.com

Research Article

Pregnancy and Childbirth Experiences of Women with Epilepsy: A Phenomenological Approach

Woo Joung Joung*

College of Nursing, Kyungpook National University, Daegu, Republic of Korea

ARTICLE INFO

Article history:
Received 23 April 2018
Received in revised form
21 January 2019
Accepted 27 February 2019

Keywords:
epilepsy
pregnancy
qualitative research
woman

ABSTRACT

Purpose: This study sought to understand and describe the pregnancy and childbirth experiences of women with epilepsy (WWE).
Methods: Data were collected from 2016–2017 through in-depth individual interviews with 12 WWE who experienced childbirth within 36 months. Verbatim transcripts were analyzed following Colaizzi's phenomenological analysis to uncover the meaning of the experiences of the participants.
Results: The pregnancy and childbirth experiences of WWE were clustered into four theme clusters and 8 themes from 20 meaning units: 1) Feeling anxious due to unplanned pregnancy and unexpected changes; 2) Standing at crossroads that never guarantee satisfaction; 3) Carrying a burden of fearful expectation and daily routines; 4) Enjoying rewards of pregnancy and childbirth as a woman with epilepsy.
Conclusion: WWE had strong anxiety about the possible abnormality of their babies during pregnancy. They had mixed feelings about delivery and had to make a tough decision about breastfeeding because of antiepileptic drugs use. After childbirth, they had increased fear about the possible inheritance of the illness and had a hard time managing the burden of childcare and seizure control. However, pregnancy allows these women to gain disease awareness and further appreciate the importance of their health. The study results indicate the need for multidisciplinary intervention for WWE, before, during, and after pregnancy to increase communication with health professionals. Especially, preconception counselling and education led by nurses are required.

Introduction

Epilepsy is the disease of the brain that is defined by two unprovoked seizures with a high risk of recurrence [1]. Epilepsy affects one in 200 women of childbearing age, becoming one of the most common neurological conditions in pregnancy [2,3].

The physiological changes of pregnancy may influence a woman's preexisting medical condition and also affect a pregnant woman's absorption, distribution, metabolism, and excretion of medications. For women with epilepsy (WWE) on antiepileptic drugs (AEDs), if medications are not adjusted appropriately, these changes can lower a pregnant woman's seizure threshold during pregnancy or increase serum drug levels and potential toxicity after delivery [4].

The challenge for WWE during pregnancy and childbirth is to maintain a balance between controlling seizures and reducing the risks to the fetus from the influence of AEDs. Therefore, many studies have evaluated the use of AEDs during pregnancy and their general influence on the mother's health and fetal development [5–8].

Most WWE continue taking AEDs during pregnancy and have uneventful pregnancies [3,8]. However, the use of AEDs in pregnancy is associated with the risk of complications such as preeclampsia, the need for induction, or caesarean section during delivery [9]. Pregnant WWE on AEDs are at a higher risk of having a spontaneous abortion than those who are not on such medication [10,11]. There is a higher mortality rate among such pregnant mothers than those with hypertensive disorders of pregnancy [12], and the number of deaths in WWE has been increasing [13]. Fetuses that are exposed to AEDs in utero have twice the higher risk of developing congenital malformations, such as neural tube defects, urogenital abnormalities, craniofacial dysmorphic features, or cleft lips, than those that are unexposed [14].

Chronic conditions such as epilepsy place increasing strain on relationships during pregnancy, ultimately lowering relationship

Woo Joung Joung: https://orcid.org/0000-0002-6189-7013
* Correspondence to: Woo Joung Joung, Kyungpook National University, 680 Gukchatbosang-ro, Jung-gu, Daegu, 41944, Republic of Korea.
E-mail address: kimsoft1@naver.com

https://doi.org/10.1016/j.anr.2019.02.005

satisfaction, which is associated with overall life satisfaction. WWE, both during and after pregnancy, have lower life satisfaction and self-esteem than those without epilepsy [15], and they have depression and anxiety more so than women without epilepsy. Unfortunately, depression in WWE may not be recognized during pregnancy [16].

There has been an increasing awareness of epilepsy risk in pregnancy and how important preconception care is for these women in the health-care community, but little attention has been paid on how to provide optimal and specialized care for these people. Previous reports claim that about half or up to 90% of WWE of childbearing age were at risk of unintended and unplanned pregnancy [17,18], suggesting that the care for WWE, in general, is insufficient. This indicates the need for a close study of WWE so that we can have an increased understanding about these people's experience during this important period of life. Therefore, this study sought to explore the experiences of WWE throughout their pregnancies and childbirth.

Methods

Study design

This inductive qualitative research, using Colaizzi's [19] phenomenological approach and analysis, examined the experience of pregnancy and childbirth in WWE. This approach is a research method in which one describes phenomena as they present themselves without concentrating on the manipulative determinants of the phenomena. This approach allows an overall deeper understanding of pregnancy and childbirth experiences of WWE by endeavoring to descriptively identify the experiences.

Setting and participants

Purposeful sampling was used to collect information-rich cases [20]. Participants were recruited with the help of neurologists at three university hospitals in Seoul and Gyeonggi province in South Korea. The investigator visited these neurologists, explained the research purpose and methods, and presented recruitment advertisement. The criteria for the participants were as follows: WWE who have given birth to a live infant within 36 months of the study; treatment with AEDs for at least 6 months before conception, during pregnancy, and after childbirth; absence of any psychological disorders; ability to participate in an in-depth personal interview; and willingness to share one's own experience. Fourteen participants were initially recruited. Two of these recruits were excluded for concurrent disease.

The participants' demographic details are shown in Table 1. The average age was 33.83 years (ranging from 28 to 37 years). The duration of illness ranged from 4 to 23 years, with a mean of 15.25 years. One participant's epilepsy was characterized by severe generalized convulsive seizures; two had infrequent, generalized convulsive seizures; three had complex partial seizures; and the remaining four had subjective sensory or psychic symptoms without motor signs. The gestational period ranged from 33 to 42 weeks (Table 1).

Ethical consideration

The study was approved by Seoul National University institutional review board (Approval no. 1612/001-008). The participants' rights were explained at the time of the interview. These included anonymity, confidentiality, privacy, self-determination regarding their voluntary participation, ability to withdraw from the study, and interview recording. After verbal and written information had been given, informed consent was obtained from all 12 participants before the study.

Data collection

Researcher's training and preparation

The principal investigator, having field experience of working as a nurse in the neurosurgical intensive care unit, has deep knowledge on epilepsy and patients with epilepsy. The investigator has acquired a doctorate degree with an emphasis on qualitative research and has completed and published several qualitative studies in academic journals.

Data were collected between December 2016 and August 2017. Face-to-face in-depth individual interviews began with open-ended questions. The main question that the participants were required to answer was “What is your experience of pregnancy and childbirth as a woman with epilepsy?” And, facilitative questions such as “Could you explain it in detail?” and “Could you give me an example?” were used to obtain more descriptive information. Each interview lasted one hour and forty minutes on average. Additional telephone interviews were conducted with two of the participants. The interviews were tape-recorded and transcribed verbatim as soon as possible. All interviews except one were performed at the participants' homes. One interview took place at a secluded café near the participant's home. The researcher continued to correspond with two participants after their interviews to clarify the interview data and increase understanding of the phenomena. All interviews were conducted and transcribed in Korean. The findings

Table 1 *Characteristics of Mothers and Newborns (N=12).*

No.	Age (yrs)	Occupation	Marital status	Duration of illness (yrs)	Seizure type	Gestation period (weeks)	Child's age (months)	Planned pregnancy	Type of delivery	Breast feeding	Adverse outcomes at time of delivery
1	Mid-30s	None	Married	22	3	34	10	Yes	C/S	No	NICU due to preterm delivery
2	Early 30s	Part-time	Married	17	2	38	25	No	C/S	No	NICU with urogenital abnormality
3	Mid-30s	None	Married	22	4	38	22	No	C/S	No	None
4	Early 30s	Full-time	Married	17	2	40	16	Yes	NFSD	Yes	None
5	Late 30s	None	Married	19	1	37	9	No	C/S	No	None
6	Early 30s	None	Married	21	3	39	20	No	C/S	No	None
7	Mid-30s	Full-time	Married	9	3	38	4	No	NFSD	No	None
8	Early 30s	Full-time	Married	4	4	33	4	No	C/S	No	NICU with preterm delivery
9	Early 30s	None	Married	23	2	38	13	No	C/S	Yes	None
10	Late 20s	None	Married	9	4	39	2	No	NFSD	Yes	None
11	Late 30s	Full-time	Married	10	3	38	3	No	C/S	No	None
12	Mid-30s	Full-time	Married	10	2	39	28	Yes	NFSD	Yes	None

Note. Seizure type: 1 = severe generalized convulsive seizures which are often accompanied by secondary traumatic injury; 2 = infrequently occurring generalized convulsive seizures with no secondary traumatic injury; 3 = complex partial seizure without generalization; 4 = subjective sensory or psychic symptoms without any motor signs
AED = antiepileptic drug; C/S = caesarian section; NFSD = normal full-term spontaneous delivery; NICU = neonatal intensive care unit; yrs = years.

were translated into English by the author, later reviewed, and edited by a native English speaker.

Data analysis

Data were analyzed following Colaizzi's [19] phenomenological analysis, in which the cyclical process of simultaneous data collection and analysis are conducted and repeated until no new information is obtained [21]. The author read all of the participants' descriptions several times to acquire a general impression of their experiences and make sense out of them. Then, significant phrases and sentences that pertained to the experience of pregnancy and childbirth in WWE were extracted and eliminated repetitions. And the author transformed participants' statements into a more general formulation. In the third step, the author attempted to discover what was hidden in each significant statement and created formulated meanings. Then, formulated meanings were sorted into clusters of specific themes. In the fifth step, the author integrated all of the results into a narrative exhaustive description. Then, the author identified the fundamental structure of the experience in unequivocal statements. In the final step, the author validated the study by asking the participants if the findings captured the essence of their experience.

Methodological rigor

Four criteria of credibility, fittingness, auditability, and confirmability helped ensure trustworthiness of this study [22]. To ensure credibility, purposeful sampling was used to recruit information-rich cases. Face-to-face interviews primarily with open-ended questions were conducted. The investigator showed the study results to two of the participants, and the participants confirmed that the interpretations were plausible and coincided with their experiences. In addition, peer review from two nursing scholars with experience conducting qualitative research was conducted to reduce the uncertainty of the interpretations. The peers examined the raw data and study findings and confirmed that the results were plausible. Fittingness was established based on the data that represented the phenomena. In this study, the author tried to find participants who had vivid stories to tell, and data were collected until saturation. In addition, the author sought to develop detailed, meaningful descriptions of each participant's experience. To achieve auditability which refers to the consistency of findings, Colaizzi's analytic steps were closely followed, and all the research procedures were carefully documented. Confirmability indicates whether the process and findings of research are free from bias. In this study, the author sought to minimize the influence of personal prejudices or biases to the research process and findings by consciously realizing and recording her own idea on the topic from the beginning to the end of research. In addition, the author cited participants' comments so that the readers can confirm that the findings were taken from data.

Results

The author obtained 20 meaning units through the phenomenological data analysis of 12 participants and integrated these units into four theme clusters and eight themes. The following is an integrated narrative description of the participants' experience (Table 2).

Theme Cluster 1: feeling anxious because of unplanned pregnancy and unexpected changes

This theme cluster is about the participants' experiences during pregnancy and is mainly about anxiety regarding possible abnormality in baby and seizure changes.

Theme 1: overwhelmed with anxiety regarding possible abnormalities in the baby due to AEDs use

After learning that they were pregnant, most participants were initially overwhelmed about the possibility of a congenital malformation. Most participants recalled they had hesitation regarding pregnancy because of their disease and treatment with AEDs but have not prepared for it. Ultimately, most participants felt a strong regret and were unsure of the future. Some participants were so fearful and frustrated that they considered abortion.

> *When I found that I was pregnant, I was so panicked that I couldn't say anything except, 'oh my God'. I should have stopped taking my medicine or adjusted the dose after consultation with my neurologist, but I didn't do anything. I went to see my neurologist not waiting until the next appointment, because it was an emergency. I wasn't happy at the news, how could I be happy when I had become*

Table 2 *Theme Clusters and Themes on the Experience of Women with Epilepsy through Pregnancy and Childbirth.*

Theme clusters	Themes	Meaning units
Feeling anxious because of unplanned pregnancy and unexpected changes	Overwhelmed with anxiety regarding possible abnormalities in the baby due to AEDs use	• Puzzled by unplanned pregnancy • In need of experiential and credible information • Conflict regarding medication compliance • Anxiety on the adverse effects on the fetus
	Taken aback by unexpected changes in seizure severity and frequency	• Refusal to increase or change medications
Standing at crossroads that never guarantee satisfaction	Mixed feelings about separation from the baby	• Escaping from the influence of AEDs • Pity for the baby for not providing a safe growing place
	Struggling with the potential harm of AEDs and breastfeeding	• Conflicting views from medical professionals • Self-blame after giving up breastfeeding • Continued concerns about safety of breastfeeding
Carrying a burden of fearful expectation and daily routines	Increased fear of passing down the disease	• Feelings of anxiety about inheritance not to be shared by others • Being alert so as not to miss the warning signs of a seizure • Absence of concerted postnatal care system
	Management of the burdens of both childcare and seizure control	• Worry about seizure occurrence as a result of childcare burden • Threatened newborn safety during seizures • Anxiety about seizure repetition and lowered confidence on parenting
Enjoying rewards of pregnancy and childbirth as a woman with epilepsy	Greater illness awareness and self-growth	• Realization of the importance of being healthy as a mom • Learning to enjoy happiness amid the mixture of anxiety and self-blame
	Being thankful for the helping hands	• Concerns and caring of family members • Relief after communication with health professionals

Note. AEDs = antiepileptic drugs.

pregnant while taking AEDs? At that time, I was so frustrated that I considered abortion. (Participant 9)

Consultation with the neurologist was effective in decreasing most participants' anxiety about congenital malformations. However, such consultations did not necessarily eliminate one's day-to-day anxieties. Most participants, being aware of the stigma surrounding epilepsy, did not share their disease with others except family members. Therefore, participants who were in need of experiential and credible information searched for information on the internet. However, although the internet provided a lot of valuable information, it was also a source of misinformation and new anxieties for these women.

My neurologist told me that the medication I took was safe for the fetus and there was no need to worry. However, I had underlying anxiety about malformations. I had no one to talk to about my disease, so I usually got information from the internet. I read lots of negative information on the internet like, 'a woman with epilepsy gave birth to malformed baby or a baby with serious health problem'. I was not sure this was real or not, but these kinds of stories on the internet made me more anxious. (Participant 1)

In addition, most participants had conflict regarding medication compliance. Although they understood that AEDs are necessary for seizure control, they also felt nervous taking them. The saying that 'no pregnant woman should take any medication with ease,' and the fact that AEDs affect the brain, made the participants hesitant in taking their AEDs. Some participants were so anxious about having malformed babies that they stopped taking their medication but later became nervous about having a seizure.

For about two decades I have been taking AEDs without hesitation. I have never seriously thought about the effects of this medication; I just took it and sometimes skipped it without thinking about it seriously, but with pregnancy, I hesitated every time I took it. Take it or not? Which is worse? Many times during pregnancy I skipped my medication and I was afraid that I might have a seizure, but the feeling of relief that my baby was not under the influence of the medication was much more important for me. (Participant 5)

Theme 2: taken aback by unexpected changes in seizure severity and frequency

Most participants experienced unexpected variability in seizure severity and frequency during pregnancy. Women who experienced seizures while pregnant had added anxiety and guilt regarding their innocently exposed fetus. For these participants, there was no time to worry about their own health. As expected, most women grew fearful of recurrent seizures.

I just worried about negative medication effects on my baby, but never expected the change in seizure severity and frequency. During pregnancy, my seizures got worse and I was very anxious and downhearted. Having a baby in my womb, I panicked every time I had a seizure. Because I am fully conscious during seizures, I know what is happening. I crouched down holding my belly, and told my baby, "It's ok, baby, it's going to end soon." I just wished the seizure would end as quickly as possible, and nothing bad would happen to my baby. I felt so sorry for my baby. How would my baby feel in my belly? (crying). I became really nervous about seizure recurrence. (Participant 3)

Changes in seizure severity and frequency required medication adjustment. Most patients were more hesitant about medication changes during pregnancy than they normally were. They found themselves trapped between two bad outcomes. On the one hand, patients felt that increasing doses would be dangerous for the baby. On the other hand, a failure to adjust their medications would increase the risk of additional seizures. Several women took the risk of having more frequent seizures instead of increasing their medication doses.

When the neurologist suggested increasing medication because of uncontrolled seizures during pregnancy, I refused. He tried to make me feel secure, saying that my medication would not affect the fetus, but no matter how safe it was, it was still being passed on to my baby. If the dose were increased, my fetus would take in more medication. I could accept taking medication, but I would not accept an increase in dosage. (Participant 4)

Theme Cluster 2: standing at crossroads that never guarantee satisfaction

This theme cluster is about the participants' experiences at the time of delivery and is mainly about feelings of separation from the baby and the hard decision of breastfeeding.

Theme 1: mixed feelings about separation from the baby

Most participants had mixed feelings about delivery. On the one hand, they were relieved by the thought that the baby was no longer under the influence of AEDs after delivery. Because they had strong concern about the possible negative effect of AEDs on the fetus, delivery meant the end of anxiety and concerns of passing AEDs to their fetuses. On the other hand, they felt so sorry and guilty about their child with the thought that they failed to provide their fetus with a safe place (womb) to grow.

I eagerly waited for the delivery because I was so afraid of seizure recurrence and AED effects on my baby. To minimize the effect of AEDs on my baby, I thought, the sooner the better I have the child. However, when I first saw the baby, he was so tiny that I felt really sorry and pity for him because I wasn't able to provide a safe environment for him to grow. (Participant 1)

Theme 2: struggling with the potential harm of AEDs and breastfeeding

Delivery seemed to mean the end to participants' anxiety regarding fetal exposure to the negative effect of AEDs. However, when they faced the decision about breastfeeding, the participants realized that breast milk was unfortunately another source of potential risk for their infants. Taking their AED medications seemed to contradict the best care for their babies again. The participants weighed the pros and cons of breastfeeding. Different experts held different views regarding the safety of breastfeeding while taking AEDs, which made the decision even more difficult. The decision was left at the mother's discretion. Taking AEDs during pregnancy was not optional. However, one could choose whether or not to breastfeed. Therefore, breastfeeding was a tough decision to make.

When I delivered my baby, I was relieved by the thought that my baby was no longer under the influence of AEDs. However, it didn't take much time to realize that AEDs still had control over me. I did want to breastfeed my baby because I thought breastfeeding was best for her, but because of AEDs, I could not breastfeed. I felt really frustrated. I had a strong desire to give my baby only the best, but I felt my illness was a stumbling block in every aspect. (Participant 3)

The opinions of health professionals were different. The neurologist and obstetrician said it would be ok, but the pediatrician was

against it. In a situation where the medical professionals didn't give me a united opinion, the decision was up to me. That's what made matters worse. (Participant 1)

The participants unfortunately felt uncomfortable whether they chose to breastfeed or not. Some participants gave up breastfeeding even without consulting their neurologists. Others gave up after continuing to weigh the pros and cons. Most women felt guilty, and some still blamed themselves for giving up. Women who decided to breastfeed continued to worry about the negative effects of AEDs on their infant's health. While breastfeeding, therefore, these women continued to have mixed feelings. They also never found absolute relief.

While the baby was in my womb, I could not prevent the medication from passing to the baby, but it was a tough decision because breastfeeding was a matter of choice. When my seizures got out of control, the neurologist added medication, which was not guaranteed safe for infants. I felt so guilty. If I had not had that disease I could breastfeed; it was my fault, I thought. Still I can't free myself from self-blame. (Participant 8)

After long consideration, I decided to breastfeed and now I'm breastfeeding but I still have concerns about the safety of breast milk because the AEDs I'm taking is contraindicated for pregnant women. After switching medications my seizures are controlled well, but every day I consider whether I should give formula or not. (Participant 10)

Theme Cluster 3: carrying a burden of fearful expectation and daily routines

This theme cluster is about the participants' experiences after childbirth and is mainly on worries about the inheritance of the disease and management of both childcare and seizure control.

Theme 1: increased fear of passing down the disease

After childbirth, the participants began to face the possibility that their children had inherited epilepsy. The abstract fear during pregnancy became more concrete once women met their infants. Few participants know the clear etiology of their disease, and there was no certainty regarding the hereditary nature of epilepsy. This uncertainty deepened their anxieties. Even the neurologists were unable to provide a clear answer about the possibility that the participants had passed their diseases to their children. Many participants had anxiety that they did not wish to share with others, including their husbands. A few of the participants even developed guilt regarding things that had not yet happened.

Since I got pregnant, and when I found out that the fetus was a girl, I have been afraid that she might have this disease like me. While feeding, if she flinches, I become so anxious that I wonder if I should take her in for a check-up. Still no one knows if she has the disease or not, but I already have guilt that all her health problems will be because of me. Sometimes I cannot bear this negative feeling, but I don't have the courage to share my anxiety and guilt even with my husband. (Participant 11)

The participants get very sensitive regarding their child's gestures, with the thought that the absence of a visible abnormality does not rule out the disease. The baby may have an abnormality in the depths of the brain that is not readily apparent. Therefore, the participants tend to be alert so as not to miss the warning signs of a seizure depending on their own experiences. Some participants expressed displeasure about the absence of a concerted postnatal care system. These concerns reflect the worries and anxiety experienced by most participants with regard to the uncertainty of disease inheritance.

I am relieved that he has no visual abnormalities but I can't feel totally free from anxiety about the disease being passed down to my child. I am very sensitive to his small gestures like pee shivers. I think I'm always tied with this disease. Even though there's some problem inside his brain, my little boy cannot express how he is feeling, that's what makes me nervous. I also didn't know that what was going on within my brain until I got diagnosed. That's why I always keep track of my baby's gestures. (Participant 7)

I think babies born from mothers with epilepsy should undergo special medical check-ups periodically. But pediatricians don't seem to consider the disease when they examine my baby. I do wish to hear that my baby is totally free from the disease depending on the results of accurate examination. When my child waves his arms lying on the bed, I wonder if I should have him undergo an EEG exam. One of my relatives has epilepsy like me, I don't know whether this means my condition is hereditary or not, but with the small possibility of it being linked to my family history, I feel like I'm living with a ticking time bomb. (Participant 1)

Theme 2: management of the burdens of both childcare and seizure control

The participants were concerned about balancing their own health and that of their babies. With fatigue and lack of sleep due to childcare, some participants experienced either a change in their seizures or increased seizure frequency after delivery. With the exception of a few participants with childcare support, most women were busy with the double burden of taking care of the baby and themselves. Seizures bring unwanted pauses in childcare. of Unfortunately, an infant may be at risk of injury if he/she is being held by a mom having a seizure or is in the vicinity during a seizure. This risk of injuring one's own child (although unintentionally) can lower a woman's confidence with regard to parenting.

I didn't expect this kind of situation before I gave birth to my baby because when I'm awake, I rarely have seizures and I was somewhat confident about raising a child. At night, I cannot get sleep deeply because I have to feed him. During the day, I get so tired and then I feel like I might have a seizure. Balancing my physical health and taking care of a baby is not an easy job. (Participant 8)

Even though I am conscious during seizures, if a seizure starts, everything stops. If the seizure lasts for one to two hours I can't do anything until it ends. My seizure severity is not that strong but the time loss is the same. I feel so anxious about seizure repetition and I'm not confident of becoming a good mother. (Participant 3)

Theme Cluster 4: enjoying rewards of pregnancy and childbirth as a woman with epilepsy

This theme cluster is about the psychological rewards WWE received through pregnancy and childbirth and about thankfulness for the help they got from their family members and health professionals.

Theme 1: greater illness awareness and self-growth

Before pregnancy, some women admitted that they did not take their disease seriously, especially if their symptoms had been rare or well controlled. However, these women became aware of their disease and its significance through their pregnancy and childbirth. The participants realized that they had to be strong to take care of

their infants. This realization led to improved awareness of the importance of medication compliance.

Before I became a mom, I didn't take my disease seriously. Even though I was the patient, I didn't care about it and skipped medication quite often. However, throughout pregnancy, I kept thinking of myself and my disease. Now as a mom of my son, I know I should prevent a possible seizure. I never skip my medication. The most important thing I should do for my son is to prevent having seizures because I realized that health is a basic requirement for being a good mom. (Participant 5).

Some participants had a hard time coping with their children's health problems at the time of delivery. Although there was no proof that the child's health problem was related to their disease, these women felt responsible and guilty. Regardless, despite challenging pregnancies, given the participants' epilepsy, seeing their infants made them proud and happy. The participants learned to enjoy happiness amid the mixture of anxiety and self-blame.

Soon after my baby saw the light of the world, he had an operation because his testicles were undescended. After that he had to have one more operation for another urogenital problem. It was a really tough time for me. I blamed myself a lot. However, that is all behind us and now he is growing well, that's the thing that I should be thankful for. Whenever I see my son, I feel pride and happiness in being a mom. (Participant 2)

Theme 2: being thankful for the helping hands

Most participants were very thankful for the help of family members during pregnancy. The participants said that they were disappointed when their family members showed strong concern instead of welcoming the pregnancy, but they said that they could understand them. The participants said that they could overcome negative feelings such as depressive mood, anxiety, and sadness with the generous care of family members.

All my family members, especially my mom was opposed for me to have a baby because of my illness. When I told her I was pregnant, she didn't welcome it, and I was hurt. Through the entire pregnancy, she worried so much about me and the fetus that she never let me be alone. My family members took turns guarding me, trying to calm my anxiety. I could recover from a depressed mood after every seizure with love, sincerity and the deepest care my family members provided. (Participant 5)

In addition, most participants showed great appreciation to the health professionals' help. The participants said that consulting with their neurologist, although the meetings were not long, was effective in helping them alleviate their anxiety. They said that not only did the professional knowledge and medication adjustments by their neurologists' helped but also the health professionals' empathetic attitude worked to ease their fears.

The neurologist listened carefully to what I said, and was very empathetic. He explained the changes I would undergo with pregnancy, the medication's safety, even blood concentrations in simple terms, and in detail. It seemed to me that he tried hard to keep me very informed so that I was not afraid about the safety of my baby. (Participant 8)

Discussion

Attention to the health of WWE of reproductive age has been increasing recently among health professionals [4–8]; however, it seems that adequate preparation for pregnancy before conception in WWE has not been achieved. The fact that most participants became pregnant without prior preparation or planning tells the lack of pregnancy preparation. The results of two previous studies indicate that 69.8% of WWE were at risk of unintended pregnancies [17] and > 90% of WWE studied had not planned their pregnancies. Many of them had associated guilt [18]. There is also a need for education and counseling for this population. As in the previous study [23], participants who had planned their pregnancies had less anxiety about fetal malformations than those who did not plan for pregnancy. This also illustrates the importance of a well-informed pregnancy preparation.

In this study, the neurologist played a critical role in the emotional stability of the participants; however, participants' need for information and counseling were not met, mainly because of the lack of time spent with their neurologist and absence of a proper support system. Therefore, a support system is necessary to provide credible and evidence-based information so that WWE can get adequate and proper care to maintain an optimal health condition in their critical period of time. In this study, the nurse's role seemed vague, and this is where nursing should become involved. Epilepsy specialist nurse–led project or support system in concordance with multidisciplinary team for helping WWE [24] plan pregnancy and postpartum follow-up is in desperate need. If special nursing care programs for WWE of childbearing age can be developed and included in various health-care programs run by health-care centers of the local government, comprehensive care can be delivered to this population.

Most participants struggled to make a decision regarding breastfeeding. It is a tough decision whether or not they should breastfeed while taking AEDs. Furthermore, it is not easy to simply compare the effects of AEDs on the child's heath with the benefits of breastfeeding. Ultimately, there is also a need for a more consolidated and comprehensive summary of the different medical opinions regarding breastfeeding with AEDs. An integrated mother–infant care system with close cooperation and communication of multiprofessional team is required for the best care of WWE in the perinatal and postnatal period. Such a resource may allow women to make a more informed decision and avoid feelings of guilt one way or the other. The close periodic monitoring of mother–infant health would also prevent severe side effects and be helpful for reducing the mother's anxiety [25].

The cause of approximately two-thirds of epilepsy is unknown [26], and this increased a woman's anxiety about the heritability of her disease. Previous study [18] has reported that WWE experienced more fear than those without epilepsy during pregnancy; after delivery, there was no difference in fear between the two groups. However, although the anxiety about the effect of AEDs on the fetus disappeared after delivery, most participants of this study developed new anxiety about disease inheritance in their child. Health professionals should not overlook anxiety about inheritance as most WWE in this study experienced self-blame and fear that they did not even share with close family members. Therefore, an integrated health service, including medical follow-ups for infants born to WWE, screening for maternal mental health status, and mother–child home visiting care for WWE with pregnancy or childbirth would facilitate improved maternal coping with the infant's potential health problems and the mother's own emotional and psychological distress. Therefore, as in the precedent example in Ireland [27], a national epilepsy care program needs to be developed and implemented so that comprehensive care can be delivered to this population.

WWE and their partners should be given extra attention in follow-up after delivery [15]. Many participants had both physical and psychological difficulties balancing childcare and self-care because of lack of sleep and the physical burden of childcare. Postpartum seizures in WWE risk the health of not only the

mother but also the infant. Therefore, WWE need to be provided with guidance about safety precautions concerning infant care [28]. For example, WWE should be guided to have consultations with their neurologist about the burden of childcare and self-care to acquire better coping measures. In addition, patient education about making emergency calls to 119 whenever she feels a seizure beginning, keeping the home safe, and maintaining risk-reducing circumstances should be relayed. Furthermore, patients should be guided to check if the community health center can dispatch a nurse to visit the home who specializes in infant–mother care. If there is no such service, health professionals should make home visitation by a maternity and epilepsy specialist nurse possible.

WWE had the opportunity to increase their awareness of their disease and realized the importance on their health through the pregnancy and childbirth. This finding proves that pregnancy and childbirth can be positive experiences for WWE. Therefore, to ensure the best possible outcome of these pregnancies, informed nursing care, specializing in the management of prenatal, natal, and postnatal period of WWE, should be provided.

Conclusion

This phenomenological study explored the pregnancy and childbirth experience of WWE. The results of this study demonstrate that WWE had strong anxiety about the possible abnormality of their babies because of unplanned pregnancy and AEDs effects during pregnancy. By the time of childbirth, they had mixed feelings about delivery and had to make a tough decision about breastfeeding because of taking AEDs. After childbirth, they had increased fear about the possible inheritance of the illness and had a hard time managing the double burden of childcare and seizure control. Despite some of the challenges, pregnancy with epilepsy also allowed women to gain disease awareness and further appreciate the importance of their health.

The results of this study indicate the need for multidisciplinary intervention for WWE before, during, and after pregnancy to increase communication with health professionals, resulting in lowered anxiety and better coping. Especially, preconception counseling and education led by nurses are required. This finding would be helpful for WWE who are contemplating pregnancy and also for health professionals in developing appropriate counseling and educational programs to support this population.

Amid a scarcity of qualitative research about epilepsy in general, this study used first-hand accounts from WWE to increase understanding of pregnancy and childbirth experience and elucidated basic needs and concerns of these people.

Conflict of interest

None.

Acknowledgments

The author would like to thank the 12 participants, who did not hesitate to share their personal experiences. The author specially thanks Dr. Huh, Kyun, Dr. Lee, SangAhm, and Dr. Heo, Kyoung for their support and encouragement for carrying out this study.

Funding

This work was supported by the National Research Foundation of Korea (NRF) funded by the Ministry of Science and ICT (MSIT) (No. 2018R1C1B5083776).

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.anr.2019.02.005.

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