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Pregnancy-related knowledge, risk perception, and reproductive decision making of women with epilepsy in Korea

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ABSTRACT

Purpose: To determine the influence of pregnancy-related knowledge and the risk perception on reproductive decision making in women with epilepsy.
Methods: We enrolled women with epilepsy, who were of reproductive age and were considering having children in the future. A questionnaire was used to assess the level of pregnancy-related knowledge, perception of the offspring's risk for developing epilepsy or for having a congenial anomaly, and discussion with a physician concerning pregnancy-related issues. We evaluated the following outcome variables: (1) the decision to discontinue anti-epileptic drug (AED) during a future pregnancy regardless of the medical indication; and (2) the decision to have fewer children because of epilepsy.
Results: We enrolled a total of 186 women with epilepsy. (1) Fifty-eight percent of the women were considering discontinuing AED during a future pregnancy regardless of the medical indication, and 25% of the women decided to have fewer children because of epilepsy. (2) The decision to discontinue AED during a future pregnancy was associated with low-level pregnancy-related knowledge. (3) The decision to have fewer children because of epilepsy was associated with an exaggerated perception of the offspring's risk for developing epilepsy. (4) The women who had ever discussed pregnancy-related issues with their physician were less likely to decide to discontinue AED during a future pregnancy; however, a discussion on this issue had no impact on their decision to have fewer children because of epilepsy.
Conclusion: More than 50% of the women would decide to discontinue AED during a future pregnancy, and 25% of the women stated that they would have fewer children because of epilepsy. These data highlight the importance of education on pregnancy-related issues and genetic risk counseling.

1. Introduction

Women with epilepsy represent a sizable portion of the general population; in the United States, an estimated 1.1 million women of childbearing age have epilepsy.[1,2] Overall, epilepsy affects 1–2% of the population, and more than 50% of the women with epilepsy are of reproductive age, i.e., between 19 and 44 years of age.[3,4]

Women with epilepsy may face difficulty in reproductive decision making. Anti-epileptic drugs (AED) are potential teratogens, and their children are at higher risk for developing epilepsy than the general population because of the genetic factor in the pathogenesis of epilepsy.[5,6] Previous studies have indicated that women with epilepsy are tempted to discontinue AED during pregnancy regardless of their medical condition and that they tend to have fewer children because of epilepsy. Published reports have documented that 15–29% of the women with epilepsy have stopped or lowered the dosage of their prescribed AED during pregnancy,[4,7] and that 34% of the patients with epilepsy reduced the number of children they planned to have because of their epilepsy.[8]

However, there is a paucity of information regarding the effect of pregnancy-related knowledge and risk perception on reproductive decision making. In fact, women with epilepsy may not be well informed about pregnancy-related issues, and they tend to overestimate their future offspring's risk of epilepsy. Previous studies have shown that clinicians are not providing sufficient

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information regarding pregnancy-related issues, although most women with epilepsy want to acquire more information.[9] Helbig et al. reported that the patients with epilepsy overestimated by 26% the epilepsy risk in the offspring of an affected parent.[8] A lower-level pregnancy-related knowledge and an exaggerated perception of their offspring's risk for developing epilepsy may have contributed to this reproductive decision making. The study on this association between an exaggerated perception and reproductive decision making may give clinicians clues regarding how to and to whom to provide reproductive counseling. However, most of the studies about reproductive issues in women with epilepsy have focused primarily on the clinical management of epilepsy during pregnancy and related issues regarding seizure control.[10,11]

The objective of this study was to determine the influence of pregnancy-related knowledge and risk perception on reproductive decision making in women with epilepsy.

2. Methods

2.1. Study population

We enrolled women who were diagnosed with epilepsy and visited the neurology clinic at Seoul National University Hospital or Seoul Metropolitan Government Seoul National University Boramae Medical Center. The eligible participants were between the ages of 20 and 45 years old, and they were able to read and understand the study questionnaires written in the Korean language. The present study was conducted from 2011 to 2012. The eligible participants were approached, and the women who consented to participate were asked to respond to the study questionnaires. We included in the analysis the women who were considering having children in the future.

This study was approved by the Institutional Review Board of Seoul National University Hospital and the Institutional Review Board of Seoul Metropolitan Government Seoul National University Boramae Medical Center.

2.2. Questionnaire contents

The self-report questionnaire included the following items.

2.2.1. Outcome variables

The participants were asked the following two outcome variables regarding reproductive decision making: (1) they would discontinue AED during future pregnancy regardless of the medical indication; (2) they had planned to have fewer children because of epilepsy. Relative the second question, the participants were asked to state the actual number of children they had, the total number of children they had planned to have, and the total number of children they would like to have if they had not been diagnosed with epilepsy. If the participants replied that they would like to have more children if they had not been diagnosed with epilepsy, they were classified as having made the "decision to have fewer children because of epilepsy".[8]

2.2.2. Predictor variables

2.2.2.1. The importance of various factors in reproductive decision making. The questionnaire asked the participants the extent to which the following factors influenced their decision to discontinue AED during a future pregnancy regardless of medical indication: the effect of anti-epileptic drugs on the fetus during pregnancy; the effect of pregnancy on seizure control; and the effect of seizures on the fetus during pregnancy.

Subsequently, the questionnaire asked the study participants the extent to which the following factors had on their decision to have fewer children because of epilepsy:[8] the offspring's risk for developing epilepsy; family history of epilepsy; their reduced ability to care for a child because of epilepsy; the effect of AEDs on the fetus during pregnancy; the effect of pregnancy on seizure control; the effect of seizures on the fetus during pregnancy; potential complications during labor and delivery. The extent of influence was designated as very important, important, medium, not important, and not important at all. The factors with very important or important influence were classified as "factors that had an important influence on decision making".

2.2.2.2. Perceived risk of having a child with epilepsy or with a congenital anomaly. The questionnaire assessed the perceived risk of the following factors: the offspring's risk for developing epilepsy if the mother does not have epilepsy; the offspring's risk for developing epilepsy if the mother has epilepsy; the offspring's risk for having a congenital anomaly if the mother does not have epilepsy; the offspring's risk for having a congenital anomaly if the mother has epilepsy without AED; and the offspring's risk for having a congenital anomaly if the mother has epilepsy with AED. The risk was classified as $\leq$1%, approximately 3%, 5%, 10%, and $\geq$20%.

2.2.2.3. Pregnancy-related knowledge. Ten true–false items were developed to assess the level of pregnancy-related knowledge. A correct response for one item was assigned as a score of 1, and a false response was scored as 0. The total score was calculated using a range from 0 to 10. The internal consistency of score was 0.6 (Cronbach's alpha). A knowledge score of 6 or more was classified to be a high level of knowledge.

The following subjects were proposed; the right answer appears within parentheses. (1) Most of the women with epilepsy have healthy children (True). (2) All AEDs increase the risk of fetal anomaly (False). (3) The women with epilepsy should stop AED in early pregnancy (False). (4) Taking folic acid before and during pregnancy may reduce the occurrence of fetal anomaly (True). (5) For AED, mono-therapy is safer than poly-therapy in terms of fetal anomaly (True). (6) Most of the women who take AED can breastfeed (True). (7) The women with epilepsy should not have children (False). (8) The epilepsy symptoms worsen during pregnancy in most of the women (False). (9) Most of the women who remain seizure-free for at least 1 year before pregnancy will not experience seizure during pregnancy (True). (10) The women with epilepsy have an increased risk of spontaneous abortion and preterm birth (False).

2.2.2.4. Information preference style and medical decision making preference style. Based on a measure adapted from Cassileth,[12] we used two items that asked the responders to rate the desired amount of information on pregnancy-related issues and how active they had been in obtaining such information. The questionnaire asked the responders' medical decision making preference style,[13] which classified the preference style as follows: I prefer to make the decision about my treatment; I prefer to make the decision after considering my doctor's opinions; I prefer that my doctor and I share the responsibility; I prefer the doctor to make the decision after considering my opinion; and I prefer that my doctor make the decision.

2.2.2.5. Experience of discussing pregnancy-related issues with doctor. The questionnaire asked the responders whether they had discussed pregnancy-related issues with their doctor. The responders were asked to assess the level of information regarding pregnancy-related issues that their doctor had provided (quite sufficient, sufficient, medium, insufficient, and quite insufficient).

2.2.2.6. Severity of epilepsy, depression, and anxiety. The questionnaire asked the responders about the frequency of their seizures to assess the severity of their epilepsy. The degree of depression and anxiety were assessed using the Hospital Anxiety and Depression Scale.[14]

2.2.2.7. Demographic and reproductive data. The data included marital status, highest level of education completed, monthly income, and occupation.

2.3. Statistical analysis

We performed statistical analyses using SPSS. We evaluated the differences using the Mann–Whitney *U* test or Fisher's exact test as appropriate. A probability value of <0.05 was considered to be statistically significant. We performed a prior sample calculation to determine how many patients would be required. We estimated that the proportion of women who decided to discontinue AED during a future pregnancy would be 50%, according to the pilot study. We determined that we would require 170 patients for the study based on the following assumptions: 90% power; a type 1 error of 5%; an estimated rate of 5:5 between the women with a higher level of knowledge and those with a lower level of knowledge; and that a lower-level pregnancy-related knowledge would increase the proportion of women who decided to discontinue AED by 75%.

3. Results

3.1. Study population

A total of 455 women were approached, and 253 women (56%) consented to participate and completed the questionnaire. Among the participants, 186 women replied that they were considering having children in the future; they were included for analysis in the present study.

3.2. Considering discontinuation of anti-epileptic drugs regardless of the medical indication during a future pregnancy

Among 186 women enrolled, 107 women (58%) replied that they would discontinue AED during a future pregnancy regardless of their medical indication. The study population was classified according to their response into the following groups: the women who would discontinue AED during a future pregnancy vs. the women who would continue AED during a future pregnancy.

The women who would discontinue AED were less likely to be married and younger (with marginal significance) than those who would continue AED (Table 1). However, there was no difference between the two groups in the level of education completed, monthly income, and occupational status.

Concern about the effect of AED on the fetus during pregnancy was associated significantly with the decision to discontinue AED during a future pregnancy. More women who would discontinue AED replied that this concern was important in their decision making than those who would continue AED (98% vs. 85%; $p < 0.005$). The effect of other concerns (e.g., concerns about the effect of pregnancy on seizure control and about the effect of seizures on the fetus during pregnancy) was not different between the two groups.

The perceived risk of all of the following factors was not different between the two groups: the offspring's risk for developing epilepsy if the mother does not have epilepsy; the

Table 1
Characteristics of study population according to the decision to discontinue anti-epileptic drugs during a future pregnancy regardless of medical indication.

	No of women replied	Group 1 discontinuation of AED ($n = 107$)	Group 2 continuation of AED ($n = 79$)	p
Age	186	30 ± 6	31 ± 6	0.057
Married	186	29/107 (27%)	38/79 (48%)	<0.005
Low income, USD (<$20,000/year)	174	37/98 (38%)	19/76 (25%)	NS
Employed	186	59/107 (55%)	43/79 (54%)	NS
Highest level of education: university degree or higher	185	73/106 (69%)	56/79 (71%)	NS
Nulliparity	165	76/92 (83%)	53/73 (73%)	NS
Factors that impacted the decision to stop AED				
Concern about the effect of AED on fetus during pregnancy	185	104/106 (98%)	67/79 (85%)	<0.005
Concern about the effect of seizures on fetus	182	83/103 (81%)	60/79 (76%)	NS
Concern about the effect of pregnancy on seizure control	183	94/104 (90%)	66/79 (84%)	NS
Risk perception				
Exaggerated perception of offspring's risk for developing epilepsy if the mother doesn't have epilepsy (≥5%)	182	33/106 (31%)	22/76 (29%)	NS
Exaggerated perception of offspring's risk for developing epilepsy if the mother has epilepsy (≥20%)	184	28/107 (26%)	13/77 (17%)	NS
Exaggerated perception of offspring's risk for having congenital anomaly if the mother does not have epilepsy (≥5%)	182	31/106 (29%)	17/76 (22%)	NS
Exaggerated perception of offspring's risk for having congenital anomaly if the mother has epilepsy without AED (≥5%)	181	46/106 (43%)	32/75 (43%)	NS
Exaggerated perception of offspring's risk for having congenital anomaly if the mother has epilepsy with AED (≥20%)	181	18/106 (17%)	12/76 (16%)	NS
Pregnancy-related knowledge score				
Median score	185	5.7 ± 2.0	6.6 ± 2.0	<0.005
High knowledge score (≥ 6)	185	53/106 (50%)	55/77 (71%)	<0.005
Want to get as much information as possible on pregnancy issues	184	91/106 (86%)	65/78 (83%)	NS
Have been proactive in obtaining information on pregnancy issues	182	20/104 (19%)	14/78 (18%)	NS
Medical decision making preference style: I prefer to make the decision about my treatment or I prefer to make the decision after considering my doctor's opinions	182	32/106 (30%)	16/77 (21%)	NS
Have ever discussed pregnancy-related issues with their doctor	158	35/89 (39%)	43/69 (62%)	<0.01
Level of information that their doctor provided regarding pregnancy-related issues: quite enough or enough	135	17/70 (24%)	26/65 (40%)	0.065
Recent episodes of seizure (<4 weeks)	164	22/99 (22%)	13/65 (20%)	NS
Recent episodes of seizure (<1 year)	164	54/99 (55%)	31/65 (48%)	NS
Depression scale	119	2.8 ± 2.2	2.7 ± 2.1	NS
Anxiety scale	119	4.7 ± 2.0	4.6 ± 2.2	NS

AED, anti-epileptic drugs.

Table 2
Relationship of various independent variables with the decision to discontinue anti-epileptic drugs during a future pregnancy regardless of medical indication by multiple logistic regression analysis.

Variables	Odds ratio	95% confidence interval	p
Pregnancy-related knowledge score	0.80	0.675–0.957	<0.05
Age (years)	0.99	0.929–1.051	NS
Marriage status (married)	0.50	0.240–1.054	0.069
Perception[a]	1.14	0.559–2.308	NS

[a] Exaggerated perception of the offspring's risk for having a congenital anomaly if the mother has epilepsy with anti-epileptic medication.

offspring's risk for developing epilepsy if the mother has epilepsy; the offspring's risk for having a congenital anomaly if the mother does not have epilepsy; the offspring's risk for having a congenital anomaly if the mother has epilepsy without anti-epileptic medication; and the offspring's risk for having a congenital anomaly if the mother has epilepsy with anti-epileptic medication.

However, the women who would discontinue AED had lower-level pregnancy-related knowledge than the women who would continue AED (knowledge score, mean ± SD: 5.7 ± 2.0 in group 1 vs. 6.6 ± 2.0 in group 2; $p < 0.005$). The proportion of high knowledge score was also lower in those who would discontinue AED than in those who would continue AED (50% in group 1 vs. 71% in group 2; $p < 0.005$). The association between the pregnancy-related knowledge score and the decision to discontinue AED remained significant even after adjustment for age, marriage status, and exaggerated perception of the offspring's risk for having a congenital anomaly if the mother has epilepsy with AED (Table 2). The following items showed different scores between the two groups: "All AEDs increase the risk of fetal anomaly" (right answer (False): 37% of the women who would discontinue AED vs. 65% of the women who would continue AED; $p < 0.001$); "Women with epilepsy should stop anti-epileptic medications in early pregnancy" (right answer (False): 26% vs. 69%; $p < 0.001$); "Most women taking anti-epileptic medication can do breast feeding" (right answer (True): 36% vs. 51%; $p < 0.05$).

Additionally, the proportion of women who had discussed pregnancy-related issues with their doctor was lower in women who would discontinue AED than in those who would continue AED (39% vs. 62%; $p < 0.01$), and more women who would discontinue AED assessed the amount of information that their doctor provided regarding pregnancy-related issues as insufficient or quite insufficient than those who would continue AED, with marginal significance (76% vs. 60%; $p = 0.065$).

3.3. Decision to have fewer children because of epilepsy

Among the 186 women enrolled, 159 women replied to the question of the decision to have fewer children because of epilepsy and 27 women provided no response. Among these 159 women who replied, 25% (39/159) had decided to have fewer children because of epilepsy. The study population was classified according to their response into the following groups: the women who would have fewer children (women with fewer children) because of epilepsy vs. the women who would not (women with no change in the number of children).

The women with fewer children were more likely to be married and older (with marginal significance) than the women with no change in the number of children (Table 3). Concern about the offspring's risk for developing epilepsy was significantly associated with the decision to have fewer children because of epilepsy. More women with fewer children replied that their concern about the offspring's risk for developing epilepsy was important in their decision making than those with no change in the number of children replied (95% vs. 76%; $p < 0.005$). Concern about their reduced ability to care for a child because of epilepsy was also associated with this decision with marginal significance ($p = 0.095$), whereas having other concerns was not associated with this decision.

The women with fewer children were more likely to have an exaggerated perception of the offspring's risk for developing epilepsy if the mother has epilepsy (37% of the women with fewer children vs. 20% of the women with no change in the number of children; $p < 0.05$), and this difference remained significant after adjustments for age, marriage status, higher knowledge score regarding fertility-related issues ($p < 0.05$) (Table 4). Other risk perceptions regarding the offspring's risk for developing epilepsy if the mother does not have epilepsy and the offspring's risk for having a congenital anomaly did not differ between the two groups.

The level of pregnancy-related knowledge was not different between the two groups and neither was the proportion of high knowledge score.

Additionally, the proportion of women who had ever discussed pregnancy-related issues with their doctor was not different between the two groups, and the evaluated amount of information that their doctor provided regarding pregnancy-related issues was not different.

The women who decided to have fewer children had higher depression scale scores; however, the anxiety scale scores showed a significant marginal difference between the two groups.

4. Discussion

The principal findings of this study were as follows: (1) more than 50% of the women would decide to discontinue AED during a future pregnancy regardless of their medical indication and 25% of the women stated that they would have fewer children because of epilepsy. (2) The decision to discontinue AED during a future pregnancy was associated with a lower-level pregnancy-related knowledge, and the decision to have fewer children because of epilepsy was associated with an exaggerated perception of the offspring's risk for developing epilepsy. (3) The women who had ever discussed pregnancy-related issues with their physician were less likely to decide to discontinue AED during a future pregnancy; however, the discussion on this issue had no impact on the decision to have fewer children because of epilepsy.

The major threats to women with epilepsy during pregnancy are increased seizure rates and risk for fetal malformations.[15] The increased risk of seizure is associated with lower seizure threshold and subtherapeutic anticonvulsant level. Of importance, the subtherapeutic anticonvulsant level is often associated with self-discontinuation of AED because of teratogenicity concerns.

The teratogenicity concerns regarding AED may be over exaggerated despite the fact that patients want more information regarding AED and pregnancy issues.[17] In the present study, 17% of the study population estimated that there was more than a 20% risk for congenital malformation attributed to AED. Although AED polytherapy or use of valproate during the first trimester is associated with an increased risk of malformation,[18] the observed risk of congenital malformation of all AEDs was 4.2% and that of valproate was less than 10%.[16] Moreover, recent evidence has

Table 3
Characteristics of study population according to the decision to have fewer children because of epilepsy.

	No of women replied	Group 1 fewer children because of epilepsy ($n = 39$)	Group 2 no change in number of children ($n = 120$)	p
Age	159	33 ± 6	30 ± 5	<0.005
Married	159	20/39 (51%)	39/120 (33%)	0.055
Low income, USD (<$ 20,000/year)	148	10/37 (27%)	36/111 (32%)	NS
Employed	159	16/39 (41%)	65/120 (54%)	NS
Highest level of education: university degree or higher	158	25/38 (66%)	87/120 (73%)	NS
Nulliparity	143	23/35 (66%)	87/108 (81%)	NS
Factors that had important influence on making decision to stop AED				
Concern about the offspring's risk for developing epilepsy	156	36/38 (95%)	90/118 (76%)	<0.05
Family history of epilepsy	151	26/36 (72%)	79/115 (69%)	NS
Concern about their reduced ability to care for a child because of epilepsy	155	32/38 (84%)	82/117 (70%)	0.095
Concern about the effect of AED on fetus during pregnancy	156	37/38 (97%)	111/118 (94%)	NS
Concern about the effect of pregnancy on seizure control	156	35/38 (92%)	95/118 (81%)	NS
Concern about the effect of seizures on fetus	154	35/37 (95%)	104/117 (89%)	NS
Concern about potential complications during labor and delivery	156	34/38 (89%)	97/118 (82%)	NS
Risk perception				
Exaggerated perception of offspring's risk for developing epilepsy if the mother does not have epilepsy (≥5%)	156	8/38 (21%)	43/118 (36%)	NS
Exaggerated perception of offspring's risk for developing epilepsy if the mother has epilepsy (≥20%)	157	14/38 (37%)	24/119 (20%)	<0.05
Exaggerated perception of offspring's risk for having congenital anomaly if the mother does not have epilepsy (≥5%)	155	11/37 (30%)	34/118 (29%)	NS
Exaggerated perception of offspring's risk for having congenital anomaly if the mother has epilepsy without AED (≥5%)	154	19/36 (53%)	51/118 (43%)	NS
Exaggerated perception of offspring's risk for having congenital anomaly if the mother has epilepsy with AED (≥20%)	155	10/37 (27%)	18/118 (15%)	NS
Pregnancy-related knowledge score				
Median score	157	5.8 ± 2.2	6.4 ± 1.9	NS
High knowledge score (≥6)	157	24/39 (62%)	75/118 (64%)	NS
Want to get as much information as possible on pregnancy issues	158	35/38 (92%)	98/120 (82%)	NS
Have been proactive in obtaining information on pregnancy issues	156	10/38 (26%)	19/118 (16%)	NS
Medical decision making preference style: I prefer to make the decision about my treatment or I prefer to make the decision after considering my doctor's opinions	156	14/38 (37%)	32/118 (27%)	NS
Have ever discussed pregnancy-related issues with their doctor	131	17/29 (59%)	50/102 (49%)	NS
Level of information that their doctor provided regarding pregnancy-related issues: quite enough or enough	114	9/26 (35%)	26/88 (30%)	NS
Recent episodes of seizure (<4 weeks)	139	7/34 (21%)	21/105 (20%)	NS
Recent episodes of seizure (<1 year)	139	16/34 (47%)	57/105 (54%)	NS
Depression scale	99	3.4 ± 2.3	2.5 ± 2.1	<0.05
Anxiety scale	99	5.1 ± 2.1	4.5 ± 2.1	0.099

AED, anti-epileptic drugs.

suggested that the risk of malformation from monotherapy with less-teratogenic AEDs is approximately 3–5%, which is comparable to the risk of malformation in the general population.[16,18–21] The reported risks may vary and depend on which classification system is used to define the presence of fetal anomaly and the methodology of the pregnancy registry that is being utilized.

Furthermore, the seizure prevention effect of AED is clearly beneficial. Discontinuation of AED may expose the pregnant women and fetus to the risk of physical injury that might result from accidents during seizures.[18] Recently, a published report indicated that non-adherence to AED was associated with an increased risk of mortality.[22]

According to the literature, 15% or more of pregnant women discontinued or greatly reduced their prescribed AED, which was confirmed by hair analysis, and most of the women who discontinued AED did not acknowledge having done so. Moreover, most of the patients discontinued AED after conception, rather than before conception, which is too late to prevent major teratogenic effects of AED, such as neural tube defect.[7]

Additionally, previous studies evaluated the discontinuation of AED in women during pregnancy.[4,7] However, the preconceptional counseling is intended for women who are planning to become pregnant and should also target women who are not planning pregnancy because approximately 50% of the pregnancies in women with epilepsy are reported as unplanned.[23,24] We were not able to find reports that assessed how many women make the decision to discontinue AED during a future pregnancy and which factor affects this decision. In the present study, more than 50% of the women of reproductive age were considering discontinuing AED; we observed that a lower-level pregnancy-related knowledge and unmarried status were associated with this decision.

Table 4
Relationship of various independent variables with the decision to have fewer children because of epilepsy by multiple logistic regression analysis.

Variables	Odds ratio	95% confidence interval	p
Perception[a]	2.55	1.062–6.101	<0.05
Age (years)	1.11	1.025–1.196	<0.05
Marriage status (married)	1.45	0.576–3.623	NS
High pregnancy-related knowledge score	0.84	0.350–2.024	NS

[a] Exaggerated perception of offspring's risk for developing epilepsy if the mother has epilepsy.

In the present study, 25% of the women decided to have fewer children because of epilepsy; we observed that concerns about the offspring's risk for developing epilepsy or about their reduced ability to care for a child because of epilepsy affected their decision making. These findings are consistent with previous reports, in which approximately 30% of the participants decided to have fewer children because of epilepsy.[8,9] In addition, we have found that more women who decided to have fewer children had significantly exaggerated perception of their child's risk to have epilepsy than those who did not.

The level of pregnancy-related knowledge and the experience of discussing this issue with their physician did not alter the decision to have fewer children. This observation is in contrast to the decision to discontinue AED, which was affected by the level of pregnancy-related knowledge and the experience of discussing this issue with their physician. This observation may be because the genetic risk of epilepsy is a real risk[5] and cannot be altered by clinical factors, although the teratogenic effect of AED could be modified by several clinical factors (monotherapy with less-teratogenic AEDs and periconceptional taking of folate).

From the previous report, only 43% of the women were reportedly advised to take folic acid during pregnancy, and the majority (84%) of the women wanted to be better informed about treatment decisions.[9] In the present study, 85% of the women wanted to obtain as much information as possible on pregnancy issues, but only 49% had ever discussed pregnancy-related issues with their doctor, and 68% of them stated the amount of information that their doctor provided was insufficient or quite insufficient. These data show that most of the women are not as well informed regarding pregnancy issues as they would like to be. According to the systematic review of Weckesser et al., there is lack of appropriate and timely information for women with epilepsy when having children and accessing healthcare services, and their demand to know more about their condition and treatment options is not adequately met.[25]

In their review article, Winterbottom et al. failed to find studies that evaluated the effectiveness of preconceptional counseling to improve pregnancy outcomes, and they indicated that well-designed studies are needed to evaluate this issue.[26] In the present study, preconceptional counseling seems to have an impact on reproductive decision making; the women who had engaged in a discussion with their doctor on pregnancy-related issues were less likely to decide to discontinue AED, whereas the experience of discussing this issue did not alter the decision to have fewer children. This finding highlights the importance of preconceptional counseling and may guide clinicians on what to target for preconceptional counseling.

The decision to have fewer children was associated with high anxiety scale scores ($p = 0.099$) and high depression scale scores ($p < 0.05$). However, the decision to discontinue AED was not associated with the subjects' level of performance according to an anxiety or depression scale. Helbig et al. found a correlation between the depression score and the decision to have fewer children.[8] We can hypothesize that the decision to have fewer children may affect mood, or the anxiety or depressive mood may influence this decision. Additional studies are warranted to evaluate this relationship between the decision to have fewer children and anxiety or depression.

In conclusion, more than 50% of the women we evaluated would decide to discontinue AED during a future pregnancy regardless of their medical indication, and 25% of the women stated that they would have fewer children because of epilepsy. The data highlight the importance of education on pregnancy-related knowledge and genetic risk counseling. This research may serve as a guide for clinicians who provide preconceptional counseling regarding who to and what to target.

Conflict of interest statement

The authors report no conflict of interest.

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