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Women with epilepsy in childbearing age: Pregnancy-related knowledge, information sources, and antiepileptic drugs

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ABSTRACT

Pregnancy-related issues in epilepsy (PRIE) are essential for management of epilepsy in women. We conducted a study among women with epilepsy (WWE) aged 15–45 years about their knowledge, sources, and needs for information regarding PRIE, which included their current antiepileptic drugs (AEDs) usage. Women with epilepsy, visitors of Croatian Association for Epilepsy webpage, were offered an online questionnaire, and 200 responses were analyzed. The mean number of correct answers about PRIE was 3.5 out of 5. Main predictors of knowledge on PRIE were a prior consultation with a neurologist and higher usage of books/brochures. A prior neurologist consultation on PRIE was stated by 45% of subjects. As the preferred future mode of being informed on PRIE, majority of women (61%) chooses their neurologist, 22% written materials distributed by a neurologist, and only 13% Internet. Levetiracetam was the most commonly used AED (34.5%). Valproate was used by 26%, and of those 59% stated no previous consultation on PRIE with their neurologist. In summary, we believe our study shows that knowledge of PRIE among WWE in their childbearing age is unsatisfactory, as are the neurologist consultation rates about PRIE. Our results demonstrate that, despite modern technologies, educational activities should be based on neurologist consultations and providing the patients with appropriate written materials. This is especially true for the relatively large proportion of women still taking valproate.

1. Introduction

Women with epilepsy (WWE) in their childbearing age are in many ways a distinct subpopulation of patients with epilepsy, where issues such as catamenial epilepsy, contraception and antiepileptic drugs (AEDs), sexual dysfunction, reproductive endocrine disorders, bone health, as well as potential risks regarding pregnancy should all be taken into account [1]. During pregnancy, WWE tend to be less adherent with taking their prescribed AEDs, with incomplete compliance going as high as 62.3%, [2] and 15% self-discontinuing their medications, in most cases without disclosing it to their physicians [3]. This can, together with pharmacokinetic changes that frequently occur during pregnancy [4], pose a serious risk to the mother as well as the fetus. Furthermore, certain AEDs given during pregnancy carry a risk of causing major congenital malformations, which in the case of valproate is a reason to avoid its use in the population of WWE of childbearing age, as implemented in the warnings of Food and Drug Administration (FDA) in 2013 [5] and European Medicines Agency (EMA) in 2014 [6]. The teratogenic potential of AEDs is a subject that WWE should be accurately and timely informed of, especially considering recent data showing that up to 65% of pregnancies in WWE are unintended [2,7]. Studies have demonstrated that educational and counseling activities can increase AED compliance [8], lead to better AED tolerance and fewer side effects [9], and specifically when done prior to conception, can help WWE reach an informed decision regarding future motherhood [10] and reduce the frequency of fetal abnormalities [11]. In order to plan for convenient, efficient, and timely educational activities, it is crucial to have an understanding of how much knowledge WWE have about pregnancy-related issues in epilepsy (PRIE), where they get their knowledge from and which AEDs they are currently taking with regard to its teratogenic potential. We have identified several studies dealing with knowledge about these issues in WWE [12–17], with only two studies also assessing information sources [13,15], and only a single study trying to find predictors of this knowledge [12]. Prior studies that have focused on information about PRIE that women reported receiving [2,18–20] all conclude that clinicians do not adequately counsel WWE on these issues, and WWE express the need for more information [13,17,19].

Our goal was to conduct a comprehensive study in a population of WWE of childbearing age to answer the following questions:

1) How much do they know about PRIE and what are the predictors of better knowledge.
2) Their usage and needs regarding sources of information on PRIE.
3) Their current AED usage and its association with their demographical/clinical traits and desire for children.

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2. Methods

During August and September of 2016, an online anonymous questionnaire was offered to all visitors of the Croatian Association for Epilepsy's website www.epilepsija.hr through a pop-up invitation window. The invitation stated that the questionnaire was intended for females aged 15–45 years, currently being treated for epilepsy. This invitation was also published on the Facebook page of the Croatian Association for Epilepsy, and users were invited to share it further. The initial part of the questionnaire consisted of demographic questions (age, country of residence, level of education), questions concerning epilepsy and pregnancy (age of epilepsy onset, current AEDs, whether they have ever been pregnant, whether they have used AEDs in at least one of the prior pregnancies, whether they had a desire for children in the future), and self-assessment of their knowledge on PRIE on a scale of 1 to 5. The second part of the questionnaire was a knowledge test on PRIE, consisting of 5 multiple choice questions (Appendix 1). The respondents were encouraged to give their best guess, without prior consultation with the Internet or other sources of information. The final part of the questionnaire included multiple choice questions about prior counseling on pregnancy and breastfeeding related issues in epilepsy received from their neurologist (if it took place and whether they were satisfied with the amount of information, when did it take place with reference to their pregnancy, and whose initiative this conversation was), about the sources of information for PRIE that they have previously used, rating the extent of usage from 0 to 3 for each of the sources (Internet, books/brochures, media, neurology specialist, another physician ⟨G.P., gynecologist or other⟩, other WWE) or to state other sources, and their preferred mode of receiving information on PRIE in the future (personally by their neurologist, written materials from their neurologist, Internet, other sources or not wishing to receive this information at all).

The responses collected in this way were later completely excluded from the analysis if at least one of the following criteria were fulfilled: country of residence other than Croatia, age outside the proposed range (15–45 years), not taking any AEDs, or failure to fill out the question on AEDs. If there were inconsistencies in some of the answers (i.e., stating a prior pregnancy in one question and no prior pregnancies in the other or stating to have talked with their neurologist about pregnancy-related issues in one question and denying it in the other) then only the answers to these questions were eliminated.

The AEDs were categorized as older or new [21]. A further classification was made by FDA pregnancy risk categories, and in case of polytherapy, the category letter of the drug which is in the highest risk category among the ones taken was assigned.

For statistical analysis, IBM SPSS Statistics, Version 20.0 was used. Nonparametric statistical tests were used as appropriate (χ^2 test, Mann–Whitney, Spearman's rho). Multiple regression analysis (enter model) was additionally used to determine the most significant variables to have the influence on knowledge scores. The value $p < 0.05$ was used as a criterion for significance of the statistical findings. The study was approved by the local ethical committee. Before proceeding to the questionnaire, the respondents were informed about the aim of the study and were guaranteed full anonymity.

3. Results

3.1. Population

The total number of respondents was 289, but when the exclusion criteria described in Methods were applied, the total sample was reduced to 200. As can be seen in Table 1, mean age was 29 ± 8.1 years, with about a third of participants having a college/university degree. On average, epilepsy started at 17 ± 9.2 years of age. Thirty-five percent of subjects have already been pregnant, out of which 67% were treated with AEDs during at least one pregnancy. Forty-three percent expressed a desire to have children in the future, with further 24% unsure.

Table 1
Subject characteristics.

	N			Mean	SD
Age (years)	200	Range 15–45 years		29	8,1
Level of education	199	Elementary School	18 (9%)		
		Secondary School	120 (60%)		
		College/School of higher education	15 (8%)		
		University	46 (23%)		
Age when epilepsy started (years)	198			17	9,2
Duration of epilepsy (years)	198			12	9,1
Prior pregnancy	199	69 (35%)			
Treated with AEDs during prior pregnancies	69	46 (67%)			
Desire for future children	189	Yes	82 (43%)		
		No	62 (33%)		
		Not sure	45 (24%)		

AEDs – antiepileptic drugs.

3.2. Knowledge of PRIE

When self-assessing their knowledge on PRIE on a scale of 1 to 5, the subjects rated themselves on average 2.32 ± 1.360 (Table 2). The question with the most correct answers (88%) was question No. 1 about the correct timing for a consultation on PRIE, and with the least correct responses (52%) question No. 5 about AEDs and breastfeeding. Total mean score on the knowledge test (range 0–5) was 3.50 ± 1.276.

Higher total knowledge score was associated with the following: older age, higher level of education, prior pregnancy, AED treatment during prior pregnancy/pregnancies, having been counseled by a neurologist, time of the first consultation prior to/during pregnancy planning as opposed to while already pregnant, higher level of using information sources in total, and higher usage of Internet, books/brochures, neurologist and other physician as sources (Table 3). Those who considered themselves more knowledgeable on PRIE also had a better total knowledge score. Using multiple regression for the total knowledge score as the outcome variable, a significant model emerged ($F_{9,123} = 3.924$, $p < 0.001$, adjusted R square = 0.166) with the following significant predictors: having been counseled by a neurologist (beta 0.275, $p = 0.016$) and higher usage of books/brochures (beta 0.292, $p = 0.039$). It should be noted here that AED treatment during prior pregnancies and time of the first consultation with reference to the pregnancy were excluded from the multiple regression analysis, as including these variables reduced the sample to only 36 which would not make it a valid result.

3.3. Sources of information on PRIE – uses and needs

Less than half (45%) of our subjects declared that they have been counseled on pregnancy and breastfeeding related issues by their neurologist, out of which 39% were not satisfied with the amount of information provided (Table 4). In total, the majority of respondents

Table 2
Knowledge on pregnancy-related issues in epilepsy (PRIE).

	N	N of correct answers	Mean	SD
Self-assessment of knowledge on PRIE	195		2.32[a]	1.360
Questions on knowledge[b]				
1. Time for consultation	177	156 (88%)		
2. AEDs in pregnancy permitted	176	132 (75%)		
3. Risk of different AEDs	175	101 (58%)		
4. Vitamin for prevention	172	129 (75%)		
5. AEDs and breastfeeding	172	89 (52%)		
Total knowledge score	168		3.50	1.276

AEDs – antiepileptic drugs.
[a] On a scale of 1 to 5.
[b] For exact question, please refer to Appendix 1.