



# Pregnancy-related knowledge of women with epilepsy – An internet-based survey in German-speaking countries

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## ABSTRACT

There are several issues, which have to be acknowledged, when treating women with epilepsy (WWE). The need for counseling WWE in Germany with epilepsy on pregnancy-related matters was stressed in several papers and medical guidelines. Physicians treating WWE in Germany therefore should be aware of the information needs of their patients. We aimed to determine the level of pregnancy-related knowledge of WWE and their informational needs concerning pregnancy and childbirth issues in German-speaking countries by an internet-based survey. The questionnaire consisted of 18 questions addressing the characteristics of the epilepsy syndromes, the patients' experience with pregnancy, and the sources of their pregnancy-related knowledge. Another 20 items addressed the level of pregnancy-related knowledge. One hundred ninety-two women (179 patients, 13 relatives; age:  $30.5 \pm 10.8$  years) participated. Most of the women got information and advice on the treatment of epilepsy from a neurologist (81%). Most of the women had obtained information concerning driving license (72%) followed by information about pregnancy and delivery (60%). The women, who remembered being counseled about pregnancy-related matters gave more correct answers to the pregnancy-related questions than the others ( $51 \pm 17\%$  vs.  $38 \pm 24\%$ ,  $p < 0.011$ ). Thirty-eight percent of WWE taking enzyme inducing antiepileptic drugs (AEDs) were unaware of the interaction with oral contraception. Forty-one percent of WWE taking valproate were unaware of its high teratogenicity, and 89% of WWE had not been counseled about potentially reduced bone mineral density. Forty-six percent of participants did not believe that the majority of WWE have healthy children. The findings of this survey reveal considerable information needs of WWE concerning pregnancy-related matters in German-speaking countries.

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## 1. Introduction

There are several issues, which have to be acknowledged, when treating women with epilepsy (WWE). In child-bearing age, hormonal influences on seizure frequency and interactions between oral contraceptives and antiepileptic drugs (AEDs) are of importance. When discussing the possibility of having a child teratogenicity of AEDs, therapeutic drug monitoring during pregnancy and in the postpartum period, breastfeeding, and safety issues for childrearing should be addressed. Last but not least, managing menopause and the risk of postmenopausal osteoporosis should be taken into consideration [1].

### 1.1. Background

In Iceland, 3.3 in 1000 pregnancies involved mothers with active epilepsy [2]. In Norway, even 7.7 of 1000 deliveries were by WWE [3].

It is reasonable to assume that in other European countries, the frequency of deliveries by WWE is also in this range. Interestingly, the estimated range of lifetime prevalence of epilepsy in high income countries is in approximately the same scope (i.e., 3.75–7.15/1000) [4]. In a recent review, it was shown that the fertility rate of WWE in Finland, the UK, the USA, and India is reduced compared with women without epilepsy to a rate of 55% to 86% [5]. Besides social factors, stigma and reduced sexual desire there may be some influential epilepsy-related factors, which may be reduced by a counseling about pregnancy-related matters, especially the fear of getting a child with disability may lead to the decision not to get pregnant. Furthermore, there may be worries about the impact of pregnancy or delivery on seizure frequency. The reservations against the decision to have a child can be reduced by a thorough counseling. The American Academy of Neurology selected the item "All female patients of childbearing potential (12–44 years old) diagnosed with epilepsy were counseled about epilepsy and how its treatment may affect contraception and pregnancy at least once per year" as one of eight measures for the quality of care for people with epilepsy [6]. There should be a good pregnancy-related knowledge of WWE in childbearing age, if this criterion is met by their caregivers.

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## 1.2. Purpose

The need for counseling WWE in Germany on pregnancy-related matters was stressed in several papers, which were published in journals distributed to all physicians in Germany (e.g., [7]), all members of the German neurological society (e.g., [8]), or all members of the German International League Against Epilepsy (ILAE) section (e.g., [9]), respectively. This issue is also detailed in the guideline on the treatment of epilepsy of the German Society of Neurology which is coauthored by experts from Austria and Switzerland [10]. Physicians treating WWE in Germany, Austria, and Switzerland therefore should be aware of the information needs of their patients. We tried to determine the level of pregnancy-related knowledge of WWE and their informational needs concerning pregnancy and childbirth issues in German-speaking countries by an internet-survey. Through this, we tried to evaluate in which ratio the newest recommendations of scientific committees are reaching the patients. Thus, we may expose topics, in which the education and counseling of the patients should be improved. Further on, we tried to determine the influence of consulting by a neurologist on the level of pregnancy-related knowledge of WWE in German-speaking countries. Further subgroup analyses were done to evaluate whether WWE with a certain history have more knowledge about pregnancy-related matters than the others. Additionally, we tried to elucidate whether knowledge of one item was associated with knowledge in another one.

## 2. Methods

### 2.1. The building of a questionnaire

A PubMed research with the items “knowledge”, “women”, and “epilepsy” on March 26th 2015 revealed 141 papers. Fourteen of them were considered relevant to our project including a review of McGrath et al. [11]. From five of these studies, we (i.e., Carolin Dierking (CD) and Johannes Rösche (JR)) extracted most of the questions concerning knowledge in our questionnaire (references are given in Table 3). The selection of the questions focused on topics stressed in the papers distributed to all physicians in Germany (e.g., [7]) or all members of the German ILAE section (e.g., [9]), respectively.

### 2.2. Data collection

The questionnaire was placed on the internet platform of a patient organization ([www.epilepsie-online.de](http://www.epilepsie-online.de)) from 4th August 2015 to 31st to December 2015. The questionnaire consisted of 18 questions addressing the characteristics of the syndromes of epilepsy, the patients experience with pregnancy, and the sources of their pregnancy-related knowledge. Another 20 items addressed the level of pregnancy-related knowledge. Each of these items consisted of a 5-point Likert scale. Likert scale answers of 1 and 2 were considered to signify disagreement, and answers of 4 and 5 were considered to signify agreement with the statement in question.

### 2.3. Participants

As consequence of the method of data collection, the description of the participants is a part of the results. We analyzed the answers of all WWE and of all female relatives of WWE regardless of their age. Excluded were answers from male patients or male relatives.

### 2.4. Data analysis

The internet survey data had been directly transferred into Microsoft Excel data. Data were afterwards analyzed with IBM SPSS Statistics 22. The collected epidemiological data are given as descriptive data. The 20 items answered on a 5-point Likert scale were characterized by mean and standard deviation. Frequency of answers in accordance with

guidelines, counseling literature, and recent reviews was examined and described in percentage. For subgroup comparisons of the number of appropriate answers, we performed the Mann–Whitney test (two tailed,  $p < 0.05$ ). We performed group comparisons between the women, who had been pregnant and those who had not been pregnant; the women taking valproate and the others; the women who were counseled by a neurologist and the others; and the women, who remembered being counseled about pregnancy-related matters and the others. We calculated the Spearman correlation coefficients of the Likert-scale score pairwise between the knowledge-related items. For assessing significance of correlation-coefficients, we used a Bonferroni–Holmes procedure with a  $p < 0.05$  as the level after correction. The level of significance for the first comparison was set to  $p < 0.00026$ . Comparisons of our data with results of previously reported studies were performed with  $\chi^2$ -tests (two tailed  $p < 0.05$ ).

## 3. Results

One hundred ninety-two women (179 patients, 13 relatives; 170 from Germany, 12 from Austria, 8 from Switzerland and two from other countries) aged 30.5 years on average (SD 10.8) participated. Patients outside from Germany were significantly younger than the Germans (26.7 vs. 31 years  $p < 0.04$ ), had experienced seizures for a significantly shorter time (9 vs. 14.5 years,  $p < 0.004$ ) and had been less often pregnant (13.64% vs. 44.12%,  $p < 0.007$ ). More often than the Germans, they were aware of the facts that malformations of the unborn child can be detected by an ultrasound scan in the 13th week of pregnancy (77.3% vs. 54.1%,  $p < 0.04$ ) and that some AEDs can pass over to the breast milk in small concentrations (81.8% vs. 55.3%,  $p < 0.02$ ). Sixty-nine (36%) of the whole group had given birth to one or more children, and another nine (5%) had been pregnant with abortion (for details see Table 1). Most women had got information and advice concerning the treatment of epilepsy from a neurologist (81%). The majority of women had obtained information concerning driving license (72%) followed by information about pregnancy and delivery (60%). Only a very few (5%) had been counseled concerning menopause-related issues (for details see Table 2). On average, 88% (range 82.8%–95.8%) of the questions addressing pregnancy-related knowledge were answered, and only 46% of these questions were answered correctly (for details see Table 3). The percentage of given answers was significantly correlated with the number of correct answers ( $r = 0.5$ ,  $p = 0.024$ ), explaining 25% of the variance. This means that in questions with a low rate of correct answers, a considerable portion of women preferred to give no answer rather than guessing.

There were no significant differences in the frequency of correct answers between the women, who had been pregnant and those who had not been pregnant ( $47 \pm 20\%$  vs.  $49 \pm 19\%$ ) or women taking valproate and others ( $42 \pm 20\%$  vs.  $46 \pm 21\%$ ). However, the women who were counseled by a neurologist gave more correct answers than the others ( $49 \pm 19\%$  vs.  $33 \pm 24\%$ ,  $p < 0.0002$ ). The women, who remembered being counseled about pregnancy-related matters gave more correct answers than the others ( $51 \pm 17\%$  vs.  $38 \pm 24\%$ ,  $p < 0.011$ ).

There were pairwise 27 significant correlations of Likert-scale scores between the 20 questions concerning pregnancy-related knowledge (for details see Table 4). Only positive correlations reached significance. But since in six items disagreement was proposed to be the correct answer, eight correlations pointed to the fact that a tendency to a correct answer to one question was associated with a tendency to an incorrect answer in the other or vice versa. The correct answers to the item 1 “Women with epilepsy should contact their neurologist when they are planning a pregnancy” were correlated to the correct answers in four other items. One of these items was item 5 “A pregnancy can increase the metabolic breakdown of AEDs in the body so that the serum level is reduced”. The correct answers to this item were correlated to the correct answers in six other items. So items 1 and 5 may present crucial parts of the information needs. Awareness of the need to contact a neurologist

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