

Enhancing the Care of Pregnant Women with Epilepsy: A Focus Group Approach

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Enhancing the Care of Pregnant Women with Epilepsy

Abstract

BACKGROUND: Through a long-standing collaboration with the Medical Center's Maternal-Fetal Medicine program, a clinical pharmacist from the Comprehensive Epilepsy program works with pregnant women with epilepsy in the High-Risk Obstetrics Clinic. Through this clinical collaboration, it has been observed that some women stop or lower their antiepileptic drug therapy during pregnancy out of concern for their baby. This puts the woman and her baby at risk from increased seizure activity during the pregnancy. **PURPOSE:** The aim of this qualitative project was to learn why pregnant women may or may not alter their antiepileptic drug therapy. This aim was achieved by conducting small focus groups in pregnant women with epilepsy.

METHODS: Pregnant women with epilepsy were recruited from the OSU Medical Center's High-Risk Obstetrics Clinic and the Comprehensive Epilepsy program. The 60 to 90 minute sessions were held at the offices of the Epilepsy Foundation of Central Ohio in collaboration with their Social Worker. Our target sample size is 20 pregnant women with epilepsy.

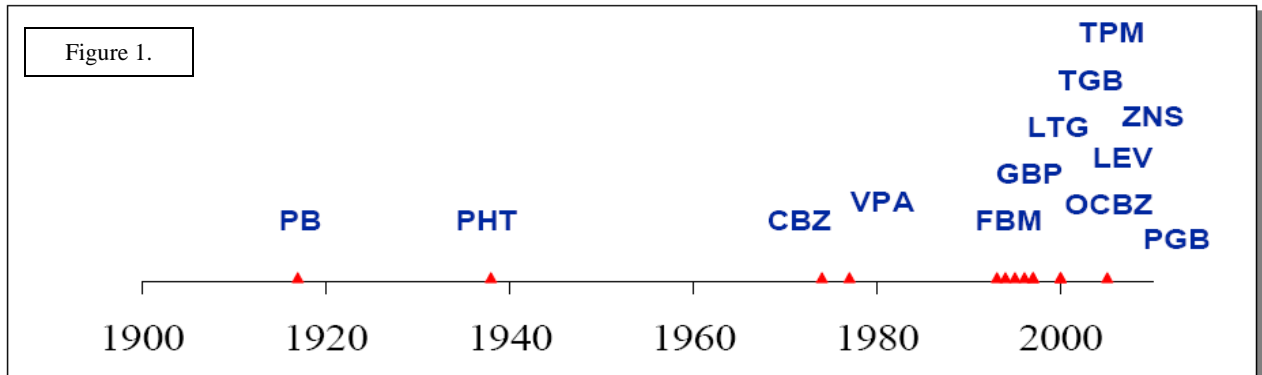
RESULTS: To date, we have conducted 3 focus groups with a total participation of 10 pregnant women with epilepsy. The average age of the participants was 25.6 years. Most women had a history of generalized tonic-clonic seizures. Six did not plan this pregnancy and this was the first pregnancy for two of the ten women. Some women reported they had self-altered their antiepileptic drugs due to side effects before pregnancy, but most women did not self-alter their medicines during this pregnancy. After holding the three focus groups, some common themes have emerged. Specific concerns that were raised by the women included the potential risk of problems in their newborns, the lack of education on whether they had to wean their baby off of antiepileptic drugs, concerns over the delivery and the concern for passing epilepsy on to their baby. These were accompanied by general concerns about epilepsy that included driving, having a plan for their children if mom had a seizure and the need for epilepsy education for family members & significant others. Some of the unintended effects of these interactive patient sessions have been the connectivity between participants. There was an expressed comfort meeting and getting to know other women with epilepsy and there was even some patient-to-patient teaching.

CONCLUSION: Once we complete patient recruitment, we believe our study has the potential to shed more light on why some women with epilepsy may or may not alter their drug therapy during pregnancy. By identifying these reasons, we hope to be more proactive in our approach to patient education and ultimately improve outcomes in women with epilepsy.

Background

Epilepsy is a common neurological problem affecting 1-2% of the United States population. Though there is a high frequency of new cases in infants and persons over 65 years of age, the diagnosis of epilepsy can be made at any age. Epilepsy has significant economic and social consequences. These can be minimized by optimal seizure control.

Antiepileptic drugs are the mainstay of treatment in this chronic disease. The number of antiepileptic drugs approved by the FDA has grown tremendously since 1993 (Figure 1).



Currently available antiepileptic drugs and the date they were introduced to the market (PB=phenobarbital, PHT=phenytoin, CBZ=carbamazepine, VPA=valproic acid, FBM=felbamate, GBP=gabapentin, LTG=lamotrigine, TGB=tiagabine, TPM=topiramate, OCBZ=oxcarbazepine, LEV=levetiracetam, ZNS=zonisamide, PGB=pregabalin)

Treatment goals for patients with epilepsy include the prevention of seizures, the reduction and/or prevention of adverse effects and drug interactions, improvement of quality of life and patient satisfaction.¹ Definable therapeutic outcomes for patients with epilepsy broken into three categories are described in the table below.

Therapeutic Outcomes

Educational	Clinical	Humanistic
<ul style="list-style-type: none"> Patients will be knowledgeable about epilepsy Caregivers and society will understand epilepsy 	<ul style="list-style-type: none"> Patients will be seizure free or have significant reductions in seizure frequency or severity Patients should experience no or minimal adverse drug effects Patients should not experience drug interactions 	<ul style="list-style-type: none"> Patients should achieve the best quality of life as possible Patients should be satisfied with their health care The psychosocial risks of epilepsy will be reduced Antiepileptic drug therapy should be cost-effective

Although it affects men and women equally, it is estimated that nearly one million American women of childbearing age have epilepsy.² There are many women's health issues in epilepsy.³ These include menstrual cycle influences on seizure activity, contraceptive-antiepileptic drug interactions, pharmacokinetic changes during pregnancy, teratogenicity of antiepileptic drugs, breastfeeding, impact of antiepileptic drugs on bone, and more. All of these issues challenge both the woman with epilepsy and the many health care providers involved in her care. Though the OSU Comprehensive Epilepsy Program focuses on all of the women's issues in epilepsy, this project focuses on pregnant women with epilepsy.

Previous Work in this Area

Optimal care of pregnant women with epilepsy requires collaboration. In 2002, discussions between the OSU Medical Center's Neurology and OB-GYN Departments regarding the number of pregnant women with epilepsy seen in the High-Risk Obstetrics Clinic without established Neurology care, resulted in a collaboration aimed at benefiting those women. Dr. McAuley, a clinical pharmacist from the epilepsy clinic, would attend the High-Risk OB clinic on a monthly basis so to extend Neurology care to that population. He was supported by his collaborating physicians and epilepsy nurse practitioner.

During the face-to-face interviews with the pregnant women attending the High Risk OB Clinic, all patients had their current drug therapy, seizure activity, presence or absence of toxicity, and medication adherence assessed. Further clinical, educational, and research interventions were suggested and documented.⁴

From 2001 to 2005, 47 women (49 pregnancies) were interviewed face-to-face by Dr. McAuley. A majority of the women were not established patients of the Comprehensive Epilepsy Program. Nearly all women were on antiepileptic drug therapy at some time in their pregnancy; only 3 were not. Most women were on monotherapy with an older antiepileptic drug (n=34). Twelve pregnancies were exposed to antiepileptic drug polytherapy. The most frequent clinical interventions Dr. McAuley made were to either make alterations to current therapy (n=10) or initiate AED therapy (n=8). *Unfortunately, a lot of the latter cases were due to women stopping or lowering their antiepileptic drug regimens once they discovered they were pregnant.* The most frequent education intervention was to suggest the women call the AED pregnancy registry (n=12). Other education topics were discussions on the fetal risks of seizure activity compared to AED exposure (n=8), the risks and benefits of breastfeeding (n=6) and care of a newborn by a mother with epilepsy (n=5). The most frequent research intervention was to recruit two patients into a multi-center trial looking at the neurodevelopmental effects of antiepileptic drugs on an exposed infant.

This clinical collaboration between the Comprehensive Epilepsy and Maternal-Fetal Medicine Programs is viewed positively. Pregnant women with epilepsy have enhanced access to the Comprehensive Epilepsy Clinic. By making necessary changes to drug therapy, they are potentially averting seizures during pregnancy in many of these women which can be detrimental to both mother and baby.

Though it is believed that the ready-access to Epilepsy expertise in the HROB clinic has enhanced the care of pregnant women with epilepsy, there is more work to be done. By retrospectively evaluating these interventions, areas for improvement were discovered. The one that this proposal focuses on is the fact that much of what Dr. McAuley does in the High-Risk OB clinic is re-start or increase doses of antiepileptic drugs in the women whom have stopped or lowered the dose of their drug therapy once they discovered they were pregnant. This is being “reactive” and it would certainly be better to be more proactive so as to prevent harm to mother and baby from seizure activity. The specific aim of this proposal is to learn more about why women do or do not alter their antiepileptic drug therapy during pregnancy. We propose to achieve that aim by conducting focus groups in pregnant women with epilepsy.

As optimal care of pregnant women with epilepsy requires collaboration, this project involves the practitioners from the Comprehensive Epilepsy and Maternal-Fetal Medicine Programs as well as the Epilepsy Foundation of Central Ohio, the local affiliate of the Epilepsy Foundation of America. One group of practitioners that has been key for this project’s success is the social workers from both the High-Risk OB clinic and the Epilepsy Foundation of Central Ohio.

Methods

Study Design

This is a cross-sectional study. The study was approved by the Ohio State University’s Biomedical Institutional Review Board (IRB). The inclusion criteria are listed below.

Inclusion criteria:

- Patients had a clinical diagnosis of epilepsy and were above the age of 18 years
- Patients were currently pregnant and able to provide consent by themselves

Exclusion criteria:

- Patients currently imprisoned

To date, ten women have been recruited from the Medical Center’s High-Risk Obstetrics and Comprehensive Epilepsy Program clinics. After patients signed the consent and confidentiality forms, demographic data was collected. The demographic data included questions about age, age at first seizure and whether the pregnancy was planned or unplanned. The unplanned pregnancy question was included because in epilepsy management it is ideal to plan a pregnancy so to optimize conditions before pregnancy. The women were also asked if they were taking folic acid prior to their pregnancy. Folic acid supplementation is taken to decrease the risk of neural tube defects in an unborn child. Since the antiepileptic drugs increase the risk of neural tube defects, all women of childbearing potential with epilepsy are advised to take folic acid. The women then participated in one ninety minute focus group held at the Epilepsy Foundation of Central Ohio’s

offices located at North Broadway and Indianola Avenues. Upon completion of the focus group, the women received a \$25 gift certificate from Wal-Mart along with a \$5 gas card.

Data Analysis

Quantitative and qualitative data were collected from 10 women in the three focus groups held thus far. It was entered into a Microsoft Access spreadsheet and Microsoft Excel was used to generate descriptive data.

Results

As can be seen from Table 1, the average age was 25.6 years and the average age at first seizure was 16.8 years. For two of the ten women, this was their first pregnancy. Six of the ten women told us their pregnancy was unplanned. Two of the seven women reported taking folic acid before their pregnancy and three of the ten women did not respond to that question.

Average age (years)	25.6 ± 4.03
Average age at first seizure diagnosis (years)	16.8 ± 7.42
First pregnancy	2 of 10 women
Unplanned Pregnancy	6 of 10 women
Folic acid taken before pregnancy	2 of 7 women 3 women unknown

Table 1. Patient Demographics

From the three focus groups, the women raised concerns specific to their pregnancy. The women were concerned about their epilepsy and what potential risks their medical condition would have on their unborn babies. The women also expressed a lack of education with respect to weaning their babies off of antiepileptic drugs. Additionally, the women voiced general concerns about epilepsy. In general, the women were concerned about their epilepsy and how it impacted their driving. The women were also concerned about the necessity of having a plan for their children if they experienced a seizure in the presence of their child(ren). Additionally, many women voiced a need for educating family members and significant others about epilepsy.

Several unintended effects of the focus group were observed. Prior to the focus groups, many of the women believed they were alone and had not met other women in their situation. The focus group allowed for them to meet other pregnant women with epilepsy. The women expressed comfort in meeting and getting to know other women with epilepsy. Also, the focus groups brought about some patient-to-patient teaching. Specifically, a few women expressed to the group a need for a plan for their children when they were having a seizure and no other adult was present. Another woman had conceived a plan for her children and shared that plan with the rest of the group. This plan was well received by the other women in the group.

Discussion

This is the first study to look into enhancing the care of pregnant women with epilepsy which has tried to understand why women may or may not alter their antiepileptic drug therapy during pregnancy.

The focus groups allowed the women to interact with others in similar situations and learn they were not alone. The focus groups brought forth women's concerns with epilepsy in general and those concerns specific to pregnancy. The majority of the women were not aware of the Epilepsy Foundation of Central Ohio. By holding the focus groups at the Epilepsy Foundation of Central Ohio's office, the women were put in touch with another support system. To date, though we are only half-way to our patient recruitment goal, we have learned more about pregnant women's concerns and how they manage their drug therapy during pregnancy.

Upon completion, the study has the potential to shed more light on the reasoning behind why some pregnant women with epilepsy may or may not alter their antiepileptic drug therapy. By identifying these reasons, we hope to be more proactive in our approach to patient education and ultimately improve outcomes in women with epilepsy.

Our study is not without limitations. Firstly, the sample size is small; thus far we were only able to recruit ten pregnant women with epilepsy to participate in the study. Also, there is a limited "generalizability" because the women recruited were all patients of the Ohio State University Medical Center in Columbus, Ohio. The results provided here are from participants in Central Ohio and may not be the same as those women from different regions of the state or country. Thirdly, this was a qualitative study, not a quantitative study.

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