Epilepsy in Pregnancy: Current Practices of Prenatal Genetic Counselors

Master’s Thesis

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Beth Rosen Sheidley, MS, CGC, Advisor

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By
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ABSTRACT

Epilepsy, Pregnancy and AEDs: Current Practices of Prenatal Genetic Counselors

A thesis presented to the Genetic Counseling Program

Graduate School of the Arts and Sciences
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Waltham, Massachusetts

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Epilepsy is a neurological disorder affecting approximately 1% of the general population. There are over 1 million women with epilepsy in the US alone, making this an important issue for healthcare providers treating them. Previous research indicates that women with epilepsy have limited knowledge regarding pregnancy related issues, but that they have a strong desire for more information. While these studies indicate that genetic counseling can contribute to the reduction of adverse outcomes in pregnancies of women with epilepsy, there have been no recent efforts to characterize the role of prenatal genetic counselors with this population. In this study, we aimed to identify current practices used by clinical prenatal genetic counselors across the United States in counseling women with epilepsy about pregnancy. We collected data from 98 prenatal genetic counselors,
recruited through the NSGC listserv, using an online anonymous survey. Over half (58%) of participants reported counseling more than 20 women with epilepsy of childbearing age. The vast majority of respondents (approaching 100%) reported discussing the balance between teratogenicity of AEDs and seizure control, and the detection of fetal anomalies. The vast majority (90%) of respondents also indicated that they typically discuss inheritance and recurrence risks with patients who have epilepsy. However, a minority of respondents (15%) reported that they discuss the molecular genetics of epilepsy and genetic testing options with patients, and only 36% of respondents indicated that they are comfortable discussing molecular genetics/testing with patients who have epilepsy. Our findings suggest that genetic counselors are lacking in awareness and/or understanding of molecular genetics and testing options with respect to epilepsy. Given that an assessment of possible genetic causes of epilepsy is an integral aspect of determining recurrence risk, it appears that there is a need for educating genetic counselors about the recent advances in epilepsy genetics.

**Key Words:** Epilepsy, women with epilepsy, prenatal genetic counselors, current practices, AEDs, seizure control, pregnancy, risk assessment, molecular genetics.
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Introduction

Epilepsy is a neurological disorder affecting approximately 1% of the general population (Dunlop and Jack, 2008; Fisher, 2010). In epilepsy the normal patterns of brain activity are disrupted, leading to unpredictable and repeated seizures. It can either be an isolated symptom or part of a syndrome (Berg and Scheffer, 2011). Although the majority (60%) of cases of epilepsy have unknown etiologies (Fisher, 2010), many factors are known to cause this condition. These include environmental factors, genetic factors, metabolic conditions, and abnormalities of brain structure (Berg and Scheffer, 2011). Genetic factors, while not always the primary cause of epilepsy, play an important role in triggering it through changes in the excitability of the brain. Furthermore, it has been suggested that the risk of epilepsy is higher in children of parents with epilepsy than in the general population (Helbig et. al., 2008). While lifetime risk of epilepsy is approximately 3%, the empiric recurrence risk of epilepsy in first-degree relatives is said to be 4-8% (Helbig et. al., 2008). In some epilepsies that follow Mendelian patterns of inheritance, the likelihood of recurrence may be significantly higher. Although dependent upon various factors and not always successful, epilepsy is typically treated with antiepileptic drugs (AED) (Fisher, 2010).

Individuals with epilepsy often struggle with psychological and emotional issues, such as stigma and discrimination (Fisher, 2010; Shostak et. al., 2011). However, women with epilepsy of childbearing age further grapple with the fears and stress associated with risks related to pregnancy, both to themselves and their unborn children (Shafer, 1998;
Pennell and Thompson, 2009; Fisher, 2010). There are over 1 million women with epilepsy in the US alone (Winterbottom, 2009), making this an important issue for healthcare providers treating them. The balance that must be sought between mitigation of seizures and the significant effects that AEDs may cause is a complex matter.

Though AEDs often reduce the frequency of seizures effectively, one of the most concerning aspects of these medications is their teratogenicity. The risk of major congenital malformations in the general population is approximately 2-3% and this risk increases 2-3-fold in the offspring of women with epilepsy, mainly due to the use of AEDs (Fisher, 2010; Dunlop and Gardiner, 2008). On the other hand, poor seizure control during pregnancy has been shown to increase the likelihood of pregnancy complications (hypoxia, congenital anomalies, developmental delay, and sometimes stillbirths) (Dunlop and Jack, 2008). To reduce these risks, providers aim to ensure that preconception counseling is provided, that a balance between seizure control and the use of AEDs is sought, and that any changes to treatment regimens are implemented prior to conception (Tomson, 2004; Dunlop and Jack, 2008; Freyer, 2008; Fisher, 2010).

Cessation of AED use or recommendation of monotherapy (use of a single drug) over polytherapy (use of two or more drugs simultaneously) during pregnancy are often considered (Fisher, 2010; Kulaga, 2011; Walker, 2009). Today, most women with epilepsy can become pregnant and bear healthy children and about 95% remain on treatment regimens during pregnancy (Winterbottom, 2009, Fisher, 2010; Pennell and Thompson 2009).

It is important to note that approximately 40% of pregnancies in women with medical conditions such as diabetes and epilepsy are unplanned (Freyer, 2008), and thus
by the time a woman knows she is pregnant (between 5-11 weeks) it is often too late to manipulate her treatment (Pennell and Thompson, 2009). Even though AEDs are known to reduce contraceptive efficacy, one of the key points stressed to women with epilepsy of childbearing age is the use of proper birth control methods to prevent unplanned pregnancies. Planning for pregnancy allows for appropriate surveillance, supplementation (i.e. folic acid) and manipulation of AED dosage in order to reduce fetal and maternal risks (Walker, 2009).

Previous research has demonstrated that overall knowledge of women with epilepsy regarding their condition and treatment options both before and during pregnancy is limited (Jacoby et. al. 1993; Shafer, 1998; Freyer, 2008; Winterbottom, 2008; Pennell and Thompson, 2009, 2010; Metcalfe et. al., 2012). In addition, this literature indicates that women with epilepsy feel that they are not knowledgeable about issues related to childbearing and are actively seeking more information regarding sexuality, reproduction, pregnancy risks, and teratogenicity of AEDs. The authors of the above mentioned studies suggest genetic counselors can provide support and comfort to women by listening and addressing questions/concerns about pregnancy and epilepsy. Genetic counselors can also provide patients with information and guidance that will allow them to make the best, informed decisions for themselves regarding childbearing and/or any other decisions that may affect their health and quality of life.

Dunlop and Jack (2008) and Winterbottom (2009) examined recommendations and guidelines for genetic counseling of women with epilepsy published by the American Congress of Obstetricians and Gynecologists (ACOG) and the American Academy of Neurology (NAA). These authors note that the guidelines emphasize the importance of
risk assessment and health promotion, discussion of balance between AEDs and seizures, monitoring of the pregnancy and fetal growth, and addressing the psychological effects of pregnancy in women with epilepsy (Dunlop and Jack, 2008, Winterbottom, 2009). Earlier publications indicated that genetic counseling of women with epilepsy can contribute to a reduction of adverse outcomes in such pregnancies (Jacoby et. al., 1993; Shafer, 1998). However, these publications are fairly dated and therefore more recent research characterizing the role of genetic counselors in the counseling of women with epilepsy is needed.

The lack of knowledge reported in the literature of women with epilepsy regarding their condition, and the current recommendations for the counseling of women with epilepsy of childbearing age point to the need for updating the characterization of the role of genetic counselors in counseling such women. In this study we aimed to investigate the current practices used by prenatal genetic counselors when counseling women with epilepsy who present either prior to or during a pregnancy (preconception or prenatal counseling, respectively). In the process we also evaluated how comfortable genetic counselors feel discussing specific topics and the challenges they identify in counseling women with epilepsy.
Methods

We sent a recruitment notice (see Appendix A) to members of the National Society of Genetic Counselors (NSGC) through the NSGC listserv. The recruitment notice included a description of the study and directed participants to an online anonymous survey (see Appendix B) hosted by Qualtrics. We recruited prenatal genetic counselors, who graduated from an ABGC accredited genetic counseling training program. To be eligible for study participation, we required that genetic counselors had experience in a clinical prenatal setting (either currently or in the past 2 years) as well as experience counseling women with epilepsy of childbearing age. Individuals who did not meet these criteria were directed to the end of the survey.

The survey was submitted to and approved by the Brandeis University Institutional Review Board. The survey was open for responses from December 11, 2012 through January 11, 2013 and consisted of 30 multiple-choice questions and one open-ended question. The questions focused on current practices of clinical prenatal genetic counselors with regard to the information and topics they discuss during genetic counseling sessions with women who have epilepsy and are of childbearing age. The survey addressed the differences between preconception counseling for this population and counseling of women during pregnancy. In addition, respondents were asked to consider the challenges of counseling women with epilepsy, and to rate their comfort in discussing specific topics.
We analyzed the data using SPSS 19. We initially ran frequencies for each of the response sets. Once the frequencies were established, we used paired t-test analysis with a 95% confidence interval (CI) to compare responses to questions about preconception counseling to those about prenatal counseling. In addition, we examined possible correlations between major demographic categories, and three areas of responses (topics, discussed, comfort level and challenges).
Results

Sample Characteristics

According to the 2012 Professional Status Survey (PSS) (NSGC, 2012) there are currently 3,039 members of the National Society of Genetic Counselors (NSGC). Of these, 1,339 completed the PSS in 2012 (NSGC, 2012). According to the PSS, approximately 29% (~388) of respondents in 2012 were prenatal genetic counselors. We targeted this cohort of prenatal genetic counselors in our recruitment and received a total of 140 responses to our survey. Of those respondents, 42 did not meet our eligibility criteria or did not complete the entire survey. Our final dataset consisted of 98 responses valid for our data analysis.

As shown in Table 1, our participants were predominantly female (95%) and between the ages of 25 and 40 years (68%). All six

<table>
<thead>
<tr>
<th>Total years of experience in a clinical prenatal setting</th>
<th>Survey Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-1</td>
<td>17.3 17</td>
</tr>
<tr>
<td>2-5</td>
<td>28.6 28</td>
</tr>
<tr>
<td>6-10</td>
<td>21.4 21</td>
</tr>
<tr>
<td>&gt;10</td>
<td>32.7 32</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approximate Number of Women with Epilepsy Counseled</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=91</td>
</tr>
<tr>
<td>1-19</td>
</tr>
<tr>
<td>20-49</td>
</tr>
<tr>
<td>50-99</td>
</tr>
<tr>
<td>100-200</td>
</tr>
<tr>
<td>201+</td>
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<tr>
<th>Age (years)</th>
<th>N=98</th>
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<tbody>
<tr>
<td>20-24</td>
<td>4.1  4</td>
</tr>
<tr>
<td>25-29</td>
<td>29.6 29</td>
</tr>
<tr>
<td>30-34</td>
<td>26.5 26</td>
</tr>
<tr>
<td>35-39</td>
<td>12.2 12</td>
</tr>
<tr>
<td>40-44</td>
<td>8.2  8</td>
</tr>
<tr>
<td>45-49</td>
<td>9.2  9</td>
</tr>
<tr>
<td>&gt;50</td>
<td>10.2 10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>N=98</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>94.9 93</td>
</tr>
<tr>
<td>Male</td>
<td>5.1  5</td>
</tr>
</tbody>
</table>
regions outlined by the NSGC PSS were represented. Respondents reported graduation between 1975 and 2012, with approximately 43% graduating within the last 5 years. Fifty-three respondents (54%) reported 6 or more years experience in a clinical prenatal setting, with 32 (33%) reporting over 10 years of experience. Additionally, while 65% (59) of participants reported counseling fewer than 50 women with epilepsy, approximately 35% (32) reported counseling more than 50 women with epilepsy.

A large majority of our respondents (93%) indicated that when they see women with epilepsy who present for genetic counseling during an ongoing pregnancy, the appointments usually result from a referral by another provider. In these instances, self-referral is rare (<7%). In contrast, women with epilepsy who are not yet pregnant and seek preconception counseling are reportedly much less likely to be referred by a medical provider. Only 39% of our respondents indicated that referral by a provider is the norm for preconception counseling among women with epilepsy, whereas 15% indicated that self-referral was most common and 25% indicated that self-referral and provider-referral were equally common.

*Genetic Counselors Endorse Previous Findings that Demonstrate a Lack of Knowledge Among Women with Epilepsy*

In the hope of learning something about the knowledge and concerns patients bring to genetic counseling sessions we evaluated genetic counselors’ perceptions in this regard. Overall, respondents indicated that women with epilepsy continue to be lacking in knowledge regarding childbearing related issues. While 72% of respondents indicated that their patients are either informed or somewhat informed about the balance between AED use and seizure control during pregnancy, they were less likely to report that
patients are knowledgeable about the fetal effects of AEDs and/or the heritability of epilepsy. Only 54% of respondents indicated that their preconception patients are either informed or somewhat informed about the fetal effects of AEDs and 42% said that their pregnant patients are informed/somewhat informed about this topic. With regard to the heritability of epilepsy, only 10% of respondents indicated that their preconception patients are either informed or somewhat informed and only 8% said that their patients who are already pregnant are informed/somewhat informed about this topic (sig.=0.007; CI=95%). In contrast to the perceived levels of knowledge, 95% of respondents reported that their patients are concerned/somewhat concerned about the fetal effects of AEDs. Furthermore, 82% of respondents indicated that their preconception patients are concerned/somewhat concerned about AED use and seizure control, and 71% of them reported that their prenatal patient are concerned/somewhat concerned about it. On the other hand, with regard to heritability of epilepsy, only 55% of respondents indicated that their preconception patients are concerned/somewhat concerned about this topic, and 41% reported that their prenatal patients are concerned/somewhat concerned about it.

**Current Genetic Counseling Practices are Limited with Respect to Discussion of Molecular Genetics of Epilepsy and Testing Options**

We asked participants to rate how often they discuss specific topics in genetic counseling sessions with women who have epilepsy and are of childbearing age. Figure 1 shows the percentage of respondents who reported they always/frequently discusses specific topics with their patients. Almost all of our respondents reported that they always/frequently discuss the effect of seizures on pregnancy, AEDs and seizure control,
utility of ultrasound in the detection of fetal anomalies, and inheritance and recurrence risk of epilepsy. This was generally the case regardless of whether the counseling occurred prior to or during pregnancy. We found that teratogenicity of AEDs was the most common topic of discussion in both settings, being always/frequently discussed with patients in both preconception (100%) and prenatal (99%) settings. However, a large majority of our respondents reported that they do not usually discuss molecular genetics of epilepsy and diagnostic testing options with their patients. In preconception sessions only 15% of respondents reported that they always/frequently discuss this topic, and in prenatal sessions only 5% reported that they always/frequently discuss it.

Counselors with more years of experience were less likely to discuss molecular genetics of epilepsy and testing options in a preconception session (correlation = -0.26; sig. = 0.03), but we did not find the same correlation with years of experience in the sessions involving patients who were already pregnant.

Note: for simplification, we combined responses of “always” and “frequently” together in our analysis.
**Genetic Counselors are More Likely to Discuss Alternative Reproductive Options.**

**Pregnancy Termination and Abstaining from Pregnancy in Preconception Counseling Sessions**

We explored additional topics that may have a more psychological impact on women with epilepsy to see how likely they are to be discussed with patients. These topics included alternative reproductive options (adoption, donor egg, surrogacy, etc.), pregnancy termination, and the choice to abstain from a future pregnancy. Figure 2 shows the percentage of respondents who indicated they are likely/somewhat likely to discuss these topics. In examining the data we found significant differences between preconception and prenatal counseling. Our data show that 40% of genetic counselors are likely/somewhat likely to talk about alternative options for pregnancy, such as donor egg, adoption, or surrogacy, in preconception counseling with women with epilepsy. However, only 7% reported being likely/somewhat likely to talk about alternative options, such as placement of a child for adoption, with patients who come to prenatal genetic counseling when they are already pregnant (sig.=0.00; CI=95%).

We found a significant difference (sig.=0.00; CI=95%) between preconception and prenatal settings with regard to the likelihood of discussing the choice to abstain from future pregnancy. While 35% of respondents reported that they are likely/somewhat likely to talk about the choice to abstain from future pregnancies in preconception sessions, only 13% reported they are likely/somewhat likely to discuss it with patients who are already pregnant. We also assessed the discussion of pregnancy termination, and found that this topic is not typically discussed. Only 21% of respondents indicated that they are likely/somewhat likely to discuss pregnancy termination with preconception
patients, and only 16% reported that they are likely/somewhat likely to discuss it with their already pregnant patients.

**Figure 2: Percent of Respondents Indicating They Are Likely/Somewhat Likely to Discuss Specific Topics**

<table>
<thead>
<tr>
<th>% Respondents</th>
<th>Alternative options (adoption, donor egg, surrogacy, etc.)</th>
<th>Pregnancy termination</th>
<th>Choice to abstain from future pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preconception</td>
<td>40</td>
<td>21</td>
<td>35</td>
</tr>
<tr>
<td>Post-conception</td>
<td>7</td>
<td>16</td>
<td>13</td>
</tr>
</tbody>
</table>

Note: for simplification, we combined responses of “likely” and “somewhat likely” together in our analysis

**Genetic Counselors Report Low Comfort Levels Discussing Molecular Genetics and Testing Options with Their Patients**

We asked participants to rate their comfort level in discussing molecular genetics of epilepsy, inheritance and recurrence risk of epilepsy, teratogenic effects of AEDs, and the balance between seizure control and AED use with women who have epilepsy. In Table 2 we show the percentage of respondents indicating high comfort levels (comfortable/ somewhat comfortable) and low comfort level (uncomfortable/ somewhat uncomfortable) in discussing these topics. We found that respondents generally felt comfortable discussing the balance between seizure control and AED use, and teratogenicity of AEDs, regardless of whether the patient was already pregnant. Similarly, respondents reported feeling comfortable discussing the inheritance of epilepsy
and recurrence risks. However, only 36% of respondents reported feeling somewhat comfortable/comfortable discussing molecular genetic testing with their patients.

We found that respondents who had counseled greater numbers of women with epilepsy were more likely to be comfortable discussing the inheritance and recurrence risk of epilepsy, teratogenic effects of AEDs, and the balance between seizure control and AED use. However, the extent of respondents’ experience with patients with epilepsy did not correlate with their comfort level in discussing molecular genetics of epilepsy and testing options.

<table>
<thead>
<tr>
<th>Table 2: Genetic counselor's comfort levels in discussing specific topics</th>
</tr>
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<tbody>
<tr>
<td>Comfortable/ Somewhat comfortable (%)</td>
</tr>
<tr>
<td>Molecular genetic testing</td>
</tr>
<tr>
<td>Inheritance of epilepsy and recurrence risks</td>
</tr>
<tr>
<td>Teratogenic effects of AEDs</td>
</tr>
<tr>
<td>Balance between seizure control and AED use</td>
</tr>
</tbody>
</table>

**Genetic Counselors Report Molecular Genetics and Testing Options to be the Most Challenging Topic to Discuss with Patients**

We asked respondents to rate how challenging they found the discussion of specific topics to be when counseling women with epilepsy. In Table 3 we show the percentage of respondents who reported high levels of challenge (challenging/ somewhat challenging) and low levels of challenge (not at all challenging/ not very challenging) in discussing specific topics. These topics included possible effects of AEDs/ poor seizure control on the fetus, reproductive options, recurrence risks and molecular genetics of epilepsy. Overall, respondents did not report being particularly challenged by the
discussion of possible effects of AEDs and/or seizures on the fetus, reproductive options (such as adoption, donor egg, abstaining from future pregnancy, etc.), or recurrence risks of epilepsy. However, the majority of respondents (55%) indicated that discussing molecular genetic testing with their patients was challenging/somewhat challenging. Respondents with more years of experience and/or who had seen more patients with epilepsy were no less likely to report that discussing molecular genetics and testing was challenging/somewhat challenging.

<table>
<thead>
<tr>
<th></th>
<th>Challenging/ Somewhat challenging (%)</th>
<th>Not at all challenging/ Not very challenging (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possible effects of AEDs on the fetus</td>
<td>33.7</td>
<td>48.0</td>
</tr>
<tr>
<td>Possible effects of poor seizure control on the fetus</td>
<td>23.7</td>
<td>53.6</td>
</tr>
<tr>
<td>Reproductive options</td>
<td>12.3</td>
<td>60.8</td>
</tr>
<tr>
<td>Recurrence risks of epilepsy</td>
<td>28.6</td>
<td>50.0</td>
</tr>
<tr>
<td>Molecular genetics of epilepsy</td>
<td>54.6</td>
<td>11.3</td>
</tr>
</tbody>
</table>
Discussion

Our study was the first of its kind to investigate current practices among genetic counselors who counsel women with epilepsy of childbearing age. We assessed the knowledge and concerns that they perceive women with epilepsy bring into genetic counseling sessions. More importantly, we explored topics that genetic counselors discuss with patients, both in preconception and prenatal settings. In the process we also investigated how comfortable genetic counselors feel discussing specific topics and how challenging they find these discussions.

Our study cohort consisted of 98 prenatal genetic counselors who are members of the NSGC. The demographic characteristics of our respondents were generally consistent with the demographics of the genetic counseling population (with respect to gender, age, and region of practice) as reported in NSGC’s Professional Status Survey (NSGC PSS, 2012). Although the number of patients with epilepsy counseled by our participants ranged from 1 to greater than 200, almost 60% of our respondents indicated that they had counseled more than 20 women with epilepsy. Therefore much of our study cohort has had considerable experience with this population and are well positioned to comment on patient knowledge and concerns regarding childbearing issues for women with epilepsy.

Although our respondents indicated that women understand the need for balance between the use of medication and seizure control during pregnancy, they reported that their patients are less knowledgeable about the teratogenic effects of their medications. Our data revealed that participants perceived patients to be most concerned about AEDs,
both in terms of their effects on fetal development, and the need for balance between the
risks that AEDs pose for pregnancy and seizure control. These findings are consistent
with previous literature, which suggests that women with epilepsy are greatly in need of
information regarding childbearing issues (Shafer, 1998; Freyer, 2008; Winterbottom,
2008; Pennell and Thompson, 2009; and Metcalfe et. al., 2012).

Current Practices of Prenatal Genetic Counselors do Not Incorporate Recent Advances
in Molecular Genetics of Epilepsy

Counselors report always/frequently discussing the teratogenicity of AEDs,
effects of seizures on pregnancy, balance between AEDs and seizure control, the use of
ultrasound to detect fetal anomalies, and inheritance/recurrence risk with their patients
who have epilepsy. This is consistent with previous recommendations regarding genetic
counseling of women with epilepsy (Dunlop and Jack, 2008; Winterbottom, 2009). In
contrast, our data revealed that genetic counselors do not emphasize molecular genetics
and testing options in counseling women with epilepsy as a whole. It would seem evident
that consideration of the molecular genetics of epilepsy is a key element of recurrence
risk assessment. However, advances in the understanding of the molecular genetics of
epilepsy are fairly recent, and it is likely that many genetic counselors have limited
knowledge of them. There is some evidence from our findings that recent graduates are
more likely to be knowledgeable about the molecular genetics of epilepsy, but since we
only noted this trend in preconception sessions it is unclear whether the overall lack of
knowledge regarding these recent advances is simply a reflection of graduate training or
whether it demonstrates a need for educational efforts targeted at all members of the
genetic counseling community who serve women with epilepsy.
We found a significant difference between preconception and prenatal counseling with regard to the likelihood that genetic counselors discuss alternative reproductive options, such as donor egg, surrogacy, placing a child for adoption, and the choice to abstain from a future pregnancy. It is possible that genetic counselors are reluctant to discuss these options with patients who are already pregnant. It is also possible that genetic counselors only discuss these options if raised by the patient, and that patients who come for preconception counseling are more likely to be interested in exploring these options.

*Counselors’ Comfort Levels Reflect Their Knowledge and Experience*

It is not surprising that respondents reported feeling most comfortable discussing teratogenicity of AEDs and the balance between AEDs and seizure control. These issues have been well reviewed in the literature for decades, thus providing genetic counselors with accessible resources when discussing such topics with patients. On the other hand, respondents reported feeling less comfortable discussing more recent information regarding molecular genetics.

Participants’ experience level seems to impact the degree of comfort they feel in discussing certain topics with patients in relevant counseling settings. Our data show that both years of experience and the total number of women participants reported counseling correlated positively with comfort levels participants reported feeling in discussing teratogenic effects of AEDs and the balance between AEDs and seizure control. This suggests that the longer participants have been in the field, and the more patients they have the opportunity to counsel, the more comfortable they become in discussing these topics. We also found that genetic counselors who had counseled more women with
epilepsy had a higher comfort level in discussing inheritance of epilepsy. This suggests that the more chances participants have to explain this topic, the more comfortable they feel discussing it, regardless of how many years they have been in the field. We did not identify a significant correlation between either the total years of experience in the field or the number of counselees and the comfort level participants indicated feeling in discussing molecular genetics of epilepsy. This suggests that regardless of how long they have been in the field or the number of women they have had experience counseling, they don’t feel comfortable with the topic. This further supports the idea that participants have limited knowledge surrounding the recent advances in the molecular genetics of epilepsy, and therefore feel less comfortable discussing it with their patients.

*Genetic Counselors Report Being Challenged by Advances in Molecular Genetics of Epilepsy*

The fact that respondents reported the highest level of challenge in the discussion of molecular genetics and testing options seems to follow the pattern of limited knowledge of participants in this area. The fact that we did not identify a correlation between the challenge level participants attribute to the discussion of molecular genetics of epilepsy and either years of experience in the field or the number of patients participants indicated they have counseled, suggests that this topic is challenging for genetic counselors regardless of the extent of their experience. The difference between the percentage (55%) of respondents who indicated that the discussion of molecular genetics is challenging and the percentages of respondents who reported other topics to be challenging (12%-34%) further supports the likely gap in knowledge of genetic counselors.
Study Limitations

The study cohort was relatively small (N=98). Based on the most recent PSS, there are approximately 881 prenatal genetic counselors who are members of the NSGC, yet only 140 prenatal genetic counselors responded to our survey, yielding a low response rate (<16%). Additionally, of those 140, twenty did not meet our eligibility criteria or did not complete the survey. This already smaller sample was further condensed when we eliminated individuals who indicated they have not been in the clinical prenatal genetic counseling field for 2 or more years. As a result, it is possible that our study participants are not representative of clinical prenatal genetic counselors as a whole. It is also possible that only those who are interested in the field of epilepsy chose to complete the survey, possibly introducing some bias to the response set. Furthermore, due to the design of our survey questions, the answer options, and the need to represent current practices, responses from individuals who have been out of the clinical prenatal setting for 2 years have also been eliminated from our dataset. It is possible that including these individuals would have changed some of the data and contributed to the representation of the cohort.

We utilized the NSGC listserv to recruit our participants. As a result only genetic counselors who are members of the organization and who subscribe to the listserv could complete the survey. Generally, the demographics of our cohort with regard to age, gender, region distribution, and years of experience in the field are representative of the 2012 PSS general demographics description (NSGC PSS, 2012). However, our study focuses on current practices of clinical preconception and prenatal settings, which may have changed since the data for the 2012 PSS was collected.
Our online, anonymous survey was an efficient way for conducting our study. However, this method of providing freedom of time and privacy in completing the survey allowed for the potential variability in interpretation of the questions without the possibility of clarification. This may have skewed the results based on misinterpretation of the questions asked. Furthermore, since the survey was multiple choice there was no option for commentary on responses participants provided, preventing them from possibly explaining their responses. Additionally, although it is well known in the literature that women with epilepsy have limited knowledge regarding their condition and pregnancy, we asked counselors to comment on patient knowledge/concerns, rather than gathering the information from the patients themselves. Therefore, it impossible to know whether the information we gathered was an accurate representation of actual patient knowledge and concerns.
Conclusions

This study explored the current practices being used by clinical prenatal genetic counselors when counseling women with epilepsy of childbearing age. We also assessed the topics genetic counselors feel most comfortable discussing with patients as well as the topics they feel are most challenging for them in counseling women with epilepsy. It appears there is a nearly universal coverage of AEDs, seizures, the balance between them during pregnancy, prenatal detection of fetal anomalies, and the inheritance/recurrence risks of epilepsy in genetic counseling of patients in both preconception and prenatal settings. Participants also indicated that they feel most comfortable discussing these topics and feel least challenged in discussing them with their patients. In contrast, our respondents indicated that they do not typically discuss the molecular genetics of epilepsy and testing options with their patients and that this is the most challenging topic for them to cover in both preconception and prenatal settings. Our findings suggest that genetic counselors are lacking in awareness and/or understanding of molecular genetics and testing options with respect epilepsy.

Risk assessment, health promotion and coordination of care are central to genetic counseling, especially for those with a chronic illness. Therefore, as an essential part of risk assessment and health promotion, genetic counselors should better emphasize the importance of molecular genetics and testing options, particularly for the purpose of making a diagnosis. As Sheidley and Poduri (2012) stated, making a genetic diagnosis “represents an end to the diagnostic odyssey that many patients and families with difficult
to diagnose conditions experience.” Additionally, in some instances a genetic diagnosis could help determine optimal treatment options for patients with epilepsy (Sheidley and Poduri, 2012).

Overall the results of this study suggest that genetic counselors generally address the concerns and needs they believe patients bring to their sessions. However, it seems that counselors should emphasize molecular genetics and testing options more than they currently report doing. Given that an assessment of possible genetic causes of epilepsy is an integral aspect of determining recurrence risk, it appears that there is a need for educating genetic counselors about the recent advances in epilepsy genetics. In addition, future research should focus on investigating genetic counseling for women with epilepsy from the patients’ perspective.
References


Appendices

Appendix A. Recruitment Notice

**Subject:** Epilepsy, Pregnancy and AEDs: Current Practices of Prenatal Genetic Counselors

During your career as a genetic counselor, have you ever practiced in a prenatal setting? Have you ever counseled a woman with epilepsy of childbearing age?

If so, I invite you to participate in a research study investigating prenatal genetic counselors’ experiences with regard to counseling women with epilepsy who are pregnant or are considering pregnancy. I am conducting this research study for my master’s thesis, and the research protocol has been approved by the Brandeis University IRB.

The purpose of this study is to explore the practices of prenatal genetic counselors and challenges they face when counseling women with epilepsy, as well as the impact of epilepsy on reproductive decisions.

Participation in this research study is open to all genetic counselors who have ever practiced in a clinical prenatal setting, and who have had experience counseling at least one woman with epilepsy regarding pregnancy.

Participation in this study is completely confidential and voluntary. Participation will involve completing an online, anonymous survey which should take approximately 15 minutes to complete. To participate in the study, please follow the link below to access the online survey:

https://brandeis.qualtrics.com/SE/?SID=SV_5axpvyJf6w09HUuh

Upon completion of the survey respondents will be eligible to enter a raffle for one of three $50 Amazon.com gift-cards.

If you have any questions or comments, please feel free to contact me at nklainer@brandeis.edu. Thank you in advance for your participation.

Sincerely,

Nira Klainer

Brandeis University Genetic Counseling Student, Class of 2013
Appendix B: Survey

Q0 Thank you for agreeing to participate in the study: Epilepsy, Pregnancy and AEDs: Current Practices of Prenatal Genetic Counselors. Participation in this study is voluntary, and all responses will remain anonymous. No identifying information will be asked or required for the completion of this survey. This study was reviewed and approved by the Institutional Review Board of Brandeis University of Waltham, MA. By clicking the "Next" button below you are consenting to participate in this study. You may choose to discontinue your participation at any time before or during your completion of the survey.

☐ Next
☐ No, thank you

If Next Is Selected, Then Skip To Have you graduated from an ABGC accre...If No, thank you Is Selected, Then Skip To End of Survey

Q1 Did you graduate from an ABGC accredited genetic counseling program?

☐ Yes
☐ No

If No Is Selected, Then Skip To End of Survey

Q2 In what year did you graduate from your genetic counseling program?

___________

Q3 What is your gender?

☐ Male
☐ Female
Q4 What is your current age?

- 20-24 years
- 25-29 years
- 30-34 years
- 35-39 years
- 40-44 years
- 45-49 years
- 50 years and over

Q5 In what US region did/do you currently practice?

- Region 1: CT, MA, ME, NH, RI, VT, Maritime Provinces
- Region 2: DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec
- Region 3: AL, FL, GA, KY, LA, MS, NC, SC, TN
- Region 4: AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, WI, Ontario
- Region 5: AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Sask
- Region 6: AK, CA, HI, ID, NV, OR, WA, British Columbia

Q6 Have you ever worked as a clinical genetic counselor in a prenatal setting?

- yes
- No

If yes Is Selected, Then Skip To Do you currently work as a clinical g...If No Is Selected, Then Skip To End of Survey

Q7 Do you currently work as a clinical genetic counselor in a prenatal setting?

- Yes
- No

If Yes Is Selected, Then Skip To How long have you been at your curren...If No Is Selected, Then Skip To How long has it been since you have w...
Q8 How long have you been at your current position?

- 0-1 years
- 2-5 years
- 6-10 years
- Over 10 years

Q9 How many total years of experience do you have in a clinical, prenatal setting?

- 0-1 years
- 2-5 years
- 6-10 years
- Over 10 years

If 0-1 years is selected, then skip to: Have you had experience counseling women who are pregnant?
If 2-5 years is selected, then skip to: Have you had experience counseling women who are pregnant?
If 6-10 years is selected, then skip to: Have you had experience counseling women who are pregnant?
If Over 10 years is selected, then skip to: Have you had experience counseling women who are pregnant?

Q10 How long has it been since you have worked in a clinical prenatal setting?

- 0-1 years
- 2-5 years
- 6-10 years
- Over 10 years

Q11 How many years did you work in a clinical prenatal setting?

- 0-1 years
- 2-5 years
- 6-10 years
- Over 10 years
Q12 What is currently your primary field of practice?

- Pediatrics
- Cancer
- Adult
- Specialty
- General genetics
- Research
- Diagnostic lab
- Other non-traditional

If Pediatrics Is Selected, Then Skip To Have you had experience counseling women with epilepsy regarding pregnancy, antiepileptic drugs (AEDs), and teratogenicity?

Q13 Have you had experience counseling women with epilepsy regarding pregnancy, antiepileptic drugs (AEDs), and teratogenicity?

- yes
- No

If yes Is Selected, Then Skip To Approximately how many women with epilepsy in total have you counseled (either preconception or post conception) in a clinical prenatal setting?

Q14 Since the beginning of your genetic counseling career, approximately how many women with epilepsy in total have you counseled (either preconception or post conception) in a clinical prenatal setting?

________________________

Q17 In your experience, most of the pregnancies in women with epilepsy have been:

- Planned
- Unplanned
- I don't know
Q16 In your experience, when do women with epilepsy of childbearing age usually present to genetic counseling?

- Preconception (prior to pregnancy)
- Post-conception (already pregnant)
- No difference

Q15 In your experience, most women with epilepsy who come for preconception genetic counseling are:

- Referred by their medical providers
- Self-referred
- Self-referred and referred by medical providers in equal numbers
- N/A, I don't have experience counseling women with epilepsy preconception

Q29 In your experience, most women with epilepsy who are already pregnant when they come for genetic counseling are:

- Referred by their medical providers
- Self-referred
- Self-referred and referred by medical providers in equal numbers
- N/A, I don't have experience counseling women with epilepsy with an ongoing pregnancy

Q18 In your experience, pregnant women with epilepsy are seen by genetic counselors:

- Once - for the initial visit
- Twice - initial visit and a follow-up appointment after delivery
- Twice - initial visit and a follow-up during the pregnancy
- Multiple times - initial visit, once or more throughout the pregnancy, and a follow-up after delivery
- Multiple times - initial visit and several times throughout the pregnancy but not after delivery
- Other (please specify) _________________
Q19 In your experience, what are the primary concerns of women with epilepsy regarding an ongoing pregnancy?

<table>
<thead>
<tr>
<th>Concern</th>
<th>Not at all concerned</th>
<th>Not very concerned</th>
<th>Neutral</th>
<th>Somewhat concerned</th>
<th>Very concerned</th>
<th>N/A - no experience counseling women with epilepsy with an ongoing pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>AED use and seizure control</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Fetal effects of AEDs</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Heritability of epilepsy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Burden of additional monitoring during pregnancy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive options, such as adoption, termination, etc.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q30 In your experience, what are the primary concerns of women with epilepsy regarding a possible future pregnancy (preconception)?

<table>
<thead>
<tr>
<th>Concern</th>
<th>Not at all concerned</th>
<th>Not very concerned</th>
<th>Neutral</th>
<th>Somewhat concerned</th>
<th>Very concerned</th>
<th>N/A - no experience with preconception counseling of women with epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>AED use and seizure control</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Fetal effects of AEDs</td>
<td>○</td>
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<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Heritability of epilepsy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Burden of additional monitoring during pregnancy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive options, such as adoption, surrogacy, etc.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q20 Please rate how knowledgeable most women with epilepsy are about the topics below when they come for genetic counseling regarding an ongoing pregnancy:

<table>
<thead>
<tr>
<th>Topic</th>
<th>Not at all informed</th>
<th>Not very informed</th>
<th>Neutral</th>
<th>Somewhat informed</th>
<th>Very informed</th>
<th>N/A - no experience counseling women with epilepsy with an ongoing pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>AED use and seizure control</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Fetal effects of AEDs</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Heritability of epilepsy</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Additional monitoring during pregnancy</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Reproductive options, such as adoption, termination, etc.</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
</tbody>
</table>
Q31 Please rate how knowledgeable women with epilepsy are about the topics below when they come for genetic counseling regarding a possible future pregnancy:

<table>
<thead>
<tr>
<th>Topic</th>
<th>Not at all informed</th>
<th>Not very informed</th>
<th>Neutral</th>
<th>Somewhat informed</th>
<th>Very informed</th>
<th>N/A - no experience with preconception counseling of women with epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>AED use and seizure control</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Fetal effects of AEDs</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Heritability of epilepsy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Additional monitoring during pregnancy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive options, such as adoption, surrogacy, etc.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q23 When counseling women with epilepsy during a pregnancy, how often do you discuss the following topics?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
<th>N/A - no experience counseling women with epilepsy with an ongoing pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effects of seizures on pregnancy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Seizure control and the use of AEDs</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Behavioral seizure prevention (ex. sleep, alcohol avoidance, etc.)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Teratogenicity of AEDs</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Alternative treatments</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Molecular genetics of epilepsy and testing options</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Inheritance and recurrence risks</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Vitamin supplementation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Utility of ultrasound for detection of fetal anomalies</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Stigma</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Guilt and shame</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q22 When counseling women with epilepsy preconception, how often do you discuss the following topics?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
<th>N/A - no experience with preconception counseling of women with epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effect of seizures on pregnancy</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Seizure control and use of AEDs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Behavioral seizure prevention (ex. sleep, alcohol avoidance, etc.)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Teratogenicity of AEDs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Alternative treatments</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Molecular genetics of epilepsy and testing options</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Inheritance and recurrence risks</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Vitamin supplementation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Utility of ultrasound for detection of fetal anomalies</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Stigma</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Guilt and shame</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Q25 When counseling women with epilepsy during a pregnancy, how likely are you to discuss the following topics?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Unlikely</th>
<th>Somewhat Unlikely</th>
<th>Neutral</th>
<th>Somewhat Likely</th>
<th>Likely</th>
<th>N/A - no experience counseling women with epilepsy with an ongoing pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Placement of child for adoption</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Pregnancy termination</td>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Choice to abstain from future pregnancy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q24 When counseling women with epilepsy preconception, how likely are you to discuss the following topics?

<table>
<thead>
<tr>
<th></th>
<th>Unlikely</th>
<th>Somewhat Unlikely</th>
<th>Neutral</th>
<th>Somewhat Likely</th>
<th>Likely</th>
<th>N/A - no experience with preconception counseling of women with epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contraception and birth control</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative options for pregnancy (donor egg, adoption, surrogacy, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pregnancy termination</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Choice to abstain from a future pregnancy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q26 How comfortable do you feel counseling women with epilepsy of childbearing age regarding the following:

<table>
<thead>
<tr>
<th></th>
<th>Uncomfortable</th>
<th>Somewhat uncomfortable</th>
<th>Neutral</th>
<th>Somewhat comfortable</th>
<th>Comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Molecular genetic testing</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Inheritance of epilepsy and recurrence risks</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Teratogenic effects of AEDs</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Balance between seizure control and the effects of AEDs on the developing fetus</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q27 How challenging do you find the following aspects of counseling women with epilepsy?

<table>
<thead>
<tr>
<th>Possible effects of AEDs on the fetus</th>
<th>Not at all challenging</th>
<th>Not very challenging</th>
<th>Neutral</th>
<th>Somewhat challenging</th>
<th>Very challenging</th>
</tr>
</thead>
<tbody>
<tr>
<td>Molecular genetics of epilepsy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrence risks of epilepsy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Possible effects of poor seizure control on the fetus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reproductive options</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial aspects of pregnancy in women with epilepsy of childbearing age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q28 What are some resources you use in order to gain knowledge regarding women and epilepsy, AEDs, teratogenicity, genetics of epilepsy, etc.? (Choose all that applies)

- ReproTox
- OTIS
- Up-To-Date
- Other (please specify) ____________________

Q32 Please use the space below to comment on anything of relevance that was not included in the survey questions or any difficulties you encountered when completing the survey.
Q33 Thank you very much for taking the time to complete my survey. Your participation is greatly appreciated. If you are interested in entering a raffle for one of three $50 Amazon.com gift-cards, please e-mail me your information at nklainer@brandeis.edu.

Nira Klainer
Brandeis University Genetic Counseling Student, Class of 2013