



Sexual and Reproductive Health Counseling: The Sooner the Better

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Sexual and Reproductive Health Concerns of Women With Epilepsy Beginning in Adolescence and Young Adulthood

Kirkpatrick L, Harrison E, Borrero S, et al. *Epilepsy & Behavior*. 2021;125:108439. doi:10.1016/j.yebeh.2021.108439.

Background: Women with epilepsy (WWE) have potentially unique concerns regarding their sexual and reproductive health (SRH). Prior studies of WWE have focused narrowly on pregnancy and preconception experiences, and have not addressed concerns of nulliparous adolescent and young adult women not actively seeking pregnancy. **Methods:** We conducted individual semi-structured interviews with WWE 18-45 years of age. We sampled to maximize diversity of age and parity, and intentionally included many adolescent and young adult nulliparous women not actively planning pregnancy. Interviews broadly addressed participants' SRH concerns and experiences. Interviews were audio-recorded and transcribed. Two coders performed qualitative analysis using thematic analysis with deductive and inductive approaches. **Results:** Twenty WWE (median age 23 years, range 18-43 years) completed interviews. Twelve were nulliparous, six had children, one had a history of miscarriage only, and two were currently pregnant. WWE's narratives revealed significant concerns about family planning and reproductive health in the context of epilepsy, including: 1) seizures endangering pregnancies and children 2) teratogenic effects of antiseizure medication, 3) heritability of epilepsy, 4) antiseizure medication and epilepsy impacting fertility, and 5) interactions between antiseizure medication and contraception. **Conclusion:** WWE, including nulliparous adolescent and young adult women who are not actively planning pregnancy, have significant concerns about how their epilepsy interacts with SRH. SRH counseling for WWE should begin during adolescence and be incorporated into the transition process from pediatric to adult healthcare. Insights from WWE may aid in the creation of relevant patient-facing educational resources as well as provider-facing training and tools to meaningfully support the reproductive decision-making of WWE throughout their childbearing years.

Commentary

Educating women with epilepsy (WWE) about sexual and reproductive health (SRH) is an important task given that approximately 1.5 million WWE are of child-bearing age in the United States.¹ There are many concerns and fears that need to be addressed, including how antiseizure medication (ASM) will impact contraception and fertility. There are also questions about heritability of epilepsy and the impact of seizures and ASMs on pregnancy. Given these concerns, some WWE may not consider having children because they have epilepsy and lack knowledge or education surrounding contraception, preconception planning, and reproductive decision-making.²

The article reviewed in this commentary took on the task to better understand SRH concerns and experiences of WWE by conducting in-depth interviews about their experiences and decision-making around contraception, childbearing and

parenthood.² This is one of the first studies to address the need to discuss these concerns early, even before transitioning to an adult clinic. This is especially important for discussion and initiation of folic acid supplementation given adolescence and young adulthood are times of increased SHR needs with higher rates of unplanned pregnancy.³ In addition, adolescents and young adults with epilepsy have reported limited resources and counseling about SRH and their epilepsy.^{4,5} Many of these WWE reported having fears and concerns about their SRH as early as 10 years of age. Lack of these conversations have led to misconceptions and misinformation that increase anxiety and result in incorrect conclusions about whether a WWE can have a safe pregnancy and deliver a healthy baby. Significant advances have been made that have improved maternal and child outcomes. Currently, the majority of WWE have routine pregnancies and healthy babies.

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However, these developments and increased knowledge need to be explicitly and clearly communicated to our patients.

In this study, individual, semi-structured interviews by phone were conducted with 20 WWE aged 18-43 (median age 23 years) who were diagnosed with epilepsy prior to 18 years of age. There were 5 themes that emerged regarding concerns about SRH: 1) Concerns about endangering pregnancies and children while having seizures, including a miscarriage or hurting a young child, particularly in the newborn period, or concerns about being unable to parent due to seizures. 2) Concerns about teratogenic effects of ASMs. 3) Concerns about having children due to fears about the heritability of epilepsy. 4) Concerns about whether ASMs or epilepsy could cause infertility. 5) Concerns about interactions between ASMs and contraception. The study focused on patients' perspectives about contraception, fertility, and heritability of epilepsy, being sure to include perspectives from WWE who developed epilepsy prior to age 18 and could comment on the SRH concerns of adolescent and young adult nulliparous WWE who were not actively planning pregnancy. Previous literature focuses largely on pregnancy and preconception concerns of WWE who were actively planning pregnancy or pregnant. However, this article highlights the need for conversations and education about SRH starting in adolescence, to ensure this population has adequate and accurate information to make informed decisions about their SRH and family planning. It also affirms the need for SRH discussions to be incorporated into the transition process from pediatric to adult care for this population, as is recommended by the Child Neurology Foundation.⁶

This publication does an excellent job in identifying concerns of WWE as early as puberty and emphasizing the need for providers to address these multiple concerns surrounding SRH and future family planning. In the remainder of this commentary, I will attempt to provide explicit responses that may be used for further educational discussions surrounding the identified areas of concern.

Fertility and Pregnancy Outcomes: It has been demonstrated that WWE, when compared to women without epilepsy, have comparable likelihood of achieving pregnancy, time to achieve pregnancy, and pregnancy outcomes (live births vs miscarriages).⁷ However, women taking enzyme-inducing ASMs were reportedly less likely to achieve pregnancy compared with women receiving other ASMs.⁷ A possible reason for this finding may be related to the induction of folic acid by enzyme-inducing ASMs, which supports the common practice of placing WWE on higher doses of folic acid if they are taking an enzyme-inducing ASM to prevent the development of major congenital malformations. Some WWE can have higher rates of developing polycystic ovary syndrome (PCOS), which is associated with infertility, compared with women without epilepsy. The higher rates of fertility issues related to PCOS are more often seen in patients who have used valproate in idiopathic generalized epilepsy syndromes.⁸

Seizure Frequency in Pregnancy: It was recently demonstrated by Page Pennell et al., that there was no meaningful difference among pregnant WWE and nonpregnant WWE in


increased seizure frequency, but there were higher increases in drug doses among the pregnant WWE group.⁹ Previous literature suggested that seizures may increase or worsen in severity in association with certain trimesters of pregnancy or during the peripartum period. However, this publication showed there were no differences between pregnant women and controls according to the pregnancy stage or seizure type including generalized tonic clonic seizures.⁹

Heritability: Many WWE also worry about the chance that their child will develop epilepsy. For all comers, if the parent has epilepsy, the risk of epilepsy in the child is 4.7%. However, if one knows the phenotype of the parent, one can be more specific. For example, if the parent has a generalized epilepsy disorder, the risk of any kind of epilepsy in the child is 7.3%. If the parent has a focal epilepsy disorder, the risk of any kind of epilepsy in the child is 2.9%. This is compared to a baseline risk of epilepsy in the general population of 1.3%.¹⁰

Contraception: Intrauterine devices (IUDs) are recommended as an effective birth control method that is not affected by enzyme-inducing ASMs. While hormonal IUDs suppress menses, it is important to note that this type of contraception does not suppress ovulation and thus does not treat seizures related to catamenial epilepsy. Depo-Provera injections are thought to prevent pregnancy by stopping ovulation and thus may be helpful in treating catamenial epilepsy. Other forms of hormonal contraception, including oral contraception pills, the patch, and the vaginal ring, can all be affected by enzyme-inducing ASMs which in turn reduce the efficacy of these birth control methods, placing the patient at risk for an unplanned pregnancy.

In summary, the information from this publication could and should be used to help develop patient education materials to improve SRH awareness among all women of childbearing age to help reduce anxiety and guide future family planning. This informational material could be used to supplement the routine provider-patient discussions and also help to improve collaboration between neurologists, primary care providers, and reproductive health providers to best serve the SRH needs of WWE.

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