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Reproductive health counseling in young women with epilepsy: Room for improvement

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Pediatric neurologists are not counseling teens and young adults with epilepsy about reproductive issues as frequently as needed, according to a recent 10-year study. Some conversations, such as those about pregnancy and the potential effects of antiseizure medications, are almost nonexistent. Sharp Waves spoke with Dr. Elizabeth Harrison and Dr. Laura Kirkpatrick about the study and possible solutions.

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Podcast Transcript

[00:00:00] **Joy Mazur:** A 2023 study published in *Epilepsy & Behavior* found that child neurologists counsel young people with epilepsy about sexual and reproductive health less frequently than recommended by experts.

The retrospective study collected data from 10 years of health records at one children's hospital. It then used natural language processing to search records for documentation of sexual and reproductive health counseling with young people with epilepsy.

Sharp Waves spoke to a couple of the authors about the study's results and implications.

[00:00:30] **Dr. Elizabeth Harrison:** Hi, my name is Elizabeth Harrison, and I'm a child neurology fellow at the UPMC Children's Hospital of Pittsburgh. I have a background in data science and my research interests are in applying that skill set to questions regarding reproductive health for youth with epilepsy. I'm joined by one of my colleagues and a co-author of the paper we'll be discussing today.

[00:00:51] **Dr. Laura Kirkpatrick:** Hi, I'm Laura Kirkpatrick. I'm an assistant professor of pediatrics and neurology at the University of Pittsburgh and UPMC Children's Hospital of Pittsburgh. My research area is also the reproductive health of youth with epilepsy, and I use a variety of methods to explore this question, ranging from qualitative methods to big data analyses.

[00:01:12] **Joy Mazur:** What prompted you both to study sexual and reproductive health counseling for young people with epilepsy and to undertake this study in particular?

[00:01:21] **Dr. Elizabeth Harrison:** Dr. Kirkpatrick and I both treat adolescents and young adults with epilepsy in our clinics. We're both very aware that young people with epilepsy are at risk for poor reproductive health outcomes like unintended pregnancy that can be prevented with good counseling.

We'd also collaborated on a couple of qualitative research projects and surveys involving both patients and providers with responses from both sides indicating a need for better reproductive health counseling.

[00:01:51] **Dr. Laura Kirkpatrick:** And just to give some specific examples before I was a doctor, I worked in a family planning clinic and I'd met several young people with epilepsy who were pregnant and upset about various things.

Like some people wondered if their contraception had failed because of the interactions with their anti-seizure medication. Some people had wondered, “Why had nobody told me that my medication could cause birth defects?”

And then in one of our qualitative studies, we had young people tell us that the neurologist said to them things like, "You cannot get pregnant because of your epilepsy," and that's a very problematic statement but even with that, they interpreted it to mean that they were infertile, like they literally could not get pregnant and they, you know, were sexually active but not using contraception and someone became unintentionally pregnant.

So these are the types of situations that we think need to be averted with good counseling and sort of the driving force behind this study.

[00:02:44] **Joy Mazur:** Are child neurologists trained in this type of counseling at all? Or are there any training options for child neurologists?

[00:02:52] **Dr. Laura Kirkpatrick:** The answer is no. Residency training is highly variable. If an institution is committed to training people in this area, they might have something. But my understanding is most institutions do not. I'm actually hoping this year to develop a training program for child neurologists to be able to do this work.

[00:03:10] **Joy Mazur:** That sounds amazing. And so with this study, can you describe generally how you collected the data?

[00:03:17] **Dr. Elizabeth Harrison:** This was a retrospective study looking at data that had been collected during visits, patient encounters, between 2011 and 2021 at a single academic medical

center.

The data we used had been de-identified prior to our use, so things like the names of patients had already been removed. We restricted the data to female patients between 13 and 21 years old, all with a diagnosis of epilepsy. All in all, we evaluated about 3,700 notes for just under 1,000 adolescent and young adults, women, with epilepsy.

We wanted to know how frequently child neurologists had provided reproductive counseling to these patients, and we decided to evaluate this by searching each clinic note for documentation on one of six relevant topics. These included menstruation, contraception, sexual activity, pregnancy, folic acid supplementation, and teratogens. Specifically, these are anti-seizure medications with an increased risk of causing birth defects or poor neurodevelopmental outcomes.

And then we developed a methodology that utilized natural language processing to expedite this process and help evaluate our data in much less time than it would have taken to read through each clinic note manually.

[00:04:30] **Joy Mazur:** And what were the results of your study? And what were the implications of those results?

[00:04:35] **Dr. Elizabeth Harrison:** Our goal was to evaluate counseling frequency based on recommendations provided by the American Academy of Neurology (AAN). So the AAN basically says we should be providing reproductive health counseling to all female patients with epilepsy at least once a year, starting the year they begin menstruating.

[00:04:54] **Dr. Laura Kirkpatrick:** And I'll also add the Child Neurology Foundation also has a guideline about transition of care that says that child neurologists should be counseling their patients with neurologic conditions at least annually about reproductive health. So at least two professional organizations say we should be doing this annually.

[00:05:10] **Dr. Elizabeth Harrison:** Our results show that for the 10-year period we studied, child neurologists provided annual counseling on any of the topics we evaluated about half of the time, which isn't phenomenal. And then when we looked at each topic individually, we were providing annual counseling on menstruation, folic acid, and contraception about a quarter of the time.

And then discussions regarding pregnancy, sexual activity, and teratogens were really quite rare. The child neurologists that we were evaluating provided annual counseling on these topics less than 5% of the time. We also looked at patient characteristics associated with increased and decreased frequency of counseling. For example, older age was associated with a higher frequency of counseling in particular topics, which is not necessarily surprising, but might be helpful in guiding and conventions going forward.

[00:06:04] **Dr. Laura Kirkpatrick:** The implications of the study are really that as a profession, we as child neurologists could be doing a much better job of informing our patients with epilepsy about important reproductive health issues, and we need to design some interventions in order to promote this counseling and make care more concordant with the existing guidelines.

[00:06:28] **Dr. Elizabeth Harrison:** I think the other thing that's really important to focus on is again why we need to be providing this counseling and better training the providers. And that all comes back to why patients with epilepsy are at risk for these poor reproductive health outcomes. Some of it has to do with the anti-seizure medications themselves, and some of it has to do with epilepsy.

Many of the medications we use to prevent seizures have the potential to interact with contraceptives. In some cases, this can result in contraceptive failure and unplanned pregnancy. And in other cases, it can lead to decreased blood levels of the anti-seizure medication, resulting in breakthrough seizures.

There are lots of other aspects too, things like menstruation that can contribute to seizure frequency or severity. And pregnancy planning, because certain medications need to be monitored or changed during pregnancy, particularly since certain anti-seizure medications can increase the risk of fetal birth defects or other developmental issues.

[00:07:27] **Dr. Laura Kirkpatrick:** It ultimately all comes back to helping the patient make good reproductive health decisions for themselves. Some of the interventions we're considering doing include, like I mentioned before, a provider communication training. Like, what are the words to say? How do you say it? We know what the topics are, but how do you get this across to a young person effectively within the limited amount of time that we have in our office visits?

Another possibility that I'm planning to roll out at UPMC within the next year is a hybrid clinic where the patients would see an epileptologist, myself, plus an adolescent medicine physician who can address their reproductive health issues directly and even prescribe contraception on the spot.

And this is really important, because adolescents as a whole have been shown to underutilize primary care. So they might see us as their specialist, but they might not be seeing a PCP or an adolescent medicine specialist who can fill in some of those gaps and actually prescribe contraception. So this is going to be more of like a one stop shop.

And then finally, we need some better initiatives in patient education. There are some really good resources out there already that have come out in the last couple of years. For example, I was involved in development of frequently asked question guides for young people with epilepsy for a website called the Center for Young Women's Health.

This is a clearinghouse of reproductive health information through I think it's maintained by Boston Children's Hospital. In addition, there's an excellent website that came out in the last year from the Epilepsy and Pregnancy Medical Consortium, largely walking patients with epilepsy through a pregnancy journey, but it also has a lot of valuable information about contraception and other reproductive health topics.

[00:09:16] **Joy Mazur:** Were there any particular results that surprised either of you?

[00:09:20] **Dr. Elizabeth Harrison:** I think overall, we weren't necessarily surprised with finding how infrequently this counseling is taking place, partly because there are other much smaller studies that show similar, if not worse, outcomes from other institutions, but I think that there were certain aspects, things like pregnancy counseling, that we had hoped would be more frequent than what we found.

[00:09:49] **Dr. Laura Kirkpatrick:** I was definitely surprised by the magnitude of some of the results. Like for instance, that sexual activity information was documented less than 5% of the time. Like that was strikingly low in my opinion.

[00:10:02] **Joy Mazur:** If you're able to speculate at all, why might healthcare providers be hesitant to have these sorts of conversations?

[00:10:10] **Dr. Elizabeth Harrison:** I think they're inherently sensitive conversations. So when a provider is prioritizing things, one of the issues is that they only have so much time. A lot of our clinic visits are very limited. And especially when epilepsy is very complicated, they might be focusing more on finding and discussing the correct antiseizure medications to control the epilepsy.

And then I do think to some extent, because these are sensitive topics, they just get lower down on the priority list. Because they're difficult, they take time. They take time to set up the question to make sure that it's done well. Whether or not you have families leave the room, the parents leave the room for youth, that can also take extra time and may even require some kind of preparatory discussions so that everyone feels comfortable with that.

And so, to some extent, I think it's a time issue. To some extent, I think, like we had noted earlier, it's a comfort level issue due to lack of training. And then I think on top of all of that, there is still some uncertainty, and we've found this in prior studies, about who's responsible for having these conversations. Is it the PCP? Is it the adolescent medicine provider, if they're involved? Is it the OB/GYN? Or, or should it be the child neurologist? And I think our feeling, and Dr. Kirkpatrick can add as well, but our feeling is that this should be a child neurologist's responsibility, but that it might help in the future if we're doing multidisciplinary clinics to work together and improve communication between these relevant providers.

[00:11:55] **Dr. Laura Kirkpatrick:** And I'll just add that among the survey-based studies we did, we did do a survey of primary care physicians, adolescent medicine specialists, and OB/GYNs who see adolescents around their knowledge, attitudes, and practices for caring for young people with epilepsy. And these specialties, unfortunately, also endorse major deficits in all their domains in caring for young people with epilepsy because they don't necessarily get specialized training in managing, you know, every single chronic condition.

And that further reinforces in my mind that the neurologist who does have that epilepsy specific knowledge really needs to be involved in this process.

[00:12:32] **Joy Mazur:** So, then on the flip side of that, why are having these conversations between neurologists specifically and people with epilepsy especially young people with epilepsy, why are those conversations important?

[00:12:45] **Dr. Elizabeth Harrison:** Again, I think that comes back to the potential for outcomes. The fact that if we don't have these conversations, patients might be starting contraceptives without their child neurology providers knowing. And that might result in contraceptive failure, or it might result in breakthrough seizures, depending on the anti-seizure medication they're on.

If they are desiring to become pregnant it's, again, I think important to prepare for that well. In terms of maybe measuring drug levels or knowing what the risks are for breakthrough seizures throughout pregnancy, knowing how to help prevent those things. And even beyond that, when if, when they decide to have children, the safety and or risks of breastfeeding and making sure that they're fully informed about all of these topics.

[00:13:45] **Dr. Laura Kirkpatrick:** I think it's also important because in our qualitative study, young people with epilepsy really emphasize that they want this information and they want it from their neurologist. They really see their neurologist as an integral figure in all aspects of their health, including how their reproductive health is affected by their epilepsy.

And, you know, even as young as childhood, like one participant told me that when she was eight years old and was first diagnosed with epilepsy, she wondered what it would mean for when she wanted to have kids later on. Because the patients want this information, we need to be providing it to them.

And a lot of young people don't necessarily have the confidence to speak up and ask questions themselves. So we need to anticipate what their questions are and provide counseling.

[00:14:28] **Dr. Elizabeth Harrison:** Just to follow that up, I think the other important aspect that we want to focus on is that the onus should not be on the patients.

We want to empower our patients to bring these topics up if they desire to, but they sometimes are difficult topics to raise within a clinic visit. Because they're sensitive, because patients may not be aware of them, it's really important for the providers to be bringing up the conversations themselves.

[00:15:01] **Joy Mazur:** Is there anything else you would like to mention about what might be done to improve sexual and reproductive health counseling for young people with epilepsy, or any advice you might have for child neurologists who are looking to implement this into their conversations?

[00:15:16] **Dr. Elizabeth Harrison:** I think there's a multi-pronged approach. Dr. Kirkpatrick and I have talked a little bit about the multidisciplinary clinic. We've talked about potentially focused training programs for providers. From my perspective, because I have a background in data science and in natural language processing, I think there are potential opportunities to fold this kind of technology into the electronic medical record. I think it has to be done very carefully, very thoughtfully, because things like alert systems can cause clinician fatigue.

So maybe there are some ways to, again, use natural language processing to identify the most at risk patients. And potentially in a multidisciplinary clinic, maybe this can provide automated deep heart education that maybe a nurse then can use their time to touch base with the families and review as necessary.

Just some potential thoughts.

[00:16:14] **Dr. Laura Kirkpatrick:** And in terms of advice for the child neurologist, you know, although these conversations do take a certain amount of time, I feel like our professional anxiety around the amount of time they have to take is somewhat exaggerated. When I develop this training program that I've alluded to, one of the main talking points of it is going to be, you know, if you only have 2 to 5 minutes, what can you get across? And you can definitely have these conversations, at least somewhat, in 5 minutes.

[00:16:40] **Joy Mazur:** What do you consider the strengths of your study and if you could also expand on any limitations or any plan for future studies on this topic as well, that would be great.

[00:16:52] **Dr. Elizabeth Harrison:** I think one of the strengths of the study was the size of the study, which again was enabled with the use of natural language processing. And just in case some people aren't familiar with that, I'm going to back up and just explain that a little bit. I think the best way to explain that for language processing is through examples.

So, when clinicians see their patients, we document information in a variety of ways. Some information essentially gets stored in tables, and that information, that data, is very easy to analyze. This includes things like medication lists, allergies, vital signs, lab results. But a lot of the meat of our documentation is in the paragraphs we write about what brought a patient in, what we think might be going on, why we plan to pursue a particular treatment plan. And information about sensitive health topics, like reproductive health discussions, are more likely to be found in these big blocks of text.

Traditionally, someone would have had to read through this text manually to identify the relevant information and sort out that data. But newer technology allows us to train a computer to identify the information for us. Essentially, we give the computer examples of texts that are relevant to menstruation or irrelevant to menstruation. And then with ongoing refinement, the computer essentially learns how to identify new relevant text that in a new clinic note says, yes, this patient did have a discussion about menses.

So that let us look at thousands of clinic notes and evaluate them in a relatively short period of time. Whereas prior studies that had used manual review were much, much smaller.

From a limitation standpoint, I think the biggest limitation is that this study does rely on documentation as a proxy for conversations. So in truth, lack of documentation in the electronic medical record doesn't really mean that counseling didn't occur. It could have occurred and it just wasn't documented.

And then on the flip side, presence of documentation doesn't mean that the counseling was of high quality or was even accurate. I think Dr. Kirkpatrick also had alluded to the fact that also sometimes when these conversations happen and they're documented, they're not necessarily even interpreted appropriately.

[00:19:26] **Dr. Laura Kirkpatrick:** Just because we think we're doing the counseling doesn't mean we're necessarily doing it well in a way that translates to a young person.

You'd also asked about future studies. Dr. Harrison and I are also doing an analysis of the data set regarding prescriptions. Like, frequency of contraception, frequency of contraception that interacts with the anti-seizure medication, frequency of folic acid prescriptions, and we presented a poster of this data at the last [American Epilepsy Society] meeting.

We're also waiting on getting access to an administrative claims database to be able to address some of those questions on a national scale.

[00:20:05] **Joy Mazur:** Is there anything else that either of you would like to add that you feel is relevant or just important to know?

[00:20:11] **Dr. Elizabeth Harrison:** For providers who are listening to this, keeping in mind that these topics are super important to discuss, and not to be scared to bring these topics up with patients. And for patients, again, not to put too much pressure on you, but I want to empower you all to bring these topics up and to keep them in mind as you continue on your epilepsy journey.

Related publications:

Sexual and reproductive healthcare for adolescent and young adult women with epilepsy: A qualitative study of pediatric neurologists and epileptologists (2020)

A survey of child neurologists about reproductive healthcare for adolescent women with epilepsy (2021)

Sexual and reproductive health concerns of women with epilepsy beginning in adolescence and young adulthood (2021)

A Survey of Healthcare Providers About Reproductive Healthcare for Adolescent Women With Epilepsy (2022)

Pediatric Neurologists' Perspectives on Sexual and Reproductive Health Care for Adolescent and Young Adult Women With Epilepsy and Intellectual Disability (2022)

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