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A mixed-methods exploration of the contraceptive experiences of female teens with epilepsy

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ABSTRACT

Purpose: We explored the contraceptive experiences of female teens with epilepsy, including their knowledge and perceptions of interactions between antiepileptic drugs and hormonal contraception and contraceptive decision-making processes.

Method: From November 2012 to May 2013, we conducted one online survey ($n = 114$) and 12 online focus group discussions ($n = 26$) with female teens with epilepsy about their contraceptive experiences and unmet needs. Survey data were analyzed using descriptive statistics and focus group transcripts were analyzed thematically using modified grounded theory methods.

Results: Both survey and focus group participants reported believing that interactions between epilepsy medications and hormonal contraceptives could lead to reductions in contraceptive efficacy and seizure control. However, their knowledge about these types of medication interactions was often incomplete. Many study participants viewed contraceptive decision making as a difficult process, and some participants reported avoiding hormonal contraceptives because of potential interactions with antiepileptic drugs. Study participants reported relying on health care providers and parents for contraceptive decision-making support. Focus group participants also reported they wanted health care providers to provide more in-depth and comprehensive counseling about contraception, and that they desired peer support with contraceptive decisions.

Conclusion: The ability to make informed contraceptive decisions is important for teens with epilepsy as interactions between anti-epileptic drugs and hormonal contraceptives can impact seizure occurrence and lead to an increased risk of unplanned pregnancy. Guidance for providers offering contraceptive care to this population is needed, as well as a contraceptive support tool that empowers teens with epilepsy to advocate for desired health care.

1. Introduction

Epilepsy is a common, chronic, and often stigmatized neurological condition characterized by recurrent, unpredictable seizures. Seizures can be triggered by flashing lights, noise, stress, hormonal shifts, and other events. The primary treatment for epilepsy is antiepileptic drugs (AEDs), which stop or reduce seizures in approximately 70% of people. Adjunctive or alternative treatments can be used in those with refractory seizures.[1]

Over one million women and girls in the United States have epilepsy and require specialized contraceptive care due to potential interactions between AEDs and hormonal contraceptives.[2] These medication interactions can lead to reductions in the efficacy of hormonal contraceptives, putting women at increased risk of unplanned pregnancy.[3] Unplanned pregnancy is of particular concern in this population as hormones brought about by pregnancy can impact seizure frequency and AED use during pregnancy can double the risk of fetal anomaly.[4] Further, medication interactions can lead to increased seizure activity,[5] increasing the risks of morbidity and mortality and decreasing quality of life.[1] At the same time, some limited research suggests that hormonal contraceptives that keep hormones in a steady state can help alleviate hormonally induced seizures.[6]

Despite the serious implications of drug interactions, research shows that adult women with epilepsy are largely unaware of interactions between AEDs and hormonal contraceptives and face challenges obtaining accurate information about them.[7–9] Several studies have found that most women with epilepsy have never received information about medication interactions[8–11] and that health care providers working with this population have limited knowledge about their contraceptive needs.[8,12–17] Given these challenges, it is unsurprising that women with epilepsy have lower

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rates of highly effective contraceptive use compared to the general population.[18]

There is a dearth of research investigating if female teens with epilepsy experience the same challenges accessing appropriate contraceptive care as their adult counterparts. While many teens, regardless of health status, experience difficulties accessing high-quality contraceptive care,[19] data indicate that teens with chronic health conditions are less likely to receive information about sexual and reproductive health from their health care providers.[20] Further, despite going to the doctor more often than the general population, teens with chronic health conditions are less likely to receive high-quality health care.[21]

Given that adolescence is a sensitive developmental period, that teens with chronic health issues face barriers accessing high-quality contraceptive care,[20,21] and that contraceptive use among teens with epilepsy has serious implications for neurological and reproductive health, investigation into their contraceptive experiences is necessary. Additionally, as more people in the United States (US) take prescription medications for chronic health conditions, issues related to medication interactions are increasingly relevant for a larger population. To date, no identifiable study has investigated the contraceptive experiences of female teens with epilepsy. To fill this gap in the literature, we conducted an online survey and online focus groups with female teens with epilepsy to better understand their: (1) knowledge and perceptions of interactions between AEDs and hormonal contraception; (2) contraceptive decision-making and experiences; (3) contraceptive supports; and (4) recommendations for improving contraceptive service-delivery.

2. Materials and methods

A two-step, mixed-methods study was selected for this investigation to allow for the development of a rich and nuanced understanding of the contraceptive needs of teens with epilepsy. The first phase of the study, conducted from November 2012 to December 2012, consisted of an online survey with female teens with epilepsy. The second phase of the study, conducted from January 2013 to May 2013, consisted of online focus group discussions with female teens with epilepsy. The study was approved by the Allendale Investigational Review Board.

Both phases of the study were conducted online and used Facebook as a recruitment method. These online research methods were selected because 95% of US teens use the Internet[22] and 73% use Facebook.[23] Further, among qualitative methods, online, chat-based focus groups were selected because the method has been shown to reach hard-to-reach populations, be preferable for teens, and facilitate disclosure of sensitive information.[24–27] The number and role of the moderators, focus group ground rules, and focus group program and features were informed by research showing best practices in online focus group research.[25,26,28–32] Additionally, focus groups were limited to three participants, as previous research has shown that smaller group size is easier to manage online while still encouraging rich discussion.[25]

Participants in both phases of the study were asked questions about their epilepsy history; dating experiences; contraceptive and pregnancy history and experiences; knowledge and perceptions about contraceptive and pregnancy issues for females with epilepsy; and preferences for decision-making support around contraception and pregnancy. This analysis focuses on the contraceptive findings.

For the online survey, a convenience sample was recruited through Facebook advertisements and online youth- and epilepsy-focused Facebook groups. Female teens; diagnosed with epilepsy; age 13–19 at the time of initial contact; fluent in English; and who, if younger than 18, had previously sought contraception or experienced pregnancy in one of the 25 US states where minors who have sought contraception or experienced pregnancy can participate in research without parental consent, were eligible to participate.[33] To ensure that the individuals did not take the survey multiple times, we removed responses that came from duplicate IP and email addresses, and had the exact same survey responses, especially to open-ended questions.

Prior to proceeding to the online survey, participants were asked several questions assessing their eligibility, and, if eligible, were asked to give electronic informed consent to participate. All participants were provided with a $15 gift card for remuneration. As the survey was exploratory, no power calculation was conducted to determine the number of survey participants. Instead, we recruited as many survey participants as feasible given our time and budget limitations.[34]

Survey data were exported from the online survey into Excel and then into SPSS. In SPSS, basic descriptive statistics, cross tabulations, and measures of association were performed. Answers to open-ended questions were exported into Word and analyzed thematically.

For the online focus groups, a convenience sample was recruited via Facebook advertisements, online youth- and epilepsy-focused Facebook groups, and an epilepsy forum on Reddit. In addition, survey participants were encouraged to participate in the online focus groups. Eligibility criteria for the online focus groups were the same as the online survey. Prior to entering the online focus groups, teens filled out a brief survey assessing their eligibility, and gave electronic informed consent to participate. All participants received a $40 gift card as remuneration. Focus group participants were recruited until thematic saturation was reached.[35]

Online focus group discussions were conducted through Chatzy, a private, password-protected, online chat service. Two research team members, trained in qualitative research methods, served as moderators during the focus groups. Moderators typed questions into the chat room and participants typed responses; no video or audio technology was used during the focus groups. Participants were also encouraged to respond to each other's comments and to ask each other questions.

Focus group transcripts were populated in the chat program. We exported the transcripts and then analyzed thematically in ATLAS.ti 6.2 (Scientific Software Development, Berlin, Germany) using modified grounded theory methods.[36] Two researchers coded each transcript to ensure inter-coder reliability. Initial codes were developed a priori based on focus group questions and subsequent revisions were made to the codebook as new inductive themes surfaced. Codes were summarized and organized thematically with representative quotes extracted. Illustrative quotes were identified for all major themes, and minor spelling and grammar issues were corrected for readability. Quotations are identified by participant's pseudonym and age.

3. Results

3.1. Survey and focus group participant characteristics

One hundred fourteen teens participated in the online survey. Survey participants were on average 18 years old (range 13–19). The majority of survey participants self-identified as White (84%) and non-Latina (88%). Participants reported having a variety of seizure types and almost all reported use of AEDs (Table 1).

Twenty-six participants took part in 12 online focus groups. Focus group participants were on average 19 years old (range 15–20)[a] and the majority self-identified as White (73%) and non-Latina (96%). As with survey respondents, focus group participants

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[a] One participant was 19 at the time of recruitment and had turned 20 by the time of the focus group.