

What Are the Experiences of Women of Childbearing Age With Epilepsy Throughout Their Motherhood Journey? Results From a Social Media Listening Study

Background

- Epilepsy affects more than 65 million people worldwide.¹
 - Approximately 15 million of these are women of childbearing age.²
- Women with epilepsies (WWE) face specific challenges related to contraception, fertility, pregnancy, breastfeeding, and parenthood.^{3,4}
- There is a lack of qualitative research on women's experiences of the motherhood journey while living with epilepsy.⁵

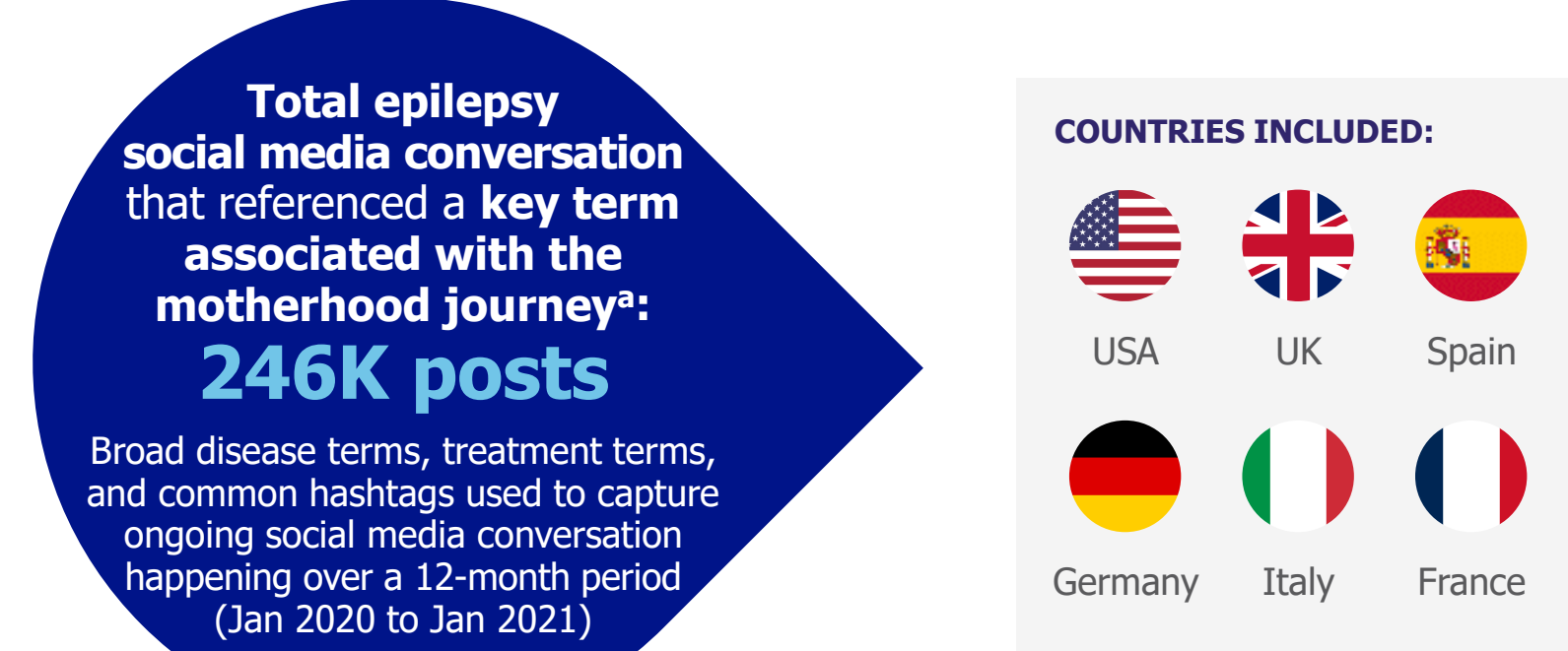
Objective

- To provide insights into the experience of WWE related to their motherhood journey and to identify their unmet needs.

Methods

- A social media listening study was conducted across six countries.
 - Sources were public social media accounts, including X (formerly Twitter), forums (eg, Reddit, Mumsnet), YouTube, blogs, Instagram, and Facebook.
- Search terms used to identify social media posts related to epilepsy were similar to those previously published⁸ and were applied to historic social media posts published over a 12-month period (January 27, 2020, to January 27, 2021).
 - A list of multilingual key terms associated with the motherhood journey was created and used to identify relevant posts among the epilepsy social media conversation.

Social listening methodology

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- Specific keyword filtering was then applied to identify conversation around the key stages of the epilepsy motherhood journey: preventing & planning pregnancy, conception & fertility, early/late pregnancy & childbirth, and breastfeeding & parenthood.
- Social media posts related to a wide range of antiseizure medications (ASMs), including UCB products, were captured.
- For transparency, the conversation was split into two data sets—one with all UCB products removed (245,000 posts) and one related to UCB products (ie, Briviact®, Vimpat®, Keppra®, Nayzilam®; 3400 posts).
 - A randomized sample of the UCB product conversation was included in the analysis (680 posts).

Overview

QUESTION

What are the experiences of women of childbearing age with epilepsy throughout the motherhood journey?

RESULTS

"If I wanted to carry a child, I would have to switch medication, mess up my internal system and perhaps have really bad side effects. It took me five years to find one that works with my body, and I don't want to mess it up."

- Patient, forum, USA

"The part that I'm really scared about is speaking to my doctor. For me, the subject of 'family planning' has been fully exhausted: I know that I don't want any children. Even when I did want a child, it would be completely irresponsible for me to bring one into the world. I require care and can't even look after myself. I would never get pregnant without being sure that I would be able to and want to look after the child in any scenario. Therefore, I really, really am sure."

- Patient, forum, Germany

Planning pregnancy

"I had actually come to terms with the fact that I would never have a child when I found out that due to my epilepsy and the string of medications I would never be allowed to become pregnant. I didn't give this a lot of thought until I was in a serious relationship in my mid-20s."

"I talked about my desire to have baby to my neuro a year before we started trying so that we could adapt as best as possible my treatment. I switched to a monotherapy and I took folic acid 5 mg 6 months before trying to conceive. That's a bit early, 3 months would have been fine but oh well it was an epileptologist that told me to start."

Conception & fertility

"I have often read that women with epilepsy are less fertile. I ask myself whether there could be a correlation between increasing my dose and our so-far unsuccessful conception. Neither my neurologist nor my gynaecologist can give me any information."

"I'm terrified that all the drugs I have to take are going to mess with my epilepsy, which has been pretty stable. Does anyone have experience here? My neuro said it could get a little rocky in the last couple weeks on fertility drugs but my nurse at the IVF clinic said that this hadn't been the case for any of her patients in the past. I just don't want it to get out of control and all of a sudden I'm spiraling into endless seizures again. New things are always petrifying with epilepsy."

Early pregnancy

"The neural tube defect risks with anticonvulsants are really getting to me and I need to stop [trawling] the internet. Can those of you who have made it through pregnancy with a healthy baby while on anticonvulsants share your stories? I could really use some reassurance."

me pregnant again and I have done the previous pregnancy, ditching the pills. I'm along and have had 2 seizures. I'm a little unsure the midwife tells me that when I have a seizure runs out of oxygen. I'm trembling with about my baby's safety. And I don't know what to do. I take the medication again or wait to see what my doctors do!"

Late pregnancy & childbirth

"My epilepsy has been fairly well controlled with medication for years. No seizures in my 1st pregnancy, but in my 2nd I had multiple seizures throughout my 3rd trimester, so I ended up staying in hospital a few times.. I think it was the pregnancy hormones & dilution of drugs which caused the seizures."

"I'm on Keppra and from what I've been told I can't give birth on the midwife-led unit as I am under consultant-led care. There is also certain pain relief meds we're unable to have, but we also have a lower threshold for an epidural or a C-section since we're not allowed to get tired during birth. I have also been told I have to stay overnight for observation."

Breastfeeding & parenthood

"I was told that my medication passes through the milk, but I should not worry because I am taking a small dose. However, I should tell my doctor if the baby has excessive somnolence."

"I can't help but picture so many awful scenarios where I could have a seizure holding my baby or falling down the stairs. I suffer from grand mal seizures so I go completely out – collapsing and thrashing. My partner and I [...] are very cautious and take precaution with pretty much everything I do with the baby. I can't go up and down the stairs with her, can't hold her in the baby carrier, and my husband has to be present if I want to feed or bathe the baby."

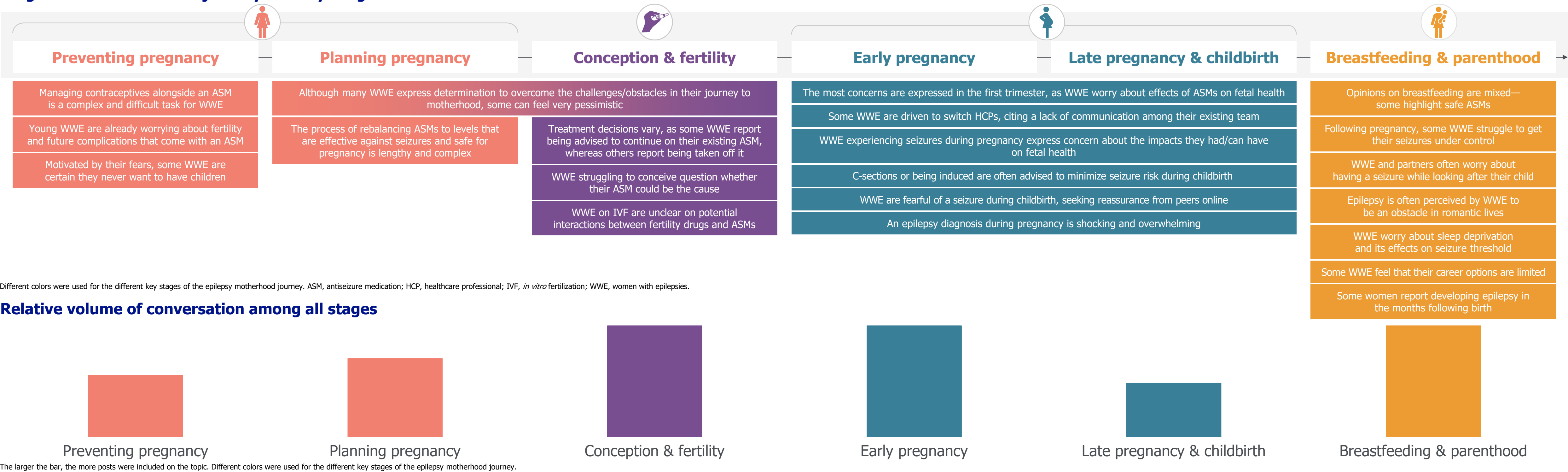
CONCLUSIONS

Often, relevant information is not provided by clinicians or is unavailable. Women with epilepsies (WWE) are given conflicting information, and open questions related to epilepsy and pregnancy remain unanswered, leading to confusion and heightened anxiety. WWE may seek answers and support from sources other than healthcare professionals, including their peers. There is a need to better support WWE and their families and provide relevant information in plain language at the right stage and time, thus supporting shared decision making and a more informed and supportive motherhood journey experience.



Results

Stages of the motherhood journey and key insights



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- Thematic analysis of these data revealed four key themes:
- (i) Uncertainty and fear arise for WWE when changing treatments, as balancing ASMs is often lengthy, complex, and can affect seizure control.
 - (ii) Worries are intensified by inconsistent communication from healthcare professionals (HCPs) and a lack of information on how ASMs affect the fetus. Fears about the safety of ASMs grow due to concerns about the fetus and child development.
 - (iii) Seizure control is often a priority but can be a difficult balance to achieve, as providing a safe environment for the fetus or infant becomes paramount.
 - (iv) The motherhood journey is perceived to be challenging, with multiple obstacles or barriers to a safe and successful pregnancy, including the lack of consistent information.

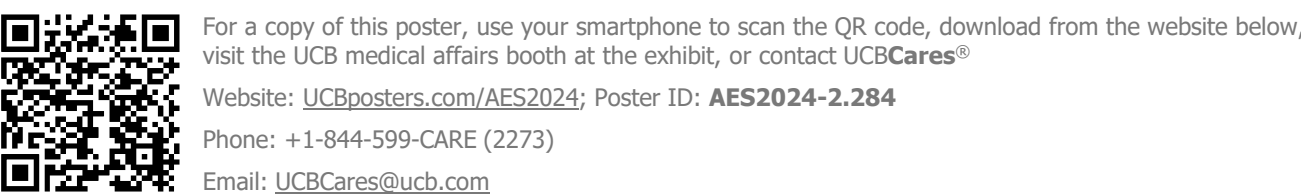
Conclusions

- WWE want to be empowered through knowledge. They seek peer counseling and detailed information online, including about ASMs, at the right time during their motherhood journey to help them feel more confident in making treatment decisions.
- Relevant information is often not provided by clinicians, difficult to obtain, or unavailable. WWE are given conflicting information. Open questions related to epilepsy and pregnancy remain unanswered, leading to confusion and heightened anxiety.
 - WWE seek answers and support from sources other than their HCPs, including their peers.
- There is a need to better support WWE and their families by providing plain language and timely information to enhance their motherhood journey.
- HCPs need more data to better inform WWE to support shared decision making.
- Our results highlight the importance of collecting data related to pregnancy outcomes. Further research is necessary to understand the impact of all ASMs and their capacity to impact on development *in utero*.
 - Pregnancy registries are underpopulated. Data could be generated faster if there was a greater collaboration among patient organizations, researchers, and clinicians.
 - There is a need for long-term monitoring of study outcomes for any child exposed to different ASMs.

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