

Experiences of Women of Childbearing Age With Epilepsy Throughout Their Motherhood Journey: Results From a Social Media Listening Study

Michelle Manzo¹
Gus A Baker²
Agnes Koncz³
Michelle Shell¹
Konrad J Werhahn⁴
Andrea L Wilkinson⁵
Jessica K Smith⁶
Dimitrios Bourikas⁷

1. UCB, Smyrna, GA, USA
2. International Bureau for Epilepsy, Washington, DC, USA
3. UCB, Brussels, Belgium
4. UCB, Monheim am Rhein, Germany
5. UCB, Emeryville, CA, USA
6. Living Well With Epilepsy, Haddonfield, NJ, USA
7. UCB, Alimos, Greece

Poster P1-001

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 potential 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

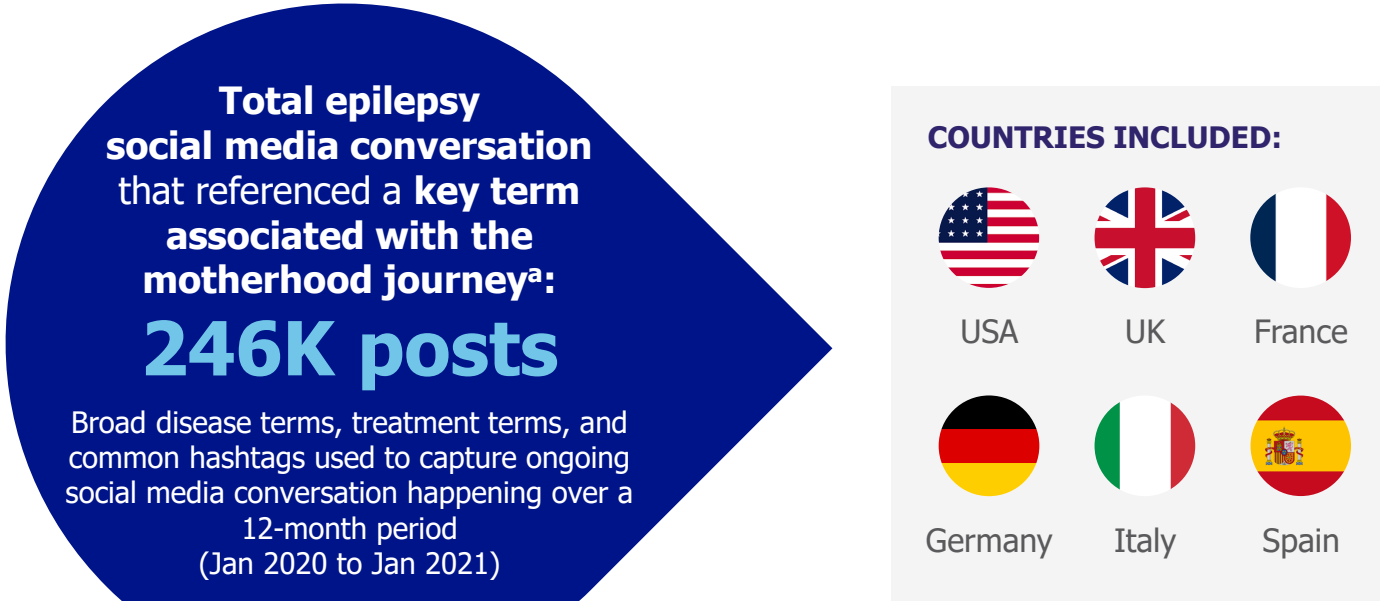
Objective

- 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 published⁶ and were applied to historic social media posts published over a 12-month period (January 27, 2020-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



Key terms used were: "(f)" OR female OR woman OR women OR ght OR ladies OR girlfriend* OR wife OR partner OR pregnant* OR child* OR baby OR family OR kid* OR obgyn OR *OB-GYN* OR gyny OR gynecologist OR gynaecologist OR obstetrician OR contraception OR contraceptive* OR conceive* OR "birth control" OR "bc pill" OR coil OR IUD OR condom* OR "using protection" OR "used protection" OR "use protection" OR "depo-provera" OR "depo shot" OR microgynon OR rigeidon OR ovranette OR minipill OR "combo pill" OR "combined pill" OR microne OR cerazette OR loestrin OR Yasmin OR nuroving OR ("I don't want" OR "not planning" OR "never going to" OR "not going to") NEAR/3 (children OR kids OR child) OR abortion OR miscarriage OR miscarried OR "still-born" OR stillbirth OR birth OR "birth complications" OR (congenital AND malformation) OR mestrin* OR sex OR "having a baby" OR "going to be having a baby" OR "first trimester" OR "1st trimester" OR "second trimester" OR "2nd trimester" OR "morning sickness" OR (early NEAR/2 scan) OR "dating scan" OR "booking scan" OR "due date" OR "growth scan" OR "antenatal screening" OR "NT scan" OR "nuchal translucency scan" OR "anomaly scan" OR "visibility scan" OR "gender scan" OR antenatal OR "little natal" OR "pre-natal" OR prenatal OR "intra-uterine" OR intrauterine OR "child birth" OR childbirth OR "C-section" OR "C-section" OR caesarian OR cesarean OR VBAC OR "baby is due" OR nesting OR "giving birth" OR "gave birth" OR "give birth" OR birthed OR birthing OR labour OR "third trimester" OR "3rd trimester" OR overdue OR labour OR induced OR "induced" OR "contraction" OR (tummy) SENTENCE (growing OR big OR huge) OR "midwife" OR "delivery room" OR "water birth" OR "natural birth" OR "home birth" OR epidural OR "umbilical cord" OR "pre-eclampsia" OR preeclampsia OR "in labour" OR "during labour" OR TTC OR ("trying to" OR planning OR pain) NEAR/4 (baby OR conceive OR pregnant) OR fertility OR fertile OR infertile OR infertility OR "low sperm count" OR IVF OR FET OR "embryo transfer" OR surrogacy OR surrogacy OR adoption OR endometriosis OR "polycystic ovaries" OR ("can't have" OR "unable to") NEAR/2 (kids OR baby OR children) OR sterile OR vasectomy OR "freezing my eggs" OR "freeze my eggs" OR "freeze my eggs" OR "pregnancy test" OR surrogacy OR conceive* OR conception OR (unplanned OR accidental OR accident OR unintended OR surprise) NEAR/2 (pregnancy OR pregnant) OR ("no birth control" OR condom OR "bc pill" OR IUD OR coil OR "used protection" OR "use protection") SENTENCE "not pregnant" OR "want another child" OR breastfeeding* OR BF OR (Looking OR looked OR care OR caring OR walking OR walk OR playing OR play OR cooking OR cook OR feed OR feeding OR fed OR sleep OR sleeping OR help OR helping OR carry OR carrying OR push OR pushing OR making OR make) SENTENCE (baby OR newborn OR infant* OR kid OR child* OR daughter OR son) OR cleaning OR chores OR laundry OR "household tasks" OR housework OR nursery OR playground OR "post partum" OR stroller OR buggy OR crib OR formula OR diapers OR nappies OR pushchair OR pram OR "baby boy" OR "baby girl" OR "new mum" OR postpartum OR cot OR cotbed OR "bottle feed" OR EBF OR lactation OR motherhood OR toddler OR toddlers OR LO OR "little one" OR "little ones" OR "potty floor" OR OAD.
English syntax was translated by local language analysts and applied in each country. *Indicates multiple endings are included; "...," quotation marks = exact phrase.

- 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® [brivaracetam], VIMPAT® [lacosamide], KEPPRA® [levetiracetam], NAYZILAM® [midazolam nasal spray]; 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?



INVESTIGATION

Social media listening study conducted across six countries (United States [USA], United Kingdom [UK], France, Germany, Italy, and Spain). Sources were public social media accounts, including X (formerly Twitter), forums, YouTube, blogs, Instagram, and Facebook.



RESULTS

Preventing pregnancy

"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 [if] 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."
- Patient, blog, Germany

"I talked about my desire to have [a] baby to my neuro[logist] a year before we started trying so 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."
- Patient, forum, France

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."
- Patient, forum, Germany

"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[logist] 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."
- Patient, forum, USA

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."
- Patient, forum, USA

"I have become pregnant again and I have done the same as with the previous pregnancy, ditching the pills. I am 8 weeks along and have had 2 seizures. I'm a little scared because the midwife tells me that when I have seizures the fetus runs out of oxygen. I'm trembling with fear, thinking about my baby's safety. And I don't know whether to take the medication again or wait to see what my doctors do!"
- Patient, forum, France

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."
- Patient, forum, UK

"I'm on [levetiracetam] 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 [Cesarean] section since we're not allowed to get tired during birth. I have also been told I have to stay overnight for observation."
- Patient, forum, UK

Breastfeeding & parenthood

"It 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."
- Patient, forum, Italy

"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."
- Patient, forum, USA

For a copy of the poster, scan:

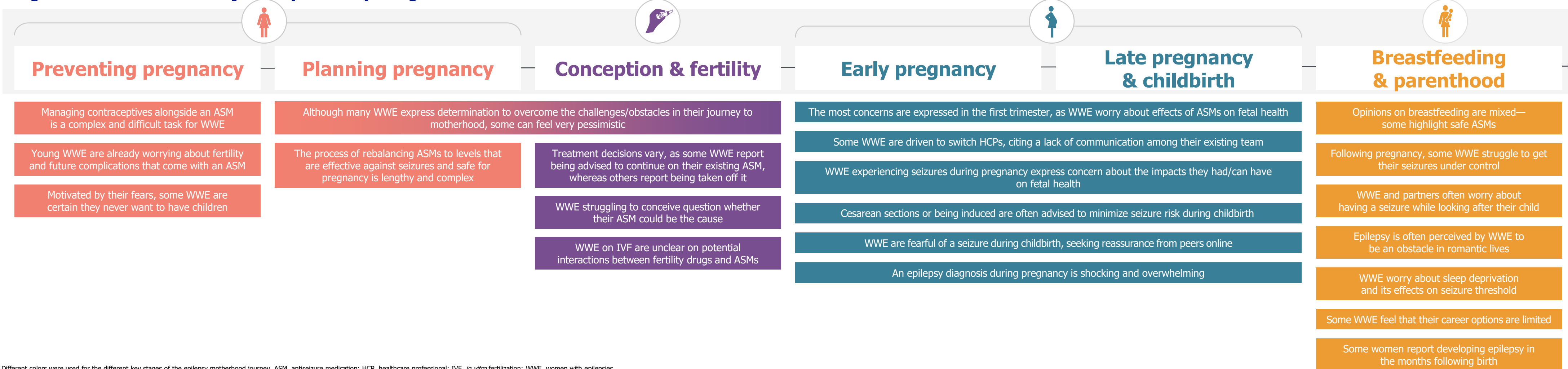


For a plain language summary, scan:



Results

Stages of the motherhood journey and key insights



Different colors were used for the different key stages of the epilepsy motherhood journey. ASM, antiseizure medication; HCP, healthcare professional; IVF, in vitro fertilization; WWE, women with epilepsies.

Relative volume of conversation among all stages



The larger the bar, the more posts were included on the topic. Different colors were used for the different key stages of the epilepsy motherhood journey.

- 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 and among healthcare professionals (HCPs) and a lack of information on how ASMs may 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 to study outcomes for children who were exposed to ASMs.

References

- Ngugi AK, et al. *Epilepsia* 2010;51(5):883-890.
- Tomson T, et al. *Epileptic Disord* 2019;21(6):497-517.
- Bangar S, et al. *Funct Neurol* 2016;31(3):127-134.
- Gauffin H, et al. *Neuropsychiatr Dis Treat* 2015;11:1291-1298.
- Weckesser A and Denny E. *Seizure* 2013;22(2):91-98.
- Fazekas B, et al. *Epilepsy Behav* 2021;116:107729.

UCB-sponsored. UCB was involved in the design of the study, the collection, analysis, and interpretation of data, and review of the poster. The authors would like to thank Cello Health Logic (London, UK) for conducting this study. The authors acknowledge Bobby Jacob, PharmD, MPH (UCB, Smyrna, GA, USA) for managing the development of the poster, and Michaela Fuchs, PhD, CMPP (Evidence Scientific Solutions Ltd., Horsham, UK) for writing assistance, which was funded by UCB. Author contributions: M Shell and Cello Health Logic designed the study. Cello Health Logic/Lumianty analyzed the data. All authors critically reviewed the poster and approved the final version for presentation. Author disclosures: M Manzo, A Koncz, M Shell, KJ Werhahn, AL Wilkinson, and D Bourikas are employees of UCB and have received stocks from their employment. G Baker and K Smith have nothing to disclose.



For a copy of this poster, use your smartphone to scan the QR code or contact UCB-Cares®
Phone: +1-844-599-CARE (2273)
Email: UCB-Cares@ucb.com



For a plain language summary, scan this QR code

American Academy of Neurology 77th Annual Meeting
San Diego, CA, USA | April 5–9, 2025

Previously presented at American Epilepsy Society 78th Annual Meeting, Los Angeles, CA, USA, December 6–10, 2024 and American Society for Experimental Neurotherapeutics 27th Annual Meeting, Bethesda, MD, USA, March 12–14, 2025