Deciding whether or not to become a parent (and if so, when, and how) is often considered one of the most important decisions women make in their lifetimes. Not only does the decision affect women’s overall life course, it also demands attention for a considerable number of years, as women spend an average of 35 years of their lives planning, carrying, or preventing a pregnancy. For women with epilepsy, these family planning decisions are of particular importance. Epilepsy is a common, though often misunderstood, neurological disorder that is characterized by the occurrence of two or more unprovoked seizures. It is the most common neurological disorder in women of reproductive age. Women with the disorder have unique family planning needs because some medications used to treat epilepsy can reduce the efficacy of popular hormonal contraceptives, such as the birth control pill or the patch, and can increase the risk of congenital malformations if taken during pregnancy. Additionally, hormonal changes brought by pregnancy or contraceptive use can influence seizure activity in unpredictable ways, meaning reproductive decisions affect not only women’s reproductive health and fetal health, but also women’s neurologic health. This does not mean that women with epilepsy should not use hormonal contraceptives or get pregnant, but instead highlights the importance of ensuring women receive adequate support from health care providers in making family planning decisions and obtaining epilepsy care.

We sought to understand the unique issues women with epilepsy encounter when making family planning decisions, as well as the clinical context of those decisions, through in-depth analysis of: 1) all current clinical guidelines for managing the family planning needs of women with epilepsy, 2) one year of posts to all online forums utilized by women with epilepsy in the US to discuss family planning issues, and 3) thirty semi-structured in-depth telephone interviews with women with epilepsy of reproductive age.

We found that women with epilepsy face challenges making and implementing informed family planning decisions due to a number of factors such as the continued stigmatization of the disorder, the segregation of neurological and reproductive health care in the health system, lacking clinical guidelines for managing epilepsy in women of reproductive age, and barriers enrolling in and utilizing insurance to obtain health care services and products. These challenges can result in a number of poor health outcomes including the use of epilepsy medications or contraceptives that lead to poor seizure control, or undesired reproductive health outcomes such as unintended pregnancy or an inability to get pregnant when pregnancy is desired. They can also negatively affect quality of life, and produce feelings of conflict or regret about family planning decisions. Despite the importance of these outcomes for women’s overall health and quality of life, women do not appear to have adequate support within the health care system to make or implement informed family planning decisions. Therefore, women develop or reach out to other networks of support, and rely heavily on their own abilities to advocate for themselves to obtain adequate resources to make and implement informed family planning decisions. Regardless, findings from this study suggest there is a continued and significant need to support women with epilepsy in making and implementing desired family planning decisions, and that intervention is necessary to ensure they experience optimal neurological and reproductive health outcomes.