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Cambridge University Press
978-0-521-65224-7 - Women with Epilepsy: A Handbook of Health and Treatment Issues
Edited by Martha J. Morrell and Kerry L. Flynn
Excerpt
More information

Part I

The woman with epilepsy

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Introduction: why we wrote this book

Martha J. Morrell

Martha J. Morrell is a Professor of Neurology at Columbia University, College of Physicians and Surgeons in New York City and is Director of the Columbia Comprehensive Epilepsy Center at New York Presbyterian Hospital. She has been elected an International Ambassador for Epilepsy by the International League Against Epilepsy and she chairs the National Epilepsy Foundation. Dr Morrell is the principal investigator on a number of epilepsy research trials examining reproductive health and hormones in women with epilepsy and bone health in women receiving antiepileptic drugs.

MJM

In many ways, epilepsy is a different disease in a woman than in a man. The differences arise because of biological differences between women and men, but also because of the different social roles they play. As a result of these biological and social differences, women with epilepsy face special challenges, especially in the area of reproductive health (Table 1.1).

The experiential differences between women and men with epilepsy became clear to me in the very earliest years of my career as a neurologist specializing in the treatment of epilepsy. My background had been in studying the effects of male and female sex hormones on certain types of behavior, so I was well aware of the significant effects these hormones could have on many brain centers. Therefore, I was not at all surprised when women with epilepsy explained to me that their seizures appeared to vary with their menstrual cycles. Nor was I surprised to hear that many women found that their seizures changed at puberty and with menopause. I was concerned to hear women tell me that their menstrual cycles were irregular and to learn from some of my patients about their difficulties in becoming pregnant. There were also stories of miscarriages and complicated pregnancies. Many women (and men) also shared with me concerns about sexuality – problems with

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Table 1.1. Special concerns for women with epilepsy

Hormone effects on seizures
Interactions between birth control pills and antiepileptic drugs (AEDs)
Effects of epilepsy on reproductive health
Effects of epilepsy on sexuality
Effects of AEDs on pregnancy and fetal development
Effectiveness and tolerability of AEDs in women

low sexual desire and sexual responsiveness. When I looked at the literature (now more than 10 years ago), I found that many of these issues were not recognized, not well understood, or not considered significant. Some medical writers believed that menstrual-associated seizures did not even exist. Those physicians who did accept the relationship between hormones and seizures sometimes delivered treatments that we now recognize are ineffective, such as hysterectomy and oophorectomy (removal of the uterus and ovaries).

In selecting antiepileptic treatment, I was dismayed to find that most of the information on the effectiveness and tolerability of the medications had been collected almost entirely from men. There was simply not enough information on whether these drugs worked differently in women, had different side effects, or were safe or not safe to use during pregnancy.

Family planning choices for women with epilepsy must take into account the interaction between hormones used for contraception and some antiepileptic drugs (AEDs). Although for more than 10 years some physicians recognized that some AEDs made birth control pills less effective, this information was not widely known by many neurologists and gynecologists. Therefore, some women with epilepsy have experienced unplanned pregnancies despite their best efforts to use contraception correctly.

One of the chief concerns for many women with epilepsy is that seizures and AEDs may make having children more risky. Women with epilepsy have been told that having children was not advisable because of the risks of transmitting epilepsy to a child and of having a baby with major physical or intellectual problems. Women with epilepsy have also been told that their epilepsy makes them unsuitable parents. Until 1982, there were even laws in some states in the USA restricting the ability of people with epilepsy to marry and have children.

Although it has been known for some time that AEDs can cause birth defects, there has been very little information about how these drugs harm the developing fetus and how treatment can be adapted so that there is as little risk as possible. As many new AEDs become available, we have not had the information that allows us to counsel women of childbearing age appropriately regarding the impact of the medications on reproductive health or the medication's safety during pregnancy. This is because, by government policy, women who are capable of becoming pregnant are excluded from the early phases of drug testing when much of the basic information regarding drug dose, effective pharmacokinetics, and tolerability is gathered. Pregnant and lactating (breastfeeding) women are excluded from any exposure to a drug being tested in order to protect the fetus against possible birth defects (teratogenecity). There are over 800 000 women in the USA with epilepsy who are in their childbearing years and probably one-third continue to have seizures despite efforts to achieve control with the older AEDs. That means that new drugs will be used in women during their reproductive years and while pregnant without health-care providers being fully aware of all the potential risks to reproductive health. Government and health-care providers are currently reassessing these drug development policies.

Fortunately, times have changed. A combination of scientific and social advances has brought issues concerning gender differences in medical illnesses to the attention of the general public, government agencies, and the scientific community. It is now recognized that epilepsy is one of the chronic medical conditions that raise special issues for women. This has increased the educational materials available to health-care providers. However, there is still very little literature available for the nonmedical public that comprehensively addresses the biological, psychosocial, and treatment issues faced by women with epilepsy. The Epilepsy Foundation has recognized the importance of encouraging educational outreach as part of the broader based Women with Epilepsy Initiative launched in 1997. This book is a part of that larger effort.

We have been able to assemble national and international experts to address issues of concern for women with epilepsy. Some are scientists researching the causes and consequences of epilepsy, others are health-care providers treating women with epilepsy, and, finally, we hear from women living with epilepsy. We have attempted to be comprehensive and scientifically sound, while interpreting what is sometimes confusing and contradictory scientific information. Each author has selected further materials in each topic for the interested reader. These reference materials are not exhaustive, but have been selected as being particularly important, thorough, and clear. Further information can also be obtained through the National Epilepsy Library at the Epilepsy Foundation or from the Epilepsy Foundation's website at www.epilepsyfoundation.org.

Box 1.1

For more information on the
Women with Epilepsy Initiative
contact the Epilepsy Foundation at
www.epilepsyfoundation.org
1-800-EFA-1000

We have also tried to provide information that will permit a woman with epilepsy to educate herself about optimal medical care – not only for epilepsy, but also to maintain the best general and reproductive health. Epilepsy is best managed when there is a partnership between the patient and health-care provider. Family and friends are also an important part of the team. Ultimately, the woman with epilepsy should understand how to access appropriate services, should know enough about epilepsy to ask the important questions, understand the answers, and be able to anticipate health issues that may arise along the way. The woman who knows most about her disease is in the best situation to benefit from treatment. People with epilepsy can also serve as the most effective advocates to ensure that access to high-quality medical care is maintained, that scientific research continues to address topics of importance to people with epilepsy, and that public misconceptions about epilepsy no longer impede social progress.

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On being a woman with epilepsy

Lisa Zobian Lindahl

Lisa Lindahl is a member of the Board of Directors of the Epilepsy Foundation, a founder of a successful start-up company (she invented and marketed the first sports bra, the Jogbra), and a woman with epilepsy. Ms Lindahl's efforts were critical to the success of the Epilepsy Foundation's Women with Epilepsy Initiative.

In this chapter, she shares her personal experience and perspective. She discusses what it has been like to live with epilepsy, how she has navigated the medical system, the questions she has asked (and has not always had answered), and how she has become an effective self-advocate. Through Ms Lindahl's voice, you can learn how to be in charge – by getting information, getting noticed, and asking directly for what you need. In Ms Lindahl's thoughtful view, taking responsibility for your own well-being is essential to living well as a woman with epilepsy.

MJM

Epilepsy, as experienced by women, is the subject of this book. Why a whole book? Because so many women, girls, and their families have so many questions, and sometimes it seems there are more questions than answers. This is due, in great part, to the fact that there has only recently been information available about why a woman's experience with epilepsy is different from that of a man's. Further, much of the information was difficult for the average person (like me) to locate. It is hoped that this book will provide the woman with epilepsy with a place to turn for information about those issues that are specific and important to her.

I would like to begin by sharing my own thoughts about and experiences with epilepsy. My credentials for doing so are simply that, having been diagnosed with epilepsy at the age of 3, I have now lived 40-odd years with this disorder. In addition, my volunteer work with the Epilepsy Foundation's

National Office – specifically in our Women and Epilepsy Initiative – has put me in touch with many other women.

As women and as patients, I believe we are dealing with what I refer to as the 'double whammy.' Many women have been culturally conditioned in two ways: (1) the doctor knows best, and (2) men are the authority. Myth or fact, these are two of the assumptions many of us start out with when we embark upon the journey from initial diagnosis to living well with epilepsy. What makes it a double whammy is that most of the neurologists in the USA are male. In addition to my own experiences, I have heard from other women how being a woman *and* having epilepsy can stifle our impetus to speak up when our questions and concerns about how epilepsy impacts our lives are either dismissed or diminished by physicians.

Historically, women have often faced prejudice in what has been a male-dominated health-care system in the USA. In many cases, their symptoms, regardless of the disease, have not been seriously addressed. Women with epilepsy are challenged not only by their epilepsy, but also by the fact that there has been confusion and lack of knowledge in the health-care community about the unique problems facing women with epilepsy.

There are many questions that women or the parents of girls with epilepsy have. These questions can arise early on, with new ones blossoming as we develop and age.

- Will the onset of menses affect the type or severity of my (or my daughter's) seizure disorder?
- How might my reproductive health be affected? Can I have safe pregnancies and healthy babies? Should I breastfeed?
- My experience is that I am far more likely to have seizure activity just prior to menses. Why? Is there anything I can do about it?
- Is the effectiveness of my medication impacted by my monthly hormonal fluctuations? Does medication work the same way on women as it does on men?
- What happens, if anything, as menopause begins and progresses? Are there any interactions between anticonvulsants and the therapies prescribed for menopause, especially hormone replacement therapy (HRT)?

These are just some of the questions facing women who have a seizure disorder. Their primary partner in addressing these issues should be their doctor. Unfortunately, for too many women this partnership has been found wanting. Part of the reason for this is that, until recently, there has been little scientific research into this area.

With a lack of scientific information about the special issues affecting women with epilepsy, guesswork and opinions surface, and they vary. This means that many women with epilepsy have been given misinformation ('You should never have children.') or, if their concerns are acknowledged, they are told there is no information about their unique issues. As a result, we, the patients, are left with many questions unanswered and symptoms ignored.

I am not alone, however. There are a number of women who have the courage to share their experiences:

> I began to keep track of the dates of my seizures and found that they occurred prior to my menstruation or during its first two or three days. When I mentioned this to my neurologist, he belittled the possibility of any correlation between the two and stated there were no proven facts to link hormonal cycles and seizures.
>
> The only issue I have regarding my epilepsy has been doctors not taking me seriously when I have told them I thought my seizures and my menstrual cycle were somehow related. It seems to me that when seizures triple in quantity the week before your period and then return to normal afterward, there is something going on.
>
> I was 10 years old when I started menstruating and 30 years old before I got a doctor to take me seriously. I usually got a token pat on the head and the typical 'You're a woman. What do you know?' look. It's a very frustrating and degrading feeling. I hate to see other young girls and teenagers endure what I have to get a doctor to listen.
>
> It is not just learning that researchers are now investigating the links between hormonal changes in women and their seizures that I find important . . . To me, after 43 years of living with seizures, it was great to see women with epilepsy treated as adults with serious questions about treatment, medications, possible causes of their seizures.

The question of catamenial epilepsy has been a long-standing issue for debate within the medical community. Loosely defined, catamenial epilepsy is a term used to describe a seizure disorder that is triggered by hormonal changes during a woman's menstrual cycle. Opinions have varied widely about whether catamenial epilepsy even exists, let alone its cause. The differing opinions on this exist despite the fact that doctors have been hearing women complain and comment upon this phenomenon for over a century.

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In fact, women have been reporting the existence of some kind of relationship between hormonal activity and seizure activity since at least the 1800s, when it first appears in medical literature. In 1881, Dr William Gowers reported that about half his female patients seemed to have more seizures before or during their menstrual cycle. Little appears in the literature until 1956, when a paper by J. Laidlaw addressed and described the phenomenon, naming it catamenial epilepsy. No further substantive inquiry was made until over 30 years later. In the last 10 years, this inattention has begun to be remedied. Recently, some medical scientists began to take women's anecdotes seriously and began to do the research.

Every day that goes by, women who are coping with seizure disorders are making decisions and living their lives without adequate information, sometimes with false information and, all too often, with fear. In my files, I have bulging folders filled with letters from women who have suffered from the lack of good information and/or have been confused by differing opinions. Women's lives have been *irrevocably* impacted as a result of being presented with misinformation instead of fact and research results. For instance:

- Upon happily finding out that she was pregnant, one woman was told, (incorrectly) that because of her epilepsy she should have an abortion.
- Another fought to adopt a child because, even though she was a successful biological mother, there was concern about whether she was a 'fit' parent.
- One girl who started having grand mal seizures at puberty was told that they would stop once she had her tonsils and adenoids taken out. She continued to have seizures after the tonsillectomy.
- A young wife in her twenties writes: 'Sexual desire wasn't a problem at first, but over time sex became less desirable because of the pain.' No one ever told her this was related to her epilepsy and to antiepileptic drugs (AEDs).

A chapter from my story

Thankfully, I am one of the lucky ones. Although I experience two different kinds of seizures – one of which is the 'grand mal' convulsion type that is most often associated with the term 'epilepsy' – I have enjoyed long periods of control. Usually, dealing with my seizures has been episodic in nature, a once-a-month concern versus a daily one.

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Nonetheless, my own story includes a few disagreeable – and I believe unnecessary – consequences of having a seizure disorder, not the least of which was the virtual loss of more than 2 years of my life. This happened because at one point, in my early thirties, I was so severely over-medicated that I was experiencing daily life in a continual fog. I had many symptoms of chronic depression: tired all the time, unable to think clearly, sad. I had just started my own business and could not afford (in any sense of the word) this obstacle.

Although my memory of this time period is understandably very fuzzy, I can clearly recall that awful sensation of not being able to think, of feeling as though my brain was straining, muffled, clumsy, and slow. Try as I might, I could not shake the murky cloud that seemed to invade my very spirit. The longer I tried, the worse I became, because my failure to 'get better' added to my grief and disappointment in myself.

It took over a year and several doctors, including a psychiatrist, to work out that my problems were, in fact, due to the medicines I was taking, their levels and interactions. It seems the newer drug recently introduced into my treatment plan had a negative, slowly cumulative interaction with my other prescribed AED. The result was an ever-increasing depressant effect. Imagine my tremendous relief to discover that this oppressive fog was not really *me.* I was not weak; I was not emotionally troubled. *I was not crazy!* I was just experiencing medication side effects.

The medication was adjusted, well below the 'recommended therapeutic level' (a level that had been established by tests done primarily on men), and I started to get well. It took months before I really felt like myself again. Then, once I was well, I got angry. Why had everyone been so quick to assume that my complaints were emotionally based rather than physically or chemically induced? Having not been forewarned about such a possibility, I had spent far too long, initially, thinking that 'This fog is all in my imagination; get over it.'

It became clear to me that my epilepsy, improperly managed, would have a devastating impact on my life and livelihood if I did not take charge of my health. I was living alone – a new circumstance and daunting enough in itself – and 'taking care of myself' could no longer just entail taking the prescribed pills. I could no longer relinquish the final responsibility