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Dissertation

**IDENTIFYING AND RESPONDING TO THE REPRODUCTIVE
DECISION-MAKING NEEDS OF WOMEN WITH EPILEPSY**

by

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ABSTRACT

Background: Epilepsy is the most common neurological disorder in U.S. women of reproductive age. For women with the disorder, decisions related to having children, managing health during pregnancy or utilizing contraception (defined here as reproductive decisions) are central to neurological and reproductive health because some epilepsy treatments reduce the efficacy of hormonal contraceptives and increase the risk of malformations in offspring. Additionally, hormonal changes due to pregnancy or contraceptive use can influence seizure activity.

Methods: This dissertation aimed to illuminate the reproductive decision-making processes and needs of women with epilepsy. The Ottawa Decision Support

Framework guided the analysis of one year of reproductive-focused postings to online forums for women with epilepsy and 30 in-depth interviews with women with epilepsy of reproductive age.

Findings: Women's reports showed that the ability to make and implement informed reproductive decisions depends upon financial and emotional resources, as well as existing capacity to clarify values surrounding reproductive and neurological outcomes, navigate a segmented health care system and weather stigma. Overall, women described feeling knowledgeable and prepared to make and implement decisions about having children and managing their health throughout pregnancy, while encountering considerable challenges with contraceptive decisions. In the worst cases, these challenges led to unplanned pregnancies, increased seizure occurrence, regretted sterilizations and lack of trust in clinical providers.

Intervention: Findings were applied to the development of a contraceptive decision aid, designed according to the Ottawa Decision Support Framework. This aid includes information about epilepsy and contraception, stories of women's experiences with contraception, a values clarification exercise and

methods for facilitating discussions of contraceptive needs with clinical providers. In a pre-post evaluation with 14 women with epilepsy, the decision aid was found to be acceptable and effective at increasing knowledge.

Conclusions: This dissertation fills gaps in awareness about contraceptive needs of women with epilepsy and moves public health practice forward. The resulting decision aid educates women with epilepsy about their specific contraceptive options, helps them explore values and guides them in implementing informed contraceptive decisions. It can serve as a model for developing similar tools for reproductive-aged women with other health conditions requiring medication.

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LIST OF ABBREVIATIONS

ACA: Affordable Care Act

ACOG: American Congress of Obstetricians and Gynecologists

AEDs: Antiepileptic drugs

BUMC: Boston University Medical Center

CDC: The Centers for Disease Control and Prevention

COCs: Combined oral contraceptives

HRQL: Health related quality of life

IOM: Institute of Medicine

IPDAS: International Patient Decision Aids Standards Collaboration

IRB: Institutional Review Board

IUD: Intrauterine Device

IUS: Intrauterine System

MEC: Medical Eligibility Criteria for Contraceptive Use

MS: Multiple sclerosis

OCPs: Oral contraceptive pills

PCOS: Polycystic ovarian syndrome

PCP: Primary care physician

POPs: Progestin-only pills

QOLIE: Quality of Life in Epilepsy Inventory

VNS: Vagus nerve stimulation

WHO: World Health Organization

GLOSSARY OF SELECT KEY TERMS

Term	Working dissertation definition
Catamenial seizure pattern	Seizure increases that are patterned during or around their menstrual cycle
Disability	Definitions vary widely, but can be understood here as an umbrella term for impairments, activity limitations or participation restrictions in which there is a dynamic interaction between health conditions and contextual factors.
Disorder	A disturbance of structure or function or both; distinct from disease
Health related quality of life	A person or group's perceived physical and mental health over time. Major domains include physical, psychological, social and vocational capacities.
Reproductive decisions	Decisions about having children, managing health during pregnancy or utilizing contraception
Quality health care	Care that maximizes welfare, improves or maintains quality or duration of life, leads to desired health outcomes and is consistent with current professional knowledge
Unintended pregnancy	Pregnancies that are mistimed, unplanned or unwanted

CHAPTER 1:

**AN INTRODUCTION TO REPRODUCTIVE DECISION-MAKING
FOR WOMEN WITH EPILEPSY**

Introduction

Epilepsy is remarkably common, affecting an estimated 65 million people worldwide, and approximately 2.2 million people in the U.S. (1). Diagnosis of the disorder, which occurs after two or more unprovoked seizures, can take place at any time in the life course. Most people with epilepsy are treated with antiepileptic drugs (AEDs), which are highly effective at preventing seizures. Yet, because of the chronic and unpredictable nature of the disorder, treatment is typically life-long, regardless of its effectiveness at preventing seizures. Despite many strides in clinical facets of epilepsy care, public understanding of the disorder remains limited, making epilepsy a common, chronic and very treatable disorder that is also heavily stigmatized (1).

Epilepsy is also the most common neurological disorder in women of reproductive age in the U.S.(2). For women with the disorder, decisions about having children, managing health during pregnancy or utilizing contraception (broadly referred to here as “reproductive decisions”), are just as relevant to their health and quality of lives as are decisions about epilepsy care. This is because some AEDs reduce the efficacy of popular hormonal contraceptives and increase the risk of malformations in offspring when taken during pregnancy (3; 4). Additionally, hormonal changes due to pregnancy or contraceptive use can

influence seizure activity in unpredictable ways (3; 5; 6). It must also be recognized that reproductive decisions influence more than women's health outcomes as the outcomes of such decisions also affect have a direct impact on the quality of women's lives and on their life course. Further, these decisions require attention for a number of years; the average woman who wants two children will spend 35 years of her life planning or preventing a pregnancy, 30 preventing pregnancy and five planning one (7).

Because of the importance of reproductive decisions to the overall health, quality and direction of the lives of women with epilepsy, it is critical that these decisions be informed. The Ottawa Decision Support Framework, described in detail in Chapter 4, asserts that informed decisions are those where individuals have access to the information and resources necessary to make and implement their preferred choices (8). In this dissertation, I sought to explore women with epilepsy's reproductive decision-making processes, experiences and needs through the lens of informed decision-making, and to develop an effective intervention tool that is responsive to women's identified reproductive decision-making needs.

I first conducted a needs assessment which explored women's reproductive decision-making processes, experiences and needs through analysis

of one year of postings made to all identifiable U.S.-based online forums for women with epilepsy and 30 in-depth interviews with women with epilepsy of reproductive age. Results of the needs assessment conducted for this dissertation, detailed in Chapter 5, show that while women with epilepsy are relatively well prepared to make and implement informed decisions about having children and managing their health throughout pregnancy, they encounter considerable challenges with contraceptive decisions. In the worst cases, these challenges lead to unplanned pregnancies, increased seizure occurrence, regretted sterilizations, and lack of trust in clinical providers.

Because challenges to informed contraceptive decision-making can negatively influence neurological and reproductive health outcomes, and because access to appropriate contraception is critical to the overall direction of women's lives, intervention is necessary. As discussed in Chapter 7, I developed and evaluated a contraceptive decision-aid targeted at women with epilepsy in response to women's unmet contraceptive decision-making needs. The evaluation results show that the decision aid is acceptable, and produced increases in knowledge, though it did not produce significant changes in values or feelings of self-efficacy.

Public Health Relevance of Dissertation Topic

Epilepsy affects over one million women and girls in the U.S. (2). Despite the prevalence of epilepsy among women, there is limited understanding of the public health issues confronting women with the disorder (1; 9; 10). As such, a number of organizations including the Institute of Medicine (IOM), the Centers for Disease Control and Prevention (CDC), the Epilepsy Foundation and others, have called for increased attention to understanding the specific needs of women with the disorder so that gaps in their quality of care can be addressed (1; 9; 10). The needs assessment conducted for this dissertation is responsive to these calls for action and will help increase understanding of women's experiences being diagnosed, living with epilepsy and seeking epilepsy treatment.

The developed intervention tool is responsive to public health goals to address the specific contraceptive and pregnancy planning needs of women generally and of women with epilepsy specifically. Reproductive health issues have been recognized as a significant component of the health of women in the general population by several major public health bodies, including the IOM, the CDC, and Healthy People 2020. These bodies all identify contraception as an important preventative health care service for women; use of contraceptive increases the likelihood of planned pregnancies, which leads to better uptake of

prenatal care and decreased likelihood of fetal and maternal illness or low birth weight, compared with unintended pregnancies (11–13). It should also be noted that contraceptive use improves quality of life (14) and is well established as one of the most cost-effective preventative care measure (15).

These public health benefits of contraceptive use have particular relevance to women with epilepsy for several reasons. First, women with epilepsy are in need of planning pregnancy so that they have the opportunity to optimize epilepsy therapy, and reduce the risk of adverse maternal and fetal outcomes (3; 4). Next, because they have lower quality of life than women in the general population, any measure that improves quality of life is important to their overall health. Third, women with epilepsy are more likely than women in the general population to experience health conditions such as irregular menstrual periods, painful or heavy periods, endometriosis and polycystic ovarian syndrome (PCOS) (16; 17) that can be treated with the use of hormonal contraceptives(18). Fourth, because some contraceptives can reduce seizures in some women (5; 6), contraceptive use has the potential to help address one of the IOM's goals of reducing or stopping seizures, since their occurrence can increase the risk of morbidity and mortality, and decrease quality of life, inhibit social

interactions, and limit employment possibilities, among other negative outcomes (1).

I posit that these benefits of pregnancy planning and contraceptive use cannot fully be realized if women with epilepsy are unable to make informed contraceptive decisions, and that the decision aid developed and evaluated for this dissertation holds the promise of supporting women in making informed contraceptive decisions and of realizing these health benefits. Others, including the authors of a 2009 Cochrane review, have called for the development of such a tool to assist women with epilepsy in their reproductive decisions (19). However, a comprehensive literature review conducted for this dissertation showed that no such tool had previously been developed.

Outline of Chapters

I address the above aims through eight chapters; the content of each chapter is outlined in brief below.

Chapter 1, “An Introduction to Reproductive Decision-making for Women with Epilepsy” provides an overview of the dissertation and the relevance

of its aims to broad public health goals.

Chapter 2, “Epilepsy: Causes, Treatments, and Consequences” describes current medical understanding of the causes of epilepsy and approaches towards treatment, as well as the impact of epilepsy on quality of life.

Chapter 3, “The Impact of Epilepsy on Reproductive Experiences and Outcomes” details the social and medical needs of women with epilepsy, with a focus on scientific literature that has investigated the contraceptive and pregnancy experiences and outcomes of this population. It also includes a critique of the clinical guidelines designed to support health care providers working with women with epilepsy of reproductive age.

Chapter 4, “Needs Assessment Framework and Methods” outlines the theoretical framework that guides the methods and findings of the dissertation, and the research methods used in this dissertation to explore the reproductive decision-making of women with epilepsy.

Chapter 5, “Needs Assessment Results” details the findings from a framework analysis of postings in online forums utilized by women with epilepsy and of-depth interviews with women with epilepsy of reproductive age.

Chapter 6, “Decision Aid Development and Evaluation Results” focuses on

the process of developing a contraceptive decision aid targeted at women with epilepsy and results of a preliminary evaluation of the tool.

Chapter 7. “Discussion and Next Steps” synthesizes the findings from original research conducted for this dissertation and reviews the findings in light of existing literature to outline steps for future research, and for clinical and public health practice. I also consider the implications of my findings for women with other conditions, disorders, or disabilities.

CHAPTER 2:

EPILEPSY: CAUSES, TREATMENTS AND CONSEQUENCES

Introduction

In this chapter, I review current clinical understandings of epileptic seizure disorders which reveal that epilepsy is a common, chronic and often misunderstood condition. In particular, it will be shown that the variety of epilepsy types, the range of seizure triggers and the impact that seizures can have on individuals beyond the moment of having a seizure, often goes overlooked. I then discuss the therapeutic strategies most commonly used to treat epilepsy, highlighting that though they are largely effective at reducing or stopping seizures, negative side effects associated with most treatments remain concerning. I close the chapter with a discussion of how having epilepsy impacts quality of life and the identified strategies for improving quality of life and quality of care for people with the disorder. In this discussion of medical issues, I lay the basis for investigating needs and developing supportive public health strategies for improving quality of life.

Clinical Overview

Prevalence

Epilepsy is the world's most common neurological condition, affecting an estimated 65 million people (1). This is equivalent to the number of women

worldwide with breast cancer or the number of men worldwide with lung cancer (20). In the U.S., epilepsy is the fourth most common neurological disorder, after migraine, stroke and Alzheimer's disease (21). It is estimated that approximately 2.2 million people in the U.S. have been diagnosed with epilepsy (1), and that 150,000-200,000 new cases are diagnosed every year (22). This means that approximately one out of every 100 people in the U.S. has epilepsy and that one in 26 people will develop epilepsy at some point in their life course (21).

Seizure types

Clinically, epilepsy is defined as two or more seizures that are not provoked by other illnesses or other circumstances. A seizure, often described as an electrical storm occurring in the brain, takes place when there is abnormal, excessive or synchronous neuronal activity (23). Sometimes this activity will start and then maintain presence within one area of the brain in what is called focal seizures. Other times the activity starts at one point in the brain and is then "generalized," or spread throughout the brain. The reason why some seizures are focal and others are generalized is unknown (24).

During a seizure, a person with epilepsy may experience a range of brief but involuntary changes in body movement, function, sensation, awareness

and/or behavior (25). The type of changes experienced depends on the nature of the seizure disorder. Though epilepsy is commonly associated with generalized tonic-clonic convulsions (previously known as grand-mal seizures), in which a person loses consciousness, shakes and falls, there are over 30 different types of seizures, which can be divided into major categories based on where the neuronal activity starts, and how it progresses, as described above (22).

Approximately 60% of individuals with epilepsy have focal seizures, which can be further classified as simple or complex focal seizures. In a simple focal seizure, individuals remain conscious but experience unusual emotions or sensations such as sudden and unexplainable feelings of joy, anger, sadness, or nausea. S/he may also experience changes in their senses and hear, smell, taste, see or feel things that are not physically present. During complex focal seizures, there are changes in consciousness, often producing a dreamlike state. People having these seizures may repeatedly make certain movements such as blinks, twitches, mouth movements or walking in a circle. While in the dreamlike seizure state, individuals with complex focal seizures may be able to continue routine activities they started before the seizure began (22).

The more commonly known, but less commonly experienced, generalized seizures can be broken down into several classifications. During absence

seizures, an individual may appear to be staring into space and/or have jerking or twitching muscles. Tonic seizures cause stiffening of muscles, generally those in the back, legs and arms. Clonic seizures cause repeated jerking movements of muscles on both sides of the body. Tonic-clonic seizures cause a mixture of these symptoms, including stiffening of the body and repeated jerks of the arms and/or legs, as well as loss of consciousness. Myoclonic seizures cause jerks or twitches of the upper body, arms or legs. Atonic seizures cause a loss of normal muscle tone, causing a person to fall down or drop his or her head involuntarily (22).

Seizure patterns and triggers

It is often said that seizures are unpredictable (1), and they are in terms of frequency. However, between 50-65% of individuals report experiencing distinctive feelings or warning signs, called auras, which provide an alert of impending seizures. The timing and sensation of auras can vary significantly. They can occur several hours before a seizure or immediately before the event. Commonly, auras include depression, irritability, nausea, headache, sleep disruption, changes in bodily sensations, an inability to interact with the outside world or changes in perception (22). Auras do not always ensure an individual can take steps to prevent seizure-related injuries (often from falling), as

sometimes the warning is not recognized, or there is not enough time to react to it (26).

Epilepsy is a unique disorder in that people with it can go for long periods without experiencing any signs or symptoms . For many people, the pattern of seizures appears random. One exception to this is that many women experience seizure increases that are patterned during or around their menstrual cycle, in what is known as catamenial epilepsy.¹ Besides hormonal changes, seizures can be triggered by lack of sleep, alcohol consumption, stress, light flashing at a certain speed (including the flicker of a computer or strobe lights), smoking cigarettes and other causes (see Table 1 below). Only in very rare instances are seizures triggered by sexual activity (22). Recurrence of seizures can be frequent or rare, but no matter the pattern of occurrence, an individual cannot be guaranteed that their seizure activity has permanently stopped (27).

Table 1. Seizure triggers in people with epilepsy (adapted from 22).

Type of trigger	Trigger
Lifestyle	Sleep deprivation, hunger/dieting, alcohol (both bingeing and withdrawal), recreational drugs, smoking, stress
Hormonal	Menstruation, pregnancy, hormonal contraceptives, menopause
Medication	Starting or stopping prescribed medications
Physical	Infection, acute illness, fever, dehydration, head injury, flashing lights/television

¹ Catamenial epilepsy will be discussed in more detail in the next chapter, focused on women's experiences with the disorder.

Etiology of epilepsy

The underlying cause(s) of epilepsy is (are) unknown in almost half of all cases, though anything that disturbs the normal pattern of neuron activity can lead to a seizure disorder. Confirmed causes include (but are not limited to) abnormality in brain wiring, infection, trauma, head injury, exposure to certain toxins; medications; or drugs, and brain damage from other disorders and conditions such as brain tumors; alcoholism; Alzheimer's disease; strokes; and heart attacks; as well as a variety of a variety of developmental and metabolic disorders. The role of genetics in epilepsy is not well understood; some researchers estimate that more than 500 genes could play a role in the disorder, and that environmental factors also play a role (22).

Diagnosis of epilepsy

Formal diagnosis of the disorder can involve one of several tests to determine the presence of epilepsy and type of seizure. Diagnosis can include EEG monitoring to detect abnormalities in the brain's electrical activity, video monitoring to view seizures, various brain scans to monitor the structure; functioning; and activity of the brain, blood tests to screen for underlying disorders or other problems that may be associated with the seizures, as well as

developmental; neurological; and behavioral tests that can measure motor abilities, behavior and intellectual capacity (22). However, two key diagnostic challenges remain. First, epilepsy cannot be accurately diagnosed prior to seizure occurrence. Second, it is unclear which individuals who have had one seizure will have additional seizures, and for which individuals a seizure is a one-time event (28).

Treatment Options

AEDs are the mainstay of epilepsy therapy. When AEDs are ineffective, or the side effects intolerable, standard alternative treatments include brain surgery, the use of electric vagus nerve stimulation (VNS) or the ketogenic diet (29). Below, I describe each of these treatment options and discuss the successes and remaining challenges of preventing seizures with limited or manageable side effects.

Antiepileptic drugs

Currently, there are two dozen medications approved to treat epilepsy in the U.S. (22). There are no indicators that a specific AED will work in an individual. Therefore, the choice of medication depends on a variety of factors

including seizure type, side effects of treatment, treatment of comorbidities, pharmacokinetic properties such as dosage, cost of medication and efficacy (30).

AEDs eliminate or reduce seizures for more than half of people with epilepsy and reduce but do not stop seizures in 20-30% of people with the disorder (1). If the first medication tried fails to stop seizures (which it does approximately 50% of the time (30)), a decision must be made to either change to a new medication or add additional medications to the original medication tried (30). For most individuals, only one medication is needed to control seizures. For those for whom monotherapy fails to effectively control seizures, polytherapy may be used, though this is avoided where possible as it often amplifies experiences of side effects of AEDs (22).

The side effect profiles of AEDs are a major concern in epilepsy treatment as struggles with side effects are common (22) and have been linked with discontinuation of medication (27). Common side effects include, but are not limited to, tiredness, cognitive problems, difficulty concentrating, sleepiness, headache, weight gain or loss and nervousness. Further, individuals on polytherapy who convert to monotherapy report improvements in energy, cognition, concern over long-term side effects of AEDs, medication adherence, trouble with leisure activities and overall state of health even without

improvements in seizure frequency (31; 32).

Brain surgery

After an individual has tried two or three AEDs without success, s/he may be a candidate for brain surgery. Several factors, in addition to the failure of AEDs, play a role in determining if surgery is an appropriate treatment: the type and frequency of seizures, the brain region involved in the surgery, and how important that region is for everyday behavior (22).

There are four types of brain surgery. The most common type, a lobectomy or lesionectomy, is the removal of a small area of the brain where seizures originate. The surgery is most successful when the area of the brain causing the seizures is small and well identified; with these factors lobectomies have a 55-70 % success rate. When seizures originate in part of the brain that cannot be removed, a multiple subpial transaction may be performed. In this type of operation, a series of cuts are made to the brain, with the aim of stopping seizures from spreading to other parts of the brain. About 70% of individuals who undergo a multiple subpial transection have notable improvement in seizure control. A third type of brain surgery, a Corpus callosotomy, in which the neural connections between the right and left hemispheres of the brain are

severed, is done primarily in children with severe seizures that start in one half of the brain and spread to the other side. Corpus callosotomy can end some types of seizures; however, other seizure types may increase after surgery. Finally, a hemispherectomy and hemispherotomy may be performed. These procedures remove half of the brain's cortex, and are performed predominantly in children who have seizures that do not respond to medication. This type of surgery is only considered as a last resort, as it can affect normal brain functioning, though children who undergo this surgery often obtain full seizure control, and with intensive rehabilitation, can often recover their normal abilities (22).

While surgery can significantly reduce or completely stop seizures for many people, it is not always successful, and some individuals must remain on AEDs post-operatively (22).

Vagus nerve stimulation

VNS is a relatively new treatment, only available in the U.S. since 1997 (33). Since that time, 32,000 individuals in the U.S. have had the battery-powered device implanted (29). Often compared to a cardiac pacemaker, the VNS system is approximately the size of a silver dollar and is implanted into the upper chest

with wires tunneled subcutaneously to attach the electrodes to the left vagus nerve. The device works by sending short bursts of electrical energy into the brain usually for a duration of 30 seconds every five minutes. The stimulator can also be activated on demand to stop impending seizures (33).

Approximately 33% of people who use VNS therapy experience a reduction in their seizures, but seizures are very rarely eliminated altogether. Therefore, it is usually necessary to continue AEDs and use the VNS system as adjunctive therapy. Negative side effects of VNS therapy can include hoarseness or discomfort in the throat, or changes in voice quality during the actual stimulation. Some positive side effects of the device have also been documented including improvements in mood, alertness, and memory (29).

Ketogenic diet

Before effective epilepsy medications were developed, a low-calorie high-fat diet that mimics fasting was commonly used to treat seizures. Indeed, more than 80 years ago the benefits of what is now known as the ketogenic diet were documented. Today this diet is primarily restricted to children who have hard-to-control epilepsy and is usually only considered when two or more medications have failed to control seizures, or when the side effects of AEDs are

intolerable. It is unknown why the diet prevents seizures, or what makes the diet work in some and not others. Approximately 33% of those who go on the diet gain significant seizure control and another third improve, but still have some seizures. Like VNS therapy, the diet is considered an adjunctive treatment, and individuals on it usually continue on AEDs. The diet is usually prescribed for approximately two years, and if there are indications of success, normal foods are slowly integrated back into the diet. Reported side effects include dehydration, constipation, pancreatitis, decreased bone density, certain eye problems, high levels of cholesterol in the blood or complications from kidney stones or gall stones. However, many parents indicate their children are more alert on the diet (29).

Living with Epilepsy

The goals of any major public health efforts related to epilepsy focus not only on seeking clinical improvements for people with the disorder (e.g. improvements in diagnosis and the tolerability profiles of AEDs), but also on advocating for improvements in the everyday quality of life for the population, which is affected by factors both in and outside of the clinical arena (1; 10).

Below, I discuss how epilepsy impacts health related quality of life (HRQL) and

why it is critical that public health efforts continue to address both the medical and social needs of people with the disorder.

Quality of life for people with epilepsy

The concept of HRQOL generally refers to a person or group's perceived physical and mental health over time. The World Health Organization (WHO) posits that the major domains of HRQOL are physical, psychological and social, though others have posited that vocational capacity and disease-specific issues also play a role in HRQOL (27). Advances in the measurement of psychological and social factors related to epilepsy did not occur until the 1990's when the first HRQOL surveys were developed, and later when the first epilepsy specific instrument (the Quality of Life in Epilepsy Inventory (QOLIE)), was developed (27). These advances led to improved understanding of disorder-specific issues related to the quality of lives of individuals with epilepsy.

Despite advances in diagnosis and treatment modalities, people with the disorder continue to struggle with decreased HRQL. It is largely accepted that HRQOL is worse in individuals with epilepsy when compared to the general population (34–37). A number of studies have sought to determine what clinical

and social factors contribute to the decreased quality of life among individuals with epilepsy.

The two clinical indicators identified as variables that decrease quality of life are AED side effects and lack of seizure control. It is unclear from existing research if some medications or side effects reduce HRQOL more than others (34; 38–41). Related to seizure control, a number of researchers have found that as the frequency or severity of seizures increases, HRQOL decreases (34–36; 40; 42–48).

Identified social factors that negatively affect quality of life in people with epilepsy include being female (35; 46; 49; 50), transportation limitations (due to not being able to drive), employment challenges, cognitive limitations, independence restrictions, psychological distress, safety issues, seizure unpredictability and worry and experiences of stigma (51; 52).

The complex and multifaceted role of experiences of stigma in reducing HRQOL requires in-depth consideration. Data suggests that a diagnosis of epilepsy is often interpreted as negative event, sometimes leading to feelings of shame (53). After diagnosis, many individuals expect negative reactions about their diagnosis from others (54). Also, some seemingly minor limitations, such as restrictions on certain activities like driving or drinking alcohol, mark an

individual as different, which may increase feelings of stigmatization (27). Other factors that likely lead to stigmatization and reduce HRQOL in people with epilepsy include inadequate education and employment opportunities, as well as restrictions in independence due to the fear of having a seizure, cognitive consequences of epilepsy and treatment and ineffective treatments (55; 56). Additionally, while there have been documented improvements in public attitudes towards epilepsy, considerable misunderstanding, fear and negative attitudes towards the disorder persist (57; 58). Misunderstandings about epilepsy are linked with negative attitudes towards people with epilepsy, including beliefs that people with epilepsy are unreliable, unable to succeed at work or in social roles and not good candidates for dating or long-term partnership (59; 60).

Anticipated or experienced stigma can have a profound effect on the daily lives of people with epilepsy and has been associated not only with reductions in HRQOL, but also with learned helplessness, depression, anxiety, impaired physical health, reduced-self-esteem, decreased social interaction and opportunities and greater difficulties managing treatment regimens (57). Documented strategies for managing adverse reactions towards epilepsy include rejecting or renegotiating the diagnosis in favor of a more socially benign one,

hiding the diagnosis from others and not disclosing seizure events for fear of having restrictions imposed by others (61).

Improving quality of life for people with epilepsy

A number of factors outside of seizure freedom have been found to improve HRQOL. These factors include social support, positive self-concept, good mental and physical health, the ability to work and be productive and feelings of security and autonomy (51; 52). Regarding social support, family members emerge as key figures in the process by which people with epilepsy learn to acknowledge and accept their disorder, though teachers and health care professionals also play a role in this process (57). In addition, many studies have found that the longer an individual has epilepsy, the higher their HRQOL becomes, suggesting that over time, it becomes easier to cope with the disorder, but also suggesting that receiving and living with the initial diagnosis presents challenges for many individuals with epilepsy (38; 40; 62).

Access to quality health care also plays a vital role in improving quality of life. Quality care is generally defined as care that maximizes individuals' welfare, improves or maintains quality or duration of life, leads to desired health outcomes and is consistent with current professional knowledge (63). Quality

care for people with epilepsy is particularly important due to the chronic nature of the disorder and the frequency with which individuals with the disorder interact with the medical system (64). Because there is little consensus about what constitutes quality epilepsy treatment, it is difficult to determine which features of care lead to improvements in HRQOL. Despite this ambiguity, improved HRQOL has been associated with access to care (36; 50), satisfaction with care and satisfaction with one's health care provider(s) (58; 65; 66).

Public health campaigns, aimed at reducing the stigma associated with epilepsy, have also played a role in improving HRQOL for people with the disorder. The worldwide Global Campaign Against Epilepsy, jointly initiated by the International League Against Epilepsy, the International Bureau for Epilepsy, and the WHO began in 1997. The goal of the campaigns was to bring epilepsy "out of the shadows" by improving prevention, diagnosis, treatment, and social acceptability. The campaign has been credited with raising awareness about epilepsy and reducing stigma associated with the disorder (67).

CHAPTER 3:

THE IMPACT OF EPILEPSY ON REPRODUCTIVE EXPERIENCES AND OUTCOMES

Introduction

I begin this chapter by outlining the prevalence of epilepsy and AED use in women of reproductive age and then review how various social and clinical factors affect women's reproductive experiences and outcomes. This review highlights that for women with epilepsy, reproductive decisions are made in the context of historical stigma and restrictions placed on the population's reproduction and a complex and evolving clinical evidence base. Further, a discussion of the limited data on the documented experiences of women with epilepsy seeking pregnancy and contraceptive care reveals that the population faces barriers obtaining care that addresses their specific needs. I close the chapter with a discussion of the ways in which clinical guidelines designed to guide health care providers who assist women with epilepsy in their efforts to plan or prevent pregnancy lack comprehensiveness.

In this chapter, I do not seek to untangle the clinical complexities of managing epilepsy in women of reproductive age, but instead to understand the impact of these complexities on reproductive decision-making. While this process occurs within a limited medical context, and is often reduced to decisions about which family planning option has fewest risks for the fetus or the woman, I posit that the decision to have a child or not encompasses a much more complex reflection on health and motherhood for

women with epilepsy than currently acknowledged.

Prevalence of Epilepsy and AED use in Women of Reproductive Age

There are an estimated 800,000 women with epilepsy of reproductive age in the U.S. (2). Most of these women are on at least one epilepsy therapy; the most common being AEDs. In fact, 53% of women with epilepsy of reproductive age are taking at least one AED, 41% are using polytherapy, and the remaining 6% are not taking any AED medication (68).

Socio-cultural Issues Affecting the Reproductive Experiences of Women with Epilepsy

In the early 1900's, the eugenics movement advocated for the enactment of a number of legal and medical policies to prevent reproduction of the "feeble minded," of which people with epilepsy were included. For people with epilepsy, their efforts resulted in gendered segregation in medical institutions, prohibitions against marriage and forced sterilization (69). Indeed, by the 1930s, a number of states outlawed marrying a woman with epilepsy who was of reproductive age (70) and other states mandated forced sterilization of both men and women with epilepsy to ensure they could not reproduce (69). Some active

sterilization programs continued informally into the early 1970's and laws prohibiting marriage to a person with epilepsy remained on the books in some states until as late as 1982 (2).

Such policies towards marriage and reproduction among people with epilepsy no longer exist in the U.S. Despite this, women with epilepsy remain significantly less likely to marry or have children when compared to the general population (though the exact differences are not well estimated) (71; 72). The reasons behind the lower rate of marriage and childbearing in this population are not well understood, though it is speculated that several social factors play a role. First, one-third to one-half of people with epilepsy experience sexual dysfunction in the form of diminished sexual desire, problems with sexual arousal or physical pain during sex; factors which may affect both marriage rates and the frequency of sexual activity (and hence pregnancy rates) (73). Second, women with the disorder may choose to remain single or childless because they put priority on seizure control (74). Third, women with epilepsy can experience significant psychosocial burden while planning pregnancy, which may lead to avoidance of desired pregnancy (75).

Medical Issues Affecting Reproductive Experiences of Women with Epilepsy

Contraceptive use and pregnancy planning can be complex for women with epilepsy as epilepsy influences hormones and hormones influence epilepsy, meaning both reproductive and neurological health can be affected by contraceptive choice or pregnancy. Below, I focus on medical issues relevant to contraceptive use in women with epilepsy, and then discuss the clinical guidelines² developed by professional organizations and suggested in the academic literature for supporting women with epilepsy in making contraceptive decisions. This is followed by a summary of the documentation of women's experiences seeking contraceptive care. I then consider medical issues relevant to pregnancy in women with the disorder, and similarly review the clinical guidelines developed by professional organizations and suggested in the academic literature for supporting women with epilepsy in making pregnancy decision. This section is closed with a review of the literature establishing women with epilepsy's experiences obtaining pregnancy care.

² As defined by the IOM, clinical practice guidelines are "systematically developed statements to assist practitioner and client decisions about appropriate health care for specific clinical circumstances" (76).

Contraceptive use in women with epilepsy

There are a number of contraceptives available to women in the U.S., allowing women to consider a range of factors when they select a method, such as efficacy rates, routes and rates of administration, duration of protection and mechanism of efficacy (e.g. hormonal versus barrier methods). Women with epilepsy must consider not only these general features of contraceptives when selecting a method, but also the interactive potential of AEDs and contraceptives. Below, I discuss the impact of AEDs on contraceptive efficacy, and then discuss the impact of contraceptive use on AED levels and seizure control.

Contraceptive efficacy and AED use

The mechanism behind how a contraceptive works plays an important role in determining the likelihood of its efficacy being affected by AED use. It is well-documented that the efficacy of non-hormonally based contraceptives are not, and generally cannot be, impacted by AED use due to the mechanism by which the contraceptives operate (e.g. it is biologically implausible for an AED to interfere with a barrier method such as a condom) (6). As shown in Table 2 below, contraceptive methods thought not to be impacted by AED use include: male or female sterilization (6; 77), intrauterine devices (IUD) or systems (IUS)

(6; 77–82), diaphragms (6; 77; 82), male or female condoms (6; 77; 80; 82), fertility-based awareness methods, withdrawal and spermicides (6; 77).

On the other hand, the efficacy of hormonal methods of contraception can be reduced for women with epilepsy, specifically women taking enzyme-inducing AEDs (83). Enzyme-inducing AEDs can enhance the metabolism of contraceptive steroids and reduce the concentration of the biologically active steroid hormone, thereby reducing contraceptive efficacy (84). Because many of the currently available AEDs are enzyme-inducing (6), women preferring a hormonal contraceptive are not always able to simply choose a non-enzyme inducing AED, and therefore must select a contraceptive method carefully.

Hormonal methods of contraception whose efficacy is thought to be reduced by the use of enzyme-inducing AEDs include the etonogestrel implant (Implanon) (6; 77; 79–81; 85; 86), the contraceptive ring (Nuva Ring) (6; 77; 85), the contraceptive patch (Ortho Evra) (6; 77; 80; 82; 85), oral contraceptive pills (OCPs) (6; 77; 79–83; 85–89), and emergency contraception (6; 81; 82; 87). Of note, there are two different types of OCPs: combined oral contraceptives (COCs) and progestin-only pills (POPs), both of which are affected by use of enzyme-inducing AEDs (6; 77; 79–83; 85–89). It is unclear how much of a reduction in contraceptive efficacy occurs with each method, though reductions in efficacy are

evidenced by reports of breakthrough bleeding (abnormal uterine bleeding that occurs between menstrual periods) and unplanned pregnancies (5; 79). The only hormonal method of contraception whose efficacy is thought *not* to be reduced is depot medroxyprogesterone acetate (Depo-Provera or “the shot”) (6; 79–82; 86).

Table 2. Established interactions between AEDs and contraception.

Contraceptive type	Enzyme-inducing AED use effect on contraceptive efficacy	Effect of contraceptive use on seizure control
Male or female sterilization	• Not impacted (6; 77)	• Not impacted (6)
Intrauterine devices (IUD; IUS)	• Not impacted (6; 77–80; 82)	• Not impacted (6; 77)
Etonogestrel implant (Implanon)	• Likely or established reduction (6; 77; 79–81; 85; 86)	• No data
Depot medroxyprogesterone acetate (Depo-Provera)	• Not impacted (6; 79–82; 86)	• Increased (6; 79; 80; 85)
Contraceptive ring (Nuvaring)	• Likely or established reduction (6; 77; 85)	• Likely or established reduction with some AEDs (83; 86)
Contraceptive patch (Ortho Evra)	• Likely or established reduction (6; 77; 80; 82; 85)	• Likely or established reductions with some AEDs (86)
Combined oral contraceptives (COCs)	• Likely or established reduction (6; 77; 79–83; 85–87; 89)	• Likely or established reductions with some AEDs (6; 77; 79; 80; 82; 83; 86; 87)
Progestin-only pills (POPs)	• Likely or established reduction (6; 77; 80–83; 85–87)	• Likely or established reductions of some AEDs (6)
Diaphragm	• Not impacted (6; 77; 82)	• Not impacted (6)
Male or female condoms	• Not impacted (6; 77; 80; 82)	• Not impacted (6)

Fertility awareness	• Not impacted (6; 77)	• Not impacted (6)
Emergency contraception	• Likely or established reduction (6; 81; 82; 87)	• No data
Withdrawal	• Not impacted (6; 77)	• Not impacted (6)
Spermicides	• Not impacted (6; 77)	• Not impacted (6)

There are a number of limitations to the research investigating contraceptive efficacy among women who use AEDs. The evidence is limited to reports that cover brief observational periods, frequently do not provide information about the dosage of AEDs or the hormonal formulation of contraceptive methods, primarily investigate COCs versus other hormonal contraceptives methods and collect limited clinical information. Additionally, there is little concrete evidence about the interactions between specific AEDs and specific contraceptives (5). Therefore, much is left to be studied about the impact of enzyme-inducing AEDs on contraceptive efficacy.

Seizure control and contraception

As when determining if AED use will affect contraceptive efficacy, it is critical to consider if a contraceptive is hormonally based or not when determining if it will impact AED efficacy, and therefore seizure control. It is biologically implausible for a non-hormonally based contraceptive to affect AED

efficacy, or seizure occurrence. Therefore, as shown in Table 2 above, there should be no impact on seizure control when the following contraceptive methods are utilized: sterilization (6), IUDs or IUSs (6; 77), the diaphragm, male or female condoms, fertility-based awareness methods, withdrawal and spermicides (6).

On the other hand, there is evidence that some hormonal methods of contraception can reduce concentrations of AED levels in the blood, and thereby reduce seizure control, regardless of if the AED is enzyme-inducing or not. Specifically, clinically significant interactions have been found with the use of AEDs and the contraceptive ring (83; 86), the contraceptive patch, COCs (6; 77; 79; 80; 82; 83; 86; 87) and POPs (6). The level of AED or seizure control reduction is largely unclear, though a systematic literature review notes that several studies have found reductions in AED levels of up to 50% with some hormonal contraceptives; reductions which were related to increases in seizure occurrence in some women (5). Additionally, many researchers suggest that Depo-Provera may actually improve seizure control (6; 79; 80; 85). Finally, there is no data about the impact on seizure control of some contraceptives including the etonogestrel implant and emergency contraception.

The literature on the impact of contraceptive use on seizure control has several major limitations. Importantly, it is not robust enough yet to address anecdotal reports from women that hormonal methods, and more specifically OCPs, can cause increases, decrease or cause no change at all in seizure occurrence (9) (anecdotal reports not reflected in Table 2). This must not be read as a targeted effort to dismiss women's reports; instead it is simply that most studies that have examined the interactions between contraceptives and AED use have focused on contraceptive efficacy and not seizure control (86); therefore there is generally a dearth of literature in the area. Another limitation is that there is little concrete evidence about potential interactions between specific AEDs and specific contraceptives, and no evidence of how different types of seizures may be impacted by drug interactions.

The limited evidence about the impact of how different types of seizures may be impacted by drug interactions is an important limitation for women because of a common seizure pattern specific to women that can be treated with contraceptives. An estimated 33% (90) to 60% (22) of women with epilepsy experience a catamenial seizure pattern. This pattern results in an increase in seizures around the time of women's periods (91). Despite centuries of evidence of the impact of hormonal shifts (such as women's periods) on seizure activity in

women, it often goes unrecognized by health care providers, or when recognized is dismissed or mistreated (75; 92). This is unfortunate because there are a number of efficacious managements strategies, one of which is the continuous use of the contraceptive ring, patch or pills to maintain hormonal consistency and thereby decrease seizure activity (6; 79; 80; 82; 86; 87; 91).³

Guidelines for providing contraceptive care to women with epilepsy

Only one professional body has developed guidelines that address (though do not exclusively focus on) appropriate contraceptive care for women with epilepsy. In 2010, the CDC introduced, for the first time, Medical Eligibility Criteria for Contraceptive Use (MECs). The MEC's are an evidence-based comprehensive review of available contraceptive methods and the appropriateness of each method for women and men with different health conditions. The MECs are meant to assist health care providers who are counseling clients about contraception choice. They were adapted from the WHO's MECs for a U.S. audience. Of note, the recommendations focus primarily on contraceptive efficacy of different methods and generally do not

Other seizure management strategies for catamenial epilepsy include increasing AED dosage during the time of increased seizure activity, taking high-dose progesterone or more extreme measures such as hysterectomy or oophorectomy (surgical removal of ovaries) (93).

“consider the use of contraceptive methods for treatment of medical conditions because the eligibility criteria in these cases may differ” (77). However, the guidelines do address interactions between contraceptives and medications for some health conditions.

What this means for women with epilepsy is that the MECs address only some aspects of the interactions between contraceptives and AEDs, primarily the impact on contraceptive efficacy. The guidelines also make mention of where interactions between medications lead to reductions in seizure control. They do not, however, address the use of contraceptives to *improve* seizure control through means such as the continuous use of select hormonal methods in cases of a catamenial seizure pattern (as described above).

The MECs state that for women with epilepsy not taking AEDs, all contraceptive methods are safe, but for women utilizing AEDs, some limitations on contraceptive use are suggested. Specifically, the MECs recommend utilization of highly effective long-acting methods of contraception and do not advise the use of barrier and behavior-based methods of contraception because of typical-use failure rates, and because “pregnancy presents an unacceptable health risk to women with epilepsy” (77). In addition, because of limitations in

research, the guidelines make only a small number of recommendations (not addressed here) about the use of specific AEDs with specific contraceptives.

Table 3 below summarizes the recommendations put forth by the MECs, as well as guidelines suggested by relevant peer-reviewed literature published since 2005. Comparing and contrasting the MECs with guidelines put forth in peer-reviewed literature reveals a small number of agreements and large number of disagreements between the MECs and other academic literature, as well as disagreements within the academic literature alone.

There is broad agreement that sterilization, IUDs or IUSs and diaphragms are appropriate contraceptive methods for women with epilepsy taking AEDs (6; 77–80; 82). There is also a general consensus that the contraceptive ring and contraceptive patch should not be recommended for women with epilepsy taking AEDs due to potential reductions in contraceptive efficacy (77; 82; 85).

However, for other methods, there is less agreement about the appropriateness of use and strategies for ensuring a contraceptive is effective. Hormonal methods for which there are conflicting recommendations include the contraceptive implant, Depo-Provera, OCPs, POPs, and emergency contraception. Regarding the contraceptive implant, some recommend considering a different contraceptive method (6; 77; 81; 85; 86), whereas others

suggest the use of additional barrier methods (79; 82) when the implant is used.

Though most literature suggests that there is no decrease in contraceptive efficacy with the use of Depo-Provera and enzyme-inducing AEDs (6; 79–82; 86) some scholars recommend administering the shot more frequently (every 10 rather than 12 weeks) to account for potential changes in efficacy(83; 85–87), though others disagree (79; 82). There are a number of suggestions for improving the efficacy of COCs revealing a general lack of agreement about the use of COCs in women with epilepsy taking enzyme-inducing AEDs: use the method continually (6; 79–81; 86), use 30 mcg dose or more (77; 85), use 50 mcg dose or more (79; 81–83; 87), use doses well above the dose needed to inhibit ovulation (80; 86) or use other (77; 85) or additional contraceptive methods (86).

Additionally, though most scholars recommend that women not take POPs while taking enzyme-inducing AEDs because the dose of progesterone is lower than in many COCs and would likely result in higher contraceptive failure rates (6; 77; 85–87), a minority of scholars suggest a woman could take double the standard dose of POPs (81; 82). Regarding emergency contraception, most researchers recommend using a higher than standard dose (6; 80–83; 86; 87), though one scholar suggests offering IUD insertion as emergency contraception instead of emergency contraceptive pills (80).

Interestingly, the only guidelines to make recommendations about barrier or behavior-based methods of contraception are the MECs, which recommend

Table 3. Recommendations to improve contraceptive efficacy for women taking enzyme-inducing AEDs.

Contraceptive type	Enzyme-inducing AED use effect on contraceptive efficacy	Recommendations to improve contraceptive efficacy for women taking enzyme-inducing AEDs
Male or female sterilization	• Not impacted (6; 77)	• N/A
Intrauterine devices (IUD; IUS)	• Not impacted (6; 77–80; 82)	• N/A
Etonogestrel implant (Implanon)	• Likely or established reduction (6; 77; 79–81; 85; 86)	• Consider other method (6; 77; 81; 85; 86) • Use additional barrier methods (79; 82)
Depot medroxyprogesterone acetate (Depo-Provera)	• Not impacted (6; 79–82; 86)	• Obtain injections every 10 weeks (instead of every 12 weeks) (83; 85–87) • Use as directed (79; 82)
Contraceptive ring (Nuvaring)	• Likely or established reduction (6; 77; 85)	• Consider other method (77; 85)
Contraceptive patch (Ortho Evra)	• Likely or established reduction (6; 77; 80; 82; 85)	• Consider other method (77; 82; 85)
Combined oral contraceptives (COCs)	• Likely or established reduction (6; 77; 79–83; 85–87; 89)	• Use continually (6; 79–81; 86) • Use 30 mcg dose or more (77; 85) • Use 50 mcg dose or more (79; 81–83; 87) • Use dose well above the dose needed to inhibit ovulation (80; 86) • Use other (77; 85) or additional contraceptive methods (86)
Progestin-only pills (POPs)	• Likely or established reduction (6; 77; 80–83; 85–87)	• Consider other method (6; 77; 85–87) • Consider other method or take double the standard dose (81; 82)
Diaphragm	• Not impacted (6; 77; 82)	• N/A

Male or female condoms	• Not impacted (6; 77; 80; 82)	• Consider other method (77) ⁴
Fertility awareness	• Not impacted (6; 77)	• Consider other method (77) ⁹
Emergency contraception	• Likely or established reduction (6; 81; 82; 87)	• Use a higher than standard dose (6; 80–83; 86; 87) • Offer IUD insertion instead (80)
Withdrawal	• Not impacted (6; 77)	• Consider other method (77) ⁹
Spermicides	• Not impacted (6; 77)	• Consider other method (77) ⁹

against their use out of concern that women will not use the methods appropriately, face an unplanned pregnancy and not be able to optimize their epilepsy therapy prior to pregnancy (77). Guidelines published in peer-reviewed literature make no mention of the potential use of condoms, fertility-based awareness methods or withdrawal for women with epilepsy. Given the lack of evidence that women with epilepsy specifically are unable to appropriately use condoms, fertility-based awareness methods or withdrawal, it seems likely many scholars, besides the MEC guideline authors, presume any contraceptive method not affected by AED use is appropriate for women with epilepsy.

The above recommendations focus on ensuring contraceptive efficacy. Literature focused on ensuring seizure control is sparse. As seen in Table 4 below, the recommendations that do exist recommend either increasing the

⁴ Consideration based on health risks of pregnancy and not efficacy of contraceptive method.

dosage of AEDs, trying a contraceptive method or using a method continuously (6; 79; 80; 82; 86; 87).

Table 4. Recommendations to improve seizure control when on a contraceptive.

Contraceptive type	Effect of contraceptive use on seizure control	Recommendations to improve seizure control
Male or female sterilization	• Not impacted (6)	• N/A
Etonogestrel implant (Implanon)	• No data	• No data
Intrauterine devices (IUD; IUS)	• Not impacted (6; 77)	• N/A
Depot medroxyprogesterone acetate (Depo-Provera)	• Increased (6; 79; 80; 85)	• Use as directed (6)
Contraceptive ring (Nuvaring)	• Likely or established reduction with some AEDs (83; 86)	• Increase dosage of AED and continuous use of contraceptive method (86)
Contraceptive patch (Ortho Evra)	• Likely or established reductions with some AEDs (86)	• Increase dosage of AED and continuous use of contraceptive method (86)
Combined oral contraceptives (COCs)	• Likely or established reductions with some AEDs (6; 77; 79; 80; 82; 83; 86; 87)	<ul style="list-style-type: none"> • Increase dosage of AED (6; 79; 82; 87) • Increased dosage of AED and continuous use of contraceptive method (86) • Tryicycle or use contraceptive method continually (80; 82)
Progestin-only pills (POPs)	• Likely or established reductions of some AEDs (6)	• Increase dosage of AED (6)
Diaphragm	• Not impacted (6)	• N/A
Male or female condoms	• Not impacted (6)	• N/A
Fertility awareness	• Not impacted (6)	• N/A

Emergency contraception	• No data	• No data
Withdrawal	• Not impacted (6)	• N/A
Spermicides	• Not impacted (6)	N/A

Women's contraceptive experiences

Women with epilepsy have lower rates of highly effective contraceptive use (the use of sterilization, IUD, IUS, hormonal pill, patch or injection) compared to the general population (53% compared to 75%) (94). There is also some evidence that a significant number of women on AEDs are utilizing an inappropriate combination of AEDs and contraceptives, leading to either reductions in the efficacy of their contraception and/or their seizure medications (94–96).

It can be speculated that two related factors—women's lack of knowledge about the interactions between AEDs and contraceptives and inadequate contraceptive counseling from health care providers—account for the low rate of appropriate and highly effective contraceptive use in the population. In fact, studies have found that women with epilepsy are largely unaware of the potential interactions between AEDs and contraception (97), and that only a minority recall having ever received this information (98–101), even though many women express interest in receiving more information about contraception

from their health care providers (102). The reason that health care providers who work with women with epilepsy on this issue (including neurologists, obstetrician/gynecologists, and primary care physicians (PCPs)) often offer no, poor or inadequate advice, may be because of their own lack of knowledge regarding the issue (92; 98; 103–107). In one somewhat dated U.S. study, only 4% of neurologists and no obstetrician/gynecologists knew about the effects of the six most common AEDs on oral contraceptive efficacy (103). Given the important role that provider recommendations have on women's selection of a contraceptive method in the general population (108), it is likely that poor counseling plays a significant role in the use of less effective or appropriate contraceptives in the population.

Pregnancy in women with epilepsy

Epilepsy is the most common neurologic condition that requires continuous treatment during pregnancy(75), and women with the disorder represent .3 to .4% of all pregnant women, translating to three or four women out of every 1,000 pregnant women (109). Additionally, approximately 25,000 children are born to women with epilepsy in the U.S. every year (110). A number of advances in research have improved the clinical evidence base about the

impact of epilepsy, epilepsy treatments and seizures throughout pregnancy; this evidence is summarized below.

Role of epilepsy in pregnancy outcomes

It was historically thought that maternal epilepsy itself was the cause of adverse pregnancy outcomes in the population (111). Though the role of having epilepsy in pregnancy outcomes continues to be in need of study as it is complicated to untangle the disorder itself from its symptoms or treatments, a meta-analysis and other existing literature, suggest epilepsy itself does *not* play a role in adverse pregnancy outcomes (111; 112). Moreover, authors of the meta-analysis concluded that the common belief that epilepsy itself represents a teratogenic risk may be the result of publication bias due to several small studies that made premature conclusions about the role of maternal epilepsy in fetal outcomes (112).

Role of AED treatment in pregnancy outcomes

The first academic article suggesting an association between AEDs and major congenital malformations was published over 40 years ago. In the report, the authors identified abnormalities in six children exposed to early generation

AEDs (113). Subsequent research confirmed that use of many of the early generation AEDs during pregnancy was associated with an increased risk of birth defects. Below, I first discuss research on congenital malformations associated with in utero exposure of AEDs, and then move to the emerging literature on cognitive outcomes in children born to women with epilepsy taking medications during pregnancy.

Most of the available data about the impact of AEDs on pregnancy outcomes has emerged from pregnancy registries. Epilepsy and pregnancy registries were developed over a decade ago in the late 1990's, and since that time, they have accrued a considerable amount of data. The registries, either population-based or run by pharmaceutical companies or independent research groups, aim to prospectively enroll large numbers of women carrying pregnancies that have been exposed to AEDs (79). There are both national and regional registries (e.g., Australia, United Kingdom, North America, Kerala, India) and international ones (European and International Registry of Antiepileptic Drugs in Pregnancy). Inclusion criteria vary among the registries, as do the methods of assessing AED exposure and diagnosis of epilepsy. Data on malformations is collected anywhere from approximately five days to 12 months after delivery. Frequency of data collection (from one to four follow ups

post-enrollment) and source of data (woman, physician or medical records) also differ amongst registries. The richness of data collected on confounding factors also varies by registry (114). Of note, data collected is purely observational; women are not randomized to take certain dosages of medications or specific AEDs. Instead, participants are classified by individual characteristics including seizure and epilepsy type, socioeconomic indicators and comorbidities, and compared to a control group (115).

As a result of registry data, and other descriptive studies, the potential effects of AEDs on pregnancy outcomes are now becoming well recognized. However, most of the data collected in registries and published thus far has examined the effects of older medications, which are currently less in use among women of reproductive age. Most older generation AEDs have been linked to a two- to three-fold increase in the risk of birth defects (116) with studies identifying malformation rates in children born to women with epilepsy taking AEDs ranging from 2.0% to 11.2% (99; 117–121), whereas for the general population, the rate of malformations is typically around 2.2% (115). Some data suggest that newer AEDs may be associated with a smaller risk of birth defects than previous generations of drugs (122), however, the data is new and many of the studies on newer generation AEDs have had insufficient sample sizes or

other problems affecting their reliability (19). Finally, though the risks of specific medications are poorly understood, it is well documented that the risks associated with polytherapy are almost double that of monotherapy (116).

Generally, the pattern of malformations in children born to women with epilepsy mirrors that of the general population, with cardiac defects, facial clefts, and urogenital defects being the most common (123). Major anomalies of the limb and of the brain, especially neural tube defects, also occur. AEDs have also been associated with facial dysmorphism and developmental disorders (124).

A separate body of literature has examined cognitive outcomes in children born to women with epilepsy using AEDs during pregnancy. A recent Cochrane Review assessed all randomized controlled trials, prospective cohorts of children of pregnant women with and without epilepsy and case control studies published from 1966-2003 that examine the adverse effects of commonly used AEDs on neuro-developmental outcomes in children exposed to medications in utero. Some of the studies in the review suggest children of women with epilepsy taking AEDs during pregnancy have increased educational requirements, reduced verbal IQ and poorer neuropsychological performance. However, authors of the review found that the majority of studies were of limited quality, and that many findings conflicted. One consistent finding

however was that polytherapy exposure in utero is more commonly associated with poorer outcomes. As with the literature on malformation, little evidence addresses which AEDs are associated with the above described cognitive outcomes (19).

Results of studies related to congenital malformations and cognitive outcomes should be viewed with caution as they have in common a number of limitations. First, most information emerged from pregnancy registries which have voluntary enrollment and often lack a valid comparison group. Further, the comparison groups differ and include unexposed pregnant women with epilepsy, pregnant women from another source population or no control group at all. Second, malformations diagnosed later than the follows up included in most registries are not included. Third, the registries are often relatively small in size, and not designed to capture specific types of malformations or compare different AEDs (115). Additionally, confounders such as type of epilepsy, seizure frequency, family history of birth defects, socioeconomic status, nutrition, exposure to other teratogens and other factors likely impact the findings, but are not always adequately measured (125). Finally, the literature on cognitive outcomes is relatively recent and further prospective studies are needed (79).

Role of VNS in pregnancy outcomes

Scant research exists that addresses the impact of VNS during pregnancy, and only one identifiable published article was found. A case study of a woman with epilepsy who used VNS in combination with other AED medications found that there were no pregnancy related complications due to the VNS. The case study suggests that adjunctive treatment of VNS may be feasible option during pregnancy (126), though more research is clearly needed.

Role of seizure activity during pregnancy

A 2009 systematic literature review established that most high-quality literature shows that there is a relatively a low rate (6-18%) of seizure recurrence during pregnancy if an individual is seizure free 9-12 months before pregnancy (127). For those who do not have seizure control prior to pregnancy, approximately 25 to 40% of women experience an increase in seizure frequency while they are pregnant, while other women experience fewer seizures during pregnancy. The frequency of seizures during pregnancy may be influenced by factors such as the woman's increased blood volume during pregnancy, which can dilute the effect of medication (22). Seizure frequency, however, does not

appear to be related to seizure type, duration of epilepsy or seizures experienced during previous pregnancies (128).

Seizures that do occur during pregnancy can have a variety of impacts on pregnancy outcomes depending on a number of factors such as the type of seizure, timing of the seizure and location and activity of the woman. Tonic-clonic seizure during pregnancy can result in maternal injury from falls, including abdominal trauma and maternal death (123; 129). Tonic-clonic seizures have also been associated with miscarriages and stillbirths (130; 131), as well as small for gestational age births (132) and decreased cognitive functioning (133) in children of mothers with epilepsy who have a seizure during pregnancy. Other more common types of maternal seizures are unlikely to cause fetal harm (129).

Guidelines for providing pre-conception and pregnancy care to women with epilepsy

Three clinical guidelines have been jointly developed by the American Academy of Neurology and the American Epilepsy Society with a focus on different aspects of managing pre-conception and pregnancy care for women with epilepsy. The guidelines, published in 2009, reflect updates of the

previously established best practices published by the groups in 1998 (127). They are highly regarded, and referenced by other organizations, including the CDC. Additionally, guidelines developed by the American Academy of Neurology and the American Epilepsy Society, are the most commonly cited guidelines in peer-reviewed literature (134). Below, I review these guidelines, as well as relevant guidelines suggested by peer-reviewed literature published since 2005. I focus first on pre-conception information needs, and recommendations regarding medication changes and folic acid supplementation prior to pregnancy. I then review recommendations for medication and ultrasound monitoring, and vitamin K supplementation during pregnancy.

The aim of pre-conception counseling is to ensure that when women begin a pregnancy, they engage with a minimum of risk factors, and are fully aware of any risks and benefits of medical treatments they are taking, and therefore able to make informed decisions about planning a pregnancy (80). The American Academy of Neurology & American Epilepsy Society guidelines recommend that women with epilepsy receive the following information about managing their epilepsy prior to and during pregnancy, and about potential maternal and fetal health outcomes unique to women with the disorder during pre-conception counseling:

- Seizure control for nine months prior to pregnancy may be associated with a high rate of remaining seizure-free throughout pregnancy;
- There is insufficient evidence to support or refute an increased risk of a change in seizure frequency or status epilepticus during pregnancy;
- There is probably no substantially increased risk (up to 2 times expected) , but there is possibly a moderately increased risk (up to 1.5 times expected) of cesarean delivery;
- There is probably no substantially increased risk (up to 2 times expected) of late pregnancy bleeding for women taking AEDs;
- There is probably no moderately increased risk (up to 1.5 times expected) of premature contractions or premature labor and delivery for women taking AEDs;
- There is possibly a substantially increased risk of premature contractions and premature labor and delivery for some women;
- There is insufficient evidence to support or refute an increased risk of pre-eclampsia, pregnancy-related hypertension, or spontaneous abortion;
- There is insufficient evidence to support or refute an increased risk of hemorrhagic complications in the newborns; and
- There is probably no increased risk of reduced cognition in children born to women with epilepsy not taking AEDS (3; 4; 127).

Guidelines outlined in the peer-reviewed literature also stress the importance of providing women with epilepsy enough information about epilepsy and pregnancy prior to conception both to allow women to make informed decisions, and to reduce risks associated with AEDs. The guidelines outlined in peer-reviewed literature generally recommended that prior to conception, women with epilepsy receive information about: epilepsy prognosis irrespective of pregnancy, the importance of planning pregnancy, whether there are conflicts between maternal epilepsy and treatment for epilepsy and fetal

well-being, the extent and nature of risks that epilepsy, seizures, or the use of specific AEDs place on the fetus, methods and consequences of prenatal screening, medication management prior to, during, and after pregnancy, strategies for reducing harms to fetal well-being, as well as information about labor, breast feeding and care of a child (79–81; 83; 87–89; 128; 129; 135–137). A minority of the literature suggests that as part of the pre-conception information gathering stage, women with epilepsy should seek genetic counseling to determine what risk there is for passing on any hereditary disorder, including the small risk of passing on epilepsy (80; 137).

Once a pregnancy is planned, a plan for AED use (or nonuse) during pregnancy must be made. Medication changes made prior to or during pregnancy may be made to address maternal issues, such as changes in AED levels or hormones that affect seizure occurrence, or to reduce the occurrence of major congenital malformations. The American Academy of Neurology and American Epilepsy Society make several recommendations regarding appropriate AED use during pregnancy. First, they recommend, during the first trimester, avoiding the use of AEDs that are strongly associated with an increased risk of major congenital malformations or cognitive deficits. Because of the small evidence base available, recommendations about not using certain

AEDs are limited, and primarily focused on not using older generation AEDs. Second, monotherapy is recommended over polytherapy when possible to reduce the risk of major congenital malformations and cognitive deficits. Third, the guidelines recommend limiting the dosage of some AEDs out of concern for fetal health outcomes. Fourth, though the guidelines generally recommend limiting fetal exposure to AEDs, they underscore the importance to maternal and fetal health of maintaining seizure control throughout pregnancy and note that for most women, seizure control is not possible without utilizing AEDs. Finally, the guidelines suggest that any changes made to medications out of consideration for optimizing pregnancy outcomes should occur “well before” pregnancy to ensure seizure control can be obtained with the AED (127).

The relevant peer-reviewed literature supports the recommendations outlined above about medication use during pregnancy. Specifically, all the literatures support the use of monotherapy over polytherapy when possible, and using the lowest effective dose of an AED (79–81; 83; 87–89; 128; 129; 135–137). Most of the literature makes recommendations about avoiding specific AEDs, usually older-generation ones (79; 80; 88; 89; 129; 135–137). Additionally, most of the literature discusses the importance of maintaining seizure control during pregnancy out of concern fetal and/or maternal health (79–81; 83; 87–89; 128; 129;

135–137). Related to the timing of a medication switch, the peer-reviewed literature supports recommendations that medication changes should be made prior to pregnancy, and recommends that they should be made at least six months to one year prior to conception (79; 88; 123; 135; 137).

Folic acid supplementation is generally recommended for all women during pregnancy to reduce the risk of major congenital malformations. Women with epilepsy may have a particular folate deficiency because some AEDs interfere with its absorption and metabolism (138). Therefore, the American Academy of Neurology and American Epilepsy Society recommend at least four milligrams of folic acid supplementation should be taken daily prior to contraception and during pregnancy for all women of childbearing potential (4).

Other peer reviewed literature supports the recommendation that folic acid supplementation be taken by all women of reproductive age prior to and after conception (79–81; 83; 87; 128; 129; 135; 137). There is some disagreement about the appropriate dosage of folic acid with most peer-reviewed literature recommending a higher dosage of folic acid (five milligrams) (80; 81; 83; 87; 89; 137) than recommended by the American Academy of Neurology and American Epilepsy Society. The minor disparity regarding dosage levels is not surprising given that it is generally difficult to determine the most effective dose of folic

acid supplementation, and not concerning given that there is little data showing that the supplement can be harmful (139).

Medication monitoring during pregnancy may be suggested to help ensure medication levels remain therapeutic during pregnancy, though there is no evidence that active medication monitoring results in any improvements in seizure control (140). Regardless, the American Academy of Neurology and American Epilepsy Society recommend monitoring the levels of AEDs during pregnancy and adjusting medication levels as needed to maintain AED levels similar to those prior to conception (140). Likewise, almost all of the peer-reviewed literature recommends active AED monitoring during pregnancy (79; 80; 83; 87; 88; 128; 129; 135–137) though one article indicates medication monitoring is unnecessary as it has not been proven effective (89).

A number of diagnostic tests, including ultrasound, Amniocenteses and alpha-fetoprotein analysis can be used to test for the presence of congenital malformations during pregnancy. Though increasingly commonly used technologies, the American Academy of Neurology and American Epilepsy Society guidelines make no mention of any tools to diagnose the presence of congenital malformations. However, almost all of the peer-reviewed literature

recommends screening for neural tube defects or for morphological issues (79–81; 83; 87; 123; 128; 137).

Vitamin K can be administered to a woman later in pregnancy or directly to the neonate in order to reduce the risk of neonatal bleeding. Some evidence suggests that enzyme-inducing AEDs increase the risk of neonatal bleeding (79). Therefore, the American Academy of Neurology and the American Epilepsy Society recommended that newborns born to women with epilepsy who took AEDs during pregnancy receive Vitamin K (as is practice for all newborns). However, they recommend against administering Vitamin K to women with epilepsy since there is no evidence of an impact of administration during pregnancy (140).

Most peer-reviewed literature recommends newborns receive Vitamin K intramuscularly or intravenously (79–81; 83; 87; 89; 128; 137). However, some literature continues to recommend Vitamin K supplement for woman later in pregnancy (80; 81; 83; 87; 89; 128; 137), and only two articles state that Vitamin K should not be administered to women during pregnancy since efficacy has not been shown (79; 135).

Women's experiences with seeking pregnancy care

During pregnancy, women with epilepsy experience a HRQOL lower than the general population (141) and lower than when they are not pregnant (142). It is speculated that reduced HRQOL during pregnancy for this population is related not only to the usual stressors women experience during pregnancy, but also to the additional stress of managing epilepsy and the potential effects of AEDs on pregnancy outcomes (142).

Studies have found that the majority of women with epilepsy of reproductive age are deeply concerned about their pregnancy options, and want more information about pregnancy from their health care providers than they currently receive (102; 143). One survey found that 38% of women with epilepsy who had children received no counseling about AED use during pregnancy, and only 24% had discussed pregnancy issues with their health care provider prior to conception (98).

The lack of information that women receive about pregnancy from their health care provider likely reveals gaps in health care providers' knowledge and/or comfort. In fact, in a recent study that asked health care providers who frequently work with people with epilepsy to identify and rank treatment

challenges, clinicians reported uncertainties about the effects of AEDs on pregnancy outcomes as one of their priority concerns (107).

Challenges Offering Appropriate Reproductive Health Care to Women with Epilepsy

Clinical practice guidelines have become increasingly important to health care providers that treat people with epilepsy because of the common emergence of new studies suggesting changes or modifications to best practices for clinical care of the population (134). However, gaps in the clinical guidelines designed to guide health care providers in supporting women with epilepsy in making reproductive decisions may limit health care providers' abilities to offer appropriate reproductive health care for women with epilepsy, and therefore limit women's abilities to make informed reproductive decisions. Below, I provide an overview of the common strengths and limitations inherent in clinical guidelines, and then summarize the strengths and limitations of the guidelines related to contraceptive and pregnancy care for women with epilepsy.

Common strengths and limitations of clinical guidelines

Clinical guidelines can be beneficial for a number of reasons. First, they are one strategy for introducing new knowledge into clinical practice, translating complex research findings into straightforward recommendations for every day clinical care, simplifying medical decision-making and reducing the delivery of inappropriate care (144–147). They are also tools for ensuring care is consistent, efficient and reflective of the scientific evidence base (145). Additionally, when client versions of guidelines are developed (such as leaflets, audiotapes or other communications materials), they have the potential to better inform clients and the general public about what kind of care they should be receiving from their health care provider. Guidelines can also influence public policy and call attention to un- or under-recognized health care issues, clinical services or populations. Finally, the most desired potential benefit of the guidelines is that they improve health outcomes (145).

At the same time, there are also a number of limitations to clinical guidelines. Foremost among the limitations is that they may be wrong or inappropriate for some clients. This may be because scientific evidence about a specific clinical decision is, as Woolf and colleagues put it, “lacking, misleading, or misinterpreted” (145). It may also be because the opinions or clinical

experience of guideline developers has swayed developers from the established evidence base. Additionally, some practices may be less than ideal for clients, but lead to improvements in cost control or produce other benefits for health care providers. Poorly developed guidelines can lead to a number of negative process outcomes including the delivery of ineffective, harmful or wasteful care. In addition, conflicting guidelines from different professional bodies can promote confusion and frustration among health care providers, and outdated guidelines can encourage the delivery of out-of-date care (145).

Strengths and limitations on reproductive health guidelines for women with epilepsy

Many of the strengths and limitations that are present in clinical guidelines generally are relevant to the guidelines that address the contraceptive and pregnancy health needs of women with epilepsy. The below assessment of the strengths and limitations of relevant professionally developed and peer-reviewed guidelines reveals gaps in whose needs and preferences are included in the guidelines, what information is included in the guidelines, clarity about the timing of some recommendations and where to obtain appropriate reproductive health care.

Women's preferences and needs are overlooked

Women's reproductive health preferences and their abilities or desires to implement reproductive health care recommendations are largely absent from the guidelines reviewed above. Additionally, little attention has been paid to the development of resources to support women themselves. I discuss these limitations in detail below.

Client preferences play an important role in determining what health care is appropriate for individual situations, particularly when health care providers are offering recommendations about health care decisions that involve substantial elements of personal choice or values (148). It is therefore discouraging that neither the professional guidelines nor the peer-reviewed guidelines reviewed above make mention of the importance of ascertaining client preferences for care, even though contraceptive and pregnancy decisions certainly involve a substantial element of choice or values, as documented in the results of the needs assessment for this dissertation. One example of the role of values from the needs assessment results is that some women place more value on seizure control than on a pregnancy free of abnormalities (particularly when women perceives the risk of fetal abnormality as quite low). They therefore prefer to stay their current AEDs rather than going on AEDs recommended for

pregnancy. Another example is that some women reported being more interested in contraceptive protection than seizure control (particularly when their seizures were infrequent or did not have a significant impact on their lives). These women preferred to select a contraceptive method based on its efficacy, and were not concerned about its impact on seizures. This limitation highlights the challenges of making clinical recommendation for women with epilepsy as a broad group, instead of acknowledging the diversity of experiences that individuals have with the disorder and with their reproductive decision-making.

Another client preference in need of specific mention that is consistently overlooked is whether a woman desires or is able to have children. A number of guidelines appear to assume all women of reproductive age desire children, or will have them, and that therapeutic epilepsy recommendations should be made with fertility in mind. For example, Sabers and Tomson suggest that “the possibility of a future pregnancy *always has to be considered* when prescribing AEDs to women of childbearing potential” (136) [emphasis added]. Likewise, Penell articulates “prescribing AEDs to females during their reproductive years should be performed with the *constant consideration* of pregnancy” (149) [emphasis added]. The described reasoning behind this approach is to reduce fetal exposure to AEDs for any unplanned pregnancies. Though reducing fetal

exposure to teratogenic medications is a reasonable goal, treating *all* women with epilepsy of reproductive age as at risk for an unplanned pregnancy in order to protect the potential for fetal health appears unnecessary given that the unplanned pregnancy rate in the population is approximately 50%, that almost half of unplanned pregnancies result in abortion (150), and, as detailed in the needs assessment results, that not all women with epilepsy desire to have children. Additionally, this framework raises concerns about women's neurological health given that the best AED choice during pregnancy may not be the best AED choice generally. More explicit discussion of women's contraceptive preferences, and pregnancy desires and potential is necessary to make appropriate epilepsy treatment recommendations during women's reproductive years.

Additionally, none of the above guidelines make mention of some components of reproductive decision-making that may be central to women, such as the acceptability or affordability of a contraceptive, pregnancy or epilepsy care recommendations. In particular, clinical recommendations about pregnancy care appear to involve significant time and costs to women (considering the suggested medication monitoring, and other testing throughout pregnancy), however women's desires or ability to implement these plans are not

mentioned in any of the clinical guidelines. Needs assessment results show that women do have preferences regarding the amount of reproductive care they seek. Hence, framing the options related to reproductive decisions in terms of a menu of options that clients can choose from based on their preferences would be more supportive of client preferences (145).

As mentioned above, client versions of guidelines can play an important role in informing clients and the general public about appropriate health care (145). However, only one set of guidelines—those put forth by the American Academy of Neurology and the American Epilepsy Society and focused on pregnancy care—include client resources, such as plain language summaries of the evidence base regarding pregnancy in women with epilepsy (151).⁵

Guideline content aims to be comprehensive and balanced, but remains lacking

The content included in the reviewed clinical guidelines, particularly the content included in the guidelines focused on pregnancy care for women with epilepsy, has a number of strengths. Below, I outline the strengths of the guidelines focused on pregnancy care for women with epilepsy, including their

⁵ In addition to the clinical guidelines, the American Academy of Neurology website hosts a number of educational materials for providers and clients including: case study examples that explain the guidelines, a slide presentation, poster presentation, and podcast of the guidelines, a clinical summary, and materials for clients and their families in both English and Spanish (151).

balance between concern for maternal and fetal health outcomes, consistency among guidelines, and their positive approach to pregnancy in the population. I then discuss the remaining gaps in content for the pregnancy care guidelines, followed by a discussion in gaps in content for contraceptive care guidelines, and for reproductive decision-making broadly.

The information and recommendations included in professional and peer-review guidelines about maternal and fetal outcomes for women with epilepsy are vital for health care providers working with women who are planning a pregnancy and trying to gain or maintain seizure control. Generally, the guidelines focus on the need to balance desire for seizure control with other maternal and fetal health outcomes (e.g. recommendations about taking monotherapy in the lowest dose possible to maintain seizure control, but also to ensure healthy pregnancy outcomes). In this approach, concerns for maternal and fetal health are positioned as of equal importance, and neither is sacrificed out of concern for the other.

Additionally, the recommendations focused on meeting the goals of protecting maternal and fetal health are remarkably consistent across guidelines, which provides a concrete evidence base from which health care providers can make recommendations to their clients regarding many facets of pregnancy care.

A third strength of the guideline content is that pregnancy for women with epilepsy is generally discussed in positive terms, with many guidelines making reference to the fact that most women with epilepsy will have healthy and uneventful pregnancies (4; 79–81; 83; 87; 123; 135; 137). This positive framing is critical for ensuring that health care providers and women perceive the risks associated with AED use during pregnancy appropriately as perceptions of risk can heavily influence decisions to continue or terminate a pregnancy (152; 153).

Despite these strengths in the guideline content regarding pregnancy care, there are some gaps in the content. Specifically, the recommendations focused on improving maternal and fetal health outcomes address only clinical or pharmaceutical measures, eclipsing other factors that influence reproductive health outcomes. Indeed, the recommendations frame the provision of support for pregnancy planning as occurring within a limited medical context, reduced to specific decisions about which clinical option has fewest risks for the woman or her pregnancy. Given that pregnant women with epilepsy have a lower HRQOL than usual, and when compared to the overall population, it appears necessary for recommendations about pregnancy planning to include an integration of clinical and social aspects of epilepsy and pregnancy planning. Examples of such

recommendations could include strategies for ensuring partner or family support to help a woman manage stigma or stress, which needs assessment results indicate are important sources of strength and resilience for women with epilepsy.

Another gap in the content of pregnancy care guidelines is that there is no explicit discussion of abortion. Only two guidelines reviewed make explicit mention of the subject, and the mention is limited in scope. For example, Tomson and Battino state, “The woman should be told inadvertent exposure to AED as such is not an indication of therapeutic abortion. Adequate counseling usually helps the woman to see the risks from a realistic perspective” (129). Certainly, all women should have access to adequate counseling to discuss a full range of reproductive health issues (including abortion), but the recommendations related to abortion are generally vague and non-directive. The overall lack of explicit discussion about abortion for women with epilepsy is surprising given the somewhat common recommendation to diagnose congenital malformations in utero. It can be surmised that underlying recommendations to diagnose fetal health is the possibility that a woman could decide to terminate a pregnancy based on the diagnosis. However, this rationale is only explicitly stated in one article that reads: “Routine screening of the fetus can detect the

majority of major malformations depending on type and severity. It may provide the mother the option of terminating the pregnancy” (80). Moreover, the guidelines provide no direction for health care providers who are working with women who have conflicted or ambiguous feelings about being tested for congenital malformations, or about the results of their diagnosis. It is left unclear how health care providers can support women in their pregnancy or abortion decision-making once screenings for congenital malformations are completed.

Next, there are only limited recommendations about contraceptive care for women with epilepsy. Most guidelines developed focus exclusively on contraceptive efficacy, and there is little concrete understanding of how contraceptives may influence seizure control (both by reducing and increasing seizure control, dependent upon a number of factors). Given the bidirectional relationship between AEDs and hormonal contraceptives, this gap in clinical guideline content is significant.

Additionally, there is no information available in any guidelines about how health care providers can best support women with epilepsy in making what amounts to a complex and value-laden decision about whether or not to parent; a decision which the needs assessment results show directly influences decisions women make about their contraceptive, pregnancy and epilepsy care.

However, the guidelines related to contraceptive and pregnancy care focus on supporting health care providers in offering women appropriate care *after* such decisions have been made.

Without recommendations for best practices in prescribing contraception that address both women's reproductive and neurological care, or how to support women in making decisions about whether or not to parent, health care providers are left with a map where some of the most important information is uncharted. With no map, clinical judgment emerging from experience—and not evidence—becomes the guiding force in clinical decision-making (134).

Appropriate timing for the delivery of reproductive health information is unclear

The most appropriate timing for the delivery of information about contraceptive use or pregnancy is left unclear by the guidelines. Some guidelines explicitly recommend counseling women about reproductive issues when they reach reproductive age, even if a woman is not sexually active (80; 89; 137).

Others suggest that contraceptive information should be offered once a woman is of reproductive age, but that pregnancy information should only be given once a woman is considering pregnancy (81). Needs assessment results show that women prefer to hear this information earlier in life.

Additionally, there appears to be an implicit assumption that women only need to receive the information one time, instead of at repeated intervals throughout her reproductive years. However, evidence-based literature suggests that health care providers should prompt discussions about a woman's reproductive plan every time a woman of reproductive age presents for an appointment so that her care can be optimized(154). This is especially true for women with epilepsy who can be diagnosed at any point in the life cycle. This means that women with epilepsy would be best served if their reproductive plans were discussed at health care visits throughout their reproductive years, not only at specific points, as the current best practice guidelines for women with epilepsy recommend.

The most appropriate source for reproductive health care is unclear

The reproductive health care decisions of women with epilepsy involve decisions that affect both neurological and reproductive health; therefore, in the best-case scenario, they would consult with a health care provider who has expertise in both areas. However, as shown in the needs assessment results, it is difficult to find such a provider. Therefore, women with epilepsy end up consulting with someone who lacks expertise in one area, but specializes in the

other, or they need to consult with multiple health care providers. Below, I outline the challenges of finding an appropriate health care provider to support women with epilepsy in making reproductive decisions.

Neurologists are the primary source for epilepsy treatment; most women with epilepsy (75%) see a neurologist to manage the disorder (102). However, needs assessment results show that some neurologists lack training and experience in discussing contraceptive options and pregnancy planning.

Obstetrician/gynecologists or PCPs are a likely source for pregnancy care for women with epilepsy given that epilepsy is the most commonly encountered serious neurological problem faced by obstetrician/gynecologists and PCPs (79). However, most obstetrician/gynecologists and PCPs lack expertise in neurological care as shown in previous research (155) and in the needs assessment. Moreover, most published guidelines about managing epilepsy in women of reproductive age are targeted at neurologists; therefore PCPs or obstetrician/gynecologists lack guideline support when working with women with epilepsy (99).

A number of health care providers with different specialties may assist women with contraceptive decisions. Three quarters of women in the overall population seek contraceptive care from private physicians (156); of those 66%

seek care from obstetrician/gynecologists, 21% from PCPs, 11% from internists and 2% from other types of health care providers (157). One quarter of women in the overall population seek contraceptive care from publicly funded family planning providers such as Planned Parenthood (156). It is unclear if women with epilepsy seek contraceptive from the same sources as women in the overall population, but if the pattern of contraceptive care-seeking is similar, women with epilepsy are interfacing with a number of different doctors who lack specialty in their contraceptive care needs, which is concerning given the lack of recommendations that address both neurological and reproductive issues for women with epilepsy seeking to prevent pregnancy.

Health care fragmentation is, of course, not a challenge unique to the population of women with epilepsy. In fact, the challenge of coordinating care within the U.S. health care system is a widely recognized problem that stems from how health care is structured and financed. It is well documented that poorly coordinated care can lead to disrupted relationships between health care providers and their clients, “poor information flow,” increases in cost, degradations in the quality of care (158), and that, in contrast, well-coordinated care can lead to improvements in the delivery of health services, particularly for individuals with chronic health conditions (159).

Guideline implementation challenges remain

None of the guidelines reviewed above provide suggestions for how to implement recommendations included in the guidelines. The lack of focus on clinical implementation of the guidelines is a concerning gap given that previous literature has documented the difficulty of implementing guidelines for managing epilepsy in women of reproductive age (98; 99; 101; 103), even when considerable effort has been made to do so (160).

CHAPTER 4:

NEEDS ASSESSMENT FRAMEWORK AND METHODS

Introduction

The literature explored in previous chapters highlights the need for information about reproductive decision-making processes, experiences and needs of women with epilepsy. To help fill this gap in the literature, I conducted a qualitative needs assessment that was guided by the Ottawa Decision Making Framework. The framework and components of the needs assessment are described in detail below.

Needs Assessment Framework

The Ottawa Decision Support Framework, developed in 1995, guided the dissertation needs assessment. The framework is widely recognized for its strength in understanding decision making needs and processes, and developing decision aids (161). Given the focus of the dissertation, it is an apt framework for conducting a needs assessment that can inform the development of a decision aid. Its application to the development of a decision aid is described in Chapter 7; I focus immediately below on the framework's relevance to the needs assessment.

Implicit in the model is that the best health care decisions are those that are informed. An informed decision is defined as one that is educated,

consistent with an individual's values and one that can be behaviorally implemented (162; 163). Each of these components of informed decision-making—information, values and implementation—are explored in the needs assessment. Additionally, the results of the needs assessment are described as they relate to these components; hence a review of each component's role in informed decision-making is necessary.

Information

Elwyn and colleagues posit that in order for a decision to be informed, it must be an educated one; without being knowledgeable about a decision and its outcomes, one would only be able to make best guesses about important health care decisions (164). To prevent such guesswork from being a central part of health care decisions, information about the nature of the decision, the relevant options, the positive and negative attributes of each option and the probabilities that they will occur must be available to an individual making a decision (164).

Inadequate knowledge and inaccurate risk perception prevent informed decision-making, and can leave individuals making complex decisions they would not make with full information about their choices (165). Other challenges to ensuring a decision is informed include cognitive deficits that can

prevent an individual from understanding the complexity of a decision, or limited language or reading proficiency that makes it difficult for an individual to read available medical materials that discuss their options. Low levels of health literacy can also make it difficult for clients to fully understand their conditions or their health care choices, leading to difficulties selecting the best option, or following up on health care suggestion (166). Additionally, interpreting the risk related to a decision can generally be challenging (167), and can be even more challenging when the medical evidence base related to the decision is unclear, evolving, or conflicting (168).

Values

An informed decision is not only an educated one, but also one that is consistent with one's values. Values are principles that reflect the broad goals of an individual and are a critical component of decision making as various health states or outcomes may have very different meanings to different individuals. A lack of values clarity can result in a decision being made that, upon reflection, is inconsistent with an individual's values or preferences. However, ensuring a decision is made that is consistent with an individual's values is complex, as an individual may feel ambivalence towards available options, hold numerous

values at one time and/or have values that conflict with one another (169).

Implementation

The third component of informed decision-making is the ability to implement a health care decision, meaning an individual can both make and act upon a decision (162). Various barriers can present themselves to individuals seeking health care, and include access to and the convenience of health services and ability to pay for health services (170). Other barriers to implementation may include pressure from people in an individual's life to implement an undesired decision (171; 172).

Needs Assessment Methods

With the Ottawa Decision Making Framework providing the structure for the investigation, a multi-method needs assessment was conducted. The qualitatively focused investigation included 1) analysis of one year of postings made to all identifiable U.S.-based online forums for women with epilepsy and 2) 30 in-depth interviews with women with epilepsy of reproductive age. The rationale behind the focus on qualitative methods, and data collection, management and analysis procedures are described below.

Rationale for qualitatively focused investigation

A qualitatively focused needs assessment was selected for two primary reasons. First, most of the literature on reproductive health among women with epilepsy examines clinical outcomes derived from medical charts and registries. There is a dearth of women's voices in the literature, and only limited documentation of some features of their reproductive decision-making processes, experiences and needs. As such, a qualitatively focused investigation is appropriate for developing a rich and nuanced understanding of these issues from the perspective of women themselves (173). Data gathered from a qualitative investigation is also particularly useful for informing the design of a decision aid and for generating ideas about what issues should be addressed in a decision aid (161).

Online forums for women with epilepsy

Performing an analysis of reproductive-focused conversations in online forums for women with epilepsy provided an opportunity to use unobtrusive measures to conduct a needs assessment. In online forums, users connect with others, ask questions and obtain information. Online forums are an appropriate and rich data source because the relative anonymity of the forums allows

individuals to discuss sensitive issues they may be reluctant to discuss in person with a health care provider or with researchers (174). The internet is also a common source of information about health care; as many as 44% of women with epilepsy access health information online (102).

To conduct the analysis of online forums, the following steps were taken:

1) identification of online forums targeted at women with epilepsy in the U.S.; 2) selection of conversations on those forums covering the calendar year 2010 that were focused on relevant reproductive health issues; 3) categorization of individual issues by thematic area; and 4) framework analysis of selected conversations.

I identified English-language forums for women with epilepsy in the U.S. by searching Google using combinations of the following search terms: contraception, pregnancy, women, epilepsy forum, and blogs. I also followed any references to new forums mentioned in identified forums. Three different online forums were identified where users based in the U.S. had conversations about reproductive issues among women with epilepsy. Forums were viewable by the public at: epilepsyfoundation.org, epilepsy.com, and topix.com. The first two of these forums are hosted by advocacy organizations dedicated to improving the lives of people with epilepsy, and the third forum is an open use

forum for users to discuss a multitude of topics, of which epilepsy is one.

Once the forums were identified, I searched for a section focused on reproductive health issues for women. If a specialized section of the forum was available, I reviewed all conversations in that section, but no other sections. If a reproductive health focused section was not available, I reviewed all conversations in the forum written in 2010, searching for those focused on reproductive health issues.

Inclusion criteria

Conversations were included in analysis if they included any individual postings specifically related to contraception, pregnancy, or parenthood for women with epilepsy. I did not include conversations related to reproductive issues outside of the dissertation's focus, such as pre-menstrual syndrome, menopause, or reproductive cancers. I also limited included conversations to those that occurred between January 1, 2010-December 31st, 2010. However, if a post from 2010 was part of a conversation between online users that began prior to January 2010, the entire conversation was included to allow for full understanding of the context of individual posts. This strategy of conversation selection was chosen to limit the number of posts to the most recent and relevant

concerns of online forum users.

Data analysis procedures

After identifying conversations for inclusion in analysis, I input the following information about each conversation into Microsoft Excel: title, date conversations were initiated and last posted in, broad area of reproductive-focus, number of users who posted in the conversation, and where available, the number of users who viewed each conversation. This data was later quantitatively summarized.

I also copied the text of each conversation into a Word document. The documents were uploaded into a qualitative software program, ATLAS.ti. Then, framework analysis methods were used to analyze the textual data. Framework analysis was selected as it is well suited for applied research projects because it is both systematic and dynamic throughout the analytic process, which allows for the rigorous exploration of predetermined questions as well as emergent themes (175). The five steps used in this approach include familiarization, identifying a thematic framework, coding, charting and mapping and interpretation; each step is discussed in detail below (175).

Familiarization involves deep immersion into the data. I first became familiar with the data during the identification and selection of conversations to be included in the analysis. Because of the amount of data collected, I also included other measures besides collecting the data to ensure familiarization. First, I read through all included conversations at least once before coding them. I also kept a list of emerging ideas and potential themes to explore as I began to code the data. Also, I continued to increase familiarity with the data throughout the remaining analytical steps.

To develop a thematic framework, I utilized the list of emerging ideas and potential themes created in the familiarization step. These *a priori* ideas were turned into a codebook that was entered into the qualitative software analysis program ATLAS.ti., and later applied to the data.

I used the initial codebook to conduct a first round of line-by-line coding. Because I frequently refined the codebook as new ideas and themes emerged in the coding process, I continually reviewed previously coded data for those themes and recoded as necessary. As the codes were applied to each transcript, the thematic framework became less tied to *a priori* codes and more rooted in emerging themes.

The next stage, charting, involved building a picture of the data as a whole, and considering the range of attitudes and experiences from each theme (175). To explore the data in-depth thematically, I summarized the overall findings of each code, and identified the range of attitudes and experiences of each participant. This helped create an overall picture of each theme, and also allowed for identification of individual response within the theme.

In the final stage, interpretation, I moved from mapping and interpreting individual codes to understanding the data as a whole (175). Though noted emerging ideas and themes throughout the process of collecting and analyzing data, this stage involved a more systematic interpretation of the data. In this stage, I reviewed all research notes and coding summaries. While doing so, I compared and contrasted perceptions, experiences, and behaviors. I also searched for explanations of patterns and connections between data. Once I identified and summarized the relevant findings from the data, I extracted illustrative quotes from the transcripts.

Semi-structured in-depth interviews with women with epilepsy

The semi-structured in-depth telephone interviews with women with epilepsy provided an opportunity for participants to share their experiences

using their own words, and allowed for probing of specific topics in-depth, leading to the collection of rich and nuanced data (173).

Interview guide development

A semi-structured interview guide was used to conduct the in-depth telephone interviews. The use of a semi-structured interview guide encouraged consistency in questioning across interviews, will also allowing for some flexibility in questioning, which aided exploration of new and emergent ideas.

The final interview guide (Appendix A) was developed in three steps. First, a number of different areas of literature were reviewed to identify the major topical areas that likely affected women's reproductive decision-making, and should be considered for inclusion in the interview guide. Specifically, literature on reproductive health in women with epilepsy (summarized in Chapter 3) was reviewed for potential epilepsy-specific areas to explore.

Additionally, literature outlining the important role that individual, interpersonal, and societal factors have on contraceptive use and pregnancy in the general population was reviewed (176). Next, literature was also reviewed that takes a life-course perspective and posits that when understanding use of reproductive health services and reproductive health outcomes, it is critical to

understand the lifetime cumulative effects of social determinants of health (177; 178). Finally, the general literature on informed decision-making (discussed in Chapters 4 and 7) was also reviewed for its presentation on issues that can affect informed decision-making.

From this review of the literature, it was determined that three primary topics needed to be included in the interview guide:

- 1) Experiences with being diagnosed with and living with epilepsy;
- 2) Experiences with “reproductive landmarks” including the decision to become a parent, management of health during pregnancy, and decisions to start and select a contraceptive; and
- 3) Suggestions for resources to aid women with epilepsy in making informed-reproductive decisions.

After determining these topical areas, specific questions in the semi-structured in-depth interview guide were developed in an iterative multi-stage process. First, findings from the online forums, which were used both as results in of themselves and as a tool to inform the content of the in-depth interview guide, were reviewed. The interview guide benefited in a number of ways from a review of findings from the online forums. Initially, the forums provided insight into “insider language” used commonly by forum users which I utilized formally in the development of the interview guide, and also informally through unscripted probes. Examples of use of insider language included the adoption of

some acronyms (VNS for vagus nerve stimulator) or short hand phrasings that were common (“meds” for medications). Some of the language used also made me aware of issues or terms I would need to be sure to clarify during the interviews, such as the term “docs” being used to signify a range of health care providers, often ones with different specialties. Though I utilized some of this insider language, I was also mindful not to appropriate language that I noted may be specific to non-verbal communication (such as users describing their experiences with “E” as a shorthand for epilepsy). Additionally, the forums called my attention to related issues that I had not initially considered germane to the topic, including the frequently misunderstood role of women’s monthly cycles on their seizures, and debates about whether women with epilepsy should adopt children instead of having biological children.

In the next step of interview guide development, I reviewed public or published questionnaires focused on sexual and reproductive health behaviors that have been utilized and tested in focus groups or in-depth interviews and large surveys. From this review, two sources emerged as resources to mine for questionnaire development. I utilized the language of some sexual and pregnancy history questions in the National Survey of Family Growth; this helped ensure the small number of background questions about reproductive

history were clear and comprehensive (179). I then modified some questions utilized in focus groups focused on reproductive decision-making for women with multiple sclerosis (MS) (180), which was most useful for questions included in the reproductive landmarks section of the interview guide.

In the third and final step of development, I piloted the interview guide with two women. One of the pilots was conducted with a woman with multiple pregnancies and one with a woman with no pregnancies. This was critical to test the length of the guide, and to ensure the questions contained within the guide, would be appropriate for women with a range of reproductive experiences. During the interview, I made note of awkward language within questions, or where question appeared repetitive, out of order or unclear. In addition, at the end of each interview, I asked the participants to provide feedback on the questions and length of the survey. Both participants said they were happy with the overall length and content of the interview. However, one participant suggested adding at least one question about relationship status, which I added into the demographic section. I also made note to probe for women's comfort in sexual relationships when this topic emerged during interviews, as the suggestion from the participant seemed to emerge from her discomfort with her sexuality, and her feelings that this was related to her epilepsy.

Eligibility criteria

Women were eligible to participate in the interviews if they met the following four criteria: have a medical diagnosis of epilepsy, are between the ages of 24 and 44, speak fluent English, and reside in the US at the time of the interview. Participants were required to be female as this dissertation is focused on reproductive decision-making, and though men certainly make reproductive decisions, they are different in nature than those made by women. Participants were required to self-disclose a diagnosis of epilepsy; I did not ask participants to provide medical documentation of epilepsy and considered self-disclosure of a diagnosis sufficient. I did not place restrictions on the type of epilepsy or the duration of time an individual had been living with the disorder. The age requirement of 24-44 years of age was selected to include women who were most likely of an age where they were making or had already made reproductive decisions. The lower age range was determined as 24 is the average age women in the US will become pregnant with their first child (181) and the upper age limit boundary was selected to ensure the sample was of reproductive age at the time of interview. Additionally, all participants were required to be fluent English speakers as I do not speak any additional languages, and based on the limited resources available for this dissertation, it was not feasible to hire

translators to conduct interviews in additional languages. Finally, all participants had to reside in the U.S. at the time of interview as part of the focus of this study is cultural perceptions of the reproductive decisions of women with epilepsy in the U.S..

Recruitment procedures

I recruited participants through epilepsy-specific online forums and blogs, community based websites such as Craigslist and Facebook and email list serves targeted at women with epilepsy. I also encouraged study participants to share information about the study with other women with epilepsy they knew, forming a snowball sample. The recruitment strategy was selected to reach a commonly difficult to identify and reach population.

Recruitment materials explicitly stated the inclusion criteria for participating in the in-depth interviews. They also invited all interested women to contact me or my research assistant on a toll free number or via email to learn more about the study and determine if they were eligible to participate. A standardized script was used to determine if women met the eligibility criteria. All women interested in participating were asked to provide their first name (real or pseudonym) and the best phone number to reach them for the interview.

Recruitment was stopped once 30 interviews were completed. I generated a sample size by first estimating the number of interviews required to obtain saturation of themes, based on past experience and a review of other qualitative investigations. I also considered the resources I had available to offer remuneration to participants.

All interviews were conducted over the phone and digitally recorded. After the interview, participants were emailed or mailed (depending on their preference) a \$50 Amazon gift card in return for participation in the in-depth interview.

Informed consent procedures

All women who participated in the in-depth interviews gave verbal informed consent prior to beginning the interview and after I read aloud the informed consent form. The informed consent process covered the purpose of study, potential risks to participants, confidentiality and data security methods, remuneration, reassurance that participants can withdraw at any time, or refuse any questions, and my own contact information as well as the contact information of the Boston University Medical Center Institutional Review Board (BUMC IRB). Participants were provided a copy of the consent form by mail or

email if they requested it. After the participant gave consent to participate in the interview, I asked for consent to record the interview, which all participants granted.

Data analysis procedures

I used the framework analysis methods, described above, to analyze the data from the in-depth interviews. There are some steps in the five steps included in the framework analysis of in-depth interviews that varied slightly from the analysis of online forums. I describe the similarities and variances that occurred during the steps of familiarization, identifying a thematic framework, coding, charting, and mapping and interpretation below (175).

As described above, familiarization involves immersion into the data. As I conducted all of the in-depth interviews, I gained firsthand knowledge of the data. As with the familiarization step of the online forums, I also included other measures outside of data collection to ensure familiarization. First, immediately after completing an in-depth interview, I summarized the key characteristics of the interviewee, as well as salient factors of the interview. Second, I listened to recordings of all in-depth interviews while reviewing their initial transcripts for accuracy. Third, I read through all transcripts of the in-depth interviews at least

once before coding them. Throughout these stages, I also kept a list of emerging ideas and potential themes to explore. I also gained familiarity with the data throughout the remaining analytical steps.

To continue the development of the thematic framework begun in the analysis of online forums, I reviewed the findings from the online forums, and the emerging ideas and potential themes I was tracking during each interview. These ideas were used to revise the codebook initially developed for coding of the online forums. Utilizing the framework and codebook that was developed for analyzing the online forums as a jumping off point for further developing a thematic framework facilitated identifying areas where the online forums and in-depth interviews were similar and where they were divergent. I used this revised codebook to conduct a first round of line-by-line coding of the in-depth interview transcripts. As with the development of the final coding of the online forums, I refine the codebook using an iterative process. As new codes emerged, I reviewed earlier transcripts from the online forums and from in-depth interviews and recoded as necessary.

The final two stages of the framework analysis of in-depth interviews, charting and interpretation, was identical to the steps described above in analyzing the web forums.

Protection of study participants

Though this project posed minimal research-related risks, protection of study participants remains a critical task. All study materials and procedures were approved by the BUMC IRB. IRB approval materials can be found in Appendix B.

All of the conversations I included in the analysis of online forums were posted in public forums, which anyone with internet access could view (though in many forums, only members could post). However, forum participants were not aware that I was utilizing the information they posted for research purposes. I therefore removed from forum transcripts any identifying information provided in the forums, including posters' names, the names of their family members, internet "handles", and other similar information. I have also decided not provide the internet addresses of the specific forums from which I conducted analyses to help protect the identities of forum participants.

Several measures were also taken to protect in-depth interview participant's confidentiality. The only link to participants' first name and contact information was in the electronic field log used to track recruitment and interview progress. The log was kept on a password protected computer, and was destroyed once interviews were completed and all participants were sent

remuneration. Digital recordings of interviews were also kept on a password protected computer, and destroyed after analysis was completed. The final transcripts used for data analysis are devoid of any identifying information, but have also been kept on password protected computers.

The primary risks of participation in this study are for in-depth interviewees, who may have felt uncomfortable or upset during the interview. Some participants may have felt nervous or uncomfortable discussing personal topics about their epilepsy or reproductive health. However, the risks of this were small, as participants self-selected to participate in the study and were aware of the general topics to be covered in the interview. Regardless, to minimize any discomfort experienced by participants, I made it clear during the informed consent and throughout the interview that participants could skip any questions they did not want to answer, or end the interview at any time. I also refrained from voicing judgments of individual's decisions and demonstrated respect for individual's circumstances by using neutral questions and probes during the interview.

CHAPTER 5:

NEEDS ASSESSMENT RESULTS

Introduction

In this chapter, I present integrated results of the online postings and in-depth interviews. Although data collection and initial analysis were carried out in sequence (first the online forums and then the in-depth interviews), in the final analysis the findings were synthesized.

There are several benefits to presenting integrated results of multi-method studies. First, presenting the results together enhances the overall explanatory results of the study (182). Second, it is the most straightforward way to call attention to the overarching findings from the needs assessment, without losing track of the salience of content in the process of going back and forth to compare sources. Third, as noted by Stange and colleagues, combining the results “activates their complementary strengths and helps to overcome their discrete weaknesses” of the methods used (182).

However, there are some drawbacks to presenting results in this way. First, a disaggregated presentation would allow for a more full exploration of differences in findings that emerged from the two different data sources. However, findings from the two sources were highly complementary and material from the online analysis alone was not sufficiently rich to allow for inferences about differences between internet postings and interview responses.

Next, combining the two data sources required considerable parsimony in writing of the results.

For the purposes of this dissertation, the benefits outweigh the drawbacks. Previously published articles have presented integrated results of multi- method studies (183–185), and I have followed this precedent in the presentation of needs assessment results.

After presenting characteristics of study participants, I describe women’s experiences with the diagnosis of epilepsy, the occurrence of seizures and their search for effective epilepsy treatment. I then discuss decision-making related to having children, managing health during pregnancy and utilizing contraception through the lens of The Ottawa Decision Support Framework. Comments from women with epilepsy are presented verbatim, with minor changes in sentence structure to enhance clarity of content, and with notes about source of data.

Participant Characteristics

Online postings

Most conversations included in analysis of online postings were from epilepsy.com, 4% were from epilepsyfoundation.org, and 2% from topix.com (Table 5). Individual conversations continued to have active postings for an

average of 152 days, though there was considerable variance in duration of conversations. There was an average of five posts authored by a mean of four unique users in each conversation. At the time of analysis, conversations were viewed an average of 30 times. This translates to a total of 252 posts within 50 unique conversations that were written by a total of 201 unique persons and viewed a total of 1,415 times.

Table 5. Characteristics of on-line forums.

Online Conversation Characteristics	n (%)
Websites of conversations included in analysis	47 (94)
Epilepsy.com	2 (4)
Epilepsyfoundation.org	1 (2)
Topix.com	
	mean (range; standard deviation) sum
Duration of conversations in days	152 (0-812; 135)
Posts within each conversation	5 (1-18; 6) 252
Unique users posting	4 (1-28; 4) 201
Conversation view	30 (3-129; 27) 1,415

In-Depth interviews

The 30 in-depth interviewees were diverse in their reported length of time living with epilepsy, type of seizures experienced,⁶ epilepsy treatment and

⁶ Because most participants could not identify the exact type of seizures they have been diagnosed with, they were asked to describe whether they had convulsive seizures (meaning their limbs shake and there is a loss of consciousness) or not.

reproductive histories. Participants also represented a broad cross section of the U.S. as they were living in 21 different states at the time of interview (data not shown). Select individual-level characteristics of in-depth interviewees presented below in Table 6.

Experiences with Epilepsy Diagnosis

Many women described being diagnosed with epilepsy as an important event that sparked radical transitions in their identities and life courses. Indeed, women's descriptions of their epilepsy diagnoses revealed that they perceived becoming a person with epilepsy as a process of taking on a new and stigmatizing identity. This new identity appeared to strongly inform what women believe they, as individuals with epilepsy, were capable of accomplishing in life. These themes are explored below as they set the stage for understanding how women with epilepsy understand their abilities to make and implement reproductive-decisions.

Table 6. Select individual-level characteristics of in-depth interviewees.

Pseudo-nym	Age at interview	Age of Diagnosis	Race/ethnicity	Type of seizures	Epilepsy treatment	# of children	Using contraception at interview	Insurance type
Delena	42	15	Non-Hispanic Black	Convulsive	Polytherapy	3	No	Private
Lauren	29	7	Non-Hispanic White	Non-convulsive	None	0	Yes	Private
Jen	28	9	Non-Hispanic Black	Non-convulsive	Monotherapy	0	No	Private
Wendy	35	27	Non-Hispanic multiple races	Both	Monotherapy	1	Yes	Public
Julie	41	1	Non-Hispanic White	Convulsive	Monotherapy	0	No	Private
Megan	44	36	Non-Hispanic Black	Convulsive	Monotherapy	2	Yes	Private
Kelsey	29	2	Non-Hispanic Black	Non-Convulsive	Monotherapy	0	Yes	Private
Danielle	29	20	Non-Hispanic White	Non-Convulsive	Monotherapy	3	Yes	Private
Misty	40	35	Non-Hispanic White	Convulsive	Monotherapy	1	No	Private
Ruth	30	8	Non-Hispanic White	Non-Convulsive	Brain surgery and polytherapy	0	Yes	Public
Denisse	28	17	Non-Hispanic White	Convulsive	Polytherapy	0	No	Public
Anne	34	16	Non-Hispanic White	Convulsive	Monotherapy	0	Yes	Private
Angie	26	22	Non-Hispanic White	Convulsive	Monotherapy	0	Yes	Private
Gretchen	43	18	Non-Hispanic White	Non-Convulsive	Polytherapy	1	No	None
Maggie	38	10	Hispanic White	Non-Convulsive	Monotherapy	1	Yes	Private
Tanya	28	6.5	Non-Hispanic White	Non-Convulsive	Polytherapy	0	No	Private
Tracy	41	2	Non-Hispanic White	Both	Brain surgery and no AED	1	Yes	Private
Suzanne	38	12	Non-Hispanic White	Convulsive	Polytherapy	1	Yes	Private
Britt	26	18	Non-Hispanic White	Convulsive	Monotherapy	1	No	Private
Sarah	32	24	Non-Hispanic White	Both	Monotherapy	2	Yes	Private

Liz	37	32	Non-Hispanic White	Both	Brain surgery and polytherapy	3	Yes	Public
Claudette	27	26.3	Non-Hispanic White	Both	Monotherapy	0	Yes	Private
Courtney	30	17	Non-Hispanic White	Non-Convulsive	Brain surgery and monotherapy	1	Yes	Private
Annie	33	16	Non-Hispanic White	Both	Monotherapy	1	Yes	Public
Tina	26	19	Non-Hispanic White	Non-Convulsive	Monotherapy	0	No	Private
Carolyn	24	14	Non-Hispanic White	Convulsive	Monotherapy	0	Yes	None
Beth	26	25	Non-Hispanic White	Both	Polytherapy	2	Yes	Public
Jessica	30	4	Non-Hispanic White	Convulsive	Brain surgery and monotherapy	0	No	Public
Wen	28	17	Non-Hispanic Asian	Convulsive	None	0	Yes	None
Raquel	29	27	Non-Hispanic White	Non-Convulsive	Brain surgery and monotherapy	1	Yes	Private

Taking on a stigmatized identity

Many women reported having little prior knowledge of or experience with epilepsy, and did not know what was happening to them when they first had seizures. This led to some women hiding their seizures prior to diagnosis because they feared that they were actually experiencing mental health issues. For example, 32-year-old Sarah who began having both convulsive and non-convulsive seizures at age 14 spent more than a decade hiding her seizures. She explained:

I honestly don't know why I never told anybody. I think I was kind of embarrassed. [...] I really thought it was a mental thing. [...] I didn't want to find out I had some sort of weird anxiety disorder or something, and have that come out and [have people] think I'm like a crazy lady [In-depth interviewee].

On a similar note, three participants who experienced seizures as children reported that their parents or caretakers hid their children's seizures from others because they presumed that the child's descriptions of seizures were signs of mental instability or demonic possession.

The ultimate diagnosis of epilepsy did not allay women's fears about their seizures. In fact, the initial diagnosis of epilepsy was overwhelmingly described as a negative experience. Women used words like "traumatic," "awful," "dooming," "a time bomb," "scary," and "a shock" to describe their diagnoses

experiences. Women reported it was difficult to be diagnosed as “epileptic” because they understood epilepsy to be a disorder of abnormality and one that indicates considerable mental deficiencies. For example, Danielle, who was diagnosed with non-convulsive seizures at age 20, described her initial reaction to her diagnosis this way:

You think of the word epilepsy and you think of [...] somebody who’s not all that bright or [...] not always in control of themselves or their futures. So, it was really horrible to hear that. [...] The word ‘epilepsy’ has a lot of negative stigma attached to it [In-depth interviewee].

Living with Epilepsy

Diagnosis only marked the beginning of understanding what it like to live with epilepsy. Living with epilepsy, women reported, meant adapting to seizure occurrence and to the effect of seizure occurrence on HRQOL. It also meant navigating challenges in access to an acceptable and effective epilepsy treatment plan. It is critical to understand how women viewed living with epilepsy, because, as shown later, the day-by-day experience of living with a seizure disorder influences how women approached reproductive decisions that can affect seizure occurrence or treatment.

Inside a seizure

Women reported experiencing changes in their physical, mental, emotional, or spiritual sense of being during a seizure.

Women commonly reported they experienced a variety of physical changes during a seizure including drooling, twitching, lip smacking, vomiting, jerking of limbs, loss of bladder control, rapid changes in body temperature and headache. For example, Angie described the changes she experiences during her convulsive seizures as follows:

I kinda stare off into space a little bit and I become unresponsive. [...] I'll just like stare at the wall and then I just start shaking. Apparently, it's like pretty violent. [...] I guess I kinda foam at the mouth for a minute or so [In-depth interviewee].

The large number of women who experienced changes in their consciousness during a seizure reported feeling that their mental activity ceased or was altered. Having a seizure was hence characterized as a brief state of "going blank," "blacking out" or feeling as though one is "walking around in a dream state."

Women who experienced changes in their emotional or mood state during a seizure described a range of sudden, but temporary changes in their feelings, including disorientation, confusion, déjà vu, anger, extreme irritability and fear.

For example, Tracy reported that when she had convulsive or non-convulsive seizures as a child, she felt very frightened and believed that a monster was following her. As an adult, Tracy reported she continues to feel fear during a seizure, though she perceives it differently, and instead of being afraid of monsters, she fears she is “being followed [...] in the city, walking down a dark alley [In-depth interviewee].”

Changes in spiritual state of being were the least commonly reported. Women’s descriptions of the spiritual changes they experienced were often (perhaps by their nature) amorphous and ranged widely from positive to negative experiences. For example, one woman said that during a seizure:

It feels as though my "soul is missing" and that it has left my body and is somewhere out in the world. Often it takes a week or two for it to reintegrate and "come home" again [Online-forum user].

Seizures and HRQOL

A number of clinical factors, described below, colored women’s perceptions of the extent to which seizures had an impact on their quality of life.

Type of seizure

First, the type of seizure and the symptoms experienced during a seizure

appeared to be the strongest predictor of impact on women's self-described HRQOL. Across the board, women posited that people with convulsive seizures have the most severe form of epilepsy because their seizures most significantly detract from quality of life. On the other hand, women with only minor changes limited to one domain (either physical, mental, emotional or spiritual) said they perceive that their seizures have relatively little impact on their quality of life. For example, Ruth who experiences only minor changes in her physical state and none in her mental state described her non-convulsive seizures as follows:

I'm completely aware of everything. I can drive, I can walk, I can talk, I can work [In-depth interviewee].

Time: Duration of seizure and subsequent recovery period

Another factor that appears to have a significant impact on how seizures influence women's HRQOL is the overall amount of time spent having or recovering from seizures. Three factors contribute to what I have termed "life-time seizure time." First, as the length of time during a seizure extends, seizures becomes increasingly disruptive to women's lives. Next, as seizures occur more frequently, they become increasingly burdensome. Third, as recovery time post-seizure increases, more time is taken away from life activities. Of note, recovery-time post seizures includes both the time it takes to return to a non-seizure state

and the time it takes to recover from injuries that occur during seizures.

Recovery time post-seizure was a particular issue for women with convulsive seizures as it was exclusively during these types of seizures that women reported experiencing seizure-related injuries such as jaw or shoulder dislocation, scrapes and bruising from falling, injuries related to crashing a car or injuries related to being attacked while in an unconscious state. Recovery time from convulsive seizures was also extended due to seizure-related muscle soreness and trauma to the tongue which women said made eating and talking painful for “days.”

Predictability of seizures

A third factor that contributed to women’s perceptions of how seizures affect their quality of life is the predictability of seizure occurrence. This theme emerged exclusively in the in-depth interviews, as online-forum users did not commonly write in detail about their experiences with auras. Interviewees commonly said that auras occurred only seconds before a seizure, though a minority of women reported the length of time between aura and seizure was unpredictable and could be hours. Regardless, interviewees reported that having any warning of an on-oncoming seizure decreased negative seizure outcomes. In these circumstances, women were able to implement strategies to

prevent injury to themselves and to those around them (e.g. not going to work, not driving, having someone sit with them). Those who did not have aura reported feeling that the most disabling part of having epilepsy was lack of a warning signal, and not the seizures themselves. Angie who has convulsive seizures with no aura said of epilepsy:

It's disabling in the sense that I don't know when they're [seizures] coming on. If I was lucky enough to have an aura [...] I would feel a lot more comfortable having it [epilepsy] [In-depth interviewee].

Challenges accessing acceptable and effective epilepsy treatment

Many women expressed surprise and frustration that it was difficult to find an effective epilepsy treatment with few side effects. Women reported navigating the following challenges when obtaining treatment: 1) identifying an effective AED with few side effects; 2) finding an acceptable neurologist; and 3) affording the high cost of healthcare visits and medications.

Identifying an effective AED with few side effects

Many women expressed considerable difficulties identifying an effective treatment regimen that had few side effects. Women commonly reported experiencing a range of undesired side effects from AED treatments including exhaustion, weight gain, trouble concentrating, difficulty with memory, feeling

as if one is in a fog, dizziness, double vision and changes in mood. Less commonly reported side effects from AEDS included hallucinations, depression and suicidal thoughts. A common refrain amongst women who continued to experience these side effects was that the “side effects [of AEDs] were worse than the seizures.” Lauren, who has infrequent non-convulsive seizures and no longer uses an epilepsy therapy expressed this idea when she said:

The medication has affected my life more than the epilepsy has affected it [In-depth interviewee].

The few women who obtained seizure control and experienced few side effects from their epilepsy therapy described the experience as “magical” or a “miracle.”

Finding a neurologist

A second challenge that women reported experiencing was finding a neurologist they felt they could trust and whom valued women’s input into their epilepsy treatment.

Negative experiences with neurologists first emerged for some women early in their epilepsy diagnoses experiences. A number of women reported struggling through several misdiagnoses of mental health issues, diabetes, headaches, migraines, allergies to cough medications and encephalitis. These

women often expressed ongoing feelings of mistrust of health care providers and described adversarial relationships with their health care providers in which they carefully measured how much of their lives and health care needs to disclose to various doctors.

Regardless of experience with diagnosis, some women reported that treatment plans were not well explained or discussed and that their neurologists had limited patience or availability to discuss women's health concerns. In response to what these women perceived as neurologists' paternalistic attitudes, they either switched to a new neurologist when one was available, or took their health care in their own hands. For example, Lauren describes how she took herself off AEDs without discussing her treatment plan with her neurologist:

I was just really unhappy with my doctor at the time, and I felt like she wasn't listening to me, and she kept cancelling appointments on me. And so, after she cancelled it for, like, the third time I was like, "You know what? I'm gonna wean myself off of this [AEDs] and see what happens [In-depth Interviewee]."

Of note, these negative experiences were not universal. An equal number of women reported finding a neurologist who was open and committed to discussing and negotiating their epilepsy treatment plan, and always had ample time to discuss emergent treatment issues, thus highlighting the diversity of care women experience. For example, Delena said in praise of her neurologist:

He tries to make me feel at ease, you know. [...] He's just there *for* me. [...] And, he's not like my other neurologist that didn't tell me about certain things that are happening to me. They would order the test, but they wouldn't tell me what was going on. [...]. And he's just been a blessing [In-depth interviewee].

Cost of care

Finally, a sizeable number of women, both those with and without insurance, reported difficulties paying for health care visits and/or AED prescriptions. Some insured interviewees reported that specific AEDs were not covered and/or that their co-pays or deductibles made health care so unaffordable they felt they might as well not have insurance. For example, Kelsey who has private insurance said:

If I have to go to the doctor or anything, I still have to pay the *full* cost for my doctor's visit. [...] I try my best not to have to go to the doctor 'cause I still have to pay the whole doctor bill. They don't really cover my medicine. My medicine is like \$55 [In-depth interviewee].

Women who were either uninsured at the time of interview, or had experienced gaps in their insurance coverage in the past, described considerable difficulties paying out-of-pocket for their medications. These women said they stopped taking AEDs or tried to take smaller or fewer doses of AEDs in order to make filled prescriptions last longer; cost-saving strategies that women said led to increased seizures.

Reproductive Decision-Making

Results reveal that women with epilepsy, like all women, consider a range of issues when making reproductive decisions. Though a number of factors outside of women's experiences with epilepsy contribute to their reproductive decisions, experiences with epilepsy and its treatment emerge as central considerations in women's decisions regarding having children, managing health during pregnancy and utilizing contraception. Three interrelated epilepsy-specific issues influence women's abilities to make informed decisions about these issues: 1) the information women have about their reproductive options; 2) the balancing of values regarding preferred reproductive outcomes and seizure control; and 3) the availability of resources to implement decisions. Further, as described in the close of this chapter, challenges accessing medical information or resources needed to implement preferred decisions impede informed decision-making, and have the potential to alter the life course of women with epilepsy and produce harmful neurological and reproductive health outcomes.

Knowledge and information about reproductive decisions

Women reported consulting a range of sources to gain knowledge about

their reproductive options including the internet, TV talk shows, radio programs and educational pamphlets. However, three sources of information rose to the top and were primary in informing women's reproductive decisions: women's own experiences, health care providers and other women with epilepsy. Below, I focus first on women's experiences obtaining information from these sources about the risks related to pregnancy and what it is like to be a parent as a woman with epilepsy, two issues that affected women's decision-making about becoming parents and managing health during pregnancy.⁷ I then turn to women's experiences obtaining information about contraception.

Knowledge and information about pregnancy and parenting

Decision-making informed by women's own experiences:

One source of women's understanding of parenting and pregnancy issues for women with epilepsy was their own experiences. Half of in-depth interviewees had children at the time of interview. Twelve interviewees reported 14 post-epilepsy diagnosis pregnancies, and two of the interviewees

⁷ On some occasions, information about parenting and pregnancy is so intertwined that it cannot be considered separately, whereas on other occasions these are very distinct issues. Therefore, I have called attention in the text when information about pregnancy is being described distinctly from information about parenthood.

had two children before they were diagnosed with epilepsy. Many online forums users posted that they had children after their epilepsy diagnoses as well. Below, I focus first on women's experiences with pregnancy and then parenthood.

Women almost universally reported accurately the maternal and fetal risks related to pregnancy for women with epilepsy. Despite most women being aware that the majority of women with epilepsy have safe and normal pregnancies with healthy pregnancy outcomes, pregnancy was frequently described as a risky and anxious experience. In addition to the common worries that women often have about health during pregnancy, women with epilepsy reported worrying throughout their pregnancies about the impact on the fetus of seizure occurrence, AED use and the potential for genetic transmission of maternal epilepsy.

Women also commonly correctly expressed that seizures had the potential to increase, decrease or not change at all during pregnancy. They primarily expressed concerns about how their seizures would affect the fetus, and only rarely voiced worries about how they would be affected by seizure occurrence. One online-forum user posted:

I am now three months pregnant going on my fourth month. [...] I've had two seizures and I am scared to have more, not for me but for the health of my baby [Online-forum user].

All women correctly reported that AED use during pregnancy could increase their risk of congenital malformations. Moreover, almost all women reported accurately that they understood that the risk of experiencing adverse pregnancy outcomes due to AED use was quite low. Women also commonly reported knowledge of the types of congenital malformations associated with AED use, at least cursory familiarity with potential malformations and knowledge of the fact that some of the congenital malformations associated with AED use could be tested for in time to abort an affected fetus if abortion services were locally available and of interest to them.

A sizeable minority of women, most of whom had difficult epilepsy experiences, expressed belief and concern about maternal epilepsy passing genetically to their offspring. For example, Maggie, who has had one child, explained in this way:

Even though I try not to let the epilepsy like, rule my life [...] [I] worried about if my child would have it or not have it. You know? I think, I had all the normal fears of being a first time mom, being pregnant, plus being an epileptic [In-depth interview].

The two interviewees and several online-forum users who experienced

repeat pregnancies after their epilepsy diagnoses reported perceiving their risks related to pregnancy as lower during subsequent pregnancies as compared to their first pregnancies, a perception commonly shared with women who do not have epilepsy. Initial positive experiences with pregnancy appear to reduce the specific perception of pregnancy as a risky venture for women with epilepsy. Sarah for example, who has had two children, both post-diagnosis, explained why she perceived the risks of adverse pregnancy outcomes as lower during her second pregnancy:

I'm sure any woman would tell you that second, third and fourth pregnancies, you're not nearly as neurotic about it. You're just like, "Ok, I know what to expect [In-depth interviewee]."

Women commonly reported that managing a chronic and sometimes unpredictable disorder made parenting challenging, and that "having seizures while parenting" reduced confidence in their capacities to be "good" mothers. Women worried that seizures scared their children or put undue responsibility on them to take care of their mothers. For example, Liz, who has both convulsive and non-convulsive seizures and has three children, sadly recounted:

My youngest son, he is only 10. I know that it's been really rather upsetting to him because they [the seizures] started when he was only five. And, when they first started, we didn't know quite everything, and so he would call 911 a lot. And he panicked. And I know that it upsets them [In-depth interviewee].

Women also said that their seizures prevented them from performing what they perceived as basic childrearing duties. This concern emerged in a number of ways. First, many women related that during a seizure they were “not there” for their children; the younger the child, the greater women’s concerns about being mentally or physically unavailable, no matter how brief the seizure. One online-forum user recommended to another:

Motherhood is more than pregnancy, and you have to think about how well your seizures are controlled and how that affects your ability to be with your child [Online-forum user].

Public seizures typically invited more concern than private ones as women worried about what would happen if they were unable to protect their children in public during a seizure. Also, in some cases, having seizures prevented women from being able to drive, either because their occurrence led to a woman losing her license or contributed to her fear of driving with her child in the car. Some women, primarily those living in rural areas, perceived their inability to drive as limiting and having a strong effect on their childrearing capabilities. Finally, a specific time when women reported parenting was difficult for them was when women tried to take care of infants who were up crying at night. For example, one online-forum user posted:

My first son didn't sleep through the night for 11 months. That's a long

time to be sleep-deprived, especially if the lack of sleep brought on seizures while there was a baby in your arms [Online-forum user].

Women commonly said that nighttime childrearing demands caused them to stay up all night to care for an infant, which led to a seizure the next day, which exhausted women more and prevented them from taking care of their child the following night.

Health care providers as sources of pregnancy and parenting information:

Health care providers, and in particular neurologists and obstetrician/gynecologists, emerged as the primary source where women with epilepsy hear both informative and affirmative messages about pregnancy and parenthood for women with epilepsy. Almost all in-depth interviewees and many online-forum users reported that they have obtained information about the possibility of parenthood and strategies for managing their epilepsy during pregnancy with their neurologist. Additionally, many online forums users and all in-depth interviewees with experiences with pregnancy described positive experiences obtaining information from obstetrician/gynecologists. However, a minority of interviewees and online-forum users reported challenges obtaining this information.

The information women reported receiving from their neurologists about

pregnancy and parenthood was largely a reflection of current and relevant clinical guidelines. Indeed, women reported being advised by neurologists about the need to plan pregnancies, the high possibility of a healthy and uneventful pregnancy, the need to identify the appropriate AED and AED dosage for pregnancy, folic acid and vitamin K supplementation, the importance of maintaining AED use and seizure control during pregnancy, procedures for measuring AED levels throughout pregnancy and procedures for testing for congenital malformations. Describing what her doctor told her about the risks of congenital malformations, Anne stated:

He had told me that the Depakote caused Spina Bifida, or showed a kinda increase. And the percentages, you know, were like 2 or 3% higher than the average population. So it wasn't like you were guaranteed to have a baby with problems, but it just was a slightly higher than average. And it was a condition that was testable [In-depth interviewee].

However, much of the information provided by neurologists that women reported as critical to decisions they made about becoming parents or managing health during pregnancy was not strictly clinical in nature. Indeed, women reported receiving information that comforted and reassured them about their reproductive potential. Annie, for example, described how her neurologist inspired hope in her by negating her previous misconception that women with epilepsy cannot have children:

Children [...] I kinda thought that I couldn't and then, he [the neurologist] told me, "No, we'll talk about it and we may switch your drug. [...]. But it's certainly not something that you can't do [In-depth interviewee]."

Reflecting on the conversation, Annie said,

I was like happy. [...] I thought I couldn't have kids. So the fact that he was kinda saying, "No [...] we just have to talk about how you go about it" was a hopeful thing [In-depth interviewee].

Women said they welcomed receiving this information and assurance long before they were actively considering having children. Many recalled receiving some basic information from a neurologist during adolescence. Tanya related that when she was 15, she read information online that indicated that women with epilepsy could not have children. She went on to say:

I got really upset. And my mom, she brings me to the neurologist and she says, "Will you talk to her? She's really upset." [...] And the neurologist *did* sit down and told me, "That's, garbage. [...] You can have babies. [...] Absolutely you can have babies." [...] He was very supportive of that [saying], "You can have children. Yes, you can [In-depth interviewee]."

Once women became pregnant, the neurologist remained a critical figure for providing accurate clinical information and for making women feel comfortable with decisions made about medication use during pregnancy. Other health care providers, and in particular obstetrician/gynecologists, were also central to women's experiences managing their health during pregnancy. All

interviewees and many online-forum users reported working with both a neurologist and an obstetrician/gynecologist when pregnant. However, women often depicted obstetrician/gynecologists as secondary resources for clinical information and assurance.

Though the women who posted or were interviewed were largely satisfied with the information about parenting and pregnancy they received from their neurologists and their obstetrician/gynecologists, they also encountered some challenges securing accurate and supportive information about these issues.

First, a vocal minority of online-forum users and in-depth interviewees reported being given information by their neurologists that either overtly or subtly suggested that women with epilepsy should not have children. A number of online-forum users and five in-depth interviewees reported their neurologist purposefully exaggerated the risks of AED use or seizures during pregnancy, directly stated that women with epilepsy should not have children, encouraged women to have an abortion once a pregnancy was underway or over-emphasized long acting or permanent methods of contraception. Beth, for example, related that two different neurologists told her that having epilepsy meant she should not have children. She angrily related:

The second one [neurologist] said, “You really shouldn’t have done this. You shouldn’t have gotten pregnant. You should have been more careful.” And the current one [the neurologist I] have now said, “You really need to consider not having any more children.” He said, “Your reproductive organs work okay, but your neurological stuff is going to cause problems [In-depth interviewee].”

Second, a small number of women fell into gaps in the health care system where neither a neurologist nor an obstetrician/gynecologist discussed pregnancy or parenting with them. Lacking appropriate information, these women made parenting decisions based on conjecture, which led them to presume they should not have children and use of permanent methods of contraception when that was not their personal preference.. Wendy, for example, related that she wished a health care provider had discussed parenting and pregnancy with her:

My husband and I came to the conclusion that we would not have any more children based on our own fear, I guess. I do wish that one of the doctors would have sat me down and said, “You know, listen, since you are of this age and you don’t have any children together if you consider it” and maybe explain the different options. But, it was never discussed [In-depth interviewee].

Additionally, the husband of 29-year-old Kelsey had a vasectomy shortly after Kelsey’s diagnosis believing that Kelsey could not safely have children. Kelsey explained,

I just assumed that *any* medications during pregnancy [...] are harmful.

Now I'm getting just a vibe from our conversation that maybe we were wrong [In-depth interviewee].

When asked, interviewees speculated the reason no health care provider had ever discussed pregnancy or parenthood with them was because of a lack of clarity about which health care provider is responsible for doing so and because neurologists, often women's primary health care provider, were uncomfortable talking about such issues. Claudette summed this up in her description of her neurologist:

It doesn't seem like they like to talk about that very much. I think maybe they assume that's more of an ob/gyn's job. I've asked before. They kinda seem unsure of the answer or uncomfortable, probably, trying to answer that question. [...] And it's a very major thing in someone's life and they just can't answer that question. So they kinda either get real quiet or they just push it off onto, you know, other doctors. [...] It's very strange. It's almost like a gray area. So the neurologist expects the ob/gyn to talk about it, but the ob/gyn kind of expected that the neurologist was supposed to be talking about it. So neither one of them says anything 'cause they just assume the other said something. [...] And then it ends up falling in this gray area where nobody even brings it up, 'cause they think the other party should be the one to talk about it.

Other women touched on similar issues, expressing that they found it difficult generally to obtain accurate and comprehensive reproductive health care information because few neurologists seem well informed about reproductive issues, and few obstetrician/gynecologists seem well informed about

neurological issues.

Third, some women reported feeling that they did not receive the right amount of information about pregnancy and parenthood at the right time in their lives. This concern emerged exclusively among women who were preparing to make parenthood decisions in the very near future. These women looked back on the basic information they had previously received about parenting and pregnancy and they were dissatisfied with as they reported feeling they had only enough information to feel overwhelmed and discouraged from considering parenthood. However, this state of dissatisfaction and frustration may be temporary as most women, as described above, felt that once they engaged with their health care providers about pregnancy and parenthood, they received adequate and supportive information.

A fourth, and commonly related challenge that emerged only during pregnancy, is the difficulty of integrating and using information from two or more different health care providers to make one health care decision. Specifically, women reported that during pregnancy it was difficult for them to receive different information from the neurologist and the obstetrician/gynecologists and then to determine the best course of action based on the conflicting information. For a minority of women this concern emerged

when they received conflicting information about minor issues including the proper dosage of folic acid or the administration of Vitamin K. These discrepancies led women to question the accuracy of the larger body of information they were receiving from their health care providers about pregnancy care for women with epilepsy.

Finally, many women expressed that they were disappointed that the information they received about pregnancy was entirely clinically focused. Instead, they wanted to ground discussions about pregnancy in women's daily lives and emotional needs. Danielle, who has had three children, expressed this when talking about the care she received from her obstetrician/gynecologists. She said:

I think he could have [...] talked more about the experience of being pregnant and about having another child come into the world and whatever, rather than just, you know, get the heart beats per minute, and the weight. 'Cause I think there's a lot more to pregnancy than that [In-depth interviewee].

Of note, this is in stark contrast to women feeling that prior to pregnancy both neurologists and obstetrician/gynecologists were adept at providing clinical information in a supportive way. This finding suggests that when women are planning or considering pregnancy, their health care providers are well prepared to give information that engages with the broader context of women's lives, but

once women become pregnant, health care providers focus too narrowly on providing information about pregnancy-related clinical issues, likely in attempts to ensure optimum maternal and fetal outcomes.

Other women with epilepsy as sources of pregnancy and parenting information:

Women commonly consulted other women with epilepsy about parenting and pregnancy issues, and reported universally positive experiences utilizing two different peer networks to obtain information: online and in-person support groups.

Online-forum users and interviewees described receiving information about parenting and pregnancy from other women with epilepsy that reflected current clinical information. Repeatedly, women who utilized in-person or online support groups related the importance of hearing this information from other women with epilepsy. For example, Claudette described how she felt after she found an online support group targeted at women with epilepsy who have children:

I think leaning on your peers and other people who have the condition is *so* helpful and *so* refreshing. Otherwise, you're just talking to people who have no idea what you go through every day, or the decisions you have to make [In-depth interviewee].

Interestingly, a small number of women spontaneously expressed not believing the information they received from their health care provider until it was confirmed by other women with epilepsy. Jessica, for example, has convulsive seizures with a catamenial pattern and has never been pregnant. Her neurologist told her she was capable of getting pregnant, but she had doubts about his advice until she heard from other women with epilepsy online who had the same type of seizures and could become pregnant. She explained:

I've joined a mothers with epilepsy support group. [...] When I talked to mothers with epilepsy, many people there were catamenial too. So evidently, people with it [catamenial seizures] still can get pregnant [In-depth interview].

Knowledge and information about contraception

Many women suspected that there is an interaction between hormonal contraceptives and AEDs. However, most women said they had no information about these interactions prior to initiating contraception and that they learned about these interactions almost entirely through their own experiences.

Women's experiences as contraceptive knowledge sources:

In relation to seizure control, women reported the gamut of experiences when taking hormonal contraceptives and AEDs simultaneously; some

experienced no change in seizure activity, some had a decrease in seizure activity and some had an increase in seizure activity. Some reported experiencing reductions in seizure occurrence when using the contraceptive shot, ring and pills, and after undergoing hysterectomy, a finding that is only somewhat consistent with current clinical understanding of the influence of contraceptive and AED interactions. Reports of decreases in seizure occurrence associated with the initiation of hormonal contraception or after a hysterectomy were limited to women experiencing a catamenial seizure pattern. On the other hand, an equal number of women with a wide variety of seizure patterns reported experiencing an increase in seizure occurrence after initiating hormonal contraceptives. Some women experienced increases in seizure occurrence when they used the contraceptive shot, patch, ring or pills, again, a finding only somewhat consistent with current clinical literature.

Experiences with reductions to contraceptive efficacy due to concurrent AED and contraception use only emerged in a small number of interviews, and not in online forums. Indeed, one interviewee reported experiencing breakthrough bleeding and two women reported having unplanned pregnancies that they believed were caused by concurrent use of hormonal contraceptives and AEDs. Courtney shared her experience getting pregnant while on the oral

contraceptive pill:

My seizure medication affected the birth control pill. It reduced the effect of it; made it less effective. So, I tried several different birth control pills trying to find one that, you know, would agree, would work, and really agree with me. [...] I got pregnant [In-depth interviewee].

Courtney ultimately miscarried that pregnancy. Suzanne also said she experienced unplanned pregnancy while using contraception—twice. She said of her first unplanned pregnancy, which she continued to term:

I did eventually get pregnant and it was 'cause I was on the pill. [...] You're eventually gonna get pregnant if you have epilepsy, you're on anti-convulsants, and your birth control is the pill. The combination of the two did not work in my favor [In-depth interviewee].

Of her second unplanned pregnancy, Suzanne sadly related:

We had decided *finally* that we weren't going to have any more children. [...] I was on the pill and, same regimen of meds and, you know, similar break though. And in that case, - the baby had neural tube defects. He had hydrocephalus [In-depth interviewee].

Suzanne and her husband terminated the pregnancy shortly after the hydrocephalus diagnosis.

Health care providers as inadequate sources of contraceptive information:

Few women reported receiving information about contraception from their neurologists. Though many women said they discussed contraception with

their obstetrician/gynecologists, few reported their epilepsy and treatment regimen was part of contraceptive discussions, meaning women were not receiving information that addressed their specific health care needs.

Several issues help explain the lack of contraceptive information delivery. First, a number of women reported that both they and their health care providers are unclear who should offer contraceptive information to women with epilepsy. Indeed, women reported that when they raised contraceptive questions with either a neurologist or an obstetrician/gynecologist, they were often referred to the other specialist, leaving the woman with no contraceptive information. Second, women expressed reluctance to initiate contraceptive discussions with neurologists either because they assumed a neurologist would not be able to offer contraceptive information or, more commonly, because women did not feel comfortable talking with their frequently male neurologists about issues related to sex and reproduction. At the same time, women often reported they did not discuss their epilepsy with obstetrician/gynecologists. The reasons they provided for not doing so included: 1) obstetrician/gynecologists did not proactively ask in-depth questions about epilepsy; 2) women assumed obstetrician/gynecologists were not knowledgeable about their neurological needs; 3) women feared they would be stigmatized for having epilepsy; and 4) women were fatigued by

sharing their medical history with health care providers, and did not want to repeat the experience.

Women who did obtain contraceptive information from either a neurologist or an obstetrician/gynecologist were not much better off than those who did. They reported several reasons that they were dissatisfied with the contraceptive information received from these providers. First, women reported feeling that the information about contraception they received from the neurologist was limited to the need to be on a contraceptive in order to plan pregnancy. Women said they desired less information about pregnancy planning and more clear and direct information about what contraceptive options were appropriate and safe for them to pursue.

Second, women commonly reported receiving little or no information from neurologists about potential changes in seizure activity related to concurrent use of hormonal contraceptives and AEDs. Moreover, women reported that when they pro-actively sought out this information after experiencing changes in their seizure patterns, their questions and concerns were dismissed. One online-forum user posted about her neurologist's disbelief that oral contraceptives could increase seizure occurrence. She wrote:

What I am frustrated with is the fact that my Neurologist does not acknowledge any correlation between taking Yaz and my seizures [Online-forum user].

Third, as alluded to above, a small number of women reported neurologists gave them what they perceived of as inappropriate contraceptive information, and advised them to pursue sterilization when the woman was interested in reversible contraceptives. Beth, for example, had difficulty finding a contraceptive that she was comfortable with, and asked her neurologist for his contraceptive advice. She explained what happened:

He told me I need to get my tubes tied. I was 25 years old. And you're telling me after one baby I should get my tubes tied? He said because there was nothing I could use that would prevent pregnancy [In-depth interviewee].

Fourth, a number of women reported consulting both their neurologist and their obstetrician/gynecologists about contraception, only to receive conflicting and inadequate contraceptive information. Annie explained that her obstetrician/gynecologists told her she could use any contraceptive with her AED. After experiencing an increase in seizures when she began using oral contraceptives, Annie consulted with her neurologist. Her neurologist told her the contraceptive prescribed to her by her obstetrician/gynecologist should not be used with her AED, but the neurologist offered her no other contraceptive

choices. Annie was disappointed with both her neurologist and her obstetrician/gynecologist. She explained:

It led me to believe that it seems that OBs don't really know a lot about seizures. And I don't know if OBs need to learn more about seizures to give women a better selection and better information or if, maybe neurologists need to know more about birth control. But somebody needs to know something more. [...] It was kind of frustrating, because it was like they both knew a little, but nobody knew enough to tell me exactly what was the right thing to do [In-depth interviewee].

Lacking contraceptive information from health care providers had two primary impacts on women. First, it caused some women to mistrust their health care providers, particularly when women who had seizure control in the past and experienced an increase in seizures as a result of a newly prescribed contraceptive. Second, many women said they took their contraceptive care into their own hands and made contraceptive choices based on their own experiences, and not on the advice of a health care provider. Women who found contraceptives reduced their seizure occurrence initiated contraception with gynecologists without disclosing their epilepsy, and without advice from their neurologists. One online-forum user posted the following about her independent decision to treat her catamenial seizures with birth control:

My neurologists have disregarded this aspect of my seizures (who knows, maybe this is why I'm still not seizure-free). [...] In my case, getting off of the pill after being on it for about 26 yrs it what triggered it [seizure

occurrence]! [...] I personally decided that it was best to go on the pill, and without advising the doctors, got a new Rx from obstetrician/gynecologists [Online-forum user].

On the other hand, women who believed a contraceptive disrupted their seizure control commonly discontinued their contraception without advice from any health care provider. A post from one online-forum user whose OCP use increased her seizure occurrence illuminates this common reaction. She wrote:

I quit taking it [OCPs] yesterday. I just made an executive decision to do so since I'm not getting any guidance from my doctors [Online-forum user].

Other women as sources of contraceptive information:

As with pregnancy and parenting information, other women with epilepsy were important sources of contraceptive information. In fact, many women said that after being disappointed by contraceptive discussions with their health care providers, they turned to online forums and in-person support groups. The online forums focused on contraception were filled with dialogues between women who were reassuring one another of the validity of their experiences with contraception and seizure occurrence. In these discussions, many women posted feeling relief that they were not alone in their experiences and seemed to feel emboldened to advocate for more appropriate contraceptive

care.

Values about reproductive decisions

Women reported weighing a number of different values when making reproductive decisions. However, their reports revealed that three values are central to different aspects of their reproductive decision-making: reproductive desires, preferences for certain levels of seizure control or for specific reproductive outcomes and preferences regarding prenatal screening. While it can be expected that aspects of the first and third value are shared with women who do not have epilepsy, there are specific issues related to epilepsy that affect each of these values.

Value 1: Reproductive desire

Most women said that at different points in their lives they had undertaken a personal evaluation of whether or not they desired children. For most women, the evaluation of childbearing desires appeared to occur at a subconscious, rather than an overt, level, and was only somewhat related to women's experiences of living with epilepsy (as detailed in the next section). Indeed, many women said they could not explain why they had the preference

they did. Women who desired children frequently referred to it as a “desire,” “yearning,” “longing” or “urge.” For example, Lauren related,

I’ve always wanted to have kids so I’ve always kinda known that was something I was gonna do whether or not I had epilepsy or whether or not I was on medications [In-depth interviewee].

Women who did not want to have children alternatively described simply a lack of such desires for children. For example, Julie stated,

I’ve just never, ever had any interest in having children. [...] It’s just I’ve never had an urge to have children [In-depth interviewee].

Finally, women who were not sure if they wanted to have children in the future simply expressed that they were undecided about the issue. Diagnosis of epilepsy did not appear to prompt re-examination of reproductive desires, or make those desires more clear, though in some cases it did alter reproductive plans, as explored next.

Value 2: Balancing preferred neurological and reproductive outcomes

Many women said they approached their reproductive decisions by explicitly asking themselves if contraceptive use, pregnancy or parenthood were the worth the risks they associated with each option. The perceived risks that women reported weighing, often against one another, were those of the loss of

seizure control, unplanned pregnancy and adverse pregnancy outcomes.⁸ In women's descriptions of balancing these risks with their reproductive desires, a typology that is described below emerged. A summary of this typology can be seen below in Table 7.

Group A:

Women commonly fell into Group A. These women explicitly placed the highest value on seizure control and perceived any chance of loss of seizure control as a matter "of life and death." Hence, they were reluctant to make any decision that had the potential to increase seizure occurrence, which had significant impact on their reproductive decisions.

Women in Group A selected contraceptives by evaluating their potential impact on seizure control. They chose contraceptives methods that they perceived would either increase seizure control or have no effect on their medications or seizures. One online poster wrote about her decision to use the contraceptive ring, despite not being sexually active:

⁸ "Adverse pregnancy outcomes" refer to women's concerns about congenital malformations associated with AED use and their concerns about passing epilepsy onto offspring. My use of "adverse" is not meant to imply that these outcomes are necessarily negative, but to underscore that women perceive them as undesired.

I was on the Nuvaring [...] and it was the only thing that stopped my sz [seizures] and it was instantaneous [Online-forum user].

Trying to find a hormonal contraceptive that improved seizure control meant that some women tried a number of methods before finding one that worked for them. However, most women in this group reported they were reluctant to “rock the boat” by initiating a hormonal contraceptive. Denisse reported that she had recently taken herself off OCPs. She said,

Table 7. Typology of values in reproductive decision-making.

Group	Reproductive desire	Perception of risk of adverse reproductive outcomes	Perception of risk of increased seizure occurrence	Effect on reproductive and epilepsy-care decisions
A	Low	Irrelevant	High	<ul style="list-style-type: none"> • Often reluctant to use hormonal contraceptives • When hormonal methods are used, prioritize finding one that improves seizure control • Prone to use of permanent methods of contraception • Reluctant to have biological children or become parents • Reluctant to change effective AED treatment to optimize reproductive outcomes • Display no decisional conflict about reproductive decisions • Display high anxiety about seizure occurrence

B	High	Low	High	<ul style="list-style-type: none"> • Tend to use temporary non-hormonal contraceptives • Often delay childbearing until seizures are under control • Tend to feel confident about the decision to stay on AEDs throughout pregnancy • Highly motivated to maintain seizure control during pregnancy and post-partum • Display little decisional conflict about reproductive decisions • Display high anxiety about seizure occurrence
C	Ambiguous	High	High	<ul style="list-style-type: none"> • Often reluctant to use hormonal contraceptives • Prone to use of permanent methods of contraception • Reluctant to have biological children • When pregnancy is pursued, display high anxiety about taking AEDs during pregnancy, though do tend to stay on AEDs • Preference changing effective AED treatment slowly and far in advance to optimize pregnancy outcomes • Open to pursuing non-biological parenthood • Display high decisional conflict about reproductive decisions • Display high anxiety about seizure occurrence
D	Mixed	High	Low	<ul style="list-style-type: none"> • Tended to select highly efficacious contraceptive • When interested in pregnancy, tend to stop AEDs • When worried about passing on epilepsy genetically, tend to forgo childbearing

				<ul style="list-style-type: none"> • Display little anxiety about seizure occurrence • Display some decision conflict about reproductive decisions
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I was afraid of the medicine interfering with the birth control. [...] If the pill is gonna interfere with the medicine, then there's absolutely no reason to take it [In-depth interviewee].

Because of worries about hormonal contraceptives, and due to interest in permanently preventing pregnancy (described next), women in Group A often selected tubal ligation or vasectomy.

Women in Group A reported that they would not consider pregnancy because of the risks of loss of seizure control they associated with pregnancy itself or with medication changes needed to reduce the risk of AED-associated fetal anomalies. For example, Ruth who has never had children said:

You go through so much to get *rid* of your seizures. [...] To go through all that pain only to do something that could cause you to have those all over again, you know, that's the reason why I didn't [get pregnant] [In-depth interviewee].

In addition to expressing that the risk of increased seizures during pregnancy was too great a risk to consider biological motherhood, women in Group A also perceived the risks of seizures occurring while taking care of a child as too great to consider non-biological parenthood. For example, Wendy

had one child prior to her epilepsy diagnosis. She reported that she does not think she can adequately look after a child given the frequency of both her convulsive and non-convulsive seizures. She explained:

If you have seizures, you can't have children. [...] I couldn't have another child anyway. I can't even babysit little kids by myself. I can't dial 911. [...] When you're out of it, you're not there [In-depth interviewee].

Women in Group A's explicit preference for seizure control also affected their preferences for neurological care. Women in this group expressed considerable frustration when health care providers placed women on a medication that was best suited for pregnancy even if it did not meet women's neurological needs. Annie, 33, reported that in her 17 years of living with epilepsy, Depakote was the only AED that worked to control her frequent convulsive and non-convulsive seizures. Despite the fact that Annie was not interested in having more children, her doctors took her off of the AED because it was not preferred for use during pregnancy. She angrily explained:

They took me off [the AED] because there wasn't enough published about being pregnant and there wasn't enough about breastfeeding with Depakote to have them feel safe enough about. [...] They just decided to keep me off of the Depakote for some reason. I've been told that it's one of the couple that they don't want to put women on [In-depth interviewee].

Group B:

Women in Group B were the least commonly represented in the sample. They are similar to women in Group A in that said they perceive the risk of seizure occurrence as high. However, they are unique from women in Group A in that they have distinct interest in having children and perceive the risk of adverse reproductive outcomes as relatively low.

Like women in Group A, women in Group B selected contraceptives by evaluating if they believed the contraceptive would either increase seizure control or have no effect on AEDs. However, because of their reproductive desires (described next), women in Group B often selected temporary contraceptives, as opposed to permanent ones. This meant that women in this group tended to avoid hormonal contraceptives and select barrier methods or IUDs.

Many women in this group worried about how having seizures would affect both pregnancy and their abilities to parent. One online-forum user with non-convulsive seizure wrote about her concerns about the post-partum period:

I am just worried that I won't be able to handle motherhood. [...] I'm less concerned about defects...more concerned with whether I'll be able to cope. I'm afraid my seizures will get worse if I can't control sleep or stress levels [Online-forum user].

Instead of concerns about seizure occurrence preventing women from considering becoming biological parents, women in Group B elected to postpone pregnancy until they felt confident their seizures were under control. Tracy explained that her decision to have brain surgery and get her seizures under control was almost entirely motivated by her desire for motherhood. She said:

I always wanted to have a child. [...] I did not want to have a child if I [...] had to be dependent on somebody, transportation particularly. It really bothered me with the whole idea of having a child who I need to take to the doctor if he or she was sick, but I can't do that myself as the mother. So it was really really important for me to try to focus on me before making that final decision to try and conceive [In-depth interviewee].

Women in Group B most often said that after thinking through the “true risks and benefits” of medication use during pregnancy, they felt that the benefits of medication use during pregnancy outweighed the risk, and hence they followed their prescribed AED regimen throughout pregnancy. For example, Sarah, who had two children after her epilepsy diagnosis, explained her decision to stay on AEDs:

I knew I was going to take the medications. [...] As soon as the neurologist said the chances are very slim of something happening as far as a birth defect, I knew that I had to take it. I mean, there's no way I would've risked having another seizure. It's just not something that I'm *ever* willing to take a risk on [In-depth interviewee].

Once they became parents, women in Group B continued to focus on their neurological care and were highly motivated to implement strategies that would control their seizures so that they could be active parents in their children's lives. For example, an online-forum user posted about her newfound adherence to AEDs after she became a parent:

I'm still on those meds, all the time thinking to stop them but i always think about my little angel, if i'm alone with my child and have a seizure what will happen then? So i have to take the medication [Online-forum user].

Group C:

Women in the study fell into Group C just as commonly as they did Group A. Women in Group C considered both neurological and reproductive outcomes. Like women in Group A, they considered most reproductive decisions to be high-risk options that would lead to poor neurological and reproductive outcomes. However, they were different than women in Group A in that they reported ambiguous reproductive desires, as opposed to low desires.

Contraceptive decisions were approached cautiously by this group, as they were interested in using an effective contraceptive that did not interfere with their seizure control, but worried this was difficult to identify. They tended

to be concerned that the initiation of a hormonal contraceptive would increase the occurrence of their seizures, even though most had not experienced such an increase. One online-forum user, for example, posted about her concerns:

I am getting ready to start taking birth control pills. [...] I am of course a little nervous about starting the new pill [...]. I have been seizure free for almost 4 months now and I don't want to take anything that may provoke a seizure [Online-forum user].

Because of their concerns about the risks related to hormonal contraceptive use and of pregnancy (described next), women in this group were highly likely to forgo biological parenthood and initiate a permanent contraceptive. Megan, who has convulsive seizures and had two children prior to her epilepsy diagnosis, explained why she and her husband decided to have him undergo a vasectomy:

It was like, well, you can't stop taking this medicine. [...] We really want more kids, but you can't do pregnancy *and* this medication at the same time. So it's like, what do you do? [...] I've already had the kids. They say it's hard to go back in and have tubal ligations once you've already had your kids. So then, you know, it was either me or him. So my husband went back in and he, he had a vasectomy [In-depth interviewee].

As suggested above, most women in Group C reported that the risks of loss of seizure control and adverse pregnancy outcomes were too high and too hard to balance to consider having biological children. Anne, who at 32 had never had children shared:

If I didn't have epilepsy, I would probably be much more anxious to have children. [...] The fact that I do have epilepsy [...] makes me less [...] attached to having to have children. Like, I'm just not able to emotionally let myself go there—that's just something I don't have to have in life. Where I probably would be there if [...] I didn't have epilepsy [In-depth interviewee].

The few women in Group C who pursued pregnancy expressed considerable anxiety about how to manage their epilepsy during pregnancy. They reported feeling “overwhelmed” by the idea that if they stopped taking AEDs during pregnancy, seizures could increase; but taking AEDs during pregnancy could “cause” offspring abnormalities. They often used words like “terrified,” “worried sick” and “fearful” to describe their thoughts about taking AEDs during pregnancy. A quote from an online-forum user sums up the difficulties women had balancing what they saw as competing concerns during pregnancy:

My husband and I have been trying to get pregnant since June. [...] I am so confused about which direction to take with this. I know seizures are dangerous while pregnant and I know meds have side effects. I am aware of the risks on both sides. To me- they are very equal [Online forum-user.]

Most women in this group who became pregnant reported staying on medications during pregnancy, though they said the decision caused considerable anxiety.

The few women in this group who did pursue pregnancy, did so cautiously and had distinct preferences for how their seizure medication was managed pre-conceptually. Specifically, women in this group on medications not recommended for use during pregnancy often stated that they did not want to switch medication, but if they were going to, they preferred to do so slowly and far in advance of conception. Women said this strategy would make them feel confident that they would have time to find a medication that is appropriate for use during pregnancy, works well to prevent seizures and has few or acceptable side effects.

Though almost all women in this group said they perceive the risk of loss of seizure control and adverse pregnancy outcomes as too high for biological childbearing, many expressed they were considering other modes of parenthood, such as surrogacy or adoption. Claudette explained that her decision not to have biological children was based on her concern about loss of seizure control during pregnancy. She went on to discuss her concerns about adverse pregnancy outcomes:

I wouldn't want to risk carrying a child and having birth defects because I don't know what the side effects are of these drugs. [...] Once I got that [epilepsy] diagnosis, the decision to have children was out the door. I may consider doing, like, surrogacy or adoption, but I don't think I'd ever

even attempt to carry a child on the drugs that I'm on [In-depth Interviewee].

Group D:

Women in Group D represent a sizeable minority of women in the study. They reported they perceive the risk of increased seizure occurrence due to hormonal contraceptive use, pregnancy or parenthood as relatively low, and that they perceive the risk of adverse pregnancy outcomes as quite high.

Women in Group D did not perceive that hormonal contraceptives could negatively influence seizure control and hence did not consider how a contraceptive would affect their seizures. Instead, they tended to focus on selecting highly efficacious contraceptives based on a desire to prevent unplanned pregnancy. Kelsey, for example, uses the oral contraceptive pill and explained that she frequently repeats a mantra to her sexual partners that she heard from a neurologist:

Planned pregnancies only [In-depth interviewee]!

Women in the group expressed a desire to avoid unplanned pregnancy because they wanted to prevent congenital malformations associated with AED use during pregnancy, or wanted to prevent genetically passing on epilepsy to offspring.

Women in Group D who were primarily concerned about the impact of AED during pregnancy, and who were interested in having children, were likely to discontinue medication use pre-conceptually or during pregnancy. Most of these women had relatively infrequent seizures that they felt were easy to control and they did not think it was likely that stopping medication would increase seizure occurrence. Lauren, for example, stopped taking AEDs to prepare for pregnancy. She explained that she perceived the risks of adverse pregnancy outcomes as high, particularly in light of her belief that her risk of seizures without medication was low. She said:

I kinda looked at it as, *yeah*, you know, there's six out of 100 women that have a child with birth defect associated with taking this medication. Like, it might not happen to me but obviously there's an issue here. It made me nervous. That was one of the reasons why I didn't want to be on the medication to begin with, just because I felt like I didn't need it, but I didn't want to be on it in the long term because obviously, I didn't want to be pregnant and on this medication and have that possibility of a child with birth defects [In-depth interviewee].

Later in the interview she further expressed,

I realize my case, I've had very few seizures and they've always been very mild so for me there was never any like question that I didn't want to be on medication when I became pregnant [In-depth interviewee].

Women in Group D who were worried about passing epilepsy onto offspring elected to forgo biological childbearing. These women tended to report

particularly difficult experiences living with epilepsy. For example, Wen explained her caution about having biological children:

My doctor said that there's a chance that it may pass on to my kids. And I don't want that. I mean, I'm suffering. I don't want anybody or even my kid to suffer [In-depth interviewee].

However, those worried about passing epilepsy on genetically and interested in having children, also said they considered pursuing adoption or surrogacy.

Value 3: Pregnancy testing preferences

Most women reported accurately that many congenital malformations associated with AED use can be detected in the womb via prenatal testing.

Because women reported knowing they were at an increased risk of experiencing congenital malformations, and because their pregnancies were commonly being screened for malformations, women had to implicitly engage with the question of whether or not they would terminate a pregnancy if it were diagnosed with a malformation.

Only one interviewee experienced a diagnosis of a congenital malformation. The malformation was incompatible with life, and hence Suzanne reported feeling her decision to terminate the pregnancy was a straightforward one. Besides Suzanne, no interviewees or online forum-users reported explicitly

engaging with a termination decision. Moreover, when probed, few interviewees said they felt they could make explicit values statements about when or if a woman with epilepsy should consider terminating a pregnancy. Instead, most interviewees stated they believed such decisions were “personal” and could only be dealt with once experienced for oneself.

Though the thought of prenatal screening sometimes raised difficult questions for women, most said they preferred to undergo it. Most women described testing in positive terms and said it made them feel reassured that the pregnancy was progressing in the way they preferred. One online-forum user posted:

I remember being soooooo worried that my baby would be born with a defect like spina bifida. I was SO relieved when I saw the ultrasound when the OB said everything looked normal/healthy [Online-forum user]!

However, many women expressed very specific preferences for *how much* screening they wanted to undergo during pregnancy. This preference was based on women’s perception of how likely a congenital malformations was as well as on women’s ability to implement a given screening plan. Specifically, women who perceived the risks of congenital malformations as quite low wanted less screening. On other hand, women who perceived the risks of congenital malformations as higher often wanted an extensive monitoring plan.

Women also expressed clear preferences for undergoing prenatal screening and discussing screening results with obstetrician/gynecologists and not neurologists. Anne expressed it this way:

I don't know that I would want my neurologist to be the one that helps me make this decision. [...] He might be a hard person for me to have the "so this is actually a testable condition" discussion with and I could decide to abort and this is the point at which I would decide to abort--type of conversation with [In-depth interviewee].

Implementation of preferred reproductive decisions

As detailed below, both financial resources and emotional and practical support from partner, friends, family and peers were important in the implementation of preferred reproductive decisions.

Resources for women's reproductive decisions

Concerns about financial resources did not emerge strongly in women's descriptions of their decision-making regarding having children. However, concerns about financial resources to implement preferred decisions did emerge in relation to access to the health care resources needed to implement pregnancy management or contraceptive decisions. These concerns were only reported by in-depth interviewees.

Though only three interviewees were uninsured at the time of interview, a number of women had experienced gaps in their insurance coverage, related to losing or changing jobs, as well to difficulties enrolling in Medicare. Four interviewees reported difficulties enrolling in Medicare because they were not considered “disabled enough” for coverage. When women did not have private or public insurance coverage, they reported they could not afford to pay for medical services out-of-pocket. Further, having insurance, did not guarantee that women could afford health services. Some insured interviewees reported they could not afford the co-pays associated with the health service they were seeking.

In relation to pregnancy management decisions, in-depth interviewees said the accessibility of affordable and covered health care services informed their abilities to implement a monitoring plan during pregnancy. Specifically, women who were not able to attend frequent doctor’s appointments because they could not afford the time away from work or the costs associated with the appointments said they went to the doctor less than they would have preferred.

Likewise, in-depth interviewees faced challenges affording required visits for prescription contraceptives or the out-of-pocket costs associated with contraceptives. Out-of-pocket contraceptive costs were especially challenging for

interviewees who were taking multiple medications for their epilepsy.

Additionally, insured women reported that not all contraceptive methods were covered by their insurance plans, and that they were limited to contraceptives covered by their insurance plan. Insured interviewees reported most commonly that sterilization and/or IUDs were not covered by their insurance. For example Beth reported that Medicaid would not cover her husband's vasectomy. She said:

I told my husband, "We're lucky. Why don't we get you a vasectomy?" [...] It was \$490. Medicaid doesn't pay for that. [...] Any other insurance doesn't pay for it [In-depth interviewee].

When women could not afford their contraceptives, they reported using a less preferred method that was less expensive, paying out-of-pocket for the preferred method or borrowing money to cover the cost of the preferred method.

Support for women's reproductive decisions

Women reported that support from partners, family members and other women with epilepsy was critical to their abilities to implement their preferred reproductive decisions. Below, I discuss the specific role each of these groups plays in women's decision to become parents and daily childrearing activities,

decisions regarding management of health during pregnancy and contraceptive decisions.

Partner and family support for parenting decisions and challenges:

Most women perceived that those closest to them were supportive, both of women's decisions to have biological children and of their decisions to forgo childbearing. Women described feeling supported when partners and family members agreed with women's own risk assessments about the safety (or riskiness) of biological parenthood. However, in contrast to women's own evaluations of the risks related to biological parenthood (described above), women reported that partners and family members were exclusively concerned about the maternal risks of biological parenthood, and did not balance maternal risks against fetal risks. For example, Carolyn fell into Group A and perceived pregnancy as too risky to consider given the potential risks to her seizure control. She decided with her husband's support not to have children. She explained that he worried, as she did, that her previously difficult to control convulsive seizures would re-emerge during pregnancy:

He thinks [...] a pregnancy would have an effect on my epilepsy. And he can't stand to see me have a seizure [In-depth interviewee].

This support aided women in feeling comfortable with their decisions about whether or not to have children and ultimately enabled women to implement their preferred decisions with little or no decisional conflict.

On the other hand, a sizeable minority of women reported that those closest to them disagreed with women's assessments of the maternal risks related to biological parenthood. In the few cases that these disagreements emerged, they usually occurred when a woman desired pregnancy, but her partner or family worried it presented excessive maternal risks (as opposed to a woman being pressured to have children when she perceived biological parenthood to be high-risk or undesirable). One online-forum user posted about this issue when she wrote:

My husband and I were planning on trying to conceive starting this next month. Had a seizure 3 weeks ago and that changed everything. I am getting impression from my husband that he is second guessing having a kid now because something "might" happen. [He asks] "What if I get hurt?" [...] I have TC's [convulsive seizures] when I have a seizure. They are pretty few and far between so it isn't like I am having them all the time. I don't know what to do...[Online-forum user].

Women who disagreed with their partner's and/or family member's perspectives on the risks of biological parenthood expressed considerable anxiety, anger, and general feelings of conflict, and rarely reported implementing their preferred decisions about whether or not to have children.

Women also emphasized that practical partner and/or family support is critical to help women with epilepsy navigate both common parenting challenges and challenges specific to women with epilepsy. Specifically, women said that reliable support system is needed for evening childcare or whenever a woman is tired; this support helps ensure that women receive adequate sleep and reduces the likelihood of having a seizure. Women also expressed that partners and family are needed resources for practical tasks such as driving a child around, particularly when a woman did not have a driver's license. One online-forum user described her experiences raising children and said:

As long as you have a good support system, motherhood is definitely a possibility [Online-forum user].

Not only did the availability of practical support help women care for themselves and their children, women said it also increased their confidence in their abilities to be adept mothers. Courtney described considerable concern about having a child; concern which was mitigated by support:

I was terrified because if I had a seizure, how was it gonna affect my child? [...] Will I be able to take care of the baby if I'm having seizures all the time? It was scary. But, with the support and help of my husband and my family, I knew that if I needed help, I would have help [In-depth interviewee].

Partner and family support for pregnancy management decisions:

Compared to women's desire for support regarding their decisions about whether or not to have children, women expressed considerably less need for support regarding their decisions about managing their epilepsy during pregnancy. Indeed, women described their decisions about whether or not to take AEDs during pregnancy as relatively independent ones that they made in consultation with their health care providers; partners and family members receded into the background of these decisions.

That said, women commonly reported that their partners and family members were entirely unsupportive of decisions to stop taking AEDs during pregnancy or while planning for pregnancy, particularly when women did not have seizure control or had only recently gained seizure control. Though women perceived that those closest to them felt that discontinuing AEDs during pregnancy unnecessarily put women's health at risk, women reported they did not encounter any overt interference in their pregnancy management decisions. For example, Lauren shared how her family and partner felt about her decision to discontinue AEDS in preparation for pregnancy:

My mom was certainly concerned. She sort of had the same reaction that my boyfriend did. She was more worried about my health, and me having another seizure than anything else. But, both with her and my boyfriend, said "Ok, you know, we're worried about you, but this is

ultimately your decision with what you wanna do [In-depth interviewee].”

In light of the limited involvement that women’s partners and families appear to have in pregnancy management decisions, lack of support for women’s decisions to discontinue medications does not appear to interfere with women’s ability to implement their preferred pregnancy management decisions. It is unclear from this research if a lack of support for *staying on* AEDs during pregnancy would inhibit implementation of pregnancy management decisions, as all women reported that their partners and families felt strongly that women should stay on seizure medications throughout pregnancy.

Partner support for contraceptive decisions:

Generally, women reported relying on support from their partners (and not family or friends) when making decisions to initiate and/or select a contraceptive. How active partners were in providing contraceptive support, and the necessity of partner support, appeared to depend upon the type of contraceptive used. For the most part, women described their partners as compliant figures who deferred decision making about the initiation of and selection of a type of contraceptive to the woman. This was particularly true

when a female-controlled method was used. Lauren, for example, said she uses the oral contraceptive pill. When asked whom she discussed the decision with, she said:

I talked to my boyfriend about it. He really didn't have an opinion about it as long as I was on something. He kinda just said, "Whatever works best for me."

On the other hand, women reported that partner input and agreement with the contraceptive decision was extremely important for methods that directly involved men: condoms and vasectomy. Women using condoms or vasectomy as their primary contraceptive reported their partners were supportive of the method choice because of worry that other hormonal contraceptive methods may interfere with their AEDs and disrupt seizure control. Women also said their partners understood that an unplanned pregnancy could disrupt seizure control. Hence, women said their partners appeared enthusiastic about using condoms or vasectomy since they are highly effective at preventing pregnancy and do not interfere with seizure control. For example, Megan described the decision she and her husband made to have her husband undergo vasectomy:

It was a mutual decision. [...] Most men are always iffy about that, but we knew that it was something that we had to do because it wasn't like we also wanted to be surprised by anything either. Because then it would be equally devastating because then I'd have to stress, which is sure to

induce a seizure. [...] After we weighed all the pros and cons, he knew it was something that we had to do.

Peer support for reproductive decisions:

Repeatedly, women expressed the critical importance of having support from other women with epilepsy for their reproductive decisions. Both in-depth interviewees and online-forum users were emphatic that other women with epilepsy were the only people who could truly understand the factors women were weighing when making such decisions. Women said that these support groups lived up to their names and provided unique forms of support that women felt they could not obtain elsewhere. Indeed, women engaged in reproductive decision-making commonly reported that after gathering clinical information about their options, they actively sought out consultation with other women with epilepsy who had made their same decisions. Consultation appeared to not only verify information from health care providers, but also to provide additional epilepsy-specific context to decision processes and outcomes that women felt their health care providers could not offer. In fact, women commonly described both in-person and online support groups as positive resources that made them feel optimistic about all of their reproductive options. Claudette who has never been pregnant and is nervous about the idea of having

children because of her epilepsy explained:

It's been really tough to think about [having kids] until I started talking to mothers with epilepsy [online] and I've heard all the success rates and everything. [...] I am a lot more confident and feel a lot better about the idea of getting pregnant. It's, it's really relieving [In-depth interviewee].

Jessica even shared that for her in person support groups were an effective tool for combating stigma associated with women with epilepsy having children.

After sharing that she felt her doctors discouraged her from having children, she said:

It's pretty sad and it takes support groups for women telling other women to be able to get that out of their heads [In-depth interviewee].

Summary of Impact of Uninformed Reproductive Decision-Making

It is clear that women in this study did face challenges obtaining accurate information about all of their reproductive options, balancing the values that informed their reproductive decisions and, on occasion, securing the resources needed to implement preferred reproductive decisions. The collection of challenges impeded informed reproductive decision-making, changing the life courses of some women, and affecting the neurological and reproductive health of others.

First, some women avoided motherhood and selected permanent methods of contraception, even though they desired children. With inaccurate perceptions of the maternal and fetal risks of pregnancy for women with epilepsy in hand, these women described going through a considerable “grieving” process in which they accepted their disorder and accepted that having epilepsy meant not having children. However, few women who desired children, but decided not to have them, were rested with their decision. For example, Ruth had a hysterectomy before she met her now husband. When asked how she felt about her decision, she said:

When you find the right person you wish you could give him a child. Sometimes you feel really guilty. [...] I just wish that I could have kids for my husband because I know I'd be a good mom. [...] Given the choice I would have just tried to get that IUD. [...] It's like one time of the month, I tend to get kinda depressed about it. I get sad 'cause everyone around me is having kids now or just because I wish I could give him [husband] that, and I can't [In-depth interviewee].

Second, some women still considering motherhood carried considerable feelings of guilt, decisional conflict, and anxiety for having, or considering having, children. One online-forum user posted about her concerns about motherhood stating:

I want a baby....I just want someone to tell me i'm not a bad person for wanting a baby while still having seizures and not knowing when they are going to affect me. I want it to be okay to take the chance. Would I be a

bad person if I took the chance? ahhhhhhhhhhhhhhhhhhhh! it's so hard!
Somebody PLEASE help me [Online-forum user].

Third, some women faced considerable difficulty identifying and accessing a contraceptive that met both their reproductive and neurological needs. This had a number of impacts on women including: misleading women about appropriate contraceptives for women on AEDs, frustration with current contraceptive, anxiety initiating or changing hormonal contraceptives, use of a less preferred contraceptive and an inappropriate combination of contraceptives and AEDs which led to decreases in both seizure and reproductive control. Moreover, women reported feeling their health care providers did not respond to their challenges selecting a contraceptive, leaving women frustrated and mistrustful of their health care providers and forced to take their contraceptive decisions in their own hands.

Finally, there is evidence that some women experienced increases in seizure occurrence when health care providers offered care that was inconsistent with women's values. Indeed, women who explicitly placed greater value on their seizure control than on biological motherhood were often frustrated with health care providers who focused on prescribing AEDs that were "good for women" in that the AEDS were not associated with increased of congenital

malformation. Of concern, a minority of women suffered through years of frequent seizures because health care providers would not place the women on a medication that was a known teratogen. Annie, who has both convulsive and non-convulsive seizures said she asked her health care providers for two years to be put her back on an AED that had previously controlled her seizures. Once back on it, her seizures were immediately under control. When I asked why she felt no one would prescribe her that AED she related:

I've been told that it's one of the couple [AEDs] that they don't want to put women on. [...] Everybody just shied away from it [In-depth interviewee].

Of note, the above challenges are primarily related to decisions surrounding contraception and decisions related to having children. Few challenges emerged in relation to making and implementing preferred pregnancy management decisions. Indeed, though women did face some challenges during pregnancy, such as coordinating care between neurologists and obstetrician/gynecologists, they generally described having the information and the resources to implement their preferred pregnancy decisions.

CHAPTER 6:

DECISION AID DEVELOPMENT AND EVALUATION RESULTS

Introduction

Findings outlined in the previous chapter show that women encounter challenges making and implementing some informed reproductive decisions. Challenges related to contraceptive decision-making appear to be the most salient, consistently encountered and impactful on both neurological and reproductive health outcomes. Therefore, they are in need of address. A contraceptive decision aid targeted at women with epilepsy is one intervention tool that has the potential to help women navigate the challenges they face making and implementing informed contraceptive decisions.

In this chapter, I detail why a contraceptive decision aid is an appropriate intervention tool and provide an overview of the objectives of decision aids and their documented benefits. Next, I describe the process I undertook to develop and evaluate a contraceptive decision aid for women with epilepsy. I then report on the results of the evaluation of the decision aid I conducted, and discuss how the results informed a revision of the decision aid.

Rationale for Chosen Intervention Tool

Needs assessment results show that response is necessary to ensure that women with epilepsy can make and implement informed contraceptive

decisions. Given that interventions are already in place to better educate health care providers about the reproductive health care needs of women with epilepsy (186), and that any improvements seen by women as a result of the health care provider trainings will take some time to occur, a response focused directly on women with the disorder is appropriate. Additionally, due to the clinical complexities of contraceptive decision-making for this population, the intervention tool must not be divorced from clinical care, but part of it. Further, because only limited information provided during a single, time-limited clinical encounter can be retained (187), any tool must be usable both inside and outside of the framework of the actual clinical encounter.

A decision aid meets these requirements to be directly focused on the population in need of support, as well as usable in and outside of clinical environments. Additionally, previous research called for the development of a tool to assist women with epilepsy in making reproductive decisions (188). However, no such identifiable tool exists. For these reasons, and because the goals and anticipated benefits of the intervention tool, described below, are consistent with women's needs, a contraceptive decision aid was selected to respond to women's documented challenges making and implementing informed contraceptive decisions.

Decision Aid Objectives

Decisions aids are evidence-based tools designed to promote informed decision-making (165). The aims of a decision aid are to:

- 1) Provide evidence-based information about a health condition, the options, associated benefits, harms, probabilities, and scientific uncertainty of decisions made about treatment strategies;
- 2) Help individuals recognize the values-sensitive nature of their decision and help individuals clarify the value they place on the benefits, harms, and scientific uncertainties associated with the decision (165); and
- 3) Provide structured guidance for going through the steps of decision-making and for communicating personal values with others involved in the decision-making, such as health care providers, family, or friends (189).

The above aims highlight that decision aids prioritize supporting individuals throughout the decision-making process by providing detailed and specific education about health care options, assisting individuals in considering and clarifying their values and communicating those values (165). These aims are different than general health education materials which are broader in perspective, and aim to help individuals understand their diagnosis, treatment and management in general terms, but not necessarily to support them in making specific health care decisions (165).

To meet their desired aims, decision aids are used as adjuncts to, and not substitutes for, clinical advice from a health care provider. They can be

implanted before, during or after a clinical encounter (165). Decision aids used prior to or after a clinical encounter can be beneficial as they help build a platform for discussion. They help clients communicate their values, or preferences for level of participation in decision-making, and/or help the client identify what questions they have about their health care decisions. Decision aids utilized during consultations with health care providers can help guide the consultation interaction and promote discussion during the health care visit (162).

The general aims of decision aids are in line with the identified contraceptive decision-making needs of women with epilepsy. Considering the documented need to provide the population with information, values clarity and communication support relevant to their contraceptive needs, a decision aid focused on ensuring women can make informed contraceptive decisions is an appropriate and much-needed intervention tool. Specifically, the needs assessment results show that women need information about contraceptive care that not only takes into consideration the clinical components of such decisions, but also acknowledges the ways in which living with epilepsy affects contraceptive selection. Further, needs assessment results made clear that the weighing of values and preferences regarding seizure control and reproductive

outcomes are central, but often overlooked, features of contraceptive decision-making for women with epilepsy. Additionally, women's documented problems receiving appropriate contraceptive care suggest a need to provide support in communicating values and needs with health care providers, particularly when women receive little or contradictory guidance from different specialists. Finally, though health care decision-making is routinely understood as occurring in one-off encounters between clients and health care providers in the confines of a consultation room, decision aids recognize that it is much more likely that health care decisions occur at multiple and varied points in time, both in and outside of a consultation room (190).

Public Health Benefits of Decision Aids

Below, I discuss the documented primary and ethical benefits of decision aids. I then apply those documented benefits to a discussion of the anticipated benefits of a contraceptive decision aid for women with epilepsy.

Primary benefits of decision aids

An ongoing systematic Cochrane Review of randomized controlled trials that evaluates the efficacy of decision aids has, as of 2009, reviewed 86 studies

that evaluate the efficacy of decision aids used for a variety of clinical decisions. Stacey and colleagues have found that use of decision aids produces a number of benefits. First, when compared to usual care, decision aids increase individual's knowledge regarding options, and detailed decision aids are significantly more likely than simple decision aids to increase knowledge. Next, the review showed that use of a decision aid with an explicit values clarification component, as opposed to use of a decision aid without such a component, resulted in a higher proportion of individuals achieving decisions that were consistent with their values. Decision aids also appear to reduce decisional conflict, decrease the proportion of people remaining undecided and stimulate individuals to take a more active role in decision making, when compared to usual care. Additionally, the review found that decision aids have a positive effect on communication between health care providers and clients (8).

The review also identified some limitations of decision aids. First, compared to alternative interventions, decision aids do no better in decreasing anxiety, or improving health outcomes (8). However, because most decision aids are used when there is no option that will clearly improve health, this is not surprising. The authors of an earlier version of the Cochrane review suggested in response to this finding that future studies should investigate if individuals

experience the health outcomes they prefer and avoid the outcome to which they were adverse (165).

Ethical benefits of decision aids

Underlying decision aids are a central tenant of Western bioethics—respect for autonomy (191; 192). Respect for autonomy, in terms of health care decisions, can be understood as the capacity of an individual to act knowledgably, intentionally and without controlling influences that prevent a free and voluntary act (193). Though autonomy is celebrated by the ethical framework underlying informed decision-making, it is by no means mandated (194). Indeed, some individuals may express their autonomy by choosing to play a passive role when making health care decisions, and by deferring to the expertise of their treating health care provider (165).

Public health benefits of a contraceptive decision aid for women with epilepsy

Given the numerous documented benefits of decision aid, a contraceptive decision aid focused on supporting women with epilepsy in making informed decisions holds the promise of improving women's decision-making and health in a number of ways. First, the tool may improve women's decision-making

process by increasing women's knowledge about their reproductive options, as well as by decreasing the proportion of women who remain undecided about their contraceptive choices. Such a tool may also stimulate individuals to discuss their contraceptive needs and concerns with appropriate health care providers, and improve communication between the client and provider. A contraceptive decision aid could also produce the ethical benefit of supporting women in making the contraceptive decisions they prefer, a critical component of women's abilities to determine for themselves if and when they have children.

Though decision aids have not been shown to improve health outcomes (8), I speculate that a decision aid focused on supportive contraceptive choice could lead to significant improvements in women's overall health and quality of lives. Indeed, contraceptive use, which helps women plan, space and time their pregnancies has been shown to lead to considerable improvements in women's health and the health of their offspring (11–13). Therefore, it can be inferred that increasing informed contraceptive decision-making has the potential to lead to increases pregnancy planning and the use of effective and appropriate use of contraceptives and AEDs, which could in turn result in improved maternal and fetal health outcomes. Further, because of the relationship between women's seizures, hormonal patterns and contraceptive use, increases in informed

contraceptive decision-making may reduce seizure occurrence and improve neurological health. Any one of these changes alone could have significant impact on the overall health and quality of lives for a large number of women and their families.

Methods for Development and Evaluation of a Contraceptive Decision Aid

One aim of this dissertation, as described previously, was to conduct a needs assessment and investigate the reproductive decision-making of women with epilepsy. The second and third complementary aims of this dissertation are focused on the translation of existing evidence and of knowledge gained through the needs assessment into an acceptable and effective intervention tool. Specifically, I aimed to develop an evidence-based contraceptive decision aid to support women with epilepsy in making and implementing informed contraceptive decisions, and to conduct a preliminary evaluation of the acceptability and effectiveness of the decision aid. To meet these aims, I followed a seven-step model for developing and evaluating a decision aid, which is described in detail below.

Step 1) Assess need

Step one is to survey individuals about their health needs, thereby conducting a needs assessment. As stated previously in Chapter 4, a qualitative needs assessment was conducted as they are well suited for providing unique insights into what evidence should be included in a decision aid and for generating ideas about what issues should be addressed in a decision aid (161).

Results from the in-depth interviews revealed that a decision aid would be an acceptable intervention tool. I asked in-depth interview participants if they thought there was a need for a decision aid, or some other resource for women making reproductive decisions. I did not ask explicitly about a contraceptive decision aid, as the focus of the tool had not yet been determined. Women almost universally expressed excitement and interest in a reproductive-focused decision aid. For example, when asked what she thought about the development of a reproductive decision aid, Angie exclaimed,

Oh my god. That's what I need! That's amazing! That's so great [In-depth interviewee]!

Other participants stated they felt current materials targeted at women with epilepsy do not focus enough on their reproductive health and often glossed

over some of the difficult aspects of living with epilepsy during the reproductive years.

Step 2) Assess feasibility

The second step in developing a decision aid is to determine if it is feasible to develop a decision aid with the available evidence and resources to deliver an accessible tool (161). To determine feasibility, I first considered the literature on contraceptive use in women with epilepsy. Because there are gaps and disagreement in the literature about how some contraceptive methods interact with AEDs, and because medical knowledge changes rapidly, I determined that it is not feasible at this time to develop a tool that provides detailed clinical information about these interactions. However, the CDC has released general guidance on contraceptive safety and appropriateness for use by women with epilepsy and specifically addresses the potential for interactions between contraceptives and AEDs. This guidance provides enough broad information about AED and contraceptive interactions to make it feasible to create a decision tool. Additionally, because decision aids are meant to be used as adjuncts to discussions with health care providers, it is not appropriate to create a tool designed to provide detailed clinical information about interactions between

AEDs and contraceptives. It is, however, feasible and appropriate to create a tool that provides general clinical information, enhances values clarity and offers guidance for enhancing communication with health care providers.

To further determine feasibility, I also considered current evidence regarding the use of decisions aids. Decision aids have traditionally been developed for single-choice decisions, such as to have surgery or not (194). However, more recently decision aids have been developed to support ongoing decisions, such as chronic diabetes therapy (194). Additionally, the WHO has developed and evaluated a contraceptive decision aid which consists of a two-sided flipchart; one side is an aid for clients and the other for health care providers. The tool uses a decision-making algorithm to systematically guide clients and providers through the family planning counseling process. Evaluations of the WHO tool have shown that it is an acceptable tool, and that when compared to usual care, the tool appears to increase knowledge about contraceptive options and made individuals feel more comfortable talking and asking their health care provider questions (195–197). Additionally, Prunty and colleagues developed and evaluated the impact of a decision aid developed to guide women with MS through the choice, of “starting, foregoing or enlarging their families,” a decision they termed the “motherhood choice.” The tool was

found to be acceptable and effective; those who received the decision aid in a randomized control trial had significant decreases in decisional-conflict, increases in self-efficacy and knowledge of MS and pregnancy, and more certainty in their choice than those in the control group (180; 198). This evidence, of decision aids being developed for ongoing reproductive decisions, and contraceptive ones in particular, provides an excellent basis for the development of a decision aid focused on women's ongoing contraceptive needs, and demonstrates that a contraceptive-focused tool can produce benefits.

Step 3) Define the objectives of the decision aid

The third step is to define clear, specific and measureable objectives for the decision aid (161). The objective of the decision aid is to increase informed contraceptive decision-making for women with epilepsy who early in their decision making process by:

- 1) Improving women's knowledge about relevant reproductive health issues in women with epilepsy;
- 2) Helping women clarify their own values about contraceptive and neurological health outcomes;
- 3) Decreasing feelings of isolation in making and experiencing the outcomes of contraceptive decisions; and
- 4) Providing guidance about how to speak to potentially unresponsive health care providers about contraceptive concerns and desires.

The decision aid is targeted at women with epilepsy who are early in their contraceptive decision-making process because in-depth interviewees said they begin considering contraceptive decisions prior to seeing a health care provider. It could be argued that the decision aid should be focused on young women who have not yet made contraceptive decisions. However, because women can be diagnosed with epilepsy at any point in their lives, women at any age may be new to making contraceptive decisions as a person with epilepsy. It can also be speculated that minors with epilepsy have different contraceptive needs than adults with the disorder. Because minors were not included in the needs assessment, the decision aid is unable to be responsive to their needs. Hence, the tool is targeted broadly at adult women who are early in their contraceptive decisions, and does not target a specific age group of women. Targeting the decision aid for use prior to seeing a health care provider is beneficial, as decision aids utilized in this manner have been shown to help individuals communicate their values and identify what questions they have about their health care decisions (162).

I developed the specific decision aid objectives after reviewing the overall results of the needs assessment. Specifically, the need assessment showed women lacked information about certain reproductive health issues, such as the

interaction between some contraceptives and AEDs, and the high probability that women with epilepsy can have safe and uneventful pregnancies. Values clarification is a goal of the decision aid because the needs assessment also revealed the important role that women's values regarding neurological and reproductive outcomes played in contraceptive decisions. Women's reports that they highly value the support of other women with epilepsy led to the development of the goal to decrease feelings of isolation. Finally, women's descriptions of the challenges they experienced seeking contraceptives highlighted the importance of designing a decision aid that helped women discuss their contraceptive needs with health care providers who might not communicate well across specialties or who would be unresponsive to needs associated with or engendered by epilepsy.

Step 4) Select a framework for decision support

Step four involves reviewing relevant decision making frameworks and selecting the one most appropriate for the decision aid being developed (161). In this case, the Ottawa Decision Support Framework, the same framework utilized for the needs assessment, was selected. As stated previously, it is a widely recognized framework both for understanding decision making and developing

decision aids. It also asserts that tools to support decisions can help lead to informed decision-making and has been used to guide the development of more than 30 decision aids, and has been evaluated in 24 randomized controlled trials (199). Evaluations of this framework have found that compared to other decision aids, support tools developed with the Ottawa Decision Support Framework are generally of higher quality compared to tools developed with no structure or with other frameworks (200).

Step 5) Select methods of decision support to be used in the aid

The fifth step involves determining how to present information, what values clarifications exercises will be included if any, what guidance about communicating decision needs will be included and how the decision aid will be formatted (161).

The method of information presentation was determined by reviewing how the WHO presents information in their contraceptive decision aid, and adapting the WHO's use of graphics and brief bullet points to allow for inclusion of epilepsy-specific contraceptive concerns. Because values clarification is a stated goal, and important part of contraceptive decision-making for women with epilepsy, a values clarification exercise is included in the decision aid. To

develop the values clarification exercise, I listed the values that the needs assessment revealed as critical to contraceptive decision-making, as well as the values included in contraceptive education tools targeted at broad audiences (201). I then followed guidance about the most effective ways to present values clarification information (202). An exercise about how best to communicate decision-making needs with health care providers and others was adapted from Prunty and colleagues in their previously discussed decision aid for women with MS considering their motherhood choices (180; 198).

To determine the format of the decision aid, I first reviewed common decision aid formats. Decision aids have been implemented in a variety of formats including simple paper-based tools such as brochures or flip charts, or more complex formats such as individual or group counseling, audiotapes, videos, computer programs or web-based programs (169). Considering the needs of the users, feasibility constraints and cost effectiveness factors, a paper-based decision aid was selected as the most appropriate format. A paper-based decision aid can be easily produced, reproduced and distributed to a large population, and is also portable in a way that electronic and other media decision aids cannot be. The aid's portability will facilitate women being able to take the decision aid into a health care provider's office and discuss the issues that

emerged for them after reviewing the tool.

After determining the methods of decision support, I drafted the text of the decision aid. The decision aid was then formatted by a professional graphic designer, Misty Dennis.

Step 6) Select the designs and measures to evaluate the aid

The sixth step involves determining the best design for evaluating the decision aid; including the sampling and design frame, the criteria for evaluation and the measurement tools that will be used to operationalize those criteria (161).

Evaluation methodology: Overall design

A pre-post test telephone evaluation of the acceptability and preliminary effectiveness of the decision aid was conducted with 14 women with epilepsy. Evaluating the acceptability of the decision aid by relevant stakeholders supported the development of a tool that can feasibly be used by the target population (161). Evaluating the effectiveness of the decision aid helped to ensure it met its desired goals (161). A pre-post test design was selected as it is a strong evaluation design that allows for the identification of changes in informed decision-making that occur as a result of individual's reviewing the decision aid

(203). In the pre-test, study participants answered a brief series of questions over the phone (Appendix C). Participants were then emailed or mailed (depending on their preference) a copy of the draft decision aid. Then, a brief post-test was conducted over the phone (Appendix D). All study materials and procedures were approved by the BUMC IRB. IRB approval materials can be found in Appendix B.

Sample size

The sample size of 14 was determined after conducting a power calculation that estimated that women would be able to answer 70% of the questions on the pre-test correctly prior to viewing the decision aid and 90% of the questions on the post-test after viewing the decision aid. For this power calculation, I set an alpha error of 5% and a beta error of 50%.

Recruitment

Women with epilepsy were recruited to evaluate the decision aid through posts to the community based websites Craigslist and Facebook. The recruitment posts invited women interested in evaluating the decision aid to call or email and indicate interest. Additionally, women who participated in the in-

depth interviews and expressed interest in being contacted for future studies were emailed, and asked to call or email if they were interested in participating in the evaluation study.

Eligibility criteria

After women indicated interest in the study, they were screened for eligibility. Women were eligible to participate in the evaluation of the decision aid if they met the same criteria outlined previously for participation in the in-depth interviews: a medical diagnosis of epilepsy, ages 24 to 44, fluent English-speakers, and residents in the U.S. at the time of the interview. In other words, they were required to have epilepsy and be likely to have made reproductive decisions so they could discuss first-hand experience, be able to communicate easily with the interviewer and be available for follow-up.

Informed consent procedures

All eligible and interested women were read aloud an informed consent form. The informed consent covered the purpose and voluntary nature of the study, potential risks to participants, confidentiality, data security, assurance that participants can withdraw at any time or refuse any questions and my contact

information as well as the contact information of the BUMC IRB. After verbal consent was given, the pre-test began.

Survey Variables

To develop measures of acceptability and effectiveness, I adapted measures put forth in the Ottawa Decision Support Framework (204).

The seven included measures of acceptability focused on comprehensibility of the decision aid, balance in presentation of information about options, tool length, amount of information provided and overall suitability for contraceptive decision-making. Additionally, the post-test survey included open-ended questions soliciting general likes and dislikes about the decision aid.

To evaluate effectiveness, a series of questions were included in both the pre and post- test. Seven questions solicited women's knowledge about issues relevant to deciding to start a contraceptive or pick a contraceptive. Two questions evaluated values clarity about the importance of pregnancy prevention and seizure control when selecting a contraceptive. Two questions evaluated feelings of self-efficacy; one focused on efficacy related to making contraceptive decisions and the second focused on efficacy speaking with health care providers

about contraceptive concerns.

Data analysis procedures

I hypothesized that after reviewing the decision aid, participants would have increased knowledge, changes in their values clarity regarding contraceptive or neurological preferences and increases in feelings of self-efficacy. To test the hypothesis, all closed-ended data collected from the survey were input and analyzed in the statistical software program SPSS, version 20. Basic descriptive statistics were then generated to summarize participant epilepsy and reproductive characteristics. Because it was appropriate to make only limited assumptions about the distribution of the data, a non-parametric statistical test was chosen to measure the effectiveness of the decision aid (205). Specifically, the The Wilcoxon signed rank test, which compares the difference between pairs, was selected to calculate the differences in responses between the pre-test and the post-test, and whether or not measured changes were significant.⁹ Responses to open-ended questions were also reviewed and summarized in a Word document.

⁹ Of note, the test does not provide confidence intervals, but it does determine statistical significance.

Evaluation results

Participants:

Between February and May of 2012, 14 women participated in the evaluation. As shown in Table 8, they were on average 32 years old. All but two participants were white, and none reported an ethnicity. The sample was well educated with all women having attended college. Participants reported their epilepsy diagnosis occurred an average of 15 years prior to study participation. Almost half of participants had non-convulsive seizures; the remainder had a combination of exclusively convulsive or convulsive and non-convulsive seizures. Half of participants took AEDs in monotherapy, 43% took them in polytherapy, and 7% were not taking medication. Participants reported a range of current contraceptives, with the majority of participants using either sterilization or no contraceptive. Participants had an average of one child.

Table 8. Evaluation participant demographic, epilepsy and reproductive characteristics.

Characteristic	mean (range; standard deviation)
Age	32 (26-44; 4)
Duration, in years, of diagnosis	15 (3-29; 9)
Number of children	1 (0-3)
n (%)	
Race	12 (86)
Non-Hispanic white	2 (14)
Non-Hispanic Black	
Education	
Some college	3 (21)
Bachelors	8 (57)
Graduate	3 (21)
Type of seizure	
Convulsive	2 (14)
Non-convulsive	6 (43)
Both convulsive and non-convulsive	6 (43)
Current epilepsy medications	
AED in monotherapy	7 (50)
AED in polytherapy	6 (43)
None	1 (7)
Current contraceptive	
Vasectomy	3 (21)
Hysterectomy	1 (7)
IUD	1 (7)
OCPs	2 (14)
Condoms	3 (21)
None	4 (29)

*Numbers may not add up to 100% because of the rounding of whole percents.

Acceptability of decision aid

As seen in Table 9, 79% of participants reported reviewing 100% of the guide, and the remaining participants estimated they read between 75-100% of the guide. Most participants estimated it took them 15 minutes to read the entire

guide. All participants rated the information included in the decision aid as of excellent or good quality. However, participants were split about the amount of information included; half thought too much information was included, 43% reported the amount of information was appropriate, and 1% thought there was too little information. When asked to provide specific feedback about content, participants gave the chart of contraceptive methods, values clarification exercises and questions for their health care providers high marks with all participants rating the helpfulness of those components of the decision aid a four or above, on a scale of 1-5.

Evaluation participants were asked open-ended questions about what they liked about the guide, and reported that it was an important and necessary resource. In fact, one participant described the decision aid as “more than educational” and said she would recommend it to other women with epilepsy. Another said she wished she would have read the decision aid prior to her hysterectomy, as it would have changed her decision. Evaluation participants also had strong and positive responses to the format of the guide, stating that it looked professional and polished and that they liked the printed size of the guide, as well as how it looked online.

However, participants also reported there were two important ways the guide could be improved. Specifically, several participants expressed concern that the guide did not mention that there were several types of epilepsy. Next, almost all participants reported the guide was too “wordy,” “dense” and “long,” irrespective of their responses about the amount of information included in the guide.

Effectiveness of decision aid

Table 10 below displays the results of the effectiveness of the decision aid, and shows that there were statistically significant increases in knowledge, but no significant increases in values or self-efficacy between the pre and post-test.

Women were asked seven questions in the pre and post-test to evaluate their knowledge of issues relevant to decisions to initiate contraception and pick a contraceptive. Evaluation of the impact on knowledge measures shows that women began with an overall low level of knowledge about issues addressed in the decision aid, with only 68% answering all of the pre-test questions correctly. By the time of the post-test, 89% of overall answers were answered correctly. This was a significant improvement in overall knowledge ($p = .003$). Accurate

responses to knowledge measure questions increased for all but one question, and these increases were statistically significant for four questions. First the Table 9. Acceptability of decision aid.

Variable	n (%)
Percentage of guide read	
100%	11 (79)
75-100%	3 (21)
50-75%	0 (0)
25-50%	0 (0)
0-25%	0 (0)
Time spent reading guide	
0-1 hour	13 (93)
1-5 hours	1 (7)
5 or more hours	
Rating of information presentation	
Excellent	6 (43)
Good	8 (57)
Fair	0 (0)
Poor	0 (0)
Rating of amount of information	
Just right	6 (43)
Too much	7 (50)
Too little	1 (7)
(scale 1-5)	mean (range; standard deviation)
Helpfulness of contraceptive chart	4.6 (4-5; .5)
Helpfulness of women's stories	4.5 (3.5-5; .7)
Helpfulness of doctor's checklist	4 (3-5; 1.2)

*Numbers may not add up to 100% because of the rounding of whole percents.

percent of participants answering correctly that some contraceptives can interfere with the efficacy of AEDs increased from 57% to 86% ($p=.05$). Second, the percent of participants answering correctly that some AEDs can interfere with

the efficacy of contraceptives increased from 57% to 86%, ($p=.046$). Third, the number of participants answering correctly that some contraceptives can reduce seizure occurrence increased from 29% to 57%, ($p=.046$). Fourth, the number of participants responding correctly that most children born to women with epilepsy do not have birth defects increased from 64% to 100% ($p=.0025$).

Women were asked two values measures questions in the pre-test and the post-test. Women were asked to state on a scale of 1-10 how important maintaining seizure control was when selecting a contraceptive, as well as how important protection from pregnancy was when selecting a contraceptive. In both the pre and the post-test, participants indicated that they place a high value on pregnancy prevention and seizure control when selecting a contraceptive. The value women placed on seizure control did not change, and held steady at 9.6. However, the value that women placed on protection from pregnancy increased from 9.5 to 9.6, but this increase was not statistically significant.

Two questions related to self-efficacy were included in the pre-test and post-test. Participants were asked to rate on a scale of 1-5 how confident they felt making contraceptive decisions, and how confident they felt speaking to a health care provider about their contraceptive concerns. In the pre-test, participants gave scores indicating they felt mildly confident to complete both tasks. In the

post-test, reported feelings of self-efficacy increased along both measures, but not at a statistically significant level.

Table 10. Efficacy of decision aid.

Pre-post test results	Pre-test	Post-test	p value
<i>Knowledge measures</i>	(%)	(%)	
Overall questions answered correctly	68	89	.003
Answered correctly that seizures can increase around women's periods	86	100	.157
Answered correctly that some contraceptives can interfere with the efficacy of some AEDs	57	86	.05
Answered correctly that some AEDs can interfere with the efficacy of some contraceptives	57	86	.046
Answered correctly that some types of contraceptives can reduce occurrence of seizure	29	57	.046
Answered correctly that most children born to women with epilepsy do not have birth defects	64	100	.025
Answered correctly that most children born to women with epilepsy do not have epilepsy	93	100	.317
Answered correctly that women with epilepsy can have safe and normal pregnancies	93	93	(n/a)
<i>Values measures</i>	Mean (sd)	Mean (sd)	
Importance of protection from pregnancy in contraceptive choice on a scale of 1-10	9.5	9.6	.581
Importance of maintaining seizure control in contraceptive choice on a scale of 1-10	9.6	9.6	n/a
<i>Self-efficacy measures</i>	Mean	Mean	
Confidence to make contraceptive decisions on a scale of 1-5	3.1	3.5	.096
Confidence to speak to health care provider about contraceptive concerns on a scale of 1-5	3.4	3.8	.126

Decision aid revisions

The evaluation showed that the decision aid is acceptable and is effective at increasing knowledge, highlighting its potential for increasing informed contraceptive decision-making and the specific components of the decision aid that worked well. However, significant improvements across all measures were not seen across the board, suggesting some areas for improvement.

First, given that there were not significant differences along three of the seven knowledge measures, and that many participants indicated that the decision aid was too text heavy and had too much information, I removed many dense paragraphs and replaced them with quick bulleted lists or short sentences that highlighted the main points of the decision aid. I also revised the language of the decision aid so that it is more straightforward. The original decision aid was written at an 11th grade level; the revised decision aid is written at a 7th grade level. Next, I made no changes to the decision aid in relation to values clarity since participants rated the value they placed on both pregnancy prevention and contraceptive control very highly. This suggests that women need to bring both issues to the table when they see a health care provider. Given the importance of communicating with health care providers, and given that women's confidence in doing so did not increase significantly, I revised the decision aid to emphasize

the importance of communication with health care providers and included strategies for speaking with health care providers when contraceptive needs remain unmet. Additionally, because participants gave high scores to the contraceptive chart, women's stories, and the checklist for doctors, I retained those components. Finally, I also retained the overall format of the guide since in open-ended responses women reported high marks for the guide's overall design. A black and white version of the revised decision aid can be found in Appendix E.

Step 7) Plan for dissemination

The last step in developing and evaluating a decision aid is disseminating the tool and promoting its use to key stakeholders (161). In-depth interviewees and evaluation participations made a number of suggestions for how to disseminate the tool. Specifically, they emphasized the importance of broad dissemination and of developing both a web-based and paper-based version of the tool. Suggested dissemination for a web-based tool included online epilepsy forums as well general social media avenues (such as Facebook). Women suggested that the paper-based decision aid should be available in print at the offices of non-profit epilepsy foundations, public health facilities, neurologists,

obstetrician/gynecologists, PCPs and family planning clinics. Strategies such as these that include print production costs will be pursued once funding for dissemination has been secured. Until that time, the tool will live on the website of Ibis Reproductive Health (www.ibisreproductivehealth.org), a non-profit organization that conducts clinical and social science research targeted at improving women's health worldwide. It will also be disseminated through contacts at the Epilepsy Foundation and the Massachusetts Department of Public Health.

CHAPTER 7:

DISCUSSION AND NEXT STEPS

Introduction

The findings of this dissertation suggest that there continues to be misunderstanding about the causes and consequences of epilepsy, and that those experiencing seizures commonly both anticipate stigma and experience it. Women's reports of their experiences with seizures also bring to light the fundamental emotional, physical and spiritual changes that can occur without warning when a seizure takes place. Women's reports further highlight that seizures can increase feelings of vulnerability and incompetence, decrease abilities to carry out everyday tasks, and in extreme cases be life threatening. Struggles to identify an acceptable treatment to prevent such occurrences pervaded the study.

Further, findings show that the reproductive decisions of women with epilepsy are heavily influenced by their experiences taking on stigmatized identities, living with seizures, the side effects of seizure treatments and concerns about the perceived risks of increased seizure occurrence and unacceptable reproductive outcomes, marking both their reproductive needs and decision-making as qualitatively different than women in the general population.

Many women in this study, though not all, prioritized their neurological health over access to a broad array of reproductive choices. Indeed, some

women avoided contraceptives that they felt would interfere with seizure control and others avoided biological pregnancy or parenthood for the same reasons. Though living with epilepsy and its treatment clearly affects women's reproductive decisions, gaps in the health care system leave women's specific reproductive health needs unaddressed, and contribute to uninformed decision-making and undesired neurological and reproductive health outcomes.

Parenting and Pregnancy Decisions: Information, Values and Resources

Women's descriptions of their decision-making surrounding having children and managing their health during pregnancy revealed a complex balancing of the risks and benefits they perceived to be associated with pregnancy and becoming parents, which was directly related to the information they had been given by their health care providers, the value they placed on seizure control and optimal pregnancy outcomes and the support they had to implement their decisions.

Most women reported their health care providers offered comprehensive clinical information about their potential to carry a pregnancy and have children. Moreover, women who were offered this information early in their reproductive lives reported feeling grateful, as decisions about whether or not to have a child

appear to percolate long before women engage with them fully. However, a minority of women reported lacking information about the possibility of biological parenthood for women with epilepsy, either because they were discouraged by health care providers from having children or because they were given no information or conflicting information about issues related to having children. The fact that even a small number of women perceived that their health care providers were unsupportive of women with epilepsy having children suggests some degree of continuing stigma, and is troubling in light of not-so-distant U.S. policies and programs that mandated sterilization of individuals with epilepsy (69).

By far, the biggest challenge women faced to making informed decisions about whether or not to have children and how to manage their health during pregnancy was balancing the value they placed on seizure control with the value placed on having a healthy child. Some women described feeling forced to decide between their own health and the health of their offspring. The typology that emerged in this study showing the different ways that women approached these decisions dependent upon the value they placed on seizure control and the value they placed on preferred reproductive outcomes, highlights the important role of values clarification and prioritization in decision-making for this

population. Indeed, results suggest that women experience the most decisional conflict about their decisions regarding having children and health management during pregnancy when they are unclear about their desires to become parents, and when they place a high value on *both* seizure control and optimal pregnancy outcomes. Women who were decided about desires to become parents or not, and those who placed a higher value on either seizure control or optimal pregnancy outcomes, displayed considerably less decisional conflict.

A second and related challenge that women faced was overcoming feelings of self-doubt of their capacities to be “good” mothers. Doubts surfaced when women’s questioned their ability to carry a healthy pregnancy, and when they anticipated feeling guilty if their children had any health problems that could be attributed to maternal epilepsy or AED use. They also surfaced when women shared the sadness they felt knowing that during seizures they could not take care of their children, and in knowing that their efforts to prevent seizures (by, for example, not disrupting sleep to take care of an infant) or seizure-related injury to their children (by, for example, not driving with their child in the car) limited them from conducting the child-rearing duties often seen as hallmarks of motherhood.

However, many women were able to resolve this particularly challenge by

involving partners and family members in childrearing. The women in this study described having ample people in their lives who prioritized maternal health over fetal health during pregnancy and pregnancy planning, and who helped mitigate epilepsy-related parenting challenges that women faced. This finding highlights that being part of a network of support is an important and perhaps necessary resource for women with seizure disorders who are planning pregnancy, pregnant or raising children. It also brings forth factors outside of the clinical environment that influence women's ability to implement reproductive decisions. It is unclear how women with fewer support resources make parenting and pregnancy decisions, or if they perceive themselves as unable to implement such decisions without similar resources.

Contraception: Information, Values Clarity and Resources

Women's experiences with contraceptive decision-making and contraceptive use revealed that women encounter a number of challenges in the process of making and implementing informed contraceptive decisions. First, women appear to largely be uninformed about potential interactions between AEDS and hormonal contraceptives prior to the initiation of contraception. Many women eventually gleaned some information about these interactions through

experience, though other women reported being fearful of initiating a hormonal contraceptive and limited their experiences with them. Second, health care providers appear to generally offer contraceptive care that women believe does not meet *both* their neurological and reproductive health care needs. In particular, women reported neurologists offered limited or poor contraceptive advice and that obstetrician/gynecologists appeared unfamiliar or uncomfortable with the specific contraceptive needs of women with epilepsy. As they sensed the segregation of neurological care and reproductive health care in the health care system, women often tried to coordinate advice and prescriptions from their neurologists and obstetrician/gynecologists, but were largely unsuccessful. Third, some women did report experiencing financial barriers to accessing contraceptives generally or to specific methods that they preferred. Finally, a minority of women lacked information about the possibility of pregnancy and parenthood for women with epilepsy, and hence made contraceptive decisions that would permanently prevent them from having biological children. In sum, these results suggest that women with epilepsy frequently lack the information necessary to make contraceptive decisions consistent with their values, and that they sometimes lack the resources needed to implement their decisions.

These challenges led women to “stab in the dark” to find an acceptable contraceptive. These stabs led to breakthrough bleeding, unplanned pregnancies, interruptions in seizure control, women initiating or stopping contraception without consulting with a health care provider, unnecessary limiting of contraceptive choices or use of permanent contraceptives, dissatisfaction with contraceptive choices and mistrust of health care providers. One positive thing that emerged from trying to navigate those challenges is that some women learned to become their own advocates in the health care setting and reported playing an active role in their health care decisions. Also, many women reported reaching out to other women with epilepsy and finding the epilepsy community for the first time after experiencing these challenges. They found that contact with other women who shared their experiences and concerns was both informational and comforting.

Contraceptive Decision Aid

Findings about the difficulties women faced obtaining care that simultaneously addresses their neurological and contraceptive needs suggested a need for prompt intervention. The contraceptive decision aid designed as part of this dissertation is responsive to the contraceptive needs identified in the needs

assessment. Results of the evaluation of the decision aid suggest that a contraceptive decision aid is not only an acceptable, but desired intervention tool. Moreover, the decision aid was found to be effective at increasing knowledge. Continued efforts to further evaluate and disseminate the decision aid are needed to promote informed contraceptive decision-making in a broad population of women with epilepsy.

Consistency with Previous Literature

Findings about women's experiences deciding to have children and managing health during pregnancy are only somewhat consistent with previous literature. Whereas the needs assessment showed that women feel relatively well-informed about these issues, previous research shows that women with epilepsy face challenges obtaining information about parenting and pregnancy from their health care providers (98; 102; 143) and that clinicians are uncertain about the effects of AEDs on pregnancy outcomes (107). Three possibilities may explain why participants in this study had largely positive reports about their experiences with health care providers and reported they had sufficient information to make informed decisions about pregnancy and parenting. First, the women in this study may have had better access to the health system or the

supports systems than women in other studies. Second, women in this study may have had more experience with pregnancy and parenthood than those in previous studies, and may be better educated than the general population. Alternatively, these positive experiences could be a result of effective dissemination of relevant best practice guidelines to health care providers, such as the 2006 and 2009 guidelines about how to manage epilepsy in women of reproductive age. It is feasible that over the last six years health care providers have become better educated about how to support women with epilepsy in considering and implementing decisions to have children and to manage health during pregnancy. The findings reported here are likely a combination of these three factors.

Findings about the struggles that some women in this study faced balancing taking care of their own health needs with the desire to ensure optimal fetal health outcomes may help explain why previous research shows women with epilepsy (141), like women with other chronic conditions requiring treatment throughout pregnancy (206), experience a lower HRQOL during pregnancy than pregnant women in the general population . Confidence in this finding is supported by previous research showing that HIV-positive women struggle to balance their own health needs with the health of their offspring,

which often result in women avoiding desired pregnancies (207) or taking on considerable guilt about the potential for fetal or offspring harm when they do have biological children (172).

Other scholarship suggests that many women in the general population, not just those with chronic conditions, suffer from reduced HRQOL during pregnancy (208). Further, literature shows that women in the general population feel considerable pressure to produce perfect children, which causes women enormous anxiety and stress (209; 210). However, the increased burden of this pressure for women with conditions whose treatment may cause direct fetal harm or whose condition can be passed to the child (either genetically, or as is the case of HIV through pregnancy, labor or delivery) must be underscored.

Challenges women in this study reported in making informed contraceptive decisions are consistent with other literature showing that women with epilepsy have little information about interactions between contraceptives and AEDS (98–101), and that health care providers are often unprepared to offer adequate contraceptive counseling to women with epilepsy (92; 98; 103–107). At the same time, women's reports in this study of their challenges with contraceptive decision-making help explain previous findings that women with epilepsy have lower rates of highly effective contraceptive use (the use of

sterilization, IUD, IUS, hormonal pill, patch, or injection) compared to the general population (94). Indeed, women in this study often reported concern that hormonal methods may interfere with their seizure control, meaning women with epilepsy may elect out of using the pill, the patch or injection, three highly effective methods commonly used by the general population.

The contraceptive challenges described by women with epilepsy in this study are also largely consistent with those reported to be experienced by women with other health conditions (211). Likewise, studies show that women in the general population face challenges accessing information about contraception and (176; 212; 213), working with health care providers on contraceptive issues (176; 212) and affording contraceptives, particularly when a woman is uninsured or health insurance does not cover the full range of contraceptive options (176; 214).

Finally, other literature suggests that the challenges identified here regarding making and implementing reproductive health care decisions are commonly encountered challenges faced by people with epilepsy whenever they seek any type of health care. In fact, in 2012, the IOM issued a report on the public health dimensions of epilepsy. The IOM's report highlighted that people with epilepsy commonly encounter stigma, have limited access to appropriate

high-quality health care information and services and struggle to coordinate their multifaceted health care needs (215). The consistency of this dissertation's findings about reproductive health with the general challenges that people with epilepsy face in the health care setting suggests that the informed decision-making challenges documented here are likely experienced by a broad population of women with epilepsy of reproductive age.

Results of the contraceptive decision aid evaluation cannot be generalized to other evaluations of contraceptive decision aids for women with epilepsy as no other tools or evaluations exist. However, results can be compared to evaluations of other decision aids. A literature review finds that well-designed decision aids increase knowledge, enhance values clarity and have a positive effect on communication between health care providers and clients, among other benefits (8). Additionally, evaluations of contraceptive-specific tools for the general population show that the tools increase knowledge about contraceptive options and make individuals feel more comfortable talking and asking their health care provider questions (195–197). Increases in knowledge were found in this dissertation's evaluation of the developed contraceptive decision aid, though changes in women's values or feelings of self-efficacy were not identified.

Generalizability

Findings about how women with epilepsy navigate the complex terrain related to their reproductive decision-making may prove fruitful for understanding how the sizeable population of women of reproductive age with other conditions, disorders or disabilities navigates similar territories.

As more women of reproductive age take prescription medications for chronic health care needs, assessing and addressing their contraceptive and pregnancy decision-making needs is becoming an increasingly important public health issue. The use of prescription medications that affect contraceptive efficacy is common in the U.S. (88), though few women taking prescription medications receive adequate counseling about the impact of prescription medications on contraceptive efficacy (216). Additionally, the number of women in the U.S. taking prescription medications during pregnancy has increased by more than 60% in the last three decades, and in 2008, almost half of pregnant women were taking at least one prescribed medication (217). Further, women being treated for migraine, depression, pain and bipolar disorder are commonly prescribed AEDs, meaning the findings and decision aid resulting from this dissertation may have direct relevance for these groups (86; 95; 217). In fact, more than 50% of AED prescriptions written in the U.S. are written for

indications other than epilepsy (6).

Moreover, the challenges to informed reproductive decision-making for women with epilepsy may have implications beyond medication issues for other women with chronic illness and/or disability.¹⁰ The features of epilepsy can be both sporadically visible (during a seizure) and invisible (while seizures are dormant), meaning people with epilepsy may have disabling moments and specific limitations in regards to driving a car, for example, but otherwise “pass” as able-bodied. For this reason, findings about the importance of values to the decision-making process and the particular challenges of coordinating specialty care with primary care may be applicable to a broader group of women.

There are some limitations to generalizing the findings about the reproductive decision-making need and process of women with epilepsy to women with other conditions, disorders or disabilities. Indeed, the specific clinical features, the necessity for continued medication during pregnancy, and the speculated outcomes of reproductive decisions may be very different for women with epilepsy compared to other women. Regardless of these clinical differences, these groups of women likely face many similar circumstances and

¹⁰ Understanding that definitions of disability vary widely, I relay on the WHO’s definition of disability and utilize it as an umbrella term for impairments, activity limitations or participation restrictions in which there is a “dynamic interaction between health conditions (disease, disorder, injuries, traumas, etc.) and contextual factors”. Contextual factors include both environmental and personal attributes (218).

weigh similar considerations when making reproductive decisions. Hence, examining the experiences and needs of women with epilepsy provides for a rich and useful study with applications for other women.

Public Health and Practice Implications

A broad public health agenda must be developed to adequately address health determinants and the health care needs of women with epilepsy, reflecting the complex interplay between individual and social-environmental factors (219). This approach acknowledges that individuals do not exist in a vacuum, but instead have relationships and exist within families and neighborhoods that are in turn embedded in larger societal organizations (10). Furthermore, as life course approaches have demonstrated, life events are interconnected even on the individual level; the reproductive years represent a sensitive developmental period that can have significant impact on women's health outcomes throughout the life cycle (177).

In 2012, the IOM took a first step at developing this agenda with the release of several recommendations for better understanding the public health impact of epilepsy and meeting the needs of people with epilepsy and their caregivers (215). Though a promising recognition of the urgent need for a public

health response for the population, the IOM's recommendations do not fully engage with the unique needs of women with epilepsy; nor do they adequately address the ways that women's needs change during their reproductive years. The IOM's recommendations will have limited potential to promote the health of those most in need of support if they do not address how gender and life cycle (among other variables such as race, ethnicity, and socioeconomic status) affect those living with epilepsy.

Therefore, I have developed a series of recommendations, grounded in the framework and findings of this dissertation, which explicitly address the needs of women with epilepsy of reproductive age. Dissertation findings emphasize the need for women-centered practices, guidelines and policies that recognize the overlap between, and critical importance of, neurological and reproductive health for women with epilepsy. These recommendations place women in the center of their reproductive decisions, are grounded in evidence, are developed from a framework that acknowledges the multi-level factors that affect women's reproductive decisions and are largely consistent with the IOM's goals and recommendations for improving the public health response to epilepsy. For these reasons, they represent powerful opportunities to promote the health of women with epilepsy. These recommendations arise from findings about the

individual experiences and values of women with epilepsy, but go beyond the level of the individual to address the determinants of perceptions about seizure control, access to information and options for medical treatment.

1. Develop evidenced based contraceptive guidelines that address the reproductive and neurological health needs of women with epilepsy. The CDC's publication of the MECs is an important step towards recognizing and meeting the contraceptive needs of women with various health conditions, including women with epilepsy. However, because the guidelines do not "consider the use of contraceptive methods for treatment of medical conditions" (77), the potential benefits of using contraception to reduce women's seizures are not emphasized, and hence the relationship between neurological and reproductive health for women with epilepsy is not fully explored. More specialized guidelines that fully consider the benefits and risk of contraceptive use in this population are needed.

2. Improve current guidelines focused on managing pregnancy in women with epilepsy. Though I speculate that current clinical guidelines focused on managing pregnancy in women with epilepsy have been powerful tools for supporting health care providers working with women with epilepsy of reproductive, the guidelines need some improvements.

Most importantly, strategies for assessing and addressing women's preferences and values must be integrated into guidelines. Specifically, guidelines must address the preferences and values that emerged in the values typology. This would mean placing women's preferences and desires at the heart of any discussion regarding pregnancy, and would require health care providers to engage in explicit discussion of women's pregnancy desires, as well as their preferences for neurological and pregnancy outcomes, in order to make appropriate epilepsy treatment recommendations throughout women's reproductive years.

Next, guidelines must address the acceptability and affordability of health care. In particular, clinical recommendations about pregnancy care appear to involve significant time and costs to women (considering the suggested medication monitoring and other testing throughout pregnancy), but ability to implement these plans is not mentioned in any of the clinical guidelines.

Third, recommendations focused on improving maternal and fetal health outcomes focus only on clinical or pharmaceutical measures, eclipsing other factors that influence pregnancy health outcomes. Results from this study suggest that recommendations would be better received by women if they integrated clinical and social aspects of epilepsy and pregnancy planning.

Examples of such recommendations could include strategies for ensuring partner or family support to help a woman manage stress.

Fourth, guidelines must provide health care providers direction for working with women around the issue of testing and diagnosis of congenital malformations. Results from this study suggest women do prefer to undergo prenatal screening, but that they also have specific preferences about how much screening they would like to undergo and which health care providers with whom they would like to discuss their results. Women's preferences about these issues must be integrated into the guidelines.

The integration of these suggestions into existing clinical would result in guidelines that are responsive to women's preferences regarding pregnancy care. Continued work is needed to disseminate guidelines to a broad array of health care providers who interact with women with epilepsy prior to and during pregnancy, regardless of integration of these suggestions into existing guidelines. As part of their recommendations, the IOM suggests that a national quality improvement strategy be developed that includes the development and dissemination of existing clinical guidelines related to epilepsy care (215). This recommendation to develop contraceptive guidelines, and to improve and disseminate pregnancy management guidelines is consistent with the IOM's

goals to improve the quality and consistency of health care for people with epilepsy through health care guidelines. It is also consistent with broader public health goals to address the contraceptive and family planning needs of women generally (212).

3. Develop systems to better integrate reproductive and neurological health care. With health care segregated, women's whole health is not addressed. Instead, neurological needs and gynecological needs are treated as separate issues when these issues are tightly intertwined for women with epilepsy. Because of this, neurologists must be trained to be responsive to reproductive health care needs, and obstetrician/gynecologists must be trained to be responsive to neurological needs or better referral systems between the two specialties need to be developed.

Difficulties women reported in this study around contraceptive decision-making highlight the critical need for better integrated care. Some women reported they feared the initiation of hormonal contraception and worried that it would disrupt their seizure control. This suggests a need for both neurologists and obstetrician/gynecologists to inquire about women's perceptions of the potential impact of hormonal contraceptives on seizure control. Moreover, until clinical research can identify the exact interactions between specific AEDS and

hormonal contraceptives, it is critical that women be screened about their willingness to try different hormonal methods in the absence of clear indication of how their seizures will be affected. If women are willing to go through a process of trial and error with different contraceptives, they must be monitored closely, and health care providers must be responsive to women's perceptions of how the contraceptive affects their neurological health. If women are unwilling to risk the use of a hormonal method, an effective non-hormonally based contraceptive must be recommended.

Until care can be better integrated, a system of referrals from one health care provider may be necessary. The preferences women expressed in this study for working with neurologists on any issues related to seizure control suggest that the most acceptable referral system would be for a neurologist to act as the initial and primary source of information, and for obstetrician/gynecologists to act as secondary providers. However, since integrated care is still an elusive goal in the U.S., it will be difficult to ensure that a system of referrals does not result in women being 'lost' in the health care system, with no one health care provider responsible for their reproductive health care.

This recommendation is consistent with the IOM's suggestion to develop systems to better coordinate neurological health care with other health care

providers, and to improve education of health care providers to ensure that they are “sufficiently knowledgeable and skilled to provide high-quality, patient-centered, interdisciplinary care (215).” Further, there is a clear opportunity to include reproductive health issues in the IOM’s suggestion to define essential epilepsy knowledge and skills for health care providers and to conduct surveys of relevant health care providers to identify knowledge gaps and needs.

4. Ramp up efforts to inform women with epilepsy about their reproductive options through the use of evidence-based decision aids. Findings that many women were unaware of the potential for interactions between contraceptives and AEDs, and that even a small number of women felt pressured to undergo sterilization, suggest the need for increased efforts to educate women about their reproductive options. Yet, results from this study suggest that women need more than education; they need an opportunity to explore and express their values and to incorporate their preferences into the decision-making process.

The developed contraceptive decision aid is one tool for helping meet this aspect of women’s unmet reproductive health needs. One important feature of the decision aid is the power that it puts in women’s hands to be equal participants in their contraceptive consultations with health care providers. It

provides women with evidence-based information about contraception, and with stories of other women with epilepsy who have had both positive and negative experiences seeking contraceptive advice from their health care provider. The decision aid also acknowledges that women may not receive ideal contraceptive care on their first try, and outlines strategies for talking with doctors about their needs, or seeking out different doctors if their needs remain unmet. Moreover, the decision aid was found to be effective at increasing knowledge. Given this evidence and that use of evidence-based decision aids in other areas of health has been shown to lead to a number of benefits including improvements in knowledge, better understanding of treatment options and more accurate perception of risks; dissemination of decision aids must be considered an important public health priority to meet the needs of this population (162).

There are emerging opportunities in relation to national health care reform for promoting reproductive-focused decision aids through policy. First, as part of efforts to improve the nation's health, the Affordable Care Act (ACA) outlines the need to develop, update, and produce decision aids. Because the ACA does not include funding for this initiative, there has not to date been significant movement at the state level to promote decision aids. However, other institutions, including the Agency for Healthcare Research and Quality and the

Patient Centered Outcome Research Institute have some funding available for the creation of future decision aids. Next, the ACA does providing funding to evaluate how reimbursing health care providers for supplying their clients with decision aids affects health care costs, delivery and outcomes. Several states have already responded to these recommendations and funding resources by establishing working groups, public-private partnerships or steering committees that will, as part of their broader agendas under health care reform, determine how best to integrate decision aids and their use into state-level policies (220).

These recommendations under the ACA suggest that there is growing momentum for developing and distributing decisions aids that can be readily incorporated into the health care system. Hence, there is an opportunity to advocate for the inclusion of reproductive focused decisions aids for people with epilepsy in a broader national agenda regarding decision aids under health care reform.

The recommendation to better educate women about their reproductive options through the use of decision aids is consistent with the IOM's recommendation to ensure that people with epilepsy are better informed about their health and health care options (220). Though, the IOM suggested developing educational materials and information, and did not explicitly call for

decision aids, I suggest that the inclusion of decision aids in this agenda item is an important way to ensure that health care decisions are not just educated ones, but informed ones.

Implications for Future Research

The findings of the needs assessment and decision aid evaluation suggest that there are several areas in need of future research in order to further promote the health of women with epilepsy of reproductive age.

First, in order to create the contraceptive-focused guidelines suggested above, rigorous research examining the clinical outcomes of contraceptive use in women with epilepsy must be conducted. Considerable progress has been made in pregnancy registries for women with epilepsy; similar contraceptive registries are needed to document the relationship between women's hormones, contraceptive type, AED type and their specific types of seizure disorder or seizure pattern (not just "epilepsy"). This work should look closely at how the catamenial pattern of seizures so commonly reported by women with epilepsy is affected by contraceptive use. Though there is currently some research in this area, it tends to focus on contraceptive outcomes and excludes neurological ones—such as the impact of contraceptive use on seizures and aura.

Next, further work evaluating the developed contraceptive decision aid must be undertaken. In particular, a larger case-control study is needed for further efficacy testing of the tool with a population of women early in their contraceptive decisions. One priority area for this area of research should be further investigation of how a contraceptive decision aid can best improve values clarity and feelings of self-efficacy. Once a larger efficacy trial is completed, consideration should be given to putting an interactive contraceptive decision aid online, as suggested by women in the decision aid evaluation.

Third, more research is needed to determine the impact of developing and distributing clinical guidelines for managing epilepsy in women of reproductive age. Findings from this study suggest that guidelines related to pregnancy may have contributed to the positive experiences women reported accessing comprehensive information about pregnancy and parenting. However, research with a more representative population of women with epilepsy is needed to confirm this speculation. Findings from that research are critical for providing feedback about the effectiveness of established clinical guidelines and for the creation of new guidelines.

Previous literature has called for research into the support needs of mothers with epilepsy, and identification of practical strategies to reduce risks of

maternal anxiety and thereby improve the mother-child relationship (75).

Though dissertations findings provide some evidence of the parenting strategies women used, more work is needed to closely investigate what the needs are of mothers with epilepsy, and what interventions can support these women in taking care of both their children and their own health. These findings could feed into the development of a decision aid targeted at helping women to decide whether or not to have children.

Additionally, continued work is needed that explores how sensitive developmental periods in the life course, such as adolescence, affect experiences with epilepsy and reproductive expectations, needs and choices. Because of the small sample size in this study, I was unable to examine how diagnosis of epilepsy at different points along the life course affected women. However, the results of this study suggest that women do retain information given to them by their neurologists early in their reproductive years. Therefore, research is needed to understand the reproductive decision-making needs and processes of adolescents with epilepsy. Findings from that work could inform the development of interventions to support informed decision-making earlier in the life course.

Another research priority is utilizing the framework and lessons learned in this dissertation for investigating and addressing the reproductive decision-making needs of women with other conditions, disorders or disabilities who experience challenges similar to women with epilepsy in making informed reproductive-decisions and whose conditions may affect their self-perceived competence to be parents. Specifically, an investigation of women taking AEDs for indications other than epilepsy would contribute to this scope of inquiry. As this research area is further developed, the inclusion of research and interventions for women with other conditions that are not neurologically-based, such as women with physical disabilities whose reproductive health care needs are commonly unmet (221), is warranted.

Finally, there were several dimensions of a public health model that were beyond the focus of this study. For example, more work is needed to understand and reverse residual stigma associated with historic policies such as prohibition on marriage, forced sterilization and institutionalization for women with epilepsy in past epochs (69). The role of advocacy organizations and support networks also needs elaboration. Perhaps most importantly, an investigation of the impact of health care disparities on reproductive options and decisions for women with epilepsy was beyond the scope of the sample for this study.

Limitations and Strengths

Needs assessment

The needs assessment has several limitations. Qualitative studies provide rich in-depth information about the experiences of a small number of participants. However, they are not designed to produce generalizable findings. Findings likely do not represent the experiences of all women with epilepsy. In particular, though low-income women and women of color are included in the study, they are underrepresented, and more research is needed to examine the intersecting role of race, class and health status on reproductive decision-making. Additionally, because all participants were English speakers, the experiences of non-English speakers are not represented. Further, women under the age of 24, and with less reproductive experiences, were not included in the study, and I therefore cannot reflect on their decision-making experiences. The sample was also not large enough to determine how different development periods in women's life courses affected the results. For example, it is unclear if the values typology represents phases of values that women go through during their reproductive years, or if their values regarding neurological and reproductive outcomes remains stable. Finally, I cannot assess the impact of non-participation bias, though it may be that women with more either extremely positive or

difficult reproductive experiences were more inclined to participate in the study.

Despite these limitations, this study has several strengths. First, it represents an important step forward in understanding the reproductive decision-making and needs of an underserved population. The fact that findings from in-depth interviews and online forums were remarkably consistent with one another, and largely consistent with previous literature, bolsters the credibility of results. Second, findings make an important contribution to understanding the public health dimensions of epilepsy by suggesting that the common health care challenges faced by people with epilepsy not only affect their neurological health, but also contribute to poor health outcomes in other aspects of their care, such as reproductive health. This is an important framing for meeting the comprehensive needs of individuals with the disorder. Additionally, the use of qualitative methods allowed for exploration of emerging ideas, such as the important and overlooked role of seizure control in contraceptive choice. Next, this dissertation compares and contrasts women's experiences with different aspects of reproductive health care, making clear that while considerable progress has been made on meeting women's decision-making needs related to deciding to have children or how to manage health throughout pregnancy, continued work is needed to ensure they can make

informed contraceptive decisions. Finally, there is no theoretical foundation identifying how the decision-making processes may or may not vary among some populations. Scholars have pointed to the need for further investigation of the influence of ethnicity, race, gender, age and other socio-demographic factors, on decision-making, as well as calling for more information on how having chronic or co-occurring health conditions influences decision making (222). Findings from this dissertation contribute to the limited evidence base about how being female and having a chronic disorder influence decision-making, providing an opportunity to advance this area of inquiry.

Developed decision aid

The developed decision aid, which is the first identifiable decision aid targeted at meeting the contraceptive needs of women with epilepsy, has several strengths. First, following an established model for developing and evaluating a decision aid helped ensure that a high-quality tool was developed. Additionally, because the decision aid is informed by women's reports in the needs assessment and decision aid evaluation, the tool is responsive to the target population's needs. Next, as shown in Table 11, the decision aid meets 10 of the 12 quality criteria for decision aids established by the International Patient Decision Aids

Standards (IPDAS) Collaboration (162). The decision aid does not meet two of the quality criteria. First, though there are no conflicts of interest to report, this is not disclosed in the decision aid. Second, it does not present probabilities of outcomes because there is no research that identifies the probabilities of outcomes such as changes in seizure occurrence or pregnancy rates.

Table 11. Contraceptive decision aid quality criteria.

IPDAS quality criteria for decision aids	Criteria met by the developed decision aid
Went through a systematic development process	✓
Provide information about options	✓
Present probabilities	X
Clarify and express values	✓
Use patient stories	✓
Guide or coach in deliberation and communication	✓
Disclose conflicts of interest	X
Deliver patient decision aid on the internet	✓
Balance the presentation of options	✓
Use plain language	✓
Base information on up-to-date scientific evidence	✓
Establish effectiveness	✓

The fact that the decision aid does not meet all 15 criteria does not diminish the overall strengths of the tool as even the IPDAS collaboration recognizes that their quality criteria represent an ideal construction of decisions aids that may be difficult to obtain (162).

Decision aid evaluation

The decision aid evaluation is limited by a number of factors. First, it cannot be determined that changes between the pre and post-test results were entirely due to the decision aid. It is feasible that after completing the pre-test, some women looked for additional information about contraception online, or in other sources. Second, all but two participants reviewed the decision aid online, as opposed to in the paper format it is designed to be reviewed in. It is unclear how the results would have been different if all participants viewed the decision aid in print. Third, few of the evaluation participants reported being early in their contraceptive decision-making. If the tool was reviewed by women early in their contraceptive decision-making the decision aid may have had a stronger impact. However, at this stage in the development of the decision aid, women who had more contraceptive experiences were able to offer perspective on what they needed early in the contraceptive decision-making process in a way that women with fewer experiences with contraceptives may not have been able to do. Additionally, there were no statically significant changes in values or in feelings of self-efficacy. This may have been because of the small sample size, the statistical test chosen (205) or because women's ratings in the areas of values and self-efficacy were already quite high, leaving little room for improvement.

Finally, evaluation participants were almost all white and all spoke English; therefore it is unclear how non-white population and non-English speakers would respond to the decision aid. Despite these limitations, the rigorous measures of acceptability and effectiveness used to evaluate the decision aid bolster confidence in the results.

Conclusion

Throughout the more than 30 years that they are of reproductive capacity (7), women with epilepsy must navigate the complex terrain of their reproductive decisions. These decisions can influence both reproductive and neurological health outcomes, the optimization of which are critical to the ensuring the population's overall health and quality of life.

Women's reports showed that their abilities to make and implement informed reproductive decisions are influenced by their success at weathering common misperceptions surrounding a poorly understood and stigmatized disorder, their capacity to navigate an inconsistent and highly segmented health care system and the information, financial and emotional support resources available to them.

This dissertation makes important contributions to building better understandings of the unmet reproductive health care needs of women with epilepsy. It also moves forward public health practice as the developed contraceptive decision aid is the only identifiable resource that educates women with epilepsy about their contraceptive options, helps them explore what they value in their contraception and guides them in implementing their contraceptive choice. Continued work is needed to promote the reproductive and neurological health of women with epilepsy and to ensure they can make informed reproductive decisions.

**APPENDIX A:
SEMI-STRUCTURED IN-DEPTH INTERVIEW GUIDE**

Study ID:

Date:

Time recorder turned on: _____ am/pm

Inform participant that the call is now being recorded.

Say the participant's study ID number so it is on the audio record.

Participant Background

1. First, why don't you tell me a little bit about yourself? (If probes needed:
Where do you live? What is it like there?)

2. Do you work right now?
 - a. If YES, What kind of work do you do? (Probe for part-time, full time?)
 - b. If NO, When was the last time you worked?
 - c. Are you a student?

3. Do you currently have any kind of health insurance?
 - a. If YES:
 - i. Where do you get your insurance from? (Through school, work, parents, the state?)
 - ii. What are some things you like about your insurance? What about things you don't like?

b. If NO:

- 1) When is the last time you had health insurance?
- 2) What happened that you went off of your insurance?
- 3) What do you do now when you need health care?

Epilepsy History

Now I'm going to ask you a few questions about your experiences with epilepsy.

- 4) What was it like when you were first diagnosed with epilepsy? (Probe: How old were you when you were diagnosed? How did you feel when you were diagnosed?).
- 5) How would you say that having epilepsy impacted your life? (Probe: How has it impacted your schooling or work or personal life?)
- 6) What kind of seizures do you have now? (Probe: How often do you have them? When was your last one? What are they like for you? Would you describe them as mild, moderate, or severe?)
- 7) What kind of doctor do you see for your epilepsy? What is your relationship like with him/her? Has that care you've received been the same or different with previous doctors? How so?
- 8) Are you taking any medications for epilepsy right now?
 - a. IF YES: How long been on them? What are some things that you like about your medication? What about things you don't like?
 - b. Do you use other strategies to try to prevent or reduce your seizures?

Thank you for sharing your history with epilepsy. Thinking about how you've described your experience with epilepsy, I'm wondering...

9) Do you consider epilepsy a disability? Tell me more about that.

10) Besides the epilepsy, how is your health generally? Are there any other mental or physical health issues that you are working with?

Contraception

Now I'll move to asking you questions about family planning, including your experiences with birth control, pregnancy, and abortion. Please keep in mind that you don't have to answer any questions that you prefer not to.

11) Are you currently using any kind of birth control?

IF YES: What kind of birth control are you using (Probe for type and brand? How long have you been using it?

IF NO: What types of birth control have you used in the past? What was your experience like using X?

a. Are you interested in using birth control currently? Tell me more about that.

12) How did you decide which birth control method to use? (Probe: Both for type and brand.)

13) Did having epilepsy impact your decision about your birth control?

If YES: How so?

14) What have you heard about how birth control impacts seizures, if anything?

- 15) Has a health care provider ever given you any advice about birth control?
- a. IF YES: What kind of health care provider? What was their advice for you? Has that advice you've received been the same or different with previous doctors? How so?
 - b. IF NO: SKIP to Q 17
- 16) What did you think about the advice they gave you? (Probe for: Did you feel like you could ask all the questions you wanted to? Did you understand all the information given to you?)
- 17) Is there anything you wish he/she would have done differently when talking with you about birth control?
- 18) Who else, besides your health care provider have you talked to about your decision to go (or not go) on birth control? What was their advice for you?
- 19) What do you think other women with epilepsy should do when considering which birth control is best for them?

Pregnancy

Next I will be asking you about any pregnancies you have had -- whether they resulted in babies born alive, stillbirth, abortion, miscarriage, or ectopic or tubal pregnancy.

- 20) How many times you have been pregnant? (IF NONE, SKIP to Q28)
- 21) How many times have you had a miscarriage?

22) How many times you have had an abortion?

23) How many times have you given birth?

24) Let's talk about each pregnancy in the order that it occurred. Thinking about the first time you were pregnant, when did the pregnancy occur?

25) Can you tell me how you found out you were pregnant?

26) How did you feel when you found out you were pregnant?

27) Did you give birth, have an abortion, or a have miscarriage for that pregnancy?

- a. What was the month and year of X?
- b. IF BIRTH OR ABORTION, what were some of the things you thought about that helped you to decide to give birth or have an abortion?
- c. IF BIRTH OR ABORTION, how did having epilepsy impact your decision if at all?
- d. IF BIRTH OR ABORTION, who did you talk to about your decision? What kind of support did they offer you?
- e. IF BIRTH OR ABORTION, how was your health during the pregnancy? (Probe for: Did you have any seizures while you were pregnant?)
- f. IF BIRTH, how old is your child now? Does s/he have any health problems? How has parenting been for you?

REPEAT Qs 24-27 FOR EACH SUBSEQUENT PREGNANCY

28) Thinking about the # of times you've been pregnant, I'll ask you a number of questions and ask you to rate your response on a scale of how 1-5, 1 being not at all and 5 being a lot. If you felt differently with each pregnancy, feel free to share that as well.

	1-5	Can you give me an example? What made you feel that way? Tell me more about that.
During your pregnancy (ies), how unsure did you feel about what to do in regards to managing your epilepsy while pregnant?		
During your pregnancy (ies), how unsure did you feel about whether or not to continue your pregnancy?		
When you were pregnant, how worried were you about what could go wrong?		
How much did you feel distressed or upset?		
On a scale of 1-5, how often were you thinking about and weighing your decision?		
During your pregnancy (ies), how much did you waver between choices or change your mind about what to do in regards to managing your epilepsy while pregnant?		
During your pregnancy (ies), how much did you waver between choices or change		

your mind about whether or not to continue your pregnancy?		
During your pregnancy (ies), how much did you delaying any decisions you had to make about the pregnancy (ies)?		
And, how much did you feel physical stressed, or tense, racing heartbeat, difficulty sleeping when considering your choices?		

29) Has any health care provider talked with you about epilepsy and pregnancy?

- a. IF YES: What kind of health care provider? What was their advice for you? Has that advice you've received been the same or different with previous doctors? How so?
- b. IF NO: SKIP to Q 32

30) What did you think of their advice? (Probe for: Did you feel like you could ask all the questions you wanted to? Did you understand all the information given to you?)

31) How did their advice impact you?

32) Is there anything you wish your health care provider would have done differently when talking with you about pregnancy?

33) Who else besides your doctor do you talk to about pregnancy decisions?

34) How did they impact your pregnancy decisions?

35) Did you ever feel that a health care provider didn't want you to have a child because of your epilepsy?

If YES: Please share what you experienced.

36) Did you ever feel that anyone besides a doctor didn't want you to have a child because of your epilepsy?

If YES: please share what you experienced. How did your experience influence your decision?

37) Are you thinking about having any/more children in the future?

38) Does having epilepsy impact your decision about having children in the future?

If YES: Please explain how.

39) What do you think other women with epilepsy should do when considering giving birth?

Preferences for decision-making support

Now, I'm going to ask you some questions about resources you may like to have to help you with making decisions about birth control, or pregnancy, or abortion.

40) As you've made different decisions about contraception or having children or not, what information has seemed most important for you to have had at the time of your decision?

41) If we were to develop something to help other women with epilepsy make these kinds of decisions, what suggestions would you have for a resource? (Probe for: What kind of information would it have? What format would it be in? How would you suggest sharing it with other women with epilepsy?)

Participant Demographics

42) Before we finish up, I'd just like to get a little bit more information about you.

- a. How old are you?
- b. Where were you born?
- c. Are of Hispanic, Latin or Spanish origin?
- d. What is your race?
- e. What is your current relationship status (single, married, etc)?
- f. How do you define your sexual orientation?
- g. What is the highest level of education you have completed?
- h. How did you hear about the study?

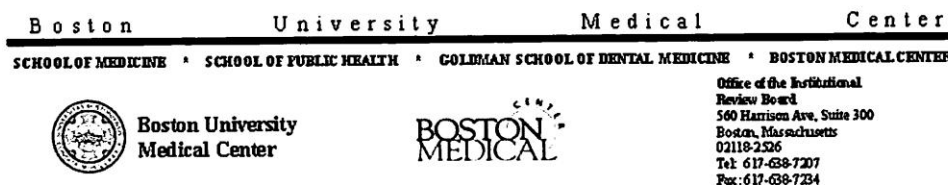
Closing

Do you have any questions at this point about the interview? Any additional points or anecdotes that you would like to share? Thank you so much for your time and willingness to participate. I really appreciate it, as this is an issue that has affected me personally and is very important to me. We'll be sending you the Amazon card and copies of your consent form as soon as possible.

APPENDIX B: STUDY IRB APPROVAL

Human Approval Letter

Page 1 of 2



Title of Study: WHEN FAMILY PLANNING DECISIONS ARE COMPLEX: ASSESSING THE UNMET REPRODUCTIVE HEALTH NEEDS OF WOMEN WITH EPILEPSY

Protocol Number: H-30039

RE: New Protocol

Review Type: Expedited

Action: Approved

Date of Action: 11/19/2010

Date of Expiration: 11/18/2011

Funding Source: Foundation/Other: Society for Family Planning
Foundation/Other Award #: None

Dear JUDITH BERNSTEIN, ADN MS PhD:

The Institutional Review Board (IRB) has reviewed the above referenced protocol and has determined that it meets the requirements set forth by the IRB and is hereby approved. This protocol is valid through the date indicated above.

This study has been approved for Waiver of Documentation of Consent in accordance with 45 CFR 46.117 (c). The consent process must still be conducted for each subject however you are not required to obtain signatures on the consent document. Subjects should be given a copy of the consent document if requested.

Revisions have been reviewed and approved as of this date 2/9/2011.

The stamped HIPAA exempt form is located in external attachments.

The signed authorization agreement between BUMC IRB and Ibis Reproductive Health is located in the external attachments.

The study may not continue after the approval period without additional IRB review and approval for continuation. You will receive an email renewal reminder notice prior to study expiration; however, it is your responsibility to assure that this study is not conducted beyond the expiration date.

Please be aware that only IRB-approved informed consent forms may be used when informed consent is required. Only consent forms validated with current approval dates (either generated by the INSPIR system or by a manual stamp by the IRB office) may be used. Manually stamped consent forms may be found under External Attachments in INSPIR.

Any changes to the protocol or informed consent must be reviewed and approved prior to implementation unless the change is necessary for the safety of subjects. In addition, you must report to the IRB unanticipated problems involving risk to subjects or others according to the process posted on the IRB website. The IRB must be informed of any new or significant information that might impact a research participant's safety or willingness to continue in your study.

https://braan.bumc.bu.edu/esp1/reports/Human/Approval.asp?protocol=767080&title_code=0 2/9/2011

Investigators are required to ensure that all HIPAA requirements have been met prior to initiating this study. Once approved, validated HIPAA forms may be found within INSPIR as External Attachments.

It is the responsibility of the PI to ensure that all required institutional approvals have been obtained prior to initiating any research activities.

Please note that the IRB is no longer stamping attachments, subject letters, recruitment materials, etc. These documents are each associated with this approved version of the protocol. They can be found by going to Letters/Protocol History in INSPIR and clicking on the highlighted (linked) word "Approved" and then clicking on the paperclip icon in the upper left corner. *This does NOT apply to consent forms, which must be validated.

Sincerely yours,

IRB Board Member

APPENDIX C:

PRE-TEST EVALUATION OF CONTRACEPTIVE DECISION AID

Decision Aid Evaluation Pre-Test

Study ID# _____

Date of pre-test_____

Thank you for taking the time to speak with me today.

1. I'd like to start off by asking you a few questions about your background.

- a. How old are you?
- b. Are of Hispanic, Latin or Spanish origin?
- c. What is your race?
- d. What is the highest level of education you have completed?
- e. How long ago were you diagnosed with epilepsy?
- f. What type of seizures do you have now?
- g. How many medications are you currently taking, if any, to treat your seizures?
- h. What type of birth control are you currently using, if any?
- i. How many children do you have now, if any?

Next, I am going to ask you some questions about where you currently get health care.

2. Which health care provider, if any, do you tend to discuss your epilepsy with?
(circle all)

Primary care physician neurologist other:_____

none

When is the last time you saw [insert month and year provider type 1]? _____

When is the last time you saw [insert month and year provider type 2]? _____

3. Which health care provider, if any, do you tend to discuss birth control with? (circle all)

PCP neurologists ob/gyn other:_____ none

When is the last time you saw [insert month and year provider type 1]? _____

When is the last time you saw [insert month and year provider type 2]? _____

4. Which health care provider, if any, do you tend to discuss pregnancy with? (circle all)

PCP neurologists ob/gyn other:_____ none

When is the last time you saw [insert month and year provider type 1]? _____

When is the last time you saw [insert month and year provider type 2]? _____

Next, I'm going to read you a series of statements and I'll ask you to tell me if you believe the statement is true or false, or if you are unsure of the answer.

5. Women with epilepsy can experience an increase in seizures around the time of their periods.

True False Not sure

6. Some types of birth control interfere with epilepsy medications and cause women to have more seizures.

True False Not sure

7. Some epilepsy medications interfere with birth control pills and put women at risk for an unplanned pregnancy.

True False Not sure

8. Some types of birth control can help reduce seizures.

True False Not sure

9. Most children born to women with epilepsy have birth defects.

True False Not sure

10. Most children born to women with epilepsy have epilepsy.

True False Not sure

11. Women with epilepsy can have safe and normal pregnancies.

True False Not sure

Next, I'm going to ask you some questions about how confident you feel making different health care decisions. Please tell me how confident you feel doing each of the statements I read by rating each item on a scale of 0 to 4, with 0 being not at all confident and 4 being very confident

12. Understand the information given to me about birth control enough to make choice myself about it.

Not at all confident 0 1 2 3 4 Very confident

13. Express to my doctors my concerns about different birth control methods.

Not at all confident 0 1 2 3 4 Very confident

Next, I'm going to read you some things that women consider when they are making decisions about birth control. Please tell me how important these things are to you by saying a number 0 to 10 with 0 being not at all important and 10 being very important.

14. How important to you is protection from becoming pregnant when making a decision about birth control?

Not 0 1 2 3 4 5 6 7 8 9 10 Very

15. How important to you is maintaining seizure control when making a decision about birth control?

Not 0 1 2 3 4 5 6 7 8 9 10 Very

Closing

Thank you so much for taking the time to answer those questions. Now what I would like to do is send you a guide that provides balanced information about the risks and benefits involved in using birth control. I can send you the guide by email or mail, whichever you prefer.

Which would work best for you?_____

What is the best [mail or email] address to send that to you?_____

Great, I will send you the guide today. I'd also like to plan a time to follow up with you by phone. The follow up will take about the same amount of time as we took today and will primarily consist of me asking you questions about what you thought about the guide. Your feedback will help us make the guide better for other women with epilepsy.

Keeping in mind that we want to give you enough time to look at the guide, when would be the best day and time for me to follow up with you? [aim for one to two weeks from current date]_____

I will send you a reminder the day before we are scheduled to talk. Would you prefer the reminder via email or phone?_____

Thanks again for your time today; I look forward to talking with you soon.

**APPENDIX D:
POST-TEST EVALUATION OF CONTRACEPTIVE DECISION AID**

Decision Aid Evaluation Post-Test

Study ID# _____

Date of post-test _____

Thanks so much for taking the time to speak with me today. First, I'm going to ask you some follow up questions about birth control for women with epilepsy.

First, I'm going to read you a series of statements and I'll ask you to tell me if you believe the statement is true or false, or if you are unsure of the answer.

1. Women with epilepsy can experience an increase in seizures around the time of their periods.

True

False

Not sure

2. Some types of birth control interfere with epilepsy medications and cause women to have more seizures.

True

False

Not sure

3. Some epilepsy medications interfere with birth control pills and put women at risk for an unplanned pregnancy.

True

False

Not sure

4. Some types of birth control can help reduce seizures.

True

False

Not sure

5. Most children born to women with epilepsy have birth defects.

True

False

Not sure

6. Most children born to women with epilepsy have epilepsy.

True

False

Not sure

7. Women with epilepsy can have safe and normal pregnancies.

True

False

Not sure

Next, I'm going to ask you some questions about how confident you feel making different health care decisions. Please tell me how confident you feel doing each of the statements I read by rating each item on a scale of 0 to 4, with 0 being not at all confident and 4 being very confident

8. Understand the information given to me about birth control enough to make choice myself about it.

Not at all confident

0

1

2

3

4

Very confident

9. Express to my doctors my concerns about different birth control methods.

Not at all confident

0

1

2

3

4

Very confident

Next, I'm going to read you some things that women consider when they are making decisions about birth control. Please tell me how important these things are to you by saying a number 0 to 10 with 0 being not at all important and 10 being very important.

10. How important to you is protection from becoming pregnant when making a decision about birth control?

Not

0

1

2

3

4

5

6

7

8

9

10

Very

11. How important to you is maintaining seizure control when making a decision about birth control?

Not

0

1

2

3

4

5

6

7

8

9

10

Very

Next, I'd like to get your feedback about the guide that we sent you.

12. First, how much of the guide did you read?

0 to 25%

25 to 50%

50 to 75%

75 to 100%

100%

13. How long did you spend reading the guide? 0 – 1 hr 1–5 hrs 5 or more hrs

14. Next, please rate what you think about the way information was presented on birth control by telling me if you think the information was poor, fair, good, or excellent:

Birth control: poor fair good excellent

15. Next, please tell me if you think we provided too much, too little, or just the right amount of information about birth control for women with epilepsy.

Birth control: too much too little just right

16. On a scale of 0 to 5, how helpful did you find the chart with different birth control methods with 0 being not at all helpful and 5 being very helpful?

Not at all helpful 0 1 2 3 4 5 Very helpful

17. On a scale of 0 to 5, how helpful did you find the stories of other women with epilepsy with 0 being not at all helpful and 5 being very helpful?

Not at all helpful 0 1 2 3 4 5 Very helpful

18. On a scale of 0 to 5, how helpful did you find the checklist for use with your health care providers with 0 being not at all helpful and 5 being very helpful?

Not at all helpful 0 1 2 3 4 5 Very helpful

19. What did you think about the format or layout of the guide?

20. What did you like about the guide?

21. What suggestions for improvement do you have?

20. Any other comments?

APPENDIX E: REVISED DECISION AID



For many women, decisions about starting birth control and picking a birth control method can be challenging. For the over one million women and girls in the US who have epilepsy, these decisions can be even more complex.

Like you, many women with epilepsy have questions about how having epilepsy affects their birth control choices. It does not matter which of the many different types of seizures you have, how often you have seizures, or what medications you take. This guide can help you make an informed birth control choice.

How Will This Guide Help Me?

Are you:

- Considering starting birth control?
- Not sure which birth control method is right for you?
- Curious how other women with epilepsy have picked a birth control method?
- Looking for ways to talk to your doctor about birth control?

If you answered "yes" to any of these questions, this guide can help. Inside you will find:

- Answers to questions women with epilepsy often have about birth control;
- Real life stories of women with epilepsy who have made different birth control choices;
- Exercises to help you figure out what is most important to you when starting or selecting a birth control method; and
- Questions to ask your health care team, so they can help you with your decisions.

Keep in mind that this guide should not replace the advice of a doctor. Instead, it will help prepare you to talk to a doctor about your birth control needs and choices.



Can Women with Epilepsy Use Birth Control?

Yes! You can use birth control that prevents pregnancy in the short-term, long-term, or permanently, depending on if and when you want to have children. Before you pick what type of birth control to use, it is important to learn about some common myths and facts about birth control for women with epilepsy.

Myth: There are laws that prevent women with epilepsy from having children.

Fact: In the early 1900's, there were laws saying that women with epilepsy should be forcibly sterilized. Those laws no longer exist. Thankfully, understanding of epilepsy has come a long way. Now, women with epilepsy can decide for themselves if they want to use birth control or have children.

Myth: It is not safe for women with epilepsy to get pregnant.

Fact: Women with epilepsy can have children and be great mothers. In fact, over 90% of women with epilepsy who have children have safe pregnancies and healthy babies that do not inherit epilepsy. To make sure their pregnancies are safe and their babies are healthy, women with epilepsy need to plan their pregnancies and talk to their doctors about their pregnancy plans.

Myth: Epilepsy medications make all birth control methods less effective.

Fact: There are two different types of birth control: non-hormonal and hormonal. Condoms and diaphragms are types of non-hormonal birth control. Birth control pills, the shot, and the ring are types of hormonal birth control. Epilepsy medications do not affect non-hormonal methods. But, if you take enzyme-inducing epilepsy medications and hormonal birth control, it could make your birth control less effective at preventing pregnancy.⁴

Myth: All birth control methods increase the chance of seizures in women with epilepsy.

Fact: If you use non-hormonal birth control, it will not affect your seizures.⁵ If you use hormonal birth control, it is hard to tell what impact your birth control will have on your seizures.⁶ Some women say hormonal birth control increases their seizures, but other women find it decreases their seizures. Still other women say hormonal birth control does not affect their seizures at all. There is a lot left to learn about this issue.

Which Birth Control Method is Right for Me?

You have a number of birth control options to choose from. The table on the following pages gives a lot of information about your choices. It even shows how different birth control methods work with epilepsy medications.

What if I have problems with my birth control method?

It is hard to tell which combination of birth control and epilepsy medications will work best for you. You might find the right combination on your first try. Or, you might try different combinations before finding the right one. During these trial periods:

- Look for signs that your epilepsy medication is not working. These signs include changes in the number, length, or kind of seizures you usually have. If this happens, take an extra dose of your medication and talk to your doctor.
- Look for signs that your birth control is not working. If you notice missed period, headaches, tender breasts, nausea or lower backaches, and you have been sexually active, these may be early signs of pregnancy. Use a back-up method of birth control (like condoms) and talk to your doctor as soon as possible.

What if my birth control fails and I become pregnant?

- If you would like to have a child, or want to consider adoption, talk to your doctor right away about ways to take care of your health for the rest of your pregnancy.
- If you are not ready to have a child, abortion is an option. Abortion is safe, common, and legal. The National Abortion Federation can give you information about abortion, and help you find out where to get an abortion and how to pay for it. You can reach them at www.prochoice.org or at 1-877-257-0012.



How Have Other Women with Epilepsy Made Birth Control Decisions?

The following stories are from women who hoped sharing their own experiences would help other women who have epilepsy.

Danielle is not ready to have a child so she uses the IUD.

At 20, Danielle was diagnosed with non-convulsive seizures. Not sure if she wanted children in the future, she asked her neurologist for birth control advice. Danielle learned that her epilepsy medications can interfere with many hormonal birth control methods. She decided to use a non-hormonal IUD. She is happy the IUD does not affect her seizures and is one of the best birth control methods to prevent pregnancy. She said, "I really like this IUD because it is non-hormonal and...you don't have to deal with it on a daily basis and whatnot.... I think the IUD is great."

Kelsey uses the pill to regulate her periods and reduce her seizures.

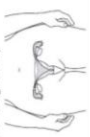





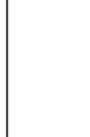
Kelsey was diagnosed with epilepsy when she was very young. At 29-years-old, she continued to have frequent convulsive seizures. She noticed her period was irregular and that her seizures increased around her period. Kelsey asked her neurologist and her gynecologist for advice. They worked together to find a birth control method that would help Kelsey regulate her period and reduce her seizures. Kelsey tried a few different brands of pills, and then found one that worked for her. She said, "Being on the pill helps me not have seizures during that time of the month 'cause that's one of the times that I'm more likely to get seizures."

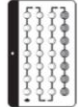



Courtney tried several birth control methods before finding the right one for her.

Courtney was 17 when she was diagnosed with non-convulsive seizures. By the time she was 30, Courtney had tried several epilepsy medications. She also had brain surgery. Then, she finally got her seizures under control. But, she had trouble finding birth control that worked. She said, "I tried several different birth control pills trying to find one that would work and really agree with me... but, I got pregnant." Courtney was upset her doctor had not warned her that her epilepsy medication and birth control pills may not work together. She ended up having a miscarriage. After that, she and her husband decided to use condoms.

Wendy's husband had a vasectomy to permanently prevent pregnancy.

At 35, Wendy had been living with epilepsy for 17 years. Despite taking epilepsy medications, she continued to have both convulsive and non-convulsive seizures several times a week. Wendy and her husband had one teenager. They decided not to have more children because they did not want to do anything that might increase Wendy's seizures. They decided vasectomy was a good option because it prevents pregnancy and does not affect Wendy's seizures. She said of their decision, "It was mutual.... After we weighed all the pros and cons, we knew it was something that we had to do."

Birth Control Method	# of Pregnancies Expected per 100 Women per Year	Benefits	Risks	Considerations for Women with Epilepsy
Female Sterilization 	1	<ul style="list-style-type: none"> One time procedure Very safe Very effective No lasting side effects Helps protect against pelvic inflammatory disease 	<ul style="list-style-type: none"> Permanent decision that must be carefully considered Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> Female sterilization does not affect seizure activity Epilepsy medications do not affect efficacy of sterilization
Male Sterilization 	1	<ul style="list-style-type: none"> One time procedure Very safe Very effective No lasting side effects 	<ul style="list-style-type: none"> Permanent decision that must be carefully considered Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> Male sterilization does not affect seizure activity Epilepsy medications do not affect efficacy of sterilization
Intrauterine Devices 	1	<ul style="list-style-type: none"> Easy to use Mirena: use up to 7 yrs, reduces cramps & bleeding ParaGard: use up to 12 yrs, non-hormonal method Helps protect against endometrial cancer Fertility returns quickly after IUD removal Can be used while breastfeeding 	<ul style="list-style-type: none"> Mirena may cause spotting between periods for first 3-6 months ParaGard may increase cramps & cause heavier bleeding Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> IUDs do not affect seizure activity Epilepsy medications do not affect the efficacy of the IUD
The Implant 	1	<ul style="list-style-type: none"> Lasts up to 3 years Helps protect against pelvic inflammatory disease Fertility returns quickly after removal Can be used while breastfeeding 	<ul style="list-style-type: none"> May cause irregular bleeding (spotting, no periods, heavy periods) May cause headaches, abdominal pain, weight changes, breast tenderness, dizziness, nausea & mood changes Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> It is unknown how the implant affects seizure activity Some epilepsy medications may decrease the efficacy of the implant
The Shot 	1 - 3	<ul style="list-style-type: none"> Each shot works for 12 weeks Helps protect against endometrial cancer Can be used while breastfeeding 	<ul style="list-style-type: none"> May cause spotting, no period, hair or skin changes, weight gain, headaches, dizziness, abdominal bloating and discomfort, mood changes, or change in sex drive Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> Use of the shot may help decrease seizure activity⁶ Epilepsy medications do not affect the efficacy of the shot
The Ring 	1 - 8	<ul style="list-style-type: none"> Inserted once a month Can make periods more regular & less painful Ability to become pregnant returns quickly after stopping the ring 	<ul style="list-style-type: none"> Can increase headaches, vaginal discharge & vaginitis May cause spotting the first 1-2 months of use Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> It is unknown how the ring affects seizure activity Some epilepsy medication may decrease the efficacy of the ring
The Patch 	1 - 8	<ul style="list-style-type: none"> Applied once a month Can make periods more regular and less painful Ability to become pregnant returns quickly after stopping the patch 	<ul style="list-style-type: none"> Can irritate skin under the patch, cause headaches, nausea, vomiting, breast tenderness, vaginitis & abdominal pain May cause spotting the first 1-2 months Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> It is unknown how the patch affects seizure activity Some epilepsy medication may decrease the efficacy of the patch

Combined-oral Contraceptives (COCs, the pill) 	1 - 8	<ul style="list-style-type: none"> May make periods more regular & less painful, improve PMS symptoms, decrease acne and lower risk of endometrial cancer, protect against pelvic inflammatory disease & decrease symptoms of endometriosis & PCOS Ability to become pregnant returns quickly after stopping the pills 	<ul style="list-style-type: none"> May cause nausea, weight gain, headaches, breast tenderness, dizziness, nausea, mood changes & change in sex drive – but these can be relieved by changing to a new brand May cause spotting the first 1-2 months Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> Mixed evidence for impact of COCs on seizure activity—some studies show no impact, others an increase & still others a decrease⁶ Some epilepsy medications may decrease the efficacy of COCs
Progestin-only Pills (POPs, the mini-pill) 	3 - 9	<ul style="list-style-type: none"> Ability to become pregnant returns quickly after stopping the pills Can be used while breastfeeding 	<ul style="list-style-type: none"> Often cause spotting, which may last for many months May cause headaches, dizziness, mood changes, breast tenderness, abdominal pain & nausea Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> Use of POPs with some epilepsy medications may increase seizure activity⁵ Some epilepsy medications may decrease the efficacy of POPs
Diaphragm 	6 - 16	<ul style="list-style-type: none"> Can last several years May protect against some STIs (NOT HIV) Can be used while breastfeeding 	<ul style="list-style-type: none"> Frequent use of spermicide nonoxonyl-9 may raise the risk of getting HIV Raises risk of bladder infection 	<ul style="list-style-type: none"> The diaphragm does not affect seizure activity Epilepsy medications do not affect the efficacy of diaphragms
Male Condom 	2 - 15	<ul style="list-style-type: none"> Available over the counter Protects against HIV & other STIs Can be used while breastfeeding 	<ul style="list-style-type: none"> Can decrease sensation Can break or slip off 	<ul style="list-style-type: none"> Condoms do not affect seizure activity Epilepsy medications do not affect the efficacy of condoms
Female Condom 	5 - 21	<ul style="list-style-type: none"> Available over the counter Protects against HIV & other STIs Can be used while breastfeeding 	<ul style="list-style-type: none"> May be noisy May be hard to insert May slip out of place during sex 	<ul style="list-style-type: none"> Female condoms do not affect seizure activity Epilepsy medications do not affect the efficacy of female condoms
Fertility-based Awareness Methods 	25	<ul style="list-style-type: none"> No side effects Does not involve taking or applying any medication Can be used while breastfeeding 	<ul style="list-style-type: none"> One of the least effective methods if used incorrectly Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> Fertility-based awareness methods do not affect seizure activity Epilepsy medications do not affect the efficacy of fertility-based awareness methods
Emergency Contraception (Plan B® One-Step, Next Choice™, etc.) 	Cuts risk by 75 - 95%	<ul style="list-style-type: none"> Available at many pharmacies, health centers, or health care providers if 17 & over Can be used while breastfeeding Must be used within 72 hours of unprotected intercourse to achieve 75% reduction in risk of becoming pregnant 	<ul style="list-style-type: none"> May cause nausea, vomiting, spotting or bleeding Does not protect against HIV or other STIs 	<ul style="list-style-type: none"> It is unknown how emergency contraception affects seizure activity Some epilepsy medications may decrease the efficacy of emergency contraception
Spermicide (Cream, gel, sponge, foam, inserts, film) 	15 - 29	<ul style="list-style-type: none"> Available over the counter Can be used while breastfeeding 	<ul style="list-style-type: none"> Frequent use may raise the risk of getting HIV May irritate vagina, penis Cream, gel & foam can be messy 	<ul style="list-style-type: none"> Spermicide does not affect seizure activity Epilepsy medications do not affect the efficacy of spermicide

All images, rates of efficacy, benefits and risks from Reproductive Health Access Project, 2012 or World Health Organization, 2012. All considerations for women with epilepsy from CDC, 2010 unless otherwise noted.

Weighing Your Birth Control Options

The following exercise is designed to help you think through what is most important to you when starting or picking a birth control method. Below, you will find things women with epilepsy think about when making birth control decisions. Please circle a number to show how important these things are to you.

How important to you is.....

	not at all important				extremely important
1. How often you have to take or use your birth control (frequency)?	1	2	3	4	5
2. The potential that a birth control method affects your seizures?	1	2	3	4	5
3. The possible benefit that your birth control could help regulate your period?	1	2	3	4	5
4. Whether you need a prescription from your doctor to get your birth control?	1	2	3	4	5
5. How well your birth control will prevent pregnancy	1	2	3	4	5
6. Protection from sexually transmitted infections and HIV?	1	2	3	4	5
7. Choosing a birth control that your sex partner(s) is OK with?	1	2	3	4	5
8. Cost and/or insurance coverage for birth control?	1	2	3	4	5

9. What other benefits of birth control are important to you? (Please specify any other benefits and rate their importance to you.)

- a. _____
- b. _____
- c. _____

10. What other reasons are important to you when thinking about why you might not want to take birth control? (Please specify any risk you have considered and rate their importance to you.)

- a. _____
- b. _____
- c. _____

Use this space to list the things that you rated highly (4 or 5).

You can use these results to talk with your doctor about what is important to you. You can also show the results to other people in your life who are part of your birth control decisions.

Talking with Your Doctors

The most important thing to remember when talking with doctors is that you are the expert on you. Your participation and input are essential. Keep your doctor up-to-date about your desire for birth control or pregnancy. That way, she or he can provide you with the best care possible.

Which doctor you talk to about birth control is up to you. Some women like to talk to a gynecologist. Others talk with their neurologist. And still other women reach out to their primary care physician or a nurse who is an expert in birth control issues. You could talk to just one of your doctors or to everyone on your health care team. You might have to search to find the right doctor who can help you with your birth control decisions. If your doctor says that there are no good birth control options for women with epilepsy, or you are unhappy with your doctor for other reasons, you can:

- Use this guide to start a conversation with your doctor about your birth control needs;
- Switch to a new doctor who might be more helpful; or
- Add another doctor to your health care team who can help you with your birth control decisions.

The important thing is to pick a doctor that you trust, who listens, and who can help you. Your doctor's answers to the questions in the checklist below can help you figure out if you have found the best doctor for you.

Questions For Your Doctor

This checklist will help you keep track of questions to ask your doctor. Be sure to add your own questions to the list as well.

- ☐ Some doctors are not sure how to help women with epilepsy pick a birth control method. What experience do you have helping women with epilepsy pick a birth control method that works for them?
- ☐ Some women with epilepsy like to work with a team of doctors, like a neurologist and a gynecologist. What is your experience working with other health care providers to find a birth control method that will work for women with epilepsy?
- ☐ One part of deciding to start birth control is deciding whether to have children. What are the risks involved with pregnancy or raising a child for me?
- ☐ I know there might be a relationship between my hormones and seizures, but I would like to learn more about it. How are hormones and seizures related?
- ☐ Given the relationship between my hormones and seizures, how might my period affect my seizures? What types of birth control can help with seizures that occur around my period? What types of birth control can help with any problems I have with my period?
- ☐ Birth control methods have lots of benefits and risks. What can you tell me about the benefits and risks of different birth control methods?
- ☐ Some types of birth control interact with some epilepsy medications. What can you tell me about interactions between my epilepsy medications and different birth control methods?
- ☐ Some women's seizures get worse when they use hormonal birth control, some women's get better, and some women's seizures are not affected. What can you tell me about how my seizures might be affected by using hormonal birth control?
- ☐ I have thought about my birth control preferences (as shown in the Weighing Your Birth Control Options exercise). What birth control method will meet the preferences I have picked?
- ☐ Other _____
- ☐ Other _____

My Support

Doctors are not the only ones who can support you in your decision to start or pick out a birth control method. Your partner, friends, family, and other women with epilepsy could all be important sources of support. Use the space below to write down the people whose opinions matter most to you when you make these decisions:

For More Information



Ibis Reproductive Health aims to improve women's reproductive autonomy, choices, and health worldwide. To learn more about the research on the reproductive health of women with epilepsy that helped create this guide, you can contact Ibis.

Phone: (617) 349-0040

Email: admin@ibisreproductivehealth.org

Website: www.ibisreproductivehealth.org



The Epilepsy Foundation of America® works to ensure that people with seizures are able to participate in all life experiences. They have a number of resources about how epilepsy affects women, including information on birth control, pregnancy, and parenting for women with epilepsy. To learn more about their programs, or to connect with other people with epilepsy, you can contact the Epilepsy Foundation.

Phone: 1-800-332-1000

Email: ContactUs@efa.org

Website: <http://www.epilepsyfoundation.org/index.cfm>

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CURRICULUM VITAE

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EDUCATION

Boston University, Boston, MA: *Doctorate in Public Health*, September, 2012

Dissertation: "Identifying and responding to the reproductive decision-making needs of women with epilepsy;" a needs assessment and development and evaluation of a decision aid focused on improving informed contraceptive decision-making for women with epilepsy.

University of Pennsylvania, Philadelphia, PA: *Master of Bioethics*, May 2007

Senior thesis: "Men and abortion;" an inquiry into the role of male partners of women at abortion clinics.

Hampshire College, Amherst, MA: *Bachelor of Arts*, May 2004

Senior thesis: "M/other;" an exploration of the juncture of reproductive technology, disability, and motherhood.

RESEARCH EXPERIENCE

Ibis Reproductive Health, Cambridge, MA

Senior Project Manager

2010-current

Project Manager

2008-2010

Research Assistant

2007-2008

- Lead a dynamic program of qualitative and quantitative research projects focused on improving access to contraceptive, pregnancy, abortion, and HIV prevention services for underserved populations, with a focus on the impact of health care policies in the US and reproductive health of women with disabilities.
- Direct all aspects of research projects including fundraising, instrument and protocol development, supervision of research support staff, literature review, data collection, study monitoring, data analysis, and preparation of manuscripts and other educational and dissemination materials.
- Oversee volunteer, intern, research assistant, and project manager hiring, training, and mentoring.

TEACHING EXPERIENCE

Suffolk University, Boston, MA

Adjunct Instructor, Sociology Department

2010-2011

- Developed and taught “WH 702, Introduction to Research Methods” to classes of 8-25 masters students over two semesters.

Harvard School of Public Health, Cambridge, MA

2008-2011

Co-instructor, School of Public Health

- Lectured in “PIH502, International reproductive health issues: Moving from theory to practice” to classes of 10-30 masters students over three semesters.

GRANTS AND AWARDS

- National Institute for Reproductive Health Grant Award, (\$2,500), 2012
- Society of Family Planning Junior Investigator Career Development Award (\$86,000), 2011
- Society of Family Planning Research Grant Award (\$15,000), 2010
- American Association on Health and Disability Scholarship (\$500), 2010

PEER-REVIEWED PUBLICATIONS

Dennis A, Clark J, Córdova D, Blanchard K, McIntosh J, Wahlin B, Tsikitas L, Edlund K. What happens to the women who fall through the cracks of health care reform? Lessons from Massachusetts. *Journal of Health Politics, Policy and Law*. In press.

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ORAL PRESENTATIONS

Dennis A. (March 2012) Access to contraception for low-income women in the wake of Massachusetts health care reform. Massachusetts Diversity Council Women's History Month Meeting. Boston, MA.

Dennis A. (October 2011) Challenges access quality contraceptive care for women with epilepsy: a qualitative investigation. American Psychological Association Conference. Washington, DC.

Dennis A. (May 2011) What happens to the women who fall through the cracks of health care reform? Lessons from Massachusetts. Reproductive Justice and Health Care Reform. Chicago, IL.

Dennis A, Grossman D. (April 2011) Strategic action session: barriers to accessing contraceptives. From Abortion Rights to Social Justice Conference. Amherst, MA.

Dennis A, Blanchard K. (November 2010) "There's no Medicaid for them:" Barriers to accessing public funding for women seeking abortions in cases of rape, incest, and life endangerment. American Public Health Association Conference. Denver, CO.

Dennis A, Blanchard K. (November 2010) "Left without a choice:" Which women are affected by restrictions on abortion coverage? American Public Health Association Conference. Denver, CO.

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Dennis A. (June 2009) Making change on the state level. National Network of Abortion Providers Summit. Chicago, IL.

Dennis A. (April 2009) Abortion access for women with disabilities. From Abortion Rights to Social Justice Conference. Amherst, MA.

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