Epilepsy & Behavior 25 (2012) 634–661

Contents lists available at SciVerse ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Special Communication

Testimonies submitted for the Institute of Medicine report *Epilepsy across the spectrum: Promoting health and understanding*

Joan K. Austin [a,*], Dale C. Hesdorffer [b], Catharyn T. Liverman [c], Andrea M. Schultz [c]
and the Testimony Group

[a] School of Nursing, Indiana University, USA
[b] Gertrude H. Sergievsky Center, Columbia University, USA
[c] Institute of Medicine, USA

ARTICLE INFO

Article history:
Received 5 October 2012
Accepted 6 October 2012
Available online 14 November 2012

Keywords:
Epilepsy
Personal perceptions
Family
SUDEP
Health care
Research
Institute of Medicine
Quality of life

ABSTRACT

The 2012 Institute of Medicine (IOM) report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, provides a vision for moving the field forward to improve the lives of people with epilepsy. The committee made 13 recommendations and identified a number of research priorities to promote accomplishing this vision. Its work was enriched by the contributions of many individuals who testified before the committee during its two public workshops and who submitted written testimony throughout the study process. Many of these testimonies included in this article were presented in-person at the committee's public workshops in Los Angeles, CA on March 21, 2011 and in Washington, DC on June 28–29, 2011. Among those providing testimony were people with epilepsy, their family members, health care professionals, and researchers specializing in epilepsy. The 36 testimonies that comprise this publication provided the committee with a more complete and current picture of epilepsy-related health care issues and the challenges that epilepsy imposes on the lives of people with epilepsy and their families.

1. Introduction

The 2012 Institute of Medicine (IOM) report,[1] *Epilepsy Across the Spectrum: Promoting Health and Understanding* [1], provides a vision for moving the field forward to improve the lives of people with epilepsy. The committee made 13 recommendations and identified a number of research priorities to promote accomplishing this vision [2]. Its work was enriched by the contributions of many individuals who testified before the committee during its two public workshops and who submitted written testimony throughout the study process. Many of these testimonies included in this article were presented in-person at the committee's public workshops in Los Angeles, CA on March 21, 2011 and in Washington, DC on June 28–29, 2011. Among those providing testimony were people with epilepsy, their family members, health care professionals, and researchers specializing in epilepsy.

The 36 testimonies that follow provided the committee with a more complete picture of epilepsy-related health care issues and the challenges that epilepsy imposes on the lives of people with epilepsy and their families. Although many testimonies focused on more than one topic, for ease of presentation we have grouped them into four broad areas and present them in the following order: personal perceptions of epilepsy, impact of epilepsy on the family, sudden unexpected death in epilepsy (SUDEP), and health care and community services. Each area is preceded by a brief introduction that identifies some of the themes and challenges described in the testimonies. Our hope is that these narratives provide a timely depiction of the current state of epilepsy in our society.

2. Introduction to personal perceptions of epilepsy

Seven adults testified about their personal experiences of living with epilepsy. Some provided insights into having epilepsy during childhood, and others described the onset of epilepsy in adulthood. Some described a life with seizures that were not controlled, while others described the challenges they had even though their seizures were well controlled. All provided glimpses into the difficulties that were unique to having epilepsy during adulthood. Although a few reported having a good support system, others reflected on struggles with interpersonal relationships and difficulties in finding needed resources and services. A major theme focused on the consequences of being unable to drive, including how transportation difficulties impact independence, limit employment opportunities, and reduce options in regard to living arrangements. One individual provided a

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* Corresponding author at: 3040 N Ramble Road West, Bloomington, IN 47408, USA.
E-mail address: joausti@iupui.edu (J.K. Austin).

[1] The full-text version of the report is available by chapter as PDFs at www.iom.edu/epilepsy. The members of the report's authoring committee, the Committee on the Public Health Dimensions of the Epilepsies, are listed at the end of this article. The authors of this article are responsible for its content, which does not necessarily represent the views of the Institute of Medicine.

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http://dx.doi.org/10.1016/j.yebeh.2012.10.003

detailed narrative of financial struggles because of expensive epilepsy treatments and the inability to obtain financial help. Others reported experiencing side effects of seizure medications and the occurrence of comorbidities that were complicated by the difficulties in getting these other conditions diagnosed and treated. Finally, many referred to the emotional aspects of having epilepsy including social isolation, fears of having a seizure in public, worry about sudden unexpected death in epilepsy (SUDEP), and problems interacting with people who lack awareness about epilepsy.

2.1. Personal perceptions of epilepsy testimonies

2.1.1. Elizabeth Musick, person with epilepsy

2.1.1.1. Biography. My name is Elizabeth Musick. I turned 38 years old in October and have lived with epilepsy for 36 of those years. My current diagnosis is idiopathic epilepsy. In the span of these 36 years, I have had periods of almost exclusively absence seizures and other periods with overwhelmingly complex partial seizures. At present, I have exclusively grand mal seizures.

For the last 7 years, I have lived in Reston, VA, a suburb of Washington, DC. I am originally from Richmond, VA where I lived from birth to 22 years; I attended college at the University of Richmond and received a master's degree from American University. Since January 2011, I have been working at the Epilepsy Foundation in Landover, MD. I make $45,000/year despite my education and personal story. Finally, at 38, I am single, without children and never married. I believe part of that is due to my epilepsy.

2.1.1.2. Duration. I was diagnosed with epilepsy at 21 months of age, so there are several things worth noting. First, epilepsy has been a constant in my life no matter how you look at things, when it is causing horrible seizures and when it is relatively controlled. There is not one without the other. Second, the question of how much it formed my personality will always linger. Third, like many chronic conditions, living with epilepsy requires not only hard medical treatment, but also soft treatments such as emotional coping skills, dealing with the unknown, and acceptance. Much of the treatment I have encountered for people with epilepsy is reactive, not proactive. Treatment reacts to a seizure by adjusting medication levels and reacts to intractable epilepsy by surgery; very little is done proactively. Aside from taking medications as prescribed and listening to the standard cautions to avoid sleep deprivation, alcohol or very stressful situations, other treatments are quite narrow (e.g., the ketogenic diet is primarily for children). Finally, with the projected length, I will have had epilepsy by the time I approach death, and with my seizures post 1992 (brain surgery) being exclusively grand mal type, there are no longitudinal data to project cases such as mine.

Two of these points are especially important in my mind. First, the proactive approach to treatment needs to be much more fully defined and actively applied. While most people only see the seizures themselves, there is far more to epilepsy. Being proactive in treatment means not only taking daily medication, but also participating in activities, talking to doctors or therapists as necessary, actively participating in school, and thriving at work. I have not done each of these well myself at times. Second, there is a dire need for a repository of information about patients with epilepsy, which we, the patients, are aware of, know how to access and are encouraged to use and update. The repository should contain demographics, date of first seizure if known, type of epilepsy, current medications, length of time as a person with epilepsy, longest period of being seizure free, any related procedures and their dates, and many similar details.

Age 2–18: School with epilepsy was less than standard. Elementary school can be described as 5–7 absence seizures each day. In middle school, my seizures were especially problematic; I was taking multiple medications 4 times daily and also told to take a midmorning break at school for a snack to keep my blood sugar up. None of these, along with the obvious seizures, helped me fit in. When I had an absence seizure, felt overly tired, or overheated, I was allowed to go to the clinic, frequently without even requiring a note from the teacher because everyone knew my story so well. As one of the oldest students in my high school class of 525, it was emotionally hard to sit through 10th grade driver's education, knowing that I could not immediately get my freedom. When I eventually took the behind-the-wheel test after surgery, the Department of Motor Vehicles wanted to use a handicapped car for my exam. There is nothing wrong with my arms or legs. These kinds of ‘mistakes’ are what should not be taking place by people who supposedly are trained in fields that require direct contact with those of us who have epilepsy. When overlooked as sweeping generalizations, it further sets progress back.

I cannot overstate how many decisions appear to be made based on the cover-your-back mentality rather than what is in the best interest of the child. As a sophomore or junior in high school (I don't recall which), I tried out for and made the varsity tennis team, coached by one of the physical education teachers. However, I was not allowed on the team due to my epilepsy; the coach was worried about the chance that I might have a seizure during a game and harm myself. That is ignorant, insulting and inexcusable among many other things. That same coach, my physical education teacher (who should, therefore, know about epilepsy and be teaching about the subject), required that I take another student with me whenever I asked to go to the bathroom. To date, I have never harmed myself during a seizure. This is about dignity and respect among other things.

Age 18–33: This period, easily categorized as post surgery, is exclusively grand mal seizures. Depending on the year, the number varies. One thing which does not change, however, is the emotional effects on the individual. Although the seizure itself may last for approximately 1–3 min and recovery time varies, too infrequently, the personal ramifications for adults are discussed. Specifically, after having a grand mal seizure as an adult, you do not have the protection of a parent to shield you from being hurt or literally pick you up and make sure things are alright. Children are resilient and tend to bounce back more easily than adults; epilepsy is no different. Adults who have a grand mal seizure must face the crowds of stares during and immediately after the seizure, straddling the topic in a work context (who to tell, whether to tell at all, potential backlash), and long-term or short-term changes to lifestyle (driving privileges, living environment). The emotional roller coaster of believing that things are stable or even improving can be wiped out by a single and poorly orchestrated event.

College and epilepsy is an odd couple. The inconsistent and absent sleep pattern, saturation of alcohol, and necessity for medications to assure no seizures is a formula for something to go wrong. We cannot bury our heads in the sand when it comes to college students and the likeliness that they will miss or skip medications, or drink alcohol. It is one thing to know the ideal situation when sitting in a sterile doctor's office but quite another when away at college with the offer to attend a party.

Age 33–37: One of my last grand mal seizures occurred at a fitness club. To avoid too much embarrassment and effectively suffer in silence, I try to find the closest solitary place before the seizure begins. In this case, I was not successful. I had a grand mal at the elevator door/main entrance for the world to see as they came and went. When this happens, people hover unnecessarily, insist upon 911 (not always required) or are shocked that I am not speaking full sentences immediately. This happens like a broken record on replay every time I have a seizure; there is no systemic improvement in epilepsy education.

Two days before Christmas 2009, I underwent Vagus Nerve Stimulator (VNS) implantation. This was intended to be an adjunct treatment to existing medications, ideally leading to tapering off at