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Counselling adults who experience a first seizure

Karen T. Legg^{a,*}, Mark Newton^b

^aQueen Elizabeth II Health Sciences Centre, Room 4706, Halifax Infirmary Site, 1796 Summer Street, Halifax, NS B3H 3A7, Canada

^bAustin Hospital, Heidelberg, Victoria, Australia

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ABSTRACT

Purpose: A first seizure can result in significant uncertainty, fear and apprehension. One of the key roles of the clinician in the setting of first seizure is to provide accurate, timely information and counselling.

Method: We review the numerous components to be considered when counselling an adult patient after a first seizure.

Results: We provide a framework and manner to provide that counselling. We focus on an individualized approach and provide recommendations and information on issues of diagnosis, etiology, prognosis, the role and importance of medical testing, lifestyle considerations, driving, medication and other key counselling considerations.

Conclusion: Accurate, timely counselling can allay fears and anxieties, remove misconceptions and reduce the risk for injury in seizure recurrence.

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1. Introduction

The experience of an unprovoked first seizure event brings with it a great deal of fear and apprehension. Although a seizure can present clinically as almost any subtle, stereotypical, recurrent event; it is rarely these subtle events that bring patients forward for medical attention. It is usually a first generalized tonic–clonic seizure that, because of its intense nature and the anxiety that follows, mobilizes a patient to seek medical evaluation. A key role of the clinician in this setting is to not only provide appropriate medical care, but also to provide accurate, timely information and counselling. The education provided through this counselling can allay fears and anxieties, eliminate misconceptions and can reduce the risk for injury if seizure recurrence happens. Having information about one's medical condition provides insight into that condition as well as providing expectations in regards to prognosis, testing, treatment options and lifestyle implications. Accurate information promotes self-management and assists patients in making informed choices. Such counsel can offer patients a semblance of control in a very uncertain and challenging time and is essential for comprehensive first seizure care [13]. It includes numerous components (Table 1) that must be considered and tailored to the individual and their own particular situation.

Detailed counselling may need to extend over a prolonged visit or a number of visits and will often require repetition once epilepsy is diagnosed. Utilizing the skills and resources of members of the interdisciplinary team to assist with the counselling process may be beneficial; as will the presence of family members or friends during the sessions. In addition to verbal counselling and information, written materials and directions to vetted websites and community resources should also be provided. For those requiring additional support and counselling the opportunity to link with trained counsellors and/or community support groups/associations should be offered. Provision of a “New Diagnosis” package will complement the counselling. Providing detailed counselling will often prevent repeat referrals, unnecessary investigations, inappropriate utilization of additional health care services and resources and personal distress.

2. Acknowledging the event

A first seizure can provoke a multitude of reactions including denial, fear, sadness or anger. The individual response to this unexpected, stressful situation depends on coping skills and life experiences, and is also influenced by our response to the person [12]. Acknowledging the emotional and physical impact a first seizure has had on the individual provides recognition of the importance of the event and forms the basis for a therapeutic relationship between provider and patient. Often the person who has experienced the seizure is completely amnesic of the event and thus not overly bothered by it. However, acknowledgement and support often needs to extend to the patient's family member

* Corresponding author. Fax: +1 902 473 4438.

E-mail addresses: karen.legg@nshealth.ca, Karenlegg@live.ca (K.T. Legg), mark.newton@austin.org.au (M. Newton).

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Table 1

Components for counselling after first seizure.

- Acknowledging the event
- Explanation of what a seizure is (and is not)
- Possible etiology and prognosis
- Purpose and limitations of tests
- Lifestyle considerations (safety, occupation, seizure threshold)
- Driving
- Seizure first aid
- Role of medication
- Medication action and side effects (if appropriate)
- Psychological implications
- Next steps and when to call for help

who might have witnessed the seizure and is traumatized by the experience. Providing adequate time for the patient to tell their story and express their concerns can further promote respect and trust. It enables the patient the opportunity to articulate the emotional aspects of this event and then focus on the information being provided.

Adults presenting with a first seizure are often surprised at how common a first seizure is. Studies indicate that we all possess a lifetime risk of between 8 and 10% of experiencing a single seizure, and a 3% risk of developing epilepsy [7]. It is further estimated that isolated unprovoked seizures occur at an incidence of approximately 61/100,000 person-years [8]. Based on current population numbers, this would mean that over 4 million individuals worldwide will experience isolated, unprovoked first seizures each year. Closer to home this translates to more than 21,000 Canadians and more than 14,000 Australians presenting with a first seizure each year. In the United States it is estimated that approximately 150,000 adults will present with a first seizure each year [6]. Making patients aware of how frequently first seizure events occur can provide some reassurance and can reduce their apprehension.

3. What is a seizure?

Once the diagnosis of a first seizure has been confirmed a clear explanation of what a seizure is will be the first point in counsel. It is important that patients understand that the seizure itself is not a disease but a transient symptom due to abnormal excessive or synchronous neuronal activity in the brain [4]. Although most first seizure presentations are of a generalized tonic–clonic seizure (GTCS) it should be explained that a seizure can present in many different ways, depending on which part of the brain is affected. Elaboration of how a seizure differs from other paroxysmal events (Table 2) is also important as these may be relevant.

Discussions should include the common clinical characteristics associated with seizure (Table 3) and specifically those factors of their individual event that are convincing for seizure. This detailed explanation assists the individual (and their family/spouse) who

Table 2

Differential diagnosis for seizure.

- Syncope
- Transient ischemic attack
- Psychogenic non-epileptic seizures (PNES)
- Cardiac disorders
- Migraine
- Medication, alcohol or drug Intoxication
- Sleep disorders
- Panic attacks/hyperventilation
- Movement disorders
- Hypoglycemia
- Transient global amnesia
- Other

Table 3

Common clinical characteristics associated with a generalized tonic–clonic seizure.

- Sudden onset
- Eyes open and rolled back
- Stiffening
- Tonic–clonic movements
- Urinary incontinence
- Tongue bite
- Post-ictal confusion
- Post event fatigue and muscle ache

has experienced the seizure in understanding why the clinician believes their experience is indeed a seizure and not a paroxysmal event of some other kind. Belief and acceptance of the diagnosis may depend on this.

Additional discussion may include the distinction between a first seizure and a diagnosis of epilepsy. Explaining that the term epilepsy refers to a condition in which individuals have a tendency to have seizures may help alleviate stigma associated with the term. Further explaining that epilepsy is diagnosed when someone has experienced 2 or more unprovoked seizures; when an epilepsy syndrome is identified on EEG; or when someone has had a single seizure in a setting of an enduring predisposition for seizure recurrence [5] will set the stage for future discussions around the role of medications after first seizure or in the event of a second. The individual presenting with their first generalized tonic–clonic seizure may have been experiencing more subtle, stereotypic events, consistent with seizure, for some time. Determining this is important as it allows a syndrome diagnosis early on and might help explain symptoms that may have been ignored, trivialized or misdiagnosed.

4. Possible etiology and prognosis

Providing information about possible causes for seizure as well as risk for further events is a key component of counselling after a first seizure. Patients need to understand some of the provocations for seizure (Table 4). Acute symptomatic seizures that occur as a result of a clearly identified cause are less likely to reoccur if the identified cause is removed [1].

The risk of a second seizure is highest shortly after the initial event and decreases with time. Berg and Shinnar [2] in their meta-analysis, found that 60–70% of seizure recurrences occur within the first 6 months and decreases exponentially over time. Epilepsy eventually develops in 34% of first seizure cases within 5 years [7].

5. Purpose and limitations of tests

A clinical suspicion for seizure will stimulate further investigation. Patients must understand that the diagnosis of seizure is usually a clinical one and is based on the description of the event. Testing is ordered to provide additional information and to assist

Table 4

Causes for seizure.

- Remote brain injury (tumour, vascular, traumatic, post-encephalitic, developmental)
- Acute brain injury (hemorrhage, encephalitis)
- Metabolic derangements
- Medications
- High fever
- Significant sleep deprivation
- Withdrawal from alcohol or drugs
- Excessive alcohol intake
- Unknown

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