

Epilepsy myths: Alive and foaming in the 21st century

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Received 19 February 2007; revised 25 April 2007; accepted 29 April 2007

Available online 29 June 2007

Abstract

Many myths are perpetuated and reinforced in the portrayal of fictional characters with epilepsy in films and on television. Common cinematic treatment myths include the necessity for immediate medical intervention in the form of an ambulance crew to stop a seizure and the placing of an object in the seizing person's mouth to prevent the person from choking on her or his tongue. Other misrepresentations include excessive "foaming" at the mouth during a seizure and frequent violence. We conducted an Internet-based survey to examine the prevalence of belief in these myths in the United Kingdom. We received 4605 valid responses. People who knew someone with epilepsy were significantly less likely to subscribe to all the myths than were those who had no personal knowledge of epilepsy. Seeing seizures in public appears to improve knowledge regarding appropriate first aid procedures, but does not have an impact on myths surrounding the presentation of a seizure. These results are discussed in relation to the "we see what we expect to see" phenomenon in relation to stereotypes surrounding epilepsy.

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Keywords: Epilepsy; Stereotype; Cinema; Survey; Seizure; First aid

1. Introduction

Epileptic seizures have been surrounded by a vibrant mythology since antiquity. Although seizures have frequently been viewed as a manifestation of the divine and demonic in the spiritual realms throughout the ages [1,2], the late Victorians shunned "such superstitious nonsense" and turned, instead, to the strict moral framework of the day to understand the etiology of seizures. Writing in the *Journal of Nervous and Mental Diseases* in 1892, Dr. Joseph Price noted that debauchery, chocolate, coffee, excessive lust, and amorous love songs were all "abundantly proven and great factors in its causation" [3].

With the advent of electroencephalography and the coming of age of neurology in the 20th century, much has been learned about the pathogenesis and etiology of

seizure disorders. The 20th century also witnessed the advent of cinema. Just as epilepsy has proved a rich source of inspiration for writers and artists through the ages [4–6], it did not take long for seizures to begin to appear on the silver screen. Characters with epilepsy frequently appear in the movies. From Disney's *Snow White*, in which Dopey appears to have a nocturnal seizure, to Oliver Stone's *JFK*, in which a person with epilepsy is implicated in the presidential assassination, epilepsy is featured in films across all genres and cinematic cultures [7]. Epileptic seizures are also frequently part of the ubiquitous hospital dramas that can be seen every night on television. Although the scientific understanding of epilepsy as a condition increased tremendously through the century, cultural attitudes have failed to keep pace [8], and to this day, cinematic portrayals continue to perpetuate many of the ancient myths surrounding the condition. Movie characters with epilepsy are frequently mad, bad, or dangerous, with demonic possession, lunacy, idiocy, and divine revelation as regular features. Although this trend may contribute to the negative stereotypes surrounding the condition, of much more

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immediate concern is the consistent misinformation these fictitious portrayals provide regarding the appearance and treatment of seizures. When a character has a seizure on screen, he or she frequently “foams” at the mouth, and passersby will immediately call an ambulance and/or attempt to put something in the unfortunate character’s mouth in an explicit attempt to stop her or him from choking or swallowing the tongue [7].

Although these are common features in fictitious plots, it is unclear whether they also have currency in the real world. Cinema goers are generally quite sophisticated in decoding cinematic shorthand: overlong exposure of a set of kitchen knives indicates these knives will be important later in the plot; on the silver screen, an isolated dwelling is almost always associated with danger, being haunted, or the lair of a psychopathic killer. We do not respond to these items in the real world in the same way we do when we see them on the screen because we understand the code. It is unclear whether the common cinematic codes for epilepsy are recognized by the general public as fictitious representations for dramatic effect. The aim of this study was to examine the prevalence of belief in common cinematic epilepsy myths among Internet users in the 21st century.

2. Methods

An invitation to complete a very brief eight-item questionnaire on the public perception of epilepsy was e-mailed to all staff and students at University College London. Questions 1–3 elicited sample demographics: country of residence, age, and gender. Questions 4–8 related to experience/knowledge of epilepsy (see Tables 2 and 3 later). Having completed the questionnaire, the respondents were encouraged to pass the link to their own e-mail contacts. The survey link was open for 6 weeks. To avoid duplicate entries, respondents found to be repeats on the basis of their ISP addresses were discounted. All responses were completely anonymous, but respondents were given the option to register for feedback if they wished. Data were analyzed using the Statistical Package for Social Sciences.

3. Results

Five thousand and four responses to the survey were posted. Fifty-two responses were incomplete and were excluded from subsequent analyses. An additional 347 responses were excluded from this study, as these respondents were not UK residents ($n = 4605$). (Cross-cultural differences in epilepsy myths are the subject of a separate study.) Women constituted 64% of the sample, and the majority of respondents fell in the age range 18–30 (Table 1). One hundred and eighteen participants registered for feedback (2.3%). Approximately half of the sample knew someone with epilepsy, whereas half of the sample had never witnessed a seizure in public. Thirty-two percent of the sample did not know anyone with epilepsy and had never seen a seizure in public (Table 2). Although the questions were deliberately worded to refer to all kinds of epileptic seizures, it was clear from the responses that most participants were referring to the schema of a tonic-clonic event when thinking about epilepsy, with two-thirds of the

Table 1
Sample demographics

Sample demographics	
Gender	
Male	35.6%
Female	64.4%
Age	
<18	0.9%
19–30	57.1%
31–50	29.3%
51–65	11.3%
>65	1.4%

sample believing that people always or often fall to the ground during a seizure (Table 3). Two-thirds of the sample reported that they would call an ambulance immediately if they saw a seizure, and one in three reported that they would attempt to put something in the seizing person’s mouth. Less than 5% of the sample believed that people with epilepsy always or frequently become violent during a seizure. More than 90% of the sample thought that seizures lasted less than 5 min (see Table 3).

3.1. Myth 1. Calling an ambulance

Gender was not a significant factor in distinguishing those who would call an ambulance from those who would not ($\chi^2(1) = 0.66$, $P > 0.05$). The proportion of respondents who would call an ambulance increased steadily with age, ranging from 34% of those under 30 to 59% of those over 65 ($\chi^2(4) = 195.2$, $P < 0.001$). People who did not know anyone with epilepsy were significantly more likely to call an ambulance than were those who did know someone ($\chi^2(1) = 67.3$, $P < 0.001$). Among those who did not know anyone with epilepsy, exposure to seizures in public had a significant effect on whether they would call an ambulance, with 68% of those who had never seen a seizure opting to call an ambulance, compared with 57% of those who had seen one public seizure and 49% of those who had seen more than one seizure in public ($\chi^2(2) = 47.8$, $P < 0.001$).

3.2. Myth 2. Put something in the seizing person’s mouth

Again, gender was not a significant factor in distinguishing those who would put something in the seizing person’s mouth from those who would not ($\chi^2(1) = 0.76$, $P > 0.05$). There was a significant effect of age. The proportion of respondents in all age groups up to the age of 65 who would put something in the person’s mouth was stable at around 30–35%. However in the >65 age group, 57% of the respondents thought that this would be an appropriate course of action ($\chi^2(4) = 21.8$, $P < 0.001$). People who did not know anyone with epilepsy were significantly more likely to try and put something in the person’s mouth (37%) than those who did know someone (28%) ($\chi^2(1) = 45.8$, $P < 0.001$). Among those who did not know anyone with

Table 2
Experience of epilepsy

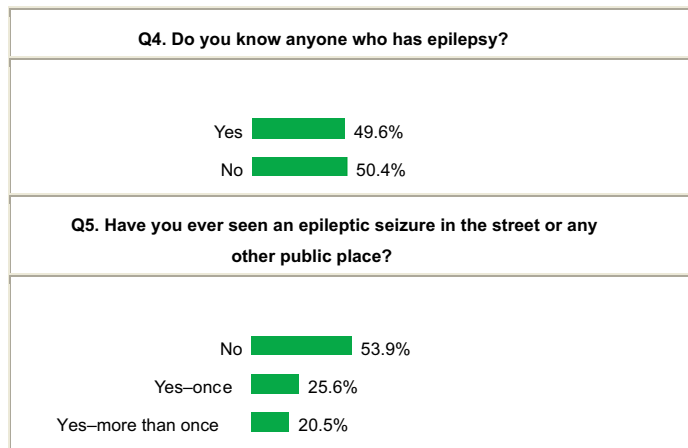
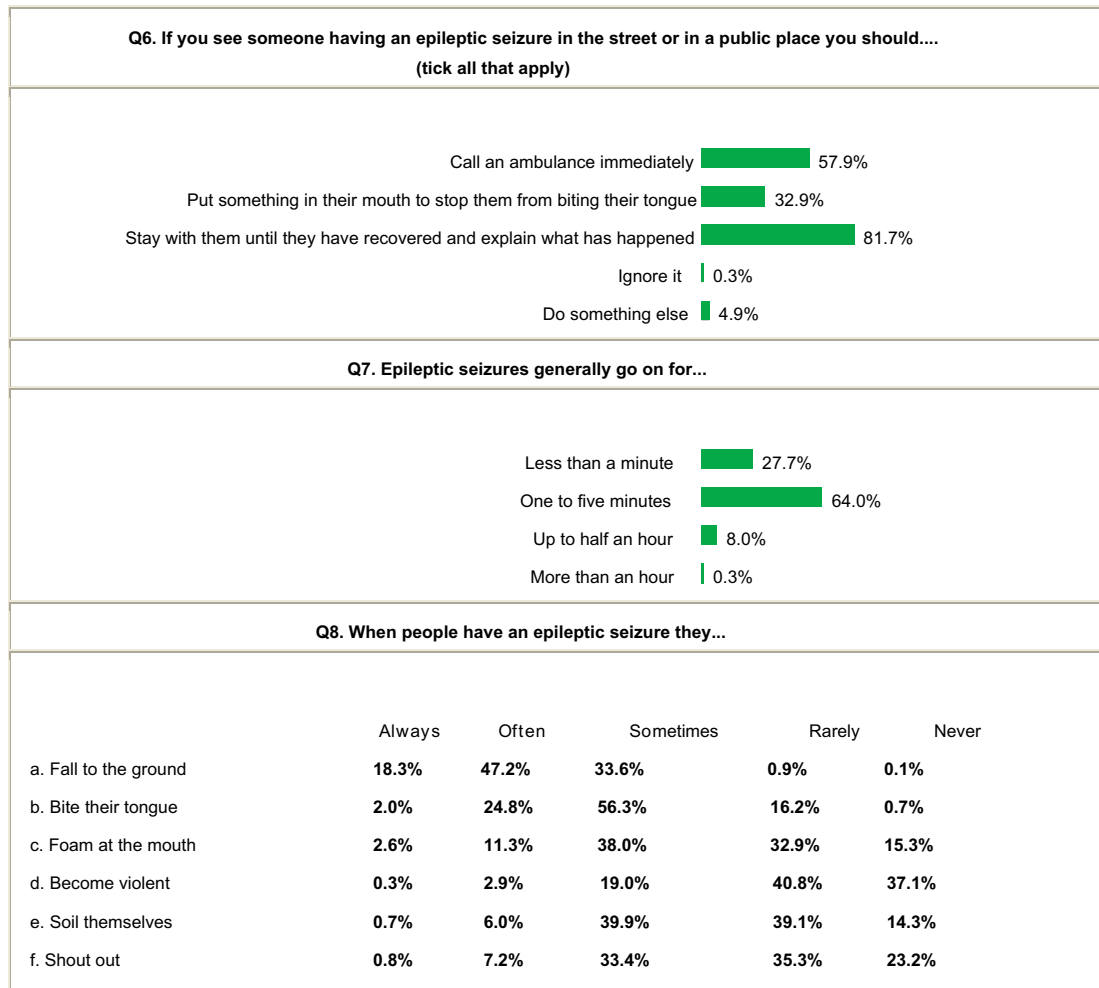


Table 3
Seizure knowledge



epilepsy, exposure to more than one seizure in public had a significant effect on whether they would put something in the person's mouth, with 39% of those who had never seen a seizure and 37% of those who had seen only

one seizure choosing to put something in the person's mouth as an appropriate course of action, compared with just 27% of those who had seen two or more public seizures ($\chi^2(2) = 12.6, P = 0.002$).

3.3. Myth 3. Foaming at the mouth

Gender was not a significant factor in distinguishing those who thought foaming always or often occurred during a seizure from those who did not ($\chi^2(1) = 1.21$, $P > 0.05$). The foaming myth was more often believed by the youngest and oldest age groups: 18–30 (16%), 31–65 (10%), >65 (20%) ($\chi^2(4) = 33.4$, $P < 0.001$). People who did not know anyone with epilepsy were significantly more likely to believe in the foaming myth than those who did know someone, 16% versus 11%, respectively ($\chi^2(1) = 22.7$, $P < 0.001$). However, in contrast to the previous two myths, for those who did not know anyone with epilepsy, witnessing a seizure in public did not have a significant effect on their belief in the foaming myth ($\chi^2(2) = 3.3$, $P > 0.05$).

3.4. Myth 4. Violence in seizures

Only 3% of the sample thought that people with epilepsy always or often became violent during a seizure. Gender was not a significant factor ($\chi^2(1) = 0.3$, $P > 0.05$). Belief in the violence myth was reported more often by those under 18 years of age, 9.5% of whom thought people often or always became violent in a seizure ($\chi^2(4) = 18.7$, $P < 0.001$). People who did not know anyone with epilepsy were significantly more likely to believe in the violence myth than those who did know someone, 3.8% versus 2.5%, respectively ($\chi^2(1) = 6.0$, $P = 0.01$). As for the foaming myth, there was no significant effect of seeing seizures in public on belief in the association of violence with seizures by those who did not know anyone with epilepsy ($\chi^2(2) = 0.43$, $P > 0.05$).

4. Discussion

Approximately half of the respondents in our sample had witnessed a seizure in public, consistent with previous survey studies [8]. However, although Jacoby et al. [8] noted a significant effect of gender on epilepsy knowledge and attitudes, with women generally having more positive attitudes, we did not find a significant effect of gender on any of our epilepsy myths. However, age was a significant factor. With the exception of the violence myth, people over the age of 65 were significantly more likely to subscribe to all of the myths compared with younger people. Those younger than 18 were more likely to believe in the violence and foaming myths than were older age groups. As only one in three of those under age 18 had witnessed a seizure in a public place or knew someone with epilepsy, their knowledge is less likely to be based on first-hand experience of the condition. These findings are consistent with previous studies that have reported significantly lower levels of epilepsy knowledge in the >60 and younger age groups [8,9].

Knowing someone with epilepsy had a significant impact on the results. People who did not personally know

anyone with epilepsy were significantly more likely to subscribe to all four myths examined.

It is interesting to note that for those who did not know anyone with epilepsy, the influence of seeing a stranger having a seizure in a public place had an impact on the “treatment” myths, but not on the myths associated with the presentation of the seizure itself. Thus, compared with those who had never witnessed a seizure, people who had seen a public seizure, particularly on more than one occasion, were less likely to choose “call an ambulance” or “put something in the patient’s mouth” as appropriate first aid. However, witnessing strangers’ seizures had no impact on belief in the violence or foaming myths.

This somewhat paradoxical finding might well be explained by the social psychological phenomena of schemata and stereotypes, where people do not simply respond to novel events, but rather they tend to interpret them on the basis of their previous experience and beliefs—experience that has become represented in memory as a schema [10]. A schema provides a basis for evaluating our experience and influences what we recall and forget about an experience. A stereotype is a schema about an identifiable group of people. One of the reasons for the existence of stereotypes is that observers often fill in information that may not be there when they encounter a member of the stereotyped group [11]. We tend to see what we are expecting to see, rather than the actual events taking place. Thus, the recollection of a seizure in a public place may well include “foaming,” as this is what witnesses strongly associate with epileptic seizures. False recall for associated, but nonpresent features has been shown to be remarkably resilient under laboratory conditions, even when people are cognizant of the effect [12,13]. So it seems with witnessed seizures, where even seeing more than one does not appear to have an impact on belief in the foaming/violence myths if they are already held.

These findings contribute to a growing body of evidence that suggests that negative attitudes toward epilepsy appear to be remarkably resistant to change. Mason et al. demonstrated that attendance at an epilepsy seminar improved overall knowledge of epilepsy, but had relatively little impact on the participants’ attitudes toward the condition, which were also unaffected by previous exposure to the condition [9]. Similarly, Jacoby et al. found that while knowing someone with epilepsy improved knowledge of the condition, it had no impact on the belief that people with epilepsy have more personality problems than others [8]. Our study design does not allow us to determine the relative contribution of negative cinematic stereotypes of epilepsy to the formation, or maintenance, or reflection of public attitudes toward the disorder. However, there have been efforts to use fictional characters to improve public awareness of the condition. In the United States, the Epilepsy Foundation has collaborated with a national broadcasting service (CBS) to create an epilepsy-related story line for an existing,

popular character in *The Young and the Restless*, a daytime soap opera. The scriptwriters went so far as to make the character into a nicer person following the onset of posttraumatic temporal lobe epilepsy. The effects of this novel approach to change public attitudes toward epilepsy have yet to be formally evaluated.

Although the numbers in this study were large, there are a number of inherent methodological limitations associated with Internet-based research, primarily the difficulties associated with sampling bias. Caution should therefore be exercised in generalizing the conclusions beyond the population sampled, specifically those with basic proficiency on, and access to, the Internet. Younger people (<30) therefore constituted the majority of the sample. As Internet use and proficiency decrease with age, particularly in those >65, it is likely that the oldest and very youngest respondents in our sample are fairly unrepresentative of the wider population. The findings from this study may underrepresent the true prevalence of these myths in the wider and older general UK population.

In conclusion, fictional movie characters with epilepsy continue to perpetuate a number of myths about the condition. These myths appear to be fairly widely held by the general population, particularly among those who have never witnessed an epileptic seizure, suggesting that people with epilepsy continue to be at risk of physical harm from one in three misguided members of the UK public who may attempt to put something in their mouths during a seizure. Although many epilepsy associations make laudable efforts to counteract the negative stereotypes associated with the condition, this study suggests that some stereotypes, particularly the “foaming” myth, may be particularly resistant to change, even in people who have witnessed a number of seizures. The myths surrounding

the condition may have evolved, but they are still very much present in the 21st century.

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