

# Knowledge and Attitudes about Epilepsy: A Survey of Dentists in London, Ontario

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## ABSTRACT

**Background:** The controversial relation between societal knowledge and attitudes about epilepsy may affect the access of people with epilepsy to dental care.

**Materials and Methods:** A questionnaire that evaluated knowledge about epilepsy, attitudes toward epilepsy and willingness to provide dental care to people with epilepsy was administered to all 288 dentists in the city of London, Ontario, Canada.

**Results:** Of the 197 respondents, 75.6% were general dentists. Knowledge was patchy about the epidemiology, causes, treatment and recognition of epilepsy. Six percent of dentists did not think that they could safely treat a patient with epilepsy in their offices.

**Conclusion:** Dental care providers' negative attitudes to and lack of knowledge about epilepsy may directly affect the access to dental care for people living with this problem.

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Epilepsy is a chronic disease characterized by the risk of recurrent seizures. In developed countries, an average of 4 or 5 of every 1,000 people has epilepsy.<sup>1</sup> In developing countries, this rate can be as high as 43 per 1,000 people.<sup>2</sup> According to the World Health Organization,<sup>3</sup> the disability caused by epilepsy accounts for about 0.5% of the global burden of the disease measured by disability-adjusted life-years. As a result, epilepsy ranks just after psychiatric conditions such as alcohol dependence. The global health care burden of epilepsy is comparable to that of breast or lung cancer.<sup>4</sup>

Some cultures believe that epilepsy represents demonic possession.<sup>5</sup> Although epilepsy arises from a transient dysfunction in the brain, fear and ignorance still lead to discrimination and feelings of shame.<sup>6-10</sup> In the public mind and in the laws of some countries,

epilepsy is strongly associated with mental illness and cognitive disabilities — unfortunate generalizations that unfairly affect many people with epilepsy. Such pervasive social stereotyping is difficult to overcome.

Previous surveys<sup>11-18</sup> testing knowledge, attitudes, beliefs and treatment of people with epilepsy have focused on the general public, students or teachers. Dentists and other health care workers, who represent one of the more highly educated and influential groups in society, however, have not been surveyed. Undoubtedly, their perspectives about people with epilepsy have an impact on their professional interactions with this patient population. Their social response to this population, independent of their provision of medical care, may influence the way their community views people with epilepsy. Because the dental care of patients with epilepsy is important,

**Table 1** Demographic data and personal experience with epilepsy

Description (total no. of responses)	No. of responses (%)
<b>Age, years (n = 197)</b>	
Mean (range)	48 (25–80)
Median	49
<b>Sex (n = 196)</b>	
Female	53 (27.0)
Male	143 (73.0)
<b>Specialty (n = 196)</b>	
General dentistry	149 (75.6)
Orthodontics	12 (6.1)
Pediatric dentistry	6 (3.1)
Maxillofacial surgery	6 (3.1)
Prosthodontics	5 (2.5)
Periodontics	5 (2.5)
Oral pathology	4 (2.0)
Endodontics	3 (1.5)
Other <sup>a</sup>	6 (2.0)
<b>Personal experience with epilepsy (n = 197)</b>	
Know someone with epilepsy	182 (92.4)
Witnessed an epileptic seizure	141 (71.6)

<sup>a</sup>One dentist had a master's in public health, 1 dentist had a master's in biomaterials and 4 dentists had more than one specialty.

and some reports in the literature<sup>19</sup> indicate there may be disparities in their care, compared with that of the general population, we surveyed all the dentists in London, Ontario, to determine their knowledge about and attitudes to epilepsy, and their willingness to provide dental care to people with epilepsy.

## Materials and Methods

### Study Population

We sent a survey to all 288 dentists listed in the city of London, Ontario. We identified them from the membership directory of the Royal College of Dental Surgeons of Ontario and mailed a questionnaire and a prepaid envelope on 3 different occasions to increase response rate. The University of Western Ontario's Research Ethics Board reviewed and approved this study.

### Survey Instrument

After reviewing several survey instruments about knowledge, attitudes, beliefs and practices used by other groups studying epilepsy,<sup>11</sup> and those studying hepatitis and AIDS,<sup>20–23</sup> we developed a 22-item questionnaire

**Table 2** Respondents' responses to questions about their knowledge about epilepsy

Responses (total no. of responses)	No. of responses (%)
<b>Prevalence of epilepsy (n = 197)</b>	
	73 (37.1)
<b>Causes of epilepsy</b>	
Accidents/head trauma (n = 195)	171 (87.7)
Inherited disease (n = 195)	164 (84.1)
Mental illness (n = 195)	101 (51.8)
Tumours (n = 195)	177 (90.8)
Birth defects (n = 195)	163 (83.6)
Strokes (n = 195)	148 (75.9)
Do not know (n = 197)	10 (5.1)
<b>An epileptic attack is (n = 197)</b>	
Convulsion/shaking	195 (99.0)
Episode of loss of consciousness	180 (91.4)
Episode of behavioural change	171 (86.8)
Period of memory disturbance	177 (89.4)
<b>Treatment of epilepsy with medications (n = 197)</b>	
Is seldom effective	10 (5.1)
Is better if 2 or more drugs are used	48 (24.4)
Has advanced in the last 10 years	136 (69.0)
Occasionally causes birth defects	24 (12.2)
Can be stopped after 1 year of control	10 (5.1)
Do not know	41 (20.8)
<b>If a patient has a seizure in the dental chair (n = 197)</b>	
Put something in patient's mouth	36 (18.3)
Hold patient tight	4 (2.0)
Put patient in Trendelenburg position	39 (19.8)
Administer oxygen	12 (6.1)
Call 911 immediately	30 (15.2)
Time it, and call 911 after 3 minutes	96 (48.7)
Move patient to a safe area	138 (70.1)

The correct answers to the questions are marked on the questionnaire (**Appendix 1**).

(**Appendix 1**). This questionnaire elicited information about demographics (3 items), personal experience with epilepsy (2 items), knowledge of epilepsy (5 items), social tolerance (4 items), current practices (2 items) and willingness to care for patients with epilepsy (6 items).

### Analysis

We entered the data twice into Microsoft Access 2007 (Redmond, Wash.) to ensure accuracy. We used SAS version 9 (Cary, N.C.) and Microsoft Excel 2003.

**Table 3** Respondents' responses to questions about social tolerance

Responses related to social tolerances (total no. of responses)	No. of responses (%)
I would object to my children associating with somebody with epilepsy ( <i>n</i> = 195)	3 (1.5)
I would object to a marriage between a close relative and a person with epilepsy ( <i>n</i> = 194)	10 (5.2)
People with epilepsy should not have children ( <i>n</i> = 187)	4 (2.1)
People with epilepsy can be employed anywhere ( <i>n</i> = 190)	166 (87.4)

**Table 4** Responses related to office practices for treatment of patients with epilepsy (*n* = 196)

Responses	No. of responses (%)			
	Strongly agree	Agree	Disagree	Strongly disagree
Medical history and physical examinations cannot identify all patients with epilepsy	62 (31.6)	93 (47.4)	26 (13.3)	15 (7.6)
Office policy is to refuse treatment to people with epilepsy	3 (1.5)	0 (0.0)	10 (5.1)	183 (92.9)
My family would be concerned if I treated patients with epilepsy	2 (1.0)	0 (0.0)	9 (4.6)	185 (93.9)
I can safely treat a person with epilepsy in the office	128 (65.3)	56 (28.6)	6 (3.0)	6 (3.1)
If I treat patients with epilepsy, other patients may be reluctant to continue in my care	5 (2.6)	1 (0.5)	21 (10.7)	169 (86.2)
As a dentist I have an ethical responsibility to treat patients with epilepsy	168 (85.7)	20 (10.2)	3 (1.5)	5 (2.6)

## Results

Of the 288 dentists in London who received the study, 8 dentists had moved out of London; 197 returned the survey (response rate, 70.4%). **Table 1** summarizes the respondents' demographic details and personal experience with epilepsy. Most (149/196, 75.6%) of the surveyed dentists were general dentists, most (182/197, 92.4%) knew someone with epilepsy, and most (141/197, 71.6%) reported witnessing an epileptic seizure.

**Tables 2 and 3** summarize respondents' answers to the questions about their knowledge of epilepsy and social tolerance. Because not all respondents answered all the questions in the survey, we calculated percentages based on the number of responses for each question. Although most dentists did not know the prevalence of epilepsy, most knew that head trauma, tumours, brain malformations and strokes can cause epilepsy and that it may have a genetic cause. About half (101/195, 51.8%) attributed epilepsy to a mental illness. All knew that an

epileptic seizure can be a convulsion or shaking; only a few (17/197, 8.6%) were unaware that nonconvulsive epileptic seizures occur. If a patient had a seizure in the dental chair, 18.3% (36/197) of respondents would put something in the patient's mouth, and 2% (4/197) would hold the patient tight.

In answer to questions about their social tolerance for people with epilepsy, 1.5% (3/195) of respondents would not allow their children to associate with people with epilepsy, 5.2% (10/194) would object to a person with epilepsy marrying a close relative, 97.9% (183/187) agreed that people with epilepsy should have children, and 87.4% (166/190) believed that people with epilepsy can be employed anywhere.

**Table 4** summarizes respondents' answers to questions about their practices. The majority (155/196, 79.0%) of respondents agreed that they could not identify all patients with epilepsy from their medical history. Three out of 196 respondents (1.5%) indicated that the office

policy where they worked did not allow them to treat patients with epilepsy; 3% (6/196) believed that knowing that patients with epilepsy were treated in the same office might make other patients reluctant to continue their care there. Ninety-eight percent of respondents (194/196) indicated that their families would not be concerned about their treating patients with epilepsy. Six percent of the respondents (12/196) did not think they could safely treat patients with epilepsy in their offices; 95.9% of respondents (188/196) believed that they had an ethical responsibility to treat this population.

## Discussion

Although the results of our sampling 100% of the dentists in a Canadian urban area are not representative of all Canadian dentists, our survey provides some interesting insights into one group of dental practitioners' knowledge and attitudes toward people living with epilepsy.

Our survey results indicate that our dental respondents' knowledge of epilepsy care was more limited than we expected from health professionals. Our respondents lacked knowledge about the prevalence of the disease and the teratogenicity of antiepileptic drugs, although most had appropriate knowledge about the cause of seizures and their ictal manifestations. One explanation may be that dentists in private practices are less exposed to patients with epilepsy because they are often treated in hospitals or they may consider their dental health the least of their problems. Of concern is the finding that almost one fifth of respondents would place something in the patient's mouth (18.3%) or would put the patient in the Trendelenburg position (19.8%) during a seizure, actions that are not recommended for patients having a seizure.<sup>24</sup> Most (70%) of the surveyed dentists knew that they must move a patient having a seizure to a safe area to avoid injuries; almost half (48.7%) knew that they must time the seizure and that if it lasted more than 3 minutes they must call 911.<sup>24</sup>

In general, attitudes toward people with epilepsy were positive, although a small percentage of respondents would not allow their children to socialize with people with epilepsy nor did they want their relatives to marry somebody with epilepsy. Results of a Brazilian study<sup>15</sup> showed the reverse dissociation between knowledge and attitudes: medical students with good knowledge of epilepsy were as likely as people of lower socioeconomic status with little knowledge of the disease to have a negative attitude toward their relatives marrying someone with epilepsy. A study<sup>14</sup> from Kentucky found that the most educated urban population had the greatest bias against people with epilepsy on the Relative Quality of Life measure, compared with rural and Appalachian residents.

Only a few (4%) dental respondents had negative attitudes about the employment of people with epilepsy, a finding potentially influenced by concerns about their safety or abilities rather than by workplace discrimination.<sup>25,26</sup> The answer to this question is important because the burden of unemployment that people with epilepsy face often negatively affects their self-image.<sup>26,27</sup>

Dentists' attitudes toward people living with epilepsy and their impact on these people's access to dental care needs further study. Health care providers' negative attitudes toward certain groups of people negatively influences their access to care.<sup>22</sup> For almost all aspects of the oral health and dental status of patients with epilepsy, their condition is significantly worse than that of age-matched groups without epilepsy in the general population.<sup>16</sup> That dental care is only partially, if at all, reimbursed worldwide may, in part, explain this problem. Only a few (1.5%) of our respondents indicated that the policy of their office was to refuse treatment of patients with epilepsy. Although we did not ask about the reason for this refusal in our survey, one explanation could be related to financial access to dental care. Because patients with epilepsy may have special needs during dental treatment, the treating dentist should be knowledgeable about the disease and about the appropriate actions to take when a patient has a seizure in the office.<sup>24</sup> Dental schools across the country need to develop more continuing dental education courses to update dental practitioners about the proper management of patients with diseases whom these practitioners may treat in a regular dental setting, and to reduce unnecessary hospital referrals.

Understanding epilepsy and seizures raises awareness about the disorder's impact on these patients' general medical and psychological health, and meets an important goal of the "Out of the Shadows" campaign of the International League Against Epilepsy, namely, "to reduce the limitations encountered by persons with epilepsy and their families."<sup>28</sup> ♦

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**Appendix 1** A survey of dentists and epilepsy: knowledge and attitudes

*To begin, it would be helpful if we had some general information about you:*

1. Your sex:    1.  Male  
                  2.  Female
  
  2. Age: \_\_\_\_\_
  
  3. What is your specialty? (*Check all that apply.*)  
 General dentistry  
 Orthodontics  
 Prosthodontics  
 Pediatric dentistry  
 Endodontics  
 Oral and maxillofacial surgery  
 Periodontics  
 Other: \_\_\_\_\_
- 

*For the following questions, choose the best answer:*

*(Editor's note: Correct answers for questions 6–10 are marked with an asterisk.)*

4. Do you know or have you ever known anyone with epilepsy?  
 yes             no
  
5. Have you ever seen anyone having an epileptic seizure?  
 yes             no
  
6. Epilepsy occurs in  
 one in every 1,000 people  
 one in every 100 people  
 one in every 10,000 people  
 one in every 50,000 people  
 one in every 1,000,000 people
  
7. What do you think causes epilepsy? (*Check all that apply.*)  
 accidents  
 inherited disease  
 insanity or mental illnesses  
 brain tumours  
 birth defects  
 stroke  
 all of the above can cause epilepsy  
 don't know

8. What do you think an epileptic attack is? (*Pick any that you think apply.*)
- a convulsion or shaking
  - a loss of consciousness
  - an episode of behavioural change
  - a period of memory disturbance
  - any of the above
  - don't know
9. What do you think about drug therapy for epilepsy? (*Check all that apply.*)
- it is seldom effective in controlling seizures
  - it is best given as two or more drugs that work together
  - it has advanced significantly over the past 10 years
  - it occasionally produces malformations in babies of mothers with epilepsy
  - it can be stopped abruptly after seizures are controlled for a year
  - all of the above
  - don't know
10. What should you do if a patient of yours starts having an epileptic seizure in your dental chair?  
(*Check all that apply.*)
- put something in the patient's mouth to prevent him/her from choking with his/her tongue
  - hold the patient tight so the patient stops shaking
  - put the patient in the Trendelenburg position
  - administer oxygen
  - call 911 immediately
  - time it, and if exceeds 3 minutes, call 911
  - move the patient to an area where he/she cannot hurt him/herself while having the seizure
11. Would you object to having any of your (eventual) children associate with persons who had sometimes epileptic seizures in school or in a playground?
- yes             no
12. Would you object to a person with epilepsy marrying a close relative of yours (brothers, sister or child)?
- yes             no
13. Do you think persons with epilepsy should have children?
- yes             no
14. Do you think that in general, persons with epilepsy should be employed at the same jobs as other people?
- yes             no

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*About your practice:*

15. Have you treated patients with epilepsy:

yes             no

16. How many patients with epilepsy have you treated in the last year (approximately): \_\_\_\_\_

For the following questions choose the most appropriate response by circling the corresponding number next to the statements

- 1 = strongly agree
- 2 = agree
- 3 = disagree
- 4 = strongly disagree

17. Medical history and physical examinations cannot identify all patients with epilepsy.

1                      2                      3                      4

18. The office policy is to refuse treatment to persons with epilepsy.

1                      2                      3                      4

19. My family would be concerned if I treated patients with epilepsy.

1                      2                      3                      4

20. I can safely treat a person with epilepsy in the office.

1                      2                      3                      4

21. If I treat patients with epilepsy, other patients may be reluctant to continue in my care.

1                      2                      3                      4

22. As a dentist I have an ethical responsibility to treat patients with epilepsy.

1                      2                      3                      4

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*Thank you for your contribution to this project. We appreciate the time you have taken to answer our questions. If you have additional comments, please list them below.*

Comments:

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