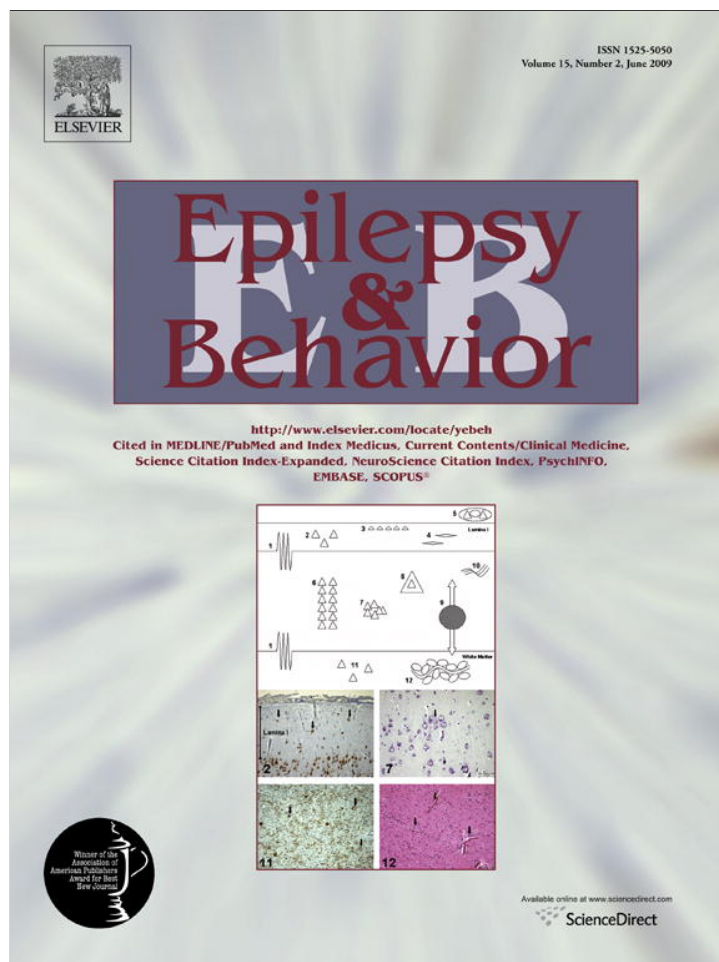


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First population study of the general public awareness and perception of epilepsy in Croatia

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ABSTRACT

Public knowledge of, perception of, and attitudes toward epilepsy in Croatia were assessed for the first time by asking 1000 randomly selected adults 12 questions. Ninety-seven percent of respondents had heard about epilepsy, 55% knew someone with epilepsy, and 44.6% had witnessed a seizure. Interviewees were quite ready to accept a person with epilepsy. Approximately 7% would object if their child played with a child with epilepsy, and 76% believed that a child with epilepsy could succeed as well as a child without epilepsy. Although 52.5% would approach a seizing person and help, 33.1% would call “911.” Positive attitude correlated with knowing someone with epilepsy and/or witnessing a seizure. General awareness of epilepsy in Croatia approaches that of other developed countries, and the majority of the population expressed acceptance of and readiness to help people with epilepsy. These results are more favorable than expected and an encouraging foundation for further improvements in social acceptance of persons with epilepsy.

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1. Introduction

Without appropriate persistent public efforts by medical professionals allied with various civic organizations, Out of the Shadows [1,2] may become a great missed opportunity, especially outside of the developed world [3] where the majority of patients with epilepsy live and continue to suffer to a great extent beyond their attacks [4]. The drastic consequences of this “deeply discrediting” disease [5] are much worse as a result of social circumstances [6,7]. Thus, progress toward a thorough understanding of the key social factors determining public attitudes toward epilepsy is a vital requirement for humanizing this reality worldwide [8,9].

For a person with epilepsy, the suffering caused by stigmatization frequently exceeds the degree of suffering from the disease itself [10–14]. Fortunately, as demonstrated by periodic surveys in the United States, public attitude has improved considerably over time despite the unchanged level of general knowledge about epilepsy [10,15]. However, a thorough understanding of current public knowledge and perception of epilepsy in a given community is necessary to target educational campaigns at further improving public attitudes toward epilepsy [12,14]. The scope of this 2004

study was to assess, for the first time, public knowledge and perception of epilepsy in Croatia.

Croatia, projected population of 4,436,400 for 2007 over 56,542 km² (Monthly Statistical Report No. 4, 2008, www.dzs.hr), was a part of the former Yugoslavia, which declared independence on 25 June 1991. More than 10 years after the Homeland War (1991–1995), which caused significant destruction and social upheaval, this small Mediterranean country is back on the road to prosperity and at the door of NATO and the EU. According to the 2001 census, 89.6% of inhabitants were Croats, 4.5% Serbs, and 5.9% other; 87.8% considered themselves Roman Catholics and 4.4% Orthodox, whereas 5.2% were not religious. Administratively, Croatia is divided in 20 counties in six traditional geographic regions [Zagreb and vicinity (ZGB & V); North Croatia; Slavonia; Lika and Banovina; Istra, Rijeka, and Gorski Kotar (IS, RI, & GK); and Dalmatia].

2. Methods

Data were collected as a part of a monthly Omnibus Survey [12,16] conducted on a two-stage stratified random sample of Croatian citizens older than 15. The first stage was stratified by the six geographic regions, and the second, by settlement size (urban and rural). Random selection was ensured by random selection of households (random walk method from randomly selected starting

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points), and random selection of respondents within selected households, by the Troldahl–Carter method [17].

The participants were asked 12 questions about epilepsy by trained interviewers in a face-to-face interview. Six questions (Q1–4, 7, 8) were taken from eight questions defined by Caveness and Gallup [10] and included in practically all subsequent relevant surveys (Fig. 1) [10,12,14,16,18–45] that assess general knowledge of, perception of, and attitude toward epilepsy; we created the remaining six questions. Our Q4 (What are the main symptoms of epilepsy?) was aimed at assessing more specific knowledge about manifestations of epilepsy; Q9 (Do you think that a child with epilepsy can succeed in life equally as a child without epilepsy?) and Q11 (What is the worst aspect of epilepsy for a person with epilepsy? 1. Attacks, 2. Fear of attacks, 3. Injuries during attacks, 4. Limited activity, 5. Limited professional opportunities, 6. Limited employment opportunities, 7. Rejection by others, 8. I do not know.) attempted to assess public perception of the profound social ramifications of being a person with epilepsy; Q12 [Imagine that you encounter a person experiencing an epileptic attack (fit) on the street. What would you do? 1. I would approach a person and help immediately, 2. I would approach a person and call Emergency Medical System (EMS), but wouldn't try to do anything personally, 3. I would call EMS and proceed without stopping, 4. I would yell to try to get more help, 5. I would proceed without stopping since I would be scared, 6. Something else, 7. I do not know] focused on assessing the population's readiness to help a person having a seizure. These latter questions were aimed at assessing the civic perception of the severity of epilepsy relative to some other diseases (AIDS, depression, epilepsy, heart attack, lung cancer, peptic ulcer, schizophrenia, and stroke) of different severity and prevalence (Q2), a need of the respondents to keep a safe social distance from persons with epilepsy (Q7), the respondent's perception of the worst aspect of epilepsy (Q11), and Q12 (What would you do in case you see a person having an epileptic seizure?) their presumed response when witnessing a seizure. The results pertaining to questions 2 (Q2) and 7 (Q7) are a focus of a separate study with an emphasis on the dynamics of sociopsychological relationships and corresponding behaviors. Standard methods of descriptive statistics were used for data analysis.

3. Results

Almost all participants (Q1, 97.3%) had either “read” or “heard” about epilepsy. Middle-aged participants (36–55), those with a

secondary school or university degree, those from Lika and Banovina (100%) or ZGB & V (99.2%), and urban citizens (98.4%) were significantly more likely to provide a positive answer to this question (Table 1).

More than half of the participants (Q3, 55.5%) knew someone with epilepsy, and this correlated with the participants' gender, age, education, and region (Table 1).

Only 18% of those surveyed (Q4) did not know any symptoms of epilepsy. Foaming (51.8%), loss of consciousness (27.2%), falling (25.8%), cramping (20.8%), trembling (19.9%), and shaking (5.4%) were the symptoms listed by at least 5% of those surveyed. In answering this open question, Croats used a total of 29 different descriptors.

Those who had witnessed a seizure (Q5, 44.6%) were more likely to be male, 46–65 years old, have a university degree, and live in ZGB & V or North Croatia.

The majority of participants (Q6, 52.9%) could name at least one cause of epilepsy. Heredity (22.1%) was the single most frequently listed cause of epilepsy. Consequence of brain disturbance (8.8%), stress (6.6%), nerve disturbance (3.9%), shock (2.7%), alcohol (1.8%), lack of oxygen in the body (1.4%), psychological disturbance (1.2%), and blow to the head (1.2%) exceeded 1%; the additional 12 factors listed totaled 3.1%; 47.1% did not know any potential causes of epilepsy.

Less than 7.0% would object if their child played with a child with epilepsy (Q8, 6.7%); significantly more of the rural population objected. The youngest (15–25) and oldest (>66) objected the most (8.8%), as did the less educated (8.5%) and those from Slavonia (9.9%) and Dalmatia (9.3%). However, there was no statistically significant correlation with gender, age, education or region. Importantly, responders who knew someone with epilepsy, had witnessed an epileptic seizure, believed that epilepsy is not a form of insanity, or believed that a child with epilepsy can succeed in life as a healthy child were significantly less likely to object to their child's association with a child with epilepsy.

The majority of Croats believed that a child with epilepsy could succeed as well as a child without epilepsy (Q9, 76.0%); these respondents were more likely female (78.2%), younger, more educated, and from IS, RI, & GK (82.9%), ZGB & VI (79.4%), or Slavonia (78.5%). This belief was also significantly associated with knowing someone with epilepsy, having witnessed an epileptic seizure, and believing that epilepsy is not a form of insanity.

Only 2.5% (Q10) of participants believed that epilepsy is a form of insanity, and this belief was significantly more likely to be ex-

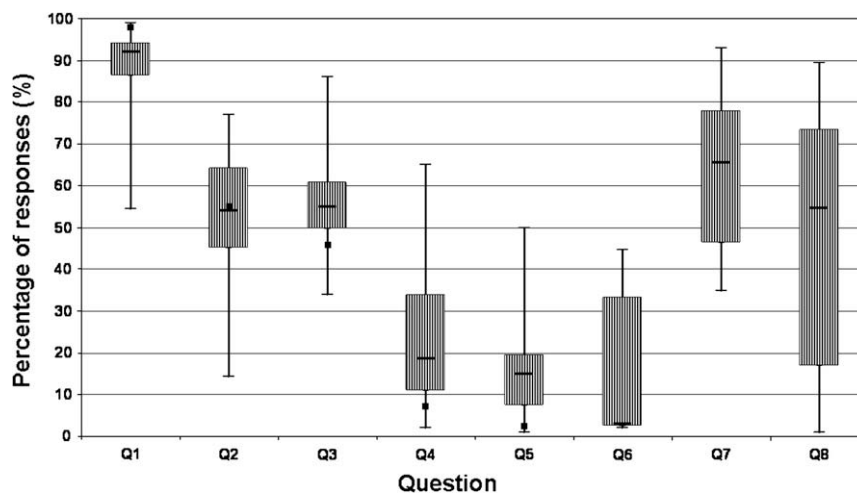


Fig. 1. A box-and-whisker plot showing the distribution of published answers to eight commonly asked questions (Q1–Q8) extracted from 36 published studies of public perception of epilepsy [10,12,14,16,18–45]. The position of data from this study is marked by a black box.

Table 1
“Yes” answers to Questions 1,3,5 and 8–10.

	N	Q1	N	Q3	Q5	Q8	Q9	Q10
Sex								
Male	475	97.4%	463	61.6%	48.0%	7.2%	73.6%	95.7%
Female	525	97.2%	510	54.7%	41.5%	6.2%	78.2%	97.3%
Age								
15–25	167	98.4%	164	47.0%	23.9%	8.6%	82.4%	98.9%
26–35	142	97.0%	137	57.9%	33.8%	5.6%	81.6%	98.4%
36–45	172	99.3%	171	67.8%	46.9%	6.5%	81.1%	96.8%
46–55	177	99.2%	175	65.4%	56.2%	7.0%	76.2%	99.0%
56–65	157	94.7%	148	60.1%	60.1%	3.5%	70.5%	97.6%
>66	186	95.3%	177	49.7%	45.5%	8.3%	65.3%	89.4%
Education								
Primary	370	94.7%	351	52.2%	40.4%	8.5%	71.5%	95.2%
Secondary	510	99.0%	504	60.2%	45.4%	6.0%	77.6%	97.4%
University	120	98.6%	118	65.6%	54.0%	4.3%	82.8%	96.8%
Region								
ZGB&V	248	99.2%	246	56.4%	51.6%	4.9%	79.4%	96.8%
North Croatia	179	97.2%	174	67.1%	50.2%	5.9%	73.2%	97.9%
Slavonia	176	98.9%	174	61.7%	42.8%	9.9%	78.5%	96.9%
Lika & Banovina	88	100.0%	88	57.0%	43.8%	5.0%	73.5%	88.5%
IS, RI & GK	119	97.2%	116	48.5%	40.7%	4.2%	82.9%	99.0%
Dalmatia	191	92.4%	177	54.3%	34.2%	9.3%	68.5%	96.8%
Settlement								
Rural	418	95.9%	401	58.5%	47.7%	10.7%	74.0%	96.0%
Urban	582	98.4%	573	57.6%	42.5%	3.8%	77.5%	96.9%
Q1:	Have you ever heard or read about the disease called epilepsy?							
Q3:	Do you know someone with epilepsy?							
Q5:	Have you ever witnessed an epileptic seizure?							
Q8:	Would you object to having any of your children play and associate with a child who sometimes had seizures?							
Q9:	Do you think that a child with epilepsy can succeed in life equally as a child without epilepsy?							
Q10:	Do you think that epilepsy is a form of insanity or not?							
Q1:	Age	$\chi^2(5) = 13.68, P < 0.05$			Q8:	Type of settlement	$\chi^2(1) = 71.95, P < 0.01$	
	Education	$\chi^2(2) = 16.43, P < 0.01$			Q9:	Age	$\chi^2(5) = 21.73, P < 0.01$	
	Region	$\chi^2(5) = 23.91, P < 0.01$				Education	$\chi^2(5) = 7.80, P < 0.05$	
	Type of settlement	$\chi^2(1) = 6.0, P < 0.05$				Region	$\chi^2(5) = 11.79, P < 0.05$	
Q3:	Gender	$\chi^2(1) = 4.67, P < 0.05$			Q10:	Gender	$\chi^2(1) = 7.26, P < 0.01$	
	Age	$\chi^2(5) = 24.17, P < 0.01$				Age	$\chi^2(5) = 20.03, P < 0.01$	
	Education	$\chi^2(2) = 8.73, P < 0.05$				Region	$\chi^2(5) = 12.47, P < 0.05$	
	Region	$\chi^2(5) = 12.83, P < 0.05$						
Q5:	Gender	$\chi^2(1) = 3.99, P < 0.05$						
	Age	$\chi^2(5) = 60.03, P < 0.01$						
	Education	$\chi^2(2) = 6.99, P < 0.05$						
	Region	$\chi^2(5) = 15.81, P < 0.01$						

Note. In boldface are the data points found to be statistically significant.

pressed by males, the oldest, the less educated (3.4%), and those from Lika and Banovina. This belief was not correlated with knowing a person with epilepsy or witnessing an epileptic seizure, but was significantly correlated with objecting to children playing and associating with a child with epilepsy and believing that a child with epilepsy cannot have the same success in life equally as a child without epilepsy.

Overall (Q11) (Table 2), seizures (25.7%), injuries (25.1%), fear of seizures (17.1%), rejection by others (16.7%), and limited activities (5.1%) were perceived as the worst aspects of epilepsy reported by more than 5% of participants.

Females considered seizures (25.1%) and males considered injuries (27.0%) as being the worst. The oldest (>66) participants selected seizures (33.4%), and the youngest (15–25), injuries (27.2%). Seizures were chosen most frequently by the oldest group (33.4%), fear of seizures by those 36–45 (22.4%), injuries (32.7%) and rejection by others (22.6%) by those 26–35 years of age. Young participants (26–35) selected limited activities (2.6%) least frequently, and those 36–45 years old, most frequently (6.7%). This choice correlated significantly with age. Those with primary school favored seizures (29.2%); those with secondary school, injuries (25.9%); and those with a university degree, the fear of seizures

(24.3%). Participants from ZGB & V (31.2%), IS, RI, & GK (29.6%), and North Croatia (29%) selected seizures significantly more often, and those from Slavonia (32.2%), Lika and Banovina (29.5%), and Dalmatia (23.3%) chose fear of seizures. The rural population significantly more often selected seizures (30.6%), injuries (26.5%), and rejection (19.1%), whereas urban inhabitants selected injuries (24.1%), seizures (22.3%), and fear of attacks (19.8%).

Those who knew someone with epilepsy chose significantly more injuries (27.3% vs 22.6%), fear of seizures (18.0% vs 15.8%), and limited job opportunities (5.3% vs 2.8%), whereas those who did not know someone with epilepsy chose seizures (27.6% vs 24.4%) and do not know (DNK) (6.1% vs 1.6%). Those who had witnessed a seizure significantly more often chose injuries (28.1% vs 22.7%) and fear of seizures (18.9% vs 15.6%), and those who had not witnessed a seizure chose rejection by others (18.3% vs 14.7%) and DNK (4.9% vs 1.6%). Respondents who held a belief that epilepsy is a form of insanity significantly more often chose fear of injuries (31.4% vs 25.1%) and DNK (17.2% vs 2.8%), and those with the opposite belief favored fear of seizures (17.1% vs 10.3%).

The majority of participants (Q12, 52.5%) would approach a person having an epileptic seizure and help them directly, 33.3% would approach a person and call EMS, and 8.1% would yell to

Table 2
Answers to Question 11.

	N	A1	A2	A3	A4	A5	A6	A7	A8
Sex									
Male	463	26.4%	17.3%	27.0%	5.3%	2.6%	3.8%	15.1%	2.5%
Female	510	25.1%	16.9%	23.5%	5.0%	2.4%	4.7%	18.1%	4.3%
Age									
15–25	164	23.4%	16.1%	27.2%	5.8%	2.3%	2.9%	21.7%	0.7%
26–35	137	15.9%	14.6%	32.7%	2.6%	4.0%	6.4%	22.6%	1.2%
36–45	171	23.0%	22.4%	21.7%	6.7%	1.4%	4.0%	17.6%	3.1%
46–55	174	26.3%	17.2%	22.8%	4.3%	2.1%	4.1%	19.8%	3.3%
56–65	148	30.7%	18.0%	24.7%	6.5%	3.3%	3.1%	9.0%	4.6%
>66	177	33.4%	13.9%	23.3%	4.8%	2.0%	5.4%	10.0%	7.2%
Education									
Primary	351	29.2%	15.3%	25.2%	2.6%	2.2%	3.9%	17.3%	4.4%
Secondary	504	24.9%	16.6%	25.9%	7.3%	2.0%	4.7%	15.5%	3.1%
University	118	19.3%	24.3%	21.5%	3.7%	5.5%	3.6%	20.0%	2.1%
Region									
ZGB & V	246	31.2%	18.5%	23.4%	1.1%	3.0%	4.3%	16.2%	2.4%
North Croatia	174	29.0%	18.2%	19.9%	0.9%	0.4%	9.4%	18.0%	4.1%
Slavonia	174	21.6%	18.2%	32.2%	5.5%	2.8%	2.7%	13.6%	3.5%
Lika & Banovina	88	16.6%	22.0%	29.5%	2.7%	2.9%	1.1%	21.2%	4.1%
IS, RI & GK	116	29.6%	13.0%	25.6%	13.9%	1.0%	3.2%	9.5%	4.2%
Dalmatia	177	21.0%	13.2%	23.3%	10.2%	4.1%	3.0%	21.8%	3.4%
Settlement									
Rural	401	30.6%	13.2%	26.5%	2.0%	0.5%	4.5%	19.1%	3.6%
Urban	573	22.3%	19.8%	24.1%	7.4%	3.8%	4.1%	15.0%	3.3%
Q11: What is the worst aspect of epilepsy for a person with epilepsy?									
1. Attacks					5. Limited professional opportunities				
2. Fear of attacks					6. Limited employment opportunities				
3. Injuries during attacks					7. Rejection by others				
4. Limited activity					8. I do not know				
	Age	$\chi^2(35) = 60.62, P < 0.01$							
	Education	$\chi^2(14) = 25.68, P < 0.05$							
	Region	$\chi^2(35) = 89.52, P < 0.01$							
	Settlement type	$\chi^2(7) = 39.16, P < 0.01$							

Note. In boldface are the answers that reached statistical significance. A1, answer 1.

get more help. Only a negligible minority would only call EMS without helping otherwise (4.3%), proceed without stopping because of fear (0.2%), or would not know what to do (1.4%). Regional differences were the only demographic factor that reached statistical significance (Table 3). Significantly more participants who knew someone with epilepsy would approach a person having an epileptic seizure and help (57.0% vs 46.3%), whereas more of those who did not know anyone with epilepsy would “approach and call EMS” (38.6% vs 29.5%) and “call EMS and proceed without stopping” (6.9% vs 2.4%). Significantly more of those who witnessed an epileptic seizure (60.1% vs 46.4%) would also approach and help directly, whereas those who had not witnessed a seizure would more frequently “approach and call EMS” (37.5% vs 28.2%) and “call EMS and proceed without stopping” (5.5% vs 2.8%). Answers to this question did not correlate significantly with the belief that epilepsy is a form of insanity or the belief about the chances of a child with epilepsy to have as successful a life as a child without epilepsy.

4. Discussion

Although it has only recently been established in a population study that the prevalence of epilepsy in Croatia ranges from 4.8 to 5.5 cases per 1000 inhabitants and is comparable to the prevalence in many other European countries [46], this kind of population study of general public awareness and perception of epilepsy had not previously been performed in Croatia. It is our hope that gleanings from this study, along with recent efforts to assess comorbidities of persons with epilepsy in Croatia [47], will

represent the foundation for coordinated efforts to improve the lives of people with epilepsy in Croatia.

In considering our results in the broader context, we stress two points: (1) Claimed beliefs may significantly differ from held beliefs, and we have no control over this factor. (2) When we compare our results with those from other countries, we assume that the translation of questions is consistent, the terms used in questions had analogous meanings in different cultural backgrounds, and implemented methodology, even though not identical, yielded comparable results except where specifically indicated.

General awareness of the Croatian public regarding epilepsy (97.3%) is comparable to that of developed countries (Fig. 1) [10–12,14,16,18,19–45] and almost matches the highest published results (99%) [37]. These results are higher than in geographically close and culturally and historically related Hungary (92% in 1994 and 93.7% in 2000) [14], and even more favorable when compared with a study performed closer in time (2003) in the more developed Austria (89%) [40]. Very hopeful results on possible improvements in public awareness of epilepsy were reported from the Czech Republic [35]. Middle-aged participants (36–55 years old) were significantly more informed about epilepsy, as were those with more education. One possible explanation for this effect of the age factor is that these respondents grew up during the stable, prosperous, and open period under the influence of popular media and pay more attention to these issues. It would be interesting to explore further the role of elements of the traditional and patriarchal mentality previously demonstrated in the Croatian population [48,49], as well as the current role of the concept of “social shame” as a strategy of covering up such a disease to prevent

Table 3
Answers to Question 12.

	N	A1	A2	A3	A4	A5
Sex						
Male	463	55.8%	32.1%	3.9%	6.8%	1.4%
Female	510	49.5%	34.5%	4.6%	9.3%	2.0%
Age						
15–25	164	50.3%	34.4%	6.3%	8.2%	0.7%
26–35	137	55.0%	34.5%	2.3%	6.7%	1.5%
36–45	171	51.8%	35.8%	3.3%	7.2%	2.0%
46–55	175	59.8%	27.3%	4.5%	7.7%	0.7%
56–65	148	55.5%	31.3%	5.7%	5.4%	2.0%
>66	177	43.7%	36.7%	3.4%	12.8%	3.4%
Education						
Primary	351	48.3%	33.9%	5.2%	10.5%	2.2%
Secondary	504	54.0%	33.5%	4.5%	6.6%	1.5%
University	118	58.9%	31.3%	0.6%	7.6%	1.6%
Region						
ZGB & V	246	58.9%	29.7%	3.6%	6.6%	1.2%
North Croatia	174	44.4%	38.8%	3.3%	12.8%	0.6%
Slavonia	174	42.4%	35.3%	7.7%	12.7%	1.8%
Lika & Banovina	88	51.7%	37.5%	6.7%	2.0%	2.0%
IS, RI & GK	116	49.5%	37.0%	2.0%	5.7%	5.7%
Dalmatia	177	64.0%	26.5%	2.9%	5.9%	0.7%
Settlement						
Rural	401	52.8%	34.0%	3.4%	8.7%	1.1%
Urban	573	52.3%	32.9%	4.9%	7.7%	2.2%
Q12: Imagine that you encounter a person experiencing an epileptic attack (fit) on the street, What would you do?						
1. I would approach the person and help immediately						
2. I would approach the person and call EMS, but wouldn't try to do anything personally						
3. I would call EMS and proceed without stopping,						
4. I would yell to try to get more help						
5. I would proceed without stopping since I would be scared						
6. Something else						
7. I do not know						
		Region $\chi^2(20) = 57.94, P < 0.01$				

Note. In boldface are the answers that reached statistical significance. A1, answer 1.

social rejection and any other negative consequences. Many studies have consistently reported the positive role of education and an urban environment [11].

The majority of surveyed citizens of Croatia (Q3, 55.5%) (Table 1) knew someone with epilepsy, which is a higher proportion than in more developed and geographically close countries like Greece (38.8%) [26] and Austria (40%) [40] and, overall, above the median of reported studies (Fig. 1) [10,12,14,16,18–45]. The positive correlation with middle age can probably be explained similarly as results for Q1, the correlation with male gender is probably a consequence of the overall higher mobility of males, and the correlation with higher education has been well established many times. The statistically significant correlation with region and the degree of difference between North Croatia (67.10%) and IS, RI, & GK (48.50%) may be a consequence of smaller settlements with closer relationships among inhabitants in North Croatia.

Only 18% of our participants (Q4) did not know any symptoms of epilepsy; foaming (51.8%) and loss of consciousness (27.2%) were the most frequently listed answers. Grouping all answers pertaining to any kind of “muscular” involvement (cramping, trembling, shaking, stiffening, and even “epileptic attacks”) yields 46.1%, surpassing what was reported for “convulsions/shaking” (36.7%) in Hungary [14]. In answering this open question, citizens of Croatia used a total of 29 different descriptors. Although it is a reasonable assumption that this open-ended question reflects “true knowledge” more objectively than multiple-choice questions, the results are hard to compare with the published series. Among all [12,14,21–24,28,34,44] studies that used different versions of a multiple-choice question asking about symptoms of an

epileptic seizure, “convulsions, shaking, or tonic–clonic movements” ranked first in eight of nine studies, with a range from 28% (Hungary, 1994) [14] to 87.8% (South Korea, 2002) [21]. Only in a study from Jordan [24], were “convulsions” (75.4%) topped by “brief loss of consciousness” (80.6%), but this question was asked differently and four answer options were presented with multiple answers allowed. In England [12], “convulsions/shaking” was the most frequent answer (79%) to a multiple-choice question about signs of seizures for which 11 choices were offered and multiple answers allowed. Thus, available evidence supports the widespread misperception among our patients that “most people with epilepsy shake,” even though convulsive seizures are not the most prevalent. For this reason, it is surprising that such an important question has not been more frequently asked and better standardized. These results imply that a completely open question is not the best approach because it prevents a meaningful comparison, while grouping similar answers may be an effective way of methodically addressing this issue.

Almost half surveyed had witnessed a seizure (Q5, 44.6%), and were significantly more likely to be male, to be 46–65 years old, to have a university degree, and to live in ZGB & V or North Croatia (Table 1). This is below the median (55%) percentage in a published series which ranged from 34% (UAE) [18] to 86.2% (Ethiopia) [41]. Although 14% of Ethiopian farmers had a family member with epilepsy [41], only 3% of our participants made this claim, suggesting a lower prevalence of epilepsy and a higher level of urbanization in Croatia [46]. Positive correlation of a response to this question with age and education is a consistent finding that is simple to explain as a matter of increased chance with a longer life and more open-

ness and interactions, respectively. Positive regional correlation with living in ZGB & V or North Croatia is probably a consequence of the higher affluence of these two regions.

In response to an open question with multiple answers allowed, a small majority of our participants (Q6, 52.9%) could name a cause of epilepsy. The proportion of those who did not know any potential causes of epilepsy (47.1%) was reported to be as high as 67.7% (Tanzania) [38]. Interestingly, this result is slightly better than in the United States (49%) [50], but much worse than in South Korea (20%) [21], Italy (16%) [19], Greece (13.5%) [26], and Vietnam (6%) [23] where a multiple-choice format was used. Even though diverse methodology precludes meticulous comparisons, it is quite evident that level of development is not a major factor.

Our participants listed heredity (22.1%) most frequently as a cause of epilepsy, whereas 71.1% of citizens in Hong Kong endorsed the statement that “the majority of epilepsy is acquired through inheritance” [28]. “Hereditary disease” or “inheritance” was also the single most frequently listed cause of epilepsy in South Korea (46.9%, multiple-choice single answer) [21], Denmark (38% if familiar with epilepsy, multiple-choice multiple answers) [16], Taiwan (28%, multiple-choice single answer) [22], and rural Tanzania (17.7%, open question) [38]. In contrast, only 1.5% of respondents in Hungary [14] and 7% of those in New Zealand [31] chose the same answer in a multiple-choice/single-answer format.

In our sample, all causes of epilepsy listed that could be categorized under “brain disease, disorder, injury” or “neurological disease” (brain disturbance 8.8%, stress 6.6%, nerve disturbance 3.9%, psychological shock 2.7%, and psychological disturbance 1.2%) would amount to 23.2%. This would be much less than in Greece (66%) [26], where 43% of those surveyed also chose “a hereditary disease”; “congenital/birth problem” and “brain disorder” were favored by 57% of UK respondents [12], “brain disease, disorder, injury” by 25% of Chinese respondents [34], and “disease of nerves” by 20.1% of Hungarian respondents [14]. Most Greeks (91.8%) believed that “epilepsy is a type of brain disorder or malfunction” [26] when asked an explicit question, whereas the vast majority of Jordanians (84.7%) chose “neurological disease” [24] as a cause of epilepsy. It is our impression that the format of the survey affected these results greatly, leading to large nominal percentage differences between our data and those from other studies, but we are not in a position to quantify its effect. It is quite evident that future studies should rely on more standardized [11,51] and culturally sensitive [11] questionnaires to avoid predictable limitations of open-ended questions and effects of cultural differences to the highest degree possible. Importantly, considering that only a few types of epilepsy have a known “hereditary” cause and realizing that the public frequently equates “heredity” with “untreatable” and may harbor negative attitudes toward a person with epilepsy, this should be one of the vital strategic points of any inclusive public educational campaign.

The proportion of those who express a negative attitude toward their child's playing and associating with a child with epilepsy varies from 2% (Swiss) [33] to 65% (Ethiopia) [10,12,14,16,18–45] (Fig. 1), and our findings (6.7%) indicate a quite positive attitude in our sample. In fact, the attitude was much better than in geographically close countries of relatively comparable development such as Hungary (16.5%) [14] and the Czech Republic (13%) [35], and even superior to that in much more developed Austria (11%) [40] and much more positive than in Greece (35%) [26]. Even though more developed countries have overall a higher acceptance of children with epilepsy (Fig. 1) [10,12,14,16,18–45], there are wide regional variations in large and diverse countries [29,37]. As previously published, lower education and rural environment were consistently associated with negative attitudes. In our case, the youngest and oldest participants were also among those who objected the most, as were inhabitants of Slavonia and Dalmatia.

The age factor was discussed in the context of the results related to a few previous questions, whereas the regional difference may be in part explained by the fact that Dalmatia has the lowest regional prevalence of active epilepsy in Croatia [46] and Slavonia is characterized by some deeply rooted cultural traditions [48,49]. However, there was no statistically significant correlation with gender, age, education, or region. One of the major findings of our study is that respondents who knew someone with epilepsy, had witnessed an epileptic seizure, believed that epilepsy is not a form of insanity, or believed that a child with epilepsy can have as successful a life as a healthy child were significantly more likely to express a positive attitude toward children with epilepsy. Because it is our consistent finding that indirect experience with epilepsy decreases the degree of prejudice toward a person with epilepsy, this should be the key element of Out of the Shadows-type campaigns [1,2]. Additionally, the medical profession and advocacy groups have to increase their efforts in fighting prejudice and corresponding negative attitudes on this basis; involving public figures could have a profound positive effect.

The vast majority (76.0%) of surveyed citizens of Croatia claimed that a child with epilepsy could succeed as well as a child without epilepsy. We find this an unexpectedly positive attitude that may in part be based on poor knowledge of epilepsy. Unfortunately, there is only one study for comparison, which originated in a completely different sociocultural context in Tanzania [38]. In that study [38], 62.2% of rural Tanzanians “would not allow a child with epilepsy to go to school at all, and 23.5% would do so only after the seizures were completely controlled or cured,” indicating “a danger of seizures” (65.9%) and/or the children's “mental deficiency and unsuitability” (54.0%) as the reasons for such a position. In our sample, younger females, more educated respondents, and those from IS, RI, & GK, ZGB & VI, or Slavonia exhibited a more positive attitude toward a child with epilepsy and his or her potential for success. Females and younger participants may have a different perception of success. Again, importantly, this belief was significantly associated with knowing someone with epilepsy, having witnessed an epileptic seizure, and believing that epilepsy is not a form of insanity. The importance and practical implications of these findings were already discussed.

A very small minority of our sample (2.5%) believed that epilepsy is a form of insanity, and this belief was significantly more likely to be expressed by older males, less educated people, and those from Lika and Banovina, probably the most traditional region of Croatia. However, this belief was not correlated with knowing a person with epilepsy or witnessing an epileptic seizure, but was significantly correlated with objecting to a child playing and associating with a child with epilepsy and believing that a child with epilepsy cannot have as successful a life as a child without epilepsy. Although only 1% of the respondents in Denmark [16] and New Zealand [31] held the same belief, it was expressed by 11% of Austrians [40], 15% of Greeks [26], and 50% of Czechs [35] in 1981. Interestingly, although the situation with respect to this belief improved from 50% (1981) to 29% (1997) in the Czech Republic [35], it slightly worsened from 1996 (15.2%) to 2000 (17.2%) in Hungary (14). Therefore, Croatian respondents expressed much more progressive beliefs regarding this issue than citizens of more developed countries such as Austria [40] and Greece [26]. Considering the close temporal relationship of these studies, the only plausible explanation is sociocultural differences that cannot be further specified based on our study. Also, as indicated previously, we have no control over the degree of discrepancy between truly held and expressed beliefs or attitudes that are more likely to play a role when pondering negative attitudes and beliefs that are not socially acceptable. Regardless, these findings emphasize the complexity of attitude formation and the importance of public education.

Overall (Q11) (Table 2), seizures, injuries, fear of seizures, and rejection by others were perceived as the worst aspects of epilepsy reported by our sample. Females and the oldest participants considered seizures the worst aspect, whereas males and the youngest participants considered injuries as being the worst. Fear of seizures was chosen most frequently by those 36–45 years old, with rejection by others chosen by those 26–35 years old. This choice correlated significantly with age as well as with education: participants with primary school education chose seizures (29.2%); those with secondary school, injuries (25.9%); and those with a university degree, fear of seizures (24.3%). In some ways, this reflects increasing understanding of the suffering endured by people with epilepsy, as it is well established that patients with epilepsy perceive “fear of loss of control” as the worst consequence of having epilepsy [6,7]. Significant regional variations are probably a consequence of more social openness and urbanization in the more developed northwestern regions of Croatia (ZGB & V; IS, RI, & GK; and North Croatia), where they selected seizures, as compared with the rest of the country (Slavonia; Lika and Banovina, and Dalmatia), where fear of seizures was “favored.” Dalmatia has the lowest prevalence of epilepsy in Croatia [46] and it is where some of the most negative attitudes were expressed, and Lika and Banovina is probably the least developed and the most traditional region of the country. Similar factors probably explain a significant difference in choices between rural (seizures, injuries, and rejection), and urban (injuries, seizures, and fear of attacks) populations. However, a much more detailed and differently structured study would be necessary to dissect these factors adequately.

Choices of participants who knew someone with epilepsy (injuries, fear of seizures, and limited job opportunities) differ statistically significantly from choices of those who did not (seizures and DNK), and probably indicate the more profound understanding of the nature and magnitude of suffering associated with epilepsy of those who have an acquaintance or a relative with epilepsy. Similarly, choices of those who witnessed a seizure (injuries and fear of seizures) were statistically significantly different from choices of those who had not witnessed a seizure (rejection by others and DNK), and probably reflect the greater distance the latter group puts between them and people with epilepsy. It is not surprising that those who believe that epilepsy is a form of insanity (fear of injuries and DNK) have a view significantly different from that of respondents who do not hold this belief (fear of seizures) and probably indicates that those with a more adequate understanding of epilepsy would empathize more with a person with epilepsy and therefore are more likely to recognize that fear of seizures is one of the worst consequences of having epilepsy [6,7].

It was somewhat surprising to us that a variation of the question What would you do in case you see a person having an epileptic seizure? was addressed in only six countries: Finland [32], Ethiopia [41], Tanzania [38], South India [37], Czech Republic [35], and Hong Kong [28]. The most comprehensive approach to this issue was implemented by Iivanainen et al. [32], who defined and assessed “helping potential” of the Finnish population as a composite variable that includes the helper’s ability to “recognize the seizure, know what to do in such situations, know how to give first aid, and maintain a positive attitude toward helping.” Importantly, using a stepwise linear regression analysis, they established that the most important predictor of “helping potential” was having known a person with epilepsy. When the simple question Do you know what to do for someone having a convulsive attack/fit? was asked in Ethiopia [41], 88.5% of those surveyed answered negatively and only 5.7% indicated that they would “protect/guard patient.” In a study of 3013 rural Tanzanians [38], similar proportions of respondents knew at least some useful first-aid measures (35.7%) and would run away or simply watch a person having an epileptic seizure (33.5%). South Indians [37] would mostly take a

person having an epileptic seizure to the hospital (79.9%), but a significant proportion of them would “make him hold a bunch of keys” (54.7%) or “sprinkle water over his face” (35.6%). Citizens of the Czech Republic [35] were almost evenly split with respect to their willingness to help a person having an epileptic seizure: 51% (“always” or “mostly yes”) versus 49% (“mostly no,” “no,” and “I do not know”). Their most frequently listed reasons for the unwillingness or hesitancy to help a person having an epileptic seizure were: lack of knowledge (33%), complexity of attack identification (25%), concern about responsibility for providing help (18%), and indifferent attitude toward handicapped people (15%) [35]. A sizable majority of Hong Kong respondents (76.7%) [28] would help a person having an epileptic seizure, whereas those who would not help listed lack of knowledge (73.7%) and fear (10.5%); only 2.0% simply “wouldn’t want to help.” Interestingly, 52.7% of Hong Kong respondents believed that it was appropriate to put an object in the patient’s mouth to prevent tongue biting, and 32.2% of them learned this from TV.

A sizable majority of our participants (85.5%) claimed a positive attitude toward helping a person having an epileptic seizure and would approach and help him or her directly (52.5%) or approach the person and call EMS (33.3%). These choices did not correlate with gender, age, education, or settlement type, and regional differences were the only demographic factor that had statistical significance. Although approaching a person having an epileptic seizure and helping her or him directly was a favored choice in all regions, residents of Dalmatia chose it most frequently, whereas approaching a person and calling EMS was chosen most frequently by inhabitants of North Croatia, and DNK was selected most frequently in IS, RI, & GK. Overall, we find these results indicative of significant openness toward helping a person having an epileptic seizure. Although Dalmatia is a region whose inhabitants hold some of the most “conservative” views, the inhabitants of this region displayed the most readiness for direct involvement in helping a seizing person, whereas more developed and Westernized North Croatia endorsed an approach with less direct involvement. Again, significantly more participants who knew someone with epilepsy displayed a more positive attitude toward helping, as did those who witnessed an epileptic seizure. This correlation is one of the critical and most consistent findings of our study and clearly indicates a direction for enhancing the “helping potential” of the citizens.

In the context of the persistence of some deeply rooted traditions, including elements of shame traditionally associated with “brain sickness,” an inferior status historically imposed by traditional rulers, and the potential implications for national self-perception, we expected the results to be less favorable as compared with more developed EU countries. Thus, the fact that our results matched or even in some aspects exceeded those from much more developed European countries represents a more favorable outcome than expected. This may simply reflect inappropriately low expectations.

5. Methodological issues

Eight classic questions [10,20] on public knowledge of, perception of, and attitude toward epilepsy have been included in many surveys but frequently incompletely or with some variations. Thus, it is not surprising that some studies have included as few as 4 questions (Laos) [43], whereas others have designed detailed questionnaires with 28 questions (Finland) [32]. The method of administration of the survey has also differed: a mailed questionnaire [32], phone interview [21], or direct personal survey [10,16,20] in various settings. The last group includes specifically designed research surveys [10,16,20,26,40] and research surveys executed as a part of the periodic national Omnibus Surveys [12,16], as was

the case with our study. We believe that this group represents a promising logistical modality for performing standardized surveys of public knowledge, attitude, and perception periodically and affordably. The studies have varied widely with respect to number of participants: from 235 [35] to 16,044 [24], with the majority of the studies having 1000–2000 participants, as did our study. Studied populations varied from a particular segment of society [e.g., 23, 38, 44], to a region [29,37], to an entire country [10,12,20, 26,40]. Although potential agreement on the usefulness of these surveys may exist in the literature, insufficient standardization represents a major obstacle for their systematic comparison and implementation.

6. Concluding remarks

The majority of the Croatian respondents claimed tolerant attitudes toward people with epilepsy, and would approach and help a person having an epileptic seizure. These results are comparable to or, in some aspects, better than those of developed countries. Although it is encouraging to find that public knowledge of, awareness of, and attitudes toward epilepsy matching or exceeding those of much more developed countries, more than enough prejudice and stigmatization persist. It is our consistent finding that the Out of the Shadows campaign has great potential for improving attitude toward persons with epilepsy if the public is informed and educated through appropriate direct exposure to those with epilepsy.

Ethical approval

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Conflict of interest

None of the authors has any conflict of interest to disclose.

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