

Necessity for comprehensive epilepsy care: experience from Croatia

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epilepsy care in Croatia

specialized epilepsy services in all bigger hospitals

epilepsy presurgical evaluation
epilepsy surgery

bi-annual national symposia on epilepsy

Methylphenobarbital
Phenobarbital
Primidone
Phenytoin
Ethosuximide
Carbamazepine
Oxcarbazepine
Sodium valproate
Clonazepam

Vigabatrin
Lamotrigine
Topiramate
Gabapentin
Pregabalin
Levetiracetam
Retigabine

Epilepsy – only a seizure disorder?

ILAE and IBE, **2005**:

Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the **neurobiologic, cognitive, psychosocial, and social consequences of this condition.**

- ❖ underemployment
- ❖ driving licence denial
- ❖ perceived stigma
- ❖ enacted stigma
- ❖ concealment

- ❖ depression
- ❖ anxiety
- ❖ cognitive problems
- ❖ lower fertility
- ❖ pregnancy problems
- ❖ associated medical disorders
- ❖ adverse drug reactions

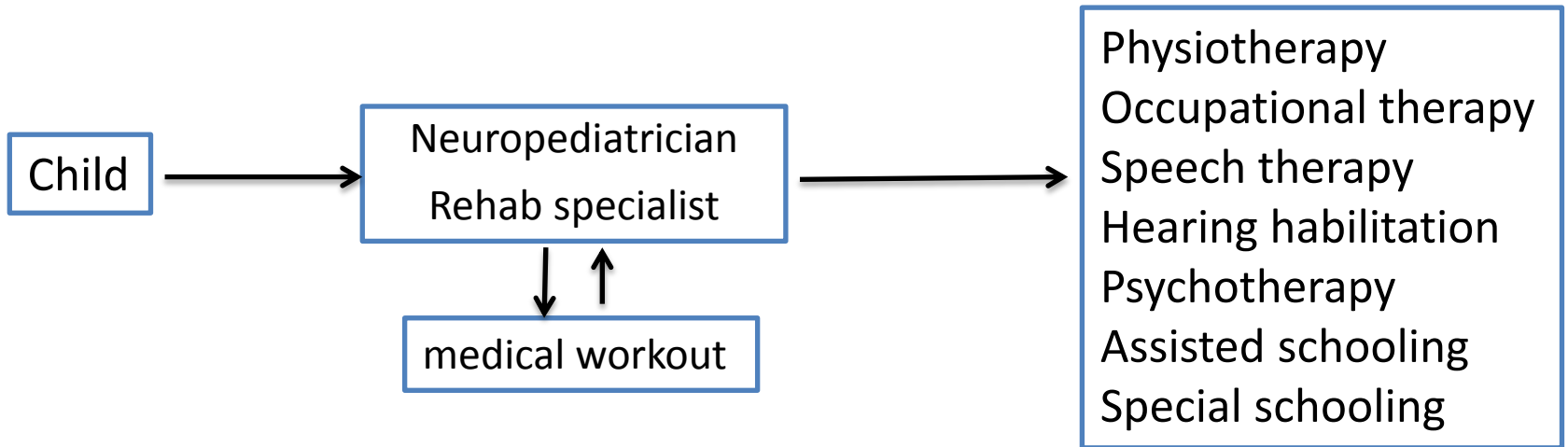
Epilepsy associated problems need a multidisciplinary approach.

Multiple impairments in preschool children

Table 1 – Frequency of impairments in children with epilepsy (N = 116).

	Number	%
Without any impairment	51	44.0
One or two impairments	28	24.1
Multiple impairments	37	31.9
Kind of impairment		
Mental retardation	46	39.7
Impairment of motor functions	54	46.6
Impairment of speech	49	42.2
Impairment of seeing	17	14.7
Impairment of hearing	11	9.5

Children with epilepsy: holistic and multidisciplinary approach



Significant proportion of preschool children is still not provided with necessary care

Table 2 – Differences in staying during weekdays between children without any and with one or more associated impairments.

	Total (N = 114) ^a	Without any impairment (N = 51)	One or more impairments (N = 63)	Difference
Stay with their families	81 (71.1%)	33 (64.7%)	48 (76.2%)	p = 0.26
Attend regular kindergartens	23 (20.2%)	17 (33.3%) ^b	6 (9.5%)	p < 0.01
Attend the kindergartens for children with special needs	4 (3.5%)	0	4 (6.3%)	p = 0.14
Permanently live in social institutions	5 (4.4%)	1 (2%)	4 (6.3%)	p = 0.13
Stay in social institutions only during weekdays	1 (0.9%)	0	1 (1.6%)	p = 0.25

a 2/116 children (1.7%) were not included due to insufficient data about their staying.


b According to the information from the Central Bureau of Statistics of the Republic of Croatia, the attendance rate of kindergartens was 29.7%.²⁰

Adults with epilepsy

underemployment
driving licence denial
depression
epilepsy stigma

unemployment rate almost 3 times higher than in general population

Population expected to be occupationally active (19–65 years, $n = 546$)	
Completing education/training, or retired	9.3%
Employed	32.7%
Unemployed	29.6%
Unemployment rate*	47.5%
Occupationally disabled	28.4%
Missing data	29/546 (5.3%)



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Rates of driving motor vehicles of PWE.

	1999 (N = 277)	2009 (N = 317)	Difference
Nondrivers	160 (57.8%)	160 (50.5%)	NS
Drivers			
Licensed	105 (37.9%)	151 (47.6%)	P < 0.05
Not licensed	12 (4.3%)	6 (1.9%)	NS

about 60% seizure- free
for previous 2 years

Adults with epilepsy

underemployment
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depression
epilepsy stigma

BDI (*Beck Depression Inventory*): **depressive symptoms in 33,3% patients**

Hečimović H, Bosnjak J, Demarin V. Coll Antropol 2008

BDI-II– 2nd Edition)

depression	score	N (%)	
No/minimal	< 14	72 (60)	60 %
mild	14-19	12 (10)	40 %
moderate	20-28	20 (16)	
severe	> 29	16 (13)	

N = 120

BDI-II: 13,6 ± 12,1

Adults with epilepsy

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Because of my attacks:

- a) I feel some people are uncomfortable with me*
- b) I feel some people treat me like an inferior person*
- c) I feel some people would prefer to avoid me*

Taylor J, Baker G, Jacoby A. Epilepsy Behavior 2011; 21; 255-60

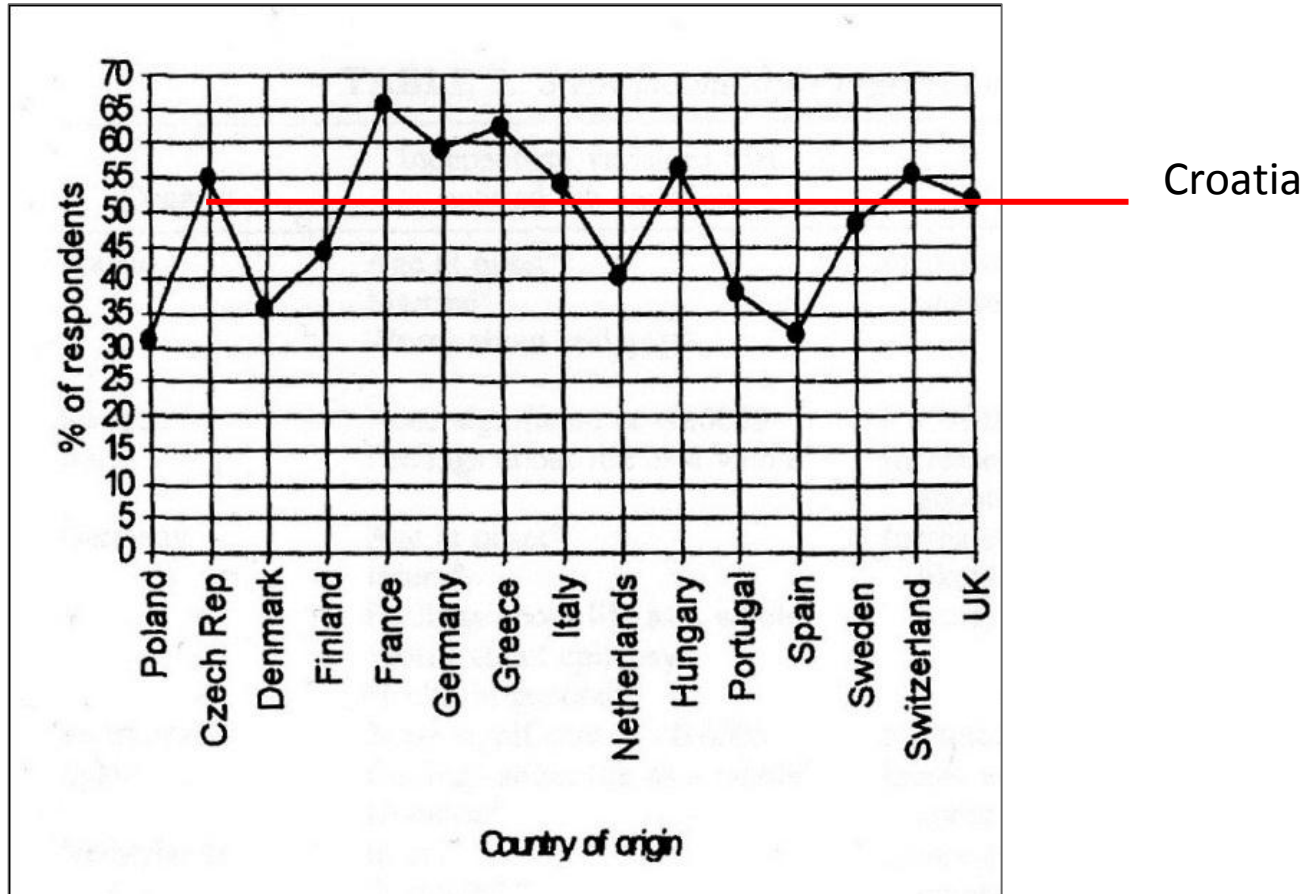
N= 310

mild to moderate stigma	136 (45%)
severe stigma	23 (8%)
Total	159 (53%)

Bielen I, Hajnšek S, Sušak R, Planjar M, Petelin Ž, Čandrlić M, Dogan D, Sruk A, Friedrich L.
10th Croatian Symposium on Epilepsy, Opatija 2012

Adults with epilepsy

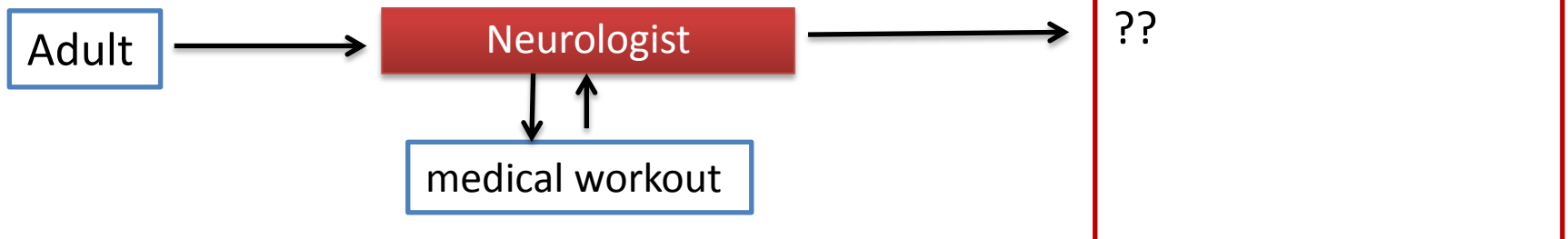
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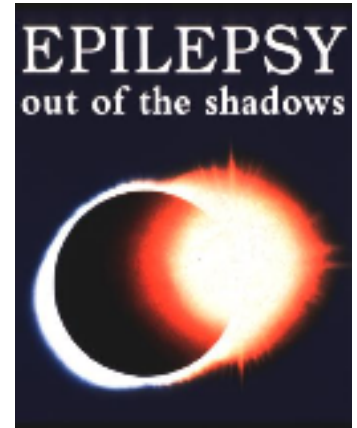
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Is it real to expect a neurologist to be able to manage all the problems the PWE face?



➤ Public-oriented activities



Croatian IBE and ILAE Chapters in collaboration:

National Epilepsy Day, European Epilepsy Day, “Purple Day”:

radio and TV shows

articles in papers and magazines

public lectures

Stand up for epilepsy!



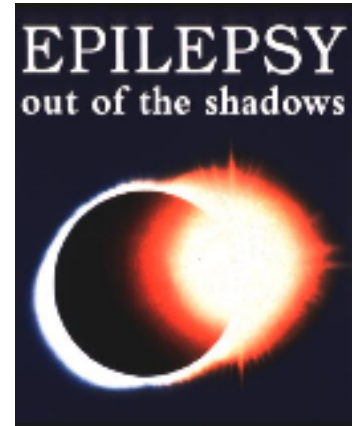
➤ Public-oriented activities

Croatian Epilepsy Association (IBE Chapter) web site and facebook

www.epilepsija.hr: about 2000 individual visits/month

facebook: 14,405 people saw our most popular post

➤ some encouraging results



Sample of college-preparatory high school students

Table 3

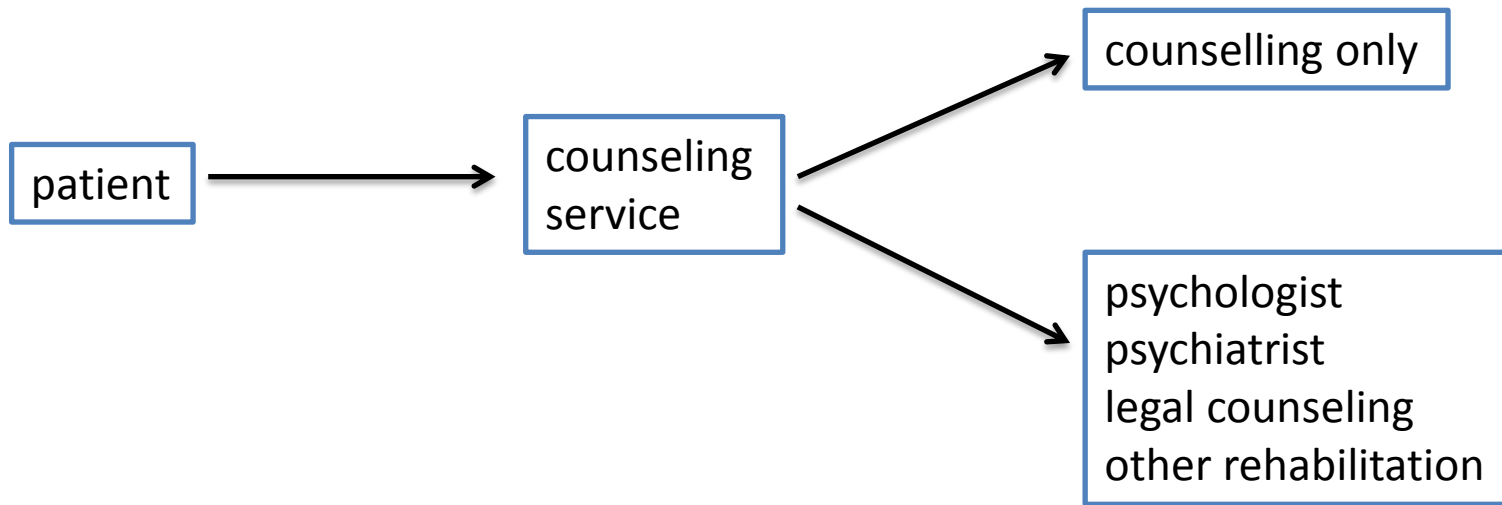
Comparison of attitudes toward PwE in 2002 and 2010.

Positive attitudes	Year 2002 <i>N</i> = 227% respondents	Year 2010 <i>N</i> = 203% respondents	Statistical difference
Playing with children with epilepsy	97.4	98.0	$p = \text{NS}$
Marrying a PwE	86.3	94.1	$p < 0.05$
Possibility of performing most jobs	68.1	82.8	$p < 0.01$

founding of epilepsy counselling services

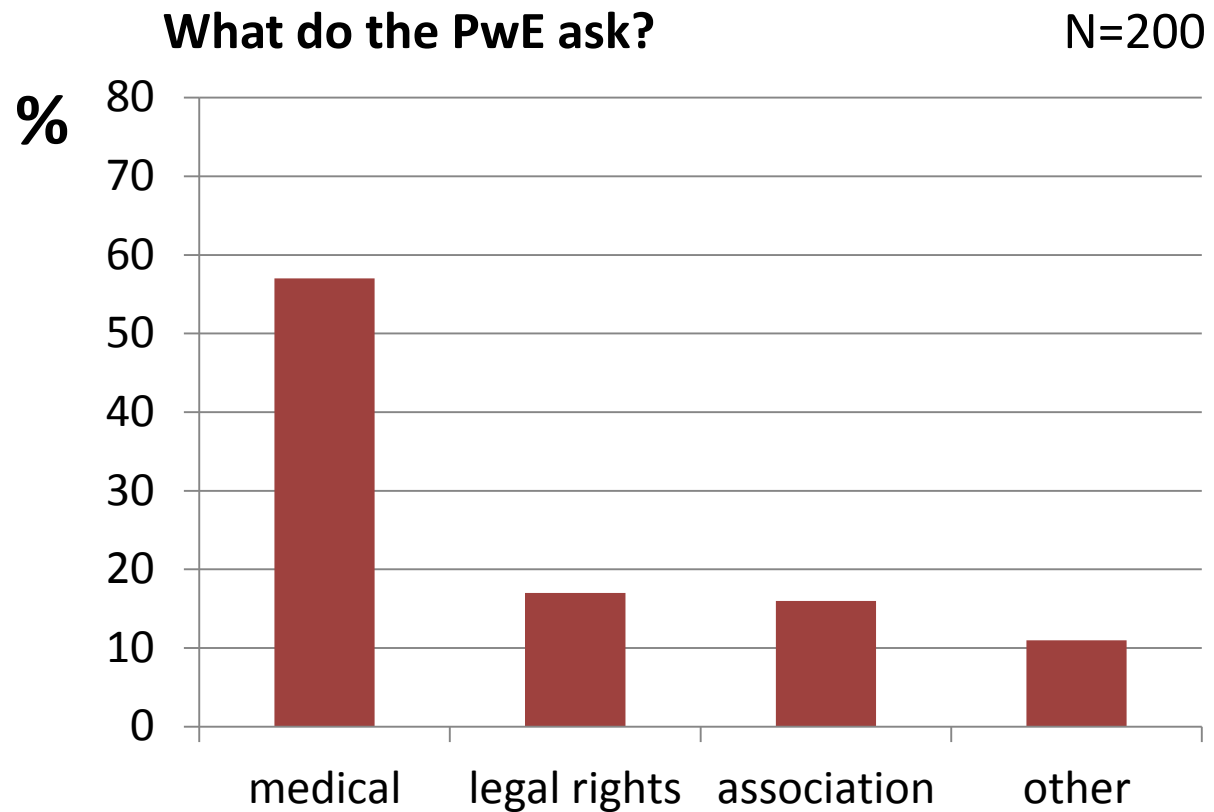
Staff not clearly defined:

young physicians, social workers, specially trained nurses



Internet counselling

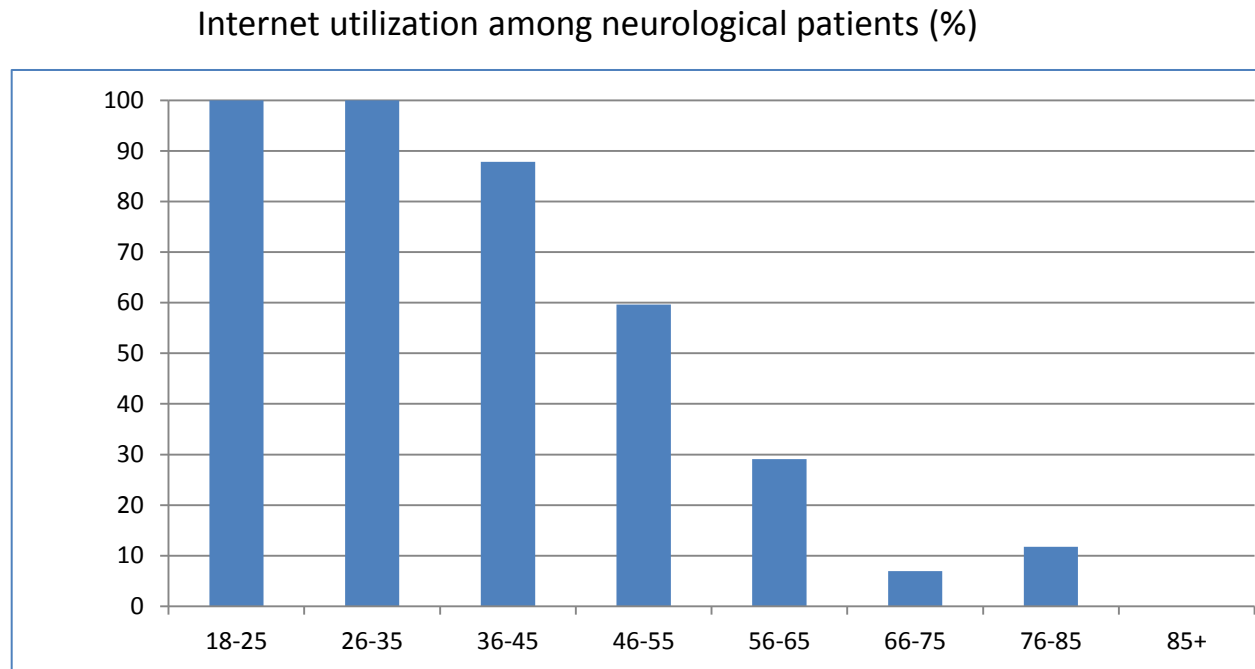
Croatian IBE Chapter
www.epilepsija.hr



Internet counseling

- about 50% of adult epilepsy patients use the Internet
- about 2/3 of users seek medical information on the Internet

N= 244



epilepsy children summer support camps

20-25 children 8 – 17 years

- educational activities
- workshops
- outdoor activities

2009: Fužine (continental Croatia)
2010-2013: Selce (seaside)



Some summer camp goals:

exchanging experiences with other children



Some summer camp goals:

improving socialisation



Some summer camp goals:

to abandon prejudices and strengthen self-esteem



In conclusion:

People with epilepsy need comprehensive care and often multidisciplinary rehabilitation

Programs for structured comprehensive epilepsy care in Croatia should be created.

Development of counselling services and interactive internet-based counselling may be important steps towards a holistic approach to people with epilepsy.