Seminar in Epileptology

Epileptic Disord 2020; 22 (5): 531-47

How to understand and address the cultural aspects and consequences of diagnosis of epilepsy, including stigma

Patricia Braga ¹, Hassan Hosny ², Angelina Kakooza-Mwesige ³, Flora Rider ⁴, Manjari Tripathi ⁵, Alla Guekht ^{4,6}

Received April 30, 2020; Accepted July 03, 2020



¹ Institute of Neurology, Facultad de Medicina, Universidad de la República, Uruguay

² Neurology Department, Cairo University, Cairo, Egypt

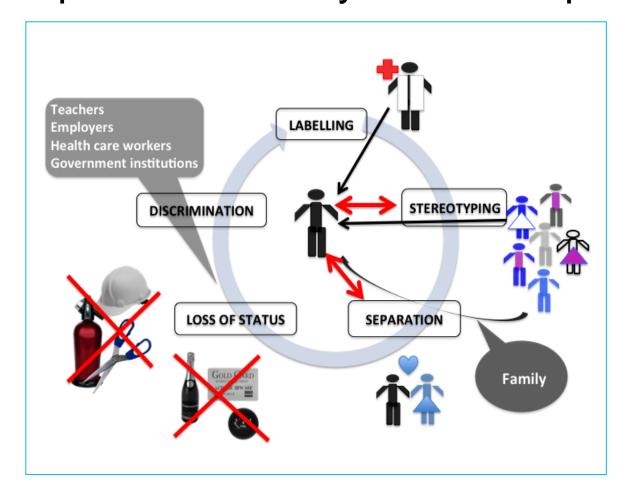
³ Department of Paediatrics and Child Health, Makerere University College of Health Sciences, Kampala, Uganda

⁴ Moscow Research and Clinical Center for Neuropsychiatry of the Healthcare Department, Moscow, Russia

⁵ Department of Neurology, AIIMS, New Delhi, India

⁶ Pirogov Russian National Research Medical University, Moscow, Russia

Origin of stigma in PWE relative to personal history and life experience



based on the stigma model proposed by Link and Phelan, 2001



General recommendations for physicians and healthcare providers to address stigma in PWE

- Discuss felt and enacted stigma at the first visit and periodically with all patients
- If a formal evaluation tool is used, consider the target population for which it was designed and available information on its validation for a particular country/culture
- Support self-empowerment of PWE
- Deliver professional counselling and support



Stigma and epilepsy



Felt stigma

refers principally to the fear of enacted stigma, but also encompasses a feeling of shame associated with being a PWE

Enacted stigma

refers to instances of discrimination against PWE on the grounds of their perceived unacceptability or inferiority





Scambler G. and Hopkins A. Being epileptic: coming to terms with stigma. Sociology of Health and Illness 8, 26-43, 1986

Most relevant determinants of felt stigma and quality of life in PWE

		Felt stigma	Quality of life
EPILEPSY- related factors	Seizures	\Rightarrow	1
	Seizure frequency/ severity	\Rightarrow	1
	AED adverse effects	1	1
	Longer epilepsy duration	?	1
	Drug resistance	1	1
DEMOGRAPHIC factors	Age	1	No effect
	Low educational level	1	\(\rightarrow\)
	Unemployment	1	\(\rightarrow\)
COMORBIDITIES	Anxiety / depression	1	1
	Behavioral problems	1	?









