

Fighting epilepsy stigma through a music video

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RESUMO

Introduction: Epilepsy imposes considerable psychological and emotional burden not only on people with epilepsy, but also on their families. It is a stigmatizing condition, as a result of uncontrolled and unpredictable seizures. Interventions to fight stigma in epilepsy exist, however, little is known about their efficacy. Therefore, this study aims to assess people's potential learning and stigma towards epilepsy before and after watching an educational music video. **Methods:** We composed a song and produced a music video (<https://youtu.be/18En8n7dX74>), addressing the most common stigma issues, attitudes, and perceptions towards someone having a seizure, and evaluated quantitatively the impact of this intervention in the general population using a previously validated protocol in Brazil, the Stigma Scale of Epilepsy (SSE). **Results:** One-hundred-and-twenty-eight individuals were interviewed in three different cities in Brazil scored 38.88 (median) before and 20.81 after watching the music video ($p < 0.0001$). This reduction of perceived stigma was directly proportional to educational level and it was most prominent among individuals who declared not having any known relative or friend with epilepsy. Forty-three (33%) individuals declared they would hold the tongue of a person having a seizure before listening to the music, while only 13 (10%) answered the same after the intervention ($p < 0.0001$). **Conclusion:** Attitudes and perceptions about epilepsy can be easily improved through simple interventions such as watching a short music video, which may be appropriate as a mass media campaign towards minimizing epilepsy stigma.

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INTRODUCTION

Epilepsy is a complex neuropsychiatric disorder characterized by an enduring predisposition of the brain to generate epileptic seizures - i.e. the transient occurrence of signs and/or symptoms as a result of abnormal excessive or synchronous neuronal activity - and by the neurobiologic, cognitive, psychological, and social consequences of this condition.¹

Sixty-five million people live with epilepsy worldwide, of whom 80% live in resource-poor countries with little or no access to adequate treatment. Epilepsy affects individuals from different ages and social classes, and uncontrolled seizures impose considerable psychological and emotional suffering and disability not only on people with epilepsy (PWE), but also on their families and society.^{2,3} People with disabilities are among

the most vulnerable in any society. This vulnerability is even greater among those with hidden disabilities such as epilepsy, where the neurological features of this condition may be associated by varying spectra of affective, behavioral and/or personality disorders in up to 50% of PWE.³ Epilepsy is a stigmatizing condition, as PWE do not conform to social norms as a result of unpredictable seizures.⁴

"Stigma" may be sociologically defined as referring to an attribute that is "deeply discrediting" and allows the stigmatized individual to be seen by others as "not quite human".⁵ Stigma, when related to epilepsy, is considered one of the major negative influences on quality of life, self-confidence, and patients' self-esteem.^{3,6} Therefore, reducing epilepsy-related stigma has important public health implications globally. Although specific practices vary from country to country, with

inherent difficulties to conceptualize and measure it, there are two main methods to reduce the epilepsy-related stigma: (1) related to patients' associations to counteract negative stereotypes and reduce their experience of stigma through campaigns and governmental and health system planners partnerships; (2) related to supporting patients individually, by increasing their resilience through tailored educational programs and counseling.³ We propose a targeted intervention through a music video, specifically designed to address the main psychosocial burden experienced by PWE and with educational purposes on how to deal with someone who is having an epileptic seizure; with the objective of measuring stigma in epilepsy in the general population before and after watching to this video.⁴

METHODS

This is an observational cross-sectional study in

Box 1. "Epilepsy" song lyrics

Brazilian-Portuguese lyrics	English lyrics
Há certo tempo, ouvi que tinha uma tal de epilepsia	Sometime ago I have learned that I had something called epilepsy
Sofri preconceito, fui desprezado, mas te mostrei que estava errado	I've been discriminated and stigmatized, but I showed you were wrong
Posso ter filhos e educá-los, com eles vou ter o cuidado	I am able to have kids and raise them, I can take care of them
Tenho sentimentos, vou te alegrar	I have feelings, I can make you happy
Contigo conjugo o verbo amar	I had learned the meaning of 'love' with you
CHORUS	CHORUS
Durante a crise, calma, não tenho dor	During my seizures, stay calm, 'cause I don't feel any pain
Deita me de lado e me proteja ao redor	Lay me sideways and protect me from the surroundings
Não me contenha e seja paciente	Don't restrain me and be patient
Pois logo mais estarei consciente	'Cause soon I will recover my consciousness
Sou trabalhador e bom estudante, dou meu melhor a cada instante	I am a hard worker and I am a good student, I always give my best
Sou esportista e vencedor, suporto desafios e a dor	I am an athlete and a winner, I can take on challenges and stand the pain
Também sou capaz, chega de sufocar, há mais formas de me cuidar	I am competent, stop overprotecting me, there are other ways of taking care of me
Vou te surpreender, não duvide assim, pois estou longe do meu fim	I will surprise you, don't doubt me, 'cause I am far from the end

The song chorus highlights the knowledge about expected actions by individuals witnessing a seizure. Its soft melody intends to bring out peacefulness, considering that, in most cases, caregivers' erroneous actions towards a seizing individual are due to anxiety or despair, such as attempts to restrain the patient, and throwing water on his face.⁸ Additionally, during the

which we investigated the potential of the song "Epilepsy", accompanied by its movie clip (specifically developed for this project by these authors, freely available at <https://www.youtube.com/watch?v=18En8n7dX74>), to decrease the stigma associated to epilepsy and to promote knowledge on how to help someone who is having a seizure. We designed two similar semi-structured questionnaires, which were applied in a face-to-face interview to community individuals before and after watching this music video. Individuals of diverse ages and socioeconomic status from the general population were recruited as a convenience sample in schools, universities, on the streets, voluntarily, in different locations in Brazil: Florianópolis - SC, São Paulo - SP, and Dourados - MS.

The lyrics (Box 1) were created to counteract the main misconceptions and stigmatizing issues faced by PWE in different environment, such as school, home, and at work, as previously detected in Brazil.^{4,6,7}

video script development, some details were on purpose: the initial scene of a PWE with a knife in his hand, for example, intended to attract the viewer's attention and suggest the risk of suicide due to depression, a frequent comorbidity in PWE.⁹ Shortly after this scene, an epileptic seizure is shown in a subtle way along with the particular tranquility and the most appropriate actions of

a caregiver towards a seizing individual.

The semi-structured questionnaire included the following socio-demographic variables: age, gender, educational level, and whether the subject had any acquaintances with epilepsy. Afterwards, we applied the Stigma Scale of Epilepsy (SSE), previously developed and validated in the general population by researchers from the State University of Campinas (UNICAMP) in Brazil, in 2007⁴. At last, questions about subject's knowledge on epilepsy were asked, before and after watching the music video.

SSE is a scale that evaluates the stigma and misconceptions of individuals about epilepsy and consists of 5 questions. These questions relate to the possible beliefs of the respondents about epilepsy and are subdivided into 24 items addressing feelings and aspects of PWE's life. Each item allows one of four possible responses (1 = No; 2 = A little; 3 = A lot; 4 = Completely). The obtained values result in a score varying from zero (minimum stigma) to 100 (maximum stigma). SSE has high internal consistency and validity, allowing the quantification of the epilepsy stigma in the community.⁴

After watching the music video "Epilepsy", the same SSE⁴ and questions about what to do during an epileptic seizure were reapplied. Also, the respondents were encouraged to freely report their opinion about the possible contributions of this music video in reducing the epilepsy stigma.

Data were collected by the researchers, stored, compared, and analyzed using IBM SPSS® Statistics Grad Pack software Premium version 26.0, and Microsoft Excel® software package for Windows, 2014. The results of the continuous variables were represented as mean ± standard deviation (SD). Categorical variables were described as frequencies and percentage values. Parametric and non-parametric tests for inferential analysis were performed according to the variables respectively. A p-value < 0.05 was considered to be statistically significant.

This study was carried out in accordance with the

Code of Ethics of the World Medical Association (Helsinki Declaration) and it was only started after approval by the Ethics Committee on Human Research of the Federal University of Santa Catarina (CEPSH-UFSC) under protocol number 2007/13 (17/10/2011). All participants had their identity kept confidential, and signed an informed consent form, voluntarily agreeing to participate in this study.

RESULTS

We interviewed 128 individuals, who had an average age of 25.98 ± 10.04 with a minimum age of 18 and maximum of 62 years. Of the total sample, 91 (71.1%) were female, and 69% completed high school. Seventy-eight (61.0%) subjects were college students.

Seventy-eight (61.0%) participants did not know anyone with epilepsy, but 19 (14.8%) had at least one friend, and 31 (24.2%) mentioned relatives with this diagnosis.

We observed a statistically significant decrease in SSE scores before and after watching the music video (median = 38.88 vs. 20.81; $Z = -8.69$; $p < 0.0001$) according to the Wilcoxon's test (Figure 1). This reduction of perceived stigma was most prominent among those individuals who reported not having any acquaintance/known relative or friend (meaning previous personal experience) with epilepsy (Tables 1 and 2). However, there was no statistically significant difference according to gender, either before or after watching the music video, while higher educational level was correlated with lower SSE scores after watching the music video ($r = -0.06$; $p = 0.04$; Spearman's correlation). All the subjects had to identify within a list of actions, what they would do to help someone during a seizure and 43 (33%) individuals declared they would pull out the tongue of a person having a seizure before listening to the music, while only 13 (10%) had the same answer after the intervention ($p < 0.0001$; Table 3).

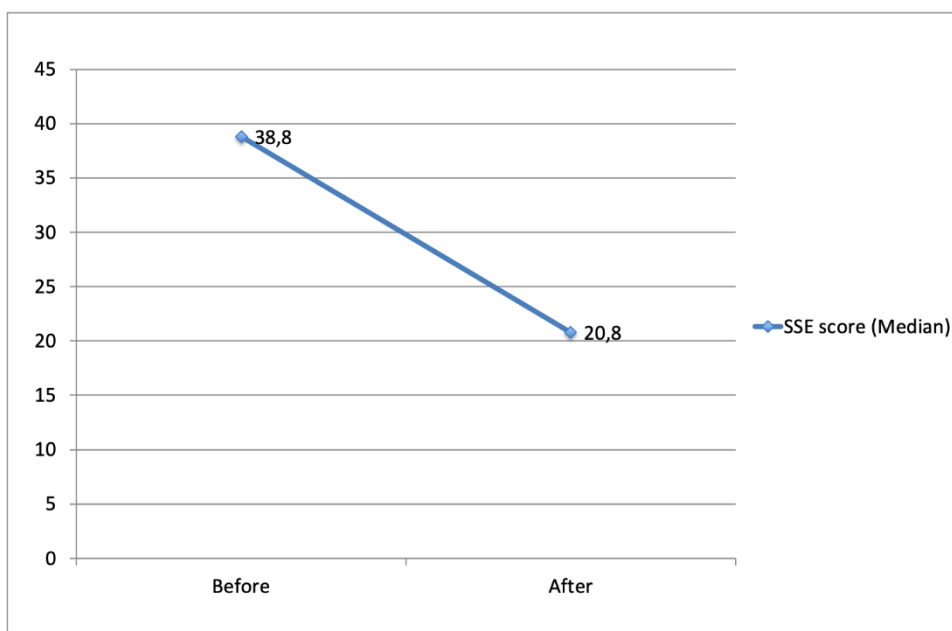


Figure 1. Stigma scale of epilepsy (SSE) before and after the intervention.

Table 1. Stigma Scale of Epilepsy scores across groups

	N	Mean	Standard Deviation	p value ^a
Total score of SSE before the music				
Male	37	36.3	12.59	0.499
Female	91	38.8	14.66	
Total score of SSE after the music				
Male	37	23.0	15.79	0.266
Female	91	24.6	14.35	

SSE = stigma scale of epilepsy. ^a Mann-Whitney's U test. ^{*} Statistically significant with $p \leq 0.05$

Table 2. Impact of people's knowledge of someone (relative or friend) with epilepsy on Stigma Scale of Epilepsy scores before and after watching to the music video

	Previous knowledge ^a	N	Median	p value ^b
SSE score before	Yes	50	37.0	0.284
	No	78	38.8	
SSE score after	Yes	50	27.0	0.440
	No	78	22.3	
SSE score variation (after - before)	Yes	50	-9.9	0.009 [*]
	No	78	-16.48	

SD = standard deviation; SSE = stigma scale of epilepsy. ^a Previous knowledge of someone (relative of friend) with epilepsy = Yes or No. ^b Mann-Whitney's U test. ^{*} Statistically significant with $p \leq 0.05$

Table 3. Knowledge and attitudes towards a person having a seizure before and after watching the music video

During a seizure a caregiver should...	Before ^a Yes (%)	After ^a Yes (%)	p value ^b
Hold the patient to avoid injuries	71	29	0.003 *
Hold his/her tongue	33	10	<0.0001 *
Throw water onto his/her face	1.6	0.8	0.01 *
Protect his/her head	84	85	0.48
Stay with the individual	53	75	<0.0001 *

^a Percentage of individuals who answered YES to each sentence. ^b Chi-square test. * Statistically significant with $p \leq 0.05$

DISCUSSION

The music video "Epilepsy" was effective for educational purposes and in reducing the stigma in epilepsy. This result can be seen by the reduction in the individual scores after watching the music video, with deeper impact on those who did not have any previous personal experience or familiarity with epilepsy, and also on those with higher educational levels.

In fact, as evidenced in our study, one in three individuals would pull the tongue out of the mouth of someone having a seizure. After watching the "Epilepsy" video, this number dropped to one in ten individuals, demonstrating that this intervention is useful in educating people towards the right actions to help someone having a seizure, however, learning is the result of a series of iterations, requiring more than simply watching a video only once to a better result.

The music video had a good acceptance among the general population, who answered positively to both questions: "*Did you like this song?*" and "*Do you believe this song can help reducing the stigma in epilepsy?*". Of note, here are some opinions: "*Yes, with a clear and easy way to understand, the song transmitted some relevant information to assist a patient with epilepsy*"; "*Yes, it showed that, despite the difficulties faced by PWE, we are equal*"; "*Yes, but I think the lyrics match best with subjects who already have some knowledge about epilepsy*"; "*Yes, it transmits peace and tranquility*"; "*Yes, it allows better knowledge and improvement of common sense about epilepsy*".

Discrimination can be demonstrated unequivocally in stories commonly reported by patients and their families. Numerous cases of bullying in schools and other environments, as well as poor relationships or job losses related to epilepsy have been reported.^{6,10-12} These reports allow better knowledge about PWE, their emotions, fears, and way of coping with life and disease,¹³ and were the inspiration for the composed song "Epilepsy".

Among the many stories told by some PWE and their families during the interviews, a patient described his difficulty in finding a job in a bakery due to epilepsy, despite of being fully competent. He never gave up, seeking for new courses to improve his techniques. This

story of resilience inspired the video script.

SSE is among the first instruments allowing quantification of stigma in epilepsy expressed as a scale, with a satisfactory content validity and high internal consistency. The average scores obtained during its validation process were 46 among patients and 49 within community⁴, with similar results in other countries.¹⁴ Our subjects scored lower, a median of 38, decreasing to 20 after watching the music video "Epilepsy" (of 4 min 24 sec. duration), demonstrating a reduced stigma in our study population and a further decrease of stigma after such a simple and quick intervention, similarly to a Bolivian study with 216 subjects who answered to SSE before and after an educational program.¹⁵

As the study "Epilepsy perception amongst university students"¹⁶, which investigated students in the first, third and sixth years of Medical School, Exact and Social Sciences courses, and other similar study conducted in Turkey,¹⁷ our results showed an inverse relationship between knowledge and stigma. The music video "Epilepsy", through an accessible language and presentation to the general population, can be a valuable tool to provide knowledge on what to do during an epileptic seizure.

Fernandes et al. have identified difficulties in actions towards reducing stigma in epilepsy among school teachers.¹⁸ They evidenced the importance of teachers' education about the disease, and their role in spreading knowledge to a higher number of individuals. The music video "Epilepsy" may be useful in spreading the information amongst the masses.

Mental health-related stigma is widespread and has major adverse effects on the lives of people with mental health problems. Anti-stigma mass media interventions may reduce prejudice, but there is insufficient evidence to determine their effects on discrimination, especially in low- and middle- income countries, as a recent Cochrane's systematic review has pointed out.¹⁹ More studies are required to establish the effects of mass media interventions on discrimination (being treated unfairly) and prejudice (stigmatising attitudes), to understand which types of mass media intervention are more suitable for diverse populations, and their cost-effectiveness.¹⁹⁻²¹

Some limitations must be taken into account

regarding this study, for example, the lack of a control group, allowing us to analyze the existence of other factors that might lead to changes in the SSE scores after watching the video. Additionally, further studies are necessary, in different social, educational, cultural and economic scenarios, since most of our population have completed high school. At last, this was a cross-sectional study with a relatively small sample and a new interview six months or one year after watching this video would verify whether its contents were really assimilated and whether individuals' stigma remained consistently reduced.

CONCLUSION

Epilepsy stigma can be reduced through simple

measures such as a short music video. Coordinated actions involving patient and Medical organizations, commercial partners and other stakeholders, through mass media campaign, may prove useful to bring awareness and minimize the negative aspects of stigma and discrimination, improving quality of life of PWE and their families.

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REFERENCES

1. Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. A practical clinical definition of epilepsy. *Epilepsia*. 2014;55:475-82. doi: 10.1111/epi.12550. Epub 2014 Apr 14
2. Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, et al. Standards for epidemiologic studies and surveillance of epilepsy. *Epilepsia*. 2011;52:2-26. doi: 10.1111/j.1528-1167.2011.03121.x
3. de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav*. 2008;12:540-6. doi: [10.1016/j.yebeh.2007.12.019](https://doi.org/10.1016/j.yebeh.2007.12.019)
4. Fernandes PT, Salgado PC, Noronha AL, Sander JW, Li LM. Stigma Scale of Epilepsy: validation process. *Arq Neuropsiquiatr*. 2007;65:35-42. doi: 10.1590/s0004-282x2007001000006
5. Goffman E. Stigma: notes on the management of spoiled identity. Prentice-Hall, Upper Saddle River, NJ. 1963.
6. Fernandes PT, Snape DA, Beran RG, Jacoby A. Epilepsy stigma: what do we know and where next? *Epilepsy Behav*. 2011;22:55-62. doi: 10.1016/j.yebeh.2011.02.014
7. Fernandes PT, Li ML. Percepção de estigma na epilepsia. *J Epilepsy Clin Neurophysiol*. 2006;12:207-18.
8. Zatorre RJ, Evans AC, Meyer E. Neural mechanisms underlying melodic perception and memory for pitch. *J Neurosci*. 1994;14:1908-19. doi: 10.1523/JNEUROSCI.14-04-01908.1994
9. Salpekar JA, Mula M. Common psychiatric comorbidities in epilepsy: how big a problem is it? *Epilepsy Behav*. 2018;98:293-7. doi: [10.1016/j.yebeh.2018.07.023](https://doi.org/10.1016/j.yebeh.2018.07.023)
10. Tedrus GMAS, Pereira RB, Zoppi M. Epilepsy, stigma, and family. *Epilepsy Behav* 2018;78:265-8. doi: 10.1016/j.yebeh.2017.08.007
11. Pitkänen A, Henshall DC, Cross JH, Guerrini R, Jozwiak S, Kokaia M, et al. Advancing research toward faster diagnosis, better treatment, and end of stigma in epilepsy. *Epilepsia* 2019;60:1281-92. doi: 10.1111/epi.16091
12. Holmes E, Bourke S, Plumpton C. Attitudes towards epilepsy in the UK population: results from a 2018 national survey. *Seizure*. 2019;65:12-9. doi: 10.1016/j.seizure.2018.12.012
13. Kane JC, Elafros MA, Murray SM, Mitchell EM, Augustinavicius JL, Causevic S, et al. A scoping review of health-related stigma outcomes for high-burden diseases in low-and middle-income countries. *BMC Medicine*. 2019;17:17. doi: 10.1186/s12916-019-1250-8
14. Tombini M, Assenza G, Quintiliani L, Ricci L, Lanzone J, De Mojà R, et al. Epilepsy-associated stigma from the perspective of people with epilepsy and the community in Italy. *Epilepsy Behav*. 2019;98:66-72. doi: 10.1016/j.yebeh.2019.06.026
15. Giuliano L, Cicero CE, Padilha S, Mayaregua DR, Villarreal WMC, Sofia V, et al. Knowledge, stigma, and quality of life in epilepsy: results before and after a community-based epilepsy awareness program in rural Bolivia. *Epilepsy Behav*. 2019;92:90-7. doi: 10.1016/j.yebeh.2018.11.036
16. Caixeta J, Fernandes PT, Bell GS, Sander JW, Li ML. Epilepsy perception amongst university students. *Arq Neuropsiquiatr*. 2007;65:43-8. doi: [10.1590/s0004-282x2007001000007](https://doi.org/10.1590/s0004-282x2007001000007)
17. Yeni K, Tülek Z, Bebek N, Cavusoglu A, Güven H, Simsek N, et al. Knowledge and attitudes toward epilepsy among students of health occupations in a university. *Epilepsi*. 2019;25:13-20. doi: 10.14744/epilepsi.2018.21043

18. Fernandes PT, Noronha AL, Araújo U, et al. Teachers perception about epilepsy. *Arq Neuropsiquiatr.* 2007;65:28-34. doi: 10.1590/S0004-282X2007001000005
19. Clement S, Lassman F, Barley E, Evans-Lacko S, Williams P, Yamaguchi S, Slade M, Rüsch N, Thornicroft G. Mass media interventions for reducing mental health-related stigma. *Cochrane Database Syst Rev.* 2013;23:CD009453. doi: 10.1002/14651858.CD009453.pub2
20. Smythe T, Adelson JD, Polack S. Systematic review of interventions for reducing stigma experienced by children with disabilities and their families in low- and middle-income countries: state of the evidence. *Trop Med Int Health.* 2020;25:508-24. doi: 10.1111/tmi.13388
21. Hartog K, Hubbard CD, Krouwer AF, Thornicroft G, Kohrt BA, Jordans MJD. Stigma reduction interventions for children and adolescents in low- and middle- income countries: systematic review of intervention strategies. *Soc Sci Med.* 2020;246:112749. doi: 10.1016/j.socscimed.2019.112749