Published in final edited form as:

Qual Life Res. 2015 June ; 24(6): 1483–1489. doi:10.1007/s11136-014-0868-4.

Reexamining epilepsy-associated stigma: validation of the Stigma Scale of Epilepsy in Zambia

Melissa A. Elafros,

International Neurologic and Psychiatric Epidemiology Program (INPEP), Michigan State University, 909 Fee Road, Room 324, West Fee Hall, East Lansing, MI 48824, USA, Department of Epidemiology, College of Human Medicine, Michigan State University, East Lansing, MI, USA

Ryan P. Bowles,

Department of Human Development and Family Studies, College of Social Science, Michigan State University, East Lansing, MI, USA

Masharip Atadzhanov,

Department of Medicine, University of Zambia, Lusaka, Zambia

Edward Mbewe,

Chainama College of Health Sciences, Lusaka, Zambia, College of Health Sciences, University of KwaZulu Natal, Durban, South Africa

Alan Haworth,

Department of Psychiatry, University of Zambia School of Medicine, Lusaka, Zambia

Elwyn Chomba, and

Zambia Ministry of Community Development, Mother and Child Health, Lusaka, Zambia

Gretchen L. Birbeck

Epilepsy Division, Departments of Neurology and Public Health, University of Rochester, Rochester, NY, USA, Chikankata Health Services, Epilepsy Care Team, Mazabuka, Zambia

Abstract

Purpose—Epilepsy-associated stigma is an important patient-centered outcome, yet quantification remains challenging. Jacoby's 3-item Stigma Scale is commonly used to assess felt stigma among people with epilepsy (PWE) yet has ceiling effects. The Stigma Scale of Epilepsy (SSE) is a 24-item instrument that measures felt stigma among PWE and stigmatizing attitudes among others. If cross-culturally valid, the SSE may elucidate stigma determinants and provide an outcome measure for interventions.

Methods—We assessed the properties of the SSE in 102 Zambian PWE using exploratory and confirmatory item response theories and compared the latent traits assessed by the SSE to those assessed by Jacoby's Stigma Scale. Differential item functioning based on forced disclosure of epilepsy was examined.

Correspondence to: Melissa A. Elafros.

Ethical standards All human studies have been approved by the appropriate ethics committees and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

Results—The SSE yielded two latent traits—the first reflected difficulties faced by PWE; the second reflected emotions associated with epilepsy. Jacoby’s Stigma Scale was associated only with the first latent trait. Forced disclosure was associated with “worry” and “pity” that were associated with the second latent trait.

Conclusions—In Zambian PWE, the SSE captured two latent traits. One trait represents feelings associated with epilepsy, which is theorized as a substantial yet unmeasured part of stigma. The SSE performs well across cultures and may more comprehensively assess felt stigma than other instruments. Further validation is required to determine whether the SSE adequately assesses stigmatizing attitudes among people without epilepsy.

Keywords

Felt stigma; Enacted stigma; Stigmatizing attitudes; Sub-Saharan Africa; Patient-centered outcome; Forced disclosure

Introduction

Epilepsy-associated stigma is an often overlooked patient-centered outcome. Influenced by age of onset [1], seizure severity [2], and societal forces [3], stigma is a substantial, yet modifiable, problem for people with epilepsy (PWE) [4]. Linked to decreased well-being [5], poor health outcomes [6], increased prevalence of abuse [7], and decreased patient satisfaction [2], stigma reduction efforts are ongoing [8]. However, little consensus exists on how to measure stigma.

From a theoretical perspective, stigma is divided into enacted and felt stigma [4]. Enacted stigma describes beliefs held by the public that would manifest as discrimination [9]. Most attempts to measure enacted stigma assess epilepsy-associated knowledge, attitudes, and practices (KAP) among the public [4, 10]. Felt stigma describes self-stigmatization by PWE resulting from epilepsy-associated shame and fear of discrimination [4, 9, 11]. International surveys suggest that stigma is a universal construct [1, 12]. Customized instruments may more completely capture the local burden of stigma, but are challenging to develop and prohibit cross-cultural comparisons. The most frequently employed instrument for felt stigma is Jacoby’s Stigma Scale [13]. This instrument measures PWE’s perception of enacted stigma in their community [14], which theoretically contributes to felt stigma but may not fully encompass it, and has been used to assess felt stigma associated with other conditions [15, 16]. The original dichotomous responses were revised to correct a ceiling effect [3], though this version is rarely used [17, 18].

A cross-cultural instrument which could quantify both KAP and felt stigma would facilitate cross-cultural studies of stigma determinants and would be valuable for stigma reduction interventions [19]. The 24-item Stigma Scale of Epilepsy (SSE) may fulfill this need [20]. Developed in Brazil [20], the SSE has been used in India [21] and Bolivia [22].

We administered the SSE and Jacoby’s Stigma Scale to Zambian PWE to assess the utility of the SSE. We conducted exploratory and confirmatory item response theory (IRT) analyses to examine the SSE’s underlying traits and to compare these traits to those assessed by

Jacoby's Stigma Scale. Lastly, as research indicated that felt stigma varies based on forced disclosure of epilepsy [3], we assessed differential item functioning of the SSE.

Methods

In October 2009, we interviewed 102 PWE using the SSE and Jacoby's Stigma Scale. Basic demographic data, epilepsy characteristics, and community disclosure status were collected. The appropriate ethical approvals were obtained.

Characteristics of the study sample

Demographic, clinical, and economic information is shown in Table 1. Interviews were conducted as part of baseline surveys for a study of peer support groups. Individuals were selected for participation from a pool of PWE receiving epilepsy care at three health centers. All individuals completed both assessments. Direct translations of the instruments were not feasible as Zambia has seven official languages and immense variation in dialects. English is the most common second language; therefore, instruments were provided to interviewers in English, so they could be translated to suit participants. A short training session was held with the interviewers during which each instrument was discussed in detail, the nuances of each item in English were mastered, and translation to local dialects was practiced.

Analytic plan

Interviews were conducted on paper and entered into Microsoft Excel. Descriptive statistics were calculated for each SSE item, and the distribution of responses was compared to the Brazilian validation [20] using χ^2 tests.

We used IRT modeling to examine the validity of the SSE for our sample [23]. We used IRT in both exploratory and confirmatory approaches to examine the dimensionality of the SSE to better understand stigma as measured by the SSE and Jacoby's Stigma Scale. A root-mean-square error of approximation (RMSEA) <0.06 was considered indicative of acceptable model fit [24]. A fundamental assumption of IRT is that variations in responses are determined by the underlying traits and not by extrinsic factors [23]. Previous research among individuals with stigmatized conditions like epilepsy and HIV suggests that those who have their condition involuntarily disclosed experience greater stigma [3, 25]. Therefore, we used differential item functioning analysis to examine the effect of forced disclosure on SSE responses.

Descriptive statistics and comparisons to data gathered in Brazil [20] were performed using SAS (version 9.3, SAS, Cary). Mplus (version 7.11, Muthén and Muthén, Los Angeles) was used to conduct the exploratory IRT analyses, which is equivalent to exploratory item factor analysis. Confirmatory IRT analyses and tests of differential item functioning were completed using IRTPRO (version 2.1, Scientific Software International, Inc, Lincolnwood).

Results

Descriptive statistics

Participants exhibited a full range of felt stigma. Using Jacoby's Stigma Scale, 41 adults (60 %) and 27 youth (79 %) reported felt stigma. Most participants provided responses to all items. Generally in IRT, a small proportion of missing item responses is ignorable and has no effect on trait level estimates.

Table 2 depicts the frequency of SSE responses from Zambian PWE to responses. These were compared to responses given by the Brazilian validation population. Generally, Zambian PWE selected responses indicating greater stigma than Brazilian PWE. Despite this, more Zambians believed that PWE can control their epilepsy ($p < 0.001$). In addition, Brazilian PWE expressed feeling more scared ($p < 0.0001$) and fear ($p = 0.003$) when they saw a seizure than Zambian PWE, as well as feeling more dependent ($p = 0.02$). Only one Zambian PWE (1 %) indicated that he thought epilepsy was not associated with prejudice (answered "not at all" to all items associated with question 5).

SSE dimensionality

The exploratory IRT analysis supported a model for the SSE with two latent traits (eigenvalues 7.956 and 3.200, respectively), as shown in the associated scree plot (Fig. 1). This model fit adequately (RMSEA = 0.057), and the three latent trait model did not provide substantially better fit (RMSEA = 0.050). The two latent trait model accounted for 46.5 % of the cumulative variance seen in item responses (Fig. 2). An item was considered to contribute to a latent trait if its promax-rotated loading for that factor was > 0.4 . Item 1 did not load onto either latent trait and was eliminated. The first latent trait included questions regarding the difficulties faced by PWE and prejudice associated with epilepsy, whereas the second latent trait included questions regarding the respondent's sentiments when he/she witnesses a seizure and how the respondent believes that PWE feel.

The latent traits were moderately correlated (-0.41) with a high correlation between items 2 and 3 (0.979). Further inquiry attributed this to translation. In two of the local languages, scared and fear are described using nearly identical words. Because fear had a higher loading, scared was removed from further analysis.

Item discriminations and difficulties for the confirmatory IRT analysis are reported in Table 3. To compare the latent traits assessed by the SSE to those assessed by Jacoby's Stigma Scale, a second confirmatory analysis was run in which the items from Jacoby's Stigma Scale were allowed to be associated with both latent traits identified for the SSE. This analysis demonstrated significant associations for Jacoby's Stigma Scale items only on the first latent trait, perceptions of difficulties and prejudices associated with epilepsy. All three items from Jacoby's Stigma Scale had factor loadings > 0.5 for the first trait, but below 0.3 for the second trait. That is, Jacoby's Stigma Scale does not assess self-stigmatization by PWE.

Differential item functioning

The effect of epilepsy disclosure on SSE responses was tested using a differential item functioning analysis. Just over half of adults reported forced disclosure. Differential item functioning was present for items 5 and 13 ($p = 0.001$ and $p = 0.046$, respectively), meaning that PWE who experience forced disclosure endorse feeling more pity (item 5) and greater worry (item 13) when they see an epileptic seizure than PWE who have not experienced forced disclosure. Both items were associated with the second latent trait, suggesting that forced disclosure may be associated with greater negative feelings associated with epilepsy.

Discussion

The distinction between felt and enacted stigma has long been recognized, as has the belief that felt stigma can be present without enacted stigma [9, 11]. Social scientists suggest that this is because felt stigma is influenced by the interpretation of discrimination as well as sentiments associated with epilepsy [14]. Our findings support concerns that Jacoby's Stigma Scale does not capture the latter component of felt stigma [9]. Researchers using this measure for other conditions may need to consider additional instruments.

The SSE identifies both PWE's perception of difficulties and prejudices associated with epilepsy as well as epilepsy-associated sentiments. Although the SSE has been critiqued for including epilepsy's impact on PWE [4], these questions represent PWE's sentiments regarding epilepsy. If these findings are confirmed using other populations, the SSE may provide substantial insight into felt stigma.

The removal of item 1 as well as a correlation between items 2 and 3 suggests that the SSE could be shortened. Previous investigations have attempted to address inter-item correlation; in Bolivia, "scared" was replaced with "shock" [22].

In addition, the standardized stigma score calculation provided by Fernandes et al. [20] does not reflect both aspects of felt stigma assessed by the SSE. Thus, we recommend creating separate scores for the two aspects of felt stigma by summing scores on the salient items associated with each latent trait (i.e., see Table 3).

As all participants were identified through clinics, respondents are not representative of all PWE in this setting due to the sizable number of Zambian PWE who are in need of epilepsy treatment but do not have access to it ("treatment gap"). Individuals not receiving care would be expected to have greater stigma as disease severity is associated with stigma [2]. In addition, the SSE was administered only to PWE, and reliability was not examined. Future research should examine SSE properties when administered to the public to assess stigmatizing attitudes.

Since initiating this study, two additional felt stigma measures have been published. The Kilifi Stigma Scale was developed as a culturally appropriate measure for PWE in Kenya; however, the authors' factor analysis indicated that, like Jacoby's Stigma Scale, only one latent trait is assessed [12]. In addition, the Stigma Scale for chronic illness was developed

to assess stigma associated with neurological conditions in the USA; however, transnational data have yet to be published [26].

Social stigma continues to be a problem for PWE in developed and developing countries. Accurate characterization is essential for stigma reduction interventions to succeed. The SSE appears to capture aspects of felt stigma that were theorized yet never quantified. As a result, this instrument may improve our understanding of epilepsy-associated stigma, especially if it is found to also accurately assess enacted stigma.

Acknowledgments

We would like to acknowledge Mr. Julius Mulenga for his contributions in collecting data for this study. The project described was supported by the Fogarty International Center and the National Institute of Neurological Disorders and Stroke (NINDS) under Award Number 1R01NS061693. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. ME was supported in part by an MD/PhD Fellowship from Spectrum Health and the Lois C. Walker Endowed Fund for Student Research in the Michigan State University College of Human Medicine. GB has received research funds from the Dana Foundation as well as travel funds from the World Health Organization. The remaining authors do not have any additional conflicts of interest to disclose.

References

1. Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: A European perspective. *Epilepsia*. 2000; 41(1):98–104. [PubMed: 10643931]
2. DiIorio C, Osborne Shafer P, Letz R, Henry T, Schomer DL, Yeager K. The association of stigma with self-management and perceptions of health care among adults with epilepsy. *Epilepsy & Behavior*. 2003; 4(3):259–267. [PubMed: 12791327]
3. Atadzhanov M, Haworth A, Chomba EN, Mbewe EK, Birbeck GL. Epilepsy-associated stigma in Zambia: What factors predict greater felt stigma in a highly stigmatized population? *Epilepsy & Behavior*. 2010; 19(3):414–418. DOI: 10.1016/j.yebeh.2010.08.017 [PubMed: 20851056]
4. Jacoby A. Epilepsy and stigma: An update and critical review. *Current Neurology and Neuroscience Reports*. 2008; 8(4):339–344. [PubMed: 18590619]
5. Birbeck G, Chomba E, Atadzhanov M, Mbewe E, Ha-worth A. The social and economic impact of epilepsy in Zambia: A cross-sectional study. *Lancet Neurology*. 2007; 6(1):39–44. DOI: 10.1016/S1474-4422(06)70629-9 [PubMed: 17166800]
6. de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy & Behavior*. 2008; 12(4):540–546. DOI: 10.1016/j.yebeh.2007.12.019 [PubMed: 18280210]
7. Mbuba CK, Abubakar A, Odermatt P, Newton CR, Carter JA. Development and validation of the Kilifi Stigma Scale for Epilepsy in Kenya. *Epilepsy & Behavior*. 2012; doi: 10.1016/j.yebeh.2012.02.019
8. Elafros MA, Mulenga J, Mbewe E, Haworth A, Chomba E, Atadzhanov M, et al. Peer support groups as an intervention to decrease epilepsy-associated stigma. *Epilepsy & Behavior*. 2013; 27(1): 188–192. DOI: 10.1016/j.yebeh.2013.01.005 [PubMed: 23454914]
9. Jacoby A. Felt versus enacted stigma: A concept revisited. Evidence from a study of people with epilepsy in remission. *Social Science and Medicine*. 1994; 38(2):269–274. [PubMed: 8140453]
10. Birbeck G. Interventions to reduce epilepsy-associated stigma. *Psychol Health Med*. 2006; 11(3): 364–366. DOI: 10.1080/13548500600595343 [PubMed: 17130072]
11. Scrambler G, Hopkins A. Being epileptic: Coming to terms with stigma. *Sociology of Health & Illness*. 1986; 8(1):26–43.
12. Mbuba CK, Abubakar A, Odermatt P, Newton CR, Carter JA. Development and validation of the Kilifi Stigma Scale for Epilepsy in Kenya. *Epilepsy & Behavior*. 2012; 24(1):81–85. DOI: 10.1016/j.yebeh.2012.02.019 [PubMed: 22481043]
13. Hyman MD. The stigma of stroke. Its effects on performance during and after rehabilitation. *Geriatrics*. 1971; 26(5):132–141.

14. Jacoby A, Snape D, Baker GA. Epilepsy and social identity: The stigma of a chronic neurological disorder. *Lancet Neurology*. 2005; 4(3):171–178. DOI: 10.1016/S1474-4422(05)01014-8 [PubMed: 15721827]
15. Donkor ES, Sandall J. The impact of perceived stigma and mediating social factors on infertility-related stress among women seeking infertility treatment in Southern Ghana. *Social Science and Medicine*. 2007; 65(8):1683–1694. DOI: 10.1016/j.socscimed.2007.06.003 [PubMed: 17673344]
16. Birbeck G, Kvalsund M, Byers P, Bradbury R, Mang'ombe C, Organek N, et al. Neuropsychiatric and socioeconomic status impact antiretroviral adherence and mortality in rural Zambia. *American Journal of Tropical Medicine and Hygiene*. 2011; 85(4):782–789. [PubMed: 21976587]
17. Bielen I, Friedrich L, Sruk A, Prvan MP, Hajnšek S, Petelin Z, et al. Factors associated with perceived stigma of epilepsy in Croatia: A study using the revised Epilepsy Stigma Scale. *Seizure*. 2013; doi: 10.1016/j.seizure.2013.10.008
18. Rafael F, Houinato D, Nubukpo P, Dubreuil CM, Tran DS, Odermatt P, et al. Sociocultural and psychological features of perceived stigma reported by people with epilepsy in Benin. *Epilepsia*. 2010; 51(6):1061–1068. DOI: 10.1111/j.1528-1167.2009.02511.x [PubMed: 20132293]
19. Reis R, Meinardi H. ILAE/WHO “Out of the Shadows Campaign” Stigma: Does the flag identify the cargo? *Epilepsy Behaviour*. 2002; 3(6S2):33–37.
20. Fernandes PT, Salgado PC, Noronha AL, Sander JW, Li LM. Stigma Scale of Epilepsy: Validation process. *Arquivos de Neuro-Psiquiatria*. 2007; 65(Suppl 1):35–42. [PubMed: 17581666]
21. Kumari P, Ram D, Haque Nizamie S, Goyal N. Stigma and quality of life in individuals with epilepsy: A preliminary report. *Epilepsy & Behavior*. 2009; 15(3):358–361. DOI: 10.1016/j.yebeh.2009.05.003 [PubMed: 19446041]
22. Bruno E, Bartoloni A, Sofia V, Rafael F, Magnelli D, Padilla S, et al. Epilepsy-associated stigma in Bolivia: A community-based study among the Guarani population: An International League Against Epilepsy/International Bureau for Epilepsy/World Health Organization Global Campaign Against Epilepsy Regional Project. *Epilepsy & Behavior*. 2012; 25(1):131–136. DOI: 10.1016/j.yebeh.2012.07.011 [PubMed: 22917806]
23. Embretson, S., Preise, S. Item response theory for psychologists. New Jersey: Lawrence Erlbaum Associates, Inc. Publishers; 2000.
24. Hu L, Bentler P. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*. 1999; 6(1):1–55.
25. Smith R, Rossetto K, Peterson BL. A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care*. 2008; 20(10):1266–1275. DOI: 10.1080/09540120801926977 [PubMed: 18608080]
26. Rao D, Choi SW, Victorson D, Bode R, Peterman A, Heinemann A, et al. Measuring stigma across neurological conditions: The development of the stigma scale for chronic illness (SSCI). *Quality of Life Research*. 2009; 18(5):585–595. DOI: 10.1007/s11136-009-9475-1 [PubMed: 19396572]

Fig. 1.
Scree plot for Stigma Scale of Epilepsy Exploratory Factor Analysis

Fig. 2.
Proportion and Cumulative Proportion of Variance Explained by Each Factor

Table 1

Demographic and clinical information for people with epilepsy completing the Stigma Scale of Epilepsy

Number (%)	Men (<i>n</i> = 38)	Women (<i>n</i> = 30)	Youth (<i>n</i> = 34)
Mean age, years (SD)	32.2 (8.7)	30.4 (9.7)	15.2 (1.9)
Rural location, yes	14 (36)	12 (40)	11 (32)
Marital status			
Never married	19 (50)	9 (30)	–
Currently married (monogamous)	13 (33)	11 (37)	
Currently married (polygamous)	3 (8)	0 (0)	
Previously married ^a	2 (5)	8 (27)	
Remarried	1 (3)	2 (7)	
Educational status (adults: mean years in school; youth: currently in school, yes)	8.2 (SD 3.7)	6.1 (SD 3.3)	27 (80)
Employment status, yes	23 (59)	5 (17)	–
Spouse employment status (if applicable)	3 (18)	11 (85)	–
Median housing quality score (IQR) ^b	11.0 (6.0–12.0)	12.0 (3.0–13.0)	13.0 (6.0–13.0)
Median household wealth in Kwacha ^c	ZMW1,220	ZMW295	ZMW902.50
Median in USD (IQR)	\$358 (52–676)	\$86 (9–256)	\$264 (123–795)
Food insecure ^d	10 (26)	10 (33)	–
Physical stigmata of epilepsy present ^{d, e}	8 (21)	14 (47)	–
Median age of epilepsy onset, years (IQR) ^d	16.5 (8–28)	14.0 (11–20)	–
Most recent seizure			
1 week ago	10 (28)	8 (27)	9 (27)
>1 week ago to 1 month ago	12 (33)	5 (17)	7 (21)
>1 month ago to 1 year ago	8 (22)	9 (31)	7 (21)
>1 year ago	6 (17)	7 (24)	11 (33)
Taking an antiepileptic drug (AED)	37 (97)	28 (93)	32 (94)
Adherent to AED	20 (54)	18 (64)	21 (65)
Disclosure of epilepsy status to community ^d			
Yes, because I told them	8 (20)	5 (17)	–
Yes, because others told them or they saw me have a seizure	19 (49)	19 (63)	
No	11 (28)	6 (20)	
Shona Symptom Questionnaire, mean (SD) ^f	5.0 (3.1)	5.6 (2.6)	5.58 (3.4)
Requiring psychiatric support ^g	18 (46)	20 (67)	15 (43)
Personal safety			
Well, stream or river used as household water source ^h	7 (18)	5 (17)	4 (12)
Kerosene/gas, candles or fire used for household lighting ⁱ	22 (56)	19 (63)	15 (43)
Wood, charcoal or kerosene stove used for cooking ⁱ	23 (59)	20 (67)	14 (40)
Familial physical abuse ^d	6 (15)	12 (40)	–
Rape (women only)	–	4 (13)	–
Transactional sex (women only)	–	3 (10)	–

^a Divorced, widowed, or separated and not remarried

^b A composite score based on a ranked score for three household building materials (walls, roof, and floor; range 0–15)

^c Based on the value of common household items

^d Asked to adults only

^e Primarily visible burn scars, interviewer assessed

^f Instrument that enumerates culturally relevant manifestations of psychiatric symptoms, range 0–14

^g Scores ≥ 5 using the Shona Symptom Questionnaire

^h Proxy measure for increased risk of drowning

ⁱ Proxy measure for increased risk of burns

Table 2

Felt stigma measures using the SSE and Jacoby's 3-item Stigma Scale

Stigma Scale of Epilepsy, number (%)				
	Not at all	A little	A lot	Totally
Question 1: Do you think that people with epilepsy feel able to control their own epilepsy?				
1. Control	39 (38.2)	21 (20.6)	24 (23.5)	18 (17.7)
Question 2: How would you feel when you see an epileptic seizure?				
2. Scared ^a	54 (52.9)	14 (13.7)	16 (15.7)	16 (15.7)
3. Fear ^a	55 (53.9)	15 (14.7)	19 (18.6)	11 (10.7)
4. Sadness ^a	26 (25.4)	10 (9.8)	22 (21.6)	42 (41.2)
5. Pity ^a	4 (3.9)	7 (6.8)	43 (42.2)	46 (45.1)
Question 3: Which difficulties do you think people with epilepsy have in their daily lives?				
6. Relationships ^a	28 (27.4)	24 (23.5)	32 (31.4)	16 (15.7)
7. Work ^a	14 (13.7)	21 (20.6)	42 (41.2)	21 (20.6)
8. School ^a	19 (19)	18 (18)	32 (32)	32 (32)
9. Friendships	23 (23)	29 (28)	35 (34)	15 (15)
10. Sexual ^a	34 (34)	18 (18)	27 (27)	20 (20)
11. Emotional	28 (28)	18 (18)	31 (30)	25 (25)
12. Prejudice	18 (18)	19 (19)	39 (38)	26 (25)
Question 4: How do you think that people with epilepsy feel?				
13. Worried	7 (7)	10 (10)	43 (42)	42 (41)
14. Dependent	38 (37)	16 (16)	30 (29)	18 (18)
15. Incapable	38 (37)	28 (28)	21 (21)	15 (15)
16. Fearful	26 (26)	14 (14)	34 (33)	28 (28)
17. Depressed	24 (24)	25 (25)	34 (33)	19 (19)
18. Ashamed	32 (31)	13 (13)	28 (28)	29 (28)
19. The same as those without epilepsy	68 (67)	10 (10)	6 (6)	18 (18)
Question 5: In your opinion, the prejudice in epilepsy will be related to?				
20. Relationships ^a	29 (29)	22 (22)	33 (33)	16 (16)
21. Marriage ^a	29 (30)	22 (23)	30 (31)	15 (16)
22. Work ^a	15 (15)	19 (19)	36 (37)	28 (29)
23. School	20 (20)	16 (16)	33 (33)	33 (33)
24. Family	41 (40)	25 (25)	23 (23)	13 (13)
Jacoby's 3-item Stigma Scale, number (%)				
"Because of my epilepsy..."				
I feel some people are uncomfortable with me, yes				54 (53)
I feel some people treat me like an inferior person, yes				48 (47)
I feel some people would prefer to avoid me, yes				45 (44)

^aLeft blank by some respondents

Table 3

Item discrimination and difficulties^a

Discriminations		Difficulties			
	Latent trait 1 (se)	Latent trait 2 (se)	Not at all to a little (se)	A little to a lot (se)	A lot to totally (se)
Question 1: Do you think that people with epilepsy feel able to control their own epilepsy?					
1. Control	Not included in model				
Question 2: How would you feel when you see an epileptic seizure?					
2. Scared	Not included in model				
3. Fear	–	1.57 (0.36)	–0.35 (0.26)	–1.26 (0.29)	–2.79 (0.41)
4. Sadness	–	1.86 (0.4)	1.6 (0.34)	0.85 (0.29)	–0.55 (0.27)
5. Pity	–	1.13 (0.29)	3.7 (0.56)	2.56 (0.39)	–0.19 (0.23)
Question 3: Which difficulties do you think people with epilepsy have in their daily lives?					
6. Relationships	–	1.45 (0.31)	1.28 (0.29)	–0.17 (0.24)	–2.25(0.35)
7. Work	0.71 (0.23)	–	1.99 (0.31)	0.69 (0.23)	–1.4 (0.26)
8. School	1.37 (0.31)	–	1.9 (0.33)	0.71 (0.25)	–1.02 (0.26)
9. Friendships	1.33 (0.29)	–	1.55 (0.29)	–0.1 (0.23)	–2.24 (0.34)
10. Sexual	1.84 (0.4)	–	0.91 (0.29)	–0.23 (0.27)	–2.1 (0.39)
11. Emotional	1.48 (0.32)	–	1.3 (0.28)	0.21 (0.24)	–1.56 (0.29)
12. Prejudice	1.28 (0.29)	–	1.97 (0.31)	0.7 (0.24)	–1.4 (0.28)
Question 4: How do you think that people with epilepsy feel?					
13. Worried	–	1.34 (0.29)	3.28 (0.47)	2.13 (0.35)	–0.46 (0.24)
14. Dependent	–	2.03 (0.42)	0.82 (0.3)	–0.32 (0.28)	–2.52 (0.42)
15. Incapable	–	1.78 (0.38)	0.74 (0.27)	–1.02 (0.30)	–2.57 (0.41)
16. Fearful	–	1.43 (0.31)	1.4 (0.28)	0.51 (0.24)	–1.36 (0.29)
17. Depressed	1.08 (0.27)	–	0.94 (0.24)	0.25 (0.22)	–1.14 (0.33)
18. Ashamed	–	1.4 (0.3)	1.52 (0.28)	0.05 (0.24)	–1.98 (0.25)
19. The same as those without epilepsy	–	0.31 (0.24)	1.56 (0.26)	1.19 (0.23)	0.7 (0.21)
Question 5: In your opinion, the prejudice in epilepsy will be related to?					
20. Relationships	1.67 (0.36)	–	1.22 (0.29)	–0.16 (0.26)	–2.39 (0.4)
21. Marriage	1.59 (0.35)	–	1.26 (0.3)	–0.14 (0.26)	–2.33 (0.38)
22. Work	1.01 (0.26)	–	2.01 (0.32)	0.77 (0.24)	–1.08 (0.25)

	Discriminations		Difficulties		
	Latent trait 1 (se)	Latent trait 2 (se)	Not at all to a little (se)	A little to a lot (se)	A lot to totally (se)
23. School	1.16 (0.28)	–	1.71 (0.29)	0.74 (0.24)	–0.89 (0.24)
24. Family	–	1.18 (0.29)	0.43 (0.23)	–0.82 (0.24)	–2.36 (0.35)

^aItem discriminations and difficulties obtained as part of a confirmatory IRT analysis conducted in IRTPRO (version 2.1, Scientific Software International, Inc, Lincolnwood)