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Alarming levels of stigma toward generalized dystonia: A cross-cultural comparison

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ABSTRACT

Introduction: Although stigma has been linked to poor quality of life, studies examining its prevalence in dystonia are lacking. Our objective was to determine prevalence and predictors of stigma against generalized dystonia in diverse cultural settings.

Method: Participants were 273 (65.9% female) patients and visitors approached at primary care clinics from three populations: León, Nicaragua (92 participants); a mostly-Hispanic Clinic in Omaha, NE USA (85 participants); and a mostly-non-Hispanic population in Omaha, Nebraska (96 participants). Participants learned about generalized dystonia, epilepsy and schizophrenia through reading a small vignette and viewing videos, followed by a questionnaire designed to identify stigma. We compared levels of stigma between dystonia and other conditions at different sites and measured variables that could affect them.

Results: Prevalence of stigma was high toward dystonia (33.00%), similar to epilepsy and lower than schizophrenia. The results showed a complex relationship between the studied variables and level of stigma, especially with age. Female gender predicted more stigmatizing answers. Country of origin, level of education and self-identification of Hispanic ethnicity did not affect stigma. Learning more personal information about the dystonia patient decreased dystonia, a proof that unjustified preliminary negative judgment was present.

Conclusions: Stigma against generalized dystonia was very prevalent across all the communities studied. Demographic and socio-cultural variables had different correlations to level of stigma, underlying the complexity of this problem. The alarming levels of stigma against dystonia justify further studies on how to minimize its impact on our patients.

1. Background

Neuropsychiatric disorders are very common, accounting for approximately 13% of the global burden of disease, a problem that is further compounded by the stigma associated with them [1,2]. Stigma affects willingness of patients to seek and adhere to treatment [3], rates of re-hospitalization of patients [4], and contributes to a high treatment gap [5,6]. Our study examines external stigma toward generalized dystonia. Dystonia is a movement disorder characterized by sustained or intermittent muscle contractions causing abnormal, often repetitive movements, postures or both. Dystonic movements can be twisting or tremulous and are often initiated or worsened by voluntary action.

The attributes that lead to stigma can be categorized into three groups: abominations of the body (such as physical illness), perceived blemishes of individual character (such as in mental illness), or tribal stigmas (such as race or gender) [7]. The recognition of an attribute in an individual that is "different" leads to the devaluation of the individual [8]. This devaluation sets the stage for discrimination.

Many factors coincide to make dystonia patients likely subjects of stigma. The level of stigma depends on six dimensions: 1) Concealability, or how detectable the distinguishing attribute is; 2) Course, whether the attribute is life-long or can be reversed; 3) Disruptiveness, how the attribute impacts interpersonal relationships; 4) Aesthetics, whether the attribute elicits a reaction of disgust or is perceived as unattractive; 5) Origin, the

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perceived cause and responsibility of the attribute; and 6) Peril, the degree to which the attribute is perceived as a threat [9]. Dystonia is particularly high in these six dimensions—it is difficult to conceal, lifelong, can disrupt interpersonal relationships, cause physical deformations, it is not well-known by the public, and can be perceived as dangerous. Stigma not only governs how the public reacts to the individual, but can also affect how dystonia patients' see themselves [10].

Studies have shown that stigma is heterogeneous and depends on various cultural, geographical and social factors [11,12]. Furthermore, culture plays a large role in the basis for disease, and diseases must be interpreted in terms of a specific culture [13]. Unfortunately, there is a worldwide dearth of health-related stigma research, especially in developing countries [14].

Some diseases, like schizophrenia and epilepsy, are known to be highly stigmatizing [15–17]. People have a difficult time recognizing mental illness and epilepsy or understanding their nature and possible treatments [18,19]. In terms of dystonia, stigma has been shown in the past to negatively affect the quality of life [20], and mental/physical health, highlighting the importance to study it's prevalence and predicting factors [21]. Furthermore, there is a lack of research from the developing world on how patient experience is affected by stigma [22] [23,24].

This study attempts to measure differences in the prevalence of stigma toward generalized dystonia in two countries (USA and Nicaragua) and compare them with stigma against epilepsy and schizophrenia. We also studied the variables that could affect health-related prejudice, including general demographics, level of education, race, and acquaintance with similar cases.

2. Methods

2.1. Ethics

Data were handled with strict confidentiality and no personal identifiers were recorded. Ethical review and approval was obtained from the Institutional Review Board of the University of Nebraska Medical Center and from the *Facultad de Medicina de la Universidad Nacional de León*, Nicaragua. Participants were invited into this study solely on a volunteer basis. All appropriate permissions were also obtained for all the videos used.

2.2. Sample and flow

Participants were patients, family members and visitors approached at a local primary care clinic. Three locations/populations were studied: one in León, Nicaragua (NIC), one Hispanic population in Omaha, Nebraska (NE-H), and a non-Hispanic population in Omaha, Nebraska (NE-C). NIC is the largest public health center in the city. NE-H is a clinic (OneWorld Medical Center) that cares for mostly uninsured or underinsured patients (including many recent immigrants). NE-C (Oakview Family Medicine Clinic) cares for mostly insured people. All of the clinics were primary care clinics linked with the University of Nebraska Medical Center. These similar clinics were chosen in an attempt to standardize the study population as much as possible and decrease selection bias. Nurses, doctors, administrators, and other clinic workers were excluded from the study.

We selected paranoid schizophrenia and epilepsy to be active controls, due to their known highly stigmatizing nature. Therefore, three cases of patients with epilepsy, paranoid schizophrenia and generalized dystonia -in that order- were used as the basis for the study. The participants first would read the short case vignette followed by watching a video depicting the patient. Then they were asked to complete a 4-item questionnaire (Table 1) for that particular patient, before advancing to the next case.

Videos were used in addition to the written vignettes, as a means to minimize the effect of language choice on the interpretation of an illness. Videos also provided a more natural exposure of a person. All videos depicted young adult patients while being evaluated by health care professionals, in an attempt to standardize the setting. The epilepsy video showed a male patient during inpatient Video Electroencephalography monitoring, first drawing normally, followed by a short seizure and its resolution. The video of the patient with dystonia reveals a male patient with a moderate generalized dystonia in a doctor's office. Both of these videos were muted, and therefore were used for both the Spanish- and English-speaking cohorts. The video of the schizophrenic patient shows a female patient in an acute paranoid psychotic state, being interviewed by her psychiatrist. The patient initially explained her fears, then revealed auditory hallucinations, and finally became unsettled, screaming back at the voices to stop talking to her. Because this case required hearing the interview, our bilingual team developed and acted out a culturally neutral translation of the video, to maximize comparability of results. The contents were reviewed by an experienced Certified Medical Interpreter (bilingual in Spanish and English) who certified that both versions portrayed the same meaning and were culturally neutral (spoken and non-verbal language).

Table 1
Case introduction excerpts and questionnaire.
Prior to viewing each video, participants were read a short preface in their native tongue (English or Spanish). The case introduction described some characteristics about the disease and the patient. Subsequent to viewing the dystonia video, additional social information about this patient was provided and participants were asked to answer the questions again.

Video preface	Epilepsy	This is a lifelong disease. This person suffers from seizures about once a month. In between seizures he is normal. Please answer these questions.
	Schizophrenia	This person has schizophrenia. She has hallucinations and a sensation that people are after her to hurt her. This is a lifelong disease but most patients get better with treatment. Please answer these questions.
	Dystonia, Part 1	This person suffers from a movement disorder, but this person has normal feelings and thinking. Please answer these questions.
	Dystonia, Part 2 (additional info)	This person is married and has four children. He is a mechanic and is the owner of his shop. Please answer the questions again with this new information.
Questions	1	Do you know anyone like this? (Y/N)
	2	Would you be willing to start a conversation with this person? (Y/N)
	3	Would you be willing to rent a room in your house to this person? (Y/N)
	4	Would this person's illness disqualify him/her from running for office? (Y/N)

After viewing the dystonia video and answering the questionnaire, more personal information was provided about this particular patient. The participants read that this patient is married, has four children, is a mechanic and is the owner of his shop. Then, participants were asked to take the questionnaire a second time. The rationale for this was to see if by providing personal information about the patient, the level of stigma would change.

2.3. Questionnaire

The ideal stigma measuring tool for our study needed to include a number of important features. It should not be specific for a particular disease (but allow all neurological disorders to be evaluated in a similar fashion). It also needed to be culturally neutral (the items must apply similarly to different countries). The questionnaire needed to be comprehensive but brief enough to allow enough time for the participants to watch the videos and consider their choices thoroughly while they were waiting to be seen at their medical centers (total acquisition time of <20 min). The wording of the items must allow for them to be written in English and Spanish in a truly culture-neutral fashion. Lastly, the questionnaire needed to be designed to assess external stigma in a general population, as opposed to assessing internal stigma of a population suffering from the disease. Review of the literature revealed the presence of a few scales for measuring stigma; however, no instrument fit the specific requirements of this project. Therefore, a new questionnaire was developed, albeit by adding questions previously used in other stigma studies. Three questions were included that could measure stigma, fulfilling the above criteria. Because knowing

someone with one of the diseases studied could affect stigma, we started the questionnaire asking that question, totaling then 4 items (Table 1). Although for each case the participants were asked these 4 questions, the first item (do you know anyone like this?) was not intended for measuring stigma. Therefore, only 9 items measuring stigma were collected from each participant (3 items for 3 diseases).

2.4. Statistical analysis

Age distribution, gender and level of education comparison between sites was performed with descriptive and Chi square statistics. Binary response variables coded (yes/no) were collected from persons located at three sites (source) and three diseases were evaluated with a generalized linear model with random effects with the site treated as fixed effect and the persons within sites treated as random effect. Comparisons illustrated in the paper are based on this definition of factors. For Questions 2 and 3, a "No" was considered possibly stigmatizing. For Question 4, a "Yes" was considered possibly stigmatizing.

The objective was to compare differences in stigma across levels of these three primary explanatory factors. Also, the differences were evaluated for other secondary between-subjects factors such as gender, level of education, Hispanic self-identification, age (treated as a continuous variable), and knowing someone with disease. Comparisons between sites were done through logistic regression. Since nine stigma responses were collected from each subject, correlations among the responses were accounted for with random subject effects with a generalized linear mixed model. The binary response models for stigma were evaluated with PROC GLIMMIX using SAS/STAT software, v. 9.3 (Cary, NC). Model fit was assessed with the estimation method of quadrature.

For significant interactions, simple effects of one factor were compared across levels of the other factor. Adjustments to *p*-values and confidence intervals for multiple comparisons were made with the simulation technique, the recommended approach for data sources having repeated measures [25]. For the final video, further personal information was provided to assess change of answers after education. The exact McNemar test was used to compare pre-education and post-education survey answers.

3. Results

3.1. Demographics

The sample consisted of a total of 273 participants, 65.93% ($n = 180$) female. Level of education was distributed as those who had not completed high school (26.74%, $n = 73$), those that had completed high school (31.87%, $n = 87$), and those that had education past high school (41.39%, $n = 113$). Age groups fell into those <25 years (21.61%, $n = 59$), those between 25 and 44 years (39.93%, $n = 109$), and those >44 years of age (38.46%, $n = 105$). Substantial variation existed between the three populations (see Table 2). Overall, NE-C had the oldest and Nicaragua the youngest participants. NE-C had the highest level of education and NE-H the lowest. Out of 3276 responses, the participants chose not to complete 51 questions (1.6%), giving a survey response rate of 98.4%.

3.2. Overall stigma

On average, responses indicated stigma in 41.7% (1004 stigmatizing responses vs 1402 non-stigmatizing) of the scenarios. However, the responses varied depending on the type of disease, as well as other variables (see Table 3). As expected, Schizophrenia bears more stigma (mean 63.1%) in all three locations, based on Type III test of fixed effects. However, Dystonia carried a great amount of stigma (mean 33.0%), in all three locations. All comparisons had an adjusted p value of <0.001.

3.3. Differences among sites

The overall level of stigma did not differ significantly by site ($p > 0.5$). However, analyzing by individual diseases within the sites, significant differences existed in three of the nine possible comparisons. NIC showed significantly more stigma than the NE-C site for both Dystonia and Epilepsy. NIC showed significantly more stigma than the NE-H site for dystonia, adding to the complexity of this relationship. The other six possible comparisons were not significantly different ($p > 0.5$ in all cases).

3.4. Gender

In our sample, females were more likely to give a stigmatizing response than males (42.9% vs 34.8%, $p = 0.019$), using Type III test of fixed effects. This held true when stratifying by disease and by location.

3.5. Education

Adjusting for the three sites, the three diseases, and any interaction between these two, level of education had no effect on the level of stigma when comparing less than high school, high school, and post-high school education levels (44.1% vs 37.7% vs 39.5% respectively, $p = 0.34$).

3.6. Age

Age had a significant effect on level of stigma through its interaction with disease ($p = 0.038$) (see Fig. 1). While stigma toward seizure disorders stayed relatively constant as the age of respondents increased (slope of 0.00252), stigma toward dystonia increased (slope of 0.1125) while stigma toward schizophrenia slightly decreased (slope of −0.00745) as the age of respondents increased producing a significant difference between these two slopes of 0.0187 ($p = 0.011$).

Table 2
Demographic variables.
Four demographic variables were obtained: gender, level of education, age, and Hispanic self-identification.

Demographic variables		NE- C	NIC	NE - H	Total
Gender*	Female	60 (62.5%)	60 (65.2%)	60 (70.6%)	180 (65.93%)
	Male	36 (37.5%)	32 (34.8%)	25 (29.4%)	93 (34.07%)
Education**	Less than high school	0 (0%)	32 (34.8%)	41 (48.2%)	73 (26.74%)
	High school	25 (26%)	31 (33.7%)	32 (37.6%)	87 (31.87%)
	Post-high school	71 (74%)	29 (31.5%)	12 (14.1%)	113 (41.39%)
Age**	<25	21 (21.9%)	25 (27.2%)	13 (15.3%)	59 (21.61%)
	25 to 44	24 (25%)	45 (48.9%)	45 (52.9%)	109 (39.93%)
	>44	51 (53.1%)	22 (23.9%)	27 (31.8%)	105 (38.46%)
Hispanic self-identification	Non-Hispanic	91 (94.8%)	N/A	10 (11.8%)	N/A
	Hispanic	5 (0.05%)		75 (88.2%)	

* Gender distribution was similar between sites (p-value = 0.510481).
** The level of education and age were statistically different between sites ($p < 0.00001$ and $P < 0.0001$ respectively). NE-C had higher level of education and older population.

Table 3
Survey responses.
Aggregated survey responses by site, disease, and question number are provided. The number of responses and percentages reflect the number of stigmatizing responses for that particular question.

	Question #	NE-C	NIC	NE-H	Mean stigma by disease
Seizure	2	2	19	10	31.40%
		2.10%	20.70%	11.80%	
	3	37	33	28	
		38.50%	35.90%	32.90%	
	4	34	51	43	
		35.40%	55.40%	50.60%	
Schizophrenia	2	21	35	26	63.10%
		23.10%	38.50%	31.00%	
	3	70	53	63	
		76.90%	58.20%	75.00%	
	4	72	75	72	
		79.10%	82.40%	85.70%	
Dystonia pre-education	2	4	16	9	33.00%
		4.40%	18.00%	10.70%	
	3	29	31	22	
		32.20%	34.80%	26.20%	
	4	42	63	44	
		46.70%	70.80%	52.40%	
Dystonia post-education	2	0	12	6	24.50%
		0.00%	13.50%	7.10%	
	3	18	23	18	
		20.20%	25.80%	21.40%	
	4	30	49	37	
		33.70%	55.10%	44.00%	
Mean stigma by site[a]		33.84%	41.47%	37.63%	

[a] Averaging seizure, schizophrenia, and dystonia pre-education.

3.7. Hispanic ethnicity

There was a significantly higher proportion of Hispanic-identifying respondents at one of the two American sites (88.2% at NE-H vs 5.2% at NE-C). Data were analyzed for effect of ethnic identification on level of stigma. There was no significant difference seen in level of stigma to the three diseases based on Hispanic identification ($p = 0.39$).

3.8. Prior knowledge of a person with the disease

Previous acquaintance with someone having a similar disease had little effect on stigmatizing responses. Knowing someone with schizophrenia reduces stigma by 20% (46.4% vs 66.4%, $p < 0.001$). This did not hold true for dystonia (28.3% vs 31.3%, $p = 0.43$) or for seizure (26.5% vs 30.7%, $p = 0.24$). Site did not play a significant role in this interaction.

3.9. Effect of providing patient's social information on level of stigma

After viewing the generalized dystonia video once, participants were presented with personal information about the patient with dystonia (see Table 1, Dystonia Part 2) and asked to answer the questionnaire again. While there was no significant difference seen in any site for Question 2, significant decrease in level of stigma was seen for Questions 3 and 4 (see Fig. 2). For the third item (would you be willing to rent a room in your house to this person?), NE-C decreased 12% ($p = 0.006$) and NIC ($p = 0.008$) decreased 9%. The decrease for NE-H was only 5% ($p = 0.22$). For the fourth item (would this person's illness disqualify him/her from running for office), NE-H decreased 8% ($p = 0.14$), NE-C decreased 13% ($p = 0.004$), and NIC decreased 15% ($p \leq 0.001$).

4. Discussion

The findings of this study provide new data on the role of demographic and cultural differences in stigma. This study is unique in concurrently assessing stigma toward both neurological and psychiatric diseases in three locations in two countries, using the same tool in two languages. The overall frequency of questions that might be considered stigmatizing was alarmingly high in all settings.

Although the degree of prejudice against patients with generalized dystonia was extremely high, our study found higher levels of stigma toward schizophrenia, a disease known to be a highly stigmatizing [15,16]. We believe that this expected higher level of stigma further validates the questionnaire.

There was no overall difference in stigma between sites, level of education or ethnicity, indicating that there may be less of a cultural influence on stigma than previously thought. Specifically, there was no ethnic group bias for higher level of stigma. Stigma has long been thought to be a culture-specific variable, especially due to the different cultural understandings for the basis of disease. This study shows that there may be less difference between populations than previously expected, a sign that stigma might be an intrinsically human behavior. Moreover, we were surprised that level of education did not affect stigma, indicating that a higher level of education is not protective against developing stigma. In fact, during an informal survey of our neurology department, questionnaire results were similar to those found in the study at-large.

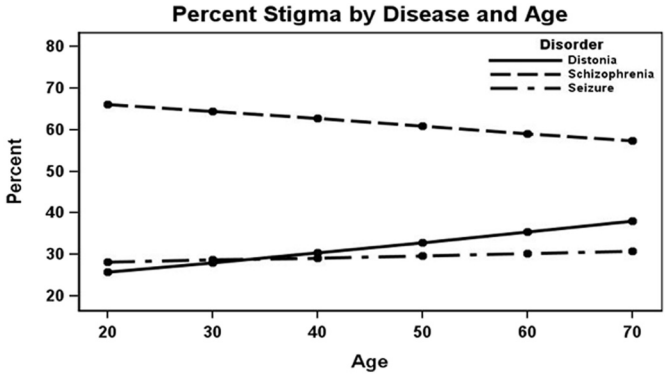

Fig. 1. Age effect on stigma, by disease. Age was treated as a continuous variable and the effect on stigma was assessed. Although overall the effect of age was slight, the effect was significant (p = 0.038). The three diseases showed differing correlations, with the slope of stigmatizing responses toward seizures changing the least (slope of 0.00252). Stigma toward dystonia slightly increased with age, with a slope of 0.1125. Stigma toward schizophrenia slightly decreased with age, with a slope of −0.00745.

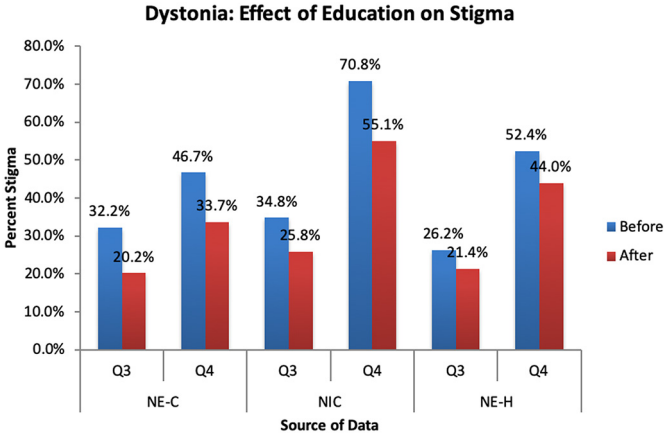

Fig. 2. Dystonia - effect on stigma after learning more about the patient. After viewing the dystonia video once, participants were offered further social information on the patient (see Table 1). The changes in stigmatizing answers to Questions 3 and 4 were significantly different across all three sites. For Question 3, NE-C ($p = 0.006$) decreased 12%, NIC ($p = 0.008$) decreased 9%, and NE-H decreased 5% ($p = 0.22$). For Question 4. NE-H decreased 8% ($p = 0.14$), NE-C decreased 13% ($p = 0.004$), and NIC decreased 15% ($p \leq 0.001$).

Women were more likely to give stigmatizing responses than men for all diseases in all locations, supporting the role of gender differences in stigma. Age had an interesting correlation with level of stigma, which differed for the three diseases. Stigma toward epilepsy stayed relatively stable with age, whereas stigma toward dystonia slightly increased with age and stigma toward schizophrenia slightly decreased with age. While the correlations seen with age were interesting, their overall trend was small.

Providing Information on social history of the dystonic patient significantly decreased stigma. This finding further validates our questionnaire as one that is measuring undue, harsh judgment and stigma, rather than other variables. This also indicates that further community education about the lives of people who suffer from various neurologic and psychiatric disorders could decrease external stigma directed toward these patients. Future studies should focus on determining which of the stigma cultural dimensions might be more helpful in reducing stigma. Studying presence of stigma within populations with high dystonia prevalence could provide further insights into prevention tools.

There are some limitations in this study. This study evaluated only external stigma. Being the first study to compare stigma in two different countries that speak different languages, no previously validated tool was available for use. Also, it is difficult to cover all possible sociocultural variables that affect prejudice, without having a much larger sample. Although the disease-specific stigma variations, and its changes after educating the participants support the questionnaire's validity, we recognize that (as with other survey-based studies) our conclusions reflect only the results produced by the designed questionnaire. Our findings would need to be replicated in the future.

The multitudes of factors that affect stigma against generalized dystonia make it a difficult topic to study. The high prevalence and lack of cultural variation in this study underscores the pervasive role of stigma in our global society. Further studies are needed to better understand stigma against Dystonia across different cultures and the role of community health literacy in decreasing stigma.

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