Stigma and Social Isolation in Patients with Non-Epileptic Seizures

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Introduction

- Stigma is an important barrier to health care engagement and treatment adherence, leading to poor health outcomes[1]
- Although **up to 87%** of patients with non-epileptic seizures (NES) report feeling stigmatized[2], there is a paucity of literature characterizing stigma and its impact on patients with NES
- In addition to prevalence and severity, we examined the association between stigma and sociodemographic characteristics as well as suicidal thoughts and self harm in patients with NES
- Three types of stigma mechanisms were evaluated:
  - Experienced Stigma
  - Perceived Stigma
  - Internalized Stigma

Methods

- Our study used convenience sampling among patients referred to our NES Clinic for treatment
- Patients completed stigma scales after an initial intake appointment at the NES clinic
- Sociodemographic characteristics and reports of suicidal thoughts and self harm were collected via chart review
- Three metrics were used to measure different stigma mechanisms
  - **Internalized Stigma of Mental Illness** (ISMI-9)[3]
  - **Epilepsy Stigma Scale** (ESS)[4] measure perceived and internalized stigma
  - **Neuro-QoL Stigma Form** (Neuro-QoL)[5] measured experienced and internalized stigma

Analyses

- Summary statistics with 95% confidence intervals were presented for stigma scales for the entire sample
- Pearson and Spearman correlation coefficients were calculated for the stigma scales with continuous and ordinal explanatory variables
- Stigma scales were fit to one way ANOVA type models for categorical explanatory variables
- Pair-wise differences in the mean stigma scale among the levels of the explanatory variable were estimated, and the hypothesis of no difference was tested with T-tests

Types of Stigma

	Definition	Sample Metric Questions
Experienced	Discriminatory acts	Because of my illness, people were unkind to me[5]
Perceived	Ideas about societal beliefs	I feel others are uncomfortable with me because of my seizure condition[4]
Internalized	Stereotypes applied to self	I can't contribute anything to society because I have a mental illness[3]

Internalized Stigma Prevalence and Severity

Total N=126

At least mild n=93 (73.8%)

Minimal to none	Mild	Moderate	Severe
n=33 (26.2%)	n=25 (19.8%)	n=27 (21.4%)	n=41 (32.5%)

			ISMI-9		ESS		Neuro-QoL	
Characteristic		**N (%)**	**Mean Score**	**Difference (p)**	**Mean Total**	**Difference (p)**	**Mean T-score**	**Difference (p)**
Gender	Female	100 (79.4)	2.50	-0.19 (0.31)	48.30	-0.99 (0.74)	61.43	1.31 (0.44)
	Male	21 (16.7)	2.69		49.29		60.13	
Ethnicity	Hispanic/Latino	18 (14.5)	2.47	-0.12 (0.57)	51.66	3.22 (0.35)	62.96	1.78 (0.48)
	Not Hispanic/Latino	106 (85.5)	2.59		48.43		61.28	
Race	White/Caucasian	99 (80.5)	2.59	0.03 (0.87)	48.65	-2.17 (0.47)	61.38	1.13 (0.60)
	Not White/Caucasian	24 (19.5)	2.56		50.82		62.52	
Insurance	Public	76 (60.4)	2.59	0.07 (0.60)	48.07	-1.73 (0.45)	61.79	1.12 (0.42)
	Private	50 (39.6)	2.51		49.80		60.66	
Education	< 4-Year College	96 (78.1)	2.63	0.25 (0.15)	49.26	0.83 (0.76)	62.23	2.88 (0.09)
	≥ 4-Year College	27 (22.0)	2.38		48.43		59.35	
Employed	Yes	55 (45.1)	2.38	-0.30 (0.02)**	46.33	-4.35 (0.07)	59.93	-2.58 (0.07)
	No	67 (54.9)	2.69		50.68		62.51	
Relationship Status	Single	52 (46.0)	2.75	0.28 (0.05)**	52.15	5.0 (0.05)**	62.61	1.59 (0.31)
	Relationship	61 (54.0)	2.47		47.18		61.02	
Driving Status	Driving	36 (28.6)	2.40	-0.24 (0.11)	45.08	-5.53 (0.05)**	59.13	-3.37 (0.02)**
	Not Driving	89 (70.6)	2.64		50.61		62.50	
NES-Epilepsy	Yes	26 (20.6)	2.43	-0.16 (0.36)	47.84	-1.16 (0.67)	59.60	-2.17 (0.14)
	No	100 (79.4)	2.59		48.99		61.77	
Self-Harm Behavior	Yes	55 (43.7)	2.66	0.11 (0.44)	48.93	-0.84 (0.74)	62.91	2.52 (0.11)
	No	58 (46.0)	2.54		49.75		60.39	
Suicidal Thoughts	Yes	83 (65.9)	2.69	0.38 (0.03)**	49.67	2.18 (0.46)	62.31	2.50 (0.15)
	No	34 (27.0)	2.31		47.49		59.81	
Suicide Attempt	Yes	46 (36.5)	2.68	0.16 (0.25)	49.44	0.73 (0.78)	63.08	2.66 (0.09)
	No	68 (54.0)	2.51		48.70		60.42	

**Statistically Significant

References

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Results

- **126 patients** enrolled and submitted stigma scales after an initial intake appointment at the NES clinic
- Stigma on ISMI-9
  - **73.8%** of patients felt at least a mild amount of internalized stigma and 32.5% of all patients felt severe internalized stigma on ISMI-9
  - Of patients who reported some amount of stigma, **44.1%** of patients reported **severe** levels of internalized stigma
  - Higher levels of internalized stigma were associated with
    - **Suicidal thoughts** (p=0.03)
    - **Single relationship status** (p=0.05)
    - **Unemployment** (p=0.02)
- Stigma on ESS
  - Patients reported a mean total score of 4.9 (SD 1.4) on the ESS, which was higher than the literature-defined neutral score of 4
  - On the perceived stigma subscale, patients reported a mean score of 4.8 (SD 1.4)
  - On the internalized stigma subscale, patients reported a mean score of 4.9 (SD 1.5)
  - Higher levels of stigma were associated with
    - **Single relationship status** (p=0.05)
    - **Not driving** (p=0.05)
- Stigma on Neuro-QoL
  - Patients rated a mean T- score of 61.3, which was 1SD above a clinical reference population
  - Higher levels of stigma were associated with
    - **Not driving** (p=0.02)

Conclusions

- Engagement in social networks, driving, and employment are important components in health and quality of life[6], and socially isolating factors were associated with higher levels of stigma across all three stigma metrics
- Internalized stigma is prevalent, severe, and associated with both socially isolating factors and suicidal thoughts
- Understanding stigma associated with NES may elucidate targets to improve quality of life for patients with NES
- Future studies should further examine the impact of stigma on quality of life and the role of group-based interventions in mitigating perceived and internalized stigma