



Internal Stigmatization and Mental Health in Patients with Stroke

İnmeli Hastalarda İnternal Stigmatizasyon ve Mental Durum

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Abstract

Objective: Patients with neurological disorders may experience emotional, cognitive and physical impairments. The previous survey studies showed stigmatization in stroke patients but unique to our study we have evaluated stigma in our stroke patient population according to their physical functional impairments.

Materials and Methods: This prospective cross sectional study was performed in the Outpatient Stroke Clinics of University of Health Sciences Turkey, Antalya Training and Research Hospital between 1 April 2020 and 1 September 2020. The patients were included if the patient experienced a stroke at least one year prior and a modified Rankin score (mRS) of 0 or 1. We applied the stigmatization scale and the general health questionnaire (GHQ) to our study population.

Results: A total of 89 (70 males, 19 females) patients were included. The mean age was 58+/-9.45. Except the stigma resistance subscale (p=0.721), there was a statistically significant difference between the alienation (p=0.01), the stereotype endorsement (p=0.02), the discrimination experience (p=0.01), and the social withdrawal (p=0.04), in mRS1 patients. In the group of mRS score of 1, the alienation (with diabetes mellitus (DM) 13.0±3.6, without DM 10.4±3.4, p=0.03) and the overall stigmatization (with DM 70.9±15.7, without DM 60.6±13.8, p=0.04) score was statistically significant in the diabetic population. There was a statistically significant correlation between GHQ and internalized stigma mean overall of score internalized stigma (r=0.435 p=0.01).

Conclusion: The strategies for correcting internalized stigma may be effective to improve the quality of life and negative health perception in stroke patients.

Keywords: Alienation, internal stigmatization, stigmatization, stroke, quality of life

Öz

Amaç: Nörolojik hastalığa sahip hastalarda emosyonel, bilişsel ve fiziksel yetersizlik meydana gelir. Daha önceden inmeli hastalarda stigmatizasyon değerlendirilmiş olmakla beraber bizim çalışmamıza özgü olarak hastaların fiziksel durumlarına göre bir değerlendirme yapılmıştır.

Gereç ve Yöntem: 1 Nisan-1 Eylül 2020 tarihleri arasında Sağlık Bilimleri Üniversitesi, Antalya Eğitim Araştırma Hastanesi İnme Polikliniği'ne başvuran hastalar çalışmaya prospektif olarak alınmıştır. En az 1 yıl önce inme geçirmiş olan modifiye Rankin skoru (mRS) 0 veya 1 olan hastalar çalışmaya dahil edildi. Genel sağlık anketi (GSA) ve stigmatizasyon testi hastalara verildi.

Bulgular: Toplam 89 hasta çalışmaya alındı (70 erkek, 19 kadın). Ortalama yaş 58+/-9.45 yılıdır. Stigma direnç alt skalası hariç (p=0,721); yabancılaşma (p=0,01), stereotip onay (p=0,02), ayrımcılık tecrübesi (p=0,01) ve sosyal çekilme (p=0,04) mRS 1 olan grupta anlamlı olarak daha yüksekti. mRS 1 olan hastalarda yabancılaşma skoru [diabetes mellitus (DM) olanlarda 13,0±3,6, DM olmayanlarda 10,4±3,4, p=0,03] ve toplam stigmatizasyon skoru (DM olanlarda 70,9±15,7, DM olmayanlarda 60,6±13,8, p=0,04) DM olan hastalarda anlamlı olarak daha yüksekti. GSA ile internal stigmatizasyon ve toplam stigmatizasyon skorları arasındaki ilişki de istatistiksel olarak anlamlıydı (r=0,435, p=0,01).

Sonuç: İnme hastalarında internal stigmatizasyonun iyileştirilmesi yaşam kalitesini artırır ve olumsuz hastalık algısını önler.

Anahtar Kelimeler: Yabancılaşma, internal stigmatizasyon, stigmatizasyon, inme, yaşam kalitesi

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Introduction

Patients with neurological disorders may experience emotional, cognitive, and physical impairments, which may cause stigmatization of social experiences when observed by others.

The literature reported many articles that evaluated the stigma in patients with epilepsy and mental disorders, but literature is sparse in evaluating the association between stigma and stroke (1). The most important obstacle to achieve the best results in post-stroke treatment may be stigma, which can lead to unfavorable results and may be an important obstacle in reaching therapy (2).

Another dimension of stigmatization is “internalized or felt” stigma in which the individual feels stigmatized although others do not. The individual develops an expectation of fear that other people will discriminate. Society’s devaluing or discriminatory attitudes are internalized by the patient and this situation causes discrimination or rejection by others. The internalized stigmatization hinders the coping strategies of the individual by the social stigma (3). Stigma restrains individuals’ social adaptation, which contributes to decreased functionality of occupation and even unemployment and may hinder individuals’ tendency for treatment (4).

Previous survey studies showed stigmatization in patients with stroke, but unique to our study is the evaluation of stigma in patients with stroke according to their physical functional impairments.

Materials and Methods

This prospective cross-sectional study was conducted in the outpatient stroke clinics of University of Health Sciences Turkey, Antalya Training and Research Hospital between April 1, 2020, and September 1, 2020. Patients who experienced a stroke at least 1 year prior and with a modified Rankin Score (mRS) of 0 or 1 were included. Patients with mRS of ≥ 2 were excluded.

The stigmatization scale and the general health questionnaire (GHQ) were applied to our study population. The stigmatization scale is a Likert-type scale that includes 29 items that measure internalized stigmatization. This scale includes 5 subscales as alienation (5 scales), stereotype endorsement (7 items), discrimination experience (5 items), social withdrawal (6 items), and stigma resistance (5 items) (2).

The stigma scale value varies between 4 and 91. The higher scores on the scale mean severe internalized stigmatization. The GHQ is a self-administered test to detect diagnosable psychiatric disorders (5,6).

Written informed consent was obtained from all study participants. The study was conducted following the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments, and the University of Health Sciences Turkey, Antalya Training and Research Hospital review board approved the study protocol (IRB approval date:13/02/2020, decision number: 3/24).

Statistical Analysis

The study data were analyzed using the Statistical Package for the Social Sciences version 21.0 for Windows (SPSS Inc., Chicago, IL). Demographic and baseline characteristics were summarized as a mean \pm standard deviation for continuous variables and as a percentage of the group for categorical variables. Non-normally

distributed data are presented as medians (interquartile range). Student’s t-test and One-Way variance analysis were used in cases where parametric test assumptions were provided. Additionally, correlation analysis was applied for relational statistics.

Results

A total of 89 (70 males and 19 females) patients were included in this study. The mean age of the study population was 58 ± 9.45 years. The demographics of the study population are presented in Table 1.

Except for the stigma resistance subscale, a statistically significant difference was found between the alienation, stereotype endorsement, discrimination experience, and social withdrawal in patients with mRS of 1 as presented in Table 2.

No statistically significant difference was found between the mean internalized stigma scale points and gender and education status (female; 62.1 ± 12.8 , male; $56, 7.1 \pm 14.6$, $p=0.364$). No statistically significant difference was found in gender and education status in patients with mRS of 0 and 1.

Patients with mRS score of 0 had no statistically significant difference between the mean internalized stigma scale points and diabetes mellitus (DM). The group with mRS scores of 1 had a statistically significant alienation (with DM 13.0 ± 3.6 , without DM 10.4 ± 3.4 , $p=0.03$) and overall stigmatization (with DM 70.9 ± 15.7 , without DM 60.6 ± 13.8 , $p=0.04$) score in patients

Table 1. Demographic properties

	Number (n)	Percentage (%)
Gender		
Female	19	(21.3)
Male	70	(78.7)
Education status		
Primary school	37	(41.6)
Secondary school	5	(5.6)
High school	34	(38.2)
University	13	(14.6)
Smoking habits	19	(21.3)
Chronic diseases		
Diabetes mellitus	36	(40.4)
Hypertension	73	(82.0)
Chronic kidney failure	2	(2.2)
Hyperlipidemia	31	(34.8)
Atrial fibrillation	8	(9.0)
Previous stroke	1	(1.1)
Coronary artery disease	4	(4.5)
Gout disease	1	(1.1)
SSRI use	7	(7.9)
Global stroke alliance		
≤ 2	63	70.8
> 2	26	29.2

SSRI: Selective serotonin reuptake inhibitor

Table 2. The distribution of internalized stigma scale points

	mRS: 0 Mean ± SD	mRS: 1 Mean ± SD	p value*
Total point	54.3±10.8	65.9±15.53	0.01
Alienation	9.5±2.9	11.7±3.7	0.01
The stereotype endorsement	10.9±3.70	13.9±3.9	0.02
The discrimination experience	8.1±3.3	10.6±4.9	0.01
The social withdrawal	9.3±2.9	13.0±7.2	0.04
The stigma resistance	16.8±3.7	16.5±3.2	0.721
GHQ	1.2±1.8	3.4±3.5	0.01

*Student t-test, Sd: Standatd deviation, mRS: Modified Rankin score, GHQ: General health questionnaire

with DM. The group with mRS of 0 had no statistically significant difference between the mean overall stigmatization score and the presence of DM.

A statistically significant correlation was found between GHQ and internalized stigma mean overall score of internalized stigma (r=0.435, p=0.01). The stigma resistance was the only subscale that showed a statistically significant association with GHQ as presented in Table 3.

Discussion

Our study results revealed a parallel high level of internalized stigmatization and mental illnesses in 89 patients who had a stroke. A relationship was found between DM and the obviousness of stigmatization.

Patients who had a stroke often undergo a major disruption in their life course, causing changes in their self-concept. Patients with stroke, especially with disabilities, may see stroke as a more important burden to their current health status, which leads to the negative perception of physical, psychological, and social effects (7).

Internalized stigmatization led to the acceptance of negative stereotypes in society, thus individual withdraws from society with negative emotions, such as worthlessness and shame. Internalized stigmatization makes it difficult for individuals with mental illness to cope with stigmatization in society (2).

Previous studies showed that the participation of a stigmatized person in perceived negative public attitudes leads to self-stigma or internalized stigma (8). People with physical disabilities face discrimination and stigmatization in different life domains, such as employment, socialization, education, and personal relationships. The majority of stroke survivors (75%) do not fully recover, of which 25% experience a minor disability and 40% experience moderate to severe disabilities (9).

Patients with stroke who have a chronic process with such a high disability rate often suffer a great deterioration in the course of life and lead to self-concept changes. A study in patients with stroke revealed that approximately 80% of patients experienced mild to moderate stigma, 14.5% (enacted stigma) accused themselves as the reason for stroke, and 13% were embarrassed by their physical limitations (internalized stigma) (1,7). Internalization of stigma in society leads to serious individual abuse (10).

The study of Zhu et al. (7) published in 2019 used the stroke stigma scale and revealed that this scale is a reliable and valid tool

Table 3. Relationship between GHQ and internalized stigma

Internalized stigma	GSA
Total point	0.435 (p=0.01)
Alienation	0.463 (p=0.01)
The stereotype endorsement	0.400 (p=0.01)
The discrimination experience	0.245 (p=0.02)
The social withdrawal	0.327 (p=0.02)
The stigma resistance	0.028 (p=0.79)

GSA: Global stroke alliance, GHQ: General health questionnaire

for measuring perceived stigma in patients with stroke. Unlike the stigma scale for chronic disease, this scale evaluated perceived stigma using physical impairment, social isolation, the experience of discrimination, and internalized stigma. Our study adopted the Turkish version of the internalized stigma scale (8) in mental illnesses developed by Ritsher et al. (4) in patients with stroke and internalized stigma was evaluated only in the form of alienation, confirmation of stereotypes, perceived discrimination, and social withdrawal subgroups. Additionally, the comparison of the groups with mRS of 0 and 1 revealed a statistically significantly higher total score in the group with mRS of 1 from all 5 sub-dimensions except for stigma resistance.

Our study revealed a relationship between DM and stigmatization. In cases with mRS of 1, a relationship was found in the group with DM in alienation subscale and total stigmatization. A potentially important consequence of living with DM is the negative social evaluation or social stigma. Internalized stigmatization is depicted by the feelings, emotions, and self-judgments of people with DM, and is particularly evident in patients with type 2 DM, expressing feelings of failure, guilt, and blame (11).

A statistically significant correlation was found between the total scores of the GHQ and the internalized stigmatization scale. These results indicate that internalized stigmatization and general

health and mental illnesses are parallel to each other and are compatible with the mental illnesses results (12).

Study Limitations

Our study has several limitations. The design of the study is descriptive. The patients are from a single tertiary care center. The number of participants studied is fairly good; however, taking this into account when generalizing the results to society is useful. The evaluation of findings postulated that the strategies for correcting internalized stigma may be effective to improve the quality of life and negative health perception in patients with stroke. Studies in psychiatric diseases support the notion that such interventions can positively affect the treatment results and quality of life (13).

Conclusion

In conclusion, cured internalized stigma is crucial for patients with stroke, as well as general health. Multicenter studies will be much more demonstrative in evaluating these conditions.

Ethics

Ethics Committee Approval: University of Health Sciences Turkey, Antalya Training and Research Hospital review board approved the study protocol (IRB approval date:13/02/2020, decision number: 3/24).

Informed Consent: Written informed consent was obtained from all study participants.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: E.Ö.G., Concept: E.Ö.G., Ş.D.K., Design: E.Ö.G., Data Collection or Processing: E.Ö.G., Ş.D.K., Analysis or Interpretation: E.Ö.G., Ş.D.K., Literature Search: E.Ö.G., Ş.D.K., Writing: Ş.D.K.

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References

1. Sarfo FS, Nichols M, Qanungo S, et al. Stroke-related stigma among West Africans: Patterns and predictors. *J Neurol Sci* 2017;375:270-274.
2. Corrigan PW. The impact of stigma on severe mental illness. *Cognitive Behavior Practice* 1998;5:201-222.
3. Perlick DA, Rosenheck RA, Clarkin JF, et al. Stigma as a barrier to recovery: Adverse effects of perceived stigma on social adaptation of persons diagnosed with bipolar affective disorder. *Psychiatr Serv* 2001;52:1627-1632.
4. Ritsher JB, Otilingam PG, Grajales M. Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Res* 2003;121:31-49.
5. Goldberg DP, Hillier VE. A scaled version of the General Health Questionnaire. *Psychol Med* 1979;9:139-145.
6. Ozdemir H, Rezaki M. Depresyon Saptanmasinda Genel Sağlık Anketi-12 [General Health Questionnaire-12 for the detection of depression]. *Türk Psikiyatri Derg* 2007;18:13-21. Turkish.
7. Zhu M, Zhou H, Zhang W, et al. The stroke stigma scale: a reliable and valid stigma measure in patients with stroke. *Clin Rehabil* 2019;33:1800-1809.
8. Ersoy MA, Varan A. Reliability and validity of the Turkish version of the internalized stigma of mental illness scale. *Türk Psikiyatri Dergisi* 2007;18:163-171.
9. Anderson S, Whitfield K. Social identity and stroke: 'they don't make me feel like, there's something wrong with me'. *Scand J Caring Sci* 2013;27:820-830.
10. Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology* 2011;37:363-385.
11. Schabert J, Browne JL, Mosely K, Speight J. Social stigma in diabetes: a framework to understand a growing problem for an increasing epidemic. *Patient* 2013;6:1-10.
12. Alonso J, Buron A, Rojas-Farreras S, et al. Perceived stigma among individuals with common mental disorders. *J Affect Disord* 2009;118:180-186.
13. Wade NG, Post BC, Cornish MA, Vogel DL, Tucker JR. Predictors of the change in self-stigma following a single session of group counseling. *J Couns Psychol* 2011;58:170-182.