

Stigma as a Barrier to Treatment: Evidence from the National Health and Wellness Survey

EPH221

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Introduction

- Stigmatized conditions (e.g., obesity, sexually transmitted diseases, visible skin conditions, mental health conditions, etc.) are often underdiagnosed and undertreated.¹
- Stigmatized conditions may be sources of shame for patients.^{2,3}
- As such, disease stigmatization may act as a barrier to proper diagnosis and treatment uptake.⁴

Objective

We assessed the association between stigmatization, proper diagnosis, and treatment uptake across a variety of stigmatized conditions in a nationally representative real-world dataset.

Methods

- Data from the 2023 US National Health and Wellness Survey, a cross-sectional, nationally representative, general population survey, were used.
- Disease-specific stigmatization was assessed with a self-report Likert-type three-item composite scale (anchored at 1 “Not at all” and 7 “Very much so”).
 - Stigma scale items:
 - “Do you feel **embarrassed** to have this condition?”
 - “Do you think that others **judge you negatively** if they know you have this condition?”
 - “Do you think that others **treat you negatively** if they know you have this condition?”
- Associations between self-reported stigmatization and outcomes of interest (i.e., proper diagnosis and treatment uptake) were assessed with Spearman correlations without adjustment for covariates.

Results

Table 1. Sample characteristics

- Analyses included 75,007 respondents, with a focus on respondents who reported at least 1 of 22 stigmatized health conditions (Table 1).

Demographics																						
	Stigmatized Conditions																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
N	2,002	347	1,754	4,116	1,586	2,429	20,653	3,437	1,568	6,980	608	1,282	14,086	1,136	3,909	4,309	1,975	4,033	5,221	996	1,957	1,322
Age; mean ± SD	44.9 ± 15.4	40.3 ± 13.1	44.4 ± 16.3	38.2 ± 13.5	39.9 ± 13.7	42.3 ± 16.2	42.3 ± 16.3	51.3 ± 16.9	40.7 ± 14.4	41.3 ± 16.6	44.6 ± 15.2	40.7 ± 13.9	39.8 ± 15.2	40.4 ± 14.1	38.2 ± 14.7	39.5 ± 15.0	36.3 ± 14.5	47.9 ± 17.2	40.6 ± 15.0	37.9 ± 13.0	42.5 ± 15.5	47.5 ± 17.4
Female (%)	49.2	27.7	58.0	56.9	38.8	52.0	64.4	100.0	45.3	63.9	23.8	47.9	70.0	44.5	65.0	70.2	67.0	51.4	71.1	43.6	44.8	51.7
Race/ Ethnicity (%)																						
African-American	22.5	13.8	12.1	17.7	10.8	11.7	14.6	10.1	14.5	16.7	26.0	14.7	12.6	12.9	9.2	10.1	12.7	8.6	12.3	22.9	11.4	14.4
American Indian	0.3	0.0	0.9	1.4	0.7	0.6	1.0	0.8	1.1	0.6	1.2	0.5	0.8	0.7	1.2	1.3	1.3	0.7	1.4	1.2	0.9	0.5
Asian	4.8	2.0	7.2	3.1	3.3	6.4	4.1	3.5	3.1	7.8	3.0	3.1	5.1	3.3	4.1	3.3	4.9	5.0	2.9	4.0	3.6	3.9
Hispanic	18.3	19.6	15.2	19.5	20.5	17.4	14.8	10.9	18.2	15.3	19.2	20.8	16.4	21.9	17.6	17.5	18.5	15.3	16.0	20.6	20.4	16.6
White	50.3	62.2	60.1	52.3	61.9	59.0	60.1	70.6	58.6	54.4	46.2	58.1	59.6	57.6	61.4	61.3	55.7	65.2	59.0	43.4	61.0	59.8
Mixed	2.4	1.4	2.9	4.7	2.0	3.6	4.1	3.2	2.9	3.8	2.6	1.4	4.0	1.9	5.0	5.0	5.4	3.8	6.3	5.6	1.9	3.0
Other	1.2	0.9	1.5	1.2	0.8	1.3	1.3	0.8	1.7	1.4	1.8	1.3	1.5	1.7	1.6	1.6	1.5	1.4	2.0	2.3	0.7	1.8

Table 2. Overall Stigmatization & Diagnostic Status

Diagnosis																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
All stigmatization (composite score)	-.07	.05	-.22	.03	-.30	-.21	.07	-.25	-.29	-.10	-.01	-.44	.02	-.39	.09	.06	.14	-.15	.06	.12	-.34	-.12

Spearman correlations (ρ) between the three-item composite stigma score and diagnostic status are displayed, wherein diagnostic status is dummy coded (0=still undiagnosed; 1=diagnosed)

Table 3. Overall Stigmatization & Treatment Uptake

Treatment Uptake																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
All stigmatization (composite score)	.15	.04	-.04	.05	-.18	-.08	-.02	.14	-.14	-.02	-.03	-.25	-.06	-.26	.08	.05	.13	-.01	.09	.12	-.16	.07

Spearman correlations (ρ) between the three-item composite stigma score and treatment status are displayed, wherein treatment status is dummy coded (0=untreated with Rx; 1=treated with Rx)

- Barriers:** Negative associations between stigma and diagnostic status/treatment uptake, with a magnitude of $p < .10$ are highlighted in red, wherein stigma may act as a *barrier* to proper care (Tables 2-3).
- Drivers:** Positive associations between stigma and diagnostic status/treatment uptake, with a magnitude of $p > .10$ are highlighted in green, wherein stigma may act as a *driver* to proper care (Tables 2-3).

Conclusions

- These results suggest that there is meaningful variation in the extent to which health conditions are stigmatized.
- Stigma may act as a barrier to proper diagnosis and treatment uptake.
- However, the magnitude (and even the direction) of this association varies by health condition and type of stigmatization. Perhaps most notably (and contrary to predictions), stigma can simultaneously act as a *barrier* to diagnosis and subsequently as a *driver* to treatment uptake in some contexts (e.g., alopecia, phobias, schizophrenia, etc).
- Future studies may choose to focus on the identification of factors that systematically determine if stigma acts as a driver or barrier to proper diagnoses and treatment uptake.
- In addition, as many individuals remain unnecessarily undiagnosed or untreated for their stigmatized condition, future studies may be well-served by quantifying the extent to which stigmatization versus other more commonly assessed factors (e.g., transportation, income, literacy) act as barriers to care.

Table 4. Embarrassment & Diagnostic Status

Diagnosis																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
Embarrassment score	-.04	.00	-.18	-.03	-.23	-.15	.03	-.26	-.28	-.08	-.14	-.41	-.01	-.37	.07	.03	.12	-.12	.02	.04	-.24	-.09

Spearman correlations (ρ) between the single-item embarrassment score and diagnostic status are displayed, wherein diagnostic status is dummy coded (0=still undiagnosed; 1=diagnosed)

Table 5. Embarrassment & Treatment Uptake

Treatment Uptake																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
Embarrassment score	.11	-.01	-.03	.01	-.11	-.05	.00	.12	-.13	.03	-.14	-.24	.03	-.25	.07	.04	.14	.01	.08	.06	-.09	.07

Spearman correlations (ρ) between single-item embarrassment score and treatment status are displayed, wherein treatment status is dummy coded (0=untreated with Rx; 1=treated with Rx)

- Barriers:** Negative associations between embarrassment and diagnostic status/treatment uptake, with a magnitude of $p < .10$ are highlighted in red, wherein stigma may act as a *barrier* to proper care (Tables 4-5).
- Drivers:** Positive associations between embarrassment and diagnostic status/treatment uptake, with a magnitude of $p > .10$ are highlighted in green, wherein stigma may act as a *driver* to proper care (Tables 4-5).

Table 6. Negative Judgment from Others & Diagnostic Status

Diagnosis																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
Judgment score	-.05	.12	-.21	.08	-.28	-.20	.08	-.25	-.26	-.11	.10	-.39	.02	-.36	.11	.07	.13	-.15	.07	.19	-.33	-.11

Spearman correlations (ρ) between the single-item judgment score and diagnostic status are displayed, wherein diagnostic status is dummy coded (0=still undiagnosed; 1=diagnosed)

Table 7. Negative Judgment from Others & Treatment Uptake

Treatment Uptake																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
Judgment score	.12	.11	-.02	.07	-.18	-.07	.03	.12	-.12	.01	.09	-.21	.06	-.23	.09	.05	.12	-.03	.08	.15	-.17	.06

Spearman correlations (ρ) between the single-item judgment score and treatment status are displayed, wherein treatment status is dummy coded (0=untreated with Rx; 1=treated with Rx)

- Barriers:** Negative associations between judgment from others and diagnostic status/treatment uptake, with a magnitude of $p < .10$ are highlighted in red, wherein stigma may act as a *barrier* to proper care (Tables 6-7).
- Drivers:** Positive associations between judgment from others and diagnostic status/treatment uptake, with a magnitude of $p > .10$ are highlighted in green, wherein stigma may act as a *driver* to proper care (Tables 6-7).

Table 8. Poor Treatment from Others & Diagnostic Status

Diagnosis																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
Treatment score	-.09	.03	-.24	.04	-.33	-.25	.07	-.24	-.28	-.12	.03	-.44	.01	-.38	.06	.05	.12	-.18	.06	.11	-.39	-.16

Spearman correlations (ρ) between the single-item treatment score and diagnostic status are displayed, wherein diagnostic status is dummy coded (0=still undiagnosed; 1=diagnosed)

Table 9. Poor Treatment from Others & Treatment Uptake

Treatment Uptake																						
	Stigmatized Condition																					
	Alopecia Areata	AIDS	Atopic Derm	Bipolar Disorder	Crohn's Disease	Dermatitis	Depression	Endometriosis	Epilepsy	Eczema	HIV	Lupus	Migraine	MS	OCD	Panic Disorder	Phobias	Psoriasis	PTSD	Schizophrenia	Ulcerative Colitis	Vitiligo
Treatment score	.11	.02	-.05	.05	-.21	-.10	.02	.11	-.15	.00	.01	-.24	.05	-.25	.06	.03	.09	-.04	.08	.10	-.20	.06

Spearman correlations (ρ) between the single-item treatment score and treatment status are displayed, wherein treatment status is dummy coded (0=untreated with Rx; 1=treated with Rx)

- Barriers:** Negative associations between poor treatment from others and diagnostic status/treatment uptake, with a magnitude of $p < .10$ are highlighted in red, wherein stigma may act as a *barrier* to proper care (Tables 8-9).
- Drivers:** Positive associations between poor treatment from others and diagnostic status/treatment uptake, with a magnitude of $p > .10$ are highlighted in green, wherein stigma may act as a *driver* to proper care (Tables 8-9).

References

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