The Prevalence of Undiagnosed and Untreated Stigmatized Conditions: Evidence from the National Health and Wellness Survey

Nate Way and Halley Costantino

Cerner Enviza, an Oracle company, Kansas City, MO, USA

Cerner Enviza
an Oracle company

EPH259

Introduction

- Certain conditions carry stigma and are sources of **shame** for patients (e.g., obesity, sexually transmitted diseases (STDs), visible skin conditions, mental health conditions, etc.).[1,2]
- Psychological factors come into play in these disease areas, and these impact behaviors (e.g., treatment uptake reluctance and hesitation to initially go to healthcare provider [HCP] for a diagnosis).[3,4]
- Consequently, stigmatized conditions may be underdiagnosed and undertreated.
- Research on missed diagnosis and treatment uptake within stigmatized treatment areas is lacking.

Objective

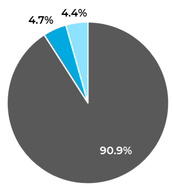
- To assess the prevalence of missed diagnosis and poor treatment uptake across a variety of stigmatized treatment areas.

Results

- Prevalence estimates are derived from the aggregate survey sample (N=75,261) and are presented in **Figures 1 through 19**.

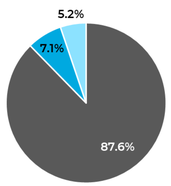
Figures 1-19. Demographics and Clinical/Health Characteristics among Unmatched Cohorts

Narcolepsy



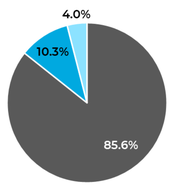
Aggregate sample includes those who self-report they "experienced" narcolepsy in the past 12 months (N=2,579).

Premature Ejaculation (males only)



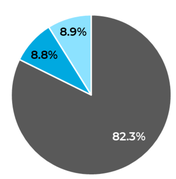
Aggregate sample includes those who self-report they "experienced" premature ejaculation in the past 12 months (N=3,478).

Celiac Disease



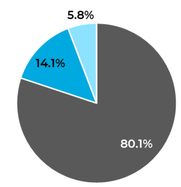
Aggregate sample includes those who self-report they "experienced" celiac disease in the past 12 months (N=2,498).

Muscular Dystrophy



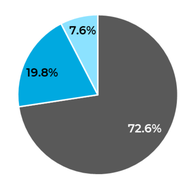
Aggregate sample includes those who self-report they "experienced" muscular dystrophy in the past 12 months (N=862).

Chronic Hives



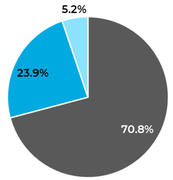
Aggregate sample includes those who self-report they "experienced" chronic hives in the past 12 months (N=2,398).

Chronic Cough



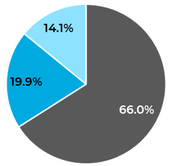
Aggregate sample includes those who self-report they "experienced" chronic cough in the past 12 months (N=4,616).

Alcoholism



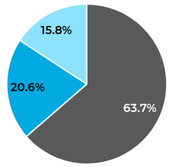
Aggregate sample includes those who self-report they "experienced" alcoholism in the past 12 months (N=4,150).

Chronic Constipation



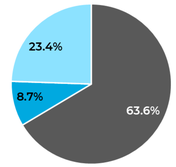
Aggregate sample includes those who self-report they "experienced" chronic constipation in the past 12 months (N=4,343).

Insomnia



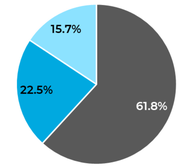
Aggregate sample includes those who self-report they "experienced" insomnia in the past 12 months (N=14,912).

Erectile Dysfunction (males only)



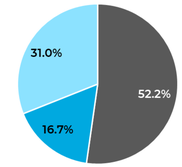
Aggregate sample includes those who self-report they "experienced" erectile dysfunction in the past 12 months (N=20,265).

Obsessive Compulsive Disorder



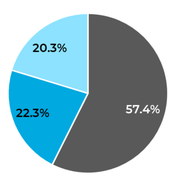
Aggregate sample includes those who self-report they "experienced" obsessive compulsive disorder in the past 12 months (N=3,466).

Bipolar Disorder



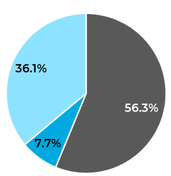
Aggregate sample includes those who self-report they "experienced" bipolar disorder in the past 12 months (N=4,565).

Psoriasis



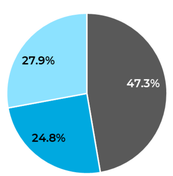
Aggregate sample includes those who self-report they "experienced" psoriasis in the past 12 months (N=4,631).

HIV



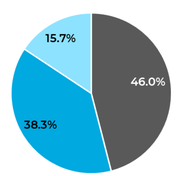
Aggregate sample includes those who self-report they "experienced" HIV in the past 12 months (N=784).

Migraine



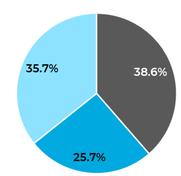
Aggregate sample includes those who self-report they "experienced" migraine in the past 12 months (N=11,990).

Irritable Bowel Syndrome



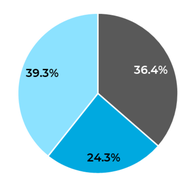
Aggregate sample includes those who self-report they "experienced" irritable bowel syndrome in the past 12 months (N=5,398).

Generalized Anxiety Disorder



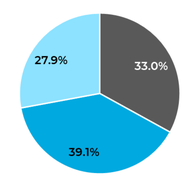
Aggregate sample includes those who self-report they "experienced" generalized anxiety disorder in the past 12 months (N=7,278).

Depression



Aggregate sample includes those who self-report they "experienced" depression in the past 12 months (N=16,896).

Post-Traumatic Stress Disorder



Aggregate sample includes those who self-report they "experienced" post-traumatic stress disorder in the past 12 months (N=3,914).

Methods

- Study data came from the 2022 US National Health and Wellness Survey (NHWS), a cross-sectional, nationally-representative, patient-reported outcomes survey administered to the general population. Prevalence of the following four cohorts within each of 19 stigmatized treatment areas was assessed via self-report.
  - Undiagnosed
  - Diagnosed
    - Treated with prescription medication
    - Untreated with prescription medication
- Respondents with stigmatized conditions were identified via self-report as those who had "experienced the condition in the past 12 months."
- Respondents with a diagnosis of a stigmatized condition were identified via self-report as those who had "a physician diagnosis of the condition."
- Respondents who were treated for a stigmatized condition were identified via self-report as those who were "currently taking a prescription medication to treat the condition."
- Unweighted prevalence estimates are presented.

Conclusions

- These results suggest that a large proportion of individuals remain **undiagnosed** or **untreated** for many **stigmatized conditions**.
- Future studies may quantify the extent to which stigmatization (i.e., shame) versus other factors (e.g., transportation, income, health literacy) act as barriers to diagnosis and treatment uptake for individuals with stigmatized conditions.

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- Third-party medical writing support was provided by Denice Freyling.

References

1. Major B and O'Brien LT. The Social Psychology of Stigma. *Annu Rev Psychol.* 2005;56:393-421.
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3. van Brakel WH, Cataldo J, Grover S, et al. Out of the silos: identifying cross-cutting features of health-related stigma to advance measurement and intervention. *BMC Med.* 2019;17, 13.
4. Health Policy Brief (August 21, 2014). The Relative Contribution of Multiple Determinants to Health Outcomes. *Health Affairs.*

Legend:

- Undiagnosed
- Diagnosed and Untreated
- Diagnosed and Treated

Email: Nate.Way@oracle.com