

Evaluation of perceptions and knowledge of mental illness in the United States through crowdsourcing

Emma C. Palmer, PharmD, BCPS, BCPP¹; Amber R. Douglass, PharmD, BCPS, BCPP²; Thomas Smith, PharmD, BCPP³; David G. Fuentes, PharmD, BCPP, CGP⁴

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Abstract

Introduction: Crowdsourcing is a method of data collection with possible benefits in assessing perceptions of mental illness in a large US population.

Methods: The objective was to describe perceptions and trends of stigma surrounding mental illness in the United States using crowdsourcing. An online survey was conducted evaluating adults in the United States recruited via the online resource Amazon Mechanical Turk. Questions evaluated demographics and perceptions of mental illness. Survey data were adjusted for demographic variables and compared via logistic regression.

Results: Respondents (n=1422) were predominately 18 to 30 years of age (n=743; 52.3%) and white (n=1101; 77.4%). Over half reported an individual close to them had mental illness (n=932; 65.5%), and more than one quarter (n=397; 27.9%) reported having a current or previous mental illness. Non-whites were less likely to agree that: medications are effective (odds ratio [OR] 0.63); they would be comfortable around a coworker with mental illness (OR 0.66); and mental illness is inheritable (OR 0.74). They are also more likely to agree that mental illness is preventable (OR 1.49). Individuals reporting mental illness were more likely to agree that medications (OR 1.34; 95% confidence interval 1.03 to 1.74) and talk therapy (OR 1.46; 95% confidence interval 1.12 to 1.90) are effective. Those reporting *some* or *no college* were more likely to agree that the United States has good access to mental health treatment.

Discussion: Crowdsourcing may be an effective way to obtain information regarding demographics, stigma, and mental illness. Personal experiences with mental illness, ethnicity, and educational level appear to continue to impact perceptions of mental illness.

Keywords: stigma, mental illness, crowdsourcing

¹ (Corresponding author) Assistant Professor, Clinical and Administrative Sciences, Sullivan University College of Pharmacy, Louisville, Kentucky, emmaclairepalmer@gmail.com, ORCID: <http://orcid.org/0000-0002-7340-2452>; ² Clinical Pharmacy Specialist - Mental Health, Tennessee Valley Healthcare System, Murfreesboro, Tennessee, ORCID: <http://orcid.org/0000-0001-5960-1941>; ³ Assistant Professor of Pharmacy Practice, Manchester University College of Pharmacy, Fort Wayne, Indiana, ORCID: <http://orcid.org/0000-0003-0258-9165>; ⁴ Professor and Department Chair, California Health Sciences University, Clovis, California, ORCID: <http://orcid.org/0000-0002-3905-5338>

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Introduction

Mental illness remains common across the United States. Data from the National Institute of Mental Health National Survey on Drug Use and Health¹ indicated that 44.7 million US adults had a mental illness, and 43.1% of those received services in 2016. According to the National Alliance on Mental Illness,² African, Hispanic, and Asian Americans used mental health services between half and one-third the rate of whites. In 2002, an estimated total direct and indirect societal cost of patients living with

severe mental illness was greater than \$300 billion yearly.³ Mental health care related expenditures ranked as high as the third costliest of medical conditions in 2006.⁴

Based on data collected by the Centers for Disease Control and Prevention⁵ in 2007, approximately 25% of adults with mental illness believed that others are sympathetic toward patients diagnosed with these conditions. The public's perceptions of mental health and mental illness have been studied in systematic reviews in regards to both individuals in public and in the workplace.⁶⁻⁹ The portrayal of mental illness in the media has also had an impact on the public's understanding of mental health and issues related to stigma.^{10,11} Reviews of university students described significant prevalence of illness, suggesting the need for both recognizing mental illness and improving education regarding stigma.^{12,13} Rusch and colleagues¹⁴ described 3 types of stigma: negative stereotypes, prejudice with negative emotional reactions, and discrimination. Considering prevalence of stigma that continues to the current day, it is imperative to continue to research these elements.

A systematic review¹⁵ evaluated a number of health and medicine-based crowdsourcing studies. Their findings suggest that crowdsourcing can be a way to quickly and inexpensively produce a high-quality research project that can benefit many. Crowdsourcing is the process of obtaining information by soliciting contributions from a large number of people, typically from the internet. It has been defined as "an online, distributed, problem-solving, and production model that uses the collective intelligence of networked communities for specific purposes."¹⁶ There are little data utilizing crowdsourcing as a primary instrument for assessing current stigma in mental health. Crowdsourcing may possibly be an untapped resource with a potential opportunity, which is one of the broad goals this study seeks to determine.^{16,17}

The primary objective of this study was to explore characteristics of the US population regarding mental illness demographics using crowdsourcing. The secondary objective was to assess demographics that may impact perceptions, stigma, and knowledge of mental illness.

Methods

A pilot survey was developed by the researchers and imported into Amazon Mechanical Turk's (AMT; Seattle, WA) database (Table 1). Amazon Mechanical Turk is an online database that uses individuals to complete various online tasks, which can include responding to surveys, tagging items, or performing other tasks that cannot be completed using artificial intelligence. The electronic

survey was posted on the internet through the AMT website and was available to individuals aged 18 to 65 in the United States. The project was approved by the Institutional Review Board at Sullivan University College of Pharmacy and was funded through an internal grant provided by Sullivan University. Due to the broader goals, the researchers developed the pilot survey to ask additional questions covering themes of cognitive and behavioral constructs in stigma.¹⁸ Areas covered included constructs regarding stereotyping, institutionalization, and mental health funding, and knowledge questions regarding treatment and disability. Survey items were independently evaluated by the institution's research committee members but not statistically validated prior to administration.

Subjects were required to have an approval rating of at least 90% based on successful completion of previous AMT tasks, which is commonly used as a measure of reliability of workers. Prior to initiating the survey, respondents reviewed an informed consent document. Subjects were then given a 45-minute time limit to complete the survey and compensated US\$0.50 for their participation, which is similar to other tasks available in AMT.

To ensure that subjects were engaged in the survey, an identical question regarding the percentage of Americans with depression was presented twice. The identity of AMT workers is anonymous with a randomized worker identification to exclude duplicate responses. Exclusion criteria were: incomplete survey submission, responders answering the duplicate question differently, and multiple submissions from the same responder. The first fully complete survey received was used in analysis.

Once collected, survey results were imported into an Excel® spreadsheet (Microsoft Office, Redmond, WA). Descriptive statistics were performed in Excel® for the primary objective. An independent biostatistician performed the statistical analyses of the secondary objective using SAS version 9.4 (SAS Institute, Cary, NC). The secondary objective was evaluated using ordered logistic regression models to quantify the strength of association while adjusting for variables. Models were adjusted for age, gender, reported close contact with mental illness, and presented as odds ratios (OR) and 95% confidence intervals (CIs). *P* values <.05 were considered statistically significant.

Results

A total of 1872 responses were received between January 12 and 14, 2015. Of these, 450 were excluded from final

TABLE 1: Survey questions

Demographics

How old are you?

What is your gender?

What is your ethnicity?

What is your highest level of education?

What state or US territory do you currently reside in?

Do you know of anyone close to you who has a mental illness?

Have you ever been diagnosed with a mental illness in your lifetime?

Are you currently seeing a psychologist, psychiatrist, or other person to treat a mental illness?

How would you rate your current MENTAL health?

- 1 - Healthy/no symptoms
- 2 - Mildly ill
- 3 - Moderately ill
- 4 - Severely ill

Accuracy check

What percentage of Americans have a diagnosis of depression each year?^a

Severity perceptions

Which of the following conditions do you feel is the MOST dangerous to your health and wellbeing?

- Diabetes
- Heart disease
- Obsessive-compulsive disorder
- Colon cancer
- Schizophrenia

Which of the following conditions do you feel is the LEAST dangerous to your health and wellbeing?

- Depression
- Asthma
- High blood pressure
- Anxiety
- Epilepsy

Perceptions questions^b

1. Mental illness is accurately portrayed in movies and TV shows
2. Medications for treatment of mental illness are effective
3. “Talk therapy” for treatment of mental illness is effective
4. People with mental illness can be “cured” so that they no longer have the illness or need treatment
5. I feel comfortable around a coworker that I know has a mental illness
6. Healthy people can have mental illness
7. People with mental illness are addicted to drugs
8. People in the United States have good access to treatment for mental illness
9. I would be/am embarrassed to tell people about having a mental illness
10. Mental illness is preventable
11. You can inherit mental illness from your relatives

TABLE 1: Survey questions (continued)

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12. The government should help pay for the care of people with mental illness
 13. People are compassionate and sympathetic to those with mental illness
 14. Primary care physicians can prescribe medication for mental illness
 15. Physical exercise can help treat mental illness
 16. If I hear about or see a violent news story, I assume it involves someone with mental illness
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^aMultiple-choice question asked twice for verification purposes.

^b1 to 16, Scale assigned from 1 = strongly agree to 5 = strongly disagree.

analysis because of incomplete survey submission (n = 380; 20%), responders answering the duplicate question differently (n = 39; 2%), and multiple submissions from the same responder (n = 31; 1.6%). Of the responses received, 1422 (76%) were included in the final analysis. Demographic data are available in Table 2, frequency distribution of survey responses is found in Table 3, and statistical analyses of demographic influences are found in Table 4.

Experience With Mental Illness

Over half of respondents reported an individual close to them had mental illness (n = 932; 65.5%), and more than one quarter (n = 397; 27.9%) reported having a current or previous mental illness.

Disease Opinions

Participants were less likely to identify a mental illness as *most dangerous*, compared to the 81% who identified heart disease, colon cancer, or diabetes collectively as *most dangerous*. Anxiety was most often reported as *least dangerous* by participants (39%).

Mental Health Status

Survey participants who reported having a mental illness were statistically more likely to agree with several statements, including: that medications (OR 1.34; 95% CI 1.03 to 1.74) and talk therapy (OR 1.46; 95% CI 1.12 to 1.90) are effective; they would feel comfortable around a coworker with mental illness (OR 2.05; 95% CI 1.56 to 2.69); and that mental illness is inheritable from your relatives (OR 1.50; 95% CI 1.14 to 1.96).

Ethnicity

Non-white participants were more likely to report that mental illness is preventable (OR 1.49; 95% CI 1.18 to 1.88) and less likely to agree that medications are effective (OR 0.63; 95% CI 0.50 to 0.80). Non-whites were also less likely

TABLE 2: Subject demographics

Demographic	n (%)
Age	
18 to 30	743 (52.3)
31 to 40	373 (26.2)
41 to 50	157 (11)
51 to 60	106 (7.5)
61 to 65	43 (3)
Education level	
Non high school graduate	7 (0.5)
High school graduate only	156 (11)
Some college	532 (37.4)
Bachelor's degree	570 (40.1)
Graduate degree	157 (11)
Ethnicity	
Non-Hispanic white	1101 (77.4)
Asian	106 (7.5)
Black	85 (6)
Hispanic/Latino	83 (5.8)
Native American	33 (2.3)
Other/Unknown	14 (1)
Gender	
Male	766 (53.9)
Female	656 (46.1)
Do you know of anyone close to you who has a mental illness?	
Yes	932 (65.5)
No	490 (34.5)
Been diagnosed with a mental illness	
Yes	397 (27.9)
No	1025 (72.1)
Current mental health	
Healthy/No symptoms	947 (66.6)
Mildly ill	364 (25.6)
Moderately ill	99 (7)
Severely ill	12 (0.8)
Currently receiving mental illness treatment	
Yes	148 (10.4)
No	1274 (89.6)
US Census region ^a	
Region 1 Northeast	300 (21.2)
Region 2 Midwest	322 (22.6)
Region 3 South	478 (33.6)
Region 4 West	319 (22.4)
Other/US territories	3 (0.2)

^aCensus region groupings are defined by the US Census Bureau. http://www2.census.gov/geo/docs/maps-data/maps/reg_div.txt.

to report feeling comfortable around a coworker with mental illness (OR 0.66; 95% CI 0.52 to 0.84) and less likely to endorse that mental illness is inheritable (OR 0.74; 95% CI 0.58 to 0.95).

Education

Compared to survey participants who *completed 4-year college degrees or higher*, survey participants who *completed some college* were more likely to report that people in the United States have good access to mental health treatment (OR 1.23; 95% CI 1.00 to 1.50) and less likely to agree that medication treatment is effective (OR 0.78; 95% CI 0.63 to 0.97). Participants who reported *no college* were also more likely to agree that people in the United States have good access to treatment (OR 1.52; 95% CI 1.11 to 2.06) and less likely to agree exercise can help treat mental illness (OR 0.54; 95% CI 0.39 to 0.74).

Discussion

Stigma not only directly affects patients with mental illness, it may deter individuals from seeking help.¹⁵ Data from previous studies have also found significant differences in perceptions based on racial/ethnic identities.¹⁹ Other concerns to consider are that laypeople may be unable to recognize specific disorders or types of psychological distress.²⁰ Studies examining and establishing themes with mental illness in the area of stigma is crucial.²¹ A survey by Yokoya and colleagues²² included 1085 respondents, and only 58.9% believed in the effectiveness of pharmacotherapy for depression. Given that disparities in perceptions and access to mental health among minority populations have been documented for many years, those disparities found within our survey are in line with previous experience in this field. In addition, a recently published study²³ examining mental health literacy in college-aged males has reported higher degrees of education contributing to lower levels of stigma, which is similar to some of the associations found in this study.

Comparing this study's demographic data to 2010 US census data,²⁴ gender and ethnicity appear similar, which gives credence to the hypothesis that crowdsourcing can provide a representative population. Participants in this survey were 46.1% female compared with 50.8% of the US population. Regarding ethnicity, 77.4% of subjects reported to be white, compared with 77.1% in census data. Asian (7.5%), black (6%), Hispanic/Latino (5.8%) compared to 4.8%, 12.6%, and 16.3% from census data respectively. It is more difficult to compare age groups as this study included respondents aged 18 to 65.

This study also supports the use of crowdsourcing to obtain data in an efficient way. Hundreds of responses were obtained from individuals over a short period of time with a relative low cost of approximately US\$0.60 per response, including AMT fees. This is in line with suggestions from the systematic review by Ranard et al¹⁸ and incorporated areas they found to be lacking in crowdsourcing publications, such as demographics of the

TABLE 3: Survey responses

Question	n (%)
Which of the following conditions do you feel is the MOST dangerous to your health and wellbeing?	
Heart disease	616 (43.3)
Colon cancer	419 (29.5)
Schizophrenia	245 (17.2)
Diabetes	116 (8.2)
Obsessive-compulsive disorder	26 (1.8)
Which of the following conditions do you feel is the LEAST dangerous to your health and wellbeing?	
Anxiety	553 (38.9)
Asthma	441 (31.0)
High blood pressure	193 (13.6)
Depression	122 (8.6)
Epilepsy	113 (7.9)
Mental illness is accurately portrayed in movies and TV shows	
A/SA	143 (10.1)
N	268 (18.8)
SD/D	1011 (71.1)
Medications for treatment of mental illness are effective	
A/SA	773 (54.4)
N	427 (30.0)
SD/D	222 (15.6)
“Talk therapy” for treatment of mental illness is effective	
A/SA	794 (55.8)
N	430 (30.2)
SD/D	198 (13.9)
People with mental illness can be “cured” so that they no longer have the illness or need treatment	
A/SA	283 (19.9)
N	397 (27.9)
SD/D	742 (52.2)
I feel comfortable around a coworker that I know has a mental illness	
A/SA	931 (65.5)
N	317 (22.3)
SD/D	174 (12.2)
Healthy people can have mental illness	
A/SA	1321 (92.9)
N	56 (3.9)
SD/D	45 (3.2)
People with mental illness are addicted to drugs	
A/SA	51 (3.6)
N	179 (12.6)
SD/D	1192 (83.8)
People in the United States have good access to treatment for mental illness	
A/SA	441 (31.0)
N	300 (21.1)
SD/D	681 (47.9)

TABLE 3: Survey responses (continued)

Question	n (%)
I would be/am embarrassed to tell people about having a mental illness	
A/SA	764 (53.7)
N	279 (19.6)
SD/D	379 (26.7)
Mental illness is preventable	
A/SA	151 (10.6)
N	387 (27.2)
SD/D	884 (62.2)
You can inherit mental illness from your relatives	
A/SA	1049 (73.8)
N	235 (16.5)
SD/D	138 (9.7)
The government should help pay for the care of people with mental illness	
A/SA	1036 (72.9)
N	250 (17.6)
SD/D	136 (9.6)
People are compassionate and sympathetic to those with mental illness	
A/SA	204 (14.3)
N	345 (24.3)
SD/D	873 (61.4)
Primary care physicians can prescribe medication for mental illness	
A/SA	927 (65.2)
N	235 (16.5)
SD/D	260 (18.3)
Physical exercise can help treat mental illness	
A/SA	984 (69.2)
N	278 (19.5)
SD/D	160 (11.3)
If I hear about or see a violent news story, I assume it involves someone with mental illness	
A/SA	235 (16.5)
N	220 (15.5)
SD/D	967 (68.0)

A/SA = agree/strongly agree; N = neutral; SD/D = strongly disagree/disagree.

participating crowd. This method of collecting data may prove to be a cost-effective, high-quality, and underutilized process that should continue to be investigated in the future.

Based on findings, a follow-up study directed at a more targeted population, such as minority groups, may be of interest. It is well known that minorities are underrepresented in clinical research, and crowdsourcing may offer an alternative approach to access these populations that

TABLE 4: Adjusted odds ratios (and 95% confidence intervals) for select variables

Survey Item	Diagnosis (Yes)	Symptoms (Any Reported)	Ethnicity (Non-White)	Education	
				Some College	No College vs Bachelor's or Higher
Medications for treatment of mental illness are effective	1.34 (1.03 to 1.74) ^a	0.75 (0.59 to 0.96) ^a	0.63 (0.50 to 0.80) ^a	0.78 (0.63 to 0.97) ^a	0.73 (0.53 to 1.00)
“Talk therapy” for treatment of mental illness is effective	1.46 (1.12 to 1.90) ^a	0.88 (0.69 to 1.12)	1.01 (0.79 to 1.28)	0.97 (0.78 to 1.20)	0.73 (0.53 to 1.01)
People with mental illness can be “cured” so that they no longer have the illness or need therapy	1.14 (0.88 to 1.47)	0.71 (0.56 to 0.90) ^a	1.23 (0.98 to 1.56)	0.95 (0.78 to 1.17)	0.75 (0.55 to 1.02)
I feel comfortable around a coworker that I know has a mental illness	2.05 (1.56 to 2.69) ^a	1.04 (0.81 to 1.33)	0.66 (0.52 to 0.84) ^a	1.11 (0.90 to 1.37)	0.93 (0.67 to 1.29)
People in the United States have good access to treatment for mental illness	0.83 (0.65 to 1.07)	0.68 (0.54 to 0.86) ^a	1.24 (0.99 to 1.56)	1.23 (1.00 to 1.50) ^a	1.52 (1.11 to 2.06) ^a
Mental illness is preventable	0.82 (0.63 to 1.06)	0.72 (0.57 to 0.92) ^a	1.49 (1.18 to 1.88) ^a	0.88 (0.72 to 1.09)	0.73 (0.53 to 1.00)
You can inherit mental illness from your relatives	1.50 (1.14 to 1.96) ^a	0.91 (0.71 to 1.16)	0.74 (0.58 to 0.95) ^a	0.91 (0.74 to 1.13)	0.3 (0.57 to 1.30)
The government should help pay for the care of people with mental illness	1.40 (1.08 to 1.82) ^a	1.63 (1.28 to 2.08) ^a	1.18 (0.93 to 1.49)	0.98 (0.80 to 1.21)	1.10 (0.80 to 1.52)
Physical exercise can help treat mental illness	1.68 (1.29 to 2.20) ^a	0.96 (0.75 to 1.23)	0.80 (0.63 to 1.02)	0.81 (0.66 to 1.01)	0.54 (0.39 to 0.74) ^a

^aIndicates statistically significant results.

otherwise are underrepresented.²⁵ The paucity of data that is available examining stigma in minority populations may be supported by this study. Cultural values of individuals may vary significantly, particularly from assumed cultural norms of whites in the United States.²⁶ Others also support this strategy, as they found that AMT offers more demographically diverse samples than some traditional methods.²⁷ Additional studies on minority groups may add valuable insights.

This study has notable limitations. Respondents were inherently required to have access to the internet and have the ability to read and comprehend English. This method of data collection makes it difficult to assess those of low socioeconomic, educational, and/or English literacy level. This is evident by the increased percentage of respondents completing higher education compared to the US population. Additionally, the survey instrument itself contains wording that might be difficult to interpret.

Specific areas involve the use of a non-validated or pretested measure. Responders were unable to ask to clarify a question that may not make sense to him or her, which could alter results. Also, data that required sophisticated adjustment for confounding variables and analysis of subgroups needed additional funding for biostatistician evaluation to confidently determine significance or lack thereof. Notable issues related to the specifics regarding remuneration can also be seen as limitations, as AMT are also cited as receiving US\$0.10 hourly. Because of the study instrument and less-specific population examined, study findings across previously published data may be difficult to generalize. While other studies have examined cross-cultural beliefs regarding psychiatric illnesses, the differing constructs of the analysis make the data difficult to compare.²⁸ Along those lines, there appears to be a gap in the literature regarding several points of discussion reported in this study. Furthermore, this study offered a specific compen-

sation, therefore individuals who may not have been interested in the task or satisfied with the offered compensation may have declined to participate.

Conclusion

Crowdsourcing may be a useful method of obtaining information regarding mental illness in the United States. These data indicate significant prevalence and awareness of mental illness, with varying perceptions of mental illness between white and minority populations. Factors that may influence perceptions of mental illness include personal experiences, ethnicity, and educational level. These data continue to describe a present force in US culture and a continuing concern. Future studies using crowdsourcing may be a practical and beneficial option in continued study of population perspectives.

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