

Collecting Individual-Level Social Determinants of Health to Inform Patient-Centered Outcomes Research in Mental Health

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Introduction: According to a 2018 World Health Organization (WHO) report, depression is listed as the largest global contributor to disability and is also a known contributor to suicide deaths.¹ Global efforts aimed at mitigating depression prevalence recognize the importance of a multimodal approach to combating poor mental health. Recent studies suggest that providing adequate access to mental healthcare alone will not attenuate depression prevalence rates, but rather through addressing social determinants of health (SDOH), more pronounced and sustainable changes can be attained.² Despite increased interest from health systems, public health agencies, and community organizations in understanding and addressing people's social, economic, and environmental circumstances, individual-level SDOH collection efforts are uncommon, typically ad-hoc and disjointed, and there remains no firm understanding about which SDOH elements patients are even willing to share with their healthcare provider, health system, or publicly. In response, a number of health systems have developed tools to facilitate individual-level SDOH data collection, but their implementation is not yet widespread and they do not collect increasingly relevant online socio-behavioral estimates. The purpose of the study is to elicit from patients, in a structured and easily-deployable manner, information about experiences with depression/mental illness and how one's particular social (physical and digital) and environmental conditions may or may not influence their mental health. We aim to use these results to design future observational and prospective studies that link individual-level SDOH data to other data sources, such as electronic health records (EHRs).

Methods: We designed a brief, anonymous, online survey to understand patient attitudes about sharing mental healthcare utilization, behavior, treatment, online/social media use, and general social determinants (factors) of health (https://github.com/jdeferio/SDOMH_Survey). Our survey was constructed using questions from several existing instruments, such as the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) tool, designed to measure SDOH as well as structural and attitudinal barriers to healthcare.^{3,4} In addition, we created new questions to describe the patient's perception of neighborhood characteristics such as, but not limited to, safety, green space, access to public transportation, and blight. The survey is targeted towards patients that are currently experiencing depression or have a history of major depressive disorder (MDD) (including bipolar disorder), as defined by diagnosis codes or a PHQ-9 score ≥ 10 . In an attempt to obtain data from a wide group of patients, we have recruited from both inpatient and outpatient settings. The survey is comprised of a total of 45 questions (multiple choice and free text), and can be completed in-person on a tablet computer set up specifically for the study at the health system clinic during their appointment, or at the patient's leisure via a shareable hyperlink. All responses are automatically uploaded to a secure, HIPAA compliant database. This study has been approved by the Weill Cornell Medicine Institutional Review Board (#171008654).

Table 1 Participant Demographics

	Number of Participants (%)
Gender	
Male	16 (50.0)
Female	16 (50.0)
Age	
18-34	18 (56.3)
35-54	6 (18.7)
55+	8 (25.0)
Race/Ethnicity	
Asian	3 (8.6)
Hispanic/Latino	5 (14.3)
White/Caucasian	22 (62.9)
Black/African-American	4 (11.4)
Other	1 (2.8)
Income	
<\$25,999	3 (9.4)
\$26,000-\$51,999	8 (25.0)
\$52,000-\$74,999	5 (15.6)
\$75,000-\$99,999	4 (12.5)
\$100,000+	8 (25.0)
Education	
High School	7 (21.9)
Bachelor's	19 (59.4)
Master's	4 (12.5)
Doctorate	2 (6.2)
Insurance Status	
Medicare/Medicaid	3 (9.4)
Employer coverage	22 (68.8)
Self-purchased	7 (21.8)

Results: As of March 2019, we have collected data from 33 adult patients out of an initial recruitment target of 200 (see **Table 1** for study population characteristics). On average, it took 9 minutes for patients to complete the survey. The survey respondents thus far include 16 men and 16 women (1 participant declined to report gender). More than half of participants (56.3%) reported being between the ages of 18 and 34.

91% of participants reported that daily events at home or in their community have caused increased sadness in the past 12 months. Almost all (93.8%) participants have felt emotionally isolated from friends, family, and their community at some point in the past 12 months, with 18.8% feeling emotionally isolated nearly every day. When asked to share specific social and environmental triggers, common themes included pressure from relationships, work, and finances.

Our preliminary findings show that when seeking mental healthcare, 36.4% of participants reported facing difficulty and barrier to access. The most prominent barriers to mental healthcare were structural and included the uncertainty of where to go or which healthcare provider to see, and the financial burden of treatment. 72.8% of participants reported that they looked online or at social media for guidance before seeking care, with one-third relying on online resources such as WebMD. 83.3% reported looking online for three months to more than one year before deciding to seek professional help.

Regarding neighborhood safety, 62.5% of participants reported that they feel comfortable walking alone in their neighborhood during the day and night, while 37.5% reported only feeling comfortable during the day time. More than half (62.5%) reported feeling physically and emotionally safe in their current living situation, although 6.3% participants reported they do not feel safe, and 28.1% reported feeling unsure about their safety in their neighborhood. A majority (71.9%) felt that having access to public transportation has made them feel more connected to their city, community and enabled improved socialization.

Discussion: This study was initiated because there remains a gap in knowledge about individual-level social determinants of mental health. While results are still preliminary, we have shown that patients are willing to share intimate details about different aspects of their lives, such as how they have dealt with their mental illness, social difficulties, and perceived neighborhood safety. We have also seen that relevant SDOH information can be collected from patients in a short amount of time, and at the patient's convenience, thus requiring less of the healthcare provider's time. Future integration with EHRs and other external datasets is another goal of this work. Survey tools like PRAPARE provide EHR templates which facilitate integration into patient clinical records, therefore it is possible for other such tools to do the same. Our study, as of March 2019, is limited by the number of participants at a single institution. In addition, the study sample suffers from bias in the population makeup, including higher SES, commercially insured, and those who are already receiving mental health care. Lastly, the study does not address issues on whether or not patients would consent to the collection of this data if the survey also included protected health information (PHI), and their results were linked to the EHRs.

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