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## Public Health Research on Severe Mental Conditions Among Immigrant Communities in the United States: Strategies From a Qualitative Study with South Asian Immigrants in New York City



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**Introduction:** The study of severe mental conditions has primarily remained under the purview of basic and clinical research. Although global epidemiological data indicate that immigrant groups are at higher risk of these conditions, U.S. data are lacking. Qualitative studies can be an important first step to bring attention to understudied phenomena.

**Methods:** This manuscript describes strategies used to conduct semi-structured, in-depth individual interviews on experiences and perceptions of severe mental conditions among South Asian individuals with psychiatric diagnoses ( $n=21$ ), family members ( $n=11$ ), and clinicians ( $n=4$ ) in New York City. These strategies were synthesized from the team's internal notes of adaptations during the study design and data collection, weekly debrief meetings during data analysis, and brainstorm sessions for this manuscript.

**Results:** The main results of the study are reported elsewhere. This section focuses on lessons learned to improve immigrant participant interest and engagement, including the strengths and limitations of the healthcare setting; recruitment by a multilingual South Asian psychiatrist; interviews by non-clinical South Asian researchers selected for a variety of ages, genders, and languages; and the interview process and content.

**Discussion:** Overall, these strategies show the feasibility of non-clinical researchers to collect high-quality data about severe mental conditions among immigrant communities, noting that the details of specific strategies and results will be particular to each immigrant community. Public health research on severe mental conditions is essential to understand and address the experiences of severe mental conditions among immigrant communities in the U.S.

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## INTRODUCTION

Public health research on mental conditions in the U.S. is primarily limited to mild and moderate mood and anxiety conditions.<sup>1</sup> Public health surveillance systems do not routinely assess other mental conditions, including those commonly labeled as "severe" or "serious" and those that include symptoms such as psychosis.<sup>2</sup> This study uses the more neutral term condition rather than

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disorder or illness, as not all individuals with lived experience identify with this pathologization. However, in clinical terms, these neglected conditions include diagnoses such as severe depression, bipolar disorder, and schizophrenia.<sup>3</sup> Although research on these mental conditions has primarily remained in the domain of basic and clinical research,<sup>4</sup> there are significant population-level inequities, including higher morbidity<sup>5</sup> and premature mortality<sup>6</sup> than individuals without these conditions and a higher prevalence of, and worse outcomes for, these conditions among marginalized than dominant groups.<sup>7</sup> A public health lens shifts from individual diagnosis and treatment to population prevention and early intervention and prioritizes the identification of the social, economic, and environmental conditions that contribute to these inequities to reduce or eliminate them.<sup>8</sup>

The absence of U.S. data on severe mental conditions is particularly notable for immigrants. In Europe, substantial evidence shows that immigrants have higher rates of psychosis-spectrum conditions than non-immigrants, primarily because of greater experiences of structural and social adversity.<sup>9,10</sup> However in the U.S., home of the world's largest immigrant population,<sup>11</sup> there are almost no data on these conditions among immigrants.<sup>2,12</sup> Qualitative studies are an important tool for exploratory research on understudied phenomena. There are a handful of qualitative studies that explore these conditions among immigrants in the U.S., primarily Chinese<sup>13,14</sup> and Latine<sup>15,16</sup> communities, driven by a few key researchers. Common themes include experiences of discrimination and trauma, cultural dimensions of stigma, and caregiver experiences.<sup>17</sup>

One research group recently documented their lessons learned in the clinical recruitment of Latine individuals with first-episode psychosis and their family caregivers (who were primarily monolingual Spanish-speaking individuals of Mexican origin), such as collaborating closely with clinic leadership, having bilingual and bicultural research staff, building trust by addressing patients' immediate needs before recruitment, and integrating families.<sup>18</sup> Given the historical and contemporary barriers to conducting research among immigrant communities,<sup>19,20</sup> it is invaluable to learn from and build on these past studies. Further, it is important to consider the immense heterogeneity within and between different immigrant communities.

For example, South Asian immigrants include those who trace their ancestry to the present-day countries of Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan, and Sri Lanka. Although Asian Indians are the second largest Asian American subgroup in the U.S. and experience high socioeconomic status in

aggregate, South Asians in the U.S. experience wide income inequality, with nearly 10% living in poverty.<sup>11</sup> Further, the region is characterized by tremendous diversity in cultures, ethnicities, languages, and religions.<sup>21</sup> Unfortunately, most studies look at South Asian immigrants in aggregate or focus on Asian Indians as the largest subgroup. However, available evidence suggests that the mental health of South Asians in the U.S. is impacted by factors related to migration, acculturative stress, family dynamics, socioeconomic status, gender, and age.<sup>22</sup> More recent work has also advanced structural factors related to state violence, xenophobia, and racism<sup>23</sup> and historical factors related to the intergenerational trauma of colonization and subsequent Partition of the subcontinent.<sup>24</sup> Given some parallels with other immigrant groups, there is value in both studying this group in depth and considering how to understand the experiences of immigrants more broadly.

National epidemiological studies of South Asians in aggregate confirm comparable rates of mood and substance use disorders,<sup>25,26</sup> which likely vary further by the additional dimensions of the heterogeneous South Asian experience. More recent studies have also focused on eating disorders<sup>27,28</sup> and post-traumatic stress disorder.<sup>29</sup> In general, research suggests that a lack of knowledge and high rates of stigma contribute to underutilization of mental health services for South Asian immigrants.<sup>22</sup> However, limited data are available about diagnoses such as severe depression, bipolar disorder, and schizophrenia. Research from England and Canada shows that South Asian immigrants and refugees have higher rates of psychosis-spectrum conditions than White individuals,<sup>30,31</sup> corroborating the importance of studying these diagnoses. As a first step, the authors recently conducted a qualitative study to understand the experiences of South Asian immigrants diagnosed with these conditions. The results of this study have been published elsewhere.<sup>32</sup>

The purpose of this manuscript is to synthesize and share strategies learned from conducting this study to improve participant interest and engagement and ensure high-quality data about severe mental conditions among immigrant communities. The immense diversity within and across immigrant communities, as with the South Asian community, precludes a single set of universal procedures. However, these strategies could help inform public and community health research by nonclinical researchers who might otherwise be deterred by inexperience or uncertainty about how to get started. In addition, although this study was conducted in psychiatric settings, another goal is to leverage these insights into community settings. Ultimately, the intention is that the

strategies in this manuscript will help make it more feasible to study severe mental conditions among immigrant communities, which is essential to achieve prevention, early intervention, and equitable treatment for this diverse population. Although some of these strategies parallel those about working with marginalized groups more broadly, it emphasizes the dimensions that relate specifically to working with individuals with severe mental conditions.

## METHODS

The original qualitative study conducted semi-structured, in-depth individual interviews to explore the experiences and perceptions of South Asian immigrants with severe mental conditions and their family members in the U.S. The interview guide included questions about illness and diagnosis, family relationships, cultural influences, gender influences, stigma and discrimination, and support and recovery and was designed to take 60 to 90 minutes. Materials were translated into Bengali, Hindi, and Urdu. Data collection took place from January to September 2021 at the outpatient psychiatry department of a large municipal hospital in New York City (NYC) serving a high volume of South Asian patients. The study was approved by the IRBs at the research center (NYU School of Medicine #i20-01325) and hospital (NYC Health + Hospitals #00002661), and informed consent was obtained from all participants. This manuscript focuses only on an analysis of the study approach; the main qualitative study analysis and findings have been reported elsewhere.<sup>32</sup>

### Study Sample or Population

Inclusion criteria were based on ICD-10 codes and included individuals who were (1) aged 18 years or older; (2) diagnosed with severe major depressive disorder (ICD-10 F33.3-33.4), bipolar disorder and subtypes (F31), complex post-traumatic stress disorder (F43.12), schizoaffective disorder and subtypes (F25.9), or schizophrenia and related disorders (F20); (3) not actively experiencing psychosis; (4) traced ancestry to Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan, or Sri Lanka; and (5) spoke English, Bengali, Hindi, or Urdu. Participants also included family members of South Asian patients who met the criteria and clinicians who work with South Asian patients at the hospital. Patients and family members were recruited individually, not as dyads. Patients and family members were each compensated with a \$75 gift card; clinicians were not compensated.

Details about the recruitment and interview processes are discussed in further detail in the next section.

Overall, 47 individuals agreed to participate, with 10 withdrawals (4 patients, 6 family members) during scheduling. Withdrawals were due to a variety of reasons, including lack of interest, lack of time, and concerns about family and stigma. One completed interview with a family member had an audio recording failure. The final sample consisted of 36 participants (21 patients, 11 family members, and 4 clinicians). The general demographic profile across patient and family member participants was similar. Most participants were first-generation immigrants who had been in the country for at least five years, including some Indo-Caribbean immigrants to the U.S. Almost half of the patient and family participants were Bangladeshi and Muslim, and almost two-thirds were female. The most common diagnosis was severe major depressive disorder, followed by schizophrenia, bipolar disorder, and complex post-traumatic stress disorder. Family members included children, spouses, and siblings.

Results presented in this analysis are not based on the study data but rather on the study's internal records about adaptations made during the study design and data collection, weekly debrief meetings during data analysis, and brainstorm sessions to generate, synthesize, and review the salient strategies that could benefit future research by others.

## RESULTS

The strategies developed to improve participant interest and engagement in this study are organized around the benefits and challenges of (1) the healthcare setting, (2) clinician-based recruitment, (3) interviewer characteristics, (4) interviewee protections, and (5) interview content, also summarized in [Table 1](#).

### Healthcare Setting

Minoritized groups, including immigrants, Asian Americans, and South Asians, are underrepresented in health research.<sup>33</sup> Preferences for recruitment vary from homes to clinics,<sup>34</sup> although a common recommendation for recruiting Asian Americans is to recruit where they congregate.<sup>19</sup> For this study, recruiting in community settings was infeasible as it would have required self-identification with diagnostic labels that are highly stigmatized and not culturally salient. This was later corroborated by the findings, where many participants did not recall the name of their official diagnosis. Recruiting based on diagnostic criteria will always be limited to those who seek and stay in healthcare; however, their experiences can also offer insights for how to reach individuals with similar experiences outside of healthcare and to provide more context for these terms for those

**Table 1.** Strategies Developed for Conducting Community and Public Health Research About Severe Mental Conditions Among Immigrant Communities

Strategy	Findings
<b>Healthcare setting</b>	
Using diagnostic labels	Recruiting in healthcare is more feasible for initial studies about diagnoses given the stigma and lack of cultural salience of diagnoses in community settings.
Leveraging provider trust	Leveraging existing trusting relationships with providers was effective for recruiting South Asian immigrant participants but may not be the same for all groups.
Navigating inpatient vs outpatient	Navigating clinical care requires building trust between researchers and providers and may be enhanced by offering wraparound supportive services.
Considering socioeconomic status	Hospitals that accept Medicare or Medicaid and serve uninsured and undocumented individuals ensures better representation of immigrant communities.
<b>Clinician-based recruitment</b>	
Accurate racial/ethnic classification	Clinician recruitment can bypass racial or ethnic misclassification in electronic health records but requires education of fellow providers and confirmation that the classifications align with people's own identities.
Respectful family recruitment	Centering the patient experience entails requiring their consent to recruit their family members, although an on-going challenge is inclusion of family in other countries.
Shared family experiences	Categorizing patients and family members separately should be done with care, because they may share similar experiences, stressors, and mental health challenges.
Clinician blinding to procedures	Close collaboration with clinicians is essential but requires additional protections including blinding during all data collection and data analysis.
<b>Interviewer characteristics</b>	
Bilingual, bicultural research staff	Age, ethnicity, gender, and religion all mattered in connections between interviewers and interviewees and were effective for building trust without clinical training.
<b>Interviewee protections</b>	
Training and debriefing	With sufficient training, practice, and debriefing, non-clinical research staff can successfully conduct studies on mental conditions including those with traumatic content.
Cognitive assessment	Additional confirmation that participants understand their rights is important, but a true/false test was challenging and open-ended questions could be more effective.
<b>Interview content</b>	
Mental health terms	After clinical recruitment, avoidance of diagnostic terms can allow participants to describe their own understanding of their experiences but precludes asking about their perspective on their official diagnosis.
Using abstract concepts	Although culture and gender can have an important influence on experiences, asking about this abstractly may be less effective than giving concrete examples.

who want to seek help within healthcare. The authors' hope is that by speaking to participants with clinical diagnoses, the study will be able to develop better terms and tools to recruit participants in community settings even without diagnoses.

As an initial start to researching this topic in the South Asian immigrant community, recruiting those receiving psychiatric diagnoses allowed the use of official diagnoses from electronic health records (EHR) even if the patients did not use the labels themselves. It also allowed the study to leverage existing trusting relationships between providers and patients. One of the biggest assets of this recruitment site was that it accepted patients on Medicare

or Medicaid and those without insurance, which allowed for better representation of low-income and undocumented immigrants. Many participants indicated that this hospital had reduced barriers to care related to insurance, costs, and citizenship status that are present elsewhere. Therefore, even healthcare recruitment should consider who has access to those services. In addition, the authors hope that initial healthcare studies such as this will help identify appropriate language and framing to talk about these experiences without relying on diagnostic criteria in future community studies.

This study intended to recruit in both inpatient and outpatient settings, based on a similar study among

Chinese immigrants that recruited from bilingual inpatient units.<sup>35</sup> In that study, the interviewers were trained clinical psychologists. For the nonclinical interviewers (discussed below) in this study, the psychiatry department leadership felt that patients receiving inpatient services were still in active treatment, and recruitment should wait until they transitioned to outpatient services. Even in outpatient services, the provider's discretion took precedence. Two patients were identified by the inpatient services as appropriate for the study once they were in outpatient services; however, the outpatient providers concluded that patients were not well enough to participate. However, one risk of waiting until outpatient care is people who are lost to follow-up. Researchers recruiting Latine individuals with first-episode psychosis observed that many were lost in the transition from inpatient to outpatient services. They shifted their recruitment strategy to first facilitate the transition into outpatient care with resources such as psychoeducation and family support groups and then saw if individuals were interested in participating in the study.<sup>18</sup> This could also be an effective strategy for recruiting within community settings.

### Clinician-Based Recruitment

Within the healthcare setting, EHR systems alone cannot be relied on to identify whether patients are South Asian given the high levels of racial or ethnic misclassification common for South Asians in medical records.<sup>36,37</sup> Further, the EHR classifications only included Asian without any subgroups. Because of the COVID-19 pandemic and the shift to telehealth services, this study could not post physical recruitment materials. Similar to the Latine first-episode psychosis study, it was essential to have a clinical co-principal investigator (co-PI) to bridge the clinical and research settings.<sup>18</sup>

The clinical co-PI in this study, a multilingual South Asian psychiatrist, bypassed challenges with racial or ethnic misclassification and diagnostic labels by knowing patients who self-identified as at least one of the ethnicities within the umbrella term of South Asian. The clinical co-PI also shared the study details with other providers through group presentations, individual meetings, and email reminders. Notably, the most common question from non-South Asian providers was defining who qualified as South Asian. One additional complication was the inclusion of Indo-Caribbeans, who trace their ancestry to the Indian subcontinent but left during the 1800s as part of colonial indentured servitude in the Caribbean. Researchers on South Asians in NYC strive to include Indo-Caribbeans given this shared heritage; some cultural, ethnic, and religious overlap; and earlier research showing a disproportionate mental health

burden among Indo-Caribbeans compared to other South Asian subgroups in NYC.<sup>38,39</sup> However, this study experienced a mixed response from potential Indo-Caribbean participants: some were willing to participate in the study, but others declined because they did not identify as South Asian.

Family member recruitment was similar, relying on family members who were involved in patient care. For practical reasons, the study did not require dyads of patients and family members. However, it did require the patient's consent to interview their family member. One challenge was when a patient suggested a family member who still resided in South Asia, which would have required applying to the local IRB in that country. Another challenge was receiving a provider referral of a family member who was not allowed by the patient to participate in their clinical team. The study respected the patient's choice around family involvement and did not include them in this study.

An unexpected limitation was that family members were recruited based on their relationship to patients; however, many described their own mental health challenges even though they did not have a diagnosis or were not receiving treatment at that specific hospital. One of the major findings was how common it was for immigrant families to have shared experiences of stress and adversity that contribute to mental distress across multiple family members. In the future, it would be useful for interviews with family members to also include questions about their mental health, diagnoses, and treatment. Even outside of healthcare settings, overlapping experiences of stress and adversity among immigrant families should be kept in mind for asking relevant research questions that might seek to classify patients and family members as separate populations.

The referral process was streamlined through the co-PI clinician to minimize patient interaction with the non-clinical study team until eligibility was confirmed. The co-PI clinician spoke with every potential participant first, including their own patients, which meant they had to be clear that the study was not part of their clinical care. To maximize protection of patient confidentiality after recruitment, the clinical co-PI was subsequently blinded from all data collection and analysis until data were de-identified, aggregated, and analyzed.

### Interviewer Characteristics

This study prioritized bilingual and bicultural interviewers who worked in community and public health. All interviews were conducted by 3 trained research team members who self-identified as South Asian and spoke at least one of the included languages. Based on hospital demographics, the study anticipated more

Bangladeshi participants, so additional dimensions of nationality, ethnicity, and religion were considered to maximize the match between the interviewer and interviewee. Interestingly, these matches did not always work as anticipated. For example, one Pakistani participant appeared to open up more about their experience when they learned their interviewer was Bangladeshi and not from their own community. Previous research suggests homophily might be less effective if the condition is severe.<sup>34</sup> Given strong gender norms in South Asian culture, gender concordance was also a primary consideration. However, the study observed some differences by age and generational status; it seemed to the study team that some middle-aged women felt validated by talking to the middle-aged male community health worker about their experiences in their own language. Thus, adapting in real time was essential to ensure optimal matches for interviewers and interviewees beyond simple identity markers. Finally, when a patient and their family member both agreed to participate, the study ensured the protection of their confidentiality by assigning different interviewers to each one.

An unexpected benefit of having interviewers who shared the same background is that the interviewee could feel comfortable dropping in words from another language. For example, the interview might primarily be in a South Asian language, but the interviewee might use English to describe their clinical treatment or medication. Similarly, the interview might be in English but the interviewee might use the word “paagal” (“crazy” in Bengali, Hindi, and Urdu) to describe how their community or family perceives mental health or their experience. Given some common familiarity around adjacent languages, this could be effective even if the interviewer and interviewee did not speak identical languages.

### Interviewee Protections

The IRB considered individuals with psychiatric diagnoses to be a vulnerable population and added additional protections in the training and debriefing processes and through a cognitive assessment before the interview.

The interview training reviewed common signs and symptoms of mental distress and provided guidance on how to navigate and validate unfamiliar experiences from a nonjudgmental, peer support perspective. Some dimensions included how to respond to distress (e.g., crying, suicidality) and to what are medically termed “psychosis” or “disorganized thinking” by providing clinical and community examples and conducting a practice interview with a co-PI. The interview team also held weekly debriefing meetings to ensure the well-being of both interviewers and interviewees. As needed, the interview team would selectively invite the clinical co-PI to

help contextualize unfamiliar comments and behaviors and traumatic content without providing participant details.

Immediately after the informed consent process, a cognitive assessment was added to confirm each participant fully understood their informed consent. This was a series of 10 true and false questions about the purpose and logistics of the study and their rights as a participant. Three questions had false options (e.g., *If I decide not to participate, I cannot continue my current treatment at [hospital name]*). However, an unanticipated challenge was that a few participants were confused about why trick questions would be asked. Sometimes the participant would provide an ambiguous answer (e.g., *good* rather than *yes* or *no*) that required the interviewer to rephrase the question. A more effective but more time-consuming option for future studies would be to ask open-ended questions to assess comprehension (e.g., *What is the connection between study participation and your current treatment at [hospital name]*). Finally, at the end of the interview, the study provided each participant with a list of resources, including the contact information of the clinical co-PI if the participant had an acute response.

### Interview Content

Challenges around interview content included creating appropriate translations of mental health terms and asking questions about abstract concepts. There was a lack of equivalent words for the diagnostic categories, and the authors had to transliterate them for official study materials (i.e., write the English diagnostic term in the South Asian language script). This aligns with previous research that translation is not straightforward and words and concepts do not necessarily align in other languages or even among different cultural backgrounds speaking the same language.<sup>34</sup>

Even though the study recruited based on diagnoses, the authors wanted to honor each participant’s understanding of their experience. Based on the translation process and earlier literature,<sup>22,40</sup> it seemed likely these diagnostic terms were not resonant. Therefore, the co-PI kept the interviewer blinded to the official diagnosis and instead asked each participant to share what they thought their condition was and what their doctor told them their condition was. This meant that during the interview, the interviewer understood everything solely within the context of how the participant understood it. This limited the type of probing the interviewer was able to do. After the interview, comparisons between the participants’ official diagnoses and what they shared in the interview revealed how most of the participants did not identify their official diagnosis. For the family member

interviews, the study initially started by keeping the interviewer blind to their relationship to the patient. However, this backfired in one case when the interviewee had multiple members with mental health challenges, and they began by talking about someone else. The protocol was changed to disclose the family member relationship, which did not appear to have a substantive impact on the study.

A strength of qualitative research is the ability to make abstract concepts such as culture and gender more concrete through the context of lived experience; participants can describe what these concepts mean to them in their own lives. However, the initial wording of these questions did not work as effectively as was hoped. The interview guide asked participants to describe their culture of origin, how it facilitated or challenged experiences of their condition, and how their experiences might compare to mainstream American culture. The interview guide also repeated similar questions for gender. These questions were intended to both solicit a broad understanding of their culture and gender and to see if or how culture and gender might have influenced their condition and its treatment. However, many participants did not think about their culture and gender as distinct from themselves and were not able to contrast it with others' experiences. Therefore, the interviewer often had to define culture and gender on the fly, before revising the guide further. Although the intent was to avoid leading questions, these concepts were easier to convey through more direct questions that included specific examples; for example, asking if someone of the opposite gender would have a different experience than them and using examples of how family members might respond.

## DISCUSSION

Immigrants in the U.S. are less likely than non-immigrants to use mental health services, despite equal or greater need.<sup>41</sup> They are also more likely to delay entry into care and disengage from care after starting it.<sup>41</sup> There is an urgent need to build the evidence base both within and outside of the medical system to mitigate the higher risk, greater severity, and less effective treatment commonly experienced by immigrant communities for these understudied mental conditions. The experience of this study in recruiting and interviewing over 30 participants from an understudied population on this highly stigmatized topic shows the feasibility of non-clinical researchers collecting high-quality data about severe mental conditions among immigrant communities.

Inclusive recruitment and engagement of immigrant communities in mental health research requires building trust and offering support. This includes leveraging resources in healthcare settings, such as collaborating with safety-net hospitals that have high provider trust, taking the time to understand the ethnic identities and family experiences of the specific communities, having a bicultural and bilingual research team, building in additional protections for both interviewers and interviewees, and being thoughtful about concepts around mental health and culture. It also requires looking into the future and determining how to translate many of those approaches into community settings. Together, this will ensure high-quality data while maximizing agency and dignity and mitigating the potential risk of coercion and harm.

However, there are some ongoing limitations in this work, many of which are not specific to the South Asian immigrant population. To begin with, there is immense heterogeneity within the category of South Asian immigrants, and the findings from this small sample cannot be generalized to all South Asian immigrants, let alone all immigrant communities. For each community, it will be important to navigate these tensions between the larger aggregate data as well as disaggregated differences across other axes of identities. For example, considering South Asians in aggregate is useful given some shared cultural beliefs and values in countries of origin and similar experiences of racialization in American society. There is also some ethnic and linguistic overlap across national borders.<sup>42</sup> However, it is also important to be mindful of the immense differences, including by nationality, ethnicity, and religion, that were largely codified by British colonization, including indentured servitude in the 1800s for Indo-Caribbeans<sup>43</sup> and the Partition and its aftermath in the 1900s for Bangladesh, India, and Pakistan.<sup>24</sup> In the U.S., there are also immense differences by socioeconomic status and generational status.<sup>11</sup> Therefore, although it is an important first step to start with exploratory research in aggregate, future research would benefit from going deeper with specific subgroups to understand their particular experiences.

More importantly, it is unclear the validity and use of the diagnoses and other medical terms such as "serious" and "severe" or "psychosis" for diverse immigrant communities. There is a tension here between navigating the high levels of stigma associated with these psychiatric labels while also ensuring cultural resonance to consider whether these labels are even appropriate. Therefore, it is important for the research team to create space for both official diagnoses and other personal understandings of experiences. In the view of the authors, using official

diagnoses would have conflicted with the individual's own self-determination, and therefore their official diagnoses were not mentioned in the interviews. Most participants did not recollect or want to share their official diagnoses, even as they were receiving psychiatric services for them. However, there is also a need for research that directly investigates how these diagnoses are understood and whether they can have utility. This type of research must be iterative. Initial studies might recruit in healthcare settings and use diagnoses in the absence of alternatives; however, these studies are opportunities to elicit more salient terms and descriptions that can both improve healthcare services and be carried forward into community settings. The study findings were also shared with some South Asian-serving community-based organizations in NYC; none had previously discussed these diagnoses in their work. However, future research must go much further in collaborating with communities and individuals with lived experience at the outset.

Finally, there is a real concern that increasing research about these types of mental conditions among immigrants could cause harm given the long history of racialized groups with "serious" or "severe" mental conditions ending up in the criminal legal system<sup>7</sup> and some evidence that immigrants commonly end up in care involuntarily.<sup>18</sup> It is well established that these "severe" or "serious" conditions are overrepresented among incarcerated and unhoused populations, and the criminal-legal system is the largest provider of mental healthcare in the country.<sup>44</sup> The U.S. also has the most extensive immigration detention system globally.<sup>45</sup> Studying these mental conditions among immigrant populations must not increase involuntary hospitalizations or other forms of incarceration, including immigration detention and deportation. Therefore, studying these conditions requires an understanding of the histories and potential harms of psychiatry, including those for immigrant and other marginalized communities.

Currently, there is almost no data on severe mental conditions among immigrants in the U.S. Too often, the lack of data is mistakenly interpreted as a lack of problems. It is essential to build these research skills in the community and public health workforce to address questions related to severe mental conditions to build the evidence base about these conditions among immigrant groups. These strategies have the potential to be applied to similar studies in the future, and the research findings can inform improvements in treatment engagement and efficacy within healthcare and in early detection, peer support, and social reintegration within communities.

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