

Understanding the Need for Meaningful Measures Across Diverse Populations

Carlos A. Larrauri, MSN

Board of Directors for the NAMI National

Co-Chair for AMP Schizophrenia Steering Committee

JD/MPA Candidate at Michigan Law and Harvard Kennedy School

Zuckerman Fellow at Harvard's Center for Public Leadership



Disclosures

- ▶ Occasionally, I receive remuneration from the pharmaceutical industry for presentations on my lived experience or non-branded disease awareness campaigns.



Personal Story

- An insight that something was “off”
- Diagnosis: Cutting Sugar Cane
- The Fog Settles In



Unmet Need

- Impact of missing objective measures on care
- Importance of meaningful measures in biomarker research



Meaningful Measures

- Challenges in developing measures for diverse populations
- Strategies for addressing measurement challenges
- Ethical Considerations



Some Insight that Something was “Off”

- ▶ I saw the school psychologist as a felt that something was “off.”
 - ▶ Trouble sleeping
 - ▶ Concentrating in classes
 - ▶ Completing routine assignments
 - ▶ Increasingly disorganized
- ▶ Nevertheless, we failed to identify the psychosis prodrome and I quickly deteriorated into a fully psychotic state
 - ▶ Missed opportunity to intervene early while I was help seeking because of lack of measurement tools

Official Diagnosis: *Cutting Sugar Cane*

- ▶ I saw close to half a dozen mental health professionals and received various diagnoses:
 - ▶ Avoidant personality disorder
 - ▶ Schizotypal personality disorder
 - ▶ Diagnosis: “Cortar Caña”
- ▶ Ultimately, I saw a team of psychologists and psychiatrists at an academic medical center and was diagnosed with “adult-onset schizophrenia.”
 - ▶ More missed opportunities and delayed treatment due to the lack of a swift and valid diagnosis.



The Fog Settles In and the Changes Care Dynamic

- ▶ All the while, I transited from a student who felt “something was off” to a more seriously ill person.
 - ▶ I had to leave school
 - ▶ Unable to retain employment
 - ▶ Relationships with friends and family were severed.
 - ▶ Traumatic experience
- ▶ By the time I was finally diagnosed, I had thought nothing was wrong with me. I was ambivalent or antagonistic toward getting care and was at risk for homelessness or criminal justice system involvement.



One Story, Thousands of Patients: The Unmet Need

- ▶ Research shows that untreated psychosis is associated with worse outcomes, yet no diagnostic tools exist to help identify people at high risk of developing schizophrenia.
- ▶ Consequently, a diagnosis is not typically made until clear symptoms of psychosis emerge and all other possible causes have been excluded.



What would multimodal measures offer for patients?

- ▶ Once identified and validated, objective biomarkers could be used for:
 - ▶ Early intervention before full-disease manifestation
 - ▶ Monitor and predict the likelihood of progression to other stages or other health outcomes
 - ▶ Show pharmacological response
 - ▶ Help study how treatments work for different groups of people
- ▶ Regarding diagnosis and clinical practice, objective biomarkers could:
 - ▶ It may reduce the impact of bias
 - ▶ Help to standardize the diagnostic process and avoid inaccurate diagnosis
 - ▶ Lead to better monitoring of patient progress, avoiding delay, or developing more effective treatments





Challenges in Developing Meaningful Measures for Diverse Populations

- ▶ Developing meaningful measures for diverse populations in CNS disorders is challenging for various reasons. These challenges include:
 1. **Cultural and linguistic differences:** various cultures may view mental health symptoms differently than others, which can impact the way that symptoms are reported and interpreted.
 2. **Socioeconomic factors:** Socioeconomic factors like income and education can also impact how individuals perceive and report symptoms.
 3. **Lack of diversity in research:** Finally, the lack of diversity in research can also contribute to challenges in developing meaningful measures for diverse populations, reducing generalizability.

Strategies for addressing measurement challenges and key ethical dimensions

► To overcome these challenges, researchers should take a multi-pronged approach that includes:

1. Engaging with diverse communities to understand their experiences and needs
2. Using culturally and linguistically appropriate measures
3. Considering cultural and socioeconomic factors that may impact symptom reporting and interpretation
4. Ensuring diversity in research samples

► Key ethical considerations

1. Informed consent
2. Privacy and confidentiality
3. Equity and Justice
4. Community Engagement

Conclusion and Take-Aways



- ▶ My story is one case study highlighting the pitfalls of the lack of measurement in psychiatric diagnosis and the need for better tools, but it is only one of the millions.
- ▶ Objective biomarkers are the key to unlocking new possibilities for early intervention, assessment, and developing novel treatments.
- ▶ There are unique challenges when working with diverse populations that require a community-engaged approach, cultural humility and competence, and enhancing diversity in research.