

TITLE FOR CATEGORY 6 SUBMISSION

Contextual Normalcy: a participatory artificial intelligence research project on creating community-driven mental health classifications and diagnoses

TOPICAL BACKGROUND

Current psychological diagnoses and popular perceptions of mental health are premised on Western norms, which were founded on nineteenth- and twentieth-century beliefs on gender, race, and sexuality. These standards of diagnosis are based on Western standards of normalcy and well-being, instead of more holistic and globally-based definitions of emotional and mental well-being that depend on culture and context. As the basis of the Diagnostic and Statistical Manual of Mental Disorders (henceforth DSM), these diagnoses are a keystone of psychological health education and practices, but fail to capture nuances with regards to individuals who fall outside of the populations the DSM is based upon.

As a result, access to quality mental healthcare is problematic for many people, such as those who have participated in our community whose gender identity is female or non-binary, and for those with recent immigration histories. In their experiences of those we have interviewed, the current diagnoses often lacked nuance with regards to their gender identities, did not acknowledge the role of community in caregiving for those with psychological illnesses, or there was simply a lack of identification for their particular case. There is clearly a case for new approaches not only for diagnosis, but for research into mental health and well-being altogether.

METHODS

Community-based approaches are at the heart of the research methods. We chose a more ethnographic and design-focused research approach to working with our larger community. The first of these were personal stories and community conversations, whereupon we engaged with members of the public in their experiences with mental health, both in personal day-to-day experience and with engagement they have had with mental health professionals.

From this, we arrived at the use of a mobile app for further engagement with a broader community and for data to segment populations by shared beliefs and definitions. Before we developed this, however, we engaged in a series of participatory workshops using extended reality (henceforth XR) to allow for participants to place how they viewed their lived emotional and mental experiences in a landscape shared by all participants. The community then used these workshops to develop the first set of questions for the app in use as a tool for collecting data on mental health and well-being.

Finally, we have developed the mobile app with a starting foundation of four community-derived questions to allow people the ability to engage physically with their emotions. Within the app, consent is center and key - one may share as little or as much information as they wish, and may remove consent for their data to be used at any time. We are currently in the process of data-gathering via the app.

When a threshold of roughly one hundred responses has been gathered, we will begin the process of determining similarities and differences - to build our variations of “normal”. We will do this by examining textual similarities between responses using an ensemble of natural language processing techniques, such as word usage and similarities (using Word2Vec or GLoVe) and phrasal similarities (using SpaCy) to build a document-space where we will define similarity based on the distances observed.

This project is seen as a multi-year, iterative research project. We will add questions, methods, and machine learning techniques as the research progresses.

RESULTS AND IMPLICATIONS FOR IMPROVING THE VALUE OF CARE

In undertaking this long-term and multi-faceted project, we are seeking to provide a bridge between mental health professionals and the diverse populations they serve. Mental health care is increasingly seen as a long underserved form of health care in our society, and increasing access and improving both the experience and diagnosis/treatment for patients is key to better well-being for society as a whole. We also seek to refocus psychological care from one standard of mental health to a multi-nodal set of norms that will empower both health care providers and the patients they seek to serve.

With increased transparency and more community participation in the development of mental health care paradigms, we hope to encourage more individuals to seek psychological care. Individuals who express hesitancy to engage in such care will hopefully express greater trust in systems based on community-created responses. By shifting the basis of mental health and wellness care and treatment, the patient would gain the ability to understand their own symptoms, how those symptoms are situated within a specific culture, and enable them to seek treatment within their dominant (or alternative) culture.

Larger implications for our project include encouraging clinicians to diagnose outside of the use of spoken and written language. By incorporating methods that include embodied data collection and location-based experiences, clinical diagnoses can extend for a greater number of patients in richer and more nuanced ways.

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