What's in the name "schizophrenia"? A clinical, research and lived experience perspective

"What's in a name? That which we call a rose by any other name would smell just as sweet". In response to the growing international momentum for renaming "schizophrenia", some people have invoked this famous Shakespearean line from *Romeo and Juliet* to suggest that changing a word is irrelevant for efforts addressing the inaccuracies and stigma associated with the term. As persons with research, lived, clinical and/or peer support experience, we respectfully disagree.

What *is* in a name is how it is used. A name should do no harm. However, since its conception over a century ago, the name "schizophrenia" has carried with it discrimination, stigma and misunderstanding. The term was first conceived by E. Bleuler in 1908 and derived from Greek to mean "split-mind", an idea that diverges from modern scientific and colloquial understandings of the experiences it describes, and from treatment advances[1]. As our colleague L. Larson from the Consumer Advisory Board of Massachusetts Mental Health Center stated, "The term schizophrenia hasn't evolved with the treatment"[2].

The term has also been used to oppress. In his book *The Protest Psychosis: How Schizophrenia Became a Black Disease*[3], J. Metzl suggests that the name was distorted to mean "racialized aggression", and was used to diagnose and institutionalize Black men who were incarcerated after participating in US Civil Rights demonstrations. The tensions within society may have transformed "schizophrenia" into an instrument of systemic racism to oppress Black Americans, at least during the 1960s.

Several initiatives around the world have attempted to address the problems associated with the term "schizophrenia". These include name changes in some Asian countries, with evidence of benefits such as decreased prejudice and stigma, more clinicians willing to disclose diagnosis to patients, and an increased number of patients willing to seek care[4]. Within the field, professional organizations, journals and the DSM-5 have revised their terminology to reflect the spectrum nature of the condition. Advocates of a new term also point to the successful name changes for other psychiatric conditions, such as from Multiple Personality Disorder to Dissociative Identity Disorder, and from Manic Depressive Illness to Bipolar Disorder. Furthermore, in a broader societal context, there is increasing attention to the importance of language and our choice of words.

Additionally, several survey studies strongly support renaming "schizophrenia", including two recent ones conducted in Italy[5] and the US[6]. The US survey[6] comprised the largest and most diverse sample, with multiple stakeholder groups including people with lived experience, families, mental health clinicians, researchers, government officials and the general public. This study uniquely partnered with people with lived experience of psychosis in all aspects of the project, thus gaining vital and under-represented expertise and perspectives. The most popular alternate name was Altered Perception Syndrome, followed by Psychosis Spectrum Syndrome and Neuro-Emotional Integration Disorder. Of note, Altered Perception Syndrome was the one alternate term from this survey coined by a person with lived experience of the condition and not used as an alternative name for "schizophrenia" in the literature or in other countries. The popularity of this term underscores how imperative it is to include the ideas and opinions of people living with the condition in all renaming initiatives.

However, far beyond beginning and ending with one word, the efforts to rename "schizophrenia" signal a call to action for the field and are part of a larger movement toward using person-centered, recovery-oriented, and experience-based language to support the well-being and aspirations of people with this and other mental health conditions. Language allows us to connect with others and to understand ourselves. It is not only based on definitions; it is intertwined with the actions we take and is affected by the world around us. The word "schizophrenia" is a particularly poignant example of the influence language bears on people, both in society's views and within identity. In a recent commentary, E. Saks writes of schizophrenia as a lifelong companion and of its name and construct becoming "too sclerotic"[7]. As she notes, "A name change may do more than anything to destabilize society's concepts".

Self- and public stigma, prejudice and discrimination are compounded by labels assigned to symptoms and experiences. Emphasizing advances in treatment and acceptance of experiences while removing the negative connotations of labels such as "schizophrenia" may encourage more people to seek support early and to advocate for their own mental wellness. Indeed, guidance has recently been published for clinicians when sharing psychosis diagnoses with individuals and their families, using the INSPIRES acronym: to use individualized, normalizing and non-stigmatizing, setting-specific, person-centered, informational, reassuring and inspiring, empathetic and empowering language, and then to express strategic next steps[8]. This approach helps "focus on instilling a sense of hope for recovery rather than simply informing individuals with illness of their symptoms and prognosis". Changing the name "schizophrenia" is one of several stepping stones on the path to improving support for the people we serve with language that illustrates the hope in recovery.

We appreciate that a name change is not easy and takes time. We also know that some people have argued that the time is not yet right for a name change; they note that a revised name should not be considered until new scientific findings emerge. But, we would ask, when exactly *is* the right time? It has been over a century since the term "schizophrenia" was coined. When will there be enough research and treatment advances to warrant a name change? We certainly still had (and have) a long way to go in our understanding and treatment of other mental health conditions whose names have already been changed.

A name change is not a panacea for the problems associated with the term "schizophrenia", and it would need to be accompa-

nied by other initiatives such as public education and legislation. As with most complex problems, the solution needs to be strategic, coordinated and multi-pronged. More research is also vital, as consensus on any new name should ideally be derived from a large, diverse sample of all relevant stakeholders and a rigorous scientific consensus. It is particularly critical to continue to include the voices of people who live with the condition, who are often marginalized and suffer inequities, a point cogently and eloquently illustrated by a recent paper in this journal[9] describing the lived experience of psychosis.

Words matter. If a name change can even be part of what leads to improved lives for people with the condition, then isn't it worth it? Why keep a name that the majority of people with the condition are not comfortable with, that they feel is stigmatizing and discriminates against them, and that dissuades them from seeking out care? Isn't that reason enough?

What's in a name? Names shift to reflect transformation, and new names catalyze change. As E. Dickinson wrote, "I know nothing in the world that has as much power as a word".

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The authors thank all members of the Consumer Advisory Board of Massachusetts Mental Health Center and other contributors to the Renaming Schizophrenia Survey Project for their ideas, inspiration, and review of this letter.

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DOI:10.1002/wps.21033

Are language features associated with psychosis risk universal? A study in Mandarin-speaking youths at clinical high risk for psychosis

Natural language processing (NLP) analyses have shown decreased coherence (tangentiality, derailment) and complexity (poverty of content) in schizophrenia and in clinical high risk (CHR) states for psychosis. We reported previously in this journal[1] that an NLP machine learning classifier, which included measures of coherence and complexity, predicted psychosis onset in two independent English-speaking CHR samples. Moreover, reduced complexity has been associated with increased pauses and negative symptoms in at-risk youths[2].

Multiple recent NLP studies in schizophrenia and CHR cohorts, using different methods, have largely found this same pattern of disturbance in the structure of language and speech[3]. Most of these studies have been conducted in English, with notable exceptions including Dutch, Portuguese and Spanish[4]. It remains unknown, however, whether NLP findings obtained in English or other Indo-European languages would generalize to less similar languages, such as Mandarin, which has very different grammatical and prosodic conventions.

This study included 20 help-seeking CHR youth and 25 healthy controls who were recruited as part of the US National Institute of Mental Health (NIMH)-funded Shanghai-At-Risk for Psychosis (SHARP) study at the Shanghai Mental Health Center, where institutional review board approval was obtained. Caseness and symptoms were determined using the Structured Interview for Psychosis-Risk Syndromes (SIPS)[5]. Subjects were Han Chinese and spoke Mandarin fluently, and they provided informed consent. Sex distribution was similar between CHR subjects and controls (55% vs. 48% female), but CHR subjects were younger (19.6±6.4 vs. 24.9±1.9 years) and had less education (11.4±4.0 vs. 16.7±1.4 years).

Interviews were approximately 30 min in length, and were based on qualitative methods previously described[6]. They were transcribed verbatim in Mandarin and translated into English using Google Translate, with verification by bilingual researchers. Audio recordings were diarized (segmented by speaker using time stamps from transcription) so that acoustic analyses could be done of subjects' speech.

NLP features analyzed for both English and Mandarin included coherence, complexity, and sentiment (i.e., emotional valence – positive, negative, neutral), as reported previously[1,7]. For English NLP only, sentiment also included anger, fear, sadness, joy and disgust; frequency of wh-words (e.g., "which') was also assessed. For Mandarin NLP only, frequency of measure words, possessives, and localizers (e.g., *gongzuo-shang*, "during work"; or *liangge-renzhijian*, "between two people") was also calculated[8]. Acoustic features analyzed in Mandarin included those characteristic of schizophrenia or CHR states among English-speaking subjects, including abnormal pauses, flat intonation, voice breaks, and