Epidemiology and Psychiatric Sciences

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Editorial

Cite this article: Guloksuz S, van Os J (2019). Renaming schizophrenia: 5 × 5. *Epidemiology and Psychiatric Sciences* **28**, 254–257. https://doi.org/10.1017/S2045796018000586

Received: 10 August 2018
Revised: 7 September 2018
Accepted: 20 September 2018
First published online: 18 October 2018

Keywords:
Diagnosis and classification; DSM 5; evidence-based psychiatry; mental illness stigma; schizophrenia

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Renaming schizophrenia: 5 × 5

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Abstract

There had been a long way to go before we felt comfortable about even discussing the issues revolving around the concept of 'schizophrenia', let alone reckoning on mere semantic revision. In this editorial, we aim to extend our discussion on the reasons behind the slow death of the concept of 'schizophrenia' and the benefits of changing the name and embracing a spectrum approach with an umbrella psychosis spectrum disorder (PSD) category (similar to autism spectrum disorder) that goes further than a mere semantic revision. We attempted to cover the topic of the renaming by providing five most pertinent points categorised under five domains: reasons, signals, challenges, promises and steps for the change. Admittedly, even a modest revision, such as classifying all psychotic disorder categories under an umbrella category of PSD, and abolishing the term schizophrenia requires careful deliberation and some effort in the beginning, but the revision is well worth the effort considering the benefits in the long run. Renaming a particular form of mental suffering should be accompanied by a broader debate of the entire diagnosis-evidence-based-practice (EBP)-symptom-reduction model as the normative factor driving the content and organisation of mental health services that may be detached from patients' needs and reality, overlooks the trans-syndromal structure of mental difficulties, appraises the significance of the technical features over the relational and ritual components of care, and underestimates the lack of EBP group-to-individual generalisability. Individuals may make great strides in attaining well-being by accommodating to living with mental vulnerabilities through building resilience in the social and existential domains. Changing the name and the concept of 'schizophrenia', which goes beyond a mere semantic revision, may become the first step that allows catalysation of the process of modernising psychiatric science and services worldwide.

Language grows and evolves, leaving fossils behind
Lewis Thomas

Schizophrenia is a severe and debilitating chronic brain disorder that is associated with high morbidity and mortality. It is not uncommon to read variations of this standard opening sentence in academic literature, media outlets of professional organisations or mass media. Despite efforts into reducing the public stigma associated with schizophrenia, the dark view of the concept of schizophrenia, of which origins can be traced back to Kraepelin's dementia praecox, continues to influence illness perception. The stigma toward schizophrenia remains to affect the lives of many people suffering from psychosis, their families and mental health professionals. Even though Kraepelin questioned his initial perspective of dementia praecox as an incurable, progressive disease in his late career, the notion that 'good prognosis "schizophrenia" is not mild schizophrenia, but a different illness' has found a large support among the 'neo-Kraepelinians' (Robins and Guze, 1970). Consequently, schizophrenia definition in the diagnostic manuals largely adopted this narrow concept of dementia praecox. With the exception of minor changes, the description of schizophrenia remained the same and so did the stigma attached to the term, which has been a reminder of an age of insanity, hopelessness and asylums. In a recent critical perspective article, we discussed the reasons behind the slow death of the concept of schizophrenia and the benefits of embracing a spectrum approach with an umbrella psychosis spectrum disorder (PSD) category (Guloksuz and van Os, 2018). We further argued that the reconstruction of schizophrenia should go hand in hand with the renaming to achieve the goals. In this brief commentary, we aim to extend our discussion on renaming schizophrenia.

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Five reasons for the change

(1) Schizophrenia, which literally means 'split mind' in Greek, is a confusing and frightening term that is recently metamorphosed to a 'fancy' expression to describe any erratic and

https://doi.org/10.1017/S2045796018000586 Published online by Cambridge University Press

aberrant behaviour, such as an incoherent and self-contradicting politician (Gerson, 2017), volatile financial trade markets (Pitt, 2016), electrons with 'split personalities' (Chase, 2008) or even a country's decision-making process (Schrieberg, 2017).
(2) Over a century, schizophrenia has been associated with insanity, hopelessness, desperation, violence, stigma and discrimination that have put a heavy burden on patients, their families and mental health professionals (Lasalvia *et al*., 2015).
(3) Patients avoid disclosing their condition because of the fear of discrimination and its repercussions, and mental health professionals likewise experience difficulties in communicating the diagnosis of schizophrenia condition with patients and their families (Allardyce *et al*., 2000; Takahashi *et al*., 2009).
(4) Schizophrenia represents only the 30% poor outcome fraction of a much broader psychosis spectrum but receives all attention and forms the prism through which all psychosis is regarded (van Os, 2016).
(5) The deterministic and gloomy prediction of schizophrenia poses a paradoxical challenge for intervention efforts – an excerpt from a psychiatrist in France: 'Persons that turn out "normal" again a few years later, I am forced to consider that I was mistaken about a schizophrenia early diagnosis (Benoit *et al*., 2017)'.

Five signals of the change

(1) Several Asian countries have already officially abolished the term schizophrenia – Japan replacing 'Seishin-Bunretsu-Byo' (split-mind disease) with 'Togo-Shitcho-Sho' (integration disorder); South Korea replacing 'Jeongshin-bunyeol-byung' (split-mind disease) with 'Johyun-byung' (attunement disorder); Hong Kong and Taiwan replacing 'Jing-shen-fen-lie(-zheng)' (splitting of the mind) with 'Si-jue-shi-tiao(-zhèng)' (dysfunction of thought and perception) (Sartorius *et al*., 2014; Yamaguchi *et al*., 2017).
(2) Following the trend in Asian countries, various different alternatives have been proposed by scholars, service patients and professional organisations across the world, each with a different emphasis and varying degrees of accompanying reconceptualisation: 'Kraepelin–Bleuler disease' (Kim and Berrios, 2001), 'Neuro-Emotional Integration Disorder' (Levin, 2006), 'Salience syndrome' (Van Os, 2009), 'CONative, COgnitive and Reality Distortion (CONCORD) syndrome' (Keshavan *et al*., 2011), 'Psychosis Susceptibility Syndrome' (George and Klijn, 2013), 'Bleuler's Syndrome' (Henderson and Malhi, 2014), 'Psychosis Spectrum Disorder' (Guloksuz and van Os, 2018).
(3) Two major academic journals for schizophrenia research have substantially revised their titles within the limits of pragmatic considerations (adding a subheading to avoid losing the impact factor): '*Schizophrenia Bulletin*' to '*Schizophrenia Bulletin: The Journal of Psychoses and Related Disorders*' (Carpenter, 2016); '*Schizophrenia Research*' to '*Schizophrenia Research: A Translational Journal of the Psychosis Spectrum*' (Keshavan *et al*., 2017)'.
(4) The spectrum approach has gained traction; and the idea of schizophrenia as a distinct categorical entity has been contested with the recent releases of the research framework of the National Institute of Mental Health, Research Domain Criteria (Cuthbert and Insel, 2010) and the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) that revised the Schizophrenia and Other Psychotic Disorders section in DSM-IV to Schizophrenia Spectrum and Other Psychotic Disorders (Heckers *et al*., 2013).
(5) The timeline of psychiatry confirms that change is the only constant – replacing dementia praecox with schizophrenia, manic depressive illness with bipolar disorder and, more recently, mental retardation with intellectual disability.

Five challenges of the change

(1) Renaming schizophrenia requires serious consideration of societal, medical, economic and legal ramifications – making it in fact all but impossible to introduce meaningful change (Keshavan *et al*., 2013).
(2) Further research is required to evaluate the positive and negative impacts of renaming (Yamaguchi *et al*., 2017).
(3) Many alternatives for the term schizophrenia have been proposed in the last decade, but there is no consensus on the replacement for the term schizophrenia (Lasalvia *et al*., 2015).
(4) Schizophrenia is arguably an established and time-tested diagnostic category that many believe has high inter-rater reliability and considerable clinical utility (Lieberman and First, 2007).
(5) A semantic revision without a conceptual change will only have a temporary effect on decreasing stigma (Koike *et al*., 2015), as the new term will inherit the public image of the illness; however, extensive reconceptualisation is even more challenging than a simple semantic revision regarding the scarcity of available data.

Five promises of the change

(1) Renaming schizophrenia differentiates the new medical term from metaphoric misuse of the term schizophrenia and its adjective labelling form 'schizophrenic' that sustains the negative public image of the illness (Sato, 2017).
(2) A name change will reduce iatrogenic hopelessness, stigma and discrimination.
(3) A new name will stimulate public awareness and anti-stigma interventions by improving the public image of the condition.
(4) A name change facilitates communication and shared decision-making between patients and mental health professionals, increase help-seeking, engagement and service use (Sato, 2017).
(5) Even a subtle semantic revision, such as an umbrella diagnosis category PSD, may serve as a platform to foster a new generation of open and critical science toward reconstructing psychosis without the restricting boundaries of schizophrenia and the illusion of a single disease entity (Guloksuz and van Os, 2018).

Five steps for the change

(1) Joining forces with patients and the creation of 'wild' joint action forums (e.g. https://www.change.org/p/american-psychiatric-association-apa-drop-the-stigmatizing-term-schizophrenia) are helpful in facilitating bottom-up momentum, educating the public and mobilising forces for change. Action platforms like these may connect with each other in movements that aim to help psychiatry to modernise such as htttp://www.madinamerica.com. Although some of the content at madinamerica.com may be considered 'anti-psychiatric', service users sometimes argue that elements of psychiatric

https://doi.org/10.1017/S2045796018000586 Published online by Cambridge University Press

practice may be considered 'anti-patient'. In other words, there is a need for a dialectical debate where the consideration of the extreme opposites allows for unbiased 'truth'-finding in the middle.

(2) European countries, where momentum for change appears to be picking up, may attempt creating, at the level of the European Psychiatric Association, a joint forum with patients, for example, the European Patients Forum, a platform to clarify the topic and conduct user and professional surveys about the direction and the pace of change.

(3) Given the status quo of paralysis and conceptual confusion at the level of international bodies and scientific societies, a top-down approach is unlikely to materialise in the short term. However, as described earlier, change can be productively introduced bottom-up at the level of (i) individual clinical practice, (ii) health care organisation and (iii) country. In other words: any clinician or organisation should be encouraged to start with using a balanced and scientific approach in working with psychopathology in the psychosis spectrum (Guloksuz and van Os, 2018).

(4) Academic psychiatry and mainstream journals may work towards a more balanced and modern science of psychosis, i.e. one that also takes seriously the 70% of the phenotype not characterised by a poor prognosis. For example, the regular seminar about psychosis in the *New England Journal of Medicine* this year for the first time was about 'psychotic disorders' rather than 'schizophrenia' (Lieberman and First, 2018). This represents a subtle but meaningful signal that the message is getting through. Hopefully, prestigious journals with similar seminar series, such as the *Lancet*, will follow suit, presenting psychosis as a full spectrum rather than summarising self-fulfilling results pertaining to the selection with the poorest outcome.

(5) Finally, modernisation of the psychiatric curriculum is urgently required, starting with those European countries where the movement for change is strongest. Top academic departments in those countries that focus on psychosis should join forces and present, together with patients, a scientific update on the aetiology, diagnosis and treatment of PSD that has the potential to become the 'standard' in the psychiatric curriculum.

Conclusion

There had been a long way to go before we felt comfortable about even discussing the issues revolving around schizophrenia, let alone reckoning on semantic revision. Unfortunately, neither DSM nor International Classification of Diseases have met the growing demands for the change. Much of the history may be considered wishful thinking, but the change is already here. Several Asian countries have already taken the next step with renaming schizophrenia, while the concept of schizophrenia as a discrete category has recently been challenged more often than not in the scientific community. Admittedly, even a modest revision, such as classifying all psychotic disorder categories under an umbrella category of PSD (similar to autism spectrum disorder), and abolishing the term schizophrenia requires careful deliberation and some effort in the beginning, but the revision is well worth the effort considering the benefits in the long run.

Of course, changing the name of a particular form of mental suffering should be accompanied by a broader debate of the entire diagnosis-evidence-based-practice (EBP)-symptom-reduction model as the normative factor driving the content and organisation of mental health services. As described elsewhere (van Os *et al*., 2018), the diagnosis-EBP-symptom-reduction model appears to be under pressure, as it may be disconnected from what patients need, ignores evidence of the trans-syndromal nature of mental difficulties, overestimates the contribution of the technical aspects of treatment compared with the relational and ritual components of care, and underestimates the lack of EBP group-to-individual generalisability. A growing body of knowledge indicates that mental illnesses are seldom 'cured' and are better framed as vulnerabilities. Important gains in well-being can be achieved when individuals learn to live with mental vulnerabilities through a slow process of strengthening resilience in the social and existential domains. These are not identified as primary objectives in traditional diagnosis-EBP-focused mental health services. Innovative models of integration of social and mental health care, and a recognition of the importance of the existential domain, are required to address this imbalance. In addition, high rates of mental difficulties in the population require the presence of a strong and well-organised public health service (van Os *et al*., 2018). It is proposed that changing the name and the concept of 'schizophrenia', which goes further than a mere semantic revision, may become the first step that allows catalysation of the process of modernising psychiatric science and services worldwide.

The road to change is long and challenging, but there is no obstacle other than our inner resistance to change.

Acknowledgements. None.

Financial support. None.

Conflict of interest. None.

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