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Author for correspondence:
Antonio Lasalvia, E-mail: antonio.lasalvia@univr.it

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Renaming schizophrenia: benefits, challenges and barriers

Antonio Lasalvia and Mirella Ruggeri

Department of Neuroscience, Biomedicine and Movement, UOC Psichiatria, Azienda Ospedaliera Universitaria Integrata di Verona and Section of Psychiatry, University of Verona, Verona, Italy

Schizophrenia is a contested word (Lasalvia, 2018).

Over the last decade there have been a number of campaigns launched by mental health users organisations all over the world asking for a name change (see e.g. the *Campaign for the Abolition of Schizophrenia Label* launched in the UK on 2006 by the 'Hearing Voices Network' and the *Asylum* magazine), based on the assumption that 'schizophrenia' is a stigmatising term that has harmful effects to those to whom it is applied (Howe *et al.*, 2014). In any culture and any part of the world, 'schizophrenia' is the psychiatric term more strongly associated with stereotypes, prejudice and discrimination (Angermeyer *et al.*, 2014); fear, stigma and social rejection towards persons with schizophrenia are very strong and have steadily increased over the last 20 years (Schomerus *et al.*, 2012). This is due to the fact that public image of schizophrenia is dominated by the stereotypes of dangerousness and unpredictability (Corrigan *et al.*, 2002), and this view is sustained by mass media that inappropriately use the term 'schizophrenia/schizophrenic' to indicate any incoherent/contradictory/deviant behaviour or criminal/violent/dangerous person (Magliano *et al.*, 2011).

Even within the psychiatric field there have been calls to change the term schizophrenia as not scientifically valid and unhelpfully focusing on a biological explanation of what is a heterogeneous and context-influenced disorder (Read *et al.*, 2004; Kingdon *et al.*, 2007). Current research evidence and clinical practice suggest that 'schizophrenia' is an umbrella term that describes psychopathological signs and symptoms of groups of patients that indeed have diversified characteristics (Moncrieff and Middleton, 2015). The significant heterogeneity in psychopathology is consequently associated to heterogeneity in biological correlates, cognitive vulnerabilities, environmental exposures, treatment response, illness course, that result in different needs for clinical care (van Os *et al.*, 2009). Even researchers in psychiatric genetics (Craddock *et al.*, 2009) see the diagnosis of 'schizophrenia' as barrier to further progress in their field. For all these reasons, a number of authors (Lasalvia and Tansella, 2013; van Os, 2016; Guloksuz and van Os, 2018*a*) have commented on the weaknesses of the schizophrenia construct for both clinical and research purposes, and have highlighted the need for adopting new approaches in rethinking and, possibly, renaming it.

However, despite years of criticism, in most of the world (with the exception of Japan and some other Asian countries, where the term has been officially replaced with other less stigmatising denominations; Lasalvia *et al.*, 2015) the entrenchment of the term 'schizophrenia' appears to be as deep as ever. The American Psychiatric Association has continued to endorse 'schizophrenia' as a diagnostic entity, and the term has finally appeared as such in the DSM-5; the term 'schizophrenia' is expected to reappear as one of the official diagnostic categories in the forthcoming ICD-11 (Biedermann and Fleischhacker, 2016); scientific journals are replete of articles reporting on research projects designed around the 'schizophrenia' construct; mental health practice continues to rely on categorical diagnostic systems, where schizophrenia is still conceptualised in terms of a 'severe and progressive brain disease'; the public is still being 'educated' about the nature of this 'disease', partly in an attempt to offset widespread stigma associated with the label and partly to reinforce the existing practices built around the currently dominating concept of schizophrenia (Poland, 2007).

Pilgrim (2007) suggests the following reasons for this diagnosis's survival: (1) the financial interests of pharmaceutical companies; (2) the prevalence of 'bio-determinists' in the 'psy-disciplines' and professional interests of psychiatry (i.e. researchers who seek grants for their interventions operate in a context in which medical authority allocates resources according to the gold-standard methodology of randomised controlled trials in clinical populations that must be carved at the joints of Diagnostic Related Groups to warrant grant allocations); and (3) a degree of investment by families of people with severe mental health problems in a simplistic explanation for a complex problem (i.e. most relatives prefer to receive an understandable and clear-cut diagnostic communication, no matter how painful this diagnosis might be, rather than living with the uncertainty).

Poland (2007) proposes three additional explanations for the failure to abandon 'schizophrenia': (1) the powerful interests served by this concept, the inertia of well-entrenched practices, and the contemporary *zeitgeist* (e.g. concerns about efficiency and technological control,

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tendencies towards pathologising problems and deviance); (2) the useful role played by the concept of schizophrenia in contemporary culture (e.g. a role in providing access to healthcare or in distributing research funds and organising scientific research programmes); and (3) the arguments put forward by the critics of 'schizophrenia' just are not as strong as they think (i.e. although the critics may make some good points, they are not good enough to justify the abandonment of the concept or the practices it supports).

More recently, Green (2018) proposed an additional explanation to the 'externalist' accounts (i.e. financial and professional interests of psychiatry and pharmaceutical companies) that draws on factors internal to the theory of schizophrenia: despite its problems, the label 'schizophrenia' continues to exist because, in certain usage contexts, it successfully refers to some aspects of reality: people who have lived experience of severe mental health problems may find that the term schizophrenia 'fits' for them, providing a framework which makes sense of why their experience has taken on a new and very different quality.

This issue of *Epidemiology and Psychiatric Sciences* (EPS) presents three editorials dealing with the issue of renaming schizophrenia: specifically, they weight benefits and disadvantages of a name change and discuss on the obstacles that the changing process may found (or has actually found) on its way.

Maruta and Matsumoto (2018) report on the long and complex process that in Japan led to the official replacement of 'schizophrenia' with the less stigmatising 'Integration dysregulation syndrome'. The renaming process went along with a parallel re-conceptualisation of the disorder, based on the vulnerability stress model and on the assumption that the condition is treatable, with recovery possible if a combination of advanced pharmacotherapy and psychosocial intervention is provided (whereas the old concept was entirely based on a biological neurodegenerative model). It is noteworthy that the process of renaming was prompted by the main national association of family members and supported through its way by the active involvement of both patients and family organisations. The name change had a number of positive effects in Japan, including the improvement of clinician–patient–family communication (with a significant increase in the number of patients and carers informed about diagnosis, prognosis and available interventions) and the reduction of stigma over the medium and the long term in the general population.

Guloksuz and van Os (2018*b*) advocate both a name change and a re-conceptualisation of 'schizophrenia' also in the rest of the world. They propose the adoption of a spectrum approach with an umbrella 'psychosis spectrum disorder' (PSD) category that goes beyond a mere semantic revision. To support this proposal, they provide a 5×5 matrix, including five reasons for the change, five signals of the change, five challenges of the change, five promises of the changes and five steps for the changes, all based on available scientific evidence. Given the *status quo* of paralysis and conceptual confusion at the level of international bodies and scientific societies – the authors claim – a top-down approach is unlikely to occur. The authors therefore propose the implementation of a bottom-up approach in which all potential stakeholders – i.e. patients, families, individual clinicians and health care organisations, mainstream psychiatric journals and top academic departments – should start using a more balanced and scientific approach when addressing issues related to research and clinical management of schizophrenia and related psychoses based on the conceptual framework of the 'PSD'.

On the other hand, Gaebel and Kerst (2018) challenge the proposals to rename and reconceptualise schizophrenia, arguing that it is still a scientifically valid construct that has shown over the years reliability and clinical utility. Further, they maintain that a name change would not resolve the stigma attached to it. They acknowledge that schizophrenia is a stigmatised condition, like however many other mental disorders. Even with a new name, the disorder would not run a better course until further improved treatment and care options will be available. Moreover, aspects of cultural diversity need to be taken into account: even if a name change was successful in Asian countries, this does not necessarily imply that a change of schizophrenia name would result in a similar improvement in western countries.

However, both Guloksuz and van Os (2018*b*) and Gaebel and Kerst (2018) come to the same conclusion that a main obstacle for a name change is the lack of consensus among professionals and users on the best alternative option. Moreover, they both agree that a name change should involve all potential stakeholders (patients and families *in primis*) and evaluate its impacts on societal, medical, economic, and legal levels. They finally agree that a semantic revision without a conceptual change would only have a temporary effect on decreasing stigma if it is not accompanied by a widespread and sustained effort to tackle mental health discrimination at all societal levels.

Despite obstacles and challenges, we think that this endeavour needs to be made, since changing the name (and the concept) of 'schizophrenia' may be the first step that allows catalysation of the process of modernising psychiatric science and mental health practice worldwide.

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