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The debate about renaming schizophrenia: a new name would not resolve the stigma

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Abstract

The concept and name of schizophrenia have been questioned in the scientific community and among various stakeholders. A name change is seen as a means and an opportunity to reduce stigmatizing beliefs and to improve mental health care. Some Asian countries have already taken the step of a name change. So far, however, the scientific community of western countries has not yet come to an agreement on any alternative name. Meeting relevant criteria for a new name, finding agreement among all involved groups and replacing the established term is a complex process. For now, the concept of schizophrenia has proven its reliability, clinical utility and validity, although schizophrenia is a stigmatised mental disorder like many others. Renaming cannot be the only answer to negative beliefs, prejudice and discrimination.

Development of the term and concept of schizophrenia: a brief overview

Early descriptions of the symptoms of a syndrome which we still call 'schizophrenia' since more than 100 years can be traced back to thousands of years ago (Tandon *et al.*, 2009). However, the modern concept and name of schizophrenia were shaped in the early 20th century when the Swiss psychiatrist Eugen Bleuler (1911) introduced the term as an extension and replacement for what was formerly coined 'dementia praecox' by Emil Kraepelin (1896). The psychoanalytically inspired intention behind the new term was to cover the observed deconnection of psychic functions among personality, thinking, memory and perception, which Bleuler assumed to be the prominent feature of the illness. He intended to introduce a broader disease concept and spoke of 'the group of schizophrenias', undermining his understanding of a heterogeneous group of diseases with different aetiopathogenesis, course and outcome – thereby introducing a much more positive prognostic concept instead of the single Kraepelinian disease entity with deleterious outcome. Bleuler made a distinction between primary and secondary symptoms, the former assumed as being closer to the underlying neurobiology, as well as fundamental and accessory symptoms (Bleuler, 1911).

Subsequently, Kurt Schneider, a pioneer by introducing operationalisation into psychiatric classification, defined first-rank symptoms and second-rank symptoms and hypothesised the former being indicative of the presence of schizophrenia (Schneider, 1967). Due to their clear definition and expected diagnostic value, these core symptoms were incorporated in the later versions of classification systems on mental and behavioural disorders being developed since the middle of the 20th century (Tandon *et al.*, 2009).

Although in the major classification systems ICD (International Classification of Diseases) and DSM (Diagnostic and Statistical Manual of Mental Disorders) the name of schizophrenia has been kept since its introduction, the diagnostic concept has undergone several revisions in the decades following. Over time, the concept varied between broader or narrower definitions (Tandon *et al.*, 2009) with resulting better or poorer outcomes (Hegarty *et al.*, 1994). Reliability of operationalised diagnostic categories improved considerably (Keeley *et al.*, 2016), but the validity of the concept itself still remained elusive. Accordingly, schizophrenia is still classified among the mental and behavioural *disorders* and not yet as a *disease* with known aetiopathogenesis despite the huge amount of correlative data from various fields of assessment. However, research is on the move towards proposals on either deconstructing schizophrenia into subtypes by using biomarkers and genetics (Allardyce *et al.*, 2010; Tamminga *et al.*, 2017), or including it into a broader diagnostic spectrum cluster due to genetic overlap (Owen *et al.*, 2010).

In the most recent version of ICD-11, some changes have been made in the chapter of schizophrenia or other primary psychotic disorders (Gaebel, 2012). Schneiderian first-rank symptoms are de-emphasised as in DSM-5 (American Psychiatric Association, 2013) and classical schizophrenia subtypes are omitted. Cognitive symptoms as symptoms of schizophrenia are introduced and specifiers to differentiate course and symptoms of the disorder are added.

Reliability measures for schizophrenia both in internet-based and clinical-based studies have yielded satisfying results (Gaebel *et al*., 2018; Reed *et al*., 2018).

Since many years there are claims, mainly among stakeholder groups but also in the scientific community, to remove the term 'schizophrenia' from ICD-11, but – after serious discussion – the name will be retained as it was in DSM-5. The reason for this claim is based on the fact that schizophrenia is associated with stigma and discrimination attached to dangerousness and unpredictability in the eyes of the public (Sheehan *et al*., 2017). Proponents see a name change as a means and an opportunity to reduce stigmatizing beliefs thereby improving the situation of patients, families and care givers (Lasalvia *et al*., 2015). However, opponents argue that wordplay is not the answer to negative beliefs, prejudice and discrimination (Lieberman and First, 2007; Tracy, 2017).

Proposals for alternative terms

Why changing the name of a disorder and how to select a new one? Is the stigma conveyed by the name or the illness itself? As mentioned above, the concept of 'dementia praecox' transported a much poorer prognosis than 'schizophrenia' or even the 'group of schizophrenias' including 20% of courses with a single, remitting episode. It may be the name itself and its translated meaning which may play a role in cases like in Japan (see below), but what exactly do people imagine by 'split mind'? Negative connotations mainly arise from the underlying or subsumed illness concept and its anticipated practical consequences, and less from the correct meaning of its name which the lay public usually does not know anyway. Whereas today the internet can give information on illness concepts, course and outcome as well as treatment options and prognosis, in former times patients, families or the public were referred to outdated 'conversation lexica' with mainly negative content to inform themselves. Certainly, schizophrenia is still one of the most severe mental illnesses, but much more differentiated information is available nowadays. However, even with a new name the illness will not run a better course until further improved treatment and care options will be available and being supported by ongoing public and targeted campaigns on awareness-building and against stigma (Gaebel *et al*., 2017).

There is no universal way to name or rename a disease. According to the World Health Organization (WHO), having released best practices for naming new human infectious diseases, 'terms that include geographic locations, people's names, species of animal or food, cultural, population, industry or occupational references and terms that incite undue fear' should be avoided (WHO, 2015). In contrast, a disease name should 'consist of generic descriptive terms, based on the symptoms that the disease causes and more specific descriptive terms when robust information is available on how the disease manifests, who it affects, its severity or seasonality. If the pathogen that causes the disease is known, it should be part of the disease name' (WHO, 2015). The best practices were set out to avoid stigmatisation of any group and to avoid the establishment of non-scientific terms in common usage. The WHO has set out these criteria only for new discovered diseases with an emphasis on the difficulty to change terms that are already established.

Schizophrenia has its roots in the Greek terms 'schízein' (split) and 'phrẽn' (mind). Schizophrenia is a well-established part of psychiatric nosology with a thoroughly characterised clinical profile and a high inter-rater reliability among the psychiatric diagnoses (Lasalvia *et al*., 2015). The name is similar in many languages, e.g. 'schizophrénie' in French, 'esquizophrenia' in Spanish, 'schizophrenia' in Polish or 'şizofreni' in Turkish, and it is conceptualised similarly across the world (Lasalvia, 2018). In contrast to these Greek-rooted versions, in Japan a literal translation of 'mind-split disease' ('seishin-bunretsu-byo') was introduced in 1937. This was changed in 1997 and replaced by 'togo-shitcho-sho' (integration disorder) (Maruta and Matsumoto, 2017).

Due to its meaning of 'split mind' and its stigmatizing attributions, the discussion around changing the term of schizophrenia is ongoing. Schizophrenia is perceived as a disorder with poor natural course, non-favourable treatment outcomes and dangerousness. It may evoke fear and anger in lay persons (Sheehan *et al*., 2017). Some patient organisations like the Schizophrenia and Related Disorders Alliance of America (SARDAA) demand a reclassification and recognition of schizophrenia as 'brain illness'. One could hypothesise that the majority of the public is not able to directly associate the word schizophrenia with 'split mind' in its literal meaning. The negative image that people have about schizophrenia is linked to their associations with the term. In order to avoid these negative connotations, there have been concrete alternative name proposals. However, there are a number of requirements for a new name. Among others, it should be precise (clearly defined), neutral, non-stigmatizing and easy to understand. It should cover the core features of the disease and it should be valid in the sense that it is supposed to clearly reflect what it claims to represent. Some propose that a new name should be an eponym, thus a word derived from a name (Lasalvia *et al*., 2015). Eponyms may be neutral and could avoid connotations. Attempts of introducing an eponym for schizophrenia had already started in times when it was a relatively new term. In the clinical daily routine, the disease had been called 'Morbus Bleuler', supposedly to reduce stigmatisation (Mirić *et al*., 2013). A more recent suggestion of this eponym is 'Bleuler's syndrome' (Henderson and Malhi, 2014). Other eponym suggestions include 'Bleuler's and Kretschmer's syndrome', 'Schneider's syndrome' or 'Kraepelin–Bleuler Disease' (KBD) (Lasalvia *et al*., 2015; Lasalvia, 2018).

Besides these eponym proposals, there are other suggestions that either focus on the biological mechanisms, the descriptions of disease core features or on patient experience.

Murray (2006) suggested 'dopamine dysregulation disorder' as a replacement for schizophrenia. Henderson and Malhi (2014) proposed 'psychotic spectrum disorder' to introduce a less stigmatised term. 'Salience syndrome' and 'salience dysregulation syndrome' have been suggested as new names which are supposed to be closer to the experience of the patients according to van Os (van Os, 2009*a*, 2009*b*). Critics evaluated this name as too vague and too unfamiliar to laypersons (Lasalvia *et al*., 2015). 'Neuro-emotional integration disorder' has been proposed to reflect a biopsychosocial conceptualisation (Levin, 2006). In the Netherlands, the name 'psychosis susceptibility syndrome' has been suggested by the Anoiksis Patient Association, but has been criticised for not covering all central aspects of schizophrenia. Keshevan *et al*. (2011) have suggested 'Youth Onset Conative, Cognitive and Reality Distortion' (CONCORD) to describe schizophrenia with a term that is less stigmatizing and more inclusive of the core features of the disorder.

Taken together, all these examples applied to a 'disorder' and not yet a 'disease' demonstrate that each of the different possibilities do have their shortcomings:

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- Eponyms: whose name should be given and why should this reduce stigma?
- Core symptoms/syndrome: psychosis is a defining part, but it does not reflect the whole picture.
- Susceptibility: this would not necessarily include illness manifestation.
- (Neuro)psychological dysfunction: describes just pars pro toto and is difficult to understand.
- Neurotransmitter dysfunction: describes only part of the illness mechanism.
- Metaphoric (Asian examples): questionable as a precise and scientific term.

Despite numerous well thought out suggestions, there is no universal agreement on any of the proposed new names for schizophrenia so far. Moreover, which one would be best suited to reduce the associated illness stigma and work in different sociocultural contexts?

Outcomes from previous name changes

The increased interest in changing the name of schizophrenia in recent years has supposedly been influenced by the movement in Japan which was the first country that introduced a new name for the disorder (Maruta and Matsumoto, 2017). In 2011, South Korea followed this development and replaced 'mind-split disease' with 'attunement disorder' (Lasalvia *et al.*, 2015). In Taiwan 'mind-split disease' was replaced by 'dysregulation of thought and perception' in 2012. Hong-Kong introduced a new name ('dysfunction of thought and perception') along with the old term 'splitting of mind' which is still in use (Maruta and Matsumoto, 2017).

There are studies that confirm the positive effect and the reduction of stigma after introduction of these name changes in Japan and South Korea. It is reported that the new names evoke less prejudice, improve communication between clinicians and patients and promote social integration (Lasalvia *et al.*, 2015; Lasalvia, 2018). But it was also found that the new term was not easy to understand for the public without further explanation. In addition, the media continued using the established name of the disorder (Lasalvia *et al.*, 2015).

However, there is little empirical evidence on the effects of renaming schizophrenia on stigmatisation (Ellison *et al.*, 2015). This is especially true for outcomes that affect patients and family members. Most studies either address professionals or samples of laypersons. There are very few studies that address patients and family members, those who are affected the most by stigma and discrimination. A systematic review by Yamaguchi *et al.* (2017) found only one study that addressed attitudes of family members of schizophrenia patients. According to the authors, this study by Nishimura *et al.* (2005) showed that the name change results in a less severe image of symptoms and less negative attitudes. However, there were no differences in perceptions of social adjustment problems or knowledge about the disorder (Yamaguchi *et al.*, 2017).

Conclusion

Renaming an established and widely used term is a lengthy and complex process and its long-term outcomes are not fully known yet. There are studies that report favourable outcomes of the name changes, like, for example, improved communication between patients and clinicians and less stigmatizing attitudes towards people with schizophrenia (Yamaguchi *et al.*, 2017). But there are also studies that found no significant differences between different names (Tranulis *et al.*, 2013). Thus, the outcomes of renaming are still inconclusive (Yamaguchi *et al.*, 2017). In addition, the majority of studies focus on professionals and not on those who are affected the most: patients and families. More studies including these groups need to be conducted in order to get a broader picture on the implications of a name change. Besides the limited evidence base, the aspect of cultural diversity needs to be taken into account. Even if a name change of 'mind-split disease' was successful in Asian countries, this does not necessarily imply that a change of schizophrenia would result in a similar outcome improvement. Changing 'schizophrenia' would be a whole new endeavour. And so far, the scientific community has not come to an agreement on any alternative name for schizophrenia. Finding a new name which all relevant groups agree on is an enormous challenge that still has to be faced. Probably, this will not be solved until the underlying causes of the disorder will be discovered so that schizophrenia can be re-conceptualised (Lieberman and First, 2007). For now, the current term and concept have proven their reliability, clinical utility and validity.

Changing names does not necessarily resolve the problem of stigma as the conflicting evidence shows (Yamaguchi *et al.*, 2017). Stigmatised properties could be carried over to a new name and a possibly positive effect would be of temporary nature (Lasalvia, 2018). What really needs to be changed is the way that mental illness is seen by the public. It needs to be ensured that all members of society are treated respectfully and have equal rights. This is the kind of activism that is effective for all discriminated groups, regardless of their naming (Tracy, 2017). Misconceptions and stereotypes need to be dissolved by education, positive advocacy and by setting good examples.

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