

## Name Change for Schizophrenia

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Psychiatric disorders carry a stigma that usually leads to discrimination and resulting problems in many walks of life. People with mental illness thus have difficulties getting a job, finding housing, and making (or keeping) friends or partners. The stigma adds misery to the life of persons with a mental disorder. It affects their families as well as professionals and others who provide them with care.

A number of studies demonstrated that people with mental disorders avoid seeking help because they are afraid of stigmatization and its consequences.<sup>1–3</sup> If they come to a service and their condition is given a diagnosis, they hide it. Doctors hesitate to tell their patients a diagnosis because it is stigmatized, linked to notions of dangerousness; incurability and unpredictability, which makes patients feel that there is no hope and that there is no point in following recommendations concerning their lifestyle or the treatment of their illness.

In recent years, several countries in which psychiatric diagnoses are used in their local language form decided to change the name of 2 most severe mental disorders: schizophrenia and dementia. This in turn should lead to better collaboration in treatment, facilitate rehabilitation, and enable the inclusion of patients in their community and other social networks.

It was accepted that a change of name must be accompanied by an updating and revision of the concepts of diseases: thus for example, the notion that schizophrenia inevitably leads to poor outcome would have to be replaced by available and accepted evidence that many people with schizophrenia who are given appropriate treatment recover and can lead a normal life<sup>4</sup> and that the condition of those whose disease is resistant to treatment can be improved to a significant degree. This article describes changes and proposals for change in several

Asian countries. Proposals to change the name of schizophrenia have been made by user groups in Europe<sup>5,6</sup> and by scientists (eg, salience disorder), but these seem to have advanced considerably less fast to the acceptance of any change by European psychiatrists or nongovernmental organizations of patients and their family than was the case in Japan and other countries in the Far East.

Japan was the first country to change the previously used name of schizophrenia, “Seishin-Bunretsu-Byo” (mind-split-disease) into the new name of “Togo-Shitcho-Sho” (integration disorder). The change of the name was accompanied by a shift from the Kraepelinian “dementia praecox” tradition to a concept based on the vulnerability to stress model. The process of renaming had been started by a formal request of the National Federation of Families with Mentally Ill in Japan (NFFMIJ) to the Japanese Society of Psychiatry and Neurology (JSPN). The change of name, it was hoped, would remove stigma carried by persons who were labeled with the old term. JSPN decided to change old term into new one, provided that (a) the change did not result in any disadvantage to the patients and (b) the term conveyed the concept that schizophrenia is a disorder defined by a clinically significant syndrome, but not a disease defined by a specific etiology, symptomatology, clinical course, and pathological findings. After consultations about the appropriateness of the new term and a public hearing, the new term was approved as new medical term by the JSPN General Assembly and announced at the WPA Yokohama Congress in 2002. One month later the Japanese Government approved the use of the new name as the official term. A survey carried out 7 months after the official approval of the use of the new term showed that 78% of psychiatric practices used the new term.<sup>7</sup>

The JSPN introduced the term Seishin-Bunretsu-Byo for Kraepelin's dementia praecox in 1937. The concept of Seishin-Bunretsu-Byo was almost the same as Kraepelin's concept of dementia praecox and described schizophrenia as a mental disorder characterized by severe mental deterioration, lack of volition, and incompetence in social and personal roles. The condition was described as hereditary and untreatable without a chance of recovery. The exclusion policy expressed by the "Seishinbyosha-Kango-Ho" (Act to keep people with psychosis under observation [1900–1950] and the Eugenic Protection Act [1940–1996]) marked the old name for schizophrenia with severe stigma, which was also attached to people who had the disease and contributed to the inhumane treatment of patients with Seishin-Bunretsu-Byo.

The new Togo Shitcho-Sho name for schizophrenia was introduced with a new concept of the disorder that was defined by a characteristic cluster of symptoms that are amenable to treatment so that patients can expect full and lasting recovery if treated with modern pharmacotherapy and given psychosocial care.<sup>7,8</sup>

An early effect of renaming the disorder and of the introduction of the new concept was an increase of the percentage of people who were informed about their diagnosis (from 36.7% in 2002 to 69.7% in 2004:  $n = 1944$ ). Moreover, 86% of psychiatrists of the 136 psychiatrists working in the Miyagi prefecture found that the new term makes it easier to inform patients and family about the diagnosis, which in turn facilitated education about the illness and psychosocial interventions.<sup>4</sup>

It also appears that the introduction of the new terms leads to realistic optimism of mental health professionals as well as consumers. People with schizophrenia now visit mental health specialists more easily and often open the session by referring to the new term of schizophrenia. Many people who experienced schizophrenia participate in spreading the modern concept of schizophrenia in society.

A recent web survey of 500 citizens (Sato et al, in preparation) reported that the new term was known to 56% of the participants and the old term to 63% of the subjects. Younger participants (>30) knew the new term significantly more often than the old term, while those aged 50 or more knew only the old term. The image of the disorder and social distance measures rated by people who knew only new term or only the old term were sharply different. Those who knew only the new term found it easier to imagine the illness (76% vs 24%), considered that the disease was less severe (23% vs 87%), felt that patients should disclose the diagnosis (93% vs 7%), and did not feel that the relationship with people with schizophrenia should be stopped (51% vs 37%). Social distance measures also showed that those families with the new term had much less of a distance from people with schizophrenia than those families with the old name.

The new term for schizophrenia with the updated concept of the disorder may in the opinion of Japanese

mental health specialists change the public image of schizophrenia from a concept marked by fatalistic pessimism to one characterized by realistic optimism and thus promote recovery reducing public stigma and self-stigma.

In Korea, the term for schizophrenia was "Jeongshin-bunyeol-byung, Jeongshin ('mind')-bunyeol ('splitted')-byung ('disorder')." The previous name of schizophrenia, which means "split-mind disorder," stigmatizes the patients with schizophrenia, their caregivers, and mental health professionals.<sup>9</sup> In addition, people confused this name with "dissociative identity disorder."<sup>10</sup> The new term for schizophrenia is "Johyun-byung (attunement disorder)," which implies that patients with schizophrenia need to "tune" their mind as they would do with strings of violin or guitar. Renaming the split-mind disorder as attunement disorder is expected to result in a reduction of prejudice and discrimination against patients with schizophrenia.

In Hong Kong, the old Chinese name of schizophrenia "Jing Shen Fen Lie" (精神分裂) meant literally "splitting of the mind" and was associated with stigma. A new name "Si Jue Shi Tiao" (思覺失調) was introduced for psychosis some 10 years ago. This new Chinese name denotes "dysfunction of thought and perception" and there is an implication of reversibility and potential for treatment. This new name is well accepted by the public and the professionals because it is considered to be less stigmatizing.<sup>11</sup> To date, there are no local studies to establish whether this new Chinese name decreases stigmatization and helps in the early detection of psychosis.

In Singapore, the Chinese term for schizophrenia is also "jing shen fen lie zheng" (精神分裂症) or "splitting of the mind." This literal translation of the word schizophrenia has ominous implication for the patient, who bears the brunt of mockery. Psychiatrists in Singapore often explain to the patient and family that schizophrenia is a "disorder of thinking" and not "madness" or "spirit possession." This approach encourages adherence to treatment and allays anxiety about poor prognosis. There is no formal proposal to change of name of schizophrenia as yet.

In China, the name of schizophrenia (精神分裂) has not yet been changed. Just like Japanese 1500 years ago brought Chinese characters into Japan, Chinese just borrowed Kanji (漢字) from Japanese when they translated English books. It was estimated that there were more than 1000 Kanji pictograms brought into modern Chinese, particularly in medicine. Therefore, a lot of medical terms used in China are actually from Japan, including those of schizophrenia and dementia: the Chinese name of schizophrenia and dementia are exactly the same as the Japanese Kanji.

Although, in China, professionals and patients as well as families believe that the Chinese language term for schizophrenia is a stigmatized name, there are no proposals thus far from either side to change it. In part, this is because the renaming process is very complex: the

psychiatric society would have to submit the application to the Chinese Medical Association for review and approval. The Chinese Medical Association would then submit this application to the Chinese Association of Science and Technology (CAST). After the approval by CAST, the application would go to the China National Committee for Terms in Sciences and Technologies, which the Chinese government authorized to review and release technical terms for general use.

In Taiwan, the traditional Chinese term for schizophrenia was based on the concept of “mind splitting disease,” which was translated as “精神分裂症” (original complex form of Chinese word, pronounced “jīng shén fēn liè zhèng,” mind splitting disease). Unfortunately, the Chinese word “分裂,” with the denotation of “splitting” in Taiwan made the original complex form of Chinese term for schizophrenia more stigmatized than those used to label other mental disorders in Taiwan. Renaming schizophrenia has been discussed for the past 20 years by several opinion leaders and during meetings and 5 years ago Professor H. G. Hwu, several senior psychiatrists, social workers, other professionals, patients, and their families initiated a movement to change the original name for schizophrenia. Public advocacy and educational campaigns regarding the importance of renaming schizophrenia have been launched. Several potential terms were proposed. Finally, 3 most popular/appropriate terms were selected as candidates for the next term vote based on the poll of the Alliance for Mental III of the R.O.C., Taiwan. In October 2012, the new Chinese term for schizophrenia (sī jué shī tiáo zhèng, 思覺失調症, disorder with dysfunction of thought and perception) was chosen by Taiwanese psychiatrists at the 51th Annual Meeting of Taiwanese Society of Psychiatry (TSP), held in Tainan, Taiwan. The TSP announced the new Taiwanese term for schizophrenia and it is expected that the government will accept the new name for schizophrenia. TSP hope the term “思覺失調症” will be used in the Chinese version of Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. A survey regarding attitude changes after the introduction of the new term from the public viewpoint is envisaged.

Preliminary findings indicate that the changes of names of mental disorders, particularly, if accompanied by changes of the concepts of the disease by an appropriate education of medical staff and by the provision of evidence to the patients, their families, and their communities can be very helpful.

Changing the names of diseases and accompanying this by a reformulation of concepts of disease may thus be a way to reduce the stigmatization that the currently used diagnostic labels seem to facilitate and perpetuate. The changes that have been introduced in China, Hong Kong, Japan, Korea, and Singapore are a major social experiment, which will produce data that should be assembled and studied. If the changes that have been

introduced do reduce or revert stigmatization, as the preliminary findings seem to indicate, a new avenue of fighting stigma will be opened. It will then be useful to proceed to similar reforms and reconceptualization of other terms used in psychiatry—in other countries of Asia and elsewhere—because that could make the life of patients and families better and the image of psychiatry more positive. Eventually this might also lead to a more general exploration of stigmatizing terms still included in the International Classification of Diseases and to the increase of attention to the use of words that might hurt in medicine. The positive results of the introduction of the concept of recovery as the goal of treatment is an example of such a change, which has revitalized thinking about rehabilitation and helped efforts leading to inclusion of people with a mental illness into society.

Stigma related to mental illness is undoubtedly the main obstacle to the improvement of mental health care. It is attached to the disorders, their names, people who are seen as being mentally ill, services which are developed to help them, and families of people with mental disorder. Stigma is related to ignorance about mental illness—providing more information and knowledge can help in the reduction of stigmatization and its consequences. Diagnoses used in psychiatry are heavily loaded with stigma and changing the name of the mental disorder provides an opportunity to say that we have learned a great deal about the disorder and that therefore it is time to also change its name. It is clear that the change of the name alone is not enough: it must be seen and experienced as part of a change of the health system, which is necessary not only to better protect human rights of the mentally ill but also because new knowledge opened new vistas and new avenues of dealing with mental illness.

The change of the name of schizophrenia in Japan went hand in hand with an effort to present an update of the concept of schizophrenia—its origin, pathogenesis, course, and methods of treatment. The first results of the change were most encouraging—seen in the relationship of patients and doctors. It will be of great importance to continue assessing the effects of the change of the name for schizophrenia. If it turns out that the early positive results are confirmed, it might be useful that psychiatric societies—such as the American Psychiatric Association—and patient associations and governmental and intergovernmental organizations, such as the World Health Organization, consider taking the same course that Japan and other countries in South East Asia have taken.

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