

A modern name for schizophrenia (PSS) would diminish self-stigma

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The first country to change the name of schizophrenia was Japan (Sato, 2006). The campaign began in 1993 after an initiative by the family movement. They approached the Japanese Society of Psychiatry and Neurology (JSPN) to find a new name for *Seishin Bunretsu Byo* (split mind). This was but a part of the programme to counter the misunderstandings and prejudices surrounding the concept of schizophrenia. After a series of polls, symposia and study days the committee of the JSPN responsible for the image of schizophrenia chose the name *Togo-Shitcho Sho* (integration dysregulation syndrome). After a public hearing the term was adopted. The result was that patients were better able to accept the diagnosis. The stigma associated with the old terminology dates back to the frightening treatment of people with schizophrenia and the poor course of the disease at the end of the nineteenth century and the beginning of the twentieth century. The psychiatric application of chlorpromazine had not yet then been discovered.

The stigma diminished as a result of the name change and accompanying dissemination of factual information. The name *Togo-Shitcho Sho* (integration dysregulation syndrome) was more acceptable to patients than “split mind”: psychiatrists were able to inform their patients of the diagnosis in a more acceptable way, resulting in better adherence and less relapse; patients were more willing to seek help; there were fewer suicides, indicating that patients had a healthier self-image and less self-stigma.

Evans-Lacko *et al.* (2012) have shown that there is a trend for patients’ self-stigma to arise from internalisation of surrounding stigmatising attitudes. By statistics the subjective is made objective: Evans-Lacko *et al.* conclude from data-sets from the Eurobarometer survey and the GAMIAN-Europe study that there is a connection between public stigmatising of mental illness and patients’ fragile self-appraisal: patients are prone to internalise the stigma attached to mental health problems by the general public. Furthermore it stands to reason that if we do not accept ourselves, warts and all, our mental health will not get any better. As a leading self-disclosed publisher of a magazine on schizophrenia, *Sz magazine*, Bill MacPhee, says: “Recovery is not wanting to be anyone else than who you are today” (Cited by permission; <http://www.mentalwellnesstoday.com/>).

We as patients/consumers/service users welcome objective evidence-based research into the public stigma attached to mental health problems. Objective evidence-based conclusions are helpful in shaping our campaigning and for our understanding of our own subjective experience. We submit that the reverse can also be true: subjective experience can enlighten the research data.

We as patients are aware of the insidiousness of internalising hostile public attitudes. Our response as members of *Anoiksis*, the Dutch association of and for people with a susceptibility to psychosis, is to provide open and honest self-portraits and information to the public about our condition as people with schizophrenia. Like the English *Time to*

Change campaign (see London and Evans-Lacko, 2010; Thornicroft, 2011) we at *Anoiksis* are working mainly through direct personal contact but also through the media. Corrigan *et al.* (2001) have shown that replacing myths about mental illness with accurate conceptions by education works: it is almost as effective as person-to-person contact in improving attributions about schizophrenia and other severe mental illnesses. (In that study protest yielded no significant changes in attributions!)

Anoiksis has recently produced a one-off glossy magazine *SKIZ'O: Het NORMAALSTE magazine van Nederland* (*SKIZ'O: The most NORMAL magazine of the Netherlands*) (ed. Muis, 2010) and a photo album with interviews, *Meer dan dat... 10 portretten van mensen met schizofrenie* (*More than that... 10 portraits of people with schizophrenia*) (Muis, 2011). Some of our *Anoiksis* members have given open and honest self-disclosing interviews to journals and national dailies and made radio and TV appearances.

We are providing insights into the condition in conjunction with a campaign to change the label “schizophrenia”. That label we experience as encapsulating the hindrance to our self-acceptance. It stands in the way of a healthy self-regard. It is not a question of exaggerating our self-esteem, but of our acceptance of ourselves as we are. It is no good fudging the negative aspects of our condition. Honest “disclosure and positive social contact”, as London and Evans-Lacko (2010) point out, is the most effective means of better informing the public about what our mental illness actually consists in (see also Thornicroft, 2011). We as patients find that the process of disclosure as well as gaining some understanding from the public helps to improve the self-regard of the individual. However, we as members of *Anoiksis* feel hamstrung by the associations of the traditional name of our condition. That a new name can offer more social opportunities to those labelled by it is shown by the case of Down Syndrome. Since this term was introduced, people with Down Syndrome are treated with greater respect and better accepted in society.

At the end of the 19th century the German professor of psychiatry Emil Kraepelin (1856–1926) introduced the term “dementia praecox” (premature dementia) to distinguish this potentially psychotic condition from manic depression. At the beginning of the 20th century the Swiss professor of psychiatry Eugen Bleuler (1857–1939) replaced that term by “schizophrenia” (Louter, 2010). Since Bleuler’s time much has changed.

In our view the name “schizophrenia” is out-of-date and out of touch with modern science: partly through medication people with “schizophrenia” can now participate in society much more easily than they could a century ago; furthermore the name “schizo-phrenia” suggests a split personality, which has nothing to do with our potentially psychotic condition. Various parties are now making proposals for a new name for schizophrenia that fits a modern (scientific) understanding. Japan played the first card. Hong Kong, Korea and China are following suit.

In 2009 the Dutch patient society *Anoiksis*, recognising the need to find a better name, held a competition. The winning name out of 320 entries was Dysfunctional Perception Syndrome, or DPS. Immediately there was criticism of this name too: a person wearing spectacles also has dysfunctional perception; you can make of DPS Dual Personality Syndrome; and “dysfunctional syndrome” is a tautology.... you don’t talk about “dysfunctional metabolic syndrome” but about “metabolic syndrome”.

The chair of the appropriate DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) work group of the American Psychiatric Association, Will Carpenter, wrote to us in an e-mail on 20 October 2012:

Stigma is a problem for many reasons. A name change may be helpful, but a name change needs universal use and should be worked out by a properly constituted work group comprising the relevant stakeholders making a recommendation to the International Classification of Diseases (ICD) and DSM processes. I think it would be proper for the World Health Organisation (WHO) to use its convening authority to address this issue. (Quoted by permission.)

The choice of a new name is under vigorous discussion globally (van Os, 2009; George, 2010a, 2010b). *Anoiksis* is now campaigning internationally for the term “Psychosis Susceptibility Syndrome” (PSS). “Psychosis” because it covers the unreality of both hallucinations and delusions. “Susceptibility” because a person with schizophrenia is in many cases not psychotic all the time. “Syndrome” because it includes the negative and cognitive symptoms that are significant elements of this whole complex condition.

“Negative symptoms” refer to deficiencies in a function that is normally present, such as affective flattening (emotional distance, loss of feelings), apathy (lack of energy, initiative and interest), asociality (avoiding company, diminished awareness of the environment, greater need to be alone), anhedonia (loss of ability to experience pleasure), alogia (poverty of speech), lack of perseverance and feeling empty (cf. Lewis *et al.* 2009).

By the “cognitive symptoms” we think of attention deficit, poor memory leading to inefficiency at work or school, indecision, difficulty solving problems and making plans, lack of ability to interpret body language (cf. Haycock, 2009). People can in severe cases get so disorganised that they need to live in a hospital.

Moreover many of us have difficulties connecting to other people. This reflects precisely what we experience. Besides the grief of the impoverishment of mental life and lost mental and practical abilities, we have to deal with stigma that our behaviour (or non-behaviour) evokes. We are lazy, uninterested and not motivated to work, they say. People tend to attribute the above groups of symptoms to the personality of a person; that’s why it is so important to educate society. Life with our “disease” is tough enough without having to cope with stigma in addition.

The discussion about the label provides us with an opportunity to relate what “schizophrenia” is actually about. As far as *Anoiksis*’ outreach is concerned this is our most important task: to continue to disclose an open and honest account of our condition in order to set up a virtuous circle. That fits with the tenor of the research by Evans-Lacko *et al.* (2012). Providing better information about mental illness and facilitating direct social contact in order to lessen the stigmatising by the general public will also enable us patients to form a healthier image of ourselves.

Declaration of interest

The authors are *Anoiksis* Foreign Affairs Co-coordinators.

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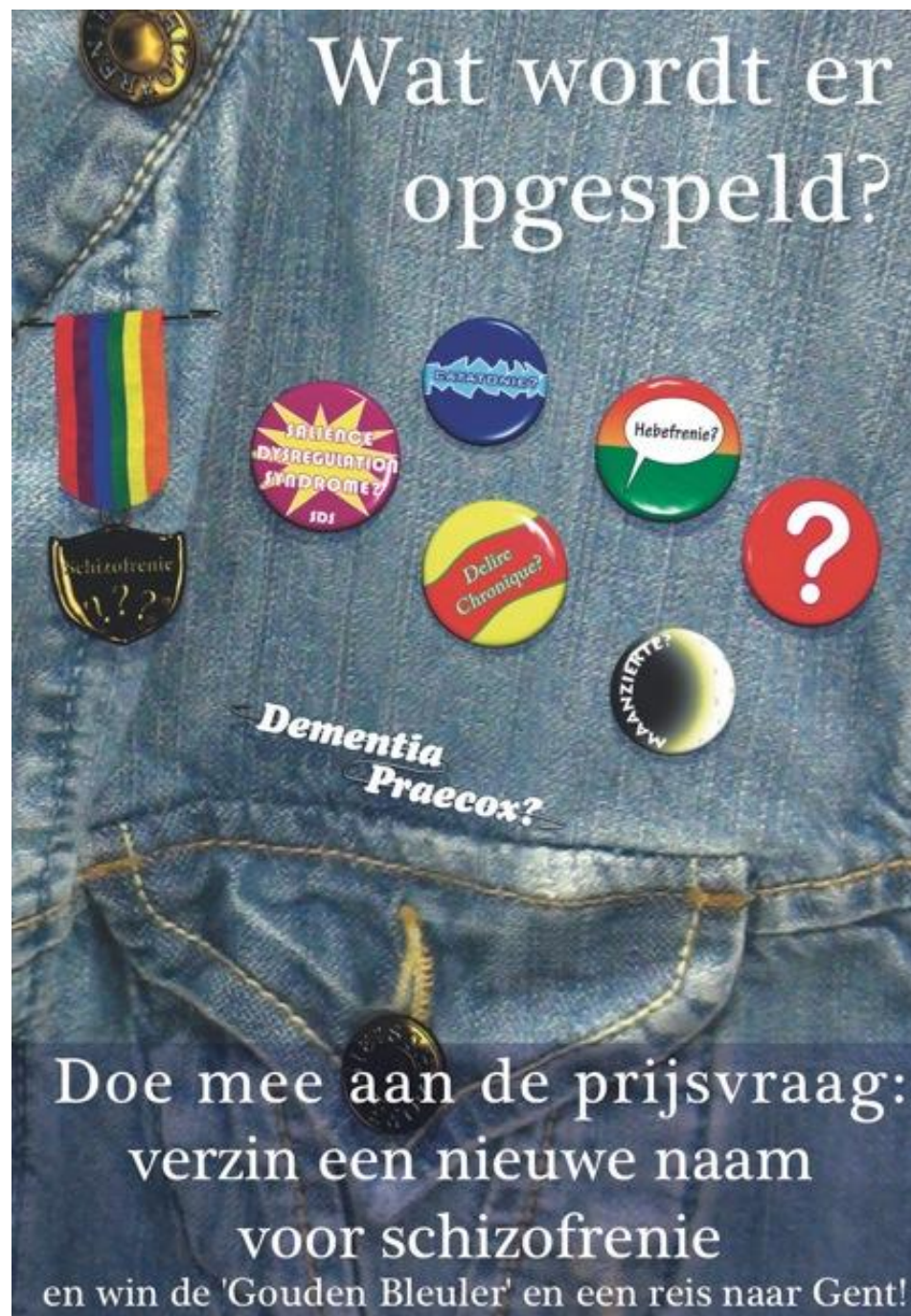
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