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Psychological Medicine, 43 (2013).
doi:10.1017/S0033291713001244

Letter to the Editor

A sweeter smelling rose: a reply to our commentators

In our recent article at the beginning of the Forum section in *Psychological Medicine* (George & Klijn, 2013) we described PSS (Psychosis Susceptibility Syndrome) – the new name for schizophrenia officially approved and promoted by Anoiksis, the Dutch patient association. The editor of *Psychological Medicine* kindly arranged for four commentaries to react to our presentation. We are indeed grateful to Sugihara & Takei (2013), Brabban *et al.* (2013), Bentall (2013), and van Os *et al.* (2013) for their commentaries. They accept that the term schizophrenia is stigmatizing. Moreover, some added, in the words of Bentall (2013) that the term schizophrenia ‘fails to achieve any of the purposes for which it was originally designed’. Further, they tacitly agreed with Bentall that ‘the problem has become not whether to replace schizophrenia, but what to replace it with’.

Nevertheless, the commentators simply ignored our main proposal – to replace the term schizophrenia by PSS (Psychosis Susceptibility Syndrome). So let us now highlight that proposal. One of the members of our patient association Anoiksis, Jeanny Severijns, has composed the following metaphor:

When someone is susceptible to colds, he does not have a cold. He does, however, need to take account of this susceptibility: he needs to put on warm clothes, not stand in a draught, and so on. When this person has a cold, we say he has caught a cold. In someone who has the diagnosis PSS the susceptibility can kick in. Then he is psychotic. When he comes out of the psychosis, he still has PSS, unless his susceptibility has been cured. *Psychosis* is a crucial factor in our proposal (J. Severijns, personal communication, cited with permission).

We choose the word susceptibility for three reasons. *Susceptibility* is less negative than vulnerability; *susceptibility* is easier to pronounce than vulnerability for a non-native speaker of English. Moreover, the patient is *susceptible* in that the psychosis is latent: there is always the ever-present danger of a relapse, more so than after a recovery from a psychosis caused by hard drugs, intoxication, LSD or certain metabolic disorders. The difference between PSS and other psychoses lies in the measure of susceptibility. Further,

for example, there is an overlap between PSS and schizo-affective disorder.

Our proposal – PSS – received no direct criticism; however, the criticism Bentall levels against one particular rebranding attempt – salience syndrome (van Os, 2009) – would be equally applicable to our proposal of PSS (Psychosis Susceptibility Syndrome). Namely that it ‘cannot apply to dimensions other than the positive’. But this is to miss the force of the word *syndrome*. A syndrome is a cluster of characteristics none of which are essential, but all of which are of the essence. Thus a salience syndrome – or a psychosis syndrome – includes the other dimensions of symptoms which tend to go together with positive symptoms, i.e. negative and cognitive symptoms. We argue that PSS covers all the dimensions by virtue of it being a syndrome. It covers negative symptoms, and also – symptoms that are receiving increasing attention in studies of schizophrenia – cognitive symptoms.

When looking at negative and cognitive symptoms, it is apparent that people with a susceptibility to psychosis have great difficulty in relating to others and are prone to a state of apathy. These individuals, as we also know from personal experience, often lack energy, the capacity to solve problems easily, and a feeling of wellbeing in general.

All the commentators make the point that: ‘If the label were [simply] replaced with a different one, fallacious knowledge about the content would not be rectified’ (Sugihara & Takei, 2013). Public education is vital for reducing stigma. In our article we took this very much into account. We explained that we were seeking a change in the nomenclature *together with* setting up educational projects as was done in Japan, when in 2002 they introduced their new term *Togo-Shitcho Sho*. Some of our members are coming out into the open in order to let people – the public as well as professionals – make contact with individuals with PSS who do not conform to the image often portrayed in the media, i.e. unstable patients who go on a violent rampage. Our argument is that with less self-stigma patients would be more adherent (a more client-friendly word than compliant) to proper psychiatric care.

The responsibility for educating the public rests with the professionals, and equally on us as experts by experience. Therefore, since the beginning of Anoiksis’ rebranding campaign we have produced the most ‘normal’ magazine of The Netherlands *SKIZ’O* (Muis, 2010); the book *Meer dan dat ... 10*

portraits of people with schizophrenia (Muis, 2011); the experience game *Kies je weg*; and the *Guide to Schizophrenia Choice* (together with the Trimbos Institute). We have organized talks and training sessions. And last but not least, some of our members have been featured in the media, not only in newspapers and magazines, but also on radio and television.

Let it not be said that we are 'merely suggesting the replacement of one term with little reliability and validity with another' (Brabban *et al.* 2013).

Declaration of Interest

The authors are Anoiksis Foreign Affairs co-coordinators.

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