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EDITORIAL

What's in a name? Client participation, diagnosis and the DSM-5

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Introduction

Patients are beginning to speak for themselves! In August, the *Journal of Mental Health* brought out an edition devoted to Diagnosis and the DSM-5 that included several articles from the patients' point of view. I can relate to this! – A special edition of the *Journal of Mental Health* (August 2010) devoted to diagnosis and the DSM-5 that also includes articles by prominent patients giving the patients' point of view! Not only that, but the editors and publishers of *JMH* have practised what they preach and have made the whole issue Open Access, so that patients can download the articles for their personal use without having to purchase a (for us) expensive subscription. Full marks!

One of the prominent authors in the August edition – Sir Terry Pratchett – writes that it occurred to him that it was like having two diseases – one Alzheimer and the other knowing he had Alzheimer. But it was better to know, and better for it to be known, because it has got people talking (Pratchett, 2010, p. 364). One might add that by getting people talking a beginning can be made to blow away the cobwebs of taboo, stigma and prejudice. This applies equally to conditions like schizophrenia.

Kjell Magne Bondevik (former Prime Minister of Norway) adds rightly, that to talk with others about your situation is a starting point for recovery – it is so important (Mitchell, 2010, p. 370). It enables one to come to terms with oneself, create a better self-image, and project a better image, not only of oneself but also of others who share the same condition.

Frederick J. Frese has contributed a paper about his experience of paranoid schizophrenia. He claims that the biggest impact on him was probably giving him a purpose and a passion to try to improve the lives of others who find themselves struck down by these serious mental illnesses (Frese, 2010, p. 378). I, too, find that it gives satisfaction and healing to tackle the effects of an iatrogenic diagnosis on public and self-stigma (see Ben-Zeev et al., 2010, p. 319). This is where the association I belong to – *Anoiksis* – comes in.

How we came to be involved

Just after the vernal equinox of 2009, *Anoiksis* with great aplomb proposed collaboration with the American Psychiatric Association. *Anoiksis* is the Dutch association of people with schizophrenia or chronic psychoses. On 28 March 2009, I wrote in an e-mail to the APA:

I would like to propose a collaboration between the American Psychiatric Association and the Dutch *Anoiksis* in the pursuit of Healthy Minds. Next week we will make public our plans to improve the image of schizophrenia, beginning with a national competition within the Netherlands to find a new name if possible that is acceptable to professionals, patients, and their families.

Naturally we did not get a reply: the APA's involvement with its critics and its supporters among patient groups and the general public was not yet that transparent. But a year later, in the spring of 2010, the APA did make itself available to comments and criticism. According to a presentation to the APA's Annual Meeting earlier this year they received the grand total of 8600 comments in response to the first draft of the DSM-5. This was the first time the APA had opened its doors for comments on drafts of their *Diagnostic and Statistical Manual of Mental Disorders*, the diagnostician's bible. It was a welcome step in the right direction. In time for the deadline of 20 April 2010 *Anoiksis* submitted two e-mails and four written submissions to the APA Psychotic Disorders Work Group (APA, 2010; *Anoiksis* Association, 2010; George, 2010a,b; Mol, 2009). The two e-mails were automatically acknowledged but there was no individual feedback to the written submissions. One of the e-mails and all four of the written submissions were about the very concept of schizophrenia. We know that our submissions, together with many others, were distributed to members of the Work Group (Jim van Os, personal communication).

The syndrome concept

One of our ideas was in support of Jim van Os' proposal to re-name schizophrenia in terms of a syndrome of symptoms. Jim van Os, a Professor of Psychiatry at Maastricht University here in the Netherlands, is himself a member of the APA Psychotic Disorders Work Group. A syndrome is a fuzzy set of features out of which a selection would qualify for the condition. For example, the metabolic syndrome is well known to us consumers. This is because it is one of the unfortunate long term side effects of the medication – or rather, it is not one side effect, but a fuzzy set of side effects. I have myself been taking antipsychotic medication for well over 50 years, starting with chlorpromazine in the late 1950s. I am now overweight, have a pacemaker, and borderline diabetes as a result of treatment for schizophrenia. These and other features tend to go together, but none of them, by itself, is a unique characteristic of the disorder. Contrast this with diabetes itself, which has a specific nature. The Psychotic Disorders Work Group is considering recommending the use of the syndrome concept to describe schizophrenia, although it is not yet being recommended in the classification of many of the other mental disorders. This might be a hurdle barring its implementation.

The *Anoiksis* competition

But what name should we give to the syndrome? It was the suggestion of Michael van Oostende, our *Anoiksis* Amsterdam regional coordinator and moderator of a schizophrenia

internet forum, to hold a competition to find the most suitable name. Should we call it the Bleuler syndrome? (in memory of the professor of psychiatry who propounded the term schizophrenia on 24 April, 1908, at the gathering in Berlin of the leading German-speaking members of the psychiatric profession (Louter, 2010)). Altered reality syndrome? (as suggested by my partner). Sensitive mind disorder? (This was the runner-up of our competition.) Out of the 320 entries, none was found by the jury to cover the ground comprehensively. The jury consisted of Jules Tielens, a high profile, charismatic psychiatrist; Marja Hasert, chair of the family association *Ypsilon*; Gijs Francken, former chair of *Anoiksis*; and Judith Pennarts, a TV editor. They chose as the winning entry Dysfunctional Perception Syndrome. Since then we are quietly dropping the 'Dysfunctional' word, as it has a negative undertone and is anyway covered by the medical concept of a syndrome. This was parallel to Jim van Os' original proposal to call the condition A Salience Dysregulation Syndrome (Van Os, 2009a). He has since also quietly dropped the word 'dysregulation' for the same reason. The jury decided against 'psychotic syndrome', as they were of the opinion that

psychosis is a loaded term with vague implication. Compare for example the term depression: most people know the feeling. That is not the case with the term psychosis. To begin with: your psychosis is not the same as mine. Although there are many similarities, psychoses are experienced variously. Thus psychosis has an unclear implication, and therefore does not meet with our criteria.

They argued that perception covers not only just seeing things and hearing things but also perceiving ideas, the latter also being subject to illusion. 'Perception can be both observation as well as thinking.'

Salience syndrome

Jim van Os has explained the concept of salience in various papers (e.g. Van Os, 2009b), the most recent of which was in this journal (Van Os, 2010). We in *Anoiksis* can relate to that as when one has a psychosis, certain details stick out, like the flank of an army, but they have a significance that does not correspond with the consensus conception of reality. This applies to hallucinations, which are sense data spontaneously arising in a part of the brain and which are not properly filtered out when being relayed by the neurotransmitters to the parts of the brain responsible for consciousness. It also applies to inappropriately salient thoughts – thoughts which arise in the mind and which, like dreams, are not censored by the synapses as having no application in reality. Delusions are often semi-rational, but incorrect rationalisations of how the thoughts come to be in the mind.

I can give examples. During my last major psychosis I was driving a car. The bushes by the side of the road had extra 'salience'. They were not simply bushes, but as I passed them by they seemed to be guiding me on the way to an unknown destination. The dysregulation of the salience was in the fact that I saw the bushes as showing me the way, whereas they were not in fact doing so. Most people can relate to this sort of experience as it is similar to dreams. As for delusions, when I felt that the thoughts in my head were not my own, I quasi-rationally explained them as coming from computers – one at work, one at my home, and one at the home of a close friend (George, 1987, 1988).

So in my view salience syndrome is an accurate name for at least some of the main features of schizophrenia. It does not cover the negative symptoms, but then it is not to be expected that a single expression *could* cover all the elements of such a fuzzy concept. And that is exactly what is meant by calling it a syndrome. *Anoiksis* does not, however,

officially support the re-naming of schizophrenia as salience syndrome. Although the term salience is quite often used in academic writing, it is not used in colloquial speech. Perception is used in colloquial speech.

Psychotic syndrome or perception syndrome?

In our submissions to the APA DSM-5 Psychotic Disorders Work Group we made a pitch for perception syndrome. Perception is something that everyone understands, and it is not hard for the man in the street to imagine what it is like when it goes wrong. There are gradations from sane to mad, just as there are grey areas between black and white. Although that is not to say that there is no difference between them.

The DSM-5 Psychotic Disorders Work Group does not (yet) accept either perception syndrome or salience syndrome. The relevant chapter title in DSM-5 may well become 'psychotic syndromes'. That, as a consumer organisation, we cannot accept. It is after all *our* experiences that the psychiatrists are talking about and legislating over. Psychotic syndrome carries with it far too negative an affect. Although accurate, it is pathological. I could accept it as applying to myself from my own mouth; I would never use it to refer to someone else; I would not accept it when it is used by someone else to refer to me. If psychiatrists are to achieve the adherence they are so anxious to achieve – in our interests – they must use neutral or positive-sounding language and in so doing have the good manners to give us back our self-respect and dignity.

Declaration of interest: The author is Honorary Coordinator of *Anoiksis* International Relations.

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