Letter to the Editor

What's In a Name?*

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Abstract

'What's in a name? This is an open letter about a new name for schizophrenia in the DSM-5. Anoiksis, the Dutch patient society of and for people with a susceptibility to psychoses or schizophrenia, has lobbied the American Psychiatric Association for a new name for schizophrenia. The most recent suggestion — *Schizophrenia* (*Bleuler's Syndrome*) — is intended to do justice also to the negative and cognitive symptoms in the syndrome. This appears to correspond in part with the ideas of the chair of the appropriate American Psychiatric Association's Work Group. The issue now is to gain support from the international mental health community.

Keywords: dimensions, DSM-5, Eugen Bleuler, Schizophrenia, Stigma

Background

On June 27, 2011, Anoiksis made a proposal by registered letter (Anoiksis, 2011) to the American Psychiatric Association to call schizophrenia Bleuler's syndrome in the DSM-5.[1] Anoiksis is the Dutch patient society of and for people with a susceptibility to psychosis or schizophrenia. To our pleasant surprise we received a gratifying and detailed reply from the chair of the Psychosis Disorders Work Group. For the sake of convenience I begin with a summary of the main points of the discussion so far.

Jim van Os, a Dutch psychiatrist from Maastricht, proposed a new name for schizophrenia in 2009: Salience Dysregulation Syndrome (Van Os, 2009a). At first I found Van Os's exposition hard to understand, not only because of the term chosen, but in general. And there were more proposals for a new name to consider, such as those that arose from a competition organized by Anoiksis, which was administrated by Michael van Oostende, whose brainchild it was (George, 2010a,b,c). One of the scientifically based proposals made in the competition was Dopamine Syndrome or Hypodopamine Syndrome. The term Dopamine Dysregulation Disorder was originally proposed by Sir Robin Murray of the Institute of Psychiatry in London (Murray in BBC News, 2006). The dopamine hypothesis on which the name was based goes back more than half a century. Since then there has been ample confirmation that dopamine is a neurotransmitter.

The disadvantage of this name is that there are many more neurotransmitters, such as serotonin and glycine, about which we know little but which may also play a role. So if a new name for schizophrenia were to be linked with dopamine, it would probably be out-of-date within a few decades as science moves on.

The term that is likely to be used in the forthcoming DSM-5, is *Psychosis Syndrome(s)* (American Psychiatric Association, 2011). *Psychosis* is a scientific term that is well known and understood as referring to a condition in which one loses contact with reality. Nevertheless, the term *psychosis* is emotionally loaded, which 'dopamine' is not.

The name that came fifth in the Anoiksis competition, Perception Disorder, is easy to understand and is not emotionally loaded (at least not yet). To me Perception Disorder suggests (not) seeing things; not in the sense of hallucinations, but in the sense of short-sightedness

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[1] From this edition onwards the DSM (*Diagnostic and Statistical Manual of Mental Disorders*) will have Arabic numbering to accommodate digital updates: 5.1, 5.2 etc.

or cataract. The same applies to the term that won the competition, Dysfunctional Perception Syndrome (Mol, 2009). This name was chosen out of 320 submissions by a jury consisting of a representative of the Anoiksis society, the family association Ypsilon, the psychiatrist Jules Tielens, and the research reporter Judith Pennarts for the Dutch television magazine *NOVA*. The jury noted, however (I quote from their report), that *no single term submitted covers all the bases* (*geen enkele ingezonden term de lading dekt*) (Anoiksis, 2009).

Salience: Standing Out

To return to Van Os, who in the meantime, influenced by the analogy with the physical condition Metabolic Syndrome, has dropped the awkward and belittling term *dysregulation*. His current proposal is Salience Syndrome (Van Os, 2009b, 2010). Now I understand what he means. It relates to my own schizophrenic experiences. When I saw the bushes along the roadside while driving directing me to an unknown destination, the bushes became very *salient* — they stood out. When I heard the car radio telling me to commit suicide for the sake of civilization, this was mistaken *salience*. When I saw a fishmonger's logo on the outside of his shop as both a ban-the-bomb symbol and as a symbol for homosexuality, then my association of the two gave the logo extra *salience*. When years ago I saw the red tooth-mugs in the mental hospital, and concluded from the color that it was a communist institution, then my *salience* was *dysregulated*. (That was during the Cold War!) My confession is: I now realize that the problem I had in understanding Van Os was my problem and not his. *Salience* is the extra significance something has; and what a person in psychosis experiences is *dysregulated salience*.

Negative and Cognitive Symptoms

None of the above concepts cover the illness aspect of the condition — the negative and cognitive symptoms such as lack of energy, lack of a sense of well-being, and poor recall and processing of ideas. One solution would be to name the disorder after one of the well-known professors of psychiatry at the end of the 19th beginning of the 20th century — Kraepelin (Kraepelin's Syndrome) or Bleuler (Bleuler's Syndrome) (Louter, 2010).

The German psychiatrist Emil Kraepelin (1856–1926) classified the symptoms of mental disorders and the Swiss psychiatrist Eugen Bleuler (1857–1939) introduced the term schizophrenia (Black & Andreasen, 1999). Using one of these historical names can cover all bases, including both the positive and the negative and cognitive symptoms: the hearing, seeing, and believing things that are not real, as well as feelings of emptiness and the lack of drive and energy, and the inability to think straight. Stefan Meijer has presented a powerful argument for the introduction of the term Bleuler's Syndrome:

> *An attempt is made to capture in a term consisting of two or three words an illness for which a comprehensive description would be appropriate. I understand the reason for doing this. But in my humble opinion the three above-mentioned terms fall short of the target. Moreover* psychotic *and* dysfunctional *are very negative words. (…)*
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> *Bleuler proposed the term* schizophrenia *for a certain illness pattern during a conference in Berlin on April 24, 1908. This is the foundation of my idea to call schizophrenia Bleuler's Syndrome.*
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> *The advantage of Bleuler's Syndrome is that a whole book full of ideas can (if necessary) be linked to it, and that therefore no term of two or three words can convey as much meaning. I plead for Bleuler's Syndrome since this name fits in with the current terminology in the medical world, and because the name does not socially degrade people who have this illness* (Meijer, 2010).

Personally, I feel it is almost a toss-up between Salience Syndrome and Bleuler's Syndrome. Both are improvements on the slander that I have a split personality. Ultimately, Meijer's reasoning clinches the matter. The term *salience* is only applicable to the Schneiderian positive symptoms (hallucinations and delusions); it does not apply to the negative and cognitive symptoms. *Dysregulated salience* is attractive because it describes my own psychotic experience; but it takes no account of my negative and cognitive symptoms. I am aware I have too little energy, flat affect, lack a feeling of wellness, and sometimes 'have a screw loose'. Consider also the fact that someone who hears voices but experiences no discomfort from them, nor is frequently distracted by them, does not fall within the scope of the diagnosis (Sommer, 2011).

Bleuler's Syndrome

After two-and-a-half years brooding over a suitable new name for schizophrenia, I incline towards Meijer and choose Bleuler's Syndrome by analogy with Asperger's Syndrome, Gilles de la Tourette's Syndrome and Down Syndrome. A whole wealth of knowledge and insight can be attached to each of these names. Bleuler's Syndrome would help clarify that the condition is not a single entity but rather a collective name for a variety of symptoms, including negative and cognitive symptoms, catatonia, incoherent speech, and social ineptitude. New scientific discoveries would be associated with the new name and would give us, the clients, a new opportunity: we would be able to make a fresh start and give our condition a more faithful, more accurate, more honest image. If we who suffer from schizophrenia will only come out, we can let it be seen that we are neither more violent nor more dangerous than the average person.

In this way we can reduce both the stigma that society attaches to us and also our self-stigma. This in turn

will reduce the risk of relapse and improve our determination to adhere to our treatment — if, that is, we need it. The introduction of a new term would offer us the opportunity to make clear that we are valuable and respected members of society. We have integrity and we are not split personalities, which is what the present nomenclature suggests.

Our proposal is that the new term Bleuler's Syndrome should at first be added in brackets to the old term schizophrenia, viz., in the DSM-5: B 00 Schizophrenia (Bleuler's Syndrome). The term schizophrenia would be retained for the time being. Once the term Bleuler's Syndrome has become established it can stand by itself.

Lobbying the Psychosis Syndromes Work Group

The forthcoming fifth edition of the DSM is the first for which the American Psychiatric Association has involved the public. There have been two previous periods in which everyone was encouraged to submit their ideas. The third period is in the spring of this year 2012. So far there have been more than 10,000 submissions recommending changes to the DSM-IV (8600 in 2010 and 2000 in 2011). There have been field trials in which new diagnostic criteria were tested.

The DSM-5 committee primarily concerned with schizophrenia is the Psychosis Syndromes Work Group. Anoiksis has lobbied this work group for the introduction of a new name for schizophrenia (Anoiksis, 2011). We received a detailed reply, including the statement that for any proposal for anything as radical as a name change for schizophrenia (a term in use for over a hundred years), not only the American Psychiatric Association but also international organizations such as the World Health Organization and the World Psychiatric Association should be involved. Anoiksis argued further that the patient movement and representatives of families of people with schizophrenia also should be consulted.

The Work Group has carefully considered several proposals that Anoiksis has put forward for a suitable new name for schizophrenia. *The chair of the Work Group thinks personally that the proposal to rename schizophrenia after Eugen Bleuler would lead to a considerable shift in the emphasis in the diagnostic criteria* (Carpenter, personal communication 2011*) from positive symptoms to negative and cognitive symptoms such as feeling ill, lack of energy, drive, and motivation, and incoherence in thought processes* (see also Keller, Fischer & Carpenter, 2011).

Anoiksis would be pleased with such a change, as in fact the negative and cognitive symptoms have the greatest impact on the lives of people with schizophrenia and their families (Carpenter, 2007). These are not only impediments, but are also difficult to treat, even with recovery-orientated treatment and for those of us who are on a recovery route. For the outsider, the delusions and hallucinations are the most striking; for the patient, feeling unwell is the most noticeable symptom. Moreover, research shows that some people who hear voices are not ill. As mentioned above, hearing voices does not by itself justify a psychiatric diagnosis.

Anoiksis sees the shift in emphasis as the swing of a pendulum. In the DSM-IV it moved in the direction of the positive symptoms, and we would like to see this distortion corrected. However, we need to ensure that the pendulum does not move too far toward the Bleulerian negative and cognitive symptoms.

The present proposal of the Work Group for the DSM-5 concept of schizophrenia strikes us as a considerable improvement (American Psychiatric Association, 2011). Schizophrenia is to be deconstructed into nine dimensions that encompass the symptoms and experiences the client/patient is aware of as well as to the observations of those surrounding him/her. This, after all, is a syndrome that can include a multitude of thoughts, emotions, and behaviors. The illness can present in a wide variety of dimensions and gradations of feelings, experiences, and behaviors.

The use of the term *Schizophrenia* (*Bleuler's Syndrome*) need not imply that a hundred years of research have gone for nothing. New scientific discoveries and advances can moreover be linked to it. We welcome the present proposal of the Work Group for DSM-5 to deconstruct the concept of schizophrenia. A new name is therefore appropriate. We hope and plan to enlist full international support for our proposal.

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