Bill George

What's in a name?

Open Letter about a new name for schizophrenia proposed for the DSM-5[1]

Dear Dr Carpenter,

On June 27, 2011 Anoiksis made a proposal by registered letter to the American Psychiatric Association to call schizophrenia 'Bleuler's Syndrome' in the DSM-5.[2] 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 you, 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 professor of psychiatry from Maastricht, proposed a new name for schizophrenia early in 2009: *Salience Dysregulation Syndrome*.[3] 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.[4,5,6] 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.[7] 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 an important 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 So if a new name for schizophrenia were to be linked with dopamine, it would probably be out-of-date within a few decades as science moves on.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 added to the list, is *Psychosis Syndrome(s).*[8] '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 or cataract. The same applies to the term that won the competition, *Dysfunctional Perception Syndrome*.[9] 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').[10]

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 proposal became *Salience Syndrome*.[11,12] Now I understand what he means. It relates to my own schizophrenic experiences. When I saw the bushes along the roadside directing me, while driving, 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 turn of the 20th century—Kraepelin (*Kraepelin's Syndrome*) or Bleuler (*Bleuler's Syndrome*).[13]

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(s).[14] 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. The writer Stefan Meijer, also an Anoiksis member, 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. (…)
>
> 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.
>
> 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.[15] (My translation)

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 more 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, and 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.[16]

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's 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 fifth edition of the DSM was the first for which the APA involved the public. There were two previous periods in which everyone was encouraged to submit their ideas. The third period was in the spring of 2012. There were more than 10,000 submissions recommending changes to the DSM-IV (8,600 in 2010 and 2,000 in 2011). There have been field trials in which new diagnostic criteria were tested.

The DSM-5 committee primarily concerned with schizophrenia was the Psychosis Syndromes Work Group. Anoiksis has lobbied this work group for the introduction of a new

name for schizophrenia.[17] 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 APA but also international organizations such as the World Health Organization and the World Psychiatric Association should also be involved. Anoiksis argued further that the patient movement and representatives of families of people with schizophrenia should also be consulted.

The Work Group carefully considered several proposals that Anoiksis had put forward for a suitable new name for schizophrenia. You feel personally that the proposal to rename schizophrenia after Eugen Bleuler would lead to a considerable shift in the emphasis in the diagnostic criteria (albeit in the right direction)[18] – from positive symptoms to negative and cognitive symptoms such as feeling ill, lack of energy, drive, and motivation, and incoherence in thought processes.[19]

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.[20] 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.[16] 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 positive symptoms are also very telling.

The proposal of the Work Group for the DSM-5 concept of schizophrenia strikes us as a considerable improvement.[8] Schizophrenia would be deconstructed into eight or nine dimensions that encompass the symptoms and experiences the client/patient is aware of as well as indications observed by 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 actions.

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 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 suggestion to rename schizophrenia after the one who first named it.

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Notes

1. This open letter originally appeared in Dutch as: What's in a name? Open brief over een nieuwe naam voor schizofrenie in de DSM-5. *Maandblad Geestelijke volksgezondheid* 2011;66:909–915; and in English in the journal *Stigma Research and Action* 2012;2:119–122.
2. 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.
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4. George B. Viewpoint: A less stigmatizing name for schizophrenia. *Mental Health Today* 2010;March:35.
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7. BBC News. news.bbc.co.uk/go/pr/fr/-/2/hi/health/6033013.stm Updated October 9, 2006. Last accessed September 30, 2011.
8. American Psychiatric Association. DSM-5 development: Schizophrenia. www.dsm5.org/ProposedRevision/Pages/proposedrevision.aspx?rid=411 Updated March 2, 2011. Last accessed 8 October 2011.
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11. Van Os J. 'Salience syndrome' replaces 'schizophrenia' in DSM-5 and ICD-11: Psychiatry's evidence-based entry into the 21st century? *Acta Psychiatrica Scandinavica* 2009;120:363–372.
12. Van Os J. Are psychiatric diagnoses of psychosis scientific and useful? The case of schizophrenia. *Journal of Mental Health* 2010;19:305–317.
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15. Meijer SA. 'Bleuler syndroom', aanvaardbaar? Discussie naar aanleiding van de onmogelijke term 'Schizofrenie'; 2010. www.psy.nl Last accessed 30 September 2011.
16. Sommer I. *Stemmen Horen: Wat is het, wie heeft het en hoe komt het.* Amsterdam: Uitgeverij Balans; 2011.
17. Anoiksis. Open Submission to the APA re the DSM-5: Confessions of an ungracious critic; 2011. www.anoiksis.nl Last accessed 4 November 2011.
18. The chair of the Work Group wrote to us: 'To change schizophrenia to Bleuler's Syndrome would mean a remarkable shift in emphasis (albeit a shift in the right direction).' [E-mail to Bill George July 7 2011, quoted by permission of the author, William T. Carpenter, Jr.]
19. Keller WR, Fischer BA and Carpenter WT, Jr. Revisiting the Diagnosis of Schizophrenia: Where have we been and Where are We Going? *CNS Neuroscience & Therapeutics* 2011;17:83–88.

20. Carpenter WT, Jr. Schizophrenia: Disease, syndrome, or dimensions? *Family Process* 2007;46:199–206.

Abstract

B. George
'What's in a name? 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 APA 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 APA Work Group. The issue now is to gain support from the international mental health community.

Keywords: dimensions, DSM-5, Eugen Bleuler, schizophrenia, stigma

Personalia

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