

A cause related alternative for the harmful concept of schizophrenia.

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The main reason why the concept of schizophrenia is harmful is because the concept itself makes it impossible to solve the patient's problems which lies at the root of becoming ill.

In order to explain this essential problem and argue a more promising, cause related alternative, I will discuss the following issues:

1. The scientific validity of the concept is Zero and it does not refer to a brain disease.
2. The diagnostic process neglects the reasons for the existing symptoms.
3. The relationships between the core symptoms and experiences in life are neglected.
4. The inter relationships between the core symptoms are neglected.
5. The core symptoms do not represent expressions of psychopathology.
6. Learning to cope with the symptoms and with the problems at hand are neglected.
7. People who recover from the illness do that outside of psychiatry.

The Scientific Validity.

Many authors have written, already quite some time, about the lack of construct as well as content validity of the illness we call schizophrenia. Three English researchers should be mentioned here because of their importance in proving the missing validity, Richard Bentall, Mary Boyle and Walter Heinrichs.

Richard Bentall shows us in various publications at least since 1990, the missing construct validity, as he says (Bentall 1998) "It would seem that schizophrenia is an illness that consists of no particular symptoms, that has no particular outcome, and that responds to no particular treatment. No wonder research revealed that it has no particular cause."

Mary Boyle (1990) has looked in a historical way at the concept of schizophrenia and shows us that it has never been validated. Her conclusion is that Kraepelin and Bleuler merely postulated the existence of a peculiar pattern of signs and symptom, which they then attempted – unsuccessfully – to validate. As she demonstrated, these studies provided no justification whatsoever for the so-called peculiarity of the cluster of symptoms at hand. She says "None of them (including Schneider as well) presented evidence of having observed a set of regularities, which would justify a new hypothetical construct. Certainly, none of them identified a syndrome." (Boyle Second edition 2002 p.80). Mary Boyle studied also the development of the DSM series and concludes: "The development of DSM III, III-R and IV is based on question begging. Like Kraepelin, Bleuler and Schneider, the devisers of the DSM did not appear to doubt the validity of 'Schizophrenia': it might be complex, but it is a diagnosable disorder which clinicians recognise when they see (it). This cognitive starting point is crucial also in making failure seem like a temporary aberration". (Boyle, Second edition 2002 p.151).

The third researcher working in England is Heinrichs (2001). He carried out a Medline search for publications appearing between 1980 and 1999, which report on objective disease markers in schizophrenia. His work constitutes a review of the results from neuroscience research. As we know many claims have been made pertaining to the presence of specific disease markers in Schizophrenia. Heinrichs calculated the effect size of each of these studies.

In Heinrichs (2001 p. 84) own words: "In summary this extensive appraisal across many areas of neuroscience reveals no common abnormality in all cases of schizophrenic illness. The strongest, most consistent evidence suggests that 50 – 70 % of schizophrenia are deficient in cognitive brain function. In comparison most of the neurobiological abnormalities in the illness, probably occur in a minority of patients. Moreover close to 40% of the biological findings are so weak and variable findings are so weak and variable that they may represent minor, unimportant, or chance abnormalities with no intrinsic link to schizophrenia". Blom (2003) who studied all arguments and literature about the validity problem of schizophrenia for his Ph.D. therefore says: "From the work of Heinrichs we may cautiously conclude that contemporary neuroscience research, likewise fails to provide persuasive means of validation for the schizophrenia concept".

What about the practicality of all this research. We are used to the diagnosis of schizophrenia. Doctors and nurses will tell you that they recognise the illness when they see patients. I have been in this profession and I agree that you meet patients with the symptoms described in the DSM under the category of schizophrenia. They tell about hearing voices they have peculiar explanations for them and they show all kind of behaviour that is socially and emotionally peculiar and can be easily interpreted as negative symptoms. What can we learn from this seemingly discrepancy between experience and science.

To my idea there is one plausible and important conclusion. There are people showing the symptoms categorised in the DSM under schizophrenia. However these symptoms do not result from an underlying illness, they might well have another origin. The fact that people show and suffer from serious complaints, we do not understand very well, does not indicate that they suffer from an illness entity like the construct of schizophrenia.

Therefore the conclusion can well be that :

The people with the symptoms exist but the illness does not exist

There are many arguments to underpin this conclusion. These arguments come from the other issues I like to tell you about.

The diagnostic process

Let us look at the diagnostic procedure. Assessment means in clinical psychiatry that a psychiatrist talks about the complaints of the patient, trying to find out how he can interpret the behaviour in terms of symptom categories. He has in his mind quite a number of interpretations of behaviours and experiences. For instance when a person tells he hears voices the psychiatrist asks for the characteristics of an auditory hallucination. When the patient answers the question: are these voices representing your own thought or are they coming from somebody or someone else, telling that the voices is not his own but from somebody else., then the psychiatrist will easily conclude that the patient suffers from an auditory hallucination. When he then asks about the explanation for those voices and gets a story that is strange to him he will easily conclude that the patient suffers from hallucinations and delusion and then according to the DSM a diagnosis of Schizophrenia is the only category available to him. So what is going on in a diagnostic procedure in clinical psychiatry the complaints and behaviour and experiences are interpreted in a reduced number of symptom categories and with those the psychiatry constructs a diagnosis within the rules laid down in

the DSM. This is in principle not a diagnosis but a category, because it is only based on the behaviour and experiences and there is no reason for that behaviour taken into account. This is what makes a diagnosis harmful because of the lacking interest in the reasons for the complaints and for the psychological suffering. **How will it ever be possible to help a person with his problems when in the diagnostic procedure there is not the slightest interest in these problems.**

There are naturally and happily psychiatrists who not only construct diagnosis but are interested in the problems of their clients. But with psychosis, mainstream clinical psychiatry is hardly interested. This is especially a problem with psychosis, because slowly over the last 30 years the idea has been formed that social emotional backgrounds are not very essential in the development of psychosis they may have a role as triggers but not so much as a cause.

The strange and harmful thing also is, that this procedure is advertised as medical. This is however not the way of working in general medicine. There one looks for the reasons for the complaints and these reasons are essential for the diagnosis.

In clinical psychiatry a diagnosis in the area of psychosis is constructed on the basis of the behaviour and experiences only. The great problem is that the treatment as a consequence is also given without analysing the causes for this behaviour and therefore the constructs are treated not the problems. These look very much alike the juridical system, which punishes the behaviour and is only slightly influenced by the reasons for that behaviour. It therefore is not strange that many patients in psychiatry are not very content with these procedures. And they are quite right.

The background of the core symptoms.

Why is it harmful to diagnose without analysing the reasons for the behaviour and experiences. There are as we know, no particular causes for schizophrenia, however we now know that there are causes for the different core symptoms of schizophrenia in the individual case. The diagnosis of schizophrenia therefore is harmful because it mystifies the cause of the various behaviours and experiences in the individual case, which have to be analysed and can be the successful focus of therapy. What are these causes

In our research concerning people who hear voices we found that in 77% of the people diagnosed with schizophrenia the hearing of voices was related to traumatic experiences. These traumatic experiences varied from being sexually abused physically abused, being extremely belittled over long period from young age on, being neglected during long periods as a youngster, being very aggressively treated in marriage, not being able to accept one's sexual identity, etc. These results were also found in research done by Mike Smith in Manchester and Babs Johnston in Dingleton. Besides these studies there are quite a number of studies showing a high percentage of experienced trauma in the population of people diagnosed with schizophrenia. (Read 2001, Morrison, Mueser 1998 etc) Although there are to my knowledge less epidemiological studies about the relationship between traumatic experiences and the development of delusions, we know of some studies and reports of individuals (Nieland 1959; Mirowsky & Ross 1983 Bullimore 2005 and May 2003 and 2005). The same holds for negative symptoms (Strauss et al 1989; Pat Deegan 1998).

These studies should open our eyes for the importance of analysing the background of the separate symptoms within the concept of schizophrenia.

This brings us to the question how does the full picture of schizophrenia symptomatology develop because the relationship between one of the core symptoms with experienced trauma does not explain the development of the other symptoms The answer is:

The inter relationship between the different core symptoms and other secondary reactions.

This important reality of the interaction between the core symptoms of schizophrenia I learned from Ron Coleman a quite well known mental health activist, who will also speak at this conference. In retrospect he analysed the different experiences of his psychotic illness and came to the conclusion that he started to hear voices and only afterwards developed the other experiences as a reaction on his hearing voices because he could not cope with his voices at that time. He now uses this interaction in an experiment in which he tries to make it clear for non voice hearers what it is to hear voices. In his experiment he asks the audience of a meeting to split up in threesomes and then two of the three have a discussion and the third plays a voice in the ear of one of the discussant. This gives a kind of feeling how a voice can be very disturbing and influence ones functioning. The participants afterwards tell how they reacted to this disturbing influence. People then realise that a lot of the symptoms we find in Schizophrenia can well be secondary reactions to this disturbing influence. You can easily verify this in your daily work with voice hearers by asking them about their reaction on their voices like the strange explanations, which are often in psychiatry called delusions. Like the concentration, problems, the ability to work, the tendency to isolate one self etc. One of the most clear interrelationships that is also more scientifically studied by Maher (1988) is the explanation for the voices. Because the voices are for the voice hearer a strange, unknown experience, the explanation they think of is also mostly strange for us and therefore easily identified as a delusion. This means that the auditory hallucinations and delusion are interrelated and not separate symptoms of an illness. This holds for many symptoms of schizophrenia, being secondary reaction on a primary symptom like hearing voices that scares the person and with which he is not able to cope.

When we look in this way at the concept of schizophrenia the symptoms are not the results of an illness entity, but the illness picture is composed of primary symptoms possibly a reaction on traumatic experiences and secondary reactions because of the inability to cope with the primary symptom. Why is this not such a strange conceptualisation.

The core symptoms are in themselves not a sign of psychopathology.

There is nowadays a great number of epidemiological studies that show us that hearing voices and also delusion are apparent in quite some individuals without psychiatric illness. There are even more people hearing voices or experiencing delusions without illness than people with these experiences that become psychiatric patients.

This is mostly very difficult to accept for mental health professionals, because they do not meet these people. The reason being: these people do not need any care, they mostly are even glad with their voices and their ideas because they are helped by them in daily life.

This reality that there are quite a number of people in the general population who hear voices or have, peculiar personal convictions, we call delusions, without being ill, force us to realise that the experiences of hearing voices or having delusions are in themselves not a sign of mental illness. This is quite an important fact in understanding psychiatric patients with these experiences, because it opens our eyes for the reasons why the person became ill. A person hearing voices becomes ill, not because he hears voices but because he can not cope with these voices and that again can be understood. Those who can not cope with their voices, can not cope with because they can not cope with the problems that set on the experience of hearing voices. This double inability makes it important not to focus on an unknown illness but: **To learn the person to cope with his voices and or delusions and with the problems that lead to them.**

In this way it becomes clear that the focus on an illness that does not even exist does not solve a persons problems that lay at the roots of becoming ill.

The essential difference between becoming ill and having an illness.

We have to realise that there is an essential difference in psychosis between becoming ill and suffering from an illness. If we focus on the illness concept and try to treat the diagnostic construct we will never be able to help the patient to solve his problems. In order to help the patient we will first have to help him to cope with his experiences as hearing voices or personal conviction that is to reduce the anxiety for these experiences which is quite well possible with cognitive interventions. But after that we will also have to help the person to learn to cope with the original problems that lead to the mental health problems. This mostly concerns a change in attitude towards these problems and those people involved with them. Not simple but rewarding.

People who recover do this outside Psychiatry

We have often met people who recover from these mental health problems and diagnosis, but they did that outside psychiatry. They started in psychiatric care, either in or outside psychiatric hospitals but became rather angry with the care they received because:

- 1) There was no interest in the distress they suffered from their psychotic experience. The focus was on the interpretation of their complaints as a symptom category not on the suffering from it.
- 2) The diagnostic procedure did not help them in any way to solve their problems, it more or less denied their human needs, of making sense of what happened to them.
- 3) There was no interest and they were never asked, what has happened to them in daily life in connection with the experience.
- 4) Demoralizing statements were made about the consequences of their diagnosis like you have to take medicine all your life and you will have to adapt to your illness and expect less of your possibilities in life.
- 5) The medication did not help for their complaints, while doctors stick to the idea that the person needed them never the less.

This anger seemed to motivate the patient to try to take his life in his own hands again or go looking elsewhere to be helped more successfully. But in mental health care it was often seen as part of the illness, although anger is not a symptom of schizophrenia, it was interpreted as lack of insight in their illness, a quite powerless making interpretation.

We generally see that people who adapt to the psychiatric care system has less chances to recover than people who protest against it and also plan their own ways.

From these experiences we should learn in mental health care. These experiences are well described by a number of ex-patients like Ron Coleman, Louise Pembroke, Rufus May, Peter Bullimore and many others in the U.K. and elsewhere.

Conclusion

Overlooking the arguments I gave you in this paper, I come to the conclusion that:

Schizophrenia as an illness entity does not exist.

The Schizophrenia Concept is harmful because:

- It mystifies the patients social emotional problems
 - It makes it impossible to solve the patients problems
- A diagnosis of “Trauma Induced Psychosis” should be recognised, as well as other cause related alternatives, like drug induced psychosis, identity induced psychosis etc.

- Mental Health care should be oriented towards
 - Learning to cope with instead of suppression of experiences
 - Analysing the causes and learn to cope with emotions
 - Recovery and the development of the person

I do not expect that you will be able to change the system and neither do I think that you as a nurse collective will start a protest against the concept of schizophrenia, because of its harmfulness.

However you are not powerless. In your own contact with patients suffering from psychosis, you can start listening to their psychotic experiences and ask them to explain to you, what they experience. Then differentiate with them the kind of experiences like hearing voices, ideas of reference, delusions, the expressions of their negative symptoms like taking no initiative, isolating them selves etc. You then can ask what is the difficulty to cope with these experiences, in order to be informed about their anxiety, depressiveness, their feeling powerless etc.. You then can discuss how these experiences are developed over time and possibly inter relate with each other. You could start to accept that experience as their reality and ask what has happened in their life that could possibly relate to these mental health problems and start with the complaint it started with. If they are confused about that then you go over their lives history asking what has happened to them in terms of illnesses, loss of a dear person, a loved one, having had problems in relation with others like friends, family parents brothers and sisters, losses in work housing finances, but also problems with emotions like aggression, like physical abuse or having been belittled or having been aggressive themselves or with sexuality, like problems with sex like sexual identity or sexual abuse etc.. When they say yes and describe the problem you ask if it could have anything to do with their voices paranoia personal convictions etc. You just have to be clear to yourself and others that psychotic experiences do not fall from heaven, but are related to serious problems a person has suffered in real life. Then you are on the way to detect the persons problems and he\she is not estranged from his/her self by their psychotic experiences.

This takes time and in the mean time you can try out some anxiety reducing interventions, like they are described in cognitive psychological interventions articles or you can read our book aking sense of voices and find those possibilities there.