

Questioning 'schizophrenia'

An independent inquiry is set to question the 'schizophrenia' label and examine its impact on people living with the label.

Suman Fernando, Jayasree Kalathil, Phil Thomas, Jan Wallcraft

About 100 years ago, Swiss Doctor Eugen Bleuler suggested the name 'schizophrenia' for a mish-mash of so-called symptoms that the German Professor Emil Kraepelin claimed to have discovered as representing a form of 'degeneration' – seen at that time as pathology in the 'mind' that could destroy human beings from within.¹ A new 'illness', a new type of 'psychosis' (madness), was born: 'schizophrenia'.

Controlling bodies

This new 'illness' was constructed to go hand in hand with another, 'manic-depressive psychosis' (now called bipolar disorder), the symptoms of which had been known since the times of Hippocrates in the 4th Century BC. Schizophrenia, seen as a biological-genetic 'illness',

became popular among alienists (what psychiatrists were then called) mainly because it was useful for justifying the incarceration of large numbers of people in asylums in Europe and North America. As Euro-American power spread, asylums, mostly said to be housing 'schizophrenics', were established in many other parts of the world.

As Europe and North America have become multi-ethnic and multicultural over the past four or five decades, it has become evident that the diagnosis 'schizophrenia' is now given much more often to some ethnic (or 'racial') groups in the West, especially black people. And this over-diagnosis is connected with excessive numbers of black people being sectioned, incarcerated in forensic institutes, deprived of talking therapies, etc. These injustices have been attributed

1 Pick, D (1989) *Faces of Degeneration: A European Disorder, c. 1848-c. 1918*. Cambridge University Press

2 Metzl, J (2009) *The Protest Psychosis: How Schizophrenia became a Black Disease*. Beacon Press

3 Read, J et. al. (2006) 'Prejudice and schizophrenia: a review of the 'mental illness is an illness like any other' approach'. *Acta Psychiatrica Scandinavica*, 114: 303-318

4 Fernando, S (2011) 'A global mental health program or markets for big pharma'. *Open Mind*, 168: 22

to a mixture of institutional racism and cultural insensitivity, and attempts to reverse them have been unsuccessful. In the USA too 'schizophrenia' has become a black person's disease predominantly.²

Dubious diagnosis

What is now evident is that the concept of 'schizophrenia' is not a useful basis for bio-genetic research or for identifying people with problems of living. And when used in a multicultural society it is conflated with racist oppression. Further, there is no evidence that medications – erroneously called 'anti-psychotics' – that sometimes help people over personal crises are effective remedies for any identifiable disease. However, there is:

- a massive industry producing drugs that seem to keep 'schizophrenics' under 'control' (at a cost to their physical health) but not 'cure' this (scientifically-speaking) non-existent illness
- a host of articles and books about 'schizophrenia'
- a prevalent ideology incorporated into popular thinking and government policies that 'schizophrenia' is the reason for criminality and dangerousness
- disabling stigmatization of people carrying the label that anti-stigma campaigns using 'mental illness is an illness like any other' approach have failed to reverse.³

Little advantage has been gained by using 'schizophrenia' as a diagnosis in alleviating suffering relating to problems of living. Nearly all the changes that have helped people carrying the label during the past 60 years have come about as a result of humanitarian movements and psycho-social approaches.

What is now evident is that the concept of 'schizophrenia' is not a useful basis for bio-genetic research or for identifying people with problems of living. And when used in a multicultural society it is conflated with racist oppression.



Meanwhile, nearly all the changes that have helped people carrying the label during the past 60 years have come about as a result of humanitarian movements and psycho-social approaches such as the therapeutic community approach in the 1960s-1970s, de-institutionalisation of the 1970s-1980s, crisis intervention in the 1980s-1990s, and the more recent Soteria approach and open dialogue approach.

Taking it global

After the 1939-45 war, WHO, thinking about promoting psychiatric treatment based on diagnosis in the 'third world', followed up people diagnosed as 'schizophrenic' on the basis of a symptom-schedule constructed at the (British) Institute of Psychiatry. Significantly, what they found was that the outcomes for these 'schizophrenics' in terms of their suffering and symptoms were much better in countries where psychiatric treatment (with drugs mainly) was under-used. Yet, a new program proposes to extend psychiatric treatment based on diagnosis in low and middle income countries.⁴

Independent inquiry

In April 2012, after e-mail correspondence among black and minority ethnic and service user groups, the authors of this article came together to set up an 'Inquiry into the 'Schizophrenia' Label' (ISL) to explore how it affects people's lives and what alternative ways there might be for both service

users and professionals to understand mental health problems so they have meaning and usefulness for service development. At the time of writing, nearly 150 individuals and over 30 organisations have signed up as supporters of the Inquiry.

We hope that people who have been given the 'schizophrenia' label, other service users, their families and friends, professionals in mental health and social care, and anyone who knows and cares about the issue will participate by giving evidence to the Inquiry. The evidence will be considered by an independent panel of six experts in mental health. People with lived experience of carrying the label and other service users are centrally placed in this independent group, which also has a mixture of ethnicities. The results of ISL, compiled into a report with recommendations, will be made widely available and be sent to NICE, the Royal College of Psychiatrists, major mental health charities and other bodies. Our intention is to hold a meeting to present the ISL report sometime in October 2012.

Find out more

- www.schizophreniainquiry.org

The whole person, not just the brain

"I have personal experiences of living with an uncle who has been in the mental health system for a number of decades, labelled with 'schizophrenia'. The label covered and hid the underlying problems that he was dealing with as a young migrant to the country, a young man who loved his parents, wanted to become a doctor and be with his friends. He ended up in Bradford, I suspect without much consultation, working in a factory and, as they say up north, 'grafting'.

I can understand the disability he suffered from getting this label: Who could he talk to? How could he share his feelings? And when he couldn't deal with it personally any more he lashed out. My uncle was silenced by the label and to this day remains distant from his wife, children and wider family. I question a monolithic system that seeks to do away with personal distress and the desire to express it; I question a system that sees the expression of the distress of an Inuit as the same as a Pakistani or an Indian Dalit, Brahmin, Sikh, Muslim woman or man. This system, at best, parks culture, language, spirituality and ways of understanding the world and distress. At worst, it sees these as the problems and precursors of a person's illness.

At the opposite end I feel that cultures evolve and mix and therefore there is a great deal of western tradition which I find important and useful that needs to be rediscovered by my own tradition and therefore in my personal life and work life I seek to bridge the two. I do this by using my faith (Islam) and its culture to be a guide in this regard."

Mohammad Shabbir

CEO, Sharing Voices Bradford