

Schizophrenia Awareness Week – Drop the Label!

“Receiving a diagnosis of schizophrenia took my last bit of hope for my own recovery away from me. The people left in my life lost their ability to know how to best support me and the treatment options offered to me were reduced to only one option; high levels of sedative medication for the supposed safety of me and those around me. No one believed me anymore, no one listened to me anymore, no one cared anymore. When I managed to drop my own label, I found strength within and was able to get good support from those who see me as a person. I found psychological and social approaches that helped me and supported my healing journey.” Amanda, Member ISPS AU

Schizophrenia Awareness Week (SAW) was created in 1986 by the then Schizophrenia Council of Australia, now MIFA, and is held in May every year to coincide with the week of World Schizophrenia Awareness Day (24 May). This year it will be held from the **20 to 27 May 2018**.

ISPS Australia would like to support the aims of raising awareness about psychosis and dispelling myths associated with these experiences. However, **we argue that the term schizophrenia is unscientific and stigmatising – it does more to harm than help people who may experience these extreme states**. We are among many around the world who are part of CASL – the Campaign to Abolish the Schizophrenia Label. Well known psychiatrists Jim van Os and Marius Romme as well as renowned psychologists John Read and Richard Bentall have long campaigned for this as have 100s of others.

The ‘International Society for Psychological and Social Approaches to Psychosis’ (ISPS) is an organisation that seeks to promote the appropriate use of psychotherapy and psychological treatments for individuals with psychosis (which often includes those with a diagnosis of ‘schizophrenia’). ISPS acknowledges all individuals who experience deep distress as a result of extreme states, and celebrates the fact that so many find unique and creative ways to survive despite the many historical, social, institutional and political barriers to recovery.

ISPS was formerly known as ‘International Society for the Psychological Treatments of the Schizophrenias and Other Psychoses’, but in 2012 made the decision to remove the term ‘schizophrenia’ from the title. This action reflected a growing consensus that the term is stigmatising and lacks a solid scientific basis. ISPS has a small but active branch within Australia who feel that ‘Schizophrenia Awareness Week’ provides an ideal opportunity to correct some of the misinformation surrounding those experiences commonly called ‘schizophrenia’ and wish to encourage others to think deeply and critically about the usefulness of the label and its contribution to the stigma experienced by those diagnosed with schizophrenia. We argue that:

It denies the impact of trauma: The label of ‘schizophrenia’ renders invisible the fact that over 70% of people diagnosed with schizophrenia have a history of trauma or abuse¹. For many people, auditory hallucinations (or hearing voices) is a response to trauma and labelling this experience as an illness can be dismissive and unhelpful. Over 77% of people who hear distressing voices identify as having experienced trauma (including adverse life experiences) and for many of these people, a diagnosis such as Complex PTSD which acknowledges how trauma has affected them has a positive impact on their recovery.

Hearing voices is a common human experience: Research has shown that hearing voices is a common occurrence among both people with a diagnosis of schizophrenia and those without this

label². In some cultures hearing voices is celebrated and embraced as a spiritual or religious experience.

The label 'schizophrenia' is incredibly stigmatising: Research has repeatedly found that schizophrenia is one of the most stigmatising of all psychiatric labels. A diagnosis of schizophrenia carries with it many stereotypes including the assumption that a person with this diagnosis is dangerous and unpredictable, will be chronically ill, and the view that there is little hope of recovery as it is an irreversible 'brain disease'. This label does not tell us anything about the cause, the prognosis, or possible pathways to recovery. It promotes unwarranted pessimism and is extremely damaging contributing to the 'social death'³ of people with this label. Countries including Japan, Hong Kong, Singapore and South Korea have renamed "schizophrenia", using terms that have improved hope and recognition of recovery, promoting the normalisation of distress rather than the biomedical disorder of schizophrenia^{6,7,8}.

The construct of 'Schizophrenia' lacks a scientific basis: 'Schizophrenia' as a construct has little or no reliability or validity⁴. This means that experts such as psychiatrists have difficulty consistently agreeing on who is 'schizophrenic' and having a diagnosis of schizophrenia does not predict things like prognosis or response to treatment. The heterogeneity of presenting problems that can be diagnosed as "schizophrenia" and the lack of specificity in genetic and etiological explanations further compounds this problem. Overall, 'schizophrenia' does not meet the accepted scientific requirements for a discrete disease entity although it is consistently described as one.⁵

It is clear that biomedical perspectives of schizophrenia are not very useful in explaining people's experiences of these extreme states, yet they continue to dominate. Biomedical understandings also serve to limit the pathways to recovery by prescribing primarily biomedical approaches to treatment, such as medication.

In no way do we seek to minimise the experiences of people diagnosed with 'schizophrenia' - these experiences can cause extreme emotional pain and distress. Instead, we argue that the stigmatising impact of the construct and label 'schizophrenia' far outweighs its usefulness. We invite readers to embark on their own research and learning (perhaps starting with the sources below) and encourage people to think critically about 'schizophrenia' as a construct and how this diagnosis could possibly engender recovery.

By Mahboub, L., Dorozenko, K., Beavan, V., Connell, M., Waegeli, A., Ball, M., Mitchell, S., Ward, D., & Jennings, K.

References

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