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Abstract:

In 1896 Emil Kraepelin revolutionised the classification of psychosis by identifying what he argued were two natural disease entities: manic-depressive psychosis (bipolar disorder) and dementia praecox (schizophrenia). Kraepelin's twin pillars have governed psychiatric thinking, practice and research for over a century. However, a growing number of researchers, clinicians, and mental health service users argue contest the claim that there are fundamental differences between schizophrenia and bipolar disorder, and call for a symptom-led approach which prioritises subjective experience over diagnostic category.

How can the published first-person accounts of experts by experience contribute to this debate?

This short paper looks at the representation of psychiatric diagnosis in two much-lauded autobiographies: Kurt Snyder's *Me, Myself, and Them: A Firsthand Account of One Young Person's Experience with Schizophrenia* (2007) and Elyn Saks' *The Center Cannot Hold: My Journey Through Madness* (2007). As well as providing a prognosis and a plan for

treatment, the psychiatric diagnosis of schizophrenia, for both these writers, gives shape and meaning to the illness experience and ultimately becomes the pivot or platform from which identity and memoir unfold. Saks and Snyder do not claim to speak for all people who receive a diagnosis of schizophrenia and it would be a mistake to read their texts in this way even if they did. But if the debate about the future of psychiatric nosology is going to respect subjective experience, the insights they and others offer in to the multiple meanings and effects of psychiatric diagnosis more than compel our attention.

Implications for practice:

- Introduces two popular autobiographical accounts of schizophrenia which may be useful resources for mental health service users and clinicians
- Highlights the complex ways in which people interpret and make meaning from their psychiatric diagnosis
- Introduces current debates about the validity of the distinction between schizophrenia and bipolar disorder
- Demonstrates that first-person accounts make an important if frequently overlooked contribution to these debates

Memoir and the Diagnosis of Schizophrenia: Reflections on *The Center Cannot Hold*, *Me, Myself, and Them*, and the 'Crumbling Twin Pillars' of Kraepelinian Psychiatry

In 1896 Emil Kraepelin revolutionised the classification of psychosis by identifying what he argued were two natural disease entities: manic-depressive psychosis (bipolar disorder) and dementia praecox (schizophrenia). A madness of moods from whose vicious cycles it was nonetheless possible to recover was sharply distinguished from a cognitive madness whose course was set towards premature dementia. Despite being complicated by the introduction of a third, supposedly hybrid entity – schizoaffective disorder – in the 1930s, Kraepelin's twin pillars have governed psychiatric thinking, practice and research for over a century.

However, with the publication of the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual* due in 2013, and the eleventh revision of the WHO's International Classification of Diseases due in 2014, long-simmering stand-offs and long-standing debates about the validity of the Kraepelinian account of psychosis are increasing in intensity (Aldhous, 2009; Frances, 2010; Goldberg, 2010; Craddock and Owen, 2010a). Adding to the ongoing critiques of antipsychiatric theorists and psychiatric survivors, a growing number of psychiatrists, nursing staff, clinical psychologists, geneticists and others working at the heart of mainstream psychiatry have argued that the Kraepelinian dichotomy should be jettisoned as a relic of the nineteenth century.

Matthew Broome, in a recent review article, deftly summarises the philosophical underpinnings of the three major approaches to psychiatric classification (Broome, 2007; see also Allardyce et al., 2007). Essentialist or realist theories presuppose an underlying essence to each disorder, whether this is 'genetic, neural, phenomenological, or cognitive' (Broome, 2007, p. 304). Anti-essentialist and pragmatic accounts, by contrast, judge psychiatric categories by their usefulness in predicting course and outcome, or response to treatment. The third approach he calls ‘eliminative mindless Psychiatry’ (Broome, 2007, p. 304) – essentially the view that existing constructs, based on psychiatry and psychology, will be eliminated and superseded by exclusively neuroscientific accounts of biological function.

Schizophrenia, the cornerstone of Kraepelinian psychiatry, has been interrogated – some might say attacked – on each of these measures and from all these different perspectives (Boyle, 1990; Bentall, 2004; Bentall, 2009; Romme and Morris, 2007; Owen et al., 2007; Greene, 2007; Craddock and Owen, 2010b; Heckers, 2008). As Richard Bentall (2004, p. 94) has argued: ‘Studies of patients’ symptoms, of the role of genes, of the course and outcome of illnesses over time, and of the response of symptoms to treatment, all point to similarities between schizophrenia and bipolar disorder rather than to differences.’ In the last few years, researchers have argued that schizophrenia is a variant of bipolar disorder, the only true form of psychosis (Lake and Hurwitz, 2006; Lake, 2008b; Lake, 2008a); that ‘bipolar disorder’ is in fact the brain’s own response to schizophrenia (Llewellyn, 2009); and that a symptom-led approach, premised on the idea of a continuum in the frequency, severity and phenomenology of abnormal and normal experiences and behaviours, would enable us to move beyond diagnostic categories altogether (Bentall, 2004).

This debate, though sometimes absurd, is not ‘merely academic’ (Heckers, 2008, p. 592). The validity of the categories schizophrenia and bipolar disorder are central to biological psychiatry’s scientificity, its clinical legitimacy, its status within medicine, and its very disciplinary identity. National mental health care infrastructure and the multinational multi-billion pound psychopharmacology industry also rest on these distinctions. Finally, the conviction that schizophrenia and bipolar disorder are discrete and opposing illnesses – or diseases of the brain – can have enormous bearing on individuals' experience – in terms of social roles and stigma, but even, I would argue, at the level of phenomenology.

Literature, and particularly literary autobiography, can make an important contribution to these debates by providing a detailed first-person account of the phenomenology of illness, its psychological and social dimensions, and its impact across all aspects of a life. In the rest of this paper, I want to examine in more detail the lengthy process of diagnosis as it appears in two contemporary memoirs of schizophrenia.

Kurt Snyder's *Me, Myself, and Them* (Snyder et al., 2007) is subtitled *A Firsthand Account of One Young Person's Experience with Schizophrenia*, following the format of the Oxford University Press Adolescent Mental Health series in which it appears. Co-authored with a Professor of psychiatry and a science journalist specialising in mental health, the cover announces that it is 'a unique combination of memoir and guidebook [which] offers hope to young people struggling with schizophrenia, helping them to understand and manage the challenges of this illness and to go on to lead healthy and productive lives.' The text does this through a clearly structured division between 'My story' (Kurt's narrative) and 'The Big Picture' (scientific and social perspectives on schizophrenia) and the addition of a glossary, resources section, bibliography and index. Elyn Saks' *The Center Cannot Hold*: *My Journey Through Madness* (2007) is a national bestseller and winner of the 'Books for a Better Life' Inspirational Memoir Award. Saks is a Professor of Law and Psychiatry, as well as a trained psychoanalyst, and reviews quoted on the cover honour her book as among the 'most remarkable' in a centuries-old tradition of literary first person accounts of madness.

I initially chose these texts for their diversity: in their mode of address and intended audience, as well as in their authors' profession, gender and social status. Yet, upon closer inspection, these differences were somewhat overwhelmed by the texts' similarities. Although unaffiliated, so far as we know, to any formal mental health advocacy group, these authors clearly have high ‘mental health literacy’ within a US context. Saks and Snyder share a vision for what they want their memoirs to achieve – they write to reduce stigma, counter mythologies of schizophrenia, provide hope, and offer evidence of recovery from psychotic experiences. Finally, and most pertinently for the purposes of the present discussion, Saks and Snyder accept that they have been diagnosed with a devastating brain disease. This is *not* activist or so-called ‘survivor’ literature but rather what is increasingly described as a form of ‘recovery’ writing which testifies to the efficacy of antipsychotic medication in managing what can be – but isn’t at the time of writing – a harrowing experience.

So what can these texts tell us about what it is like to be diagnosed with a particular kind of psychosis?

Diagnosis – the recasting of psychotic experience as specifically symptomatic experience – is a process assembling the multiple perspectives of psychiatrists, mental health nurses, family members, friends, and the patient in question. In these accounts, it is a process preceded and actively structured by treatment, especially psychopharmaceutical intervention; and its telos – a label that is perceived by psychiatrist and patient as accurate, acceptable and enduring – is not easily reached.

Snyder’s initial psychotic experiences involve paranoid and delusional thinking, but as he refuses to discuss this with psychiatrists he initially receives a diagnosis of bipolar disorder based on testimony from his family and friends. Months later, and after being given antipsychotic drugs, his diagnosis is changed to paranoid schizophrenia, but it is only after suffering a severe episode of depression, for which he receives antidepressants, that he starts to recognise his thinking as delusional. Saks’ situation is even more complex: as a teenager in Florida she is sent to years of rehab after experimenting twice with marijuana; in the UK as a graduate student she is treated for anorexia and severe depression, both in psychiatric hospital and psychoanalytic therapy; back in America she is diagnosed variously with delusional depression, chronic paranoid schizophrenia, schizoaffective disorder depressive type, atypical psychosis, and, finally, schizophrenia.

The fact that Snyder and Saks received multiple diagnoses can be interpreted in a number of ways – as evidence of the presence of successive or co-morbid illnesses; as proof of the imperfect ways in which contemporary psychiatric classifications are sometimes applied in practice; or as testifying to the inadequacy of psychiatric classification itself. However, as we shall see, both Saks and Snyder are clear in their resolution of the apparent problems that multiplicity poses. Diagnoses do not, as the authors of the DSM would have us believe, simply describe experience and determine an appropriate drug regime; they are enormously powerful in shaping people's experience and perceptions. This is where, for Saks and Snyder, the many distinctions between schizophrenia and bipolar disorder come sharply into focus.

While on antipsychotic medication, Snyder experiences a period of severe depression. He writes:

> I knew at this point that I was experiencing mental illness, as far as my depression was concerned. I knew that my behavior and mental status weren't normal. Other people weren't lying in bed all day like I was doing. However, I still did not believe that I had been insane, and I *certainly* didn't believe that I had schizophrenia. Depression was an acceptable diagnosis for me, but schizophrenia was not. (Snyder et al., 2007, p. 104)

Depression is recognised and accepted as a departure from normality; schizophrenia remains dark, taboo, terrifying. It requires extensive treatment, trust and courage to be persuaded of its accuracy.

This theme resonates throughout *The Center Cannot Hold*, where Saks admits that despite reading the DSM cover to cover and recognising aspects of her experience in a range of diagnoses, when it came to the entry for schizophrenia she

> simply refused to believe on any conscious level that this had anything to do with me. And now, here it was, in writing: The Diagnosis. […] I'd always been optimistic that when and if the mystery of me was solved, it could be fixed; now I was being told that whatever had gone wrong inside my head was permanent and, from all indications, unfixable. Repeatedly, I ran up against words like 'debilitating', 'baffling', 'chronic', 'catastrophic', 'devastating' and 'loss'. For the rest of my life. *The rest of my life*. It felt more like a death sentence than a medical diagnosis. (Saks, 2007, pp.168-9)

Saks is convinced that even psychotic depression is 'acceptable' by virtue of being 'primarily a disorder of feelings' whereas her then diagnosis, schizoaffective disorder, 'felt like death' (Saks, 2007, p. 221). Only years later, and thanks to the antipsychotic drug Zyprexa (Olanzapine), she experiences her first sustained relief from psychotic thinking, which, somewhat belatedly, leads to a new perception of the phenomenology of her illness:

> I am not someone whose illness consists primarily of having high and low moods. And that aspect of my illness – its cognitive nature – was central in my decision to write this book. Many people who suffer from manic depression and depression lead full and rich lives […] However, people with thought disorders do not keep a list of famous and successful people who share their problem. They can't, because there *is* no such list. Comparatively few schizophrenics lead happy

> and productive lives; those who do aren't in any hurry to tell the world about themselves. (Saks, 2007 p. 329)

It is to our collective advantage that both these writers have hurried to tell the world about themselves. Their insights are many and valuable. Reading these narratives with the care they deserve, we must recognise that they are written from a subjective position fundamentally invested in the specificity of diagnosis. Not all memoirs of madness share this commitment to Kraepelinian psychiatry – survivor and mad pride anthologies are full of stories of people who reject their diagnoses or the biomedical explanations of psychosis that underpin them. But for these authors, exactly *which* diagnosis matters; it matters because it gives shape and meaning to their illness experience; it matters because it is a prognosis and a plan for treatment; it matters because it inserts them into a cultural context that is beyond their control, as well as beyond the control of their psychiatrists.

Accepting the diagnosis of schizophrenia – understood as a discrete if still mysterious disease of the brain – is the pivot or platform from which identity and memoir unfold. Kraepelin's twin pillars of schizophrenia and bipolar disorder may well be crumbling, but what the work of Snyder and Saks accomplishes is a forceful reminder of just how much is at stake if the roof of diagnostic certainty caves in.

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