

Diagnosed and Misdiagnosed Within the System: A Personal Testimony

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This article is written as a personal testimony from a man once considered the most violent and dangerous man in his locality. He is now a man who has completely turned his life around. Hindsight has enabled me to recognize that bipolar disorder has affected me the whole of my adult life. It was only once that I was diagnosed with bipolar disorder that all began to make sense. This knowledge helped to explain, but not to excuse, much of my offending behavior. As I sit writing this, there is only one thing that I regret, and that is how I have hurt others, whether that is physically or psychologically, intentionally or unintentionally. I have never let myself think 'poor me'. I take full responsibility for every action I have ever taken. I do however believe that if I had been diagnosed and treated earlier then, there would have been far fewer victims.

My primary aims in writing this article is to raise awareness of significant issues that are very prevalent in the current way that offenders with bipolar disorder are receiving incorrect diagnoses and how their symptoms are interpreted and thus exacerbated by professionals that surround them. I suggest that this is in part due to the current focus of the prison service on offenders with personality disorder and the dominance of psychologists working with such offenders. These psychologists often have little or no training in, or understanding of, mental illness. These psychologists work within the main prison system and more specifically within the numerous services and units that have been set up throughout the UK known as the Offenders with Personality Disorders Pathway. The lack of knowledge of mental illness, especially bipolar disorder, can lead to offenders being misdiagnosed and consequently remaining ineffectively treated and misunderstood.

As a child, I was no stranger to mental illness as both a parent and a grandparent had a diagnosis of schizophrenia and I grew up being pulled between the two of them. This gave me a true understanding of the effects of mental illness, not only on the sufferers, but also on the family. Despite this knowledge, I still did not realize that I myself was a sufferer. Throughout my teens and early 20s I lived a life of criminality. In my highs, I was unchallengeable and had no fear, but I instilled fear in others. I now realize, that without being consciously aware of it, I managed my lows by self-medicating with illicit drugs that raised my mood. By the time I was 27, I was in prison and I serving an indeterminate sentence, being regularly moved from one segregation unit to another as I was considered uncontrollable. I fluctuated between deep suicidal urges alternating with aggression which was borne out of my beliefs in my invincibility and refusal to be dominated and controlled. I was getting deeper and deeper into the prison system and I eventually realized that I needed help. I agreed to be assessed for one of the original high secure units set up for those offenders who were considered to be highly dangerous and who met criteria for a diagnosis of personality disorder.

Initially, a psychologist diagnosed me as having 4 personality disorders, antisocial, borderline, paranoid and narcissistic. The assessment and treatment unit however was unique in the prison system, as it also had an in-house psychiatrist. I was initially reluctant to speak to her but it was she who diagnosed me with bipolar disorder. At the time, I was relieved not to have a diagnosis of schizophrenia, which to my mind would have meant a lifetime of being sectioned and being in and out of psychiatric hospitals. I was so afraid that I would be given

a diagnosis of schizophrenia that I often masked many of the darker aspects of what was truly going on in my mind. Once I was diagnosed, I began to study bipolar disorder and it was as if I was reading a book written about my own life. From my earliest reading, I refused to accept the simplistic cycles of separate 'highs' and 'lows'. I began to study and document my own struggles during my 'highs', 'lows' and my 'middle ground'. I have no degrees, no doctorate, no academic titles, but I do have expertise in this field, as I am now an expert on my own lived experience. I would describe my bipolar disorder as rapid cycling. For example, different to many others with this diagnosis, for me, sleep deprivation is a feature of both manic and depressive episodes. Once I understood what is normal and abnormal in the feelings sense, for myself, I could begin to tackle the problems. The more that I learnt about the disorder and my experience of that disorder, the more it enabled me to develop strategies to manage, and even micromanage, highs and lows. Reflecting on my history, I have realized, for example, that colors represent my mood. I would so often be drawn to greys and blacks which were representative of my low moods and yellow represented my high moods. I have many yellow clothes and even a yellow convertible car among my car collection. This car was bought many years ago when I was in a manic phase when I had no understanding of what bipolar disorder was or that I had that illness. Different food and drinks are highly associated with my different moods, as are differing wants and needs. I initially resisted medication, as I believed that it would numb my emotions and I wanted to experience everything that I needed to experience, as I was undergoing an intensive 5-year individual and group therapy programme. Prior to my diagnosis and treatment, I would often not know the actual emotions that I was feeling, even though the feelings were extreme during the highs and lows. I wanted to truly feel, recognize and understand the emotion and I believed that medication would stop me from feeling. I did, and at times still do, battle hard with my disorder. On occasion, I have refused to allow myself to fall into a depressive low but each time the battle is harder than the time before. I realize that sometimes, the fall is inevitable and all I can do is manage it. The way that I would feel in a depressive episode meant that I simply wanted to die as death meant release. I managed my illness, using purely psychological strategies, for more than 3 years but after a deep-low that left me close to suicide, I agreed to take a mood stabilizer, Lamotrigine. Since taking that medication, I have had a better quality of life and it certainly has not stopped me feeling my emotions. In addition to medication and psychological strategies, my use of expressive writing, has helped me by enabling me to communicate my lived-experience. Importantly, it has allowed me

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to give both professionals and members of my support network an in-depth insight into my 'highs' and my 'lows'. There are still times when I want to be alone, and at these times I will tell people that I am low and I am not pushing them away but I need space. It was the pieces written during the darker phases of my disorder that truly opened the eyes of both non-suffers and sufferers of this disorder with whom I shared my writing. It was particularly difficult to write when in the lowest phase of my cycle. Even when I completed pieces, these were often discarded, so many of the pieces written in these low times had to be recovered from the bin. When high, I have often felt as if I could fly. In fact, in hindsight, I have no real rationale as to how I did not jump from a building and attempted to fly. Even now in manic phases, I will sometimes train in the gym 3 times in one day. It is only the following day, when I awake, that it hits me that I am no longer a man in my 20s, as my body will ache from head to toe.

The more that I read about bipolar disorder, the more that I realized that the personality disorder diagnoses that the psychologist had made in relation to me, were most likely to be misdiagnoses. The literature clearly states that it is common that people with bipolar disorder are misdiagnosed as having borderline, paranoid and narcissistic personality disorders, as the symptoms are so similar. I asked for these diagnoses to be reconsidered, as I knew that one of the criteria for any diagnosis of personality disorder to be made, is that the pattern of symptoms is "not better accounted for as a manifestation or consequence of another mental disorder" [1]. It was clear from the report written about me, that the criteria that the psychologist was relying on to form her diagnoses of personality disorder, were the symptoms of my bipolar disorder. Initially, both the borderline and paranoid diagnoses were removed. At the end of treatment, the narcissistic diagnosis was also removed. In the 'high phase' of my cycle, I certainly have narcissistic traits but in a 'low phase', nothing could be further from the truth. For a diagnosis of narcissistic personality disorder, the traits need to be persistent across time and situation and that is certainly not the case. Despite these issues being strongly argued in the literature, it was, and still is, very difficult to get psychologists and psychiatrists to accept the mistake. I have since met two other men who had this combination of diagnoses and who I suspect were actually suffering from bipolar disorder. When each of these men had access to a psychiatrist, bipolar disorder was diagnosed. For both these men, once they took a mood stabilizer, their symptoms significantly reduced and they no longer met criteria for the personality disorder diagnoses. I propose that this mistake is made more often than is recognized. As the current zeitgeist within the criminal justice system is to recognize, diagnose and treat offenders with personality disorder, it is highly likely that, because most offenders are connected to psychologists rather than psychiatrists, many people with bipolar disorder will be misdiagnosed. They will not respond effectively to psychological treatment alone and will continue to suffer with their mental health and their risks will not be reduced.

Despite the initial misdiagnoses, I know that I benefitted greatly from being in treatment in the unit for people with diagnoses of personality disorder alongside many other men, some of whom, like myself, also had dual-axis diagnoses of mental illness. As the treatment was individual as well as group therapy, I could benefit from the sessions, taking from them what I needed and working hard on myself between the sessions. Indeed the combination of accurate diagnosis, psychological therapy, coping strategies and medication completely changed my life [2].

After the treatment programme ended, I should have moved out of the unit, but for reasons out of my control, I could not do so. It is one thing

living in such an environment when you are in treatment, but quite a different experience to live in that same environment, when you yourself have a diagnosis, but you are well. Importantly, there is something about professionals that find it very difficult not to observe every day interactions and pathologies those interactions, labeling them within the context of the diagnosis, whereas the same interactions in a person without that diagnosis would be considered 'normal'. For example, when I became more intense and passionate about an issue, my assertiveness was easily given labels such as aggression and hostility, although these were not the emotions I was feeling at the time. If I laughed loudly at a joke, was really happy about the birth of my grandchild or had a good idea for a piece of writing, the professionals asked if I was becoming 'high'. I do not fear the labels but it is the misrepresentation that angers me. When I am level, I know I am level, but as being level is different from how I am in a high, professionals then say 'you are in a low'. For a long time, I found it difficult to contradict them. I now recognize that feeling flat at times, is completely normal it does not mean that I am in a 'low'. This is a problem when you are living in a treatment facility, having a normal change in mood, just as anyone else can have, can often be misinterpreted by a psychologist as a sign of psychopathology rather than a normal expression of emotion. The key issue is that until I knew myself well enough to know what for me is the range of normal moods, I did not know what was misinterpretation by others and what was an accurate reflection. This led me to greater confusion rather than clarity. In my opinion, it would have been more helpful for the professionals, or indeed anyone, to simply ask the question about how I am feeling, rather than just presume. I myself will ask others if they are "feeling ok", not just as a figure of speech, but a genuine question to enquire on that person's wellbeing. If I was a person that did not know myself, these misinterpretation of professionals could trigger me into a 'low' or even a 'high'. Within such an environment it would be difficult for anyone to remain in remission; nevertheless, I did remain in remission for more than a year following treatment. To do so, I needed to have considerable insight into my own thoughts, feelings and behaviors, as well as understanding the behaviors of the professionals. Once I left that environment and I moved to a non-treatment environment, my mental health stabilized almost immediately to the extent that, unless a person was directly told that I had a diagnosis of bipolar disorder, no one would know that this is the case.

Like any mental health issue, bipolar disorder is a unique experience for each individual. It is only when more people share their thoughts, feelings and behaviors will there be a greater understanding of the disorder from a personal rather than a professional perspective. As a sufferer, I believe that all sufferers have a responsibility to share their lived-experience so that more people can be helped to manage their own disorder. Reading other sufferers accounts can be just what a person needs so as not feel alone and isolated; such a connection, even through the written word, can even prevent a suicide. For many years, I believed that I was the only person who felt such extreme heights and depths of thoughts, feelings, behaviors and even physical reactions. It was only when I was diagnosed and I read and heard about the experiences of fellow sufferers, that I no longer felt alone. When I was open about my illness, I realized how many others began to speak-out about their own diagnoses. For example, in the unit where I was placed, when I was spoke about my diagnosis, 3 of the prison officers based on that unit discussed with me that they were also sufferers of bipolar disorder. It is time that the voices of sufferers are heard and acknowledged as the experts by experience that they are, so that they can help and support each other to live more 'level lives'.

In more recent times, people in the public eye, including younger

members of the British royal family, are raising awareness of mental health issues, including bipolar disorder. This has highlighted the fact that bipolar disorder affects people of all ages, genders, races, professions and walks of life. It is vital that an individual can tell their employers without fear of discrimination. It may be personally exposing, but being open and honest from the outset may also be met with understanding and support. I myself, always tell potential employers of my bipolar disorder and, rather than being shunned and avoided, I find that my openness is both respected and embraced. I now have different organizations contacting me and asking me to assist in developing their workplaces to become more aware, and more active, in the support of the many people who are hiding their mental illness through fear. I learnt long ago not to live in fear, as fear feeds fear, and extreme fear is the root of so much violence. Since I conquered my fear and have been open about my illness, I have learnt to manage it. My mind is now settled and I am at peace with myself. I am in the most psychologically settled period in my life, thus far.

DARKNESS INTO LIGHT

*To be at peace, to be mentally well, as I sit in my cell
Will be confusing to most that I've known
But the path I've travelled, the emotional journey
This is how much I've grown
I was angry and tough, a black diamond so rough
The trauma and brutality, damaged me mentally
My face was contorted, my thoughts so distorted
How could I truly love with so much anger and hatred inside
No-one to trust in, nor in whom to confide,*

*Surrounded by thugs, front, back and side
As a child, hit, burnt, kicked, battered and bruised
A punch-bag, a servant, that's how I was used
Boarding schools, institutes, these were my house,
Survival of the fittest, my choice, to be an elephant or a mouse
I was labelled Top Dog or The Daddy, these titles they used
No longer connected to the little boy who was abused
Narcissism, self-aggrandising, replaced all my fears
Not showing vulnerability or sadness, never allowing tears
Ferocity, brutality was normal life in criminality
A mental illness that was never diagnosed
My life was hell, between highs and lows
Sometimes flying like a bird in the sky
Other times letters written, as I was ready to die
All became so dark, so bleak, nothing was good, struggling to walk, and
even to speak
A constant blackness through day and night, but now I can see the light,
at the end of that long dark tunnel, shining through, and day by day,
I take a step towards the light
The light of freedom, the light of change*

References

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