

Shifting sands: re-discovering hidden elements in Diagnosis, Mental Health Services and Community.

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We talk as if Personality disorder is a 'thing' – recognisable, measurable, solid, but you can't do a blood test to confirm PD, diagnosis is always a subjective opinion. My presentation to you today is about this being a hidden element that affects diagnosis, mental health services and stems from the community we live in. Nearly 30 years ago I used to attend a monthly self-advocacy group at Colchester Mind. At that time, it was felt that PD was untreatable so this was the diagnosis of discharge and people with a PD diagnosis came to Mind because they had no other service. But the people I met there didn't have just a PD diagnosis, most of them had a series of a dozen or so diagnoses, one for each psychiatrist they met. They only got a PD diagnosis when the people who cared for them could not think of anything else to do with them. People with this diagnosis were not considered suitable for therapy at the time.

The uncertainty of diagnosis

Surely things are different now from when I met my first people with a PD diagnosis? Although Personality Disorder is still considered to be a state of being rather than being an illness, now it is thought that some aspects of a PD presentation are treatable and should be treated. I work in an old-fashioned psychotherapy department. We are a small team of 2.4 Whole Time Equivalents. All referrals now go to an access and assessment team. They do not send many patients straight to us, we take referrals from all the teams in North East Essex but the bulk of our caseload comes from the specialist mental health team. They deal with all diagnoses except psychosis, dementia, primary substance dependency and primary eating disorders that all have a separate team.

It is still quite difficult to definitely diagnose PD a lot of the time. At our rough guess, a fifth of patients in Colchester could be either Psychotic or Personality Disordered and they are treated in whatever way seems appropriate at that point in time. It is customary for patients to be tried on different types of medication or several medications in various combinations until some kind of balance is achieved. Diagnosis is not part of my remit but I sometimes feel that this is decided by what medication seems to be working rather than the other way about.

There are fashions in diagnoses. Over the last year, a number of my patients arrived for assessment thinking they have Bipolar, this being the celebrity disease of the moment, but they were diagnosed with Emotionally Unstable Personality Disorder. Clinicians as well as patients are susceptible to fashions. I do not have any patients with a diagnosis of Borderline Personality Disorder but it seems to me that Emotionally Unstable Personality Disorder has superseded this diagnosis in our area. And the same as the people I met at Mind all those years ago, many patients are regularly re-diagnosed between Personality Disorder, Psychosis, Bi-polar, Dissociative Identity Disorder or Post Traumatic Stress Disorder. I do not think this is because they change symptoms, but I do think that they change presentation depending on who they see. If they get on with the staff member and feel they are being understood, they will react calmly and show insight. If on the other hand, they feel the staff member does not care, they may get angry and try to force the clinician to understand how they feel.

Our psychotherapy department has official acceptance criteria but it might be said that our traditional role in our organisation is to contain the uncontainable patients, and this is why we still exist. I do not know how representative my caseload is but this is data I have access to, so here is a 'quick and dirty' picture of the 30 or so people in my care recently. A third of them have an ICD 10 diagnosis of EUPD, the single largest diagnosis. Another third were not assessed by a psychiatrist so an ICD 10 code is not recorded. Those of us who are not psychiatrists have a separate list of reasons to refer. The remaining third have diagnoses of PTSD, DID, chronic Eating Disorder and the old favourites, Anxiety and Depression. It seems that Dissociative Identity Disorder is becoming fashionable too, but these patients were diagnosed with personality disorder first.

What all my patients have, regardless of diagnosis, is a history of difficult, painful childhood experiences. From my perspective, I deal with a group of people whose diagnoses vary greatly on paper and yet they all have something what we would call 'Borderline' in their presentation, that is, if they have a neurotic problem, there will be a psychotic problem underneath, and vice versa.

The difficulties inherent in the NHS mental health service

I have no reason to separate out those with PD because what defines my caseload as a whole is their inability to respond well to standard, shorter treatments and their family histories of physical, emotional, or sexual abuse, or neglect. One of the hidden elements in PD is it is hard to be precise in

diagnosing people with traumatic backgrounds. I turn next to the difficulties inherent in mental health services when it is assumed that PD is a concrete reality instead of a shifting concept.

Some of you will be aware that separate Personality Disorder pathways are very popular in the NHS right now, and meetings are happening at present to see if we should have one. There is an unspoken assumption that this group of people would benefit from more specialist care (what this might be is not yet clear). And there is probably a subtext that a specialist treatment will be shorter, more successful and therefore cheaper. The hidden element I would like to bring forward here is this. If only some of my patients have a PD diagnosis but they all have borderline traits, and then if a new pathway is set up with resources taken out of the current teams because there is no new money, thus impoverishing resources for those who do not have a PD diagnosis, it seems to me that a lot more people will be labelled as having PD because it gets them treatment that they might not otherwise be able to access. But the costs for the new pathway will be based on the existing numbers. This is something that we experienced with the development of the first pathways.

A couple of years ago and in common with most NHS mental health organisations, our old geographically based generic teams were divided between Specialist Mental Health and Psychosis teams and many patient/staff relationships were disrupted to achieve this. The size of the new teams was carefully planned to meet national recommendations including NICE (National Institute for Clinical Effectiveness) recommendations and to take advantage of economies of scale so the old small teams were replaced with three large teams, but we think, fewer clinicians overall. Access and assessment, the third team, was designed to ensure that all patients met our minimum criteria and were placed in the most appropriate treatment team first time. When it is overlooked that a diagnosis is a subjective opinion and not a concrete certainty, it is also not acknowledged that clinicians, including GPs, will change the factors they record for referral and assessment to meet the new criteria and patients will behave differently when this is necessary to get help. No-one anticipated the dramatic increase in the number of referrals for much more unwell patients. I worry that introducing a PD pathway could have the same effect.

Before the introduction of the pathways there were national service changes based on research evidence and included the expansion of CBT. It is standard in any kind of research to exclude any subjects who do not meet a carefully defined set of criteria, in order to be able to demonstrate whether an equally

carefully defined hypothesis brings about improvement in treatment. Unfortunately, these studies, which were used to justify sweeping changes in clinical practice nationally, are all but unrelated to the service for the whole range of those who seek mental health care, not just those who meet the study criteria.

The move to evidence based practice started about 15 years or so ago, when the government decided to fund IAPT, (Improving Access to Psychological Therapy), in an attempt to get a large proportion of people on sickness benefits back to work. This group was diagnosed with anxiety and depression but did not meet the criteria for secondary mental health care. It was thought that enough of them could be returned to work for the scheme to pay for itself. But there are always unintended consequences.

Our Commissioners chose to instruct us to stop seeing people in Care Clusters 1 – 4 as these people were covered by IAPT, and we should save our resources for those with suicidal ideation or complex personal histories. IAPT offers 6 weeks' therapy, and possibly this is enough to make people think about how they feel and it highlights people who feel suicidal who, I wonder, perhaps did not make their way to us before.

It is reasonable to want to know whether money for mental health services is well spent and supports service users in the most effective way, and we who work in state funded mental health do need to engage with showing how it works and how could it be improved. In the last several years, Care Clustering, which is based on HoNOS (Health of the Nation Outcome Score), was introduced and was designed to group patients into pathways which could then be given different tariffs. It was thought that this would lead to better treatments being adopted as it became clear which services were most efficient. I project managed the initial Care Cluster training for our clinicians in our Trust. If you sit 12 clinicians down with a paper vignette based on a patient, reliably, 11 out of 12 of them will score the patient more or less the same. However, if 12 clinicians all meet the same patient, their Care Cluster scores will be wildly different because they each come from a different perspective and have a different subjective relationship with the patient. When we conducted data evaluation exercises, patients did anything except neatly follow the chart of being diagnosed and then steadily improving to discharge. When I look at the Care Clusters of my little group of patients during their pathway before they reached me, it does not seem to mean anything apart from we have complied with a requirement to record a measure.

The uncertainty of social causes of PD

We do need a description of PD so we know more or less what we are talking about but the ICD 10 descriptions share something of the problems I have already described in Care Clustering. The descriptions themselves are concise, useful and recognisable. It's just that actual patients come in infinitely more shades than any paper description and this is further clouded by their presentation being distinctly variable depending on the inter-subjective relationship between them and the person they are talking to at the time. In my opinion, people who attract a PD diagnosis are acutely sensitive to others but also prone to misinterpreting what is said as being attacking towards them and they react accordingly. In view of their personal histories this does not seem at all surprising, but it seems to me that time and time again this results in their seeking help but being rejected. Their social matrix is tuned differently to the average.

It also seems to me that the patient's diagnosis is not much help, it is far more important to sit with them and let them talk but I think this is an anachronism remaining only in psychotherapy. The national desire for pathways and evidence based, time limited treatment rules this out. All my colleagues outside of psychotherapy have been driven into a sort of assembly line approach. Patients are batched for Psychology courses or Recovery courses but they are rarely ready for discharge after the first course. A young Egyptian junior doctor who joined us recently is astonished by the levels of deprivation in our collective caseload – she did not think a prosperous provincial town in England would be like this. She thinks we should automatically diagnose all our patients with Post Traumatic Stress Disorder since this is inevitably part of what we see now.

When I started seeing patients in the department about 10 years ago as an honorary psychotherapist, I don't think this was the case. I think then we saw many more people who were more like those described in case studies in the psychoanalytic literature, except for Winnicott whose case studies seem somewhat closer to what we see now but of course, he worked with young people who were described as delinquent.

Our patients today seem to be younger and more acutely ill. There seem to be many more parents of young children. The patients on our female ward that I visit sometimes seem very young; the older chronic patients who were regularly in and out of hospital seem to have disappeared. Our wards are now expected to provide focussed therapy and discharge to our Home Treatment Team in 11 days or less, a very different model to the old services. Has this

reduced the number of chronic patients or are a lot more people being sucked into mental health services? And what will happen when they are older?

Conclusion

I start my conclusion by wondering why would social circumstances suddenly change so radically and if so, when did this happen? Yes of course we can make a case for things changing, the young patients we see today have all grown up with mobile phones and internet access, and this surely makes things worse in that they can easily find out about self-harm and acquire the tools they need to cut, ligature or overdose. But the childhood abuse they report. Has this only existed recently? I don't think so, but I think talking about it has stopped being taboo. So where were this group in the past – maybe the clue is in Winnicott's studies of delinquent boys. When we changed PD from being the diagnosis of discharge to a treatable mental illness, did we inadvertently re-define a group of people formerly regarded as bad into mad? And by restricting access to those who have suicidal ideation and intent, have we forced those who seek help to escalate their behaviour to meet our criteria?

A sociologist called Norbert Elias is credited in Group Analysis with having a good explanation for how society works. Every minute of every day, hundreds of thousands of personal decisions are made, based in the social matrix that connects us all but relating to our individual agendas. The outcome is that these decisions roll into each other and direct society into social movements that no-one is in charge of, they just happen. He suggested that while there is room in society for upward movement, all is well. But when there is no space for people's lives to continuously improve, there will be unanticipated consequences. I am wondering if we are at one of those times.

About 70 years ago an American Functionalist Sociologist called Talcott Parsons invented a rule called Parson's sick role. He described sickness as socially sanctioned deviance, where the sick person is allowed to be non-productive and is exempt from social obligations on condition that they accept help from acknowledged professionals and try to get well, but this was criticised as it does not allow for chronic conditions. It seems to me that this is exactly what is not allowed in mental health treatment today. Whereas once we did not discharge people who remained unwell despite our best efforts and we managed a chronic caseload, now we only provide fixed term 'solutions' to identified problems and we find ourselves looking after a different set of people.

There is no reliable data to tell us if there are more people with borderline and destructive states of mind today than formerly because the diagnosis is a

subjective decision affected by circumstances, personal and social. What is reliable is that if discharge must follow, clinicians will hold back from using this diagnosis, and if services are only available to those with a PD diagnosis, there is a reason to give someone this still pejorative label. No one person made choices to make this happen, it is a social shift that follows the same path identified by Durkheim that particular types of society promote social anomie and increase suicide. Suicidal ideation has become a major route into receiving secondary mental health care in my service. I think the assumption that mental illness divides into fixed concrete categories is itself a product of the social matrix of the society we live in, and it also shapes the patient population when sanctioning some behaviours as fit for treatment and not others, changes over time.

Young people around the millennium cannot take for granted that their lives will be as good as or better than their parents. It seems to me there is a current underlying assumption that those who 'fail' in one way or another, including mental illness, are held to be at fault for not trying hard enough. Parsons was right, just ahead of his time.

I think borderline and destructive states have always been there along with the social deprivation that seems to be at its root, but I think we may have inadvertently re-categorised people who express their feelings this way as being -mentally ill instead of as being delinquent. Younger people seem to be more at risk of being identified by the system and suicide is no longer taboo. I do not think borderline and destructive states of mind are the *diagnosis* of our times; they are the unintended consequence of our current social matrix.