



**Out of a shared sense of alienation, as a result of being diagnosed with personality disorder, service users set up a group to study the adverse effects associated with being given this diagnosis. Heather Castillo and colleagues report**

# The hurtfulness

## User research about

**T**his paper aims to highlight service users' views regarding the diagnosis of personality disorder (PD). We believe this study is unique in that, as far as we are aware, this is the first time that current users of psychiatric services have attempted to research a clinical diagnosis. Here service users have been able to define themselves effectively within a system and so contribute to scientific knowledge by suggesting ways forward in terms of understanding and practice.

The history of the diagnosis of personality disorder spans almost 200 years and the category has been handicapped by poor theory. Without a valid theory, response and treatment are of uncertain benefit and agreed measures of prevention will not be correctly developed and supported. Indeed, the category remains an elastic concept which may include a wide range of people and encompass a variety of presentations.

Diagnostic definitions suggest that those with this diagnosis may display certain character traits, but these definitions do not say why. Within psychiatry, beliefs that a condition

is negatively enduring can be stigmatising.

The classification of PD continues to generate a kind of moral panic in society, even though its clinical definitions range from the most timid to the most dangerous among us. The diagnosis is characterised by confusion and lack of agreement. Where understanding is required, fear has emerged.

### Summary of the service user's view

For the service user, finding out that you have a diagnosis of PD can be a traumatic and bewildering experience. All too often, such a diagnosis brings with it a change in attitude from other people. You only have to read the negative terminology in the European and American psychiatric manuals, *ICD 10* and *DSM IV*, to realise that there is little hope associated with a diagnosis of PD. We are classified with traits described as deeply ingrained, enduring and inflexible; which infers untreatability. As a group we already feel threatened and vulnerable, but we are often tarred with the brush of being 'bad' as well as 'mad'. It is hard for any of us who have

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# of a diagnosis: personality disorder

experienced extreme trauma and abuse to forget the past, but this does not mean that we do not want to change and to move on.

Along with our responsibility to try to help ourselves comes the professional's responsibility is not to throw us on life's 'scrap-heap' and deem us untreatable. Those of us with a PD diagnosis can, unintentionally, elicit a negative response and a kind of aloofness from professionals. We are often a mass of churning emotions and can be seen as attention seeking and as 'acting out'. Many of us, especially those who have been severely traumatised and abused as children, have little or no control over our lives: food, drink, self-harm and the use and misuse of medication, and other substances, can be employed as coping mechanisms and a means of gaining some kind of internal equilibrium (Van der Kolk 1996).

Sadly, these coping strategies can be misunderstood by some professionals who view them as an unwillingness to cooperate, although this is rarely the case. Unfortunately such behaviour on the part of clients may only serve to add to the indifference and less than sympathetic approach that some professionals display towards people with a PD diagnosis.

A common human failing, and one particularly prevalent in the medical arena due to professional socialisation, is that of the need to distance, diagnose, categorise or separate. Perhaps if more people could accept, understand, sympathise and not

judge, the world would be a better place. We all deserve to be treated as individuals, no matter what our problems and difficulties, and those of us who have attracted a PD diagnosis are no different. But we cannot truly call ourselves a civilised society when so many of us feel like outcasts. For our group, the decision to investigate the diagnosis began to gain impetus from a shared sense of alienation.

## The study

The study examines the diagnosis of PD from the service user's perspective. With support and funding from Anglia Polytechnic University and Colchester Mind, over a period of one year, 18 service users with the diagnosis formed a group in which experiences were shared. Nine group members created written narratives exploring life events, and four members were trained to interview 50 people from north east Essex with this diagnosis.

The service users who had attracted the diagnosis set out to study the problem from the inside. The scientific authenticity of such a method is described by Freire (1970) as an approach which challenges the validity of the 'privileged', effectively analysing the 'underprivileged'. Therefore, in our research the 'view from above' has been replaced by the 'view from below'. In this study the research tools have been given to 'the people' and with these tools they have been able to make us aware of

their sufferings and contexts. These explorations attempt to provide a missing part of the total system of factors concerning the diagnosis which has come to be known as PD (Castillo 2000).

### The findings

Literature shows that people in this category are often misunderstood and stigmatised (Gostin 1985, Lewis and Appleby 1988), but that dysfunctional behaviour can be trauma-related and distorted attachment experiences in childhood result in a dissociative core self (Fonagy 1997). The findings of the study, both in terms of its narrative data and survey results, indicate that for a significant proportion of people classified as having PD, life events involving early trauma offer a theory regarding the aetiology of the disorder. It also suggests that the PD label is very stigmatising and can compound the effects of trauma. Within the survey sample of 50 respondents, 88 per cent had experienced abuse and, for 80 per cent this was childhood abuse. Seventy-two per cent of users in the study considered they had experienced bad treatment because of the diagnosis.

Confirming that such a categorisation is stigmatising, respondents describe being treated as a 'service's leper'. Others said 'you're ignored', that a PD label aroused 'hostility', that it was not a 'mental illness', was 'brought on oneself', that 'people seem to be scared of the diagnosis', or 'it's saying trouble maker'. Many service users discovered indirectly that they had the diagnosis from records, reports or at social services meetings. Others appear to have been told after many years, yet others were told by professionals only after they asked. The sense of exclusion and hopelessness expressed by respondents on making this discovery gives some insight into the impact the information might have on an individual already labouring with the task of living with the truth of an early abusive history.

Our study involved 20 men and 30 women. Forty-two per cent (21) had been violent to others – consisting of 20 per cent women (10) and 22 per cent men (11). More than 75 per cent (23) of those with a borderline diagnosis were women and over 75 per cent of those with a dissociative diagnosis were men (11).

None of the men with a borderline diagnosis had been violent to others. Thirty-five per cent (8) of women with a borderline diagnosis had engaged in violent acts, yet had retained the borderline categorisation. Does this suggest that violence in men might attract a diagnosis of psychopathy more easily than for women? Does it highlight the greater likelihood of a prison disposal on the basis of gender? Certainly, 26 per cent of men (13) in our study had experienced prison, compared with 12 per cent of women (6). Fifty per cent of the men (11) with a dissociative diagnosis consider their strengths to be care and compassion. Rather than the stereotypical notion of the psychopath viewing fellow human beings as 'empty vessels', they characterise themselves as 'Jekyll and Hyde'; an embodiment of both compassion and aggression. They highlight the fact that aggression has a



context, and that strengths may go unrecognised. Whether the categorisation is borderline or dissociative, our study shows high incidences of early abuse, self-harm and suicidality across categories.

One of the few variables was a notably higher rate of suicidality and early sexual abuse (70 per cent) among women with a borderline diagnosis. Women with a dissociative diagnosis all had a history of early emotional abuse; none had a history of childhood violence yet 67 per cent (4) had been violent to others. Where men had experienced early violent abuse, some went on to harm others. Some engaged in self-harm.

These findings suggest that violence does not necessarily beget violence, but that early, unresolved and unassimilated trauma can result in the perpetration of harm. This may be directed inwards as self-harm, or outwards as harm to others. This questions the validity of the diagnosis of personality disorder and also its sub-categories.

In the study, 88 per cent claimed to have experienced hospitalisation and 60 per cent have been 'sectioned' under the Mental Health Act. For some, the association with mental health services spans decades, for others it was more than ten years. Seventy-eight per cent experienced isolation and 88 per cent lived on welfare benefits. Many are still depressed and anxious. The fact that a 'revolving-door' syndrome exists says something about the need for a wiser use of limited resources. Even where the anti-social aspect of destructive behaviour may lead to a perception that someone is less deserving of receiving health care, this can still place a high demand on health as well as social and criminal justice services, suggesting that effective and lasting therapeutic treatments should not be considered an expensive luxury.

An analysis of what was most helpful revealed a positive rating for therapy. The findings include service users' observations about a wide variety of therapeutic interventions. Cognitive analytic therapy (Ryle 1990) received the highest therapy rating in our study. One service user commented: 'I've seen him [the therapist] for over a year. He's done more than the whole services put together.'

Where an individual's symptoms include features such as the kind of complex stress disorder described in our study, there is no adequate diagnostic category to give validity to such difficulties. This points overwhelmingly to the need for a reframing and renaming of the diagnosis into a category which suggests clearer aetiology, and offers a better understanding of this condition.

### Comment

Psychiatric diagnoses are not morally neutral; they live in the minds of patients, sometimes as a helpful explanatory force.



But in the case of a PD diagnosis this can be less than helpful. Nowadays, individuals are informed enough to look up diagnoses and the ICD 10 definition, which refers to pervasive and inflexible deficits which are stable over time. This gives them no cause for any hope.

One can argue that diagnosis is a scientific process and is not designed to give people hope or help them to feel better. However, the term 'personality disorder' does not have much scientific credibility and is often hidden from patients, poorly or too briefly explained. It usually results in a worsening of staff members' attitudes towards the patient and rarely helps the person to understand his or her plight. It is not an 'illness', but neither is it 'wellness', and the person can suffer from being excluded from both categories. Being 'ill' entitles a patient to certain types of medical care, hospitalisation and a degree of tolerance. This has advantages which can counterbalance the negative effects of diagnosis. Not being ill means being well, implying responsibility for one's actions, and if these actions are a problem for others, then one is 'bad', causing rejection by health services and the withdrawal of patient privileges.

The term borderline PD, which was applied to 58 per cent of the individuals engaged in this research, is a hybrid term; adding the concept of the borderline syndrome to the concept of PD. Its complex historical origins seem abstruse and irrelevant to most patients. The term borderline can have so many different connotations. In her book *Prozac Diary* (1998), Lauren Slater described the term as ... 'the most mysterious word of all, suggesting the line of the horizon, a flat world, a ship tipping over into a star-filled night'.

This research has been carried out by a self-selected sample of service users who, in common with groups in other parts of the country, provide each other with care, support and information. It is clearly not objective in the usual scientific research sense, but then again, there are limitations to the purely scientific and clinical approach. Patients (who are only patients when they are seeing us) can

provide an additional perspective outside the clinical context and can become partners in the effort to understand.

This research shows clearly that childhood abuse, particularly sexual abuse, is very common in people diagnosed with PD. This finding concurs with various clinical studies, especially those concerning borderline PD (Meinchenbaum 1994), and adds an additional perspective. Abuse is a very important aetiological factor and its effect on the developing personality is variable, and other aetiological factors are significant. It is suggested that these individuals would feel less hurt and gain more credibility within mental health services if professionals re-examined their own attitudes in light of modern research (Cloninger *et al* 1993, Van der Kolk 1996) and engaged in a dialogue with service users.

#### Implications for practice

Service users in this study may help others to look at not just how they are, but how they came to be that way. They might not always know what is helpful, but they usually know what is unhelpful, what is upsetting, and what provides a trigger for the worsening of their difficulties. They seem to be saying that understanding and acceptance will get professionals half way there.

The most often reported, and unpopular, professional response in this study is being told one is 'attention seeking'. To say that someone is attention seeking is to imply that the person is not worthy of attention. It is dismissive. Professionals might rather see behaviours such as self-harm, continual neediness, and suicide attempts as attachment seeking, which might be better understood in terms of attachment theory and separation anxiety (Bowlby 1988).

Service users in the study have highlighted that 'living in fear comes from the childhood, self-harm, panic attacks, eating disorder, alcohol and drug addiction, fear of coping alone, depression' and are suggesting that 'a lot of people see you as untreatable, you're not offered the help and support. You're not seen as a human being but as a diagnosis'. What they are asking for is a legitimisation of their difficulties, professional understanding, to be listened to and accepted, access including 24-hour phone lines, alternatives to hospital such as crisis houses and safe centres, and appropriate therapies ●

#### REFERENCES

- Bowlby J (1988) *A Secure Base*. London, Routledge.
- Castillo H (2000) Temperament or trauma? Users views on the nature and treatment of personality disorder. *Mental Health Care*. 4, 2, 53-58.
- Cloninger R *et al* (1993) A psychobiological model of temperament character. *Arch Gen Psychiatry*. 50, 975-990.
- Fonagy P (1997) When Cure is Inconceivable: The Aims of Psychoanalysis with Borderline Patients. Paper to New York Freudian Society 4/4/97.
- Freire P (1970) *Pedagogy of the Oppressed*. New York, Herder & Herder.
- Gostin L (1985) *Secure Provision*. London, Tavistock.
- Lewis G and Appleby L (1988) Personality disorder: The patients psychiatrists dislike. *British Journal of Psychiatry*. 153, 44-49.
- Meinchenbaum D (1994) *Treating Post Traumatic Stress Disorder: A Handbook and Practice Manual for Therapy*. Chichester, John Wiley & Sons.
- Ramon S *et al* (2001) Experiencing Personality Disorder. Paper submitted to the *International Journal of Social Psychiatry*. (in press)
- Ryle A (1990) *Cognitive Analytic Therapy: Active Participation in Change*. Chichester, Wiley.
- Slater L (1998) *Prozac Diary*. London, Hamish Hamilton.
- Van der Kolk B (1996) *Traumatic Stress*. London & New York, Guilford Press.

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