

Diagnosis or

Few clinical diagnoses are as burdened with pejorative moral judgements and negative professional attitudes as personality disorder. What is it like for those given such a diagnosis and what are the implications for the help they are likely to be offered? Heather Castillo, advocacy service manager for Colchester Mind, received R&D funding to lead a unique study which looked at the diagnosis of personality disorder from the patient's perspective.

Personality disorder is seen as either causing problems to self and/or others, or viewed as so antisocial as to be a danger to society. Although patients range from the most timid to the most dangerous, the enduring perceptions evoke fear rather than understanding. The age-old question of 'mad or bad' raises the issue of treatability: whether patients can be treated, but also whether they deserve to be. With assistance from Heather Castillo, 18 people who had been diagnosed with personality disorder formed a group to challenge those public and professional perceptions.

"The group wanted to know about people's experiences both of life events and of the system. By attempting to distinguish between the cause, resulting condition and behavioural consequences of personality disorder, the study aimed to discover what interventions have been and might be helpful," explains Heather Castillo.

"In this way, we hoped to contribute to the development of a framework for treatment and support that might better meet the needs and vulnerabilities of people with this diagnosis."

Data collection involved collecting journals, poems and letters and records of discussions among the study group members; open-ended interviews with 50 people with the diagnosis; and quantitative questions to ascertain demographic, diagnostic and experiential data.

With the assistance of Anglia Polytechnic University, four of the group completed training as research interviewers (a fifth person was unable to complete the training through ill health) and devised an interview questionnaire, which they first tested out on each other. Fifty interviews, each lasting around one hour, were completed between July and December 1999. Four people



responded by post and the rest took place either at the Mind social centre, in the respondents' homes or in hospital. All interviewers had periods when they were too unwell to work.

The majority of the interviewees (88%) were on long-term sickness or other benefits and only one worked full-time. Most had other conditions, such as depression, anxiety and eating disorders, which are treatable. "Allotted a category that is recognised as psychiatrically untreatable, they are effectively abandoned in a hinterland devoid of real legitimacy and thus disadvantaged from the start in terms of response and treatment," Heather Castillo argues.

The common view that people with personality disorder have a limited capacity to express feelings is starkly at odds with the often moving degree of self-awareness and anguish revealed in the interviews and writings.

"I do have some insight into the causes of my mental state and I also know I can't simply forget the past."

"[My therapist] simply ignored what did not fit into her theory."

One of the most disturbing findings was that 44 of the 50 had been either physically and/or sexually abused as a child or adult or both. One stated: "I am a victim of

Consumers in Research

The NHS R&D strategy is committed to involving consumers in the work it undertakes – not as 'subjects' of research, but as active participants. 'The Consumers in NHS Research' group aims to ensure that consumer involvement in R&D in the NHS improves the way that research is prioritised, commissioned, undertaken and disseminated.

Our strategic objectives are:

- To develop strategic alliances with key groups in order to promote greater consumer involvement in health research
- To empower consumers to become more involved in research and development in the NHS
- To monitor and evaluate the effects of consumer involvement in NHS research & development

Further details can be found on their web site:

[web http://www.hfht.org/ConsumersinNHSResearch/](http://www.hfht.org/ConsumersinNHSResearch/)

judgement?

“Perhaps if more people could accept, understand and sympathise rather than judge then this world would be a better place.”

childhood sexual and ritual abuse...I am not yet a survivor...I don't see why I should be deprived of the care and expert counselling that I need.”

“Perhaps if more people could accept/understand/ sympathise/not judge then this world would be a better place.”

“All I know is that we cannot call ourselves a civilised society when so many people are outcasts and are simply not understood.”

Thirty-six per cent said their family had helped them most and one-third said therapists, frequently cognitive analytic therapy or occupational therapy. Also of help were psychiatrists, medication, the community mental health team, the

advocacy service and voluntary sector. However, nearly three-quarters thought they had been either badly treated by mental health services or had received mixed treatment that included inappropriate, bad or no treatment. One commented: “As a group we already feel sub-human, misunderstood and vulnerable, and now we are tarred with the brush of being bad as well as mad.”

Heather Castillo believes that life events involving early trauma may offer a theory about the aetiology of the disorder. The study also indicates that the stigma attached to personality disorder can of itself compound the effects of trauma,

both by reinforcing a damaged sense of self and precipitating a negative service response. Heather Castillo stresses the need for training to increase understanding and skills along with more support for those providing treatment and care. “A ‘revolving-door’ syndrome apparent among some of our sample may say something about the need for a wiser use of limited resources,” she adds

She concludes that ‘this points overwhelmingly to the need for a reframing and renaming of the concept of personality disorder into a category that offers a better understanding of this human condition.’

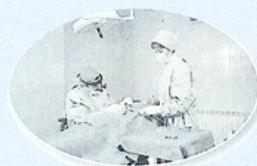
For further information, email Heather Castillo at mail@colchestermind.org

Staying long in the tooth

An R&D funded prospective study of molar apicectomies over the last 26 years has uncovered valuable and long-awaited evidence that could save thousands of teeth.

Whereas anterior and premolar apicectomy (surgically removing the tip of a tooth root from front or side teeth) have been common and effective treatments for many years, dental and oral surgeons have tended to view molar apicectomy (back teeth) with scepticism. The main reasons for this are concern about the potential risk of lower lip numbness, the lack of studies to enable extrapolation of reliable cure/fail rates and little understanding of what can cause failure.

Consultant oral surgeon, Colin Wesson, has been one of the leading exponents of molar apicectomy over the last quarter of a century, treating his own patients and many referrals. Recently retired, he had collected data on 1,000 cases between 1974 and 2000 with a minimum five year post-operative follow-up for patients up to 1995. Tim Gale, who is R&D development



“If it stimulates oral surgeons to think again about molar apicectomy it could save countless teeth from unnecessary extraction.”

facilitator for East and North Herts NHS Trust, set up a prospective study of the data aided by an R&D research grant.

At five years, each procedure was classified as full cure, a partial cure or a failure. Only when a patient reported no problems and the tooth was shown by x-ray to be fully intact, was it considered a full cure. The overall cure rate of 60% is broadly similar to anterior and premolar apicectomy which, says Tim Gale, “suggests that the use of time-honoured amalgam accounts for the majority of failures.”

Advances in recent years in the materials used to seal root canals is likely to considerably improve prognosis. The evidence on lower lip numbness was also encouraging, with only nine cases from 1,000 patients. The research is in current submission to the British Dental Journal.

Tim Gale concludes: “We now have an accurate assessment of the real risk associated with the procedure. If it stimulates oral surgeons to think again about molar apicectomy it could save countless teeth from unnecessary extraction.”