

What is it about DID? A patient and clinician perspective¹

COMMENTARY

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SUMMARY

The diagnosis of dissociative identity disorder (DID) remains a contentious area in mental health. Patients experiencing such difficulties are often harshly identified as suggestible neurotics and interested clinicians as fanatics. However, for the sufferer, DID is as real and has as much impact as any other psychiatric diagnosis.

This commentary challenges psychiatry's dismissive and disbelieving attitude towards DID. The authors (a person with DID and a clinician) acknowledge the limited understanding of DID's aetiology and the paucity of associated neurological findings, but ask whether this is not the case for many other accepted psychiatric conditions. They call for UK psychiatric practice to move on from the debate and for the Royal College of Psychiatrists to take the lead, with inclusion of DID in core psychiatric training and guidelines on approaches to diagnosis and treatment.

KEYWORDS

Dissociative disorders; post-traumatic stress disorder; individual psychotherapy; education and training; stigma and discrimination.

So, what is it about the DID diagnosis? – An introduction by A.C.

In a previous issue of *BJPsych Advances*, Paris (2019) presented dissociative identity disorder (DID) as a diagnosis that should be consigned to history, citing absence of research evidence, the Hollywood societal effect and suggestible fantasy-prone patients under the care of fanatical believer therapists as evidence to support this. He does not deny dissociation as a symptom, but he states that DID is an artefact of the therapeutic process.

As a patient living with DID, I was confused by this statement, given my experience of symptoms for many years before contact with services or indeed therapy. I do not know any clinicians, past or present, specialist or generalist, who would try to or would know how to 'create this disorder' in their patients. Equally, for patients to be called suggestible and fantasy prone is insulting and unprofessional. Would this set of adjectives be applied to any other patient groups in the medical literature and,

equally, would such comments survive peer review to edited print? So why for those with DID? What is it about the diagnosis of DID that seems to allow behaviours in clinicians that are not compatible with the guidance of the UK's General Medical Council on good medical practice for doctors (General Medical Council 2019)? Why does the diagnosis of DID seem to raise so much objection in the medical community, allowing the dismissal of patients' symptoms and a pejorative stance that includes the damning of medical colleagues as fanatics causing harm?

Dissociative disorders

The theory of dissociation was first penned by Janet in 1892, and latterly supported into the 21st century by Van der Hart et al (2006). Currently known as the theory of structural dissociation, it outlines how three levels of clinical dissociative experience manifest, culminating in the presentation of DID. An increasing evidence base of neurobiological studies supports DID's validity. A study by Reinders et al (2019) found that researchers could discriminate between people with and without DID on the basis of neuroimaging biomarkers with a sensitivity of 72% and specificity of 74%. Blihar et al (2020) completed a systematic review of neuroanatomical findings in DID demonstrating that people with DID had differences in brain imaging and neural responses compared with controls.

A fad diagnosis?

Despite DID classification alongside other recognised psychiatric disorders in the ICD-11 (World Health Organization 2018), Paris (2019) identified the best understanding of DID as a medical 'fad'. The Oxford English Dictionary (2019) defines a fad as 'a shared enthusiasm for something, a short-lived craze'. The patient contributors to this article have lived with these symptoms across lifespans ranging from 20–60 years and can attest that they are not short lived and there is no enthusiasm for having them. Living with DID is intensely difficult. The amnesia and lack of personal narrative, alongside consequences of behaviours you would not consciously choose to carry out, leaves you feeling confused and self-diagnosed as 'mad'. This feeling

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can be compounded by the lack of knowledge and understanding among clinicians, regular disbelief in the diagnosis, significant gaps in available appropriate treatment, an absence of National Institute for Health and Care Excellence (NICE) guidelines and all despite the increasing biological empirical evidence.

Diagnosis in the UK is a core skill completed by psychiatrists with specialist training to a framework approved by the Royal College of Psychiatrists (2017) requiring a working knowledge of the international diagnostic classification system of the World Health Organization's ICD (World Health Organization 2018) and the American Psychiatric Association DSM. The diagnostic process involves an assessment that brings together specific questioning, observations and experience. The 'skill' of diagnosis relies on the clinician having developed knowledge and clinical experience in conditions. Dissociative disorders, other than depersonalisation and derealisation, do not form part of this working training framework. This results in the absence of understanding and therefore ability to appropriately enquire and consider DID within differential diagnostic assessment. Clinicians understandably will fit presentations to those they know and have experience in. It is no surprise that general psychiatrists may then report rarely having 'seen a case'.

We believe that inclusion of all the ICD-listed dissociative disorders in RCPsych training and the resulting greater awareness developed would alter this.

The patient-contributors to this article – experts by experience – are clear that DID is not a diagnosis that is 'wanted' or due to histrionic tendencies. For most, the diagnosis is something that has been held predominantly hidden and disguised as best possible. The symptoms are terrifying, and you feel out of control. How do you explain to a clinician that you 'come round' to severe self-injury or having carried out behaviours you would not normally engage in and might be abhorrent to you? You know you must have done it but have no memory of it and are so ashamed by it. You know it sounds 'crazy and made up'. Self-injury itself is often followed by a judgemental response by clinicians, so how do you tell them the rest? The clinician's absence of appropriate knowledge and enquiry about this does not make it any easier for patients and so symptoms are not discussed or are missed, misdiagnosis occurs and so difficulties and their impact continue.

This might begin to be addressed by incorporating open questions within the review or risk assessment process that seek to discover whether the patient recalls their actions and intentions. Do they feel that the patterns of behaviour fit with who they are

and how they were feeling prior to the event? Do they recall any level of planning or insight into the event? Introducing such a curious enquiry into presentations of repeated self-harm or suicide attempts could provide valuable insight into whether these incidents are potentially dissociative in nature and origin. This might help to create a more 'normalised' opening for dialogue about something that feels incredibly difficult for the sufferer.

The fallacy of only recovered memories in those with DID

An absence of trauma memories pre-therapy, which are then 'recovered', as quoted by Paris, is not the experience of the patient-contributors to this article. Pre-therapy memories can vary, from detailed trauma narratives to fragmented misunderstood individual elements such as intense emotions, sensory and body experiences alongside image 'snap shots' within a re-experiencing of a post-traumatic stress disorder (PTSD) type. Events in life, not therapy, often increase these, with a subsequent impact on functioning, which in turn precipitates access to services.

Current UK treatment approaches and treatment harms

Treatment manuals by Boon et al (2011) and Steele et al (2017) outline the current treatment approach for DID in UK and Europe. This focuses on improving daily functioning, reducing harmful behaviours, addressing deficit areas with skills training, and promoting *intrapersonal* connection, communication and collaboration with the individual's dissociative system. The focus is on empowering, developing agency within the patient and promoting and encouraging personal responsibility for themselves as a 'whole'. Paris (2019) focuses on the use of clinical hypnosis in treatment, yet in the consensus treatment guidelines by International Society for the Study of Trauma and Dissociation (2011) (which he mentions), only a small subsection relates to the use of hypnosis and potential concerns about this modality are raised, with clear statements on approaches to minimise these. What Paris fails to mention is the damage arising from misdiagnosis of DID as better known conditions such as psychotic, mood and personality disorders. Such misdiagnosis can result in cycling through services, leading to iatrogenic harms from medications, from a lack of understanding of the impacts of interventions such as restraint and from boundary transgressions arising because of the patient's interpersonal dysfunction (Brand 2011). In our experience (as patients and clinician), medications for 'symptomatic'

treatment do little other than over-sedate and can be the cause of considerable side-effects.

Why the continued controversy?

What we struggle to understand is who is served by this ongoing controversy and what purpose it has. It causes significant harm to those of us experiencing DID and multiple barriers to those trying to treat it. This needs to change. We believe that the RCPsych should lead the way in ending this by publishing a position statement on the condition, ensuring the inclusion of all dissociative disorders in the updated core curriculum and developing a College Consensus Statement accepting the diagnosis and Report on approaches to diagnosis and treatment.

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Author contributions

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Declaration of interest

M.T. previously worked for Schoen Clinic York, which is commissioned to provide treatment for people with the described condition.

ICMJE forms are in the supplementary material, available online at <https://doi.org/10.1192/bja.2020.92>.

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