

Diagnosis

BLOG

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DID OR OSDD: DOES IT MATTER?



by Carolyn Spring

Note: DDNOS (dissociative disorder not otherwise specified) was renamed OSDD (other specified dissociative disorder) in the latest update to the psychiatric diagnostic manual, the DSM-5. In this article we're using the terms interchangeably whilst mainly using the term 'OSDD' for brevity.

WHAT IS THE DIFFERENCE BETWEEN DISSOCIATIVE IDENTITY DISORDER (DID) AND OTHER SPECIFIED DISSOCIATIVE DISORDER (OSDD)?

One of the many questions I frequently hear is about OSDD – other specified dissociative disorder. I'll explain technically what OSDD is in a moment, but a quick (although inadequate) definition might be 'dissociative identity disorder without distinct parts of the personality'. Many people with DID struggle with what their

diagnosis means to them – they may resent it or disbelieve it, but there is at least some understanding, and an increasing amount of literature, on the nature of dissociative identity disorder. The same cannot be said for OSDD. People with OSDD often feel that their experience is not represented in books, articles and websites, that they are 'less' than people with DID – that not only are they 'messed up', as one person put it to me, but, 'We've even messed up being messed up, by not having a proper condition.'

OSDD – THE MOST COMMON DISSOCIATIVE DISORDER?

This is a painful position to be in, and yet a variety of studies have regularly found that OSDD is either the most common or among the most common dissociative diagnoses: it is diagnosed, according to O'Neil et al (2008), in 40% of cases. ▶



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Suzette Boon reports that OSDD 'actually involves the majority of people who seek treatment for a dissociative disorder' (Boon et al, p.10). And Spiegel et al (2011, p.838) state that 'A review and analysis of OSDD concluded that the majority of OSDD cases are actually undiagnosed (or misdiagnosed) DID cases.' So something is clearly going wrong.

According to the American Psychological Association, the predominant feature of OSDD is:

presentations in which symptoms characteristic of a dissociative disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate, but do not meet the full criteria for any of the disorders in the dissociative disorder class.

(APA, 2013)

In other words, someone with OSDD has dissociative symptoms but they do not meet sufficient criteria to be diagnosed with either depersonalisation disorder, dissociative amnesia, dissociative fugue or dissociative identity disorder.

FOUR TYPES OF OSDD

There are four presentations of OSDD listed in the DSM-5:

1. Chronic and recurrent syndromes of mixed dissociative symptoms
2. Identity disturbance due to

prolonged and intensive coercive persuasion

3. Acute dissociative reactions to stressful events
4. Dissociative trance

OSDD - 'NOT QUITE' DISSOCIATIVE IDENTITY DISORDER?

In practice, subtype 1 is much more common than the others. The DSM-5 adds some detail to it, saying: 'This category includes identity disturbance associated with less-than-marked discontinuities in sense of self and agency, or alterations of identity or episodes of possession in an individual who reports no dissociative amnesia.' In other words, OSDD often presents as 'not yet' or 'not quite' DID - people who haven't yet met the criteria for dissociative identity disorder but may well do so in the future, or people who have slightly atypical forms of DID, for example by not having amnesia.

This of course begs the question of whether OSDD/DDNOS-1 and DID are in fact the same thing, and just different points on a spectrum, and whether the diagnostic criteria for DID are too tightly applied. Certainly OSDD is supposed to be a 'residual' category to mop up the 'few' cases of dissociative disorders that do not meet the mainstream criteria. But if up to three times as many people receive a diagnosis of OSDD/DDNOS compared to dissociative identity



disorder, it would suggest that the definition of DID is too narrow. This is certainly the view of a number of experts in the field.

For example Colin Ross (2007, p.142) says:

The dividing line between DID and most cases of dissociative disorder not otherwise specified is arbitrary. Most cases of DDNOS are partial forms of DID which lack either clear switching of executive control, full amnesia barriers between identity states, or clear differentiation and structure of identity states. They are partial forms of DID with the same patterns of childhood trauma and co-morbidity.

Similarly James Chu (2011, p.53) writes:

Dissociative disorder not otherwise specified (DDNOS) is a catch-all category for dissociative disorders that do not fall into other groups. However, included in the DDNOS category is a commonly seen group of patients who do not have the extreme identity separation of dissociative identity disorder, but who have a range of dissociative experiences and significant identity confusion and alteration. Patients with this kind of almost DID do not see themselves as having multiple identities, but frequently feel so differently at the time that they see themselves as a series of different 'me's' (e.g. 'I know it was me, but I felt as though I was observing myself. I couldn't

believe what I was saying and how I was behaving.')

Also included in the DDNOS category are atypical DID cases in which there are classic DID symptoms but no amnesia between identities, because the diagnosis of DID includes the requirement for the presence of amnesia.

OSDD AND DISSOCIATIVE IDENTITY DISORDER – A SPECTRUM?

So on the one hand we have a vast swathe of people who are, or would be, diagnosed with OSDD as opposed to dissociative identity disorder but who show almost all of the symptoms of DID. Many people therefore see DID and OSDD as appearing on a spectrum, and prefer to conflate the two conditions so that DID/OSDD represents a range of dissociative experiences with more or less amnesia and greater or less elaboration and distinctive identity states or parts of the personality.

It is also what happens in practice: very few people would realistically distinguish between DID and OSDD. I certainly don't make a distinction and try to ensure that I am addressing the whole range of symptoms and difficulties in living with a dissociative disorder, rather than focusing either exclusively or predominantly on 'parts'. We see the presence of these dissociative parts of the personality as really important, and



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of course it is the stand-out feature of DID, but we also recognise that parts develop in response to trauma and disorganised attachment, as do a whole range of other symptoms. So our focus is on living with that entire range of symptoms, and being able to deal with the underlying cause.

THE IMPORTANCE OF VALIDATING OSDD

At the same time, however, it is important to note that there are differences between someone whose constellation of symptoms would identify them as being at the DID end of the spectrum, and someone whose similar but slightly different set of responses might place them at the OSDD end of the spectrum. When there is often a strong emphasis on the dissociative parts of the personality, people with OSDD can feel unheard and unseen, and so I feel that it is very important to validate the reality of the experience of people with the OSDD label.

We have touched on two major differences already – less elaboration or switching to distinct parts, and less amnesia. But people may be diagnosed as OSDD as opposed to dissociative identity disorder simply because their ‘parts’ didn’t show up on cue at a diagnostic interview. Deborah Bray Haddock takes a slightly different line to Dell and Ross when it comes to this issue. She says:

My advice to clinicians is that until they have met an alter, it is not DID. They may suspect that someone has DID and their suspicions may prove to be correct, but each of the four criteria must be met to diagnose someone with DID. Until that time, a diagnosis such as dissociative disorder not otherwise specified (DDNOS) might be more appropriate.

(2001, p.9)

This is a complex area of debate, because as Spiegel et al, in their paper *Dissociative Disorders in DSM-5* (2011, p.839), point out:

According to Kluft and Dell, only 15% of dissociative identity disorder cases regularly manifest easily observable alternate identities during diagnostic interviews. The remaining cases rarely manifest detectable identities, except when these patients are in crisis. Kluft used the term ‘window of diagnosability’ to capture the latent nature of clear-cut switching phenomena in dissociative identity disorder patients.

So for some people, their alters or parts are only obvious to other people during times of crisis. Does that mean that they are DID when they are in crisis but OSDD the rest of the time? Surely not. Many commentators such as Dell and Kluft argue convincingly in a number of places that switching is hard to detect,



and one of the least frequent 'signs' of DID, and should not therefore be a core diagnostic criterion.

It can therefore be very frustrating for some people with the OSDD label not to have the full diagnosis of dissociative identity disorder and be placed in a seemingly sub-category because they haven't 'played the game' with the psychiatrist, or at least not sufficiently well. But other people with OSDD do indeed have less obviously distinct parts of the personality and report feeling perplexed when they read about people with DID talking about their 4-year-old part called Alice or their 6-year-old boy part called Ricky. The following personal communication from someone with OSDD (reprinted with permission) is revealing:

I don't have 'parts' like other people seem to. I have a sense of myself as being different at different times, feeling younger, or feeling aggressive or withdrawn or panicked, and it's as if I'm watching myself at times like this. Things come out of my mouth, stuff I'm saying and I don't know why I'm saying it. I can watch everything that I'm saying and doing, but it's like I can't do anything about it and I don't know what's going to happen next. These other 'parts' of me aren't clear though - they're not distinct. They all respond to my name.

We feel 'younger' at these times, but I couldn't put an age on it. A lot of people

don't even realise that I've changed - I just get told that I'm moody or something like that. But I know it's more than that. It doesn't feel like 'me', and when I'm like that I can remember things that I don't remember the rest of the time, although I'm always worried that I'm making it up. But also when I'm like that, I can't do other things I normally can, like tell the time. I can just stare and stare at my watch and I know I should be able to figure it out but I just can't. It's really weird.

DISSOCIATIVE AMNESIA: PART OF THE CRITERIA FOR DISSOCIATIVE IDENTITY DISORDER

Then there is the whole question of amnesia. This seems to me to be a real issue that again the DSM criteria do not sufficiently address. In order to receive a diagnosis for dissociative identity disorder, you must display 'Recurrent gaps in the recall of everyday events, important personal information, and/or traumatic events that are inconsistent with ordinary forgetting.' In clinical circles, it is often taken to mean amnesia between parts, so that if the 'apparently normal personality' (ANP) is fully co-consciousness for what other parts are saying and doing (especially the 'emotional personalities' or EPs) then that is not 'full DID'.

And yet I know and have spoken to dozens and dozens of people with DID who are fully conscious of themselves



when other parts are 'out'. More common is amnesia for past trauma, although parts often seem to have memory for this. And very few people with apparently diagnosed dissociative identity disorder that I have met claim to have full memory of their past, with no amnesia at any time – which would seem to contradict their diagnosis.

But an interesting point in this concerns the progress of therapy, which is to re-integrate traumatic memories into mainstream consciousness. At what point, when that is happening, could you state that you no longer have amnesia, and should your diagnosis change from DID to OSDD? (And if parts are 'integrating' or 'fusing' during therapy, at what point should you likewise shift along the spectrum and change your diagnostic classification?) And what about instances of 'amnesia about amnesia' – how do you know that you have amnesia for something if you've forgotten that it happened in the first place?! It all seems very muddled.

OSDD: A MATTER OF DEGREE?

In terms of other differences, it seems that as a general rule the degree of the trauma or attachment difficulties leading to OSDD will be less severe than people who are diagnosed with dissociative identity disorder, especially polyfragmented dissociative identity disorder. People with OSDD may for example have had some 'good enough'

attachment experiences, or other mitigating factors. On a neurobiological level, differences can be seen in studies measuring the volumes of the hippocampus, a key component of the brain largely associated with memory formation and retrieval. People with DDNOS were reported to have a 13% reduction in hippocampal volume compared to healthy controls, whereas people with DID showed a reduction in the region of 25% (Ehling, Nijenhuis & Krikke, 2003). This has led clinicians such as Elizabeth Howell (2005) to suggest that the degree of dissociation correlates to the degree of severity of the trauma, which may be true. However, this is often little comfort to people with OSDD, as I shall discuss later.

All of these points present certain issues for people with the OSDD label. Most strikingly perhaps, people labelled as OSDD may not feel that their condition is taken as seriously as dissociative identity disorder. Some people with DID may resent the 'multiple personalities' connotation, but at times it is the easiest way of explaining it to other people when time is short or openness limited. But how do you describe OSDD? The temptation might be to describe it in terms of what it is lacking – 'It's sort of DID except not quite' or 'It's like PTSD but with more dissociation.' I wonder how many people with OSDD therefore feel short-changed, as if somehow they are not deemed worthy of a 'proper' condition, only a 'residual' one, which



is terribly unfair. The trauma and disorganised attachment that leads to OSDD is incredibly severe, and so people in this area of the spectrum of dissociative distress need just as much understanding and recognition as people with dissociative identity disorder.

NO PLACE TO BELONG?

And that gives rise to the difficulties that many people with OSDD have reported, of feeling that they don't belong anywhere. Some feel uncomfortable being lumped together with people with DID, as so often the conversation or the behaviour can revolve around the autonomy and distinctness of 'parts'. Some people with OSDD may prefer the company of people with dissociative identity disorder who keep their parts as much as possible in the background in public situations, but still the lack of distinct 'parts' can be felt to be in some way as if they are getting it 'wrong'. Of course they are not, and their experience is valid exactly because it is their experience. But that can be cold comfort, and it is a basic human need to feel that we 'fit in', that we have somewhere to belong.

And as the 'OSDD' appellation is so often dropped in favour of 'DID' – due not least to its incredibly cumbersome name, which hardly rolls off the tongue! – then people in this range of the spectrum can feel unheard, unvalidated and as if they are the only one suffering

with the symptoms they have. That of course is a myth, as the vast majority of people presenting for help with a dissociative disorder, as we have seen, have a diagnosis of OSDD. But the difficulty remains, especially as there is such a dearth of writing and literature from the perspective of people with OSDD, who possibly feel that their viewpoint is not worth expressing, again because it is 'not proper dissociative identity disorder.'

THE STRUCTURAL MODEL OF DISSOCIATION

Clinicians have also noted difficulties that arise in therapy for people with OSDD, as opposed to DID. According to Van der Hart et al's structural model of dissociation (The Haunted Self, 2006), dissociative identity disorder is a case of tertiary dissociation with multiple ANPs and multiple EPs, whereas OSDD is a case of secondary dissociation with a single ANP and multiple EPs. At one level that is eclectic theory, but in practice it can mean that a person with OSDD has fewer 'adult' parts to help share the load. Where EPs are also less autonomous and less likely to be 'out', these traumatised parts of the personality can end up being neglected or ignored: if a person with OSDD has non-distinctive traumatised parts of their personality, it can be harder to give them a voice and the time and space they need to bring their trauma to the fore, than it is for a clearly individuated EP with a name and age.



Another issue, mentioned by a number of people without either distinct parts or amnesia, is that they have less 'distance' and 'protection' from the traumatic nature of their memories, or the raw emotion of the traumatised parts of themselves. Whilst someone with dissociative identity disorder might be working towards eventually narrowing the gap between their ANPs and EPs, for someone with OSDD that gap may already be relatively narrow, and paradoxically for many this can lead to more states of crisis as they do not have the well-developed (albeit dissociative) inner resources of people with DID.

Indeed, one of the hallmarks of DID is the extremes of coping capacity – in their ANP state, people with DID can present as high-functioning and extremely competent, only to crash for example at night when their EP states take over. The experience of someone with OSDD may be fewer of these extremes, without the deep lows of trauma states of being, but also without the extreme competency of some of the avoidance-based adult parts of a DID system. Furthermore, where there is a high level of co-consciousness between different self-states in OSDD, there is a lower risk of self-harming episodes where the adult 'host' has (dangerously) no awareness at all of what has happened. But at the same time, shame and embarrassment also run deep, as people with OSDD experience themselves in a

semi-'not-me' state, but feel unable to do anything about it.

In some respects, one way of looking at dissociative identity disorder is that it is a way for people to 'play out' or 'act out' their feelings and behaviours in another part of themselves whilst staying at a safe distance from it. So what would be otherwise unbearable feelings or thoughts can be tested out in this 'alternative' mindscape, before gradually being reconnected with. The person with OSDD with less elaborated parts may find this harder to do, and the perceived shamefulness of such actions and expressions may inhibit this exploration of dissociated aspects of the personality and the person's past experience. Undoubtedly, it is a mixed bag of negatives and positives for each person.

IS THERE ANY VALUE IN THE DIAGNOSIS?

All of this therefore begs the question of whether or not it is worth getting a diagnosis, and whether a differential diagnosis between DID and OSDD has any value. Indeed, Spiegel et al (2011, p.841) point out the inherent flaws in the current diagnostic criteria for dissociative disorders and say:

If the diagnostic criteria for dissociative identity disorder were changed to reflect the typical clinical presentation of DID (i.e. a complex dissociative presentation with no confirmed alter identities), these



complex DDNOS patients would meet diagnostic criteria for DID.

So one option, favoured by many people that I have been in contact with, is to merge the categories and to count the condition as 'DID/OSDD' and leave it at that. Certainly where private therapy is being sought and there is no need for a definitive statement on some official piece of paper or medical record, this may be the preferable option for a large number of people.

But some people do justifiably feel the need for an 'official diagnosis' – for a number of reasons, including the pursuit of treatment on the NHS (although a diagnosis of either DID or OSDD is never a guarantee of appropriate therapy); in order to receive better care from the NHS than the pejorative catch-all 'personality disorder' label will elicit; to justify or at least corroborate a claim for welfare benefits; to negotiate appropriate support from an employer; or to determine the pathway of treatment, amongst other reasons. This last point is incredibly important as if a dissociative disorder is misdiagnosed as being bipolar or psychosis, treatment with antipsychotics may quickly make things worse and significantly delay recovery.

But there are a range of difficulties in gaining a diagnosis at all, not least the fact that very few NHS staff are trained to spot dissociative symptoms,

let alone administer the 'gold standard', the SCID-D assessment tool. And in the UK, medical staff tend to prefer the diagnostic manual known as the ICD-10 (International Classification of Diseases, version 10) published by the World Health Organisation which is notoriously backward in addressing dissociative disorders. Indeed Spiegel et al (2011, p.826) in their incisive critique say:

Importantly, the ICD-10 describes dissociative disorders as primarily acute disorders that usually remit within a few weeks or months, and that have an onset in the immediate context of events that are highly stressful, traumatic, and/or that involve intolerable, insoluble problems. In contrast, the DSM-IV-TR conceptualises several dissociative disorders as long-term, chronic disorders, including dissociative identity disorder and some forms of depersonalisation disorder, dissociative amnesia, and DDNOS.

They further state:

The ICD-10 description of dissociative identity disorder is not based on an understanding of DID as a childhood-onset, complex, posttraumatic developmental disorder. Rather, this description is based on the literature that pre-dates the body of research on dissociative disorders since the publication of DSM-III.

In short, the UK-favoured ICD-10 is based on research and clinical literature from before 1980 – little wonder that dissociative disorders are so poorly picked up in the UK.

And even successfully obtaining a diagnosis can cause difficulties – in work situations, in applying for life insurance or even travel insurance, and in the stigma that surrounds so many mental health conditions. Each person needs to weigh up the pros and cons on an individual basis and do what is right for them.

OSDD AND DISSOCIATIVE IDENTITY DISORDER: SURVIVAL STRATEGIES

So what is the solution? I wish ‘the answer’ were easy to find, and equally easy to put into practice. In the harsh reality of the state of awareness of dissociative disorders in the UK today, we have to just keep moving in the right direction and not be dispirited at the challenges that still lay ahead. People with OSDD need to understand that their experiences are valid and real and not inferior in any way to people with dissociative identity disorder. And whilst recognising the differences, we can also recognise the underlying similarities. In the words of Sue Richardson (2011):

Both OSDD and DID are the result of the spontaneous action of the brain in response to trauma. Both contain different self-states, holding shards of

memory and ‘unformulated experience’ (Stern, 1997). Both can be helped by similar approaches to therapy which encourage neuronal repair and result in brain growth such as increased hippocampal volume. Above all, all forms of dissociation need to be validated for their unique contribution to survival.

It may be important for some people with OSDD to distinguish their experience from that of people with dissociative identity disorder and it would be good for people in this category to come forwards and write about their experience to help people, clinicians in particular, understand the unique characteristics of life with OSDD. For others, it may be validating to recognise that the distinguishing line between OSDD and DID is largely arbitrary, and to subsume the diagnosis of dissociative identity disorder into their own self-definition of being a dissociative survivor.

The important thing is that the labels people give themselves are helpful to them, to meet their specific needs. For some people, that means rejecting labels altogether. For others, that means fighting to have their own particular label recognised and acknowledged. As long as we have a pragmatic and even utilitarian view of diagnosis that leads people towards recovery and health, I think we’re near enough on the right tracks. ●

