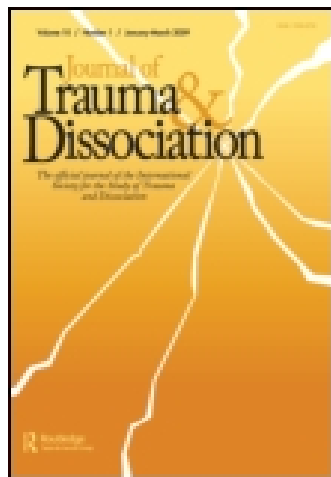


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Fighting the Whole System: Dissociative Identity Disorder, Labeling Theory, and Iatrogenic Doubting

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Fighting the Whole System: Dissociative Identity Disorder, Labeling Theory, and Iatrogenic Doubting

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This research examines how individuals diagnosed with dissociative identity disorder construe their experiences of being labeled with a contested diagnosis. Semistructured interviews were conducted in the United Kingdom with 5 women and 2 men diagnosed with dissociative identity disorder. A framework analysis was conducted. The analysis identified 2 overarching themes: diagnosis cross-examined and navigating care systems. The diagnosis appeared to be continually assessed by participants for its fit with symptoms, and the doubt among professionals seemed to be unhelpfully reflected in participants' attempts to understand and come to terms with their experiences. The findings are considered in light of labeling theory, the iatrogenic effects of professional doubt, and current debates concerning the reliability and validity of psychiatric diagnostic systems that have been reinvigorated by the publication of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

KEYWORDS *childhood trauma, psychiatric diagnosis, dissociative identity disorder, labeling theory, iatrogenic doubting*

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Dissociative identity disorder (DID) is a diagnosis that divides even those who advocate the practice of psychiatric diagnosis. Dumit (2006) referred to such labels as “emergent” or “contested” diagnoses. A classic example is chronic fatigue syndrome (CFS), which has attracted debate regarding its legitimacy since it was first proposed in 1988 by the Centers for Disease Control and Prevention. Dumit noted a key interplay between diagnosis and legitimacy, whereby the lack of a diagnosis or acceptance by the medical system can increase the risk that the individual is denied social recognition of his or her distress and deemed to be faking it.

In a thorough and comprehensive review of empirical work relating to DID, Dorahy et al. (2014) noted that the disorder “is linked to antecedent severe, chronic abusive and traumatic experiences in childhood, typically at the hands of an attachment figure” (p. 408). The authors emphasized that what often differentiates DID from other dissociative disorders is the trauma having been particularly severe and of earlier onset. In addition to early trauma, other factors shown to have a role in the development of DID are family dynamics, child development, attachment, and cultural constructs of selfhood (Dorahy et al., 2014). Dorahy et al. also reviewed epidemiological studies that found prevalence rates between 1.1% and 3.1% in the general population and between 0.4% and 14% in clinical populations, with prevalence increasing with the severity of the clinical population. They cited methodological and cultural differences as accounting for the variation, with studies having been conducted in various European countries (although not in the United Kingdom) and in North America.

In spite of the availability of this empirical work, detractors claim that DID is an iatrogenic condition created by overzealous therapists in collusion with their highly suggestible clients (e.g., Paris, 2012; Piper & Merskey, 2004). Further debates around DID entail polarized views on whether to ignore presenting alters in therapy (dismissing them as a patient’s fantasies) or whether to address them (Kluft, 1999; Merckelbach, Devilly, & Rassin, 2002). Although many professionals would agree that an individual presenting with different identities and high levels of dissociation is distressed, other diagnoses given might include personality disorder (Lauer, Black, & Keen, 1993) or schizophrenia (Coons, 1984). Consequently, individuals may receive several different diagnoses from different professionals over their years of contact with services.

In the United Kingdom, specialist assessment using the Structured Clinical Interview for *DSM-IV* Dissociative Disorders (SCID-D; Steinberg, 1993) is available at two independent clinics. Individual assessments are funded by patients’ regional National Health Service (NHS) commissioning body on a case-by-case basis, which adds to the sense of DID being a peripheral disorder. There are currently no National Institute for Health and Care Excellence (NICE) guidelines for dealing with patients who have

a dissociative disorder; thus, specialist DID services exist on the fringe of mainstream NHS services, reflecting their contested status.

The current study is designed to investigate the subjective experiences of individuals in the United Kingdom with a recent formal diagnosis of DID. It seeks to understand how patients construe their experiences of living with this contested diagnosis, the significance for them of obtaining a formal diagnosis of DID, and their experiences of navigating the health care system before and after attainment of the diagnosis in the context of professional doubt. The aim is to explore the sense they make of being diagnosed with a condition that can polarize professional opinion—a diagnosis that they may have actively sought or struggled to obtain for some time.

METHOD

A qualitative approach using individual semistructured interviews with framework analysis (Ritchie & Spencer, 1994) was used.

Participants

Maximum variation sampling (Patton, 1990) was used to select participants with diverse circumstances in terms of their current treatment status that may have had an impact on how they thought about their diagnosis. Thus, of the seven participants, two were not receiving any treatment for DID, one was receiving nonspecialist NHS treatment, one was receiving private specialist DID treatment, and three were receiving specialist DID treatment funded by the NHS. Five were female and two were male. Ages ranged from 22 to 48, and all participants were White British. All participants had received a formal diagnosis of DID within the past 5 years following an NHS-funded specialist assessment using the SCID-D (Steinberg, 1995). Participants were recruited through an invitation letter forwarded to eligible participants by the two clinics as well as through adverts placed on the websites of relevant service user organizations, advocacy groups, and charities.

A favorable ethical opinion was provided by the NHS Research Ethics Service.

Interviews

In-depth semistructured interviews were carried out ranging from 45 min to 2 hr. Participants were asked about their help-seeking attempts, their understanding of being given a diagnosis of DID, the meaning of the diagnosis to them, and the impact of the diagnosis on their lives. All of the interviews were digitally recorded and transcribed verbatim. Participants were

reimbursed for their travel but were not offered any remuneration for their participation.

Analysis

The data analysis was conducted using qualitative data analysis software following framework analysis (Ritchie & Spencer, 1994). Framework analysis is a tool for conducting qualitative research and follows an explicit protocol for examining data (Ritchie & Spencer, 1994). The approach is broadly thematic and does not prescribe any particular theoretical or epistemological assumptions, although in interpreting the data we adopted a broadly interpretivist stance (see Rabinow & Sullivan, 1987) in that we attempted to explore how participants made sense of their experiences, taking into account that participants were each located in particular linguistic, cultural, and historical contexts. The stages of analysis were familiarization with the data, development of a thematic framework (which was data driven, theory driven, and analytical), indexing (systematically applying the thematic index to all transcripts), charting (creating matrices representing each theme and each participant containing distilled summaries from transcripts), and finally mapping and interpretation (in which we attempted to synthesize the characteristics of the data and interpreted the full data set; Rabinow & Sullivan, 1987).

RESULTS

It is important to note that the findings from this study relate to this particular sample of people, context, and time and therefore do not necessarily present an account representative of all individuals diagnosed with DID. Nevertheless, the findings presented here are a useful exploration of the impact of receiving a diagnosis that is contested by professionals. The thematic framework consisted of two overarching themes—diagnosis cross-examined and navigating care systems—each with a number of subthemes.

Diagnosis Cross-Examined

This theme explored issues connected with participants' rationalizing and questioning relating to the experience of receiving the DID diagnosis. There was a sense of stigma relating to having a psychiatric label, particularly one as "extreme" as DID. In some cases, the stigma appeared to have been internalized ("self-stigma"). In contrast, the diagnosis also provided a sense of hope and a framework for understanding experiences, although for some

the diagnostic criteria were felt as limited, not fully reflecting their lived experiences.

Stigma. Several participants described the fear of being seen to be “mad” when diagnosed with a mental health problem; this was connected to discussions about self-worth:

Is society saying that people like me aren't worth it? I think there's some truth in it . . . (P4)

There were particular fears that others would be afraid of them based largely on stereotypes of DID that were thought to derive from the media:

I know that there have been like horror films and things like that that have . . . come out with people who've got . . . multiple personality disorder and I think . . . if my friends knew what people knew about my diagnosis, I think they'd be too scared . . . I don't think I'd be trusted with anything. . . . I've got my children and . . . my children can have their friends back for tea but I reckon if people found out about this, people would be wary . . . I would be as a parent if I didn't know anything about it. (P7)

Another participant said,

People with . . . dissociative disorders are crazy. “Sybil,” “Three Faces of . . .” . . . you know all that . . . they're crazy . . . Or there's always an axe murderer . . . yeah right, as if! (P6)

Participants had experienced others being both curious as well as afraid of them:

I think a lot of the time actually, which had been quite surprising and nice is that people are . . . really interested, sometimes too much [laughs] . . . like ask lots of questions or sometimes they ask a few more questions about my experience . . . but . . . still a lot of the time they kind of feel afraid, like you're gonna switch and . . . hurt them or something. (P3)

Many of the participants talked as though they had internalized the stigma of DID:

It's very hard to do any kind of work that involves interacting with people. I couldn't go back into a classroom . . . I don't trust myself anymore. . . . I can't rely on myself anymore . . . Having had the diagnosis, I know that it's not a good idea either to put me in charge of a group of kids, or in any situation where people are looking to me for leadership . . . because it might happen or it might not . . . (P5)

A destigmatizing diagnosis. In contrast, a DID diagnosis also seemed to signal the hope of recovery through specialist treatment to provide for some a destigmatizing acknowledgment that they were not inherently malformed in some way but had been psychologically “deformed” by what others had done to them:

To be like diagnosed as that is also recognition of the trauma . . . that they’ve [alters] survived to get to that point. (P3)

In this vein, some participants saw the manifestation of DID as an adaptive form of coping with trauma rather than a pathology as such:

You know how people . . . become DID, is for a survival . . . so it helped me to understand that . . . I’m not ill or I’m not . . . less than . . . you or somebody outside . . . I’m . . . the same, I just have had terrible, terrible things happen to me and I needed some extreme coping mechanism and this . . . is it. (P3)

Reconstructing the past. Diagnosis was described by some to be a source of validation in that it not only legitimized their experiences but also in a sense acknowledged the trauma and subsequent unusual symptoms they had experienced:

Everything makes sense . . . when I was still at [university] . . . it’s not like all of a sudden I started switching . . . I always have been but it never used to make sense before. (P1)

The diagnosis provided a new vocabulary for describing and constructing these unusual experiences:

When they started talking about fugue states . . . immediately then I sort of had a name for it . . . because . . . prior to that I was sort of trying to [tell] people that it was almost like . . . time jumped or went miss[ing] . . . and then suddenly they called it “fugue states.” I knew . . . what that was. (P5)

Similarly, prior to the DID diagnosis, P3 explained that his diagnosis was schizoaffective disorder, and so he reported mood changes in keeping with schizoaffective discourse. On reflection he felt that this had not matched his experience, as his mood remained relatively constant. Another participant (P6) described how she selectively attended to her experiences after being diagnosed with posttraumatic stress disorder in that she ignored experiences that were incompatible with the diagnostic criteria of posttraumatic stress disorder.

The change in diagnosis to DID could also result in professionals reinterpreting symptoms and hence changing the medication regime, which in itself could have an immediate impact on everyday psychological experiences:

[Diagnosis] meant that I could come off antipsychotic drugs. (P3)

and

I'd been telling them for years, this [Stelazine] makes me off my face. It makes me feel like I've got permanent, chronic PMT [premenstrual tension] . . . where I'm a complete fry head. (P6)

Yet although the diagnostic event was seen to contribute to participants' reconstruction of their past experiences, it was not necessarily adopted wholesale by all for this purpose, as for some it did not encapsulate their experiences fully:

We're not as simplistic as that [alters having typical roles] . . . Yes there are roles there, but it's not that simple. It kind of almost . . . shattered parts of a whole, none of whom had any roundedness and we're not that simplistic. (P6)

I'm sure something's wrong here, because the problem . . . with the disorder is that it's so . . . different for everyone and you try and sort of compare yourself to others and you try to put yourself in this really strict [*Diagnostic and Statistical Manual of Mental Disorders*] diagnosis and it's just like well . . . it don't work. (P1)

The strict diagnostic criteria led participants to question its utility, particularly as it was seen by many to be a stumbling block to obtaining help due to the fact that many professionals remained skeptical about its legitimacy.

Encountering skepticism. Participants showed a strong sense of awareness of the debate regarding the legitimacy of DID, including experiences of professionals explicitly dismissing their diagnosis:

She went, "No I don't believe you and you're a liar," and . . . my carer . . . was there so he was . . . witness to it and he asked me to leave the room because she was being so aggressive and then I could hear her shouting from outside the room saying, "I'm not going to substitute what I have to say for anyone," and . . . she was the psychiatrist [laughs] and it was really horrible. (P3)

I said to [my therapist], "I'm struggling with denial and what's going on," and he said, "Well yeah I am too," . . . and that was a bit like . . . "What do you mean you are too? You're not supposed to be!" (P1)

This skepticism was also implicit or inferred by participants:

I know what they're thinking. They're thinking that it's . . . not real . . . They're thinking that everybody to some extent has different ego states and yes, they do, I'm not saying they don't. I know they do . . . but this is completely different . . . (P1)

Perhaps as a result of encountering professional skepticism and finding themselves at the center of an ongoing debate, participants seemed to grapple with the philosophical debates relating to the invisible nature of psychopathology:

It's all abstract . . . unlike physical stuff when you . . . say, "I think my leg's broken." They . . . can say yes or no, look here's a picture of it to prove it. (P1)

Another participant said,

I suppose with physical it's much easier to see it isn't it? . . . Any damage that's been done, you can actually see it, then . . . you can tick all your boxes and . . . mark what's wrong and there's . . . nobody to . . . argue it with you, but I think that anybody who puts anything that's sort of mental health in question, they've always got to know that they've got to spend their lifelong career being prepared to argue it, haven't they? (P7)

Participants also made the link between the diagnosis and its etiology, expressing awareness of how extreme trauma can be unbelievable or too hard for some to hear, particularly given that DID is often associated with the most severe forms of organized abuse:

I think it's more the not wanting to know about the terrible reality that . . . keeps people like her GP [general practitioner] from reading more about it or learning more about it because you have to kind of do both to really understand . . . and so I can't blame her for that, but at the same time it makes me a bit annoyed that she doesn't want to educate herself. (P3)

. . . but it's more about cults and all that sort of thing which can be associated with DID. It's more about that sort of thing where people will think no . . . it doesn't happen anymore and they're just making it up . . . ritual abuse and all that sort of stuff. (P2)

In spite of their attempts to rationalize and understand professional skepticism, it was nevertheless hurtful to be the subject of disbelief:

When somebody . . . disbelieves it or . . . if they don't say it . . . it does hurt . . . well what do you think I'm doing? . . . I find it very . . . cruel and hurtful when somebody says that they just don't believe . . . It's . . . not nice. (P3)

You have people on here [blog sites] saying,

"Oh these people haven't been abused," and all this stuff and, "They're making it up," and it's like why would I wanna make it up? (P2)

I feel like if everybody understood that . . . ritual . . . torture has . . . a mental toll, it has an effect and . . . that a lot of the time, is DID. If everybody understood that there would be . . . nothing scientifically to disbelieve and it's just I don't know, a bit exhausting to be controversial. (P3)

Constructing the unreliable witness. It seemed that professionals' skepticism of the diagnosis could lead some to question the label; the self-doubt thus instilled may help to construct the patients as unreliable witnesses concerning their own experience:

I didn't know whether I did have DID . . . if somebody . . . seeing you is questioning it then . . . I mustn't have it . . . It's quite difficult to hold onto . . . a diagnosis yourself . . . I was questioning kind of everything anyway and so just one bit of doubt would have led into that, but a lot of doubt . . . made it difficult to feel anything else, to feel otherwise. (P3)

I go on a right rampage and I'm like, "It's not true, I've been fooling everyone . . . none of this is real, I'm just . . . I dunno bored or want something to do." You come up with the weirdest things . . . to try and explain away something that . . . should make sense but it doesn't . . . because . . . no one else really understands it. (P1)

Lack of professional agreement and the ensuing disagreements over what help and support patients should receive also appeared to result in problems of trust between participants and NHS bodies, with several participants commenting that they no longer trusted the NHS. Being afraid to disclose all relevant information out of lack of trust could potentially lead to participants being perceived as unreliable or difficult.

It's changed my views on mental health professionals . . . I trust them even less than I used to . . . It makes life very difficult working with them because I don't trust them, so I won't tell them anything. So how they're supposed to know what's going on with me? (P6)

I mean the amount of people I've told . . . count on my hand basically because . . . I don't trust what people are gonna say . . . especially after what the NHS people said and . . . how it's wrong . . . it's something else . . . and I actually . . . know people who their therapists have said to them, "Don't tell anyone." (P1)

Although a formal diagnosis of DID provided hope for some that recovery may be possible through specialist treatment, a number of barriers to care seemed to emerge in light of the diagnosis.

Navigating Care Systems

This theme encompassed participants' experiences of accessing services for their difficulties. It was apparent that many had encountered multiple difficulties trying to secure treatment for their distressing experiences. These ranged from reports that professionals lacked knowledge and expertise, to discussions about how participants had modified their behavior to access alternative support, as well as some experiences of being offered treatments that were deemed to be unhelpful or "scraping the surface" of their difficulties. In essence, the diagnosis was largely viewed as a hindrance rather than a key to accessing services.

Uncharted territories. Aside from the skepticism of experts in the know, a further problem participants encountered was a more widespread lack of knowledge among professionals that left participants unable to access various levels of care or feeling uncontained by lack of expertise:

There was one time when I ended up in A&E [Accident and Emergency department] recently . . . Either I told them or my partner told them about the diagnosis and they just was like "What?" [pulls face] . . . They had no idea what it was at all and some of them will even sort of think it's . . . a schizophrenia kind of thing. (P1)

I'm dealing with people who don't have the skills or the training to come close to having a clue of how to deal with me. If a clinical psychologist is out of her depth, what on earth makes CPNs [Community Psychiatric Nurses] and social workers think that they can make decisions about my life? (P6)

This could also contribute to the way in which professionals may construe patients:

I get labeled difficult and . . . manipulative. I'm actually frightened . . . (P6)

Another participant said,

I'd been through a CPN [Community Psychiatric Nurse] who didn't give a s**t either and [laughs] didn't know nothing and then she sent me to the psychiatrist 'cos basically she didn't know what to do with me and so I was angry with the service at that point . . . 'cos I just thought well nobody actually, what service am I getting? None! (P1)

Access denied. In addition to having frustrating experiences in mainstream services, many participants felt an injustice at being denied specialist treatment for DID following the diagnosis and being offered perceived inadequate or inappropriate alternatives:

She figures I can go to a group. Haha you'll love this, this is hilarious! They figure their alternative . . . is for me to go a group of complex special needs. "It won't be with other people with dissociation necessarily, could be across the spectrum of mental health . . . It will be intense and get straight to the issue and it will be group," and I was like well groups, not great for DID. We have enough inside thank you. Intense? No! Get straight to the point and to the bottom of it? No! Did you even read [DID professional]'s report? "Oh well . . . if you would be more open minded you'd see how great our group is." It's not gonna happen lady! (P4)

. . . before they'd even consider a referral [to DID clinic], I'd have to have psychotherapy [locally], but I'd have to also give up my therapist . . . and I just thought they didn't understand it at all, because they don't have anyone specialized with dissociative disorders. He didn't even know what it was and yet just to follow protocol he was saying that I'd have to see a psychotherapist there for a year . . . and give up . . . my counselor, who I've known for 10 years . . . It took me about 6 years before I even told my therapist anything and . . . it just took so long for us to get where we've got and . . . that's something I feel really upset about. (P7)

Some participants spoke about accepting alternative diagnoses or changing behavior in order to access some minimal support such that the contested status of the diagnosis within the health care system appears to again reconstruct participants' experiences:

I know quite a few people who have no choice but to stay under the NHS and . . . deep down they know what it is . . . but they can't fight it any more so they just say, "Okay then, I am bipolar. Give me lithium, give me what you want. It won't help . . . but at least I'm getting someone to talk to every week" . . . and it's really sad. (P1)

You do just spend the rest of your life kind of thinking, “Well is this real? Am I psychotic? If it’s not that then . . . what *is* wrong with me?” . . . I’m a member of . . . a support group online and the amount of posts you get that basically say . . . “This is me just making it all up. This is rubbish, I need to stop this. I’m going to stop this now.” They’ll come back the next day. “I couldn’t stop it.” You can’t stop it . . . but you feel like you have to, to (a) get any help from the NHS and (b) be accepted. (P1)

Mainstream services that were taken up were often felt to be,

scraping the surface. (P1)

Participants felt that these often failed to tackle what they saw to be the core of the problem:

It’s like my anorexia is the leaves, it’s not the tree and . . . I’d always expressed it like that . . . but again the professionals had never helped me find out what the trees and the roots were. We’d just got stuck at the leaves, which was the outward manifestation of anorexia. DID is the one with the roots and the main trunk of the tree and self-harm and depression and anxiety and OCD [obsessive-compulsive disorder] and suicide and all of that stuff are the . . . basically, instead of being characteristics, it’s like anorexia is an “alter” and she’s got her own thing and she’s come out to say her stuff, just happened to take the platform for an exceedingly long length . . . but actually I never was pure anor . . . I mean I didn’t fit in with the other guys on the [eating disorders] unit so it made a whole load of sense. (P4)

Unwelcome companions. A number of participants also highlighted the treatment of alters as a further source of controversy. For instance, one participant reported declining to be assessed by one service, having conducted research into the treatment philosophy and discovering that the service took the position that they would only speak to the host. She felt strongly that this would not benefit her, as she believed that in order to help her she needed professionals to communicate with all parts of her because of the separate pieces of memory they held of the trauma she had experienced. During this interview the participant had switched to a younger alter who expressed similar views, that in order to help her and the host, professionals needed to communicate with all of them. The alter stated that she had rung up the service herself to express this and that staff had asked the host and not her to contact them. The participant described the experience as follows:

My perspective on it was that if they want to treat me, they’ve got to treat all the others as well because . . . if they’re saying . . . to some of them, “No you can’t talk,” to me that makes the whole situation worse. You’re

just fighting against . . . the whole system. You're not bringing them all together . . . I think you've gotta talk to the others to make that happen and if you're only just talking to me, what's gonna happen when I leave that hospital for treatment? . . . I kept thinking yeah I can just see it. They're [alters] gonna get angry, they're gonna start doing this, that and the other and fighting against it. What's the point in that? (P2)

DISCUSSION

The nature of psychopathology is a persistent philosophical debate. Medical naturalism argues that disease exists *prima facie* within the external world and that diagnosis is simply a matter of detecting and categorizing it, as was Kraepelin's approach when creating his classification of mental disorders (Hoff, 1995). Social constructionism, in contrast, highlights the complex and dynamic nature of disease, suggesting that a disease exists only once it has been identified, classified, labeled, and treated (Rosenberg, 1992). Indeed, labeling theory (Scheff, 1966) proposes that the very act of labeling certain behaviors deemed as deviant from the social norm directly creates mental illness. In this vein, Moncrieff (2010) argued that psychiatric labeling is a political device that can legitimize predetermined social responses aiming to control individuals who are deemed to be disturbed. Moreover, Bentall (2003) and Boyle (2007) argued that diagnoses are poor predictors of interventions, outcomes, and individual symptoms. Boyle noted that explanations of comorbidity and dual diagnosis are increasingly adopted to capture the patient's difficulties, which further pathologizes the individual.

However, labeling theories also concede that there may be benefits derived from diagnostic practices. For instance, a formal diagnosis can enable an individual to access funding for assessment or treatment for specific difficulties. A diagnosis can allow an individual to access medical insurance in some countries, such as the United States, enabling him or her to afford treatment or to access specialist services for treatment in state-funded health systems. In addition, a diagnostic label provides a means of short-hand communication between mental health professionals. Without a shared agreement between professionals regarding the patient's difficulties, it is difficult for care to be discussed and treatment planned for (Cromby, Harvey, & Reavey, 2007). Moreover, it is argued that diagnostic categorization facilitates the conducting of research into treatment evaluation, enabling clinicians to select the appropriate and most effective treatment for people with a particular diagnosis based on the evidence (e.g., Corrigan, 2007). Some service users report feeling a sense of validation and reassurance after diagnosis in knowing that others have a similar condition. Others report feeling empowered and having a sense of control, as a diagnosis enabled them to research what might be helpful for them (Horn, Johnstone, & Brooke, 2007).

The data from the present study appear to indicate that the diagnosis of DID, contested as it was by some professionals encountered by the participants, was not accepted straightforwardly by the participants either, in spite of the efforts that may have been involved in obtaining it. Rather, the diagnosis appeared to be constantly cross-examined by participants in a circular interplay of experiences of symptoms, comparison against the diagnostic criteria, self-doubt, and professional doubt. It appeared that participants' experiences were under constant reconstruction and internal review. Some described doubting their experiences, wondering if they were imagining things or if it was just "a phase."

The diagnosis appeared to have been examined in detail by participants as to its suitability to reflect their experiences. Although several participants described rejecting the utility of diagnostic criteria, others gave accounts of how they had "tried on" different diagnoses to determine fit; however, this was also considered problematic in that the individuals reported feeling "attached" to a diagnosis, which then affected how they construed their experiences. For example, one participant described how when diagnosed with schizoaffective disorder, he began to refer to his "alters" as voices, reporting variance in his mood, which in retrospect he believed remained constant. This seems to provide some support for Scheff's labeling theory described previously, which supposes that a diagnosis can directly influence how service users view themselves and their subsequent behavior, particularly if they identify with the label. Examples were given by some participants of how they tried to refrain from reading about a diagnosis initially in order to have a "pure" experience without being unduly shaped by the label so that they might assess the fit from a more "objective" viewpoint.

In addition to supporting the main tenet of labeling theory, the data presented also seem to reveal a possible modification, based on the status of the label as contested. Labeling theory predicts that providing deviant individuals with labels could lead them to eventually develop deviant behavior and symptoms. Yet it would appear that by being provided with a label that is contested and debated by those who purport to be labeling experts, the labeled individuals reflect this controversy in their own self-doubt, magnifying the degree to which they appear to be unreliable in testifying to their own experiences. This seems to result in a further undermining of the sense of self and experiential memory, which is already poignantly damaged in this group of participants. Hence, although labeling theory talks about iatrogenic labeling, the present study indicates the possibility of iatrogenic doubting; in other words, the lack of professional consensus and controversy around the diagnosis can ultimately do further harm to patients.

Sometimes participants talked about how they had taken action and had started blogs or contacted mental health websites to raise awareness of DID, a clear indication of feeling empowered by their diagnosis. At other times the same participants recounted how they had withdrawn from social

engagements, family, and friends, and in one case a participant had given up his employment as he no longer trusted himself to be responsible to supervise children. This vacillating between self-stigma and self-empowerment is arguably constructed by the vacillation of the more powerful professional community over this label and its meaning.

In spite of this, there was an overall sense that the diagnosis provided some hope and some validation, not just of symptoms but of past traumas. Participants in this study believed that with the “right” help they would be able to overcome their difficulties. This view was linked to the idea that the DID diagnosis represented what had been done to a person rather than what was “wrong” with him or her. The idea that DID was considered to be an extreme coping mechanism for extreme circumstances was noted by several participants. This belief also served to destigmatize the label, as it could be reframed as an adaptive response (i.e., a reaction to the extreme circumstances of their earlier lives rather than something pathological inherent in them, like personality disorder).

The potency of a diagnostic label for shaping perceptions was not limited to the reported experiences of participants themselves; some described instances of professionals seeming to treat them according to the diagnosis written in their medical records, even when this was at odds with a patient’s reported experience or when patients complained that medication had been ineffective. This implied that the diagnosis had come to be seen as a “true” experience and that a medication regime could change in association with a change in diagnosis rather than in response to patient experience.

The experiences of hostility and dismissal of the diagnosis common to experiences of individuals seeking a diagnosis of CFS (Dickson, Knussen, & Flowers, 2007) or DID is a reflection of the ongoing contested statuses of these diagnoses. In the case of CFS, it is argued that the nonspecific complaints brought by service users make diagnosis difficult (Sharpe, 2005). With DID, participants in this study described how professionals struggled to hear stories of childhood abuse. This led to participants experiencing the skepticism as further rejection and negation of the trauma they had experienced, often describing the reaction as feeling like a repetition of earlier experiences of not being believed when reporting abuse.

Countering arguments that a diagnosis can enable access to care and thus help those experiencing distressing symptoms, the diagnosis of DID in the present study was perceived to be an obstacle to getting appropriate treatment. This suggests that if the label is contested, access to services is not facilitated by the label. Indeed, in some cases, the diagnosis seems to have been felt to prevent access to services.

Clarke (2000) proposed a model illustrating the process through which service users go in order to obtain a diagnosis of CFS, which included shopping around for doctors who were more sympathetic, conducting their own

research into CFS, and presenting their research to their general practitioner and other professionals whom they believed to be lacking in knowledge about CFS. Similarly, participants in the present study had experienced professional differences of opinions regarding DID. Some had approached staff at the two specialist clinics for advice on how best to proceed with obtaining the diagnosis and/or treatment. Most had looked on the Internet for information and had found support websites such as First Person Plural. Yet it seemed that almost as if by doing this research and entering the community of DID expertise, participants were reducing their credibility with other professionals and reducing their chances of accessing care. Several were offered NHS treatments that they viewed as unsuitable or as “scraping the surface.” In some cases participants reported having to “give up” the diagnosis (and accept treatment for an alternative one) or “give up” a therapist working with the diagnosis in order to access NHS care.

Clinical Implications

Like many diagnosed with mental health disorders, people diagnosed with DID report extreme childhood traumas and appear to experience high levels of distress and impaired function. Whatever the debate over the causes, the true extent of abuse, or the proper label for the behavior and symptoms, there is an imperative to provide care. Yet it appears that those experiencing symptoms of DID face a paradoxical dilemma. In order to obtain specialist DID care, they must first obtain a formal diagnosis. Yet once they have obtained a formal diagnosis from a formally recognized specialist assessment team that has used the correct assessment tools as validated within the diagnostic paradigm, service users must then find a referrer (and/or a commissioner) who believes in the diagnosis in order to receive further treatment. The system within which the patient finds himself or herself then is one that imposes diagnostic rigor as the only route to care and then, once the hurdle is crossed, switches the paradigm to a system of belief. This is similar to McGoey's (2012) theory of strategic ignorance in that in certain contexts institutions deploy ignorance rather than knowledge as a means of asserting power and commanding resources.

With the recent publication of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (American Psychiatric Association, 2013), there is a resurgence of debate about the value of diagnostic labels generally in mental health, including a critique of their potential for harm to service users through discrimination, disempowerment, and marginalization of experiential knowledge (Division of Clinical Psychology, 2013). That certain issues and expressions of symptoms can engender such disagreement among the experts in favor of diagnostic classification provides support for much of the argument that the psychiatric system has questionable reliability and validity

(International *DSM-5* Response Committee, 2013). The present study suggests that when professionals cannot agree, harm may be done to patients because their already fractured sense of self is damaged further by the continual questioning and doubt about their memories of trauma, past symptoms, and here-and-now experiences. Moreover, not only is patients' access to care not helped by their being given a label, but in some cases access to care is denied, and patients already struggling with their sense of self and reason find themselves in an irrational system in which the paradigmatic rules are inconsistent. It is important for all professionals and indeed service commissioners on both sides of the debate to be mindful of this when discussing diagnoses and treatment options for individuals with extreme dissociative presentations and severe trauma histories. The British Psychological Society Division of Clinical Psychology has proposed a renewed emphasis on formulation as an alternative to diagnosis (Division of Clinical Psychology, 2013), and this study appears to indicate that a shift in emphasis such as this may be beneficial to patients with DID presentations.

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