Discovering and Uncovering: A new Perspective on Dissociative Identity Disorder

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Abstract

Dissociative identity disorder is not new. Yet, there exists a paucity of emic research on the topic due to its covert nature. In this research, the disorder is presented and understood from the perspective of the person who must live with it on a daily basis. Through the newly discovered theory of discovering and uncovering, the reader will gain a more nuanced perspective of the disorder.

Keywords: dissociative disorder, classic grounded theory, neurodiverse, traumagenic, multiplicity, post-traumatic stress disorder, ketamine

In life, the idea of an elevator speech is extremely important. Consider a job interview where the interviewer states, "Tell me about yourself." In approximately one minute or less, an interviewee needs to present a comprehensive picture of who he or she is. This situation seems innocuous enough to a neurotypical person. But, for someone with a dissociative disorder, a question like "Who are you?" or a request to talk about oneself can potentially be stress-provoking and confusing.

Additionally, there is a famous line from an old song "I hear singing and there's no one there" (Richard D., 2022). With respect to the lyricist Irvin Berlin who wrote the words to the song, people who suffer with a dissociative disorder can legitimately say "I hear voices and there's no one there." People suffering from a dissociative disorder such as dissociative identity disorder (DID) or otherwise specified dissociative disorder (OSDD) may indeed hear internal voices and have internal conversations; they believe that nothing unusual is going on (Anonymous, 2018). As one participant remarked, after all, don't we all talk to ourselves at times?

The foundation for a discussion about dissociative identity disorder is evident in these two seemingly different examples. The idea of one's identity--whether it is an elevator speech for a job interview or hearing internal voices--becomes a crucial and fundamental component for a person who experiences dissociative identity disorder.

Because of a paucity of scholarly research presenting and explaining DID from the perspective of the patient, the goal of this research is to understand more clearly and comprehensively what it is like to live with the dissociative disorder. To achieve this emic objective, a discussion about the disorder with a common language is needed.

Methodology

The research design used in this study is classic grounded theory. One benefit of this design is to understand in a more nuanced manner the main concerns of participants as they address their main concern: living with a dissociative disorder. The author adhered to the principles of classic grounded theory (Glaser, 1965, 1967, 1998). Procedurally, gerund codes were created from the data collected during the data gathering process. Through constant comparison (Glaser, 1965), memos were written to discover and explain connections that were not previously evident. Further comparisons were made among the codes to generate broader categories. Memos were constantly compared one with another as the data were conceptualized ultimately to develop a theory which explains how people deal with their dissociative identity disorder.

Instrument

As a research design, classic grounded theory is a bit unusual when compared with other (qualitative) research designs. With classic grounded theory, the objective is to "instill a spill" (Glaser, 2009, p. 22): a manner in which participants can talk openly and freely about whatever issues they might have regarding their main concern (Spradley, 1979). The beauty of classic grounded theory is that a single instrument is used instead of a semi-structured interview with a list of questions to be validated. In classic grounded theory, a typical instrument is a single "grand tour question" (Leech, 2002, p. 667). For a study like this, the grand tour question was "What is it like living with a dissociative disorder?" With such a question, one would imagine that participants would be able to interpret the question in any way they desire. However, given the nature of this study and the vulnerable population, a slightly different protocol was employed.

Barney Glaser (1998) had a well-known dictum: "All is data" (p. 8; 2007). The significance of this statement cannot be understated, especially in light of this research involving a vulnerable population. With this precept in mind, the researcher was able to use the aforementioned grand tour question as a research question to look at publicly available data on from different online sources (different websites, Facebook, YouTube, and Reddit). With this grand tour question in mind, a total of 20 sources were reviewed. By attempting to simulate a *tabula rasa*, to the extent possible (Simmons, 2011), and through extensive and detailed memo writing, the researcher developed the theory of discovering and uncovering.

Literature Review

In the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), a distinction exists between DID and otherwise specified dissociative disorder (OSDD). While DID "is characterized by a) the presence of two or more distinct personality states or an experience of possession and b) recurrent episodes of amnesia" (DSM-5, 2013, p. 291), one characteristic of OSDD is that the alters are less distinctive. Sometimes, with this reduced

distinction of alters, one alter may blend with another (Otherwise Specified Dissociative Disorder, 2021). The result is that the host is not entirely certain which alter is present. Additionally, OSDD-1b presents without amnesia (Christensen, 2022). While these distinctions may be valuable to medical professionals, for the purpose of this research, the term of "dissociative identity disorder" will be used with no distinction to OSDD and its variants.

Definitions

With a brief explanation of DID given, there is potentially great value in having a common language to understand the experiences of participants. To that end, several important definitions are presented here. Given that the author is not a mental health professional, I had to educate myself on the various psychiatric terminology presented here.

Alter: An alter is one specific personality or part of a host. Alters--however similar to the host--are caused by childhood traumas ("Dissociative Identity Disorder," 2022) and post-traumatic stressors (DSM-5, 2013). Alters can have separate memories and awareness from the host.

Co-consciousness: When one or more alters know what is happening with the body and can communicate internally with the host (Dissociative identity disorder research [DIDR], 2022).

Fronting: Fronting occurs when one of the alters presents him or herself and is in control of the body and voice of the host. This personality is said to be dominant (Patrichi et al., 2021). In such an instance, the alter who is fronting may have similar or very different mannerisms and speech from the host.

Host: A host is the physical human being another person sees in everyday life.

Multiple Personality Disorder: This disorder is the older name of dissociative identity disorder. In the DSM-3, until 1994, the name multiple personality disorder was used (Paroma & Ankit, 2021; Pietkiewicz et al., 2021).

Plurality: The idea of two or more alters being associated with one physical body is termed plurality (Reinders et al., 2017). With dissociative identity disorder, multiple personalities exist (Costabile et al., 2018).

Switching: Switching is the term used to mean changing from either the host to an alter, or between alters (Cudzik et al., 2019). A switch may sometimes be seamless or may be more prominently presented.

System: A system is all the alters and host together. When viewed all as a collective concept, the term supports the idea that all the parts make up the entire person (HealthyPlace, 2011). Alters should all work together to keep the collective body and system working well.

Traumagenic: The term traumagenic refers to "the dynamics by which a traumatic event may have long-term negative consequences, including the development of a mental disorder" (American Psychological Association, 2022).

With a basic understanding of what DID is, along with common terms associated with the disorder, a brief discussion of the etiology and diagnosis of DID is valuable. Though this research focuses on the emic aspects of DID, as a non-medical professional, I needed to familiarize myself with the science behind the diagnosis.

Etiology and Diagnosis of Dissociative Identity Disorders

When researchers look at dissociative disorders, three foundational elements come into play which make etiology and diagnosis difficult and delayed: (a) trauma, (b) defense mechanism, and (c) variety. In this section, each element will be discussed and connected to the etiology and diagnosis of DID.

First, traumatic events underpin the disorder. Trauma may consist of abuse, neglect, or any form of mistreatment resulting in post-traumatic stress disorder (Trifu, 2019). Such horrific acts were done to children during their early years of life. Since adults are not usually willing to admit that they were childhood victims of "prolonged child abuse (PCA)" (Gold, 2009, p. 227) and traumatic events--especially if the deeds were done by people who were supposed to be taking care of them--many people are misdiagnosed (Snyder, 2021), undiagnosed, or diagnosed later in life, many years after the symptoms first appeared (Reinders et al., 2018). Also, because each person's manifestation of DID is unique and highly nuanced, and because of the covertness of DID, diagnosis is not made immediately (Reinders et al., 2018), to the detriment of the patient. A diagnosis in children is rare (Wilkinson, 2021). Regardless of the reason for the incorrect or delayed diagnosis (Pietkiewicz et al., 2021), many people suffer unnecessarily with the ever-present condition (Anonymous, 2018).

Second, since dissociation is a defense mechanism (Cudzik et al., 2019), the person might not realize that DID exists. Gold (2009) commented that some adults may selectively recall childhood events thereby further supporting the idea of a defense mechanism put forth by Cudzik et al. (2019). Because of their repeated traumatic events (Cudzik et al., 2019), patients develop different alters as defense mechanisms to cope with the various post-traumatic stress from childhood (Trifu, 2019). The term "traumagenic multiplicity" (Christensen, 2022, p. 1), then, would be when alters are created because of a traumatic event thereby causing long-term negative consequences.

Finally, Kluft (1999) summed up DID succinctly stating that DID has a "chronic, polysymptomatic, and pleiomorphic posttraumatic dissociative psychopathology" (p. 290). More easily understood, DID is a long-term condition with many symptoms which can vary from person to person. Additionally and tangentially, pleomorphism adds to the complexity of DID because what may manifest for one patient may not be completely applicable or present for another. Thus, such variety offers an additional potential reason to explain why a delayed or inaccurate diagnosis of DID occurs (Pietkiewicz et al., 2021).

The lack of talking about PCA (Gold, 2009) may potentially be the primary reason that only 1.5% of the global population has been diagnosed with DID (Paroma & Ankit, 2021). In the United States, the prevalence of DID in adults is 1.5% (DSM-5, 2013) and in Poland, according to Cudzik et al. (2017), DID is a "niche issue" (p. 117). Trifu (2019) believed that 5% of the world population has DID). According to Cudzik et al. (2019), women are "three to nine times more" (p. 118) likely to develop DID than men. Snyder (2021) believed the percentage of people in the world with dissociative disorders is up to 10%. Regardless of these varied percentages, people with a dissociative disorder form a minority in the mental health realm. Yet, these people are not to be forgotten or ignored.

Dissociative amnesia

Many years ago, I was taking a long road trip. The highway was many miles long and consisted of a straight road with little visible scenery. As I was driving, I "zoned out" and lost time; when I realized that happened, I discovered myself a few miles ahead of where I had initially been. In another unrelated situation, many years ago, I began playing a popular online questing game and was so engrossed in it, that several hours passed before I was aware of external reality again. In both these situations, I experienced a type of amnesia. More colloquial synonyms for these two experiences are hyperfocus (Ashinoff & Abu-Akel, 2021) or flow (Marty-Dugas et al., 2020); they are common and everyone has these experiences at one time or another in their lives Patrichi et al., 2021).

Based on the two aforementioned experiences, there was clearly no cause for concern for me. However, what is characteristic of dissociative amnesia is the disruption of the "person's sense of Self" (Patrichi et al., 2021, p. 207). According to Snyder (2021), dissociative amnesia falls "on a continuum, and at the extreme end, pathological dissociation can cause debilitating impairment that affects all aspects of an individual's life" (para. 4).

In the aforementioned two situations, no loss of identity took place. Had I switched and had an altered state of myself compounded with amnesia (Costabile et al., 2018), the situations and root causes would have been very different. Yet, a similarity is present between "zoning out" and dissociative amnesia.

With an understanding of dissociative identity disorder--however superficial it may be, a foundation has been laid to discuss the theory of discovering and uncovering.

Discovering and Uncovering

In the theory of discovering and uncovering, three broad categories exist: destabilizing, opening up, and accepting. Throughout these three categories are two overriding elements--the ideas of non-linearity and flexibility. Before each of the categories can be addressed, a brief discussion about non-linearity and flexibility is needed.

Though one might think, at the outset, that the three categories of discovering and uncovering are linear, because understanding DID is multilayered and iterative, the theory of discovering and uncovering cannot unfold in a linear fashion; a great deal of flexibility and movement between categories exist in this theory.

Flexibility is needed and is a vital component in understanding DID and presents itself in different ways which are inextricably tied one to another. First, regardless of the subject (including DID), the process by which a person learns new information takes time. During discovery, by its nature, neurological flexibility is needed because a person needs to see different perspectives and be willing to learn about those varied ideas.

Next, though DID originates from horrific repeated childhood traumas, the brain is sufficiently flexible and mysterious in its ways to protect the host. In fact, DID is an "ingenious disorder," according to one source, as a defense mechanism to allow a person to escape and hide from the bad and prolonged situations by having alters when physically removing oneself from the environment is not possible.

Finally, one reason that DID is covert is highly individualized of the disorder. How DID presents itself for one person will be different for another. For example, even the alters and the internal world are different for each person. With the sheer variety of alters, their traits, likes and dislikes, mannerisms, and so on, uniformity and inflexibility do not exist.

A foundation now exists for a discussion and deeper understanding about what it is like to live with DID. In the process of understanding what it is like to live with DID, three stages exist: destabilizing, opening up, and accepting. Each stage is discussed in turn in the following section.

Destabilizing

In the first stage, as a person initially experiences symptoms of DID, he or she becomes destabilized. During this stage the patient may present one way externally and feel another way internally.

Externally, the person may push DID away because of disbelief and fear. Minor behavioral changes may be present but they are discounted and possibly ignored. The person wants to "get rid of" DID because of either a misunderstanding or lack of understanding. In short, DID cannot be happening, so it is not true. For example, people who do not understand DID think of Sybil or perhaps Dr. Jekyll and Mr. Hyde. Often, people think that a person with DID is dangerous. Both examples are not the case.

The disbelief and wanting to "get rid" of DID is self-sabotage, a symptom of the disorder. For example, self-sabotaging can manifest itself, according to one participant, as "dissociative imposter syndrome–an inaccurate feeling of inadequacy or fraudulence." The person is justifiably scared of what is happening and feels like DID cannot be real.

Internally, the person questions and cannot justify feeling different, confused, and scared. He or she is trying to make sense of a seemingly illogical condition. Thus, when a person doesn't believe something, a feeling of antagonism toward or fear against that object may exist. DID is no exception. There is heightened anxiety during this period. He or she is in crisis and not completely certain of how to get healed or what is happening. With increased instability and unbalance, the next phase occurs.

Opening up

The second broad category of DID is opening up. During this stage, the person with DID may experience more frequent switches. As the host goes through switching, he or she continues to try to make sense of the scary process. During this time, he or she attempts to process and understand switching as well as any associated underlying traumas. The process of switching is complicated and can be understood as blurring and balancing, with its component of unraveling and discovering; each will be discussed in turn.

Blurring and balancing

When a person switches, any or all of these three components may take place: (a) physical sensations, (b) blurring and balancing, and (c) dissociative amnesia. Each behavior is presented in this section.

If a person is feeling "switchy," he or she may or may not exhibit any physical sensations or discomfort before the switch occurs. If sensations or discomfort do occur, they can manifest in different ways such as a headache or a tingling sensation. As the switch becomes stronger, a blurring or losing control occurs. Here is when the host might not "feel" like him or herself. The idea of feeling blurry can be nearly instantaneous or can take a long time. Sometimes, for example, from the perspective of an alter, if the switch is not instantaneous, it can feel like "pushing through molasses." On the other hand, sometimes the switch can be nearly instantaneous.

The experience of switching can be viewed as balancing a scale where, as an alter fronts and the host fades (or blurs) into the background, the scale tips from one side to another. During a switch, a feeling of loss of control occurs as the "balance of power" shifts from the host to the alter. From the perspective of an observer, a physiologic change may also occur where the host's face and body relax and a neutrality is momentarily present before the alter appears.

After the host has again fronted, if there had been dissociative amnesia associated with the switch, he or she will most probably be scared because a feeling of being out of control is experienced. Along with blurring and balancing, the idea of unraveling and discovering--a concept connected with dissociative amnesia--occurs.

Unraveling and discovering

A direct result of blurring and balancing is unraveling and discovering. During this period, the host experiences more regular switching and continues to learn about DID and about his or her alters. This discovery helps reduce confusion and fear about DID. Additionally, the host learns about any dissociative amnesia that might have occurred during the previous switch(es). And, as the person explores his or her DID and begins to "[unravel] the mystery," according to one participant, two things happen.

First, as traumas are processed and flashbacks are presented, unraveling of the traumas occurs. Simultaneously, there is a sense of discovery that takes place. The host learns about the alters and their wants and needs along with their roles, purposes, and characteristics. For example, alters are as different as humans are and may or may not share similar traits, characteristics, or gender of the host. They can have different skin

color, accents, genders, even different capacities to endure pain and different brainwave patterns, according to one medical profession from one of the websites that was reviewed. Alters may even exhibit different medical conditions from the host, according to the same source.

Second, as the person begins to understand switching and alters, and processes the underlying traumas, a sense of relief starts to occur in the host and in people around him or her. An understanding of DID emerges. One participant commented, the discovery of DID "explain so much." Participants and observers are now able to explain heretofore "weird" experiences. Unraveling mysterious behaviors helps the host not only understand DID but also be more open to discovering and unraveling the hidden traumas.

The process of discovery needs to occur not only between the host and the alters but among the alters. To give an example of discovery, I will share two personal stories (used with permission of the host and alters). One of my family members had an accident on a cruise ship. In the medical facility, there was a second incident with the stretcher because it was not locked in place. Once the patient was safely on the stretcher, one of his alters, Tom, appeared. Tom looked around and exclaimed, "Oh, this can't be good." While this statement might be a great example of dry humor, it also shows how sometimes a disconnect exists between the host and the alters.

The second story involves internal alters discovering the needs of their peer alters. If all the alters in a system do not communicate with each other, internal frustration can and will ensue. In one instance with a family member, one of his alters, Barb, ate some appetizers before dinner while another alter, Blaine, was hoping to front that evening and enjoy a nice full steak dinner. Because Barb had filled up on some appetizers, Blaine was no longer hungry and chose not to front. As one would imagine, Blaine was annoyed at Barb. Barb discovered Blaine's annoyance and the next day, Barb let Blaine front and have a nice dinner. In this case, internal discovery led to forgiveness and amends being made. In each of these two stories, the process of discovery is necessary for everyone, alters and hosts alike.

Accepting

During the final stage, acceptance is prominent. There are different layers and types of acceptance. First, the person with DID needs to understand the disorder and internalize its existence. While full understanding would be ideal, functional understanding acceptable. Functional understanding means having a clear acceptance and tolerance about the different alters, what they are like, and their needs. Realization and awareness are mandatory. With this understanding, perhaps the alters can help the host further accept the disorder and even begin (or continue) to process some of the associated traumas.

With a functional understanding, too, given the inner dialogue or background chatter that exists in the head of the host, he or she may or may not always know who is communicating inside. And, from the many resources consulted, it is acceptable if the host is not always aware of the alter; the host needs to accept that inner dialogue or background chatter. Sometimes, this acceptance is a major step forward for the host.

Additionally, during this stage, as a person learns about, and deals with, this disorder, getting help and taking care of oneself are vital. As life improves, so will DID. The feelings of overwhelm and "craziness" that had existed during the initial stages of the disorder should dissipate. According to many of the sources reviewed, support and social media groups exist to help reduce any isolation that might still be experienced.

Discussion

From the perspective of a patient, there is a great deal of work to accomplish with DID. For many patients, memory work and trauma processing take time and effort. From the perspective of a medical or psychological professional, there is a great deal of work to be done as well. As a way to continue the discussion about DID, there is value in repeating that DID is a covert disorder due to the oftentimes deep denial about trauma, and the misunderstanding and misrepresentation of the disorder in society.

Researchers, medical and psychological practitioners, patients who have DID, and their family members must help remove its stigma by openly talking about the disorder. With talking comes understanding and acceptance. The time has come for tolerance for not fear and misconception of the disorder.

With a sense of acceptance and belonging, the patient will no longer need to mask his or her plurality "to fit in," according to one source, with society. The need for belonging should be present in everyday life. As a society, people need to get away from the Dr. Jekyll and Mr. Hyde mentality and move toward something more realistic and wholesome. Society has taken that first step to reverse the stigma associated with DID with a television program like Moon Knight, which can potentially do a great deal to reverse the stigma associated with DID.

From a more academic perspective, various authors have proposed different methods which may aid the patient and professional in unmasking and unpacking the traumas. One potential option, the use of ketamine, is presented here.

Several authors (Cudzik et al., 2019, Dore et al., 2019; Gold & Quiñones, 2022) have proposed that ketamine may be a viable tool in treating posttraumatic stress disorder. According to Gold and Quiñones (2022, ketamine, in combination with therapy, can help minimize the symptoms of C-PTSD [complex post-traumatic stress disorder] (Feder et al., 2014). Dore et al. (2019) reported that "profound psychedelic experiences . . . may improve mental health" (p. 190). In fact, as of 2019, Dore et al. commented that ketamine along with various other psychedelic drugs are being used in psychotherapy and being tested in clinical trials. Given that DID stems from PTSD or C-PTSD, it seems reasonable, at least on the outset, that ketamine might aid in uncovering and unpacking the various components of DID. This belief is strengthened with the fact that there are several benefits of ketamine.

First, it is safe and generally tolerated by patients (Dore et al., 2019). Equally important is that ketamine helps promote neuroplasticity (Gold & Quiñones, 2022) in two ways: through "'synaptogenesis' (creation of new synapses between neurons) and 'neurogenesis' (growth of new neurons)" (Gold & Quiñones, 2022, section 4). With the creation of new synapses and neurons, new neural pathways may be created to help the

person make new connections between statements made during therapeutic sessions and hidden traumas.

Additionally, ketamine allows patients "access to difficult states of mind with less fear of those encounters . . ." (Dore et al., 2019, p. 192). Thus, ketamine could allow the "pressure cooker" feelings that may be building up in a patient to lessen. Anything to help alleviate the patient of the burdens he or she experiences because of DID is worth considering and exploring.

Limitations

In this study, several limitations--to use the broad term--are present. First, in a grounded theory study, participants usually are in the foreground. In this study, though, one might view the lack of participants as a limitation since interviews were not conducted and IRB approval did not happen. However, the choice to use publicly-available data was more of a delimitation. Yet, there was an initial limitation present.

Second, according to Cudzik et al. (2019), women are "three to nine times more" (p. 118) likely to develop DID than men. Thus, men's experiences with DID are not as abundant as women's perspectives and experiences pointing to another limitation.

A third limitation is that data came from a slice of the online population willing to talk about DID. There are, no doubt, many other people who are do not have an online presence and are not as willing to be open about their psychological condition. This limitation presents an opportunity for further research on the topic of DID.

Finally, though all the "participants" in this study were very much aware of DID and working through the later phases of the disorder, investigating people who are in the early stages of the disorder would be valuable. Presenting the voice of these people could and would be highly valued to the DID community as well as to family members and mental health professionals.

Conclusion

The new theory of discovering and uncovering explains the process through an emic perspective, which was rarely considered in the past. The theory sheds light on the internal and external struggles of people diagnosed with a serious dissociative disorder. This new research can be helpful to people beginning their exploration and understanding of DID as well as mental health professionals and other health care workers who are treating these patients. Additionally, family members of people with DID will find this research valuable as it may help explain what their loved ones are experiencing internally.

In many societies or communities, a possibility does not always exist to identify differences in people (Chevrette & Eguchi, 2020). Because of such invisibility--made even more apparent by the covertness of dissociative identity disorder--sensitivity when dealing with alters and systems is vital. And the same is true for using a system name or the names of different alters. To discount one or more alters or a system is insulting, disrespectful, and hurtful. A need exists, therefore, for people to be mindful of what is said and done. "Knowing what to say and how to behave are excellent ways to 'check yourself' before a

situation turns bad" (Chametzky, Winter 2021, para. 1). With the DID community--as with any community--being non-judgmental is needed. People need to put prejudices and opinions aside. If an outsider (that is, a person who does not have DID) has questions, he or she should ask them to learn more about the disorder, the system, and the alters.

As everyone becomes open and inviting, any feelings of powerlessness and disempowerment will (hopefully) dissipate thereby allowing DID to be more overt. No longer would the patients feel powerless or disempowered because of their traumas and feelings of invisibility. From the statistics mentioned previously, approximately 1.5% of the population throughout the world has been diagnosed with DID (Paroma & Ankit, 2021). Though it may seem small, the percentage means that more than 100 million people are diagnosed with DID. There is no way to know how many more people remain undiagnosed. Through research like this and through many online resources and groups, help can come to everyone who suffers from and is affected by this disorder. No one--host, alter, or family member--needs to feel lost, forgotten, or ignored. This research goes a long way to give a voice to these people.

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