

The Narratives and Lived Experiences of People with Derealization-Depersonalization Disorder

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ABSTRACT

Derealization-Depersonalization Disorder (DPDR) is a dissociative disorder that causes individuals to feel disconnected from their surroundings or from themselves. Despite affecting a significant number of people, the disorder remains underdiagnosed and poorly understood, especially in terms of lived experience. This study uses a qualitative case study approach to explore the personal experiences of two individuals diagnosed with Derealization and both Derealization and Depersonalization. The data was collected through open-ended surveys and analyzed using thematic analysis to identify key themes such as emotional disconnection, difficulties in relationships, misdiagnosis and personal coping strategies. The findings show that DPDR has a serious impact on the emotional well-being, social life and daily functioning of the participants. Both of the participants' responses show a strong sense of detachment, and along with that emotional numbness and challenges in receiving proper support are also reported. The participants also highlighted the need for patient-centered care, a greater need for awareness among mental health professionals and the requirement of valuing personal narratives in understanding the full scope of the disorder. While the sample size limits the generalizability of the results, the study adds to the limited qualitative research on Derealization-Depersonalization and suggests directions for future research on including more in-depth interviews, family perspectives and long-term treatment outcomes.

Keywords: *Derealization, Depersonalization, Lived experiences, Subjective experiences*

This paper examines Derealization-Depersonalization disorder (DPDR), which falls under the category of Dissociative Disorder. Dissociative disorders are defined as “a disruption, interruption or discontinuity of the normal, subjective integration of behavior, memory, identity, consciousness, emotion, perception, body representation, and motor control.” (Keepers et al., 2020). Although Derealization-Depersonalization (DPDR) is considered as a single diagnosis, it has two different aspects: depersonalization and derealization (Sutar & Chaturvedi, 2020; Wilkhoo et al., 2024).

According to the DSM V, derealization is an “experience of unreality or detachment from one’s surroundings”. The individuals who experience derealization often feel like having a boundary between themselves and their identity, they feel that the world around them appears

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to be artificial and robotic which creates distortions in their vision (APA, 2013). Derealization can occur due to various factors, including extreme stress, alexithymia (Brewer et al., 2016), severe trauma or childhood abuse (Dell, 2011), substance usage (Madden & Einhorn, 2018). A research by Hunter reported that derealization symptoms more commonly affect around 26% to 74% of people at some point in their lives at a traumatic event (Sierra et al., 2004). Further, an article by the Mayo clinic highlighted that individuals with Derealization felt it hard to focus on everyday activities because they felt that their surroundings were unreal (Depersonalization-derealization Disorder - Symptoms and Causes, n.d.).

Depersonalization on the other hand, involves a sensation of being “detached from one’s own body” (Sierra & David, 2010). Individuals may feel as though they are observing their own body from an outside perspective. One of the main characteristics of Depersonalization is that the individual feels difficulty to express their feelings, which is otherwise referred to as “Anhedonia” as per the literature (Depersonalization-Derealization Disorder, 2025).

In the ICD-10, DPDR was classified under the broader category of “other neurotic disorders” which generally included conditions related to anxiety, stress and other emotional difficulties. However, in the recent revision, the ICD-11 reclassified DPDR under ‘Dissociative disorder’ as a category that includes disorders characterized by disruptions in the normal consciousness, memory, identity and perception (Reed et al., 2019c).

Derealization-Depersonalization disorder is difficult to comprehend as it disrupts normal consciousness (Sutar & Chaturvedi, 2020b). Personal narratives and subjective experiences are important to understand derealization-depersonalization disorder (DPDR) because they provide insights into individuals’ minute experiences. These narratives help to understand the personal and unnoticed aspects of DPDR that are not easily captured through clinical assessments (Ciaunica et al., 2021).

REVIEW OF LITERATURE

Despite affecting 2% of the population, derealization-depersonalization remains as a highly misunderstood and underdiagnosed mental health disorder (Spiegel, 2023; Sierra et al., 2005). Studies report that DPDR often begins in young adulthood with some cases being reported in the adolescence period, middle adulthood period (Michal et al., 2016c; Simeon, 2004b), and also co-occurring with other mental health disorders (Yang et al., 2022).

The factors that contribute to DPDR include experiencing traumatic experiences being the most recurrent factor (Simeon et al., 2003) followed by emotional abuse (Michal et al., 2016c), high levels of childhood anxiety (Salami et al., 2020b), early life stressors (Reji, Felcia. 2024) and interpersonal abuse (Yang et al., 2022c). A paper by Dell suggested that history of trauma, in particular, has a strong association with the onset of DPDR. The researcher’s findings also aimed at emphasizing the importance of examining personal history and conducting a detailed analysis of past trauma (Dell, 2011).

DPDR is associated with a significant emotional and cognitive detachment. Individuals often experience a loss of resonance and detachment from their experiences and this further leads to a feeling of disconnection from reality and self (Pienkos & Sass, 2022). Due to this detachment, strong emotions can or may trigger and intensify DPDR episodes (Čolić et al., 2020). A few neuroimaging studies from the literature have shown structural and functional alterations in various parts of the brain, including the left temporal lobe and right

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temporoparietal areas (Sierk et al., 2018). Another research also highlighted that impairments caused in the processing of sensory signals also played a role in developing the symptoms of DPDR. This means that the disruption of these signals could also contribute to the detachment and altered perception of the individuals with DPDR (Salami et al., 2020c).

According to the theories, most researchers usually agree on the statement that the prefrontal cortex, which is the part of the brain that handles thinking and analyzing, becomes extra active. When an individual's prefrontal cortex becomes extra active, it reduces the activity of the limbic system, the part that usually helps the brain feel our emotions (Cunningham & Lees, 2024). Similarly, another study that used fMRI to study patients with DPDR reported that the patients generally have reduced activity in parts of their brain that responds to emotional situations, that is referred to as hypo-responsivity (Phillips et al., 2001).

While existing research has mainly focused on the neurobiological mechanisms, the qualitative studies that explore the lived experiences remain limited. For example, Watson in his research used an autoethnographic approach to highlight the stigma and also shed light on how individuals were affected by societal perceptions and personal struggles. The study showed that individuals with DPDR faced a lot of challenges in explaining “what they were going through to others” (Watson, 2022). Similarly, a case study of a nursing student who experienced a DPDR attack during an exam pointed out how individuals who never previously experienced mental health issues can suddenly be struck by DPDR and create a sense of confusion and fear, these qualitative accounts showcase the multifaceted nature of DPDR (Jones & Abraham, 2019). Furthermore, studies have also revealed that individuals with DPDR face difficulties in daily activities. The quality of social interactions and quality of life has also been reported to be low (Uzun, Sevda, 2024).

The treatment for DPDR involves using various methods such as pharmacotherapies, neuromodulation, and psychotherapies. However, even though there are different ranges of treatment available, the extent to which method is effective remains very low (Wang et al., 2023b). While Cognitive Behavior Therapy shows an effectiveness, it is difficult to confirm its effectiveness due to small sizes in the existing studies (Flückiger et al., 2021). A systematic review identified 30 different treatment methods for DPDR since 1955, yet it still emphasized a need for higher quality research to better understand the treatment outcomes (Wang et al., 2023). Currently, there has also been a growing importance and recognition given to ‘person-centered’ approach treatment for DPDR patients. This approach emphasizes understanding the unique experiences that each patient faces and further tailoring personalized treatments based on individual experiences for better support (Eve et al., 2023).

Despite these advancements, the several gaps that remain in the literature include:

- The lack of qualitative studies on lived experiences – Most studies have focused on the quantitative aspects with limited research examining the emotional, social and personal dimensions of the disorder. Given the difficulty in diagnosing DPDR and frequent misdiagnosis, incorporating a subjective focus can put light on the personal struggles of individuals with the disorder.
- Insufficient understanding of social impact – While some studies touch on the social challenges faced by the individuals with DPDR, more research is needed to fully understand how the disorder affects daily life work and interpersonal relationships (Watson, 2022; Uzun et., 2024).

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- Diagnostic challenges – The current diagnostic criteria is primarily based on observable symptoms, often overlooking the subjective experiences. Since each person's experience with DPDR can be different, the existing framework may not fully capture the complexity of the disorder. Therefore, a more comprehensive understanding of DPDR is required, potentially leading to an updated diagnostic criterion that accounts for individual differences in how the disorder manifests.

METHODOLOGY

This research adopts a qualitative case study methodology to explore the lived experiences of the individuals with DPDR. By using narrative writing and open-ended questions this study aims to gather rich subjective data that can highlight the unique ways DPDR affects individuals lives (Crowe et al., 2011).

The study consists of 2 participants, both clinically diagnosed by licensed mental health professionals. The participants were recruited through an online poll on the Reddit platform and via personal invitation. Individuals who self-reported dissociation alone were excluded from the study as dissociation is a broader range of experiences that fell outside the specific focus of this research. The inclusion criteria required participants to have a clinical diagnosis either for DPDR, DP or DR. This criteria ensures that the study remains focused on the specific lived experiences of individuals meeting the criterion.

Before collecting the data, each participant was informed about the study purpose and informed consent was obtained from all participants. This was done to ensure that they understand the purpose of the research, their rights to withdraw and how their data will be used. The participants' responses will remain anonymous and each individual will only be identified by the initials put by the researcher to ensure confidentiality.

The responses were collected through digital surveys distributed via google forms. This method will allow the participants to express their experiences in their own words and will help to get a deeper understanding of how DPDR impacts them. The use of open-ended questions will give the participants the freedom to reflect on their symptoms, triggering moments and other broader and small details that often get unnoticed.

The data collected will be further analyzed using thematic analysis, Thematic analysis is well suited for this research because it allows for the exploration of recurring patterns in the participants' experience with DPDR. The analysis will follow the Braun and Clarke's 6-Step thematic analysis process which includes the following steps (Braun & Clarke, 2006):

1. Familiarization with the data – This step involves thoroughly reading the survey responses multiple times to gain a deep understanding of the participants' experience with DPDR. The aim is to become familiar with the overall content before detailed analysis.
2. Generating initial codes – During this stage, meaningful segments of the data are highlighted and labeled with initial codes. These codes will represent specific aspects of the experience.
3. Generate initial themes – The initial codes will be grouped into broader themes that will further capture significant patterns in the data.
4. Review the themes – This step involves reviewing the themes to ensure that they accurately reflect the data.
5. Defining the themes – Each theme is clearly defined by summarizing its core concepts and explaining what it represents.

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6. Writing – The findings are then written up by explaining each theme in detail supported by direct quotes from the participants.

Further, Microsoft Excel will be used to organize and manage the data for analysis. Excel will help to systematically code the responses, categorize codes and arrange everything in a clear and structured manner.

Given the sensitivity of the topic and the potential emotional distress associated with sharing personal experiences of DP and/or DR, the questions are carefully designed to create a sense of safety and comfort for participants. The questionnaire progressed gradually from less intrusive to more emotionally evocative questions to avoid overwhelming participants from the beginning itself. The questionnaire followed a clear, non-clinical language to reduce discomfort.

RESULT

This section presents the six key themes that were identified through the thematic analysis process from two participants, one with both Derealization and Depersonalization and the other with only Derealization. The themes are as follows:

1. Disconnection from Reality and Self:
 - Both participants have described their experiences to be a deep disconnection from reality and their sense of self.
 - P1 has explained Depersonalization as “You have their memories, emotions and personality but you know they are not yours.” Similarly, for Derealization P1 has said that: “Everything feels unreal, the world around you is fuzzy... it all feels so dream-like.”
 - P2 has described their experience for Derealization as “Living inside a bubble and not being able to connect to reality.” The participant also used metaphors such as “pixels”, “transparent sheet” to describe the altered perception.
2. Emotional Blunting and Psychological Exhaustion
 - P1 stated a lack of emotional connection as a core experience – “I can’t really feel anything... my emotions are kind of not my own, so I have to just been numb”
 - P2 expressed similar emotional detachment – “Derealization doesn’t let you enjoy even the smallest emotion... I lost my childhood due to this.”
 - Both the participants, P1 and P2 responses shows a significant mental fatigue and psychological drain.
3. Relationship Isolation and Conflicts
 - The responses indicated difficulties they had faced while maintaining or keeping relationships.
 - P1 mentioned identity-dependent behavior changes: “I’ll treat my partner and feel different about them depending on which friends we’re with.”
 - P2 described intergenerational misunderstanding: “Parents try their best, but they still don’t know the pain I’m going through”
 - Both participants have also noted having to mask their symptoms in front of their friends.
4. Distraction in Works
 - Both participants' responses show that DPDR and DR impaired their ability to carry out daily tasks.

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- P1 stated that ‘Since nothing feels real, I tend to forget very real things like homework.’
 - P2 shared that ‘‘Oversleeping during high episodes.... crying all day.... no mental strength to study.’’
5. Misdiagnosis and Lack of proper support
- Proper misdiagnoses were central to both the participants.
 - P1 reported that ‘‘In 2021.... counselors had diagnosed me with depression, they weren’t wrong, but that was more the symptom than the cause.’’
 - P2 shared a longer journey of misdiagnosis ‘‘The doctor gave me a placebo.... I eventually found out myself using Google.... even after doctors know your problem, they don’t have the concern to respond.’’
6. Coping Mechanism
- Even through a lot of challenges both the participants had developed their suitable coping methods.
 - P1 found journaling useful ‘‘Use the present tense for every part of the day.... its helps ground you’’
 - P2 benefited from mindfulness ‘‘Splashing cold water, breathing, and reminding myself that this is temporary.’’
 - Both the participants have also expressed a heavier need for more accessible, affordable and empathetic mental health care.

DISCUSSION

This study aims to explore the lived experiences of individuals with depersonalization and both DPDR using the qualitative lens. The goal of this research was to address 3 main research gaps:

- Lack of subjective accounts in the existing literature.
- The limited understanding of how DPDR affects social life and functioning.
- And the diagnostic challenges people face.

The first theme is ‘‘Disconnection from Reality and Self’’, this theme shows how the participants used metaphors like ‘‘bubbles’’, ‘‘pixels’’ and ‘‘fuzzy’’ to describe how they feel when they are detached from their surroundings and from themselves. These symbolic expressions shows that the standard diagnostic tools fails to fully capture the deep personal and emotional nature of the disorder. Although tools like the Cambridge Depersonalization Scale are widely used, they still heavily rely on the self-report responses and it can miss the little and significant emotions and feelings that the individuals feel. Therefore, incorporating personal narratives like these in research and diagnosis is important for understanding the complexity of the disorder DPDR.

The second theme is ‘‘Emotional Blunting and Psychological Exhaustion’’, this aligns with the research that describes DPDR as a dissociative defense mechanism that initially protects individuals from overwhelming emotions. The neurobiological studies in the literature support this by showing that changes in the brain areas are responsible for emotional regulation and threat-detection, which therefore suggests that DPDR may arise as a protective response to trauma or intense stress (Murphy, R. 2023). In this study, the participant also reported that when emotional disconnection stayed for a longer period, it lead to deeper emotional pain and confusion, which is further supported by qualitative research indicating that individuals often experience a loss of meaning, detachment from

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familiar feelings and emotional numbness that contributes to long-term psychological suffering (Pienkos, E., & Sass, L.2022; Fino et.al 2024).

The third theme, “Relational Conflict and Isolation” highlights a significant gap in research on the social effects of DPDR, as both participants shared that their symptoms were often misunderstood or dismissed by their friends and family. This clearly aligns with the earlier studies showing that individuals with DPDR frequently struggled to explain their condition and faced lack of validation especially from one’s family or one’s environment where mental health is not openly discussed (Pienkos, E., & Sass, L. 2022). This experience is further worsened by personality traits such as high negative affect and limited social support which can also contribute to increased loneliness and emotional distress (Fino et al.2024).

The fourth theme, “Distraction in Works”, further supports the idea that DPDR can significantly interfere with a person’s ability to live a normal life, as the participants reported challenges such as oversleeping, loss of focus, academic difficulties and disconnection from daily routines, it aligns with the existing research that states that DPDR as a disabling condition impacting the body, memory and personal identity across time, and in some cases, these disruptions are made worse by physical symptoms like spatial disorientation or anxiety, especially when it is related to coexisting conditions such as vestibular dysfunction. (Elyoseph, Z et.al. 2022).

The fifth theme, “Misdiagnosis and Lack of Proper Support” shows how difficult it can be for individuals to obtain an accurate diagnosis or better support, with both participants recounting about how their symptoms were misunderstood or minimized by professionals, a challenge that is well supported by existing literature shows that DPDR is often confused with anxiety, depression or psychotic disorders due to overlapping symptoms and this is further complicated due to the difficulty in articulating the individuals subjective experiences, which then contributes to underdiagnosis, particularly in regions like India where DPDR is rarely recognized (Sutar et.al. 2020; Murphy et.al. 2023).

The final theme, “Coping Mechanisms” reflects the resilience of individuals who attempt to manage DPDR independently through strategies such as journaling, mindfulness and grounding while also emphasizing the importance and urgency of more accessible and affordable mental health services. Both the participants mentioned that they only found meaningful relief after consulting with therapists who truly understood their experiences, reinforcing the necessity of training clinician specifically for DPDR care. Adding on from other literature presented, programs tailored specifically for DPDR can help shorten the gaps in professional knowledge and further improve care delivery (Jaelani et.al.)

CONCLUSION

This study explored the lived experiences of two individuals who are diagnosed with Derealization and both Derealization-Depersonalization disorder. Through their lived experiences it is evident that DPDR is not only a clinical condition but also a disorder that deeply disrupts one’s sense of self, daily life and relationships. The findings from this study emphasizes how people with DPDR often feel detached from their surroundings and themselves and how they experience emotional numbness and struggle being misunderstood.

This study highlights the importance of including patient voices in treatment planning. It shows that the professionals and caregivers that even the invisible symptoms have strong emotional effects on the individual facing this. Mental health education should include training on how to recognize and treat depersonalization and derealization, and at the same

time creating support groups, improving therapy access and encouraging about the importance of how a simple listening could make a big difference in how these individuals feel supported.

Limitations

The study has a small number of participants and the results therefore do not represent all people with the disorder. There should be more detailed interviews and observations as it can provide richer insights into this disorder. The language and cultural differences aren't explored and that limits the study's reach. The future work should include more people who may have also had DP/DR as a comorbid disorder and include different types of data collection to get more insights. As this is a qualitative case study, the findings may not be generalizable to all individuals with DPDR given the small sample size. This approach was chosen not for generalizability, but to allow for an in-depth, rich and detailed exploration of the subjective complexity of DPDR which is often lost in larger quantitative studies. The nature of this case study also limits the ability to capture the full range of experiences that may exist within the wider population of individuals with DPDR. Additionally, the self-reported data also has its limitations as the participants may not always be able to fully articulate their experiences or maybe influenced by their current emotional state.

Future Direction

Future research should continue to focus more on real stories of those living with depersonalization and derealization. The researchers should also involve families and therapists to gain their insights on how they perceive the disorder and how they respond to it. There is also a need to study how therapy and medication works for different people over time.

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Conflict of Interest

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