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Lived Experience of Individuals with Dissociative Disorders: A Phenomenological Study

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ABSTRACT

Purpose: This study aims to explore the disorder and the interrelations among its components from the perspective of individuals affected by it.

Methods and Materials: This study is conducted by adopting an interpretivist philosophy, a qualitative approach, a phenomenological strategy, content analysis techniques, and in-depth interview tools. The study sample includes 12 individuals diagnosed with dissociative disorder, selected through purposive and convenient sampling until theoretical saturation was reached. Ultimately, the experiences of individuals with dissociative disorder indicate that this condition is fundamentally a traumatic disorder that profoundly affects the individual's entire cognitive and functional system.

Findings: Four key dimensions—personal characteristics, environmental conditions, personality disorder, and psychological disorder—not only constitute the essence of this disorder but also influence it significantly.

Conclusion: This study highlights the complex interplay of personal, environmental, personality, and psychological factors in the development of dissociative disorders. It emphasizes the importance of integrated treatment approaches, combining clinical interventions with social and familial support for effective management.

Keywords: *Dissociative disorder, lived experience, phenomenology*

1. Introduction

Dissociative disorders can be considered a type of psychological disorder often characterized by a disruption and/or discontinuity in the normal integration of consciousness, memory, identity, emotion, perception, bodily representation, motor control, and behavior (Rahardanto, 2024; Rostami & Mehdiabadi, 2024). This disorder can manifest across a range of experiences, from transient detachment from past events to chronic and ambiguous conditions such as Dissociative Identity Disorder—previously known as Multiple Personality Disorder—and Dissociative Amnesia (Mansuroğlu, 2025; Tarakçıoğlu, 2024).

In investigating the causes of this disorder, it is often associated with past traumas, particularly those experienced in childhood or unresolved prolonged traumatic memories. The field of psychology has continuously aimed to provide theoretical models and standardized criteria for diagnosing and understanding this disorder (Balch et al., 2024; Doss, 2024), each addressing various aspects of it. For instance, variable-based assessments structured around standardized questionnaires are commonly used. These are often conducted through structured clinical tools such as the DSM-IV, DSM-5, or psychometric evaluations like the MMPI. Another method includes observation-based assessments, ranging from simple behavioral observation to advanced neurophysiological techniques like QEEG (Quantitative Electroencephalography), which records brain wave activity (Poli et al., 2023; Soffer-Dudek, 2023).

In this context, the lived and subjective experiences of individuals with dissociative disorders constitute a vital area for deeper investigation that has received relatively little attention. Most studies in this domain rely heavily on instrumental assessments and standardized criteria, thus being primarily quantitative in nature. In terms of qualitative studies, while various components and schemas have been identified, the internal constructs and subjective dimensions involved from the patient's perspective have rarely been explored (Nakamura & Tanaka, 2023).

For example, in a 2024 study, Robinson and colleagues attempted to center qualitative components and schemas. However, this study primarily presented panel groups and group therapy methods aimed at stigma reduction, research enhancement, clinical program development, professional training, and public awareness, and did not explore lived experiences through identified components (Robinson et al., 2024).

Alternatively, in the 2022 study by Obsvik et al., the researchers utilized a qualitative approach and in-depth interviews to identify the lived experiences of individuals affected by dissociative disorders. Key components identified in that study included a sense of detachment and alienation from self, impact on daily functioning and relationships, the role of stress and trauma, ambiguity, and confusion. However, a reductionist view focused on limited components can be seen upon review, and the interrelations between the extracted components were never explored, thereby failing to establish logical connections between qualitative insights and quantitative objectivity (Opsvik et al., 2022).

It is important to recognize that the necessity of developing treatment approaches grounded in the lived experiences of individuals with dissociative disorders primarily arises from the fact that personal and subjective narratives reflect the psychological and social challenges faced. Thus, superficial analysis of components is insufficient for meaningful extraction. Most existing quantitative and qualitative studies tend to focus on diagnostic symptoms and prevalence, while qualitative research—especially the phenomenological approach—offers a unique lens to understand the essence of these experiences. By focusing on what it is like to live with dissociative disorder, this study aims to provide a nuanced and in-depth understanding that can inform clinical practice, contribute to theoretical development, and influence social attitudes.

2. Methods and Materials

The research methodology of the present study, in terms of epistemology, ontology, and methodological orientation, follows the interpretivist paradigm. This paradigm asserts that many concepts applied in the current world—especially in the human domain—are influenced by social, political, economic, and individual components. Consequently, no phenomenon can be considered as isolated or independent from other phenomena. In line with this paradigm, the qualitative approach is adopted as the principal research methodology in this study.

This approach, utilizing a phenomenological strategy, aims to identify the components involved in dissociative disorders from the perspective of patients' lived experiences. Accordingly, through the content analysis technique and the use of in-depth interview tools, the study identifies these

components and subsequently examines the relationships among them.

It should be noted that, in terms of validity, the content of this study has been repeatedly verified and aligned with participant feedback. Regarding reliability, 20% of the interviews were coded by an independent coder, and the agreement rate between coders was estimated to exceed 81%, which is considered an acceptable threshold.

Ultimately, the statistical population of the present study consists of all individuals diagnosed with dissociative disorders. Based on the principle of theoretical saturation and through purposive and convenient sampling, 12 participants were selected.

The inclusion and exclusion criteria of the study are as follows:

Inclusion Criteria:

- Voluntary consent to participate in the study, including willingness to engage in interviews and share personal experiences
- Completion of the informed consent form
- A minimum of three months since the initial diagnosis of a dissociative disorder
- Awareness of one's own diagnosis
- Age between 18 and 50 years
- Minimum educational attainment of a high school diploma
- Ability to verbally communicate and sufficient cognitive literacy to share experiences

Exclusion Criteria:

- Inability to communicate in Persian
- Unwillingness to discuss personal and sensitive issues

- Withdrawal or lack of interest in continuing the interview process
- Severe memory impairments or inability to recall relevant experiences
- Strong hostility or refusal to cooperate
- Substance addiction or drug abuse
- Psychotic spectrum disorders (psychosis conditions)
- Presence of severe positive or negative dissociative symptoms (Positive dissociative symptoms include the intrusive and involuntary emergence of dissociative experiences into consciousness and behavior, typically accompanied by a disruption in the continuity of subjective experience, such as identity fragmentation, depersonalization, and derealization. Negative dissociative symptoms refer to the inability to access information or control mental functions that are normally accessible or controllable, such as amnesia) (DSM-5-TR, 2022).

For data analysis, the Strauss and Corbin coding system was employed, involving three stages of coding: open coding, axial coding, and selective coding.

3. Findings and Results

One of the most important aspects of thematic content analysis is achieving theoretical saturation. This feature is, in fact, the primary factor in determining the sample size. In the present study, theoretical saturation was reached through 12 interviews, enabling the categorization of themes. It should be noted that the characteristics of each interviewee can be a significant factor in the formation of psychological themes. Accordingly, this section examines those characteristics.

Table 1

Characteristics of Interview Participants

No.	Variable	Categories	Values
1	Gender	Female	7
		Male	5
2	Age	26–30	3
		31–35	2
		36–40	4
		Over 40	3
3	Education	Less than High School Diploma	1
		High School Diploma	1
		Bachelor's Degree	6
		Master's Degree	3
		Doctorate	1

4	Marital Status	Single	6
		Married	6
5	Personal-Social Behavior	Multiple relationships	2
		Substance use	1
6	Occupation	Debt collector	1
		Laborer	6
		Accountant	1
		Administrative staff	3
		Housewife	1
7	Number of Children	No children	10
		One child	0
		Two children	2
8	Hospitalization History	No	4
		Yes	5
9	Medication History	Yes	5
		No	3
10	Psychotherapy History	Yes	10
		No	1

Based on the data obtained from the interviews, among the 12 participants, 7 were women and 5 were men, aged between 26 and 49 years. Educational levels ranged from less than a high school diploma (1 person), high school diploma (1 person), bachelor's degree (6 persons), master's degree (3 persons), to doctorate (1 person). Regarding marital status, 50% of participants were single and 50% were married. The most common occupation was administrative staff. Ten participants had no children, while two had two children. Four interviewees had no history of hospitalization, while five had been hospitalized. Five had a history of medication use, and three had none. Finally, ten participants had undergone psychotherapy, while one had not. (It is worth noting that discrepancies between total counts and the number of participants are due to some participants not answering certain demographic questions during interviews.)

As Saldaña (2009) has pointed out, there is no predetermined or fixed method for coding, giving researchers flexibility in their approach. He refers to multiple coding types, including process coding, descriptive coding, in vivo coding, open coding, axial coding, selective coding, first cycle coding, and second cycle coding. This study adopted the comprehensive Strauss and Corbin grounded theory framework, which includes three types of coding: open, axial, and selective coding. Each of these is addressed below.

Open Coding:

Charmaz (2006) discusses two levels of coding: first cycle and second cycle coding. Open coding essentially consists of initial coding and categorization. At this stage,

the researcher labels meaning units and groups them accordingly.

- **Initial Coding:** In this study, 205 initial codes were extracted. After merging, refining, and summarizing, 217 initial codes remained, with a total frequency of 753 occurrences.
- **Categorization:** As noted, the study followed the approach of Strauss and Corbin (1998), aiming to group key interview concepts. Categorization represents the final phase of open coding. Concept grouping in content analysis can vary; in this study, it was guided by supervisory experts, the researcher's theoretical insight, and MaxQDA software's capability for identifying conceptual overlaps. A total of 21 main categories were extracted. Categorization, in essence, abstracts the initial codes: either an initial code is abstract enough to encompass others, or overlapping codes together form a new, named category.

Based on Newman (2006), overlapping codes are those that identify differences between various coding strategies. If units of meaning consistently receive both label *a* and label *b*, and this pattern is repeated, it suggests a relationship between *a* and *b*, which could be either causal (regression-based) or correlational (covariance-based).

Axial Coding:

As discussed, various types of coding exist in content analysis. Axial coding—or second cycle coding—is one such method that applies inductive logic, moving from the specific to the general. In this phase, the categories identified earlier are further abstracted. In thematic analysis, these represent the core themes; in variable analysis, these are the

key constructs. Quantitative variables are often derived at this stage. Traditional paradigmatic models may also be introduced here.

While the Strauss and Corbin approach is reviewed critically, Glaser's view suggests incorporating statistical methods at this stage. However, since this study focuses on

the lived experiences of individuals with dissociative disorders, statistical approaches were not applied. Instead, the researcher relied on previous methods—personal theoretical insight, expert consultation, and MaxQDA's conceptual overlap analysis—to identify the core themes of the study.

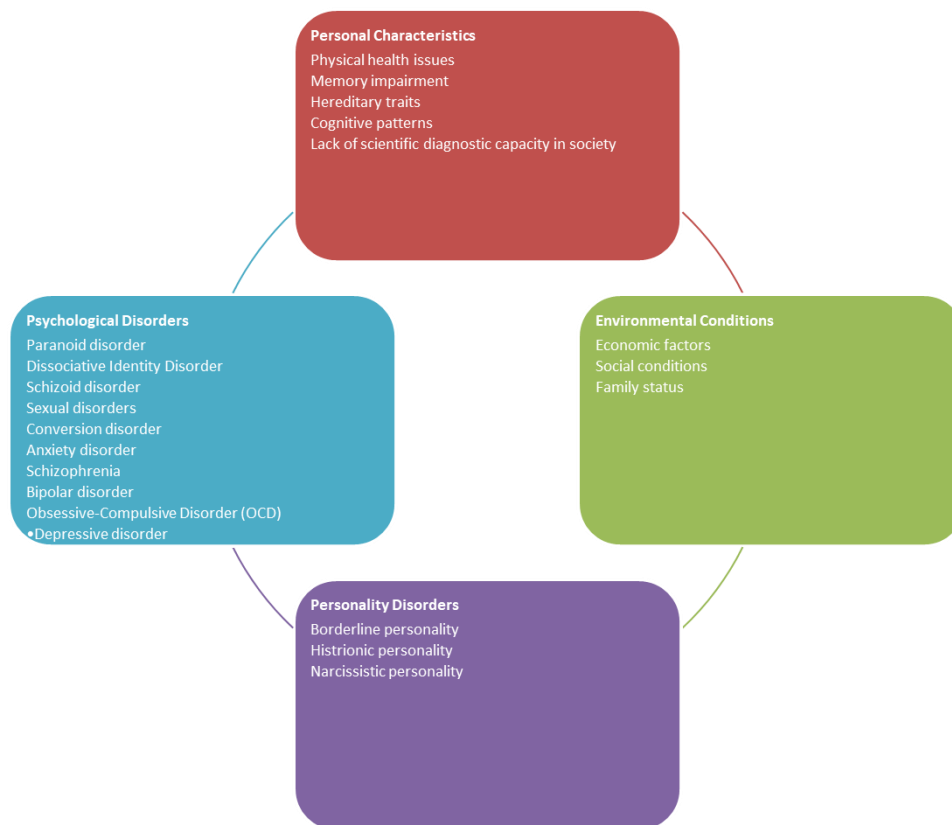
Table 2

Axial Codes

Axial Code	Categories	Frequency of Concept
Personal Characteristics	Physical health issues	43
	Memory impairment	1
	Hereditary traits	18
	Cognitive patterns	45
	Lack of scientific diagnostic capacity in society	3
Environmental Conditions	Economic factors	20
	Social conditions	6
	Family status	1
Personality Disorders	Borderline personality	136
	Histrionic personality	49
	Narcissistic personality	22
Psychological Disorders	Paranoid disorder	2
	Dissociative Identity Disorder	162
	Schizoid disorder	52
	Sexual disorders	31
	Conversion disorder	18
	Anxiety disorder	67
	Schizophrenia	10
	Bipolar disorder	76
	Obsessive-Compulsive Disorder (OCD)	62
	Depressive disorder	82

Figure 1

Final Conceptual Model of the Study



4. Discussion and Conclusion

In response to the main objective of this study—identifying the contributing components of dissociative disorder within the lived experience of individuals affected by it—it must be stated that, in general terms, dissociative disorder involves a disruption in brain function, particularly in the domains of memory, consciousness, emotion, perception, and identity. These disruptions may lead to outward symptoms, such as motor and behavioral dysfunction. Individuals with this disorder often perceive themselves as disconnected from their external environment and reality. Consequently, depersonalization, memory impairment, and the experience of multiple identities are among the most prominent symptoms. In many cases, dissociative symptoms appear to be a form of synthesis or adaptation in response to life events. In this context, individuals protect themselves against psychological trauma by employing defense mechanisms and distancing themselves from reality.

According to the interview findings, four primary dimensions were identified by participants as contributing factors in the manifestation of this disorder: personal characteristics, environmental conditions, personality disorders, and psychological disorders.

This dimension includes physical problems, memory impairments, hereditary traits, and cognitive patterns. The most impactful individual characteristics are genetic predispositions and hereditary features. This dimension exhibits a causal relationship with physical factors, memory dysfunctions, and personal schemas—collectively forming essential elements in the development of dissociative tendencies. However, personal factors are never viewed in isolation or as the most critical elements; this is also evident in participant narratives. For instance, one interviewee stated, *"My memory is generally fine and functions well, but when I'm stressed, I forget everything—even proverbs, names, or words."* Here, it is apparent that an external factor, such as stress, can impair memory. Another participant noted, *"Everything was going well. I was a good student in school and university. But after some painful memories, I feel like I'm becoming someone else."* These accounts illustrate that personal factors often act as secondary contributors.

Scientific evidence also supports this. Pierre Janet proposed that some individuals, when confronted with crises or unresolved traumas, exhibit physical, emotional, and psychological symptoms typical of dissociative disorders. However, these manifestations do not occur in isolation; external factors are critical for their emergence. The most

significant personal factor is arguably the genetic and hereditary dimension. Biologists argue that specific neurological structures and functions may alter trauma responses, particularly affecting memory and identity. Genes related to calcium regulation (e.g., *CACNA1C*, *CACNB2*), serotonin transmission, monoamine oxidase, BDNF, and stress-regulation genes are seen as potential contributors. Chromosomal changes in chromosomes 3 and 10—also found in motor and speech disorders such as autism—are relevant (Eve et al., 2024).

Participants emphasized themes such as dependency, existential anxiety, shame, defectiveness, and abandonment. These reflect how individuals process core existential concerns (e.g., death, loneliness, freedom, and meaninglessness). Rollo May posited that anxiety is a central shared factor between cognitive schemas and dissociation, acting as a trigger for defense mechanisms. Marcel Proust, in *In Search of Lost Time*, emphasized memory reconstruction as a mechanism through which individuals develop cognitive schemas—thereby forming the foundation for dissociative defense mechanisms.

Despite this, dissociation cannot be solely attributed to personal factors, which often act as mediating variables. They become relevant primarily in the presence of external triggers—an interpretation supported by both biological and behavioral science.

The second major dimension identified by participants includes inadequate scientific diagnostic capabilities, economic hardship, social disadvantage, and problematic family conditions. Participants noted limited psychological expertise in Iran, inconsistent diagnoses, and lack of access to proper treatment. Several shared stories of chronic poverty, repeated relocations, and family abuse, describing their early environments as unstable and stressful.

The third dimension involves borderline, histrionic, and narcissistic personality traits. Misdiagnosis is common, particularly between dissociative and personality disorders. Although personality disorders are not classified as mental illnesses, their stable emotional-behavioral patterns can create vulnerability to psychiatric conditions.

Interviewees described emotional instability, identity confusion, and impulsivity—hallmarks of borderline personality disorder. One participant remarked: *"Sometimes I have to cut myself to feel real... I don't know who I am. I get angry and destroy things or fight until I calm down."*

The fourth dimension includes comorbid conditions such as paranoid disorder, schizoid disorder, sexual disorders, conversion disorder, anxiety, schizophrenia, bipolar

disorder, OCD, and depression. One participant recounted: *"I once saw my spirit leave my body... I hear voices that aren't mine. Over the years, I've been told I'm schizophrenic, bipolar, depressed—every label you can think of."*

These aligns with prior studies (Emran et al., 2021; Eve et al., 2024; Kalagate et al., 2024; Opsvik et al., 2022; Parry et al., 2018; Robinson et al., 2024; Yang et al., 2023).

According to participants with lived experience of dissociative disorder, the most critical elements defining the disorder include personal characteristics, environmental conditions, personality disorders, and psychological disorders. Dissociation is fundamentally a trauma-related disorder that disrupts the individual's entire cognitive and functional system. Early-life dissociative experiences—fragmented and unintegrated—require a safe and nurturing environment to form coherent narratives. The absence of such conditions contributes to chronic dissociation in later life.

Effective treatment requires integrative approaches, combining advanced clinical interventions with social and familial support. On average, it takes seven years from the onset of symptoms to accurate diagnosis, with most patients initially misdiagnosed with bipolar disorder or schizophrenia, leading to inappropriate treatments.

Authors' Contributions

This article is derived from the first author's doctoral dissertation. All authors significantly contributed to this study.

Declaration

In order to correct and improve the academic writing of our paper, we have used the language model ChatGPT.

Transparency Statement

Data are available for research purposes upon reasonable request to the corresponding author.

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Declaration of Interest

The authors report no conflict of interest.

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Ethical Considerations

In this study, to observe ethical considerations, participants were informed about the goals and importance of the research before the start of the interview and participated in the research with informed consent.

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