Original Article

The Effect of Depersonalization Disorder on Quality of Life, the Case of Turkey: A Phenomenological Study

Sevda Uzun, PhD
Asistant Profesor, Department of Nursing, Gumushane University Faculty of Health Sciences, Gumushane, Turkey

Correspondence: Sevda Uzun, PhD, Asistant Profesor, Department of Nursing, Gumushane University Faculty of Health Sciences, Gumushane, Turkey. E-mail: sevdauzun50@gmail.com

Abstract

Objective: This study aimed to deeply examine the quality-of-life perceptions and experiences of individuals with depersonalization disorder.
Material-Method: The study was conducted with 13 individuals diagnosed with depersonalization disorder using phenomenological research design, which is a qualitative research design. Interviews were conducted individually and face-to-face using semi-structured forms. The data were analyzed using Colaizzi's phenomenological analysis method.
Results: In the analysis of the data, two categories, nine main themes, and twenty-one sub-themes emerged. These are the categories of "effects of depersonalization on the individual" and "quality of life perceptions". The category of the effects of depersonalization on the individual was examined under three sub-themes as mental, physical, and social effects. Individuals with depersonalization disorder experience feelings of hopelessness/despair, depression, sadness, loneliness, and dream/simulation. The diagnosis of depersonalization disorder was determined to cause many adverse conditions like internalized stigmatization and social isolation. In addition, individuals with depersonalization disorder experience problems in daily life activities, which impair their perception of quality of life.
Conclusion: Individuals with depersonalization disorder experience psychosocial problems, their daily life activities are negatively affected, and their perception of quality of life is low.

Keywords: Depersonalization-derealization disorder, quality of life, qualitative study

Introduction

Dissociation and its accompanying disorders, which have attracted worldwide attention and inspired many books and films, unfortunately, remain mysterious due to their etiological causes and neurobiology. Dissociative symptoms (such as depersonalization, derealization, memory problems, etc.), which can occur from time to time in healthy individuals at a low level that does not impair functionality, become pathological dissociation if they become frequent and at a level that affects the quality of life and impairs functionality. Pathological dissociation manifests as a main or accompanying symptom in a wide range of psychiatric diseases. Depersonalization/derealization disorder, dissociative identity disorder, the dissociative subtype of posttraumatic stress disorder (as described in DSM-5), and borderline personality disorder are the most common ones (Mutlu, 2022; Mishra et al., 2022). Depersonalization/derealization disorder is defined as a persistent and distressing condition characterized by detachment from oneself and/or one's surroundings (Sierk et al., 2018). Depersonalization is a subtype of dissociative disorder and causes a feeling of separation from the self. The two are often observed together, and there is a state of dispersion in both (Schlax et al., 2020). Unreal experiences accompany depersonalization. Among these are the sensations of viewing oneself from the outside as a second eye. People suffering depersonalization may also feel detached from their bodies, lose control over their physical motions, and be detached from cognition and emotion. In derealization, there is a detachment from situations other than oneself. Derealization results in inaccurate experiences with colors, time, the location of the individual, the items around him/her, and the sensation of being in a dream (Tuna and Oncul-Demir, 2020; Mishra et al., 2022).

Depersonalization and derealization may also be triggered by fatigue and substance abuse in healthy individuals or may accompany medical or mental illnesses. Depersonalization has the function to protect the self-integrity of the individual. It enables the individual to survive

after an adverse life experience. It can be said that depersonalization has a holding role here. It also provides psychobiological stimulation. Depersonalization and derealization are likely to become chronic (Schlax et al., 2020; Mutlu, 2022). A traumatic experience may occur in conjunction with a triggering stimulus and other mood disorders. Emotional neglect and abuse alter the psychobiological structure of the brain. Some changes arise in the limbic system, which plays a role in the brain's emotional system. Emotional neglect and abuse enhance the chance of depersonalization or derealization. Derealization can arise as a result of sexual abuse or a traumatic childhood experience. The earlier the trauma starts, the stronger effect it has on the occurrence of derealization. Parental attitudes may potentially cause the child to undergo derealization and depersonalization in the future. Children who have been subjected to emotional neglect may suffer from psychological damage just as much as children who have been physically harmed. Emotional neglect in children can also lead to self-disintegration. Depersonalization and derealization can also occur shortly following a traumatic event. According to the psychoanalytic viewpoint, the individual develops obsessive self-control because of overly demanding parenting approaches, and underlying this obsessive self-control is a sense of inadequacy (Hoyos et al., 2019; Mutlu, 2022; Millman et al., 2022).

Depersonalization disorder is believed to reduce the quality of life of individuals by creating a sense of inadequacy in individuals. Various studies on depersonalization disorder have been conducted in the literature, but no qualitative studies, to our knowledge, have evaluated the quality-of-life perceptions. Based on this consideration, this study was conducted to deeply examine the quality-of-life perceptions and experiences of individuals with depersonalization disorder.

Material and Method

Type of Research and Study Group: Phenomenological research design, a qualitative research design, was used to deeply examine the quality-of-life perceptions and experiences of individuals with depersonalization disorder. This design was chosen as it allows for a great deal of freedom in expressing a new phenomenon (event or experience) from the participant's point of view, while also providing rich data and detailing their experiences (Yildirim and Simsek, 2016). This approach is about unraveling the essence of the phenomenon under investigation and presenting the experience 'exactly as it presents itself, neither adding to nor subtracting from it' (Morrow et al., 2015; Willing, 2013).

In this study, the snowball sampling method was used to determine the sample. The basic logic in this sampling method is the principle of chain access to the participants. While conducting the study, the researcher may ask the subjects for the names and addresses of other volunteering subjects they know or request their help to contact those people (Guler et al., 2013). Firstly, the researcher interviewed a student with depersonalization disorder and asked for help to reach others with the same disorder. The student communicated with people suffering from depersonalization disorder via social media channels and groups. As a result, the participant group was formed through volunteerism.

The inclusion criteria were being diagnosed with depersonalization, having insight, agreeing to participate in the study voluntarily, and speaking and understanding our language. The exclusion criteria from the sample were having a comorbid disease and not meeting the inclusion criteria. The sample size was determined according to data saturation (Yildirim and Simsek, 2016), and accordingly, a total of 13 participants were interviewed.

Data Collection: The data were collected by the researcher between 01.01.2023-01.02.2023. Semi-structured interviews were conducted individually. Each potential participant was first informed about the purpose of the study over the phone. An appointment was made with the participant who agreed to participate in the study. The researcher interviewed these participants by scheduling an appointment with them so that they felt comfortable expressing their experiences. The interviews were conducted by an experienced researcher trained in qualitative research interview techniques. Collaboration was established with the participants and techniques such as unconditional acceptance, active listening, and explanation were used to improve the authenticity of the data. At the beginning of the interview, the participant's age, marital status, education, employment status, occupation, and the elapsed time since the diagnosis of depersonalization disorder were questioned. Then, 7 open-ended questions prepared by the researcher in consultation with 5 academic staff with at least a Ph.D. in the field of psychiatry were used to examine the quality-of-life perceptions and experiences of individuals with

depersonalization disorder. The questions in the semi-structured interview form are as follows.

1. What does the word depersonalization mean to you? What does the word depersonalization not mean for you?
2. What do you think about depersonalization? Do you think you experience stigma?
3. When you were diagnosed with depersonalization disorder, with whom did you first share this diagnosis? What kind of reactions did you get? How did you feel about these reactions?
4. What are the effects of depersonalization disorder on the individual (What are the psychological, physical, and social effects)?
5. Do you think you can cope effectively with depersonalization disorder? What are your sources of support in this process?
6. How does a person with depersonalization disorder feel in society? Do you experience internalized stigmatization and what are the reasons?
7. Do you think your life is of good quality? What are the reasons? What were your most important experiences of depersonalization?

Only one interview was conducted each day between the data collection dates. The interviews lasted approximately 40-50 minutes and all interviews were recorded with the permission of the participant, and the audio recordings were transcribed within 24 hours by the interviewer. In addition, short notes were taken by the researchers during the interviews.

Data Analysis: The 7-stage analysis procedure devised by Colaizzi (1978) for phenomenological investigations was utilized to analyze the qualitative data obtained from the interviews (Morrow et al., 2015). In this context, two researchers read the interview texts independently and repeatedly to comprehend what was attempted to be explained in the data. The remarkable statements in the interview transcripts were selected, reorganized, and outlined, and then the data that the statements were trying to convey were identified and analyzed. The researchers formulated and confirmed the meanings by discussing them until they agreed. The researchers then grouped and organized the themes into main and sub-themes. The themes and sub-themes of the research were developed with clear statements. The accuracy of the themes and substance was improved by presenting the research findings to the participants. In addition, by including the statements of the participants, the reader was able to verify the interpretation and analysis of the data.

Ethical Aspects of the Research: This research was approved by the Gümüşhane University Scientific Research and Publication Ethics Committee (number no: E-95674917-108.99-149377). Informed consent was obtained from the participants before starting the interview. Recordings and transcripts were stored on a password-protected device. Each step of the research was written following the Consolidated Criteria for Reporting Qualitative Research (COREQ), which was developed for use in reporting qualitative research (Tong et al., 2007). The study was carried out under the principles of the Declaration of Helsinki.

Results

Nine of the participants in our study were single, and seven were unemployed. The mean age of the individuals was 26.85±6.80 (min 17, max 39). Two categories, nine main themes, and twenty-one sub-themes emerged from the interviews.

Table 1. Effects of depersonalization on the individual

Theme	Sub-themes
Psychological Effects	Hopelessness/despair
	Sadness/grief
	Depression/collapse
	Loneliness
	Unhappiness due to dream/simulation sensations
Physical Effects	Immobility
	Overeating
Social Effects	Social isolation
	Internalized stigmatization

Theme 1: Psychological Effects

As a result of the interviews with individuals with depersonalization disorder, it was determined that individuals were mentally affected. They experienced feelings of hopelessness/despair, sadness/grief, depression/collapse, loneliness, and unhappiness due to dream/simulation sensations. Throughout the interview, the participants' voices trembled and sobbed at times while recounting the process they went through.

Hopelessness/despair: Most participants stated that they felt hopeless and helpless from time to time due to their diagnosis.

"I was terribly unhappy and despairing when I discovered I had depersonalization disorder." (P7).

Sadness/grief: All the participants expressed that they felt sad because they were diagnosed with depersonalization disorder.

"I feel very sad. I am very stressed, I get sad thinking that it isn't working, why this happened to me." (P10).

Depression/collapse: Being diagnosed with depersonalization disorder means unhappiness and depression for individuals, and all participants are very upset about this situation.

"I became asocial because of this disorder. I can't be happy like I used to be, and I am very unhappy, and I feel depressed...It is demoralizing to spend one's best times in this way" (P5)

Loneliness: The participants stated that depersonalization disorder caused feelings of isolation and loneliness that was difficult to cope with and that they felt lonely.

"I get lonely, asocial, and I don't talk much. It makes me feel horrible because I have no one to discuss my feelings and no one who understands me" (P12).

Unhappiness due to dream/simulation sensations: Some participants stated that depersonalization disorder creates a feeling of simulation in individuals.

"Because of depersonalization disorder, I feel like I'm in a simulation as if everything is a game and nothing will ever be the same... It distracts me from reality..." (P3).

"The feeling of simulation or dream usually happens when I worry too much about some things and when I think about what the people, I talk about my discomfort think about me and I get very upset and unhappy..." (P6).

Theme 2. Physical effects

Most participants indicated that after being diagnosed with depersonalization, they went through a tough process in which they avoided social interactions and did not speak with others. In this context, they stated that they wanted to spend time at home all the time, that they were immobile, and that they gained weight because of this.

Immobility: Most participants stated that they were immobilized and asocial due to their illness.

"I don't want to go out in public much and I always want to spend time at home, so I am very immobile, and I am overeating."(P5)

Overeating: Some participants stated that they were immobilized and overeating due to their illness.

"I don't want to go out in public much and I always want to spend time at home, so I am very immobile, and I am overeating." (P5)

Theme 3. Social Effects

As a result of the interviews, it was determined that the diagnosis of depersonalization disorder also negatively affects individuals socially.

Social isolation: Most participants stated that they experienced social isolation.

"I have been experiencing severe stigmatization due to this disease. I do not want to communicate with people because of this..." (P7).

Internalized stigma: It was determined that most of the participants wanted to isolate themselves from society and stigmatized themselves because of their illness.

"Society thinks that I have schizophrenia and avoids me when they find out about my illness, this makes me sad I don't want to see anyone..." (P8)

"I feel stigmatized and unhappy ..." (P11).

The category of quality-of-life perceptions of individuals with depersonalization disorder was determined as six themes and twelve sub-themes. (Table 2).

Theme 1. **Mobility**

Immobility*:* Most participants stated that they were immobilized and asocial due to their illness.

"I don't want to go out in public much and I always want to spend time at home, so I am very immobile, and I am overeating." (P5)

Fear of making mistakes about movements*:* *Some of the participants reported feeling as if they were in a simulation game, so they could not*

control their movements and were afraid of making mistakes.

> *"Everything is like a dream, sometimes I feel like I am watching myself from the ceiling, I see myself from above... Because of this, I have fears that I might do wrong... I think I cannot control my behavior..." (P4)*

Theme 2. **Food and drink**

Overeating*:* Some participants reported being immobilized and overeating due to their illness.

> *"I don't want to go out in public much and I always want to spend time at home, so I am very immobile, and I am overeating" (P5).*

Weight gain*:* *Some participants stated that they gained a lot of weight due to overeating.*

> *"I am at home all the time because I am asocial, I have gained weight a lot...." (P6).*

Theme 3. **Maintaining a safe environment**

Social isolation*:* Many participants stated that they experienced social isolation.

> *"I have been experiencing severe stigmatization due to this disease. That is why I do not want to communicate with people...." (P7).*

Fear: *Some participants stated that they constantly experienced anxiety and fear.*

> *"I am constantly trying to find the source of my anxiety; I cannot find it and I am terrified that it will always be like this..." (P8).*

Theme 4. **Sleep**

Insomnia*:* *Some participants stated that they had sleep problems, especially insomnia, due to anxiety.*

> *"I constantly feel anxious, so I went to a psychologist and used medication. I did vagus nerve exercises and read books to stop thinking. I heard that vagus nerve exercise is good, but it didn't help my sleep problem." (P10).*

Difficulty falling asleep*:* *Some participants stated that they had sleep problems due to anxiety, especially difficulty falling asleep.*

> *"I have a poor quality of life...Especially falling asleep is a big problem for me..." (P5).*

Theme 5. **Communication**

Withdrawal from society*:* Participants reported that depersonalization disorder caused feelings of isolation and loneliness that were difficult to cope with and that they felt isolated and withdrawn from society.

> *"Depersonalization disorder has caused me to withdraw from society. I don't want to communicate with people because they will stigmatize me..." (P12).*

Communication problems*:* Most participants expressed that they had communication problems with individuals in society.

> *"I don't want to go out in public much and I always want to spend time at home, so I am very immobile, and I am overeating (P7).*

Theme 6. **Work and leisure**

Inability to feel pleasure*:* *Most participants stated that they did not enjoy what they did due to the feeling of simulation and dreaming.*

> *"Sometimes I want to have fun, I want to forget, but it does not allow me to do so, I feel as if I were always in a dream, always in a simulation...It is as if I were watching myself from the outside..." (P13).*

Reluctance to work and learn*:* *Most participants stated that they were reluctant to work and learn due to the feeling of simulation and dreams.*

> *"I have a poor quality of life...I am a student, but sometimes I don't even want to go to school, I feel as if my soul is shattered, a constant anxiety, a constant fear...a perception disorder...I can't be happy as I used to be..." (P1).*

Discussion

There is a paucity of literature on depersonalization disorder. Thus, the study is expected to contribute significantly to the literature on depersonalization disorder experiences. It aimed to reveal the problems experienced by individuals with depersonalization disorder by evaluating their perceptions of quality of life. The results show that individuals with depersonalization disorder are psychologically adversely affected. People with depersonalization disorder believe they are in a simulation dream/game, resulting in feelings of sadness, hopelessness, and loneliness. Likewise, Mutlu (2022) reported that individuals with depersonalization disorder experience fear and anxiety, and loneliness (Mutlu, 2022). Depersonalization disorder is characterized by dream-like states and visual and sometimes auditory hallucinations (Mishra et al., 2022). Based on these results, it is concluded that individuals with depersonalization disorder feel very negative emotions due to the problems accompanying the disorder.

The participants involved in the study wanted to spend time at home because of social isolation, which leads to problems like excessive immobility and overeating. Gentile et al. (2014) also emphasized that these people prefer staying at home all the time and rarely go out (Gentile et al., 2014). Based on these results, it can be said that individuals suffering from depersonalization disorder have physical, social, and mental issues, which have a detrimental impact on

their functionality and quality of life. People face internalized stigma because of their illnesses. According to Fedai (2016), most people with depersonalization disorder experience internalized stigma (Fedai, 2016). This is assumed to be because most people with depersonalization diagnoses have insights. Individuals with depersonalization in our study experienced difficulties in daily activities in the study. Their daily activities, such as walking, eating, drinking, and maintaining a safe environment, can be challenging. Participants are afraid of making mistakes and losing control of their movements. Siegert et al. (2007) also noted that participants experienced fear of losing control (Siegert et al., 2007). Simulations, dreams, and games are believed to be the main cause of these experiences.

Sleep problems such as insomnia and difficulty falling asleep were also observed in these people. Similar to the study, Poerio et al. (2016) found that participants had a deterioration in sleep quality (Poerio et al., 2016). People with lower sleep quality and more unusual sleep experiences (e.g., sleep terrors, sleep paralysis) are reported to daydream more frequently (Denis and Poerio, 2017). According to the relevant literature, markers of sleep disturbance (e.g., sleep duration and quality) may also be linked to a higher incidence of daydreaming in dissociative disorders. It was determined that some participants had problems related to work and leisure activities, like being reluctant to work and learn. In the study conducted by Schulz et al. (2016), it was stated that the participants were generally male and unemployed (Schulz et al., 2016), suggesting that the functionality of these individuals is significantly affected. Participants involved in the study had communication issues in society and were isolated. Sutar and Chaturvedi (2020) discovered that these people mostly communicate with their own relatives and feel lonely (Sutar and Chaturvedi, 2020), which is assumed to be related to internalized stigma.

Conclusion: Taking into account the results of the study, it was concluded that individuals with depersonalization disorder are negatively affected psychosocially, have difficulties with daily living activities, and have a low quality of life perceptions. In this direction, efforts should be made to prevent or reduce internalized stigma through effective intervention plans for individuals with depersonalization disorder. The fact that the present study was conducted with a small number of individuals limits the generalizability of the results.

Acknowledgements: This research was supported by the Gumushane University Scientific Research and Publication Ethics Committee. The study was carried out under the principles of the Declaration of Helsinki.

References

Denis, D., & Poerio, G. L. (2017). Terror and bliss? Commonalities and distinctions between sleep paralysis, lucid dreaming, and their associations with waking life experiences. Jour of Sleep Res, 26(1)38-47.

Fedai, U. Investigation of sociodemographic and clinical characteristics of dissociative identity disorder patients. Harran University, Faculty of Medicine, Medical Specialization Thesis, Sanliurfa, Turkey

Gentile, J. P., Snyder, M., & Gillig, P. M. (2014). Stress and trauma: Psychotherapy and pharmacotherapy for depersonalization/derealization disorder. Innovations in clinical neuroscience, 11(7-8), 37.

Guler, A., Halicıoglu, M.B. and Tasgın, S. (2013). Qualitative research methods in social sciences. Ankara Turkey: Seçkin Publishing

Hoyos, C., Mancini, V., Furlong, Y., Medford, N., Critchley, H., & Chen, W. (2019). The role of dissociation and abuse among adolescents who self-harm. Austr & N. Zeal Jour of Psych, 53(10), 989-999.

Millman, L. M., Hunter, E. C., David, A. S., Orgs, G., & Terhune, D. B. (2022). Assessing responsiveness to direct verbal suggestions in depersonalization-derealization disorder. Psych Research, 315, 114730.

Mishra, S., Das, N., Mohapatra, D., & Mishra, B. R. (2022). Mindfulness-based cognitive therapy in depersonalization-derealization disorder: a case report. Indian Journal of Psychol Medicine, 44(6), 620-621.

Morrow, R., Rodriguez, A., & King, N. (2015). Colaizzi's descriptive phenomenological method. The Psychologist, 28(8), 643–644.

Mutlu, E. (2022). Investigation of the Effectiveness of EMDR Therapy in Young Adult Cases Experiencing Depersonalization and Derealization: A Case Report. Academic Social Resources Journal 7, (37), 595-601.

Poerio, G. L., Kellett, S., & Totterdell, P. (2016). Tracking potentiating states of dissociation: an intensive clinical case study of sleep, daydreaming, mood, and depersonalization. Frontiers in psychology, 7, 1231.

Schlax, J., Wiltink, J., Beutel, M. E., Münzel, T., Pfeiffer, N., Wild, P., Blettner M., Ghaemi J, Kerahrodi, & Michal, M. (2020). Symptoms of depersonalization are independent risk factors for the development or persistence of psychological distress in the general population: Results from the Gutenberg health study. Journal of Affective Disorders, 273, 41-47.

Sierra-Siegert, M., & David, A. S. (2007). Depersonalization and individualism: the effect of culture on symptom profiles in panic disorder. The Journal of nerv and mental disease, 195(12), 989-995.

Sierk, A., Daniels, J. K., Manthey, A., Kok, J. G., Leemans, A., Gaebler, M., Lamke JP, Kruschwitz J, & Walter, H. (2018). White matter network alterations in patients with depersonalization/derealization disorder. Journal of Psychiatry and Neuroscience, 43(5), 347-357.

Sutar, R., & Chaturvedi, S. K. (2020). Symptom profile and diagnostic utility of depersonalization–derealization disorder: A retrospective critical review from India. Indian Journal of Psychiatry, 62(1), 91.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care, 19(6), 349–357. https://doi.org/10.1093/intqh c/mzm042.

Tuna, E., & Oncul-Demir, E. (2020). Abnormal psychology according to DSM-5. Ankara: Nobel Arc.

Willig, C. (2013). Introducing qualitative research in psychology, 3rd ed. Open University Press.

Yildirim, A., & Simsek, H. (2016). *Qualitative research methods in social sciences*, 10th ed. Seckin Publishing.