ISSN: 2717-3216 Volume 11, Issue 1 (2024) https://www.ijfpjournal.ir/

Journal of Family Psychology

Research Paper

10.22034/ijfp.2024.2019783.1292

# Phenomenology of the Lived Experiences of Families with Members with Acquired Disabilities

Sedigheh Rezaei Dehnavi[1*], Mojtaba Hemayatkhah Jahromi[2], Forogh Madani far[3]

1 .Department of Psychology, Payame Noor University, Tehran, Iran
2 .Department of Sociology, Payame Noor University, Tehran, Iran
3. Department of Psychology, Payame Noor University, Tehran, Iran

**Article Info.**

**Received:** 08 February 2024

**Revised:** 09 April 2024

**Accepted:** 03 June 2024

**Keywords:**

*Family,*

*phenomenology,*

*lived experiences,*

*acquired disability*

**Abstract**

## Abstract

Acquired disability is a disability that is developed during life as a result of an accident or illness. The objective of this research study was to analyze the lived experiences of families with a member with an acquired disability. To achieve the goals of the present research, a qualitative method based on the phenomenological approach was used. The samples were selected using the purposive sampling method in Shahrekord in 2022. Moreover, the data were collected through the semi-structured interview technique. The participants in this research study included the mother, father, sister, brother, and spouse of a person with an acquired disability. The data was saturated through interviews with 15 family members. Data analysis was done based on the seven-step method of Claysey. The findings showed that the experience of the families participating in the study could be classified into eight main themes, including change in normal life, stigma, negative feelings and reactions, family problems, disturbed life, life-giving actions, lack of specialized, financial, social, and legal support, and rehabilitation counseling. Finally, the results indicated that the families of people with acquired disabilities suffered from a severe lack of support in society and negative feelings and disability. These psychological, social, and caring pressures increased when the caregiver lived in smaller, traditional, and less developed areas. Thus, the lack of facilities was more visible. It seems that participating in psycho-educational classes and raising awareness of the individual growth of families would help to face stress and psycho-social pressures. In addition, it would not be possible to reduce care pressures without taking into account the cultural context and the use of service and support resources such as subordinate organizations in the direction of rehabilitation of disabled people.

*Corresponding author
Email: srezaeidehnavi@pnu.ac.ir

## Introduction

Acquired disability is defined as a permanent impairment of physical or organ functions that may be caused by disease or injury and developed at some point after birth (e.g., in adolescence or adulthood). A person with an acquired disability has problems independently performing daily life activities or other activities necessary to lead an independent life without the need of others. This experience not only entails physical, psychological, and economic challenges but also creates a potential discontinuity in the person's identity and turns the person into a member of a social minority group with which he was not previously associated (Haslamet al., 2021). Having a patient with a variety of disabilities is a complex and stressful emotional experience for each family member, which is difficult to face in many ways; caring for these patients creates threatening situations for the health, social, political, economic, and psychological status of the person, family, and society (Howard et al., 2022).

Acquired acute illnesses usually require high levels of care in all life activities, most of which are provided by family members, friends, or informal caregivers. Caregivers must cope with both the condition of the disease and the multiple consequences of the disease, including physical, psychological, and cognitive disabilities (Roland & Chappell, 2019). Neuropsychiatric symptoms such as anxiety, restlessness, lack of inhibition, aggressive behavior, and sleep disorders are more related to caregiving barriers and have more negative consequences such as reduced general health, quality of life, and social isolation. The objective of this research study was to analyze the lived experiences of families with members with acquired disabilities.

## Methodology

To achieve its objective, the current research used a qualitative method based on the phenomenological approach which tries to clearly explain and identify phenomena as they are perceived by people in a specific situation. In this study, the Claizian descriptive method was used to analyze the findings. This method consists of seven steps. In the first step, after the interview with the participants, the recorded voice was transcribed, read, and reread at least three times to reach a general idea. In the second step, by reviewing the transcripts and interviews, important phrases related to the investigated phenomenon were extracted. In the third step, for each important phrase, a short explanation was given. In this process, by conceptualization of each of the extracted meanings, an effort was made to summarize their meanings. In the fourth step, all the summarized concepts were organized into units that were the main structure of the sub-categories. In the fifth step, the themes were merged to form separate main themes, and by merging them, the overall structure of the subject was extracted. In the sixth step, the findings were reduced. More specifically, additional, vague, and inappropriate descriptions were removed from all sections. In the seventh stage, the validation of the results was done, and the findings were communicated to the participants; they confirmed the accuracy of the results and their correspondence with their experiences.

The main objective of this research study was to describe and deeply understand the experiences of families with an acquired disabled member. Acquired disability includes the creation of any disability as a result of injury or defect caused by an accident or disease that occurs after a period of natural development; it includes all types of physical and psychological disabilities. The participants were selected through convenience sampling method; they were selected from families with members with acquired disabilities, with the help of the Shahrekord Welfare Organization. The inclusion criteria were having a family member with an acquired disability, having a relationship and living with these people (i.e., mother, father, sister, brother, and child). By conducting a semi-structured interview with 15 people, data saturation was reached. Moreover, the 7-step method of Clazy was used to analyze the findings. The quality of data was investigated by the four criteria of credibility, transferability, dependability, and confirmability.

## Results

The demographic findings of this study showed that the majority of disabled people had a diploma and bachelor's degrees. Among the 15 interviewees, 9 of them were married. Meanwhile, most disabled members were married. The cause of the acquired disability was different; three of them had secondary disability due to Alzheimer's disease and three others due to MS. The duration of caring for a secondary disabled person was between 2 and 18 years. Disabled people in this interview were between 30 and 87 years old. The findings of the lived experiences of families about their acquired disabled members showed that these experiences could be divided into eight main themes and 42 sub-

categories. The main themes included changes in normal life, social disgrace, negative feelings and reactions of the family, family problems, disturbed life, reduction of stress, lack of specialized, financial, social, and legal support, and rehabilitation counseling. These themes are presented in Table 1.

*Table 1. The main themes and sub-categories extracted from the interviews*

| Themes | Sub-categories |
|---|---|
| Changes in the normal course of life | Social withdrawal |
| | Dropping out of school |
| | Disintegration and confusion of the family |
| | Loss of life opportunities of the disabled person |
| Social disgrace | Negative attitude of others |
| | People's curious concerns and question |
| | Feeling humiliated and pitied by those around you |
| Negative feelings and reactions of the family | Depression and isolation |
| | Trouble in concentration |
| | Self-blame |
| | Making fun of others |
| | Crying |
| | Feeling afraid |
| | Feeling embarrassed |
| | Feeling worthless |
| | Being harassed and disrespected |
| | Feeling guilty |
| | Anger and jealousy |
| | Changing the beliefs |
| | Being worried about the future |
| Family problems | Lack of peace and chaos in the family |
| | Marital dissatisfaction |
| | Desperation and confusion of family life |
| Disturbed life | Monotony in life |
| | Constant fear and anxiety for the future of children and family members |
| Reduction of stress | Hiding the truth |
| | Religious beliefs |
| | Attending forums |
| | Not talking about the patient's physical problems |
| | Stress-free environment |
| | Leaving the patient alone |
| | Sense of usefulness and occupational dignity |
| | Positive thinking |
| | The disabled person's participation in household affairs |
| | Acceptance of the patient's disability due to belief in God |
| Lack of specialized, financial, social, and legal support | Lack of insurance coverage and lack of medicine |
| | Lack of financial support |
| | Few specialized treatment centers |
| | The pressure of medical expenses |
| | Lack of financial support, treatment, and care of husband and relatives |
| Rehabilitation counseling | Providing counseling and psychiatric services to disabled people and holding group counseling services and meetings |
| | Suggesting how to adjust the family's budget and financial situation according to the patient's condition |

## Conclusion

The present study was conducted to investigate the effectiveness of couple therapy based on domestic violence in domestic violence, sensitivity to rejection, sexual arousal symptoms, and burnout of couples who were referred to the counseling centers in Tehran. As the results showed, domestic violence-based couple therapy was effective in reducing domestic violence in couples. This finding is consistent with the results of other studies (e.g., Stith et al., 2019). In explaining this finding, it can be stated that violence-based couple therapy seeks to "stop all types of violence in the relationship". Moreover, couple therapy based on domestic violence was effective in reducing the rejection sensitivity of couples. This finding is consistent with the results of other studies (e.g., Follingstad et al., 2012; Stith et al., 2011). In explaining this finding, it can be mentioned that rejection sensitivity causes people to behave in such a way that the possibility of maintaining a close, supportive, and satisfying relationship decreases.

As the results showed, couple therapy based on domestic violence was also effective in improving couples' sexual arousal symptoms. This finding is consistent with the results of other studies (e.g., Stith et al., 2019). In explaining this finding, it can be stated that by participating in violence-based therapy, couples with marital problems become familiar with different emotional and behavioral skills and techniques through which they can concentrate on using their strength to resolve conflicts and moving their relationship toward greater satisfaction and intimacy, including sexual intimacy. This study had no follow-up phases. It is suggested that this treatment approach be used by counselors and specialists in Couple Therapy and Family Therapy.

## Conflict of interest

There is no conflict of interest in the present study.

## Acknowledgment

The researchers consider it necessary to thank all participants for participating in the research study.

## References

Deng, Y., Chen, Y., & Liu, X. (2019). Romantic relationship and appearance-based rejection sensitivity: A moderated mediation model of self-rated attractiveness and appearance contingent self-worth. *Personality and Individual Differences, 142*, 295-300 doi:10.1016/j.paid.2018.09.010

Follingstad, D. R., Rogers, M. J., & Duvall, J. L. (2012). Factors predicting relationship satisfaction, investment, and commitment when women report high prevalence of psychological abuse. *Journal of Family Violence*, 27(4), 257-273. doi:10.1007/s10896-012-9422-8

Haley, P. B. S. (2013). *Couples perceptions of a Brief Intimate partner violence Intervention: A Qualitative Analysis.* A thesis in Marriage and family Therapy, Texas Tech University. http://hdl.handle.net/2346/50283

Hasson-Ohayon, I., Ben-Pazi, A., Silberg, T., Pijnenborg, G. H., & Goldzweig, G. (2019). The mediating role of parental satisfaction between marital satisfaction and perceived family burden among parents of children with psychiatric disorders. *Psychiatry Research*, 271, 105-11010.1016/j.psychres.2018.11.037

Stith, S. M., McCollum, E. E., Rosen, K. H., Locke, L. D., & Thomsen, k (2011). Domestic violence-focused couples treatment. In J. L. Lebow (Ed.), *Handbook of Clinical Family Therapy.* (pp. 406-430). John Wiley & Sons Inc.

Stith, S.,. M., Spencer, C., Ripoll-Núñez, K. J., Jaramillo-Sierra, A. L., Khodadadi, F., Nikparvar, F., Oksman, R., & Metelinen, J. (2019). International adaptation of a treatment program for situational couple violence. *Journal of Marital and Family Therapy*, 1-16 doi: 10.1111/jmft.12397

Zmaczyńska-Witek, B., Komborska, M., & Rogowska, A. (2019). Emotional intelligence and marital communication among married couples at different stages of marriage. *Hellenic Journal of Psychology*, *113*(76)-143-152. https://repo.uni.opole.pl/info/article/UO292cacbb92b043a09c87e4014be4e7cf/

©The Author(s). Published by Family Psychology Association of Iran
This article is an open access article licensed under the Creative Commons Attribution 4.0 International (CC BY 4.0)