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ORIGINAL RESEARCH

# Feelings, Thoughts and Experiences of Caregivers of Individuals with Substance Use Disorder

**Fatma Mahperi Uluyol**[1], **Kerime Bademli**[2]

[1]Department of Psychology, Akdeniz University, School of Literature, Antalya, Turkey
[2]Department of Psychiatric Nursing, Akdeniz University, School of Nursing, Antalya, Turkey

**ORCID iDs of the authors:** F.M.U. 0000-0002-7879-9807; K.B. 0000-0002-3969-9010.

**Main Points**

- There is a need for treatment systems in which families are also supported in the fight against addiction in Turkey.
- Caregivers of individuals with substance use disorder had higher emotional burden. The process experienced by them is too difficult due to the changes in their lives.
- Development of intervention programs not only for the patient, but also for the caregivers of the patient in the treatment process of substance abuse can also positively affect the luxury rates and the treatment process of the illness.
- Since addiction is a chronic disorder, economic problems caused by substance abuse in families with low income had more destructive role on the well-being and functionality of this families.

**Abstract**

This qualitative study was carried out to determine the burden of care on Turkish caregivers of patients with substance use disorder. The sample included relatives of 42 patients hospitalized in the Akdeniz University Alcohol and Drug Addiction Research and Application Center. Individual in-depth, open semi-structured interviews were used for data collection. Moreover, demographic questions and an interview guide with questions were also used. According to the results of this study, the following themes were evaluated: difficulties experienced, coping, and needs. The findings showed that substance abuse has adverse consequences and negatively affects both the patients and their relatives in terms of economic, psychological, and social aspects. Furthermore, because of the social stigma of substance abuse, the families receive very limited social support from the environment. This weakens the well-being of the family members and increases intrafamily conflicts. We conclude that ensuring the well-being of the caregivers of patients with substance use disorder is useful in maintaining a successful treatment of addiction. Thus, policymakers should include the relatives of patients with substance use disorder in prevention and intervention programs to increase the effectiveness of the interventions.

**Keywords:** Caregiver, addiction, family experience, substance use disorder, coping skill

**Corresponding author:**
Mahperi Uluyol
**E-mail:**
mahperiuluyol@gmail.com

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## Introduction

Substance use disorder, which negatively affects individuals, their families, and the community, is gradually becoming more common worldwide. It is a public health problem with significant medical, psychological, and social consequences (Karakaş & Ersöğütçü, 2016; Mattoo et al., 2013). In a recent study, it has been considered that 1.4 million people in the European Union (EU) countries receive substance abuse treatment and that 1.6 million people are substance abusers when candidate countries such as Turkey and Norway are added to those ratios (European Drug Report 2017). Although substance abuse is a worldwide problem, prevalence rates may increase according to geographical location and culture. According to the European Drug Report 2014, in the screening conducted by the drug and drug addiction monitoring center in 2011, although the lifetime substance use rate in Turkey was 2.7%, this ratio was found to

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be 1.5% among school-age children. The ratios are considerably higher in studies carried out in university samples. In a study conducted by Dayı, Gulec, and Mutlu (2015), lifetime prevalence of tobacco use was determined to be 40.2%, the prevalence of alcohol abuse was 60.8%, and the prevalence of illegal substance use was 11%. In another study, it was found that 22.9% of the students used alcohol, and 3% of them used illegal substances (Bertan, Özcebe, Haznedaroğlu, Kırcalıoğlu, & Bülbül, 2005).

Turkey is at risk for widespread substance abuse owing to its geographical location and population profile compared with the European countries. Turkey is located at the transit point between the production and consumption zones in illegal drug trafficking. Therefore, Turkey is affected by the traffic of substances originating from Europe and the traffic of opium and its derivatives originating from Afghanistan (European Drug Report 2017). According to the European Drug Report, higher ratios of marijuana, heroin, and hemp oil are caught in Turkey than in the EU countries. Furthermore, the fact that 50% of Turkey's population is under the age of 30 years and this group includes 19 million young people between the ages of 14 and 29 years (TSI, 2013) as well as its geographical location are the important risk factors in the development of substance abuse.

Substance use disorders are a multidimensional problem that threatens the quality of life of not only the individual but also their families, causing increasing stress (Kaur, Mahajan, Deepti, & Singh, 2018). Substance use disorder is defined as a disease, which may lead to psychological and physiological symptoms related to stress or trauma in the family of the addicted individual and may cause a deep effect in these individuals (Lee et al., 2011). When an individual family member is addicted, 1 of the other family members must assume the caregiver's role (etc. Lee et al., 2011). The care provided by family members to this individual is multidirectional and includes personal care, financial aid, management of disease symptoms, and continuation of treatment (Kaur, Mahajan, Deepti, & Singh, 2018). Family life is affected negatively in many aspects, including interpersonal and social relations, leisure time activities, and financial resources. At the same time, the presence of a substance abuser in the family usually increases intrafamily conflicts and may negatively affect the well-being of other family members (Sharma, Sharma, Gupta, & Thapar, 2019).

Long-term substance use causes cognitive, emotional, and behavioral changes in individuals. When the problem is noticed in the family, feelings, such as denial, anger, shame, guilt, and sorrow, may be experienced, and they often do not know how to deal with the situation (Gethin, Trimingham, Chang, Farrell, & Ross, 2016). In addition to being unable to cope with the negative feelings, intrafamily relations are broken down, and all the family members are negatively affected by this situation. As a result of the stress they experience, caregivers of the individuals with substance use disorder are found to have a high prevalence of divorce, crises, economic losses, legal problems, stigmatization by the society, and withdrawal from the society (Mattoo, Nebhinani, Kumar, Basu, & Kulhara, 2013). The families living with the individual with substance use disorder experience both emotional and financial burden because of these negative effects, and there is a decrease in family functionality (Dakof, 2000; Salize, 2013). In the study by Lee et al. (2011), it was reported that the family members of the individuals with substance use disorder had lower psychological well-being than that of healthy controls and that the family members used ineffective coping styles. Similarly, in other studies carried out with the family members of the individuals with substance use disorder, it was determined that the family members used ineffective coping methods, blamed themselves, exhibited intolerant attitudes toward the family member using the substance, withdrew from the society, and had high depression rates. (Krishnan et al., 2001; Lee et al., 2011).

Although it is understood that the mental and physical health of these caregivers are adversely affected, very limited studies have been performed in Turkey on this topic. Caregivers of the individuals with substance use disorders should also be considered and supported during the treatment process. It is important to determine the needs of caregivers of the individuals with substance use disorder by evaluating their experiences, thoughts, and feelings to implement intervention programs for their needs. There is little culture-specific knowledge about how to be a patient parent in our country from the perspective of relatives of the patients with substance use disorder. Through this context, this qualitative research sought to examine the feelings, thoughts, and perceptions of individual caregivers of patients with drug use disorder.

## Methods

The research was performed using a qualitative and phenomenological approach to examine and evaluate the thoughts, feelings, and perceptions of caregivers of patients with drug use disorder. The phenomenological approach focuses on individuals we know but about whom we do not have a comprehensive and accurate understanding. Among the studies that seek to explore cases that are not only unusual but also do not provide definite results, the phenomenological approach provides a good basis for study. Phenomenology, often referred to as case science, is a method that seeks to answer the question, "What is real?" The basis of phenomenological method lies in human experiences. In this method, the researcher discloses the participant's individual experiences and examines his/her perceptions of the individual and the meanings he/she assigns to events (Yıldırım & Şimşek, 2005).

### Data Collection Process

The study was conducted in Akdeniz University Alcohol and Drug Addiction Research and Application Center (ADARAC). ADARAC department is a center where alcohol and drug addicts are treated through inpatient and outpatient follow-up. Alcohol and heroin addicts are mainly treated in the center. In accordance with their consent, inpatients receive informative training in addition to medical treatment at the center for approximately 4 weeks. In the first week of the inpatient treatment process, the detox stage, the patients are accompanied by their relatives. Within the scope of this study, the aim of the study was explained to the relatives of the patients who received inpatient treatment during the detox phase, and volunteers were included in the study. A total of 42 caregivers were included in the sample. The research was carried out using purposeful sampling method. The data collection continued without calculating the sample size until reaching the point of "saturation."

In this qualitative research, data were collected using a semi-structured questionnaire guide to an interview. The first part included demographic questions on age, sex, educational status, patient

relationship, and length of their caregiver responsibilities. The second part of the questionnaire included 4 open-ended questions about the feelings, opinions, and perceptions of the caregivers. We conducted interviews in the interview rooms of the ADARAC of Akdeniz University and recorded them via a tape recorder. The interviews lasted between 30 minutes and 1 hour and were digitally recorded and transcribed verbatim.

The questionnaire included open-ended questions like the following:

1. What are the views of carers of people with substance use disorder about being a caregiver?
2. How are the feelings of caregivers of individuals with substance use disorder?
3. What are the caregiver's views of people with substance use disorder while they are carers?
4. What has changed in your life?

**Ethical Procedures**

The study protocol was approved by the Clinical Research Ethics Committee of Akdeniz University School of Medicine (2012-KAEK-20). Informed voluntary consent was obtained from all participants. All the required legal permissions were obtained after informing the ADARAC. During the interview, consent form was read to the participants, and a copy of the consent form was given to participants. In addition, reading of the consent form and the participants' verbal consents were recorded on the audiotape before starting the interview.

**Statistical Analysis**

The technique to content analysis was used in the data analysis. First, the answers were classified under the headings related to the questions and entered into the computing system. Both the researchers read the caregivers' perspectives in the study process. The researchers discussed, analyzed, and coded them separately until a consensus was reached. The responses given to the questions were then discussed and interpreted, and the researchers determined the common and important statements. After determination of the meaning of each statement received from the caregivers, the topics were determined by discussion until consensus was reached. The themes were identified after the participants determined the meaning of each statement received, and 3 themes were eventually identified. These themes were "difficulties," "coping strategies," and "needs of the family caregiver."

The data were collected using 2 methods to improve the study's internal validity (credibility): individual interviews and the analysis of documents. Throughout the content review, the themes, the relationship between the sub-themes that formed the themes, and the relationship between each theme and with each other were regulated, and honesty was ensured. Furthermore, the results and comments were obtained with the data sources immediately after confirmation of data collection, and the participant's confirmation was provided. Signing an agreement on the use of data collected in the interview should be used only for scientific purposes and secured with mutual trust for its confidentiality. Thus, the collected data during the interview process were ensured to assess the true condition.

Detailed definitions of the research model, research group, data collection method, data collection process, and data analysis were used to increase the external validity of the study. In addition, voluntary interviews with the caregivers were performed using the purposeful sampling approach to expose the events and details and their varying characteristics. All the findings were addressed explicitly to improve the internal reliability of the analysis without making interpretations. In addition, the researcher who was experienced in research design carried out separate coding of the data obtained in the interview, compared the codes, and calculated the consistency ratio as 0.897. The validation review was performed by providing all the data collection methods, data collected, and coding for external expert review during the analysis stage to improve the study's external reliability.

## Results

When the participants were grouped according to their sociodemographic characteristics, it was observed that 29 of the caregivers were mothers, 8 of them were fathers, 2 of them were spouses, 1 of them was a child, and 1 of them was a full sister/brother. Nearly half of the individuals in the study group were married. Most caregivers (22) were primary school graduates, 8 were secondary school graduates, 5 were literate, and 1 was illiterate. Caregivers reported that their relative's duration of substance use was between 2 years and 20 years.

**Theme 1: Difficulties**

This theme focused on the caregiver's experience about being a caregiver of an individual with substance use disorder. Caregivers reported that they had financial problems, psychosocial difficulties, and difficulties in the relationship with the environment. Of the 42 participants, 38 stated that they had financial difficulties and had become indebted to people around them, and 5 stated that they sold the patient's belongings at home. Almost all the caregivers stated that they were mentally affected negatively by the incidents experienced because of the addiction process. Of the caregivers, 30 indicated that there were breakdowns in their intrafamily relations, and they kept the illness a secret from their relatives and neighbors. Some of the caregivers' experiences about being a caregiver are as follows.

*"I sold my car, took out loan, borrowed money from my neighbors, and financially regressed"*

*"I run out of money, I get into debt, and I sold my phone to find money."*

*"He financially bankrupted the family; he committed a theft when he run out of money."*

*"I have an emotional burnout, I feel depressed and overwhelmed, I feel like being crushed between two stones."*

*"I feel I am overaged; I feel unhappy and alone."*

*"I have forgotten to laugh, I don't want to laugh, I feel so lonely."*

*"I feel sorry, I cry as it comes to my mind, I don't want to talk to anyone, I can't sleep." "I can't tell anything to anyone, feel uneasy, I feel ashamed that he would be excluded."*

*"I do not tell my relatives thinking that they would look with an evil eye."*

*"My neighbors don't come, they look down on me, there are a lot of discussions in the family."*

*"I do not talk to my neighbors, they get angry with me, but I fear they would ask about my son."*

**Theme 2: Coping Strategies**

This theme focuses on the caregivers' coping experience. Caregivers use effective and ineffective methods to cope with substance use disorder.

Caregivers are reported to use coping strategies such as crying (9/42), praying (7/42), going out for a walk (7/42), talking with relatives (7/42), sleeping (1/42), mutual support of their spouses (2/42), inability to cope and inability to do anything (4/42), working in the garden and soil (1/42), and being pollyannaish (1/42) for coping with the stress. Some of the caregivers' experiences about coping with stress are as follows.

*"I feel being tested from a religious point of view."*

*"I can't do anything, I can't work, I can't go anywhere with my friends, they utter insulting words."*

*"I feel relieved when I go to work, I am into my work at the workplace."*

*"I pray."*

*"I can't cope."*

*"I am crying, crying, crying, crying, I sometimes fall asleep while crying, sometimes I can never sleep until the morning, I went to work without sleeping at all."*

*"I am pollyannaish. I always dream that good things will happen."*

**Theme 3: Needs of Family Caregiver**

This theme focuses on the caregivers' unmet needs in providing care. Caregivers reported that they had some unmet needs. The majority (12/42) of the caregivers needed financial support; some of them needed social support (6/42), psychological support (6/42), long-term inpatient treatment (8/42), prioritization of their relatives in the treatment process (4/42), information about the patient's compliance with the treatment (2/42), and the presence of a person to share the burden of care (4/42).

*"I can't get any support from anywhere, I'm ashamed, I am ashamed of my family and environment."*

*"Spiritual support and financial support that will not destroy human's hopes."*

*"There is nothing to eat at home, I would buy food and clothes for the children."*

*"I want to be appreciated."*

*"I wish a longer in-patient treatment. This reduces our burden."*
*"The presence of people to whom I can talk and tell something"*

*"Spiritual support is important but I cannot receive spiritual support, people say it does not interest us, they accuse me by saying even his family does not care, why he is using substance, for what I made, I tell them but they don't understand me. I always have to understand my spouse and children, no one listens to me, I have also psychological problems and I need to relax."*

**Metaphors Produced by the Patient's Relatives**

The metaphors produced by the caregiver for having a relative with a diagnosis of substance use disorder were examined and are shown in Table 1.

## Discussion

In this study, we aimed to elicit the emotions and experiences of caregivers of the individuals with substance use disorder. A total of 3 main themes were obtained from the experiences of caregivers. Considering the results of these qualitative data, it is ap-

Table 1.
*Metaphors Given by Caregivers, Describing Their Experience Caring for a Patient of Substance Abuse Disorder*

| | |
|---|---|
| I live in a dungeon; I live in a prison | Adventure: Sorrow and distress at every moment about whether something bad would happen to abuser, the police would call, he would fight, he would sell the house, or he would break the car |
| Series | An empty world |
| Imaginary world (2/42) | It is like a tunnel, as if I would never see that light inside the tunnel. As if I were in the dark |
| Suicide | I'm suffering a lot |
| A difficult illness | I'm afraid I'm deadlocked |
| An empty life | I am like a mouse trapped thinking what it would of and which solution it would find to go out, but it cannot |
| Dungeon | A load I can't carry |
| They put rock; I cannot stand up | I can't compare to anything because it's so different that it doesn't even compare |
| An ant fallen in the well | An empty jar, let everything get empty so everything gets in order |
| A huge well, empty pit | I compare roping the mother to tree and cut her child in front of her. |
| War. A constant struggle | Family exam |
| Nightmare (2/42) | I do not know (8/42) |
| Destiny, not knowing what to expect tomorrow | Despair |
| Emptiness, unhappiness | |

parent that some negative changes occur in the caregivers' lives. Most of the participants indicated that they had negative experiences throughout the disorder process. In Turkey, although there are studies examining the psychological well-being of the families caring for individuals with chronic disorders, such as cancer, schizophrenia, and autism spectrum disorder (Demirtepe Saygılı, 2013; Meral & Cavkaytar, 2015), no study examining the well-being of the caregivers of individuals with substance use disorder was found during the literature review performed by the authors. Although substance abuse is known to be a lifelong illness, the reduction of the general functionality of the patients during the treatment period and the fact that the families have to care for them are sources of great stress for the families (Orford, Copello, Velleman, & Templeton, 2010). In this context, substance abuse may negatively affect the patients and their caregivers from economic, psychological, and social aspects because it is a chronic disorder (Corrigan, Kuwarabara, & O'Shaughnessy, 2009). Similarly, as a result of this research, it was revealed that caregivers had financial problems, conflicts in relations with their families and their immediate surroundings increased, and their well-being broke down. When the caregivers were asked about their needs in the treatment process, financial support ranked first. Families indicated that they used various methods, such as selling property, taking loans from the bank, or borrowing money, to financially meet the patient's treatment costs or personal needs because the patient was unable to work. It was thought that this result could be because of the fact that most of the study sample had low and middle socioeconomic status. In the studies examining the profile of substance abusers in Turkey, like this study, the great majority of the addicted group had a low level of education, and they were unemployed or worked in low-paid jobs (Bilici et al., 2012; Kulaksızoğlu et al., 2015). When the socioeconomic levels were examined according to the substances used, it was determined that heroin and cannabis users applied to state hospitals, whereas cocaine addicts mostly preferred private hospitals and had higher socioeconomic levels (Türkcan, 1998). In this study, heroin was the main substance used by the individuals who applied to our center, and most of them did not work on a job. Therefore, the loss of workforce of these patients negatively affected the quality of life of their families.

Families may need more economic support because they spend the economic resources limited to the addiction process for the supply of substance or treatment. Therefore, it can be said that the economic problems caused by substance abuse in families with low income may have a more destructive role on the well-being and functionality of families. For example, the caregivers of individual with substance use disorder may have more financial and moral difficulties than those with other chronic diseases, such as diabetes and asthma. In a group of studies, it was found that the well-being of the caregivers increased after the treatment of the patients. However, there were also findings indicating that the health problems of the families increased because of the previously masked problems (Ray, Weisner, & Mertens, 2009). When the results were evaluated in general, it was reported that the caregivers of individuals with substance use disorder who continued or discontinued substance abuse had more medical expenses than those of the relatives of the patients who were treated previously. In a 5-year follow-up study, it was found that the medical expenses of the families of substance abusers gradually increased compared with those of the families in the control group. Furthermore, mental and physical disorder rates were also higher in these families (Weisner, Parthasarathy, Moore, & Mertens, 2010).

Moreover, individuals with substance use disorder are perceived as more depraved and irresolute and have lower self-worth in many societies, and it is indicated that prejudiced attitudes regarding the fact that they are at risk of committing a crime are exhibited. This prejudice may cause the addicted individuals to have difficulties in many areas (Santos da Silveria et al., 2018). For instance, the difficulties experienced in recruitment owing to the discriminatory attitude may lead to economic difficulties. Furthermore, the exclusion of these people by their environment prevents them from being supported by their environment when they need it (Kuleszaa et al. 2016; Livingston, Milne, Fang & Amari, 2011). Similarly, prejudiced attitudes and behaviors may cause the addicted individuals and their families to feel ashamed and steer away from the people in their immediate surroundings (Fleming, Bradbeer, & Green, 2001; Silveria et al., 2018). In particular, it was indicated that women were further affected by the stigmatization to which they were exposed in this process, and they had more mental problems (Fleming, Bradbeer, & Green, 2001). In this study, it was also revealed that caregivers experienced various problems in their intrafamily relations and relations with their immediate surroundings. Families stated that they had lesser participation in social activities than they formerly had, that the people in their immediate surroundings moved away from them, and that there was a lack of communication and conflicts in intrafamily relations. Similarly, in other studies carried out in this field, it was reported that the fact that one of the family members is a substance abuser negatively affects the family's financial status, routines, leisure activities, and the physical and psychological health (Shyangwa, Tripathi, & Lal, 2008). Moreover, in substance abuse, unlike other chronic illnesses, the social support that the individuals and their families receive from the environment during the illness process may be limited (Orford, Copello, Velleman, & Templeton, 2010). It is thought that focusing on the social support resources for the family may contribute to the treatment process.

Therefore, intervention for the exclusion of families and, accordingly, reduction in the social support systems, resulting in difficulties experienced by patients and their caregivers during the treatment process, are important for these families to maintain their well-being (Dobkin, Civita, Paraherakis, & Gill, 2002). Hence, the fact that listening to the problems of the caregivers tolerantly and sympathetically in the adaptation process after treatment may be a protective factor for the emotional change. Nevertheless, to perform interventions only for the patients and not their families does not ensure a holistic approach and may decrease the success of treatment (Albayrak & Balcı, 2014). In the studies carried out in this field, leisure time activities with the relatives of the family were important in terms of treatment and increased the well-being of caregivers because they developed positive interactions in the family (Albayrak & Balcı, 2014; Ertüzün et al., 2016). Therefore, there is a need for holistic treatment approaches in which the families are also supported in the treatment system.

Multiple studies have suggested that the social support system is an important basis in the treatment of the sociological and

psychological problems of the individual in terms of solution, prevention, and being able to cope with challenging situations (Fong et al., 2017). Furthermore, it has been supported by different study findings that the levels of psychological symptoms, such as depression, loneliness, and anxiety, increase when social support resources decrease (Durak Batıgün & Kılıç, 2011; Mutlu & Duyan, 2012). Therefore, it is thought that the development of intervention programs not only for the patient but also for the caregivers of the patient in the treatment process of substance abuse may positively affect the success rates in the treatment process. For instance, it has been indicated that the family's motivating attitude and good family relations provide support for people to quit the substance in the period when the patients experience a shift (Albayrak & Balcı, 2014; Dekkers & De Ruysscher ve Vanderplasschen, 2020; Orford et al., 2010).

Finally, when the relatives of the patients were asked to compare the process, they compared their experiences with being in a dungeon, on an adventure, in a nightmare, a trapped mouse, in a dream world, a load, in a huge well, and a rock. These comparisons indicate that the caregivers have difficulty in dealing with the problems they face and that their burden has increased. It can be said that the metaphors, such as despair, uncertainty, perceptions of the lack of solutions to the problem, and problems associated with addiction, are great sources of stress not only for the patients but also for their families.

In this study, we aimed to determine the feelings, thoughts, and needs of the relatives of patients with substance use disorder. The results obtained from the study revealed that the relatives had a process that was very difficult to express, and they had a higher emotional burden. The key finding of this study is that it is very important to understand how the families cope with the burden and the importance of development of intervention programs related to mental health conditions of patients and their caregivers. In particular, the limited number of inpatient treatment centers in Turkey and treatment for only the patients in these centers are among the biggest shortcomings. There is a need for treatment systems in Turkey in which the families are also supported in the fight against addiction.

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**Ethics Committee Approval:** Ethics committee approval was received for this study from the Clinical Research Ethics Committee of Akdeniz University School of Medicine (2012-KAEK-20).

**Informed Consent:** Written informed consent and informed voluntary consent was obtained from all participants who participated in the study.

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