

Research Article

Relationship Between Caregivers' Care Burden and Their Social Functioning Perceptions Toward Addicted Patients: A Cross-Sectional Survey

Dilek Ayakdaş Dağlı^{ID}, Leyla Baysan Arabacı^{ID}, Gülsenay Taş Soylu^{ID},
Ayşe Büyükbayram Arslan^{ID}

Department of Mental Health and Psychiatry Nursing, İzmir Katip Çelebi University, Faculty of Health Sciences, İzmir, Turkey

ORCID IDs of the authors: D.A.D. 0000-0001-7531-3552, L.B.A. 0000-0002-0314-6350, G.T.Ş. 0000-0002-8153-4316, A.B.A. 0000-0001-9954-9973

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Abstract

AIM: The aim of this study is to examine the relationship between social functioning perceptions of the caregivers toward their patients, and their perceived care burden.

METHOD: The descriptive, cross-sectional and correlational study was carried out between September 2017-September 2019 using two measurement tools, in addition to an introductory information form: the Burden Interview and Social Functioning Scale. The study was conducted with caregivers of the 76 addict outpatients and inpatients of the Alcohol and Substance Addiction Treatment Center of a university hospital in Turkey. The study data were evaluated using descriptive statistical analysis and correlation analysis.

RESULTS: Of the caregivers, 69.7% were female and had a mean age of 43.32 ± 13.35 years; 52.6% and 47.4% of the all caregivers provided care to substance abusers and alcohol abusers, respectively. Of the addicted individuals receiving care, 78.9% were male, 60.5% were single, and 56.6% were unemployed. The mean age of patients was found to be 35.94 ± 11.75 years, and patients had been given treatment for an average of 7.56 ± 7.26 years. It was found that as caregivers' total mean Social Functioning Scale scores and mean subscale scores increased, their mean Burden Interview scores decreased ($p > .05$), though this value was not found to be statistically significant.

CONCLUSION: These results are important to support not only the addicted individual but also their caregiver, and to conduct the related treatment and care holistically.

Keywords: Alcohol and substance abuse, care burden, caregiver, social functioning

Introduction

Alcohol or substance addiction is a situation characterized by the profound desire to take an addictive substance; increasing its use to achieve a certain effect; suffering from deprivation when not taken, continuing to take the alcohol/substance despite the experience of physical, mental, or social problems; and the inability to stop taking the alcohol/substance (Baysan-Arabacı et al., 2018; Ögel et al., 2012; Savasan et al., 2013). Alcohol/substance addiction not only threatens the physical and mental health of the abuser, but also disrupts familial relationships, social functioning, and workplace harmony. Problems related to alcohol/substance addiction, both globally and in Turkey, have become a significant health issue that threatens the health of individuals and society

(Acheson et al., 2011; Akvardar et al., 2003; Mares et al., 2011).

Alcohol/substance addiction may lead to mental, physical, professional, economical, and legal problems. Furthermore, it disrupts interpersonal relationships and familial life of the affected individuals, increases the number of family issues, and causes and exacerbates conflicts between spouses. Addiction that affects individuals and their families in a multidirectional way, may act as a "chronic stressor" among the family members (Fuller & Warner, 2000; Kaptanoğlu et al., 1997). These stressors cause the family members to undertake self-care and assume many of the familial and social roles of the affected individuals in their stead, causing them emotional, physical, economic, and social difficulties. When a

caregiver takes the responsibility for both themselves and their patient, they are forced to play many roles, and this makes them feel burdened (Caqueo-Urizar & Gutiérrez-Maldonado, 2006; Doğan, 1996; Hoffmann & Mitchell, 1998; Ögel, 2014).

Care burden is a concept that is negatively interpreted in the literature (Arslantaş & Adana, 2012). For individuals with a chronic disease, their caregiver is usually a family member in a country like Turkey, therefore the changing social and economic conditions makes assuming the role of the caregiver more difficult for that family member (Atagun et al., 2011). Caregiving roles may transform into a unidirectional situation, disrupting the social and working life of both the addicted individual and their caregiver. At this point the “care burden” concept is used to define the effect of physical, economic, or social problems, negative situations, or experiences they have in daily life in the family (Arslantaş & Adana, 2012; Platt, 1985).

Family members struggle to maintain familial integrity, despite the addicted individual’s loss of control, and in doing so often deny the reality of such loss of control. This is a mission on its own. The family of the affected individual often tries to overcome this difficult situation by systematically eliminating certain perceptions regarding awareness, forming alternative explanations to the perceived situation, or else reversing or mixing the cause and effect relationship. For this reason, the needs, requests, and feelings of family members remain in the background when compared with those of the addicted individuals (Schmid, 2008). The necessity for the relatives of addicted patients to do more work, feeling the need to support the affected individual, not only reduces the social relationships of both individuals but may furthermore reduce opportunities for personal progress or career development. Additionally, it may reduce opportunities for them to maintain a hobby or sport, or engage in club activities, thereby negatively affecting the social functioning of other family members.

In Turkey, nurses play an important role in preventing and combating alcohol substance addiction. Strengthening the functions of the family, as specified in the National Strategy Document and Action Plan on Fight Against Drug Addiction (2018–2023), can only reach significance if nurses are also a part of this process (General Directorate

of Public Health, 2018). Psychiatric nurses cannot individually provide interventions for the patients who receive treatment and care in the clinic. It is very important for the family to be a part of this treatment and care. It is necessary to support family members, to identify the problems they experience, to enable family members to express their feelings, to be a part of the family’s treatment and care process, and to ensure healing together (Engin & Kutlu, 2015). Accordingly, psychiatric nurses’ ability to define family status, functionality, and care burden in alcohol/substance addiction and to define the care needs of the family can increase the quality of care for both the individual and the family. The well-being of the family is important for the well-being of the patient. Addiction is a disease that affects not only the individual but also the family. Therefore, psychiatric nurses play a major role in the care processes of both the family and the individual.

In the literature, care burden studies have generally been conducted with the relatives of the patients followed-up with chronic mental illnesses, such as schizophrenia, bipolar disorder, Alzheimer’s, dementia, and obsessive–compulsive disorder (Yıldırım et al., 2017). Few studies have been conducted on this subject that consider the physical, emotional, and economic burden of an alcohol/substance abuser on caregivers. In a study conducted with female substance abusers, Biegel et al. (2007) emphasize the burden of the caregiver, and state that the number of studies on this subject is inadequate.

Although ethically discussed, the priority of care and treatment may change, especially in situations such as pandemics. As a result of the recent changes in the treatment and care policy, it is becoming more difficult for these patients to reach treatment. In such circumstances, the care and treatment of these patients need to be carried out by their caregivers in the home environment. At this point, determining the care burden of family members becomes more important. It can also guide the intervention programs to be planned for caregivers. In this regard, this study aims to examine the relationship between social functioning perceptions of the caregivers toward their patients, addicted outpatients, or inpatients of the Alcohol and Substance Addiction Treatment Center of a university hospital, and to examine their perceived care burden of the caregivers.

Research Questions

1. What is the care burden of caregivers of individuals having alcohol/substance abuse problems?
2. What are the social functioning levels of caregivers of individuals having alcohol/substance abuse problems?
3. What is the relationship between care burden and social functioning of caregivers of individuals having alcohol/substance abuse problems?

Method

Study Design

This study is a descriptive, cross-sectional, and correlational study.

Sample

The study was conducted with caregivers of the 86 addicted outpatients and inpatients of the Alcohol and Substance Addiction Treatment Center in the psychiatry clinic of a university hospital. The data were collected from the relatives/caregivers who came to visit the patients, on the basis of accessibility and randomness. Data collected from 10 individuals were excluded from the study assessment and analyses because they did not complete 80% or more of the questionnaire. This research was then completed using responses in the remaining 76 questionnaires.

Inclusion and Exclusion Criteria

The study included individuals providing care to individuals diagnosed with alcohol and substance addiction, and who volunteered to participate in this study. Caregivers who were illiterate, or who had a psychological disorder which made them unable to respond to the questionnaires, were excluded from this study.

Data Collection

Data was collected over two years, from September, 2017, to September, 2019. According to the rules of the clinic, visiting days for the relatives/caregivers are every Tuesday and Thursday afternoon. For this reason, data were collected only on Tuesdays and Thursdays from relatives/caregivers who visited the patients. At the data collection stage, accessibility and randomness were the basis. Patients stay in the clinic for an average of one month. Therefore, the relatives/caregivers of the patients can come repeatedly. It was ensured that only one caregiver-relative of each patient filled out the questionnaires.

Data Collection Tools

Study data were collected using two measurement tools: the Burden Interview (BI), and the Social Functioning Scale (SFS), along with an introductory information form, Cronbach's alpha values of the scales for this study sample were found to be 0.94 and 0.75, respectively.

Introductory information form: This form was developed by the researchers and comprises 21 open and closed-ended questions including the sociodemographic characteristics of the addicted patients and their families (Biegel et al., 2007, Vaishnavi et al., 2017, Yıldırım et al., 2017).

Burden Interview: The BI was developed by Zarit, Reever and Bach-Peterson in 1980. It is a scale used to evaluate the stress of the caregivers of the individuals or old people needing care. The scale, which can be completed by the caregivers themselves by the researcher or on their behalf, comprises 22 statements determining the effect of caregiving on the life of the individual. Responses are given according to a four-point Likert-type, and are scored as never, rarely, sometimes, quite frequently, or nearly always (Zarit & Zarit, 1990). Studies have found the internal consistency coefficient of the scale to be 0.87–0.94 and the test-retest reliability to be 0.71. The Turkish reliability and validity study of the scale was conducted by İnci and Erdem (İnci & Erdem, 2008); the maximum and minimum scores possible from the scale are 0 and 88, respectively. The scale items generally concern social and emotional areas, and a higher scale score indicates a higher level of distress (Zarit & Zarit, 1990).

Social Functioning Scale: This scale developed by Max Birchwood et al. in 1990. Erakay conducted the Turkish reliability and validity study of this scale in 2001 (Erakay, 2001). The SFS is a tool that evaluates the role functions that require the judgment of the whole social role of the individual. The scale quantitatively evaluates basic competences and social behavior, and comprises seven subscales: withdrawal, interpersonal functioning, pro-social activities, recreation activities, independence–competence, independence–performance, and employment. Concerning the scoring of these subscales, the withdrawal subscale includes five items with the minimum score of zero and a maximum score of 15; the interpersonal functioning has four items, but items one and two are summed up, thus the minimum score and the maximum score possible

from the subscale are zero and nine, respectively. The minimum and maximum scores for independence/competence, independence/performance, recreation activities, and pro-social activities subscales were found to be 0 and 39, 0 and 39, 0 and 45, and 0 and 66, respectively. In the employment section, two items are completed, if applicable, but these items are ignored if the individual had not worked in the past six months or if they were not looking for a job. The total minimum and maximum scores possible from this scale were 0 and 223, respectively. A higher total score for each of the subscales indicates a positive improvement in functioning.

Statistical Analyses

For the data analysis, a licensed Statistical Package for Social Sciences 22.00 (IBM SPSS Corp., Armonk, NY, USA) program was used. Study data were evaluated using descriptive statistical analyses (percentage, mean) and correlation analysis. Statistical significance at $p < .05$ was accepted for all the study analyses.

Ethical Consideration

Ethical committee approval was received for this study from the ethics committee of İzmir Katip Çelebi University (Date: October 24, 2017, No: 31829978-050.01.04-E.1700074699).

Results

Of the caregivers of addicted individuals, all caregivers had a mean age of 43.32 ± 13.35 years and 69.7% were female. Of the caregivers, 85.5% were married, and 35.5% and 30.3% regularly provided care to their children and spouses, respectively; caregivers had provided care for an average of 8.56 ± 8.57 years, and 60.5% had a regular job (Table 1).

On examination of the characteristics of the patients receiving care from the caregivers, 52.6% were substance abusers and 47.4% were alcohol abusers. Patients had been under treatment for an average of 7.56 ± 7.26 years, and their mean age was 35.94 ± 11.75 years. Of the patients receiving care, 78.9% were male, 60.5% were single, and 56.6% did not have a job. Of the caregivers, 42.1% indicated that their patients regularly used medication, 46.1% indicated that their patients were regularly checked by a doctor, 39.5% indicated that their patients had

Table 1.
Caregivers' Sociodemographic Characteristics (N=76)

	Number (n)	%
Mean age of caregivers: 43.32 ± 13.35		
Gender		
Female	53	69.7
Male	23	30.3
Marital status		
Married	65	85.5
Single	11	14.5
Relationship		
Mother	4	5.3
Father	7	9.2
Children	27	35.5
Spouse	23	30.3
Sibling	13	17.1
Other	2	2.6
Level of education		
Illiterate	6	7.9
Primary school	21	27.6
Middle school	9	11.8
High school	19	25.0
University	21	27.6
Working status		
Yes	46	60.5
No	24	31.6
Retired	6	7.9
Monthly income status		
Income>expenditure	6	7.9
Income=expenditure	50	65.8
Income<expenditure	20	26.3
Mean caregiving duration (years)	8.96 ± 8.56	

never stayed in the hospital before, and 59.5% indicated that they had received inpatient treatment at least once (Table 2).

The total BI mean score of the caregivers was found to be 51.47 ± 18.91 . The mean SFS scores of the caregivers were found to be 8.04 ± 3.21 for the withdrawal subscale; 4.96 ± 2.78 for the interpersonal relationships subscale; 11.46 ± 9.53 for the pro-social

Table 2.
Sociodemographic Characteristics of Patients (N=76)

	Number (n)	%
Mean age of the patient receiving care	35.95 ± 11.74	
Mean disorder duration: 5 years (Min: 1, Max: 30)		
Gender		
Female	16	21.1
Male	60	78.9
Marital status		
Married	30	39.5
Single	46	60.5
Education level		
Illiterate	3	3.9
Primary school	12	15.8
Middle school	22	28.9
High school	28	36.8
University	11	14.5
Working		
Yes	31	40.8
No	43	56.6
Retired	2	2.6
Substance abused		
Alcohol	36	47.4
Substance	40	52.6
Using medication		
No	2	2.6
Regularly	32	42.1
Taking sometimes	8	10.5
Missing sometimes	34	44.7
Doctor's follow-up		
Unknown	3	3.9
Regularly	35	46.1
No	38	50
Number of hospitalizations		
None	30	39.5
One hospitalization	24	31.6
Two hospitalizations	8	10.5
Three hospitalizations	5	6.6
Four hospitalizations	4	5.3
Five hospitalizations	4	5.3
Six hospitalizations	1	1.3

Table 3.
Total Scale Mean Scores

	Mean ± SD
Burden interview	51.47 ± 18.91
Social functioning scale subscales	
Withdrawal	8.04 ± 3.21
Interpersonal relationships	4.96 ± 2.78
Social activity	11.46 ± 9.53
Recreation activities	12.84 ± 6.60
Independence/competence	28.61 ± 9.36
Independence/performance	24.59 ± 7.00
Employment	3.94 ± 4.92

activities subscale; 12.84 ± 6.60 for the recreation activities subscale; 28.61 ± 9.36 for the independence/competence subscale; 24.59 ± 7.00 for the independence/performance subscale; and 3.94 ± 4.92 for the employment subscale (Table 3).

As shown in Table 4, as caregivers' total SFS score and mean subscale scores increased, their BI mean scores decreased. Statistical analysis did not find this relationship to be statistically significant ($p > .05$) (Table 4).

Discussion

This study was conducted to examine the relationship between social functioning perceptions and the perceived care burden of caregivers of addicted outpatients and inpatients of a university hospital's Alcohol and Substance Addiction Treatment Center. Most of the participant caregivers were family members of the addicted patients, and most were women who were above middle age; mothers or spouses mostly took the responsibility of providing care to addicted individuals. A similar finding is reported by Rospenda et al. (2010) who conducted a study to determine the care burden of the families of alcohol abusers, and found that most of the caregivers were women with a mean age of 42.1 years (Rospenda et al., 2010). In a similar study, Vaishnavi et al. (2017) found the mean age of the caregivers of alcohol abusers to be 41.6 years (Vaishnavi et al., 2017). Several similar studies in the field found most caregivers to be the mother or spouse of the patient (Gülseren et al., 2010; Maskill et al., 2010; Steele et al., 2010; Taşdelen & Ateş, 2012; Van Der Voort et al., 2007). Furthermore, studies from the literature argue that

Table 4.
Relationship Between Caregiving Scale and Social Functioning Scale

		Withdrawal	Interpersonal Relationships	Social Activity	Recreation Activities	Independence/Competence	Independence/Performance	Employment
Burden interview (BI)	<i>r</i>	-.108	FN_Source	-.027	-.111	-.185	.001	.021
	<i>p</i>	.355	.997	.816	.338	.110	.991	.856
	<i>n</i>	76	76	76	76	76	76	76

gender is a significant variable in the caregiving role (Arslantaş & Adana, 2012; Dökmen, 2012). In accordance with traditional gender roles, behaviors that require self-devotion—such as caring, feeding, growing, helping, and supporting—are more expected from females among those cultures with a patriarchal family structure; caring is perceived as the duty of females, and females are thereby expected to fulfill this responsibility. In light of this information, it is clear that gender is a significant determinant in caregiving, which was also determined by this study.

In line with the literature, this study found that individuals receiving care for substance or alcohol abuse were male, and that they had a mean age of 38; furthermore 52.6% used substances while nearly half of them used alcohol.

Families' care burden scores were found to be above average, indicating that family members had difficulty in the caregiving role they undertook. Similarly, a limited number of studies also found caregivers of alcohol- and substance-addicted patients had difficulty in providing care (Rospenda et al., 2010; Vaishnavi et al., 2017). The literature indicates that the longer the duration of the disorder, the greater the perceived care burden (Ampalam et al., 2012). This study also determined that caregivers provided care for an average of nine years. Alcohol- and substance-addicted individuals were a financial burden on their families, had a potential to harm others, had irritable behaviors, had a high risk of becoming involved in fights, risked the creation of legal problems, and made repetitive attempts to quit; all of these materially and morally exhausted families in terms of their time and energy. Thus, the distress felt at having to provide care may cause the caregiver to perceive the care burden. Both the financial burden, and the inability to spend effective time with one's family, have been found to increase the care burden of caregivers (Mattoo et al., 2013; Vaishnavi et al., 2017). An examination of caregivers' mean SFS scores revealed that caregivers had the perception/opinion that addicted individuals were

not functioning in the employment and interpersonal relationships subscales. Accordingly, it was found that being nonfunctional in the employment subscale brought about economic hardships, while being nonfunctional in the interpersonal relationships subscale brought about domestic conflicts; and the distress experienced as a result of such hardships increased the caregivers' perceived care burden.

In the evaluation of the caregivers' perception of the social functioning of their addicted patients, caregivers gave a score below average in the withdrawal and recreation activities subscales; this indicates that they perceived social activity and recreation activities of the individuals under their care to be inadequate. Addicted individuals did not feel any withdrawal, therefore, they stayed at home longer, neglected their responsibilities, and this caused domestic conflict since they could not perform their duties, and their caregivers could not allocate time to themselves. This overburden on caregivers caused the patient to be accused and excluded, potentially leading them to relapse (re-use of substance). This study also indicated that 59.5% of the participating patients were repeatedly hospitalized.

As caregivers' total SFS and subscale mean scores increased, their BI mean scores decreased. However, this relationship between these two variables was not found to be statistically significant ($p > .05$). This finding may result from the sample characteristics, with the inclusion of participants who were highly responsive to treatment due to regular medication, regular follow-up sessions with the doctor in nearly the half of the participant patients, and almost 40% of the individual patients being given treatment for the first time, in a limited sample size. In the event that the caregiver evaluates the functioning of the addicted patient to under their care to be high, though not to the degree of statistical significance, it is expected that distress felt by the caregiver due their caregiving responsibilities will be low. This study found the distress/burden felt by caregivers due to

caregiving to be high. In Turkish culture, in accordance with the traditional societal gender role of women (as a mother or wife), women are expected to undertake the care of the addicted individuals and to cure them. If the caregiver is a woman who exerts a high level of effort to meet this expectation, she can throw the social functioning of the addicted individuals out of focus. Therefore, a caregiver with a high care burden appears against an addicted individual with a low level of social functioning. The care burden that might form as a result of this vicious cycle can cause the caregiver to experience psychosocial hardships and poorer physical and mental health, in addition to feelings of desperation. For this reason, during the struggle with alcohol or substance addiction, it is important to support not only the addicted individual but also their caregiver, as well as to conduct the related treatment and care holistically.

Study Limitations

This study was conducted in a single center and had a small sample size; accordingly, the results of this study cannot be generalized to the population.

Conclusion and Recommendations

The findings of this study indicated that women above middle age mostly took the responsibility of caregiving of an addicted family member, and that the care burden of those caregivers was above average. Furthermore, it was found that as the patient's social functioning levels increased, the perceived care burden of the caregivers decreased, though this finding was not statistically significant. In accordance with these results, health staff working in the addiction centers, especially psychiatric nurses who are in touch with patients more often, should be aware that the disease not only affects the patient, but also increases the care burden on the family. It is recommended that interviews are held to help determine situations of increasing care burden by including the families of the patients in the treatment process, and to plan interventions on developing effective coping methods for both the individual and their family.

Determining the care burden of caregivers is also significant in terms of nursing care provided to addicted patients under treatment in the clinic. When interventions are conducted for addicted individuals and their families within the scope of nursing diagnosis, such

as "Ineffective Family Coping" (Erdemir, 2012) and "Interrupted Family Processes" (Erdemir, 2012), they can change the quality of life of the family by increasing social functioning of the family. This may increase the quality of nursing care. In this context, it is recommended that nurses create psychoeducation programs for both the family and the individual to reduce the care burden, and evaluate their effects on the care burden.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of İzmir Katip Çelebi University (Date: October 24, 2017, No: 31829978-050.01.04-E.1700074699).

Informed Consent: Written informed consent was obtained from the participants who participated in this study.

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