Overprotection and the Associated Factors Among People with Epilepsy: A Cross-sectional Study

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Abstract

Objective: To examine overprotection in people with epilepsy and the demographic and clinical factors affecting it.

Methods: The study was a descriptive, cross-sectional investigation involving 104 people with epilepsy attending the neurology outpatient clinic of Giresun Training and Research Hospital between September 2022 and February 2023. While a descriptive information form and an overprotection scale were used to collect research data, descriptive statistics (percentages, mean, and standard deviation) and linear regression analysis were used to analyze the data.

Results: It was determined that 66.3% of the participants were male; 53.8% were primary school graduates; 53.8% were married; 34.6% had generalized epilepsy; and 69.2% did not have seizure control. The overall mean score on the perceived overprotection scale was 29.09±12.63. The linear regression analysis using the significant regression model (F=5.111; p=0.000) revealed that 24.2% (R^2=0.242) of the change in overprotection was explained by demographic and clinical variables.

Conclusion: Primary and high school education, polytherapy, and generalized epilepsy were associated with higher perceived overprotection, whereas being married was associated with lower perceived overprotection. These findings underscore the importance of interventions focusing on patient and family education.

Keywords: Adult, epilepsy, perceived overprotection

INTRODUCTION

Epilepsy is a neurological disorder characterized by recurrent seizures and associated cognitive, psychological, and social consequences.[1] There are approximately 50 million people with epilepsy (PWE) worldwide, with about 2 million new cases recorded each year.[2,3] The prevalence of epilepsy is 6 per 1,000 in developed countries, compared with 18.5 per 1,000 reported in developing countries. The prevalence of epilepsy in Türkiye is 6.1-10.2 per 1,000 population.[4,5] Epilepsy has been recognized as a dangerous and feared condition since antiquity.[3,6] PWE more often contend with psychosocial problems related to seizures than with the seizures themselves. Therefore, treating epilepsy as a neurological disease alone is insufficient.[4]

Research on overprotection has primarily focused on children and adolescents with epilepsy.[7,8] According to Thomasgard and Metz,[9] overprotective parenting is characterized by excessive control and caution, difficulty with separation, and the inhibition of a child's independent behaviors. Overprotection is associated with controlling behaviors, such as excessive physical or social contact, infantilization, parental overcontrol, intrusiveness, and anxious parenting.[8] Overprotected children with epilepsy may face risks, including excessive dependence, heightened emotionality, delayed maturity relative to peers, and failure to acquire essential social skills.[10] Consequently, this pattern may lead to significant psychological problems such as reliance on others and low self-esteem.[6,11]

Across studies conducted in different countries, findings indicate that autonomy, epilepsy type, educational level, and familial overprotection affect employability. Many restrictions appear to stem not from objectively increased seizure-related risks but from excessively protective caregiving behaviors; caregivers are frequently reported as overprotective, a pattern associated with feelings of shame, reduced social participation, and social isolation. Conversely, some individuals—particularly those following surgery or awaiting surgical treatment—report increased independence and greater engagement in social activities.[1,3,12-17] In light of Kleinman et al.'s[18] emphasis on the cultural shaping of illness perceptions, these results suggest that perceived restrictions influence notions of dignity, vulnerability, and independence

among PWE, and that further comparative research is required to disseminate and deepen understanding of these cross-cultural dynamics.[19]

Research on perceptions of overprotection among PWE in Türkiye is limited. Existing studies predominantly address the medical aspects of epilepsy, while its social and psychological consequences remain underexamined. Although findings concerning stigma and mental health have been reported, the specific effects of perceived overprotection on social participation, independence, and psychological wellbeing have not been thoroughly investigated. While relevant international literature exists, further comparative research is needed to determine the applicability of those findings to the Turkish context. The aim of this study was to evaluate perceived overprotection and associated demographic and clinical variables among PWE in Türkiye.

METHODS

Study Design

This research was a descriptive, cross-sectional study conducted between September 2022 and February 2023. The data were collected face-to-face, and each form took approximately 15 minutes to complete.

Population and Sample

The research was conducted in Giresun, Türkiye. The study population consisted of 132 PWE who were registered at Giresun Training and Research Hospital, attended the neurology outpatient clinic for examination, and were treated in the neurology clinic. In the power analysis conducted using the G*Power 3.1.9.4 package, based on the study of Aydemir,[17] an effect size of d=0.372, a 95% confidence interval, a 0.05 margin of error and a minimum sample size of n=96 were calculated. Of the PWE individuals constituting the universe, 24 did not meet the inclusion criteria, and 4 did not agree to participate in the study. The sample comprised 104 patients meeting the study's inclusion criteria. The data were collected by the researcher using face-to-face interviews in an empty room in the outpatient clinic and in patient rooms in the inpatient clinic. Each interview lasted approximately 15 minutes. Criteria for inclusion in the study;

- having been diagnosed with epilepsy in the last year,
- aged 18 years or older,
- having no problems with vision, reading, writing and communication,
- no neurological disease or psychiatric disease other than epilepsy,
- agreeing to participate in the study.

MAIN POINTS

- People with epilepsys who went out alone and took responsibility often reported overprotection.
- Generalized type epilepsy and multiple antiepileptic drug use often led to overprotection.
- The participants who were married reported less overprotection.

Data Collection Methods and Tools

Descriptive Information Form

The researchers created a survey based on previous studies. The survey included 10 questions on participants' demographic and clinical information, including age; duration of epilepsy; education; marital status; professional activity; type of epilepsy; seizure control; number of medications used; unintentional harm to others during a seizure; and accidents.

Overprotection Scale

The scale was adapted into Turkish by Kaya and Yildiz[20] This scale was developed to assess a person's perceived parental overprotection in the context of epilepsy (e.g., "my family does not allow me to go out for a movie or a walk unless a family member or a friend is with me"). It consists of 10 items with a single factor. Responses are rated on a five-point Likert scale (5=strongly agree; 1=strongly disagree). The minimum score on the scale is 18; the maximum is 83. Higher scores indicate higher perceived overprotection. The reliability of the original scale is 0.85.[20] In this study, the reliability of the scale, measured using Cronbach's alpha, was 0.958.

Statistical Analysis

SPSS version 22.00 was used for data analysis. Percentages, means, and standard deviations were used for descriptive statistics. Homogeneity of variances was evaluated using Levene's test. Parametric methods were used to analyze the data. Multivariate linear regression was applied to determine the factors associated with overprotection. Variables with high representativeness and relatedness, identified by pairwise comparisons (univariate analysis), were included in the model. Categorical independent variables were encoded as dummy variables. Linear regression analysis was performed to determine the impact of descriptive information on overprotection. The significance level was set at $p<0.05$.

Ethical Considerations

This study was approved by Ordu University Clinical Research Ethics Committee (approval no: 202, date: 02.09.2022). Written informed consent was obtained from participants in face-to-face interviews; the consent form provided necessary explanations about the purpose of the research and the data collection. The study was conducted in accordance with the Declaration of Helsinki.

RESULTS

Of the participants, 66.3% were male; 53.8% were elementary school graduates; 53.8% were married; 34.6% had generalised epilepsy; 69.2% did not have seizure control; 59.6% received single-drug therapy; 65.4% did not have an accident during a seizure; and 89.4% did not harm anyone during a seizure. The participants' mean age was $\bar{x}$=39.88±16.61 years; mean epilepsy duration was $\bar{x}$=16.35±14.08; and mean overprotection score was $\bar{x}$=29.09±12.63 (Table 1).

Item 1 exhibited the highest negative response, whereas items 2 and 7 exhibited the highest positive responses (Table 2).

Overprotection perception scores in PWE differed significantly by educational status (F=4.194, p=0.018, η^2=0.077). The observed differences indicate that the overprotection perception scores for primary school graduates ($\bar{x}$=29.125±12.758) and for high school graduates ($\bar{x}$=32.688±12.460) are higher than those for university graduates ($\bar{x}$=21.813±9.745) (p<0.05). The overprotection perception scores of married PWE ($\bar{x}$=26.196) were lower than those of singles ($\bar{x}$=32.479) (t=-2.597, p=0.011, d=0.511, η^2=0.062). Furthermore, overprotection perception scores varied significantly by epilepsy type (F=3.557, p=0.017, η^2=0.096). Specifically, individuals with generalized epilepsy ($\bar{x}$=33.750±12.573) had higher perceived overprotection scores than those who lacked sufficient information about their epilepsy diagnosis ($\bar{x}$=23.862±11.376) (p<0.05). Additionally, overprotection perception scores of those without seizures ($\bar{x}$=25.063) were lower than those of participants with a seizure frequency of at least once per month ($\bar{x}$=30.889) (t=-2.210; p=0.029; d=0.470; η^2=0.046). Similarly, overprotection perception scores of individuals on monotherapy ($\bar{x}$=25.113) were lower than those of individuals on polytherapy ($\bar{x}$=34.976) (t=-4.210; p<0.001; d=0.841; η^2=0.148). No significant differences in overprotection perception scores were found by gender, occupational activity, or having an accident or harming someone during a seizure (p>0.05). Correlation analyses of overprotection perception scores with age and with epilepsy duration did not reveal statistically significant relationships (p>0.05). Consequently, the variables identified as being strongly represented in these pairwise comparisons (univariate analyses) were included in the regression analysis.[21,22]

Table 1. Demographic and clinical characteristics of the participants

	n=104	%
Gender		
Female	35	33.7
Male	69	66.3
Educational status		
Primary education	56	53.8
High school	32	30.8
University	16	15.4
Marital status		
Married	56	53.8
Single	48	46.2
Occupational activity		
Not working	84	80.8
Working	20	19.2
Epilepsy type		
Generalized epilepsy	36	34.6
Focal epilepsy	21	20.2
Epilepsy of unknown onset	18	17.3
Unclassified epilepsy	29	27.9
Seizure control		
My seizures are under control (I have not had a seizure in the past year)	32	30.8
My seizures are not under control; I have had at least one seizure in the last year	72	69.2
Number of medications used		
Single medication therapy	62	59.6
Multiple drug therapy	42	40.4
Having accident during your seizure		
Yes (once or twice)	36	34.6
No	68	65.4
Hurting someone during seizure		
Yes (just once)	11	10.6
No	93	89.4
	±SD	**Min-max**
Age	39.88±16.61	18-83
Duration of epilepsy (year)	16.35±14.08	1-31
Overprotection scale	29.09±12.63	10-50

$\bar{x}$: Mean, SD: Standard deviation, min: Minimum, max: Maximum

A regression analysis was conducted to determine the cause-and-effect relationships between primary school graduation, high school graduation, marital status, types of epilepsy (generalized, focal, and unknown-onset), uncontrolled seizures, number of medications used, and overprotection perception scores. Significant relationships were identified (F=5.111, p<0.001). The total variance in overprotection perception levels, amounting to 24.2% (R^2=0.242), was explained by being a primary school graduate, being a high school graduate, marital status, having generalized, focal, and unknown-onset epilepsy, uncontrolled seizures, and the number of medications used, demonstrating that these factors influence the perception of overprotection. Overall, the change in perceived overprotection levels was explained by a combination of these factors. Attaining a primary school education (β=0.335) and a high school education (β=0.285) were associated with increased perceived overprotection. Conversely, being married (β=-0.270) was linked to lower levels of perceived overprotection, whereas having generalized epilepsy (β=0.225) and being on multiple medications (β=0.286) were linked to higher levels. However, focal epilepsy (p=0.170), epilepsy of unknown onset (p=0.638), and uncontrolled seizures (p=0.569) did not significantly influence levels of perceived overprotection (Table 3).

DISCUSSION

This study aimed to determine whether participants' responses to the perceived overprotection scale varied according to demographic variables and to explain any observed variance. Most participants answered "totally agree" or "agree" to items related to going out alone. This may reflect the family's concerns about the possibility of PWE having a seizure outdoors, the lack of family support during seizures, and the possibility of PWE having an accident. Family members may also be worried about the possibility of inappropriate interventions during seizures. For instance, in South Vietnam, PWE avoid all bodies of water, including lakes, rivers, and ponds, all of which are extremely common in the region, because of fear of seizure-related harm.[6,23] Shore et al.[24] reported that PWE were overprotected by their families, particularly by not being left alone in social settings. Thus, the present results are consistent with the literature. In addition, participants provided predominantly positive responses to items concerning greater familial tolerance and reduced responsibility for PWE. While family members are overprotective, they are unlikely to be malicious. However, this behavior can undermine autonomy and independence in PWE, impair their social bonding skills, and have

Table 2. Responses in percentages to different items of the overprotection scale

	Item content	Completely agree	Agree	Not sure	Disagree	Completely disagree
1	I believe my family is overprotective of me because of my epilepsy	12.5	20.2	5.8	27.9	33.7
2	My family does not let me go out, for example, to the cinema or for a walk, unaccompanied by a friend or family member	42.3	25.0	9.6	10.6	12.5
3	I believe my family is more tolerant toward me because of my epilepsy	13.5	24.0	11.5	26.0	25.0
4	I think my family gives me less responsibility than I am able to manage because of my epilepsy	25.0	22,1	11.5	15.4	26.0
5	I think that if I did not have epilepsy, my family would have higher expectations of me	25.0	24.0	14.4	19.2	17.3
6	I think my family's high level of concern for me stems from my epilepsy	27.9	24.0	10.6	17.3	20.2
7	My family never allowed me go out alone	38.5	25.0	5.8	14.4	16.3
8	I think my family gives me fewer domestic responsibilities because of my epilepsy	24.0	26.0	6.7	20.2	23.1
9	I think my family shows me excessive attention	19.2	20.2	9.6	26.9	24.0
10	I think my family shows greater concern for my welfare because of my epilepsy	21.2	21.2	13.5	23.1	21.2

Table 3. Factors affecting overprotection

Independent variable	Non-standardised coefficients		Standardised coefficients	t	p	95% confidence interval	
	B	SE	ß			Lower	Upper
Fixed	18.551	3.436		5.398	0.000	11.728	25.373
Level of education (being an elementary school graduate)	8.459	3.818	0.335	2.216	**0.029**	0.879	16.039
Level of education (being a high school graduate)	7.754	3.653	0.285	2.123	**0.036**	0.502	15.005
Marital status (married)	-6.815	2.403	-0.270	-2.836	**0.006**	-11.585	-2.044
Type of epilepsy (generalised)	5.954	2.887	0.225	2.062	**0.042**	0.223	11.685
Type of epilepsy (focal)	4.464	3.230	0.142	1.382	0.170	-1.948	10.877
Type of epilepsy (epilepsy of unknown onset)	1.614	3.421	0.049	0.472	0.638	-5.178	8.407
Seizure control (my seizures are not under control)	1.541	2.695	0.057	0.572	0.569	-3.809	6.891
Number of drugs used (multi-drug therapy)	7.343	2.386	0.286	3.078	**0.003**	2.607	12.079

Dependent variable: overprotection, R=0.549, R2=0.242, F=5.111, p=0.000, Durbin-Watson value =1.727, p<0.005

negative economic consequences in their work life.[8,17] Yetkin et al.[25] reported that overprotective attitudes in patients with epilepsy significantly reduced quality of life and, together with depression, constituted independent predictors of poorer outcomes. In another study conducted by Yetkin et al.,[26] perceived overprotection and stigma were found to significantly contribute to suicidal ideation in patients with epilepsy. This highlights that overprotective behaviors, which are often driven by concerns for safety, may exacerbate psychosocial distress and increase vulnerability to severe mental health problems. Therefore, overprotectiveness, even if well-intentioned, may be harmful to PWE in the long term.[27]

Moreover, several descriptive characteristics were associated with perceived familial overprotection, either positively or negatively. In this study, PWEs with elementary or high school education perceived greater familial overprotection. Indeed, as individuals' levels of education increase, their health literacy, positive lifestyle behaviors related to the disease, and adherence to treatment also increase.[28,29] Therefore, as individuals with higher levels of education develop disease management skills, the need for family members to intervene may decrease; this may lead to a lower perception of overprotection. Therefore, perceived familial overprotection may be lower among people with higher education levels. Previous studies have reported that unemployment rates are higher among PWE with low educational attainment.[3,30] Wo et al.[1] argued that education level affects the ability of PWE to work. Therefore, the economic burden of accessing health professionals in case of problems may lead to excessive protection of PWE with lower educational levels.

In this study, married participants reported lower levels of overprotection, which may reflect reduced parental control and intervention associated with cohabitation with their spouses. Marriage expands the social support networks of PWE, enabling them to receive emotional and practical support beyond the family.[31] Increased social support can enhance autonomy and independence, thereby reducing the need for overprotective behaviors by family members.[32] Additionally, marriage has been associated with improved health management. Married PWE are more likely to achieve better seizure control and demonstrate higher treatment adherence, which may contribute to a decrease in overprotective attitudes among family members.[33] However, comprehensive longitudinal and descriptive studies are needed to clarify the causal relationships between marital status and perceived overprotection.

Furthermore, individuals with generalized epilepsy perceived greater familial overprotection. According to Wo et al.[1] generalized epilepsy predicted employability among PWE. Another study found that forgetfulness and fatigue-like complaints were common in PWE, attributable to involvement of the seizure focus and to the side effects of antiepileptic drugs.[34] Individuals with generalized

epilepsy may experience increased familial overprotection as a result of these issues. Furthermore, the adverse effects on social integration and quality of life may reinforce familial overprotection tendencies.[35] These findings are in line with Yetkin et al.,[25] who reported that heightened overprotection not only limits autonomy but also interacts with stigma to increase the risk of psychological burden, including suicidal ideation, thereby amplifying the negative consequences of severe clinical forms of epilepsy. Consequently, neurological and treatment-related challenges faced by individuals with generalized epilepsy may elicit excessive familial protection, thereby restricting patients' social and economic participation.

As expected, the overprotection perceived by participants receiving multi-drug therapy was higher than that perceived by participants receiving single-drug therapy. Antiseizure medications have adverse effects, including effects on cognitive function (e.g., thinking and memory), fatigue, and dizziness. These drugs also have adverse effects on social lives, including social isolation, dependent behaviour, lower marriage rates, unemployment, and decreased quality of life.[36] Beghi et al.[37] emphasized that quality of life is lower in individuals receiving polytherapy and that these individuals require greater family support. Loring et al.[38] showed in a systematic review that the use of multiple antiseizure drugs had significant negative effects on basic cognitive functions such as attention span, memory retention, and processing. Park and Kwon[39] stated that antiseizure drugs affected cognitive functions, although the effects varied depending on the dose taken, and that these effects were especially evident in individuals receiving polytherapy. Another review by Gilliam et al.[40] indicated that polytherapy reduced an individual's physical functioning and could limit their ability to perform activities of daily living independently. Such cognitive and psychological problems limiting the daily living skills of PWE may cause family members to perceive the individual as fragile or in need of protection. As family members witness these difficulties, they may lose confidence in the individual's ability to assume responsibility independently and instead make decisions and intervene. Thus, well-intentioned but overprotective behaviors may develop. This may lead to a weakened independence, reduced self-confidence, and social withdrawal in PWE. As a result, individuals who take multiple medications may experience greater overprotection due to both physiological and environmental factors.

Study Limitations

This study had several limitations. First, this study was conducted at a single center and included a limited number of patients. This may prevent the generalization of research results to other regions. Second, although the participants did not have diagnosed cognitive or psychiatric disorders, they were likely to have memory deficits, which may have affected the accuracy of their answers.

CONCLUSION

In this study, the participants reported that they were largely overprotected with respect to going out alone and assuming responsibility. Groups reporting higher levels of overprotection included elementary and high school graduates, individuals with generalised epilepsy, those with uncontrolled seizures, and those on multiple medications. Married participants reported lower levels of overprotection. There is growing evidence that excessive familial overprotection may adversely affect the psychosocial well-being of PWE, including reduced autonomy, impaired social functioning, and an increased risk of emotional distress. Therefore, it is crucial that future studies comprehensively examine the psychosocial burden resulting from overprotection. Such research will contribute to a better understanding of the long-term effects of overprotection on quality of life and mental health outcomes and provide a foundation for developing interventions that balance necessary support with the promotion of independence among PWE.

Ethics

Ethics Committee Approval: This study was approved by the Ordu University Clinical Research Ethics Committee (approval no: 202, date: 02.09.2022).

Informed Consent: Written informed consent was obtained from participants in face-to-face interviews; the consent form provided necessary explanations about the purpose of the research and the data collection.

Footnotes

Authorship Contributions

Surgical and Medical Practices: F.G.O., G.A., D.Ş., Concept: F.G.O., G.A., D.Ş., Design: F.G.O., D.Ş., Data Collection or Processing: F.G.O., D.Ş., Analysis or Interpretation: F.G.O., Literature Search: F.G.O., G.A., Writing: F.G.O., G.A.

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