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The Role of Stigma, Perceived Social Support, and Task-Oriented Coping Style in Relation with Life Satisfaction in Primary Caregivers of Children with Epilepsy: A Multiple Mediation Analysis

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Abstract

Objective: Stigma exacerbates poorer life satisfaction among caregivers of children with epilepsy (CWE); however, the underlying reasons for this connection are still not fully understood. This research aimed to investigate how coping strategies and social support can impact the connection between stigma and life satisfaction.
Method: A cross-sectional descriptive study was conducted on 210 primary caregivers of CWE from August to November 2023. The participants were selected through convenience sampling. The study included information on participants' demographics (such as gender, age, education level, duration of epilepsy, age of onset, seizure frequency) and four established self-report questionnaires. Caregivers completed self-report scales of perceived social support, stigma, life satisfaction, and coping style. We used the PROCESS 4.1 macro proposed by Hayes to analyze the direct and indirect associations between variables. In addition, SPSS-27 software was used to conduct Pearson correlation.
Results: The research findings confirmed that both perceived social support and task-oriented coping mechanisms played a mediating role in the connection between stigma and life satisfaction (β perceived social support = -0.11; 95% bootstrap CI: -0.12 to -0.02; β task-oriented coping = -0.14; 95% bootstrap CI: -0.26 to -0.05), respectively. Furthermore, the results of serial mediation analyses revealed that the link between stigma and life satisfaction is influenced by perceived social support and task-oriented coping in a sequential process (B = -0.029, 95% bootstrapped CI: -0.060 to -0.006).
Conclusion: These findings shed light on the role of perceived social support and task-oriented coping as serial mediators of the relationship between stigma and life satisfaction. Thus, identifying and correctly understanding the sources of support, as well as teaching effective task-oriented coping through mental health professionals, is necessary to reduce the stigma experienced by these caregivers and improve life satisfaction.

Key words: *Coping Skill; Epilepsy; Life Satisfaction; Mediation Analyses; Social Stigma; Social Support*

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Epilepsy is a neurological disorder characterized by the occurrence of two or more unprovoked seizures with a gap of at least 24 hours between each seizure (1). Epilepsy and its treatment have not only a severe negative impact on the physical and mental development of children (2, 3), but also destructive effects on the whole family (4, 5). Parents often act as the primary caregivers of children with chronic diseases (6, 7), who must also cope with challenges such as high medical costs, stigma from relatives and friends, and restricted family social interaction (8, 9). Growing evidence has shown that children with epilepsy (CWE) parents' life satisfaction is reduced due to the above issues and ongoing caregiving (10). Life satisfaction is a person's judgment of how satisfied he/she is with his/her current situation based on criteria that each person sets for himself/herself (11). Studies have shown that parents of CWE have lower levels of life satisfaction than other parents (2, 10). Therefore, assessing life satisfaction among caregivers of CWE and investigating its comprehensive influencing factors are of crucial importance in providing intervention strategies.

One of these factors is perceived stigma. It may have two distinct elements: the shame of having epilepsy based on feeling unable to control the child's seizures, and the fear of facing enacted stigma that may cause parents to try to hide their child's health status (12). The fact that epilepsy becomes overtly visible only during seizures causes some parents to limit disclosure or even keep their child's diagnosis a secret, while avoiding social events and family time for activities outside the house is transferred indoors (13). The sociocultural context may contribute to stigma among caregivers of CWE (14). Cultures that value collectivism are more inclined to stigmatize individuals who do not conform to social norms compared to cultures that emphasize individualism. Several comparative studies between Iran and Sweden have been conducted by Forsgren *et al.* regarding the experience of stigma in people with epilepsy (15, 16). The results showed that the Iranian society experiences more stigma. Parents in collectivist societies such as Iran often experience feelings of guilt when their children are diagnosed with epilepsy (17); this negative attitude adversely affects the life satisfaction of parents (10). Study results provide important information on the negative correlation between stigma and life satisfaction among primary caregivers of chronic illness (18, 19). However, these studies only examined the correlation between stigma and caregivers' life satisfaction without exploring possible mediating variables as proposed by the stress process model (20).

In the conceptual framework based on this model, the caregiver base is defined with four domains. First, there are contextual variables that include the demographic characteristics of caregivers. Second, there exist stressors (e.g., perceived behavioral problems or cognitive functioning of the care recipient). Third, there are mediators of the relationship between stressful factors and its consequences, such as social support and coping strategies. Finally, there are outcomes, e.g., well-being. The main premise of this model is that stressors have a direct and indirect relationship with outcomes (20). Consistent with the stress process model and several studies, we conceptualized stigma as a stressor for life satisfaction (21, 22). In addition, we propose that social support and coping strategies mediate the effect of stressors on life satisfaction. Our reason for choosing these factors as mediators was because they have been cited most frequently in the literature (19, 23, 24). Perceived social support is one of several factors that affect the caregivers' life satisfaction (25). It represents how available and sufficient social connections are perceived, indicating the perceived level of support from family, friends, and significant others (26). Numerous studies have shown that social support plays a crucial role in predicting the life satisfaction of caregivers of children with chronic illnesses (25, 27). Research has shown that social support both mediates and moderates the effect of stress on life satisfaction of parents of children with chronic disorders (19).

Another mediating variable in the present study model is coping strategies. In several studies, coping strategies have a mediating role between psychological distress and health outcomes (23, 28). Coping involves cognitive and behavioral strategies that are used to avoid or lessen stress (29). While there are several ways to understand coping, it can be thought of as consisting of three main domains: task-oriented coping, emotion-oriented coping, and avoidance coping. A task-oriented strategy is a problem-oriented approach and involves problem-solving activities to reduce stress (30). In the present study, only a task-oriented strategy was used as a coping strategy. The process of coping can change the relationship between the stressful factors of life and health (31), so the type of strategy used by these parents in the process of coping with the chronic stress of having a child with epilepsy is important.

In recent years, more studies have been conducted to assess life satisfaction around the world (32-34). These studies have shown that several factors such as perceived stigma, support resources, and coping strategies may influence how a chronically ill patient experiences care. Stigma poses a significant challenge for parents of children with epilepsy, requiring special attention from the health system (17). Hospital admissions and increased costs in patients with epilepsy notably impact the health and socioeconomic status of patients, as well as their life satisfaction (35). What is important is that the examination of these variables has been examined pairwise in the studies. On the other hand, a model that examines these four concepts at once was not found in the studies. Such a model can be the foundation of intervention strategies for decreasing stigma, as well as strengthening the social support and task-oriented coping style are needed to inform in primary caregivers of children with epilepsy, thus improving their life satisfaction. Moreover, it is unclear whether perceived social support and task-oriented coping play a role in the connection between perceived stigma and life satisfaction. Therefore, the aim of this study was to investigate the impact of perceived stigma on life satisfaction and further clarify the role of perceived social support and task-oriented coping as mediators of effects among caregivers of CWE. Specifically, based on the stress process model, it is hypothesized that higher levels of stigma decrease the levels of life satisfaction (H1); the relationship between stigma and life satisfaction is mediated by perceived social support, meaning that a higher level of stigma is associated with lower perceived social support, which in turn is associated with a lower level of life satisfaction (H2). We also hypothesize that the relationship between stigma and life satisfaction is mediated by task-oriented coping (H3), meaning that a higher level of stigma is related to a lower level of using task-oriented coping, which, in turn, is associated with a lower level of life satisfaction. Finally, we hypothesize that perceived social support and task-oriented coping co-play a serial mediating role in the relationship between perceived stigma and life satisfaction among caregivers of CWE (H4).

Materials and Methods

Participants and Procedures

A cross-sectional descriptive study was conducted on 210 primary caregivers of CWE who referred to the epilepsy departments of the hospitals affiliated to Larestan and Shiraz Universities of Medical Sciences, Fars Province in southern Iran, from August to November 2023. The inclusion criteria for caregivers were (1) primary caregivers (mothers or fathers) of a CWE for at least one year; (2) age ≥ 18 years; and (3) able to read and write in Persian. The inclusion criteria for CWE were (1) children under the age of 18 years and diagnosed with epilepsy; (2) children with comorbid attention-deficit/hyperactivity disorder, specific learning or behavioral issues (due to the prevalence of these disorders in children with epilepsy); (3) children with the presence of two or more unprovoked seizures at least 24 h apart; and (4) children under treatment with antiepileptic drugs (AEDs) for a minimum of 6-month duration. Caregivers who had gone through traumatic events like intense natural disasters, accidents, or sudden loss of family members in the previous six months, and those who could not or were not willing to cooperate, were illiterate, or were unable to read and complete the questionnaire were excluded from this study. To select the study samples, we prepared a list of all children meeting with inclusion criteria who had records in the study settings. Then, a convenient sample of the family caregivers with the inclusion criteria was invited to participate in the study. The process of sampling continued until the sample size needed was attained. All parents voluntarily participated in the study and signed an informed consent form. According to the recommendation of Wolf *et al.* (36), who suggest that to calculate the sample size, 5 to 10 observations per estimated parameter are necessary, in the present study with 39 parameters, a sample size of at least 195 was necessary. Ultimately, we were able to select 218 caregivers to participate in the study and complete questionnaires. Of these, 210 questionnaires were deemed suitable for analysis, resulting in an impressive response rate of 96.33%. After explaining the goals and obtaining informed consent from them, we distributed the questionnaires among the caregivers to be completed in a quiet room in the epilepsy department. The entire survey took approximately 20 to 30 minutes to complete. They were assured that their information would strictly remain confidential.

Instruments

The study included information on participants' demographics and four established self-report questionnaires.

Demographic and Clinical Information

The self-designed survey was utilized to gather information on the demographic features of caregivers of CWE. The information of primary caregivers included gender, age, education level, and occupation, and the demographic characteristics of CWE including age, duration of epilepsy, age of onset, seizure frequency, seizure control, comorbid disorders and number of AEDs.

Life Satisfaction Scale

This scale was developed by Diener *et al.* It consists of five items. An example item is “The conditions of my life are excellent.” Each item is scored using a 7-point Likert scale ranging from 1 (completely disagree) to 7 (completely agree). The total scores on this scale can range from 0 to 35, with higher scores reflecting higher levels of life satisfaction (11). The Persian adaptation of this survey was developed by Maroufizadeh *et al.* (2016), with a Cronbach's α of 0.87 (37). Cronbach’s α coefficient was 0.87 in the original version (11). In this study, the Cronbach's α was 0.88.

Perceived Stigma

This scale is a five-item instrument developed by Austin *et al.* to assess the caregivers' belief that their child is or may be stigmatized due to epilepsy. An example item is “People who know that my child has a seizure condition treat him/her differently.” Each item is scored on a 5-point Likert scale ranging from 1 (completely disagree) to 5 (completely agree). The scale measures stigma levels on a scale of 0 to 25, with higher scores reflecting increased stigma (38). The original version had a Cronbach’s α coefficient of 0.83 (38). The Persian version of this questionnaire was developed by Gholami e*t al.* (39) and its Cronbach’s alpha was reported to be 0.92. In this study, the Cronbach's α was 0.72.

The Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS was developed by Zimet. This scale contains 12 items categorized into three sections: family (4 items, Cronbach's alpha = 0.88), with an example item "My family really tries to help me," friends (4 items, Cronbach's alpha = 0.91), with an example item "My friends really try to help me," and significant others (4 items, Cronbach's alpha = 0.87), with an example item of "There is a special person who is there when I am in need." All three sources were included in the analysis. The rating system for each item is based on a 5-point Likert scale, where 1 represents complete disagreement and 5 represents complete agreement. The scores for each family, friends, or significant others subscale range from 4 to 20; higher scores indicate higher perceived social support (26). The total scores on the MPSSS fall within the range of 12 to 60, with higher scores reflecting higher levels of perceived social support. The Persian version of this questionnaire which was developed by Besharat *et al.* in 2019 evaluated its psychometric properties, and its Cronbach's alpha is reported to be 0.84 or higher (40). In this study, the Cronbach's α was 0.87.

Coping Inventory for Stressful Situations-Short Form (CISS-SF):

The CISS-SF was developed by Endler and Parker. This scale consists of 21 items categorized into three sections: task-oriented (7 items, Cronbach's alpha = 0.92), emotion-oriented (7 items, Cronbach's alpha = 0.82), and avoidant coping (7 items, Cronbach's alpha = 0.85). Based on the purpose of the present study and the presented conceptual framework, only the task-oriented strategy subscales were used. An example item is "Focus on a problem and see how I can solve it." Higher scores in each domain indicate a stronger tendency towards that coping style (30). Each item is scored on a 5-point Likert scale ranging from 1 (never) to 5 (very much). Kakabaraei *et al.* (2012) translated the CISS-SF into Persian and evaluated its psychometric properties, and its Cronbach's alpha is reported to be 0.74 or higher (41). In this study, the Cronbach's α was 0.77.

Statistical Analysis

IBM SPSS Statistics version 24.0 was used to perform statistical analysis. Demographic characteristics and four main variables (perceived stigma, task-oriented coping, perceived social support and life satisfaction) were analyzed descriptively. Continuous data were described as mean ± standard deviation (SD). Categorical data are described using frequencies and percentages. Pearson correlation was used to determine the relationship between these variables. SEM using AMOS 26.0 was used to evaluate the model fit. According to the normal distribution of the variables, the maximum likelihood (ML) method was used, which was inferred with skewness (±3) and kurtosis (±3). To test the mediating effect of perceived social support and task-oriented coping on the relationship between perceived stigma and life satisfaction (Figures 1 and 2), we used the PROCESS 4.1 macro proposed by Hayes (Model 4) (42); we used the PROCESS macro proposed by Hayes (Model 6) with the bias-corrected bootstrap 95% confidence interval (CI) based on 5,000 bootstrapping to test perceived social support and task-oriented coping as serial mediating role in the relationship between perceived stigma and life satisfaction. If the 95% CI of indirect effect did not contain zero, it indicated that the mediating effect was significant. A two-sided P-value < 0.05 was considered statistically significant.

Ethical Consideration

The present study was approved by the local Ethics Committee of Larestan University of Medical Sciences, Larestan, Iran (ethical code: IR. LARUMS. REC.1402.018). Prior to engaging in the study, all participants provided written consent after being fully informed of the study's objectives and methodologies. They were also reassured regarding the confidentiality and anonymity of their data.

Results

Preliminary Analyses

Among 210 parents of CWE, 151 (71.90) were mothers and 59 (28.10%) were fathers. The average age of caregivers was 36.04 ± 8.529 years, with a range of 19-59 years. CWE had a mean age of 7.19 ± 5.000 years, ranging from 1-18 years. Most of the children were on a single anti-epileptic drug (AEDs) (36.9%). 113 (53.8%) of children experienced seizure daily or weekly, in 109 (51.9 %) children the age at seizure onset was 2 years and above, and duration of seizure in 111 (52.9) was 11 seconds or more. Other sociodemographic characteristics are presented in Table 1. Correlations for all study variables are presented in Table 2. Perceived stigma was negatively correlated with perceived social support ($r = -0.199$, $P < 0.01$), task-oriented coping ($r = -0.277$, $P < 0.01$), and life satisfaction ($r = -0.298$, $P < 0.01$). Perceived social support was positively correlated with task-oriented coping ($r = 0.320$, $P < 0.01$) and life satisfaction ($r = 0.353$, $P < 0.01$). Task-oriented coping was positively correlated with life satisfaction ($r = 0.401$, $P < 0.01$).

Fitness of Structural Model

We employed SEM to examine the model, where perceived stigma was considered as the independent variable, perceived social support and task-oriented coping were treated as the mediating variables, and life satisfaction was identified as the dependent variable. Initially, we assessed the normality of the data by examining the skewness (-3 to +3) and kurtosis (-3 to +3) values, which met the criteria for normal distribution; based on the data, the skewness and kurtosis values for perceived stigma, perceived social support, task-oriented coping, and life satisfaction were between -2 to +2. Therefore, the obtained results are consistent with the assumption of normal distributions

(43). Chi-square/degrees of freedom (χ2/df) ≤ 3, Comparative Fit Index (CFI) ≥ 0.90, Tucker-Lewis index (TLI) ≥ 0.90, Incremental Fit Index (IFI) ≥ 0.90, Root Mean Square Error of Approximation (RMSEA) ≤ 0.08, and Standardized Root Mean Square Residual (SRMR) ≤ 0.05 were used to evaluate the model fit (44). The findings from the SEM analysis indicated that the structural model had a good fit to the data (38), with χ2/df = 1.623, CFI = 0.935, IFI = 0.937, TLI = 0.923, RMSEA = 0.055, and SRMR = 0.647.

Table 1. Demographic Characteristics of Study Subjects (N = 210)

Characteristic	Categories	N (%)	Mean (yr) ± SD	(n = 210)
				Range (yr)
Age of parents			36.04 ± 8.52	19-59
Age of child			7.19 ± 5.00	1-18
Caregiver's gender	Mother Father	151 (71.90) 59 (28.10)		
Level of education	High school or below Academic or above	137 (65.20) 73 (34.80)		
Job	Employed Unemployed Retired At home due to necessity of caregiving	79 (37.60) 115 (54.80) 9 (4.30) 7 (3.30)		
antiepileptic drugs (AEDs)	single ASMs two ASMs three or more ASMs	78 (36.9) 72 (34.20) 60 (28.90)		
Seizure frequency	Daily or weekly monthly seizures once or twice per year no seizures during the previous year	113 (53.80) 69 (32.90) 23 (11.00) 5 (2.40)		
Age at seizure onset	< 2 ≥ 2	101 (48.10) 109 (51.90)		
Usually for how long the seizure last?	5 sec 5-10 sec ≥ 10 sec	36 (17.10) 63 (30) 111 (52.90)		
Seizure types	generalized tonic-clonic seizures partial seizures absence of seizures	93 (44.30) 92 (43.80) 25 (11.90)		
Comorbidities in child	Yes No	94 (44.70) 116 (55.30)		

Testing for the Mediation Analysis

First, we examined the mediating effects of the hypotheses tested using linear regression analysis. The three correlating variables (perceived stigma, perceived social support, and task-oriented coping) were introduced as potential predictors of life satisfaction. The results showed that stigma was negatively correlated with perceived social support (β = −0.45, P < 0.01), task-oriented coping (β = −0.25, P < 0.001), and life satisfaction (β = −0.55, P < 0.01). Further details are shown in Table 3. Consequently, we used the PROCESS 4.1 macro proposed by Hayes to test the mediating effect. In the model with perceived social support as the mediator, perceived stigma had both direct (c’ = -0.43, 95% CI: -0.67 to -0.20) and indirect effects (a1b1 = -0.11; 95% bootstrap CI: -0.12 to -0.02) on life satisfaction via perceived social support. These results supported the meditational hypothesis. More details about the relationships between the variables are displayed in Figure 1. In the model with task-oriented coping as the mediator, perceived stigma had both direct (c’ = -0.40, 95% CI: -0.63 to -0.17) and indirect effects (a1b1 = -0.14; 95% bootstrap CI: -0.26 to -0.05) on life satisfaction through task-oriented coping. These results supported the meditational hypothesis. More details about the relationships between the variables are displayed in Figure 2. Second, we conducted serial mediation analyses using hypothesized models derived from the correlation matrix and a simple mediation model. The significant basic characteristics of caregivers and CWE were controlled as control variables in the structural model. Only caregivers’ age and comorbid disorders in CWE were significant for the dependent variable.

Table 2. Mean and Standard Deviation and Correlation between Stigma, Perceived Social Support, Task-Oriented Coping and Life Satisfaction in Primary Caregivers of Children with Epilepsy

	1	2	3	4
Stigma	1			
2. Perceived Social Support	-0.19**	1		
3.Task-oriented coping	-0.27**	0.32**	1	
4. life satisfaction	-0.29**	0.35**	0.40**	1
M	15.90	42.90	19.46	19.50
SD	4.37	9.91	4.92	8.09

Using bivariate correlation analysis
** P < 0.01

Table 3. Testing Mediations with Linear Regression Analysis for Stigma, Perceived Social Support, Task-Oriented Coping and Life Satisfaction in Primary Caregivers of Children with Epilepsy. Robust Standard Errors in Parentheses.

Variables	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6	Model 7	Model 8
stigma	-0.551***	-0.451**		-0.439***	-0.255***		-0.404***	-0.349***
	(0.127)	(0.174)		(0.127)	(0.0800)		(0.124)	(0.123)
Perceived Social Support			0.288***	0.250***				0.183***
			(0.0491)	(0.0505)				(0.0514)
Task-oriented coping						0.660***	0.579***	0.472***
						(0.101)	(0.107)	(0.108)
Constant	28.27***	50.07***	7.136***	15.77***	23.52***	6.651***	14.66***	8.017**
	(2.068)	(2.688)	(2.220)	(3.601)	(1.248)	(2.074)	(3.546)	(3.977)
Observations	210	210	210	210	210	210	210	210
R-squared	0.089	0.040	0.125	0.179	0.051	0.161	0.206	0.251

*** P < 0.01, ** P < 0.05, * P < 0.1.
Model 1: life satisfaction = b0 + b1*stigma + e; Model 2: Perceived Social Support = b0 + b*stigma+e; Model 3: life satisfaction = b0 + b* Perceived Social Support + e; Model 4: life satisfaction = b0 + b1*stigma + b2* Perceived Social Support + e; Model 5: Task-oriented coping = b0 + bstigma + e; Model 6: life satisfaction = b0 + bcoping + e; Model 7: life satisfaction = b0 + b1stigma + b2 Task-oriented coping + e; Model 8: life satisfaction = b0 + b1stigma + b2 Perceived Social Support + b3 Task-oriented coping + e

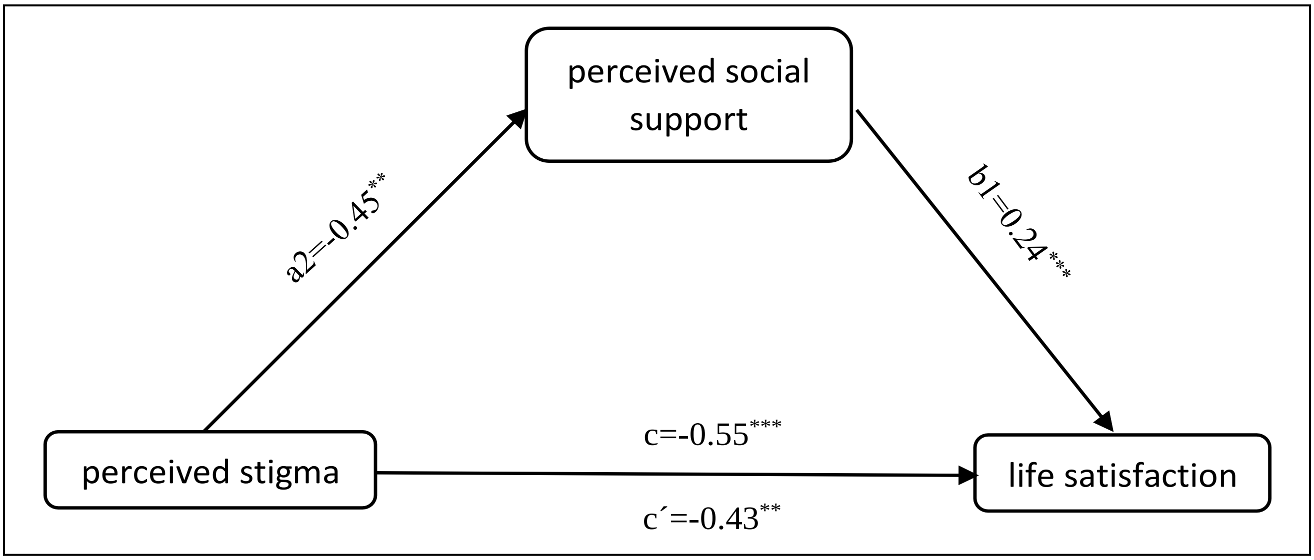

Figure 1. The Single Mediation Role of Perceived Social Support in the Relationship between Perceived Stigma and Life Satisfaction in Primary Caregivers of Children with Epilepsy. *P < 0.05, **P < 0.01.

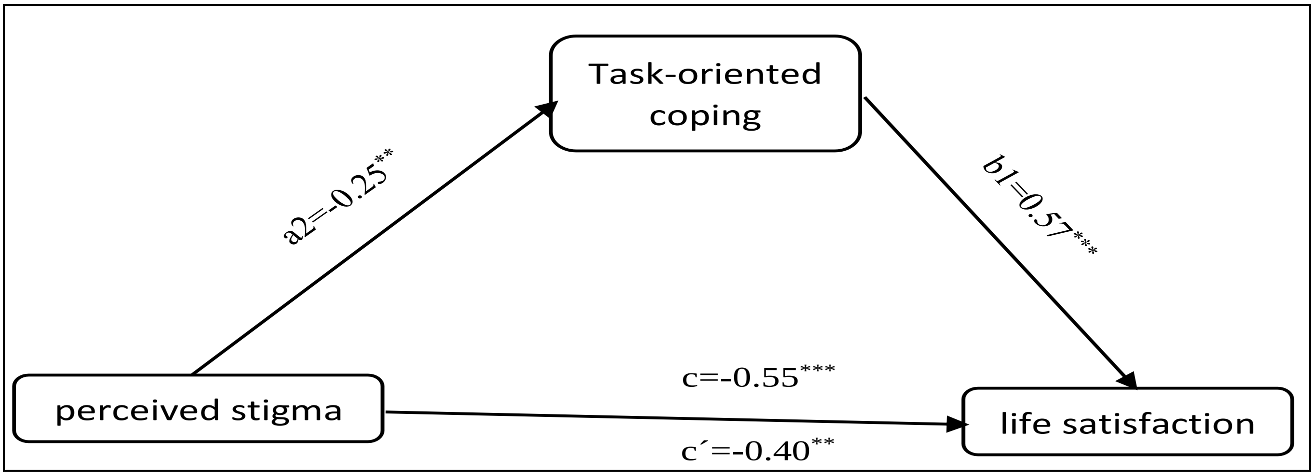

Figure 2. The Single Mediation Role of Task-Oriented Coping in the Relationship between Perceived Stigma and Life Satisfaction in Primary Caregivers of Children with Epilepsy. *P < 0.05, **P < 0.01.

The regression results are shown in Table 3. In accordance with our serial mediation hypotheses, as displayed in Figure 3, perceived stigma had a total effect on life satisfaction (c = -0.51, 95% CI: -0.75 to -0.28). Specifically, perceived stigma was negatively associated with perceived social support (a1 = -0.46, 95% CI: -0.76 to -0.15), which in turn was positively associated with task-oriented coping (d21 = 0.14, 95% CI: 0.080 to 0.21). Task-oriented coping was positively associated with life satisfaction (b2 = 0.43, 95% CI: 0.23 to 0.63). The direct effect of perceived stigma on life satisfaction decreased (c' = -0.30, 95% CI: -0.52 to -0.09). It was revealed that perceived stigma, perceived social support, and task-oriented coping explained 57% of the variance in life satisfaction (see Table 4 and Figure 3). Moreover, the model supported the mediational hypothesis (R2 = 0.33, F = 16.84, P < 0.001). Supporting our hypotheses, the specific indirect effect of perceived stigma on life satisfaction through both mediators (perceived social support and task-oriented coping) in serial (X→M1→M2→Y) was also significant (a1b1 + a2b2 = -0.029, 95% bootstrapped CI: -0.060 to -0.006) (see Table 5).

Table 4. Regression Coefficients for Life Satisfaction Based on Stigma, Perceived Social Support, and Task-Oriented Coping Style in Primary Caregivers of Children with Epilepsy (N = 210).

Path	β	SE	t	P	BC 95% CI	
					Lower	Upper
stigma → life satisfaction	-0.30**	0.11	-2.79	0.0050	-0.52	-0.09
stigma → social support	-0.46**	0.15	-2.99	0.0030	-0.76	-0.15
stigma → Task-oriented coping	-0.18*	0.07	-2.49	0.0130	-0.33	0.03
social support → Task-oriented coping	0.14***	0.03	4.38	0.000	0.08	0.21
social support → life satisfaction	0.21***	0.05	4.23	0.000	0.11	0.31
Task-oriented coping → life satisfaction	0.43***	0.10	4.27	0.000	0.23	0.63
age → life satisfaction	-0.10	0.05	-1.09	0.054	-0.21	0.00
comorbidity→ life satisfaction	1.01	0.41	2.43	0.015	0.19	1.82

Note. *P < 0.05, **P < 0.01, ***P < 0.001.

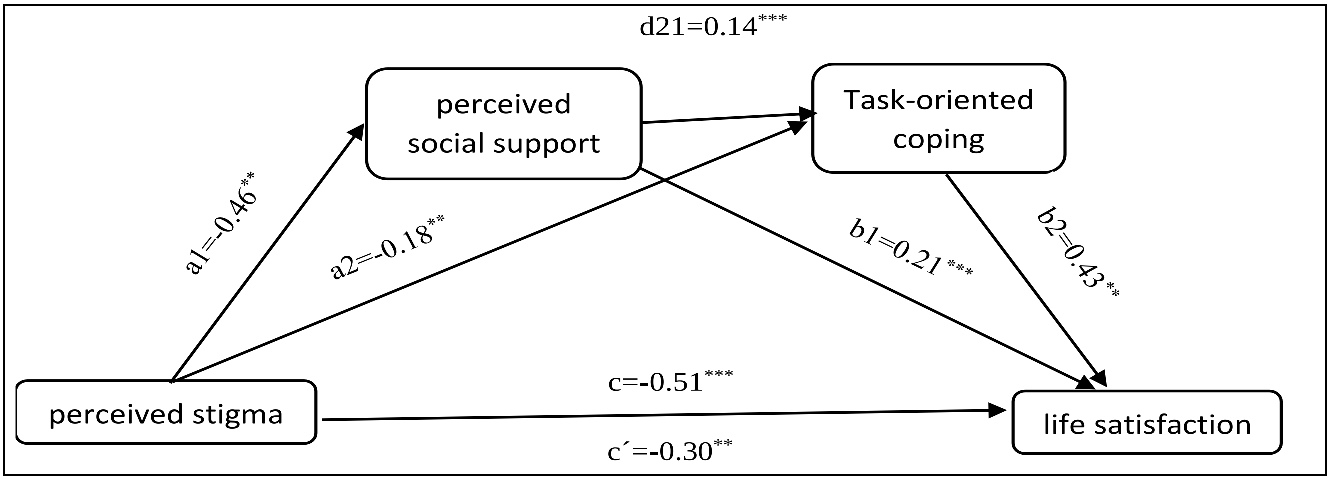

Figure 3. The Serial Multiple Mediation Role of Perceived Social Support and Task-Oriented Coping in the Relationship between Perceived Stigma and Life Satisfaction in Primary Caregivers of Children with Epilepsy. *P < 0.05, **P < 0.01.

Table 5. Total, Direct and Indirect Effects of Perceived Stigma (X) on Life Satisfaction (Y) through Perceived Social Support (M1) and Task-Oriented Coping (M2) in Primary Caregivers of Children with Epilepsy (N = 210)

Effect	Estimate	SE	95%CI		t	P
			Lower	Upper		
Total effects	-0.51***	0.11	-0.75	-0.28	-4.36	0.000
Direct effect	-0.30**	0.11	-0.52	-0.09	-2.79	0.005
Total indirect effect	-0.20	0.06	-0.34	-0.08		
Indirect effect (X→M1→Y)	-0.09	0.04	-0.19	-0.02		
Indirect effect (X→M2→Y)	-0.08	0.03	-0.17	-0.01		
Indirect effect (X→M1→M2→Y)	-0.02	0.01	-0.06	-0.006		

Discussion

In this research, we constructed a model with multiple mediations to explore how perceived stigma influences caregivers' life satisfaction and how perceived social support and task-oriented strategy act as protective factors against negative impacts on caregivers' well-being. Perceived stigma negatively and significantly predicted life satisfaction (supporting hypothesis 1).

Meanwhile, it also confirmed that perceived social support and task-oriented coping could increase the level of life satisfaction (supporting hypothesis 2 and 3). Significantly, a sequential mediation process was observed linking perceived stigma to caregivers' life satisfaction, via perceived social support and task-oriented coping (confirming hypothesis 4).

In the present study, it was indicated that there was a direct link between stigma and life satisfaction, which aligns with previous studies (13, 18, 22, 25). Research findings show that parents who are ashamed of having a child with seizures may inadvertently pass this stigma on to their children (45, 46). Therefore, implementing supportive measures for parents to foster a comprehensive understanding of epilepsy to reduce stigma and embarrassment seems to be beneficial (3). It seems that by increasing the information about epilepsy and the factors involved in its occurrence, it is possible to help improve the attitude and, consequently, the level of well-being of parents.

This research found that the perceived social support mediated the connection between perceived stigma and life satisfaction in caregivers of CWE. Iranian society has a traditional culture and Islamic beliefs regarding the role of the family in caring for patients. This may explain why family social support scored higher than friends and significant others in this study (16). Hence, it is important to provide compassionate care for a sick family member, especially when the family member is a child. Social support is a positive and predictive factor for increasing life satisfaction. These findings are in the same line with previous studies (39, 47). It can expand one's social network, resist or eliminate stress, and promote health (48, 49). The results of the present study show that social support is a mediator between perceived stigma and life satisfaction. Patients who feel more socially excluded due to stigma seem to experience a lower life satisfaction. Patients who have a certain degree of stigma reduce their help-seeking and medical behavior, which aggravates the symptoms of their disease and affects the recovery of the disease, thereby affecting the quality of life of the patients. Lee *et al.* found patients with a high sense of stigma cannot understand people's opinions correctly and have an inferiority complex in the process of interpersonal communication, which results in behaviors such as escape or withdrawal, which greatly affect the quality of life (49, 50).

The present study also examined the mediating effects of task-oriented coping between perceived stigma and life satisfaction. In other words, this study showed that in addition to direct effects, perceived stigma indirectly affects life satisfaction through task-oriented coping in caregivers of CWE. The findings of a research study revealed that utilizing problem-focused coping methods can lessen the adverse effects of stigma on life satisfaction (51, 52). Caregivers who used problem-focused coping addressed the problem that was causing distress, and they were active in problem solving and adapting to the situation through rational cognitive appraisal (4). Noteworthily, the serial mediation path of "perceived stigma → perceived social support → task-oriented coping → life satisfaction" is significant. This pathway suggests that CWE primary caregivers with low levels of perceived stigma will perceive more social support from others, which may increase their task-oriented coping and thus their life satisfaction. It can expand a person's social network, resist or eliminate levels of perceived stigma, and promote well-being (24, 50). This could be attributed to the positive mindset towards crises within these families, as well as their adaptable family structure and effective communication, which facilitate the use of proactive coping strategies (50-53). It seems that perceived social support from various sources can encourage caregivers to use active coping strategies to participate in the treatment of epilepsy patients, and how patients and caregivers cope with this disease should be considered (34, 51).

Limitation

While this study uncovered valuable insights, some limitations need to be addressed. Firstly, the use of convenience sampling may have introduced bias, so future studies should implement random sampling methods for better representation. Secondly, the cross-sectional survey design in this study only captures the relationships between variables at a single point in time. To truly understand causal relationships, longitudinal research is recommended to track changes over time. Thirdly, the non-completion rate could potentially lead to sampling bias, as the characteristics of participants who completed the questionnaires may differ from those who did not. Additionally, the reliance on self-report questionnaires to evaluate stigma, social support, coping style, and life satisfaction may lead to inflated estimates due to subjective bias from both participants and researchers. Further, additional investigations should consider physiological assessment. Fourthly, another limitation is that the study was conducted with a relatively small sample size. This approach limits the generalizability of the results. It is suggested that similar studies be carried out in big cities and rural regions of Iran with a larger sample size, and that the results be compared. Finally, since the data was collected in a region in the south of Iran, it is suggested that it should be investigated in other cultures and other parts of the country. Also, other clinical or demographic information such as participants' self-rated health, religiosity, number of children in the family, birth order, and location of the child with epilepsy should be investigated in other studies.

Implications for Further Research

The results of this research have important implications for parents of CWE. Perceived stigma seems to play a vital role in determining life satisfaction, and it is essential to decrease stigma using various approaches to enhance the life satisfaction of parents. Improving family and friends' support can help lessen the negative impact of perceived stigma on life satisfaction through perceived social support and task-oriented coping (13). It seems that parents' performance and well-being play an important role in improving children's performance. When parents react negatively to a child's epilepsy, the child may feel ashamed, and their functioning may suffer. Paying attention to parents' health, their attitudes and use of positive coping strategies is important to help improve both functioning and life satisfaction (22, 46). Given the detrimental impact of stigma on overall life satisfaction and the multiple sources of support and coping, it is important to address even relatively low rates of stigma which should be taken seriously, and culturally appropriate measures by health policymakers are required.

Conclusion

Overall, the study findings indicate that it is valuable to enhance our understanding of the direct and indirect influences of various factors on the life satisfaction of caregivers of CWE, including their use of task-oriented coping strategies and their perception of social support. Therefore, according to the results of this research, it can be concluded that improving the life satisfaction of Iranian parents with CWE, which has a significant effect on the rehabilitation and treatment interventions of their children, requires identifying and correctly understanding the sources of support. On the other hand, teaching effective coping strategies through mental health professionals is necessary to reduce the stigma of these parents, and should be prioritized in the support programs of the guardian organizations.

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Conflict of Interest

None.

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