How to Cite:
Abdulameera, A. B., & Al-Dujaili, A. H. (2022). Social stigma and psychological distress among caregivers of children with epilepsy. *International Journal of Health Sciences*, *6*(S6), 7296–7305. https://doi.org/10.53730/ijhs.v6nS6.12044

Social stigma and psychological distress among caregivers of children with epilepsy

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***Abstract*---**Background: Epilepsy is a widespread health issue that has major consequences for people of all ages. Since they appear to be more likely to experience despair, stress, worry, and discomfort, parents of children with epilepsy have reported greater negative effects and poor psychological and physical health. Many caregivers struggle with patience and effective adversity adaptation. Therefore, easing parents' psychological distress and stigma will enable them to give their kids the greatest care possible, which will aid in the children' recovery. Objective aims to: Assess stigma and psychological distress among caregivers of children with epilepsy and Find out relationship between psychological distress and stigma of caregivers and their socio-demographic data. Methodology: A descriptive (correlational) quantitative study design has been carried out from September 22th 2021 to February 11th 2022 in order to assess stigma and psychological distress among caregivers of children with epilepsy and to find out the relationship between stigma and psychological distress of caregiver and their socio-demographic characteristics. A non-probability sampling technique (purposive sample) of (72) caregivers of children with epilepsy in Najaf City / Najaf Health Directorate / Sadr Medical City (Middle Euphrates Center for Neurosciences in Najaf Governorate). Results: The study found that the majority of caregivers are mothers (63.9%), and (36.1%) of them were in the age group range between (41 -49) years, married (80.6%), average education level (31.9%)were secondary school, barely sufficient income (45.8%), housewives (43.1%) live in the city (77.8%), The results of the study revealed that caregivers of children with epilepsy have moderate level of psychological distress(47.2%)and moderate level of social stigma(41.7%) , it also revealed a statistical relationship between psychological distress, stigma and some of socio- demographic data at $p \leq 0.05$. Conclusion: The majority of subjects have moderate level

of stigma (41.7%) and moderate level of psychological distress (47.2%). There is a significant relationship (P < 0.05) between level of stigma and some of the socio-demographic characteristics (caregiver, age , number of children and level of education). The measure of the level of psychological distress as well as the level of social stigma were average that a positive significant correlation (r=0.502) between psychological distress and social stigma. Recommendations: The present study recommends that educating families of epileptic patients through (educational programs) can help parents feel less stressed out by educating them about the disease, its symptoms, and how to interact with the patient. Collaborating with religious organizations to eliminate any stigma or stereotype about the condition that impacts children with epilepsy's future in all spheres of life, including as school, job, and marriage, thereby reducing the psychological burden on the patient and his family.

***Keywords*---**stigma, psychological distress, caregivers, epilepsy.

Introduction

Disabilities, physical mortality and morbidity, and poor social functioning can all be caused by psychiatric disorders. Additionally, psychological problems can make social burden and economic insecurity worse in a variety of societies around the world. Mental health disorders have emerged as major public health concerns globally[1]. At least 65 million people worldwide are directly affected by epilepsy, which is a prevalent and significant health issue that affects people of all ages. It is a global health concern for children and adolescents, with prevalence ranging from (3.2-5.5/1000) in rich nations to (3.6-44/1000) in underdeveloped countries, and it indirectly affects fewer than 500 million people [2].Injury, a higher risk of premature death, and disease-related developmental abnormalities that last into adulthood are the main causes of mortality and morbidity in epilepsy[3]. Epilepsy is thought to affect one in 150 children. A very significant risk of developmental and behavioral problems results from the early onset of most severe seizures, which are accompanied by a mix of seizures and growth slowing or regression.

When children are diagnosed with epilepsy, parents experience stress and become too preoccupied with caring for them, which can negatively affect how well their children get along with their siblings and cause serious psychological problems[2]. A type of emotional upheaval known as psychological distress (PD) is characterized by a confluence of symptoms of depression and anxiety. In Europe and the US, up to 50% of parents of children with chronic illnesses report experiencing psychological distress [1]. The phrase "psychological distress" refers to the emotional suffering typified by depression and anxiety; the American Psychiatric Association (APA , 2013) specified psychological distress as “a set of symptoms and experiences that are held to be annoying, troubling, or out of the ordinary ” [4]. The presence of these symptoms for two weeks may indicate a state of distress; however, just because a person does not experience these symptoms does not mean that he or she is entirely healthy. Other symptoms of psychological

distress include anger or irritability, anxiety, and exhaustion, as well as a tendency to devalue and a desire to isolate, stay away, and refrain from engaging in activities with others[5]. The family structure can be significantly impacted by childhood-onset epilepsy, with mothers being especially vulnerable to poor functioning.

Mothers of children with epilepsy usually struggle with sleep issues and psychological distress are more common among them ,Epilepsy has long been linked to stigma, which is frequently stronger than that connected with other chronic illnesses and is comparable to that associated with mental health issues, in addition to increasing challenges in mother functioning[6]. Although providing care is a crucial aspect of parenting, it can be very taxing when the demands are excessive and ongoing. Overwhelming duty may negatively impact the physical and mental health of caregivers [7]. Stigma impacts those who care for children with epilepsy when the family accepts other people's judgmental behaviors and attitudes as well as their own, which causes unpleasant physiological reactions such anxiety, depression, and stress [8]. Epilepsy still has a stigma with serious social repercussions. Epilepsy, which is defined as a lack of control over a person's conduct, can influence a patient's daily life, lowering their quality of life and causing psychological distress for their parents. The unpredictability of the occurrence of these seizures is one of the most stressful aspects of the disease [9]. Epilepsy in young children causes a very significant effect on stress and parental burden largely as a function of it.

The symptoms of anxiety and depression are reported by caregivers of both children and adults with intellectual disability. These high levels of anxiety are likely to have an impact on the parents' health and ability to care for their children because caregivers of children with intellectual disability are frequently distressed, many of the children have unmet needs that are not being addressed by services, and the degree of unmet need is related to caregiver distress [10], [11]. Family caregiving raises two types of safety risks that all nurses should be aware of. First and foremost, caregivers are referred to as "secondary patients," who really need protection and guidance. Second, family caregivers are unpaid employees who frequently need assistance in becoming skilled, healthy volunteers who can help protect their family members (i.e., care recipients) from harm [12].

Materials and Method

Design of the Study

A descriptive (cross-sectional) quantitative design study was carried throughout the present study to identify stigma and psychological distress among caregivers of children with epilepsy. During the period from 9th September 2021 to 16th February 2022.

Setting of the Study

The study was conducted at Al-Najaf city (Middle Euphrates Center for Neurosciences in Najaf Governorate).

Sample of the Study

A non-probability sampling technique (purposive sample) of (72) caregivers of children with epilepsy are included in the study.

Instrument of the study

The researcher constructed a self-administrative questionnaire for the purpose of present study. The final research instrument is made up of three parts.

- **Part 1: Caregiver's Socio-demographic Characteristics**
  A socio-demographic characteristics sheet of (12) items, including (ID, who are caregiver, age, family member, marital status, number of children, level of education, job, monthly income, residency area, the house ownership , Degree of kinship).
- **Part 2: Social stigma scale**
  Stigma Questions shows social stigma for caregivers. This part consists of (15 items) using a three-level Likert rating scale (apply, sometimes, never applicable) rated and scored 3 apply, 2 sometimes, and 1 does not apply, the total score was 15, the range of social stigma levels.
- **Part 3: The Kessler Psychological Distress Scale (K10)**
  The Kessler Psychological Distress Scale (K10) is a well-known, clinically useful measure of psychological symptoms that has undergone rigorous validation. It is renowned for its simplicity, accessibility, high predictability, and good factorial and construct validity. The 10-item questionnaire was created to generate a global assessment of distress based on inquiries into a person's past four-week experiences with anxiety and depressive symptoms. Each question on the scale had a five-value response option that ranged from all the way down to never (all the time), most of the time (most of the time), some of the time (some of the time), and never (none of the time).Participants' scores were categorized as follows: 20 to 24 as mild stress, scores of 25 to 29 as moderate stress, and scores of 30 to 50 as severe stress [13]. The assessment in present study is based on the statistical scoring system that indicated total mean of scores between (1-2.33) as (poor) ; and those between (2.34-3.6) as (moderate) , those with scores more than (3.66) as (good) .

Data Collection

The researcher has gathered the data by using the developed questionnaire with the aid of arranged interview. The researcher used (semi-structured interview) technique with the caregivers as they were individually interviewed in and each subject of study sample was interviewed in the same way by using the similar questionnaire and using Arabic version of questions.

Statistical analysis

The data were analyzing through application of the descriptive and inferential data analysis methods, included:

Descriptive Data Analysis

- Tables (Frequencies, and Percentages).
- Statistical figures (Bar Charts).
- Statistical mean and standard deviation.
- Mean of Score (MS).

Inferential Data Analysis

- chi-square
- Pearson's correlation

Results

Table 4.1
Statistical distribution of study sample (caregivers) by their demographic data

Demographical data	Intervals	Frequency	Percent
Caregiver	Father	26	36.1
	Mother	46	63.9
Age/years	<= 31	11	15.3
	32 – 40	16	22.2
	41 – 49	26	36.1
	50 – 58	14	19.4
	59+	5	6.9
Family Member	<= 3	6	8.3
	4 – 6	47	65.3
	7 – 9	14	19.4
	10+	5	6.9
Marital Status	Married	58	80.6
	Widowed	5	6.9
	Divorced	4	5.6
	Separated	5	6.9
Number Of Children	<= 3	33	45.8
	4 – 6	32	44.4
	7+	7	9.7
Level of education	Illiterate	5	6.9
	Literacy	11	15.3
	primary school	19	26.4
	secondary school	23	31.9
	Institute	14	19.4
Job	employed	15	20.8
	free work	26	36.1
	house wife	31	43.1

Monthly Income	sufficient	9	12.5
	barely sufficient	33	45.8
	insufficient	30	41.7
Residence area	Urban	56	77.8
	Rural	16	22.2
House Ownership	Freehold	29	40.3
	Rental	19	26.4
	Mortgaged	24	33.3
Relative	There is no	38	52.8
	Son, niece / uncle, aunt	34	47.2
	Son, niece / maternal aunt	0	.0

Table (4.1) displays the statistical distribution of the study sample based on socio-demographic data, and it describes that the caregivers' subgroup has the highest percentage of: caregivers between the age group (41 – 49) (36.1%), female caregivers (63.9 %), family member at category(4-6) were (65.3%) those are graduated in institute and college (27.9 %), those with barely sufficient monthly income (54.1 %), those who are married (86.9 %) ; those who are housewives (43.1 %) ; those who live in urban areas (77.8 %) ; those who are freehold owning their houses (40.3 %) .

Table 4.2
Descriptive statistics of caregiver's subgroups according to their total mean of score of social stigma scale

Overall assessment		Frequency	Percent	MS	Asses.
Social Stigma	Low	18	25	1.89	Moderate
	Moderate	30	41.7		
	High	24	33.3		

Freq : Frequency ; MS : Mean of Scores ; Low : MS = 1-1.66 ; Moderate : MS = 1.67-2.33 ; High : MS ≥ 2.34.

Table (4.2) shows the overall assessment of social stigma scale, According to this table, the majority of caregiver have moderate level of social stigma (41.7%), while 25% had low level and 33.3% with high level of social stigma.

Table 4.3
Descriptive statistics of caregiver's subgroups according to their total mean of score of Kessler psychological distress

Overall assessment		Frequency	Percent	MS	Asses.
Kessler psychological distress	Poor	31	43.1	2.61	Moderate
	Moderate	34	47.2		
	Good	7	9.7		

Freq : Frequency ; MS : Mean of Scores ; Poor : MS = 1-2.32 ; Moderate : MS = 2.33-3.66 ; Good : MS ≥ 3.67.

Table (4.3) displays the overall assessment of Kessler psychological distress, it demonstrate that the majority of caregiver have moderate level of distress (47.2%), while 43.1% had low level and 9.7% with high level of distress.

Table 4.4
Pearson's correlation coefficients between overall score of Kessler psychological distress and social stigma scale

Scales	Overall Kessler psychological distress
Overall Stigma scale	P.value = 0.001*

*Correlation is significant at P.value 0.01

Table (4.4) illustrates the relationship between overall assessment of Kessler psychological distress scale for caregivers and social stigma scale; it shows that there is a significant relationship between overall assessment of Kessler psychological distress scale for caregivers and social stigma scale at P.value = 0.001*

Table 4.5
Relationship between total score assessment of social stigma Scale for caregivers and their demographic data

		Mean	Std. Deviation	Frequency	P.value
Caregiver	Father	1.67	0.41	8.96	0.00*
	Mother	2.01	0.48		
Age/years	<= 31	2.35	0.26	8.78	0.00*
	32 – 40	2.11	0.50		
	41 – 49	1.57	0.36		
	50 – 58	1.86	0.45		
	59+	1.88	0.38		
Family Member	<= 3	1.82	0.40	0.35	0.79
	4 – 6	1.93	0.50		
	7 – 9	1.80	0.46		
	10+	1.80	0.56		
Marital Status	Married	1.91	0.49	0.88	0.46
	Widowed	1.64	0.44		
	Divorced	2.12	0.51		
	Separated	1.76	0.41		
Number of children	<= 3	2.04	0.49	3.39	0.04*
	4 – 6	1.74	0.44		
	7+	1.83	0.46		
Level of education	Illiterate	2.23	0.40	8.30	0.00*
	Literacy	2.13	0.44		
	primary school	2.18	0.40		
	secondary school	1.62	0.44		
	Institute	1.62	0.30		

* Significant at P<0.05

Table (4.5) illustrates the relationship between overall assessment of social stigma scale for caregivers and their demographic data. It reveals that there is significant relationship between overall assessment of social stigma scale for caregivers and some of their demographic data(caregivers, age, number of children and level of education).

Discussion

The analysis of findings revealed that most of samples were married mothers (80.6%) of children with epilepsy, falls in the age group (41 - 49) years old and graduated from secondary school (31.9%) with barely sufficient monthly income (45.8%). This finding was backed up by Al-Bahadli & Adai (2019), who found that mothers accounted for 74% of all parents. Also this approves with study of Hassoni & Zainy, (2021). The study results indicate that the more caregiver (34%) were falling in the age group (42 - 49) years old. Table (1) demonstrates that the majority of the subjects' jobs (43.1 percent) are housewives. This finding is corroborated by Muhe AL-(2014) deen's study, which discovered that (70%) of the samples were housewives. According to the perspective of our culture, fathers spend the majority of their time at work and have provider responsibilities, and mothers have the responsibility for household and child care, so mothers spend all of their time for their children.

In regarding to residence area, the study's results reveal that the highest number of caregivers (77.8%) were in the urban areas. This result is in line with Saeed & Adai, (2018) who claimed that the caregiver's area is urban .in addition to Masulani-Mwale et al., (2018) have done a study that show (88.3%) of parents were from urban sitting. Table (4.2) shows that the overall assessment of social stigma scale was moderate(41.7%) for the study subjects .This result is agreeing with the study of Hassoni & Zainy, (2021) who found that the overall assessment of social stigma scale was moderate (44%). Table (4.3) shows that the overall assessment of Kessler Psychological Distress scale was moderate(47.2%) for the study subjects .This result is agreeing with the study of Abdulameer & Al-dujaili, (2021) who found that the overall assessment of Kessler Psychological Distress scale was moderate with mean of scores = 2.78 . Tables (4.4) show that there is a significant relationship between total score assessment of social stigma scale and family members. This is perhaps due to the increase in the sample number in this category (<= 3 member) compared to other categories, the result was of significance.

Conclusions

The researcher has reached the following conclusions based on the discussion and analysis of the study findings:

- The study came to the conclusion that the majority of caregivers experienced mild psychological distress and social stigma.
- Psychological distress and social stigma were statistically significant among females.
- Caregivers, age, number of children, and level of education were statistically significant while other parameters were not significant.

- The caregivers were under the age of fifty and more than half of the caregivers were mothers. The majorities of the subjects were married, had completed secondary school and had a barely sufficient income.
- According to the study, social stigma and psychological distress have a strong relationship with one another and their combined effects.

Recommendations

According to the findings of the present study, the researcher recommends the following:

- Parents must receive sufficient information about how to interact with their children through educational programs, sessions and a brochure.
- To help parents of children with epilepsy cope with stress and social stigma, the media should focus on coping strategies.
- Additional research should be done in the form of a survey.
- Preparing a qualified healthcare practitioner to respond to negative patient outcomes and emotional recovery effectively to improve outcomes for children and their families.

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