



Effect of Psychological Empowerment Program on Feeling of Burden and Self-efficacy among Mothers of Children with Epilepsy

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ABSTRACT

Background: Epilepsy is one of the most common neurological disorders affecting children. Mothers are primary caregivers of those children, they suffer from several psychological challenges in the form of low self-efficacy and a sense of burden. **Aim of this study:** was investigate effect of psychological empowerment program on feeling of burden and self-efficacy among mothers of those children. **Research Design:** A quasi-experimental design was utilized in this study (one group pre/post-test). **Setting:** The study was carried out at outpatient clinic for epilepsy at Psychiatric/Mental Health Hospital, Benha City, Qalyubia Governorate. **Subject:** 40 convenience mothers having children with epilepsy was constitute subject of study. **Tools:** Three tools were used: Structured Self-administered Questionnaire included socio-demographic data of mothers and demographic data and medical history of their children, The Zarit Burden Interview, and Revised Scale for Caregiving Self-Efficacy. **Results:** More than half of mothers have severe level of burden pre-program implementation, this percentage improve after implementation of program to become mild burden presented by two thirds of mothers. For self-efficacy, less than two thirds of mothers had low self-efficacy before program implementation, while almost three quarters of them have high self-efficacy post program implementation. Also, there is a highly statistically significant negative correlation between total burden and total self-efficacy among the studied mothers post program implementation. **Conclusion:** The psychological empowerment program has a positive effect on reducing feeling of burden and improving self-efficacy among mothers of children with epilepsy. **Recommendations:** Psycho-educational program should be part of care provided to mothers with epileptic children to promote their self-efficacy and decrease burden of them.

Key words: - Burden, Empowerment Program, Epilepsy, Mothers of children, Self-efficacy.

Introduction

Epilepsy is a neurological disorder that causes seizures as well as cognitive, psychological, and social consequences. This disease is a medical emergency and a life-threatening condition due to

its high rate of illness and mortality. Epilepsy is the most common chronic childhood condition, accounting for approximately 25% of all cases and affecting about 1% of children (Sheijani et al., 2020). However, when a family member,

especially a child, has this disorder, the family structure undergoes numerous adjustments, due to The hidden and unpredictable nature of epilepsy and various elements of family life change. Usually, caregiver of this child most of the time will be his mother .in spite of she is considered as one of the most aids in his care process she is not recognized as being an individual who experiencing emotional distress, and who requires assistance and support (**Abd El-Mouty & Salem, 2019**).

The primary child care usually are mothers e, and as a result, they are the most impacted by their children`s chronic illness. On the other hand When the children suffer from medical or emotional issues, parents especially mothers face intense stress, due to their increased dependence on their mothers. On the other hand when the individual compare between children with other chronic disorders, women with epilepsy often experience significant physical and mental health issues, unfavorable attitudes toward their disease, stress, and low self-efficacy. One's self-efficacy in managing seizures is the capacity to start and finish actions associated with each epileptic treatment (**Gholami et al., 2022**).

Self-efficacy is a term that refers to a person`s belief in their capacity to act competently and confidently under specific situations. It is makes reasonable that caregivers with higher senses of efficacy would view their obligations as challenges they can conquer, be more resilient in the face of setbacks, and be persistent in their efforts to learn coping mechanisms. Conversely, caregivers who

have lower levels of self-efficacy are more likely to dwell on the results of their mistakes and their own shortcomings which will affect how they manage and care for their children (**Tan et al., 2021**).

Taking care of children who have epilepsy is an extremely taxing and demanding experience that is linked to a heavy workload and psychological morbidity among workers, particularly mothers. It's possible that parents and other family members struggle to strike a balance between being protective of and restricting their children out of fear of being stigmatized. Mothers in particular may experience anxiety, frustration or depression as they need to put greater effort to get adequate and suitable support for raising an epileptic child. The burden among mothers may also grow due to their lower level of education and longer periods of time spent providing care. The emotional suffering, they endure can have an impact on quality of care which in turn can have an impact on the children`s prognosis (**Babalola et al., 2020 & Karakis et al., 2020**).

The concept of burden of care is a complex construct that encompasses various aspects, including emotional, psychological, physical, and economic consequences. It is also associated with negative emotions such as anger, guilt, shame, and self-blame. Burden can be described as objective or subjective. Subjective load is made up of subjective distress, whereas objective burden is tied to changes in functioning linked to household routine, family or social relationships, job, leisure, and physical health. Mental health issues can arise when caregivers of children with chronic illnesses, such as epilepsy, are overburdened. In the end, this

has an impact on the prognosis for the condition overall and treatment compliance. An under-reported problem is how pediatric epilepsy affects the family (**Pokharel et al., 2020**).

Empowerment programs play a crucial role in assisting these caregivers in managing the situation and delivering quality care to lessen feelings of burden by enhancing their skills, knowledge, talents, and self-efficacy. Empowerment entails helping others achieve their objectives and fostering flexibility and self-assurance while retaining control over one's own destiny. Empowerment is considered the cornerstone for improving society's health system since it prioritizes independence, self-assurance, and problem-solving abilities. Empowerment programs have been demonstrated in studies to improve the independence and problem-solving ability of parents of children with impairments such as epilepsy (**Gholami et al., 2022**).

Nurses can play a central role in providing optimal care, information, and support to patients with complex medical conditions like epilepsy and their allied families. Because nurses have unique opportunities to interact with family members, they can provide the knowledge, expertise, and support needed to maintain the quality of care at home as well as play a significant role in program empowerment for families. There has been an increase in the involvement of nurses in overseeing the management of patients with complex medical conditions like epilepsy (**Buelow et al., 2018**).

Significance of the study:

Epilepsy affects around 50 million people worldwide and makes up a sizeable component of the global disease burden. Between 4 and 10

persons out of every 1000 are thought to have active epilepsy, meaning they are either still experiencing seizures or require medication. Epilepsy is estimated to impact five million people globally each year. In Egypt, there were 6.98 instances of epilepsy for per 1000 individuals in 2016. In Lower Egypt, the prevalence is 7.2/1000, while in Upper Egypt, it is 9.7/1000 (**WHO, 2023**).

Childhood epilepsy is a prevalent disorder that places a significant strain on caregivers due to the unpredictability of seizures, coexisting medical conditions, and higher than average levels of low self-efficacy among these caregivers (**Shahin & Hussien, 2021**). Mothers' empowerment has been demonstrated to be facilitated by education, and nurses can play a role in educating mothers of children through support and enhanced caregiver confidence in managing epilepsy, the development of skills, and access to resources (**Foronda et al., 2020**). Moreover, research that support the utility of psychological empowerment program in decreasing feeling of burden and improving self-efficacy among mothers of children with epilepsy haven't been conducted at Qalyubia governorate before.

Aim of the study:

Investigate effect of psychological empowerment program on burden feeling and self-efficacy among mothers of children with epilepsy. This was achieved through:

- Assessing levels of feeling of burden and self-efficacy.
- Developing and implementing psychological empowerment program.
- Evaluating effect of psychological empowerment program.

on feeling of burden and self-efficacy among mothers of children with epilepsy.

Research hypothesis:

After implementing psychological empowerment program the feeling of burden among mothers of epileptic child will be decreased, and her level of self-efficacy will be improved.

Theoretical and operational definitions:

1-Burden:

Theoretically burden is "a new term in the literature that describes the physical, emotional, social, and economic difficulties faced by family caregivers. The term "burden" describes the stress that comes with providing care for a sick individual who is unable to carry out his or her everyday activities, including starting and finishing tasks related to managing epilepsy on a daily basis. Operationally burden defined as scores on the Zarit burden interview developed by **Bédard et al., (2001)**, to assess the burden on caregivers of individuals with chronic diseases.

2-Self-efficacy

Theoretically self-efficacy is defined as "the belief that an individual has in their ability to act with competence and confidence in specific situations". Operationally self-efficacy defined as scores on the revised scale for caregiving self-efficacy developed by **Steffen et al., (2002)**, to assess caregiver's confidence at overcoming these difficulties.

Subject and Methods:

Research Design: to achieve the study's goal, a quasi-experimental design (one group pre – post test design) was used.

Research Setting:

The research was carried out at outpatient clinic for epilepsy at Psychiatric / Mental Health Hospital, Benha City, Qalyubia Governorate, which is affiliated to General Secretariat of Mental Health.

Research Sample:

Subject size: This study consisted of (40) mothers.

Sampling type:

A convenience sampling who met the following:

The inclusion criteria:

- Children aged 1-12 years old.
- His mother responsible for his care only
- No prior history of substance abuse by mothers.

The exclusion criteria:

- The mothers suffer from chronic illness.
- Absence from more than one session of the empowerment program.

Tools of the Study: data was gathered using the following instruments. The researchers translated all of the tools into Arabic, then retranslated them into English and checked for accuracy.

Tool I: Structured Self-administered Questionnaire:

To collect the mother's socio-demographic characteristics, demographic data of epileptic child, and medical history of their children. It was divided into three parts:

Part 1: Concerned with socio-demographic characteristics of mothers, including as age, marital status, educational level, occupation,

monthly income, had training in caring for child with epilepsy? and had experience in caring for child with epilepsy?.

Part 2: Included demographic characteristics of children as age, sex, child order, number of siblings, level of education, and additional children with epilepsy.

Part 3: Concerned with the medical history (Epilepsy features) of child including onset of disease, frequency of seizures/ month, duration of seizures (minutes), and child has other chronic diseases.

Tool II: The Zarit Burden Interview:

This scale designed by **Bédard et al., (2001)**. It used to assess caregiver burden administered previously in various neurological disorders, including epilepsy. The interview is self-administered and consists of 22 items that explore detrimental effects on the mental and physical health of caregivers. The items cover a range of topics, including health, relationships, personal and social life, emotional status, and financial resources. There are five alternative answers to each question on a Likert-type scale: never (0), rarely (1), occasionally (2), rather frequently (3), and almost usually (4). The new scale's testing reliability was 0.89.

Scoring system:

Each item's frequency is used to calculate the burden level, and the total scores range from 0 to 88, where 0 denotes no stress and 88 denotes a higher level of difficulty. The scale is divided into bands:

Mild burden = < 44.

Moderate burden = 44-60.

Severe burden = 61-88.

Tool III: Revised Scale for Caregiving Self-Efficacy:

This scale adopted by **Steffen et al., (2002)**. It contained 15 items describing issues or scenarios that caregiver may encounter pertaining to a 3-factor model, namely Self-Efficacy in Obtaining Respite (SE-OR), Self-Efficacy in Responding to Disruptive Behaviors (SE-RDB) and Self-Efficacy in Controlling Upsetting Thoughts (SE-CUT), that individually consist of five items. Every item on the scale has three possible answers on a Likert-style scale: disagree (1), uncertain (2), and disagree (3). Caregivers were asked to rate their confidence at overcoming these difficulties. Testing reliability of revised scale for caregiving self-efficacy was 0.85.

Scoring system:

The highest possible score was 45, with higher scores denoting increased self-efficacy.

Low self-efficacy = < 22.

Moderate self-efficacy = 22-30.

High self-efficacy = 31-45.

Methods:

Preparatory phase:

A comprehensive literature review was carried out on the study area, including electronic studies, readily available books and papers, doctoral dissertations, research and peer interaction, as well as ideas from other sources and periodicals to create a knowledge base pertinent to the study field and to obtain a comprehensive understanding of everything and every detail in

connection with the research topic for the program and tools design.

Validity of the instruments:

Prior to the onset of data collection, five professionals with specialized knowledge in psychiatric and mental health nursing evaluated the instruments to ensure that the questions were relevant, clear, complete, and applicable. The jury's suggestions led to the necessary changes being made, and the final form was developed.

Administrative approval:

Primary official approval letter retrieved from the Ethics Committee of the Benha University Faculty of Nursing. The suggested study will then be carried out with a letter from the dean of the nursing faculty to the director of psychiatric and mental health Hospital. It was feasible to conduct the study with the least amount of resistance after its goals and design were made clear.

Ethical considerations:

Every participant in research was made aware that their involvement was entirely voluntary. The confidentiality and anonymity of each participant would be valued and safeguarded. The subjects were made aware that the information contained in the tools would only be utilized for research and that they might choose to leave the study at any moment or not participate at all. They had to sign a consent form after deciding to take part in the study.

Pilot Study:

Prior to beginning fieldwork, it conducted to verify the instruments' relevance and accuracy and determine how long it would take to finish each

task. It was conducted on 10% of the sample (4 mothers), who were excluded from the final sample. In light of pilot study's results, no modifications were needed.

Field of work:

The program was conducted for mothers suitable for the study (fulfilled the inclusion and exclusion criteria). Data collection for this study was carried out from January 2023 until the mid of May 2023. It passed through the following phases:

1-Assessment phase (pre-test):

Assessment phase involved interviews with mothers who accompanied their children to the study settings to collect baseline data. The researchers were visited Benha University Hospital two days/ weeks (Monday and Wednesday) by rotation from 9 AM and extended to 1.00 PM. Prior to data collection, the researchers greeted mothers, discussed the goal, duration, and activity of the study, and obtained their oral agreement to participate in the study. Tools were distributed individually to the study subjects. Mothers completed the questionnaires in the presence of researchers, asking questions as needed, and it took them anything from 15 to 20 minutes to finish. This stage sought to ascertain the program's baseline needs for the mothers under study.

2-Planning phase:

After reading the most current relevant literature, the researchers examined the pretest data that they had collected during the assessment phase from **Hasan, 2018; Abo-a said, 2017 & Shahen, (2017)** for preparation the program that was created, edited, and changed to increase self-efficacy and lessen the sense of burden. The

program's content was tailored to mothers' understanding level using basic Arabic language. Based on the identified needs, training materials were created and a strategy for the program was created. In addition, a booklet containing the timetable, lesson plans, media, and handouts was created.

Program has general objective to decrease feeling of burden and improve self-efficacy of mothers of children with epilepsy, included both theoretical and practical parts, with a set of general and specific goals for each.

Objectives of theoretical part of program to enhance mothers' knowledge about the concept of epilepsy, determining perceived threat which emphasis on empowerment of the mothers about how to implement emergency measures. Also, overview about psychological empowerment, feeling of burden and self-efficacy. Meanwhile the objectives of practical part of the program were empowering the studied woman with apply practical skills to improve their self-efficacy about (problem solving skill, time management skill, and self-dialogue skill), apply skills of psychological empowerment "will making skill, independence skill, persuasion and influencing others skill and self-management skill". Also apply skills of time management, problem solving, self-dialogue, positive thinking and reduce negative thoughts. Furthermore apply relaxation techniques (breathing exercise, muscle relaxation exercise, meditation exercise and guided imagery exercise).

3-Implementation phase:

Twelve sessions were required to implement the empowerment program: an introductory session, two theoretical sessions, eight practical

sessions, and a summary of all the previous sessions was held in the final session. Mothers included in the study were divided into five subgroups, with eight mothers in each subgroup. Twelve sessions were attended by each subgroup; two sessions /week on and two distinct groups per week. Each session lasted about 60 minutes.

The mothers were motivated to participate in the practice session and discussion by the researchers, who also served as facilitators and teachers. As a means of rewarding the mothers with positive reinforcement, the mothers received a training booklet at the conclusion of the program.

The theoretical session was conducted through lectures, handouts, and group discussions. White papers, power points, and handouts were also used as teaching aids to encourage active participation in the discussion and to get the mothers under study to share their experiences with the real world of work and life. The researchers created an eye-catching power-point presentation in simplified Arabic, which was used to deliver the lecture in an easy-to-understand manner. In order to guarantee that the moms comprehend the program's material, each session began with a recap of the previous session's instruction and an explanation of the new session's goals in plain language to accommodate all mothers.

In the practical sessions: The researchers employed role play, modeling, demonstration, and re-demonstration as a means of imparting practical skills. There were also talks in small groups, lectures, and movies. The mothers themselves as well as the mothers and the researchers engaged in role-playing. The mothers were given the

opportunity to exercise critical thought, and a wide range of responses to the various scenarios were obtained and examined by the researchers. Following that, the researchers discussed the best course of action for each scenario and provided

justification for each decision. The researchers informed the participants of the time of the following session and gave a summary at the conclusion of the current one.

The content of empowerment program sessions was as follows:

Session. No.	Content
Session 1	Introductory session (acquaintance between the researchers and mothers, introduction and description of the program schedule and presentation of the program content and perform pre/test).
Session 2	Overview about the concept of epilepsy (definition, risk factors, etiology, types, symptoms during and after epileptic seizures, stages of epileptic seizures, frequency of epileptic seizures, common complications of the disease, diagnosis, types of treatment, importance of adherence to treatment, dose and side effects of antiepileptic drugs)
Session 3	Determining perceived threat (empowerment the mothers about how to implement emergency measures such as (first aids during child epileptic seizures and after the seizure, guidelines about antiepileptic drugs and precautions must follow for child safety and prevention methods from epileptic seizures).
Session 4	Overview about psychological empowerment, feeling of burden and self-efficacy (contains information about concept, indicators of psychological empowerment, types, importance, skills of psychological empowerment. Furthermore information about concept of burden (definition, and causes of caregiver burden, types, and methods to reducing feeling of burden. Also, information about the concept of self-efficacy (definition, importance, types, characteristic of people with high and low self-efficacy, sources and methods to build mother's self-efficacy)
Session 5	Apply psychological empowerment skills "will making skill" (definition, stages of will making skill, importance and scientific methods to acquire strong will making skill and determination) independence skill (definition of independence personality, compare between characteristic of independence and dependence personality, apply methods for independence skill)
Session 6	Continue to apply psychological empowerment skills (persuasion and influencing others skill and self-management skill).
Session 7	Apply time management skill (definition, obstacles of time management, benefits of time management, causes of inability to management time, steps to apply time management skill) problem solving skill (definition, importance, apply methods to problem solving skill).
Session 8	Self-dialogue skill (definition, importance of self-dialogue, apply steps of self-dialogue skill).
Session 9	Positive thinking and reduce negative thoughts skill (definition of negative thoughts, causes of negative thoughts, effects, shapes of negative self-talk, apply techniques to reduce negative emotions by positive thinking)
Session 10	Apply relaxation techniques (breathing exercise, muscle relaxation exercise) to control anger and to relax the body and mind
Session 11	Apply relaxation techniques (meditation exercise and guided imagery exercise) to control anger and to relax the body and mind
Session 12	Summary about program session and perform post/test.

4: Evaluating phase (post-test):

Immediately, after implementation of the program for mothers, the researchers using the

same formats of pretest to evaluate the effect of psychological empowerment program to decrease

feeling of burden and improve self-efficacy of mothers of children with epilepsy.

Data Analysis:

After collecting, labeling, totaling, and statistical analysis, all the data were analyzed. The statistical analysis was performed using the Statistical Package for Social Sciences (SPSS version 20.0); data processing and graphical display were done using Microsoft Office Excel. Descriptive statistics were employed to analyze the data, using mean and standard deviation for quantitative data and frequency and percentages for qualitative factors. The chi-square test was utilized to compare qualitative category variables. The Pearson correlation coefficient was calculated between the variables. At a p-value of $p < 0.05$, statistical significance was deemed to exist, and at a p-value of $p \leq 0.001$, highly statistical significant was acknowledged. Parametrical tests, including the independent (t) test, which compares mean scores between the sample as a whole, and the paired (t) test, which compares mean scores between the same samples at various research stages.

Results:

Table (1) reveals that, almost half of them (45%) are between ages from 30 to less than 40 years old with mean age SD 37.02 ± 4.86 years, the majority of them (90%) were married than one third (35%) have secondary education, almost two thirds (65%) are housewives and more than three quarters of them (77.5%) have not enough monthly income. Also, the majority (82.5%) of them aren't trained in caring for their child with epilepsy. As well, almost two thirds of them (65%) haven't experience in caring for child with epilepsy.

Table (2) shows that, less than half of the studied children (47.5%) are between ages from 4 to less than 8 years old with mean age SD 9.45 ± 3.70 years old, more than two thirds (62.5%) of them are female, less than half (47.5%) are the second in their birth order. Regarding to number of siblings, more than three quarters of them (77.5%) have 1-2 siblings, half of them (50%) have primary education and less than one sixth (15%) of them have additional child with epilepsy.

Table (3) states that, two fifths of children (40%) their onset of disease between $4 < 8$ years, more than half of them (57.5%) the frequency of seizures occurs 3-4 times / month, while the duration of seizures that occur to more than three quarters of them (80%) about 1-2 minutes. Also, more than one sixth of them (17.5%) have other chronic disease.

Table (4) illustrates that; there is a marked improvement in the total of burden domains of the studied mothers` (Interference in the caregiver's personal life, patient's dependence, irritation or intolerance, feelings of guilt, feelings of insecurity, feelings of embarrassment) following program implementation with a highly significantly statistical difference between the pre- and post-intervention at P value = $<0.01^{**}$

Figure (1) shows that, more than half (55%) of the studied mothers have severe burden before program implementation, while almost two thirds (62.50%) of them have mild burden post program implementation comparing to preprogram implementation.

Table (5) reveals that, there is a marked improvement in the total of self-efficacy domains

of the studied mothers (Obtaining respite, responding to disruptive patient behaviors, controlling upsetting thoughts about caregiving) following program implementation with a highly significantly statistical difference between the pre- and post-intervention at P value = $<0.01^{**}$.

Figure (2) shows that, less than two thirds (60%) of the studied mothers have low self-efficacy before program implementation, while almost three quarters (70%) of them have high self-efficacy post program implementation.

Table (6) states that, high significant model detected through F test value was 18.113 with p value. 000. This model explained that additional

child with epilepsy, increase frequency of seizures/month and other chronic disease had high frequency positive effect on burden level at p value $<0.01^{**}$. While, experience in caring for child with epilepsy had high frequency negative effect burden at p value $<0.01^{**}$. On other hand, employee mothers and siblings more than two had slight frequency positive effect on burden at p value $<0.05^*$. Meanwhile, high education level had slight negative effect on burden at p value $<0.05^*$.

Table (7) represents that, there are a highly statistically significant negative correlation between total burden and total self-efficacy among the studied mothers post program implementation at p = $<0.01^{**}$ r. = -0.654.

Table (1) Distribution of the studied mothers regarding to their socio-demographic characteristics (n=40).

Socio-demographic characteristics	N	%
Age(years)		
20 - <30 yrs.	7	17.5
30 - <40 yrs.	18	45.0
40 - <50 yrs.	11	27.5
≥50 yrs.	4	10.0
Mean±SD	37.02±4.86.	
Marital status		
Married	36	90,0
Widowed	1	2.5
Divorced	3	7.5
Educational level		
Illiterate	6	15,0
Read and write	9	22.5
Basic education	5	12.5
Secondary education	14	35,0
University education	6	15,0
Occupation		
Employee	14	35,0
Housewife	26	65,0
Monthly income		
Enough	9	22.5
Not enough	31	77.5
Training in caring for child with epilepsy		
Yes	7	17.5
No	33	82.5
Experience in caring for child with epilepsy		
Yes	14	35,0
No	26	65,0

Table (2) Distribution of the studied children by their characteristics NO40

Children` characteristics	N	%
Age (years)		
1 - < 4 yrs.	8	20,0
4 - <8 yrs.	19	47,5
8 – 12 yrs.	5	12,5
≥12 yrs.	8	20,0
Mean ±SD	9.45±3.70.	
Sex		
Male	15	37,5
Female	25	62,5
Child order		
First	13	32,5
Second	19	47,5
Third	8	20,0
Number of siblings		
1 - 2	31	77,5
3 - 4	9	22,5
Level of education		
Nursery	8	20,0
Primary education	20	50,0
Preparatory education	8	20,0
Secondary education	4	10,0
Additional child with epilepsy		
Yes	6	15,0
No	34	85,0

Table (3) Distribution of the studied children related to their medical history (n=40).

Children` medical history	N	%
Onset of disease (years)		
1 - < 4 yrs.	14	35,0
4 - < 8 yrs.	16	40,0
8 – 12 yrs.	10	25,0
Frequency of seizures/ month		
1-2 times	20	50,0
3-4 times	23	57,5
≥5times	7	17,5
Duration of seizures (minutes)		
1 - 2	32	80,0
3 – 5	8	20,0
Child has other chronic disease		
Yes	7	17,5
No	33	82,5

Table (4) Effect of empowerment program on the studied mothers` burden pre and post implementation of program (n=40).

Burden domains	Pre program		Post program		Chi-square P value
	n	%	N	%	
Interference in the caregiver's personal life					
Mild					
Moderate	5	12.5	21	52.5	12.098
Severe	13	32.5	11	27.5	<0.01**
	22	55	8	20	
Patient's dependence					
Mild	9	22.5	26	65	14.560
Moderate	15	37.5	10	25	<0.01**
Severe	16	40	4	10	
Irritation or intolerance					
Mild	7	17.5	24	60	11.870
Moderate	15	37.5	12	30	<0.01**
Severe	18	45	4	10	
Feelings of guilt					
Mild	12	30	25	62.5	13.400
Moderate	18	45	12	30	<0.01**
Severe	10	25	3	7.5	
Feelings of insecurity					
Mild	8	20	26	65	16.248
Moderate	17	42.5	9	22.5	<0.01**
Severe	15	37.5	5	12.5	
Feelings of embarrassment					
Mild	6	15	23	57.5	14.103
Moderate	15	37.5	11	27.5	<0.01**
Severe	19	47.5	6	15	

**Highly statistically significant

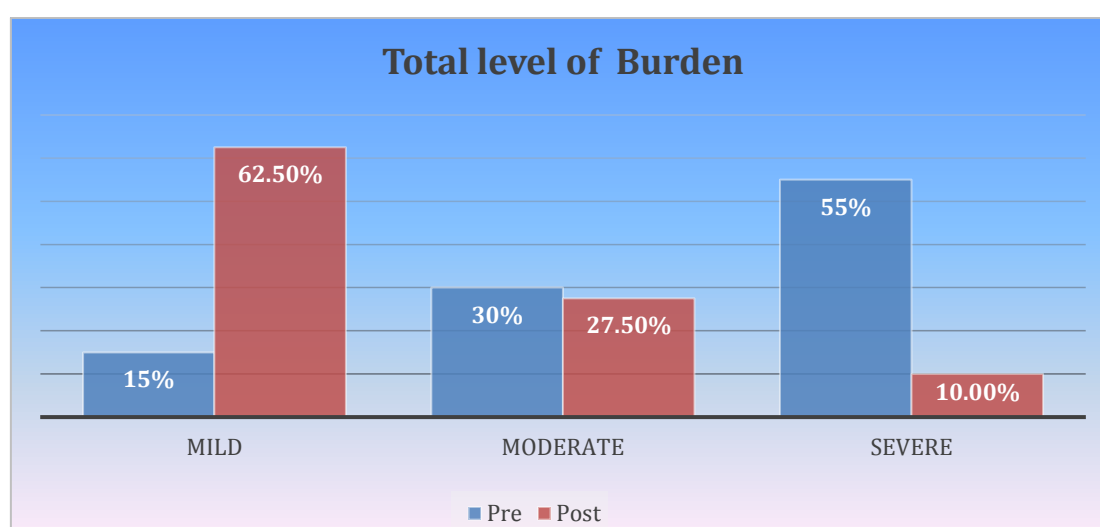
**Figure (1)** Distribution of the studied mothers regarding to their total level of burden pre and post program implementation (n=40).

Table (5) studied mothers self-efficacy pre and post implementation of program (n=40).

Self-efficacy domains	Pre Program		Post Program		Chi-square P value
	n	%	N	%	
Obtaining respite					
High	4	10	26	65	17.039 <0.01**
Moderate	16	40	9	22.5	
Low	20	50	5	12.5	
Responding to disruptive patient behaviors					
High	6	15	24	60	16.011 <0.01**
Moderate	10	25	9	22.5	
Low	24	60	7	17.5	
Controlling upsetting thoughts about caregiving					
High	7	17.5	24	60	19.013 <0.01**
Moderate	8	20	12	30	
Low	25	62.5	4	10	

**Highly statistically significant.

Total level of self-efficacy

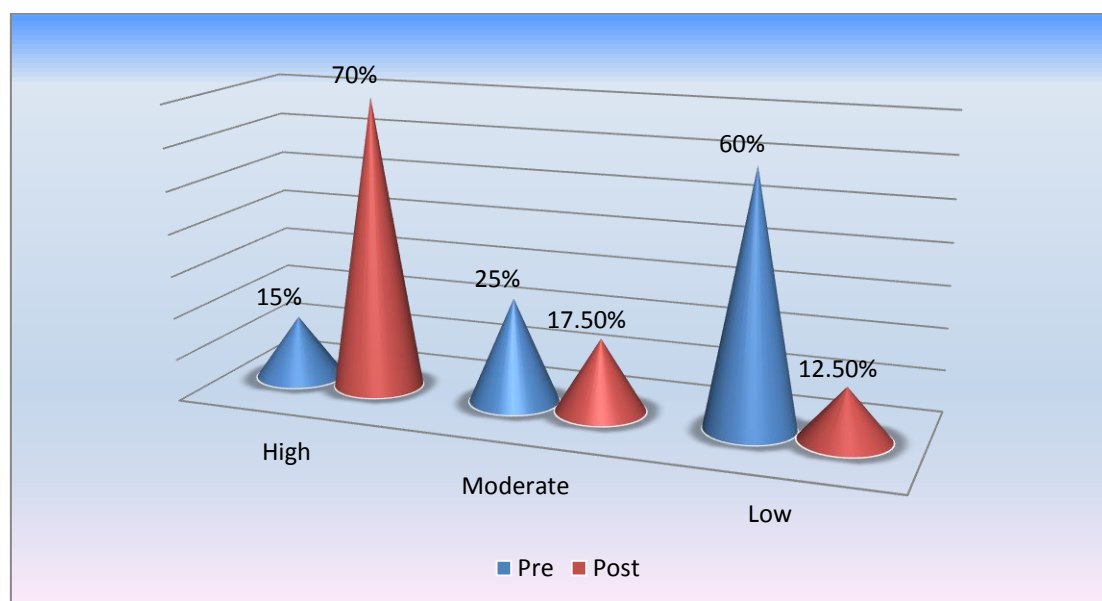


Figure (2) Distribution of the studied mothers regarding to their total level of self-efficacy pre and post program implementation (n=40).

Table (6): Linear regression model for total burden post program implementation (n=40).

Coefficients ^a					
Model	Unstandardized Coefficients		Standardized Coefficients	T	Sig.
	B	Std. Error	Beta		
Educational level of mother "High"	-.198	.033	.125	4708	<.05*
Occupation "Employee"	.259	.046	.199	3.646	<.05*
Experience in caring for child with epilepsy "Yes"	-.280	.063	.213	5.879	<.01**
Number of siblings "3-4" siblings	.197	.031	.182	3.201	<.05*
Additional child with epilepsy "Yes"	.208	.040	.176	5.308	<.01**
Frequency of seizures/ month "≥5times "	.290	.051	.237	6.142	<.01**
Other chronic disease "yes"	.240	.027	.198	7.011	<.01**

a. Dependent Variable: Total burden
Predictors: Educational level of mother "high", Occupation "employee", Experience in caring for child with epilepsy "yes", Number of siblings (3-4), Additional child with epilepsy "yes", Frequency of seizures/ month "≥5times " and Other chronic disease "yes"

* Statistically significant

**Highly statistically significant.

Model Summary			
R Square	df	F	Sig. F Change
.715	6	18.113	<.001**

Table (7) Correlation between total burden and total self-efficacy among the studied mothers post program implementation (n=40).

Scale	Total Burden	
	r.	P
Total Self-efficacy	-0.654	<0.01**

**Highly statistically significant

Discussion:

Due to the unexpected nature of seizures and related underlying diseases, epilepsy is becoming a more common problem in children and causes a

significant burden on caregivers. As a result of disease's nature, chronicity, handicap, and stigma, caregivers have significant emotional, financial, and physical strain as well as decreased self-

efficacy (**Senthil, 2019**). Empowerment program is crucial in helping caregivers to better manage their circumstances and deliver good caregiving by enhancing their knowledge, attitude, abilities and self-efficacy (**Balouchi et al., 2021**).

In relation to the socio-demographic characteristics of mothers, the results of the current study illustrated that the majority of them were married and almost two thirds were housewives. This could be because, in our society, mothers are usually the ones who tend to their children's needs, especially when they are ill, and because caring for epileptic children takes a lot of time. Other reasons include the fact that careers' quality of life and health are greatly impacted because it can be difficult to strike a balance between work and caregiving obligations. These results were in same line with the study conducted by **Abd El-Mouty & Salem, (2019)** who reported that most of study sample were married with about three quarters were not working.

Concerning to educational level of mothers, the result of the current study showed that more than one third of them had secondary education. This may be because the majority of women would rather not complete their education and get married. This result was consistent with the study conducted by **Shahin & Hussien, (2021)** who found that almost half of the studied sample had secondary education. The result also showed that more than three quarters of them had not enough monthly income. This may be due to almost two thirds of the studied mothers were housewives and

unemployed as well as the cost of their children's treatment. This result was in agreement with the study carried out by **Rahgoi et al., (2019)** who found that more than half of the studied sample had poor economic status.

The result of study illustrated that the majority of mothers were not trained in caring for their child with epilepsy and two thirds of them hadn't experience in caring for child with epilepsy. These results were in agreement with the study performed by **Bevan et al., (2018)** who mentioned that many caregivers of patients with epilepsy report that they do not have sufficient skills and training for long term care of their patients, which indicates the importance of training them by nurses.

Concerning to characteristics of children, the result of the current study reported that less than half of them were between ages from 4 to less than 8 years old with mean age $SD 9.45 \pm 3.70$ years old. This may be due to that childhood is the most prevalent age at which epilepsy occurs. This result was in disagreement with **Lumbasi, (2020)** who revealed that the majority of the respondents their aged between 16-20 years. In addition, the present study showed that, more than two thirds of them were female. This result was in disagreement with the study carried out by **Sheijani et al., (2020)** who reported that findings of the study indicated that the majority of children with epilepsy were male with a mean age of 5.5 years.

As regard to medical history of children, the result revealed that two fifths of children their

onset of disease between $4 < 8$ years. This may be due to that epilepsy most common among childhood. This result was in disagreement with the study carried out by **Hagemann, et al., (2016)** who stated that onset of disease of the children was 1-5 years. Also, the present study revealed that, more than half of children the frequency of seizures occurs 3-4 times/month. This may be due to the result of study stated that more than two thirds of children with epilepsy were female where seizure activity increased in females due to hormonal influences and due to nature of this illness. This result was in same line with the study performed by **Shahin & Hussien, (2021)** who found that in most of children the frequency of seizures occurs 3-5 times/month.

Concerning to the duration of seizures (minutes), more than three quarters of them experienced seizure from 1-2 minutes. This may be due to epilepsy is the most common chronic neurological disorder in childhood, which is created like recurrent seizures due to sudden, periodic, and so much discharge of brain neurons. This result was in agreement with the study carried out by **Wasilewski, (2020)** who found that most of the children have 1-2 minutes duration of seizures. Also the present study finding revealed that more than one sixth of them had other chronic disease. This may be due to epilepsy is chronic disease and cause physical complications for the children.

Regarding to the effect of empowerment program on mothers` burden before and after implementation of program, the result of the

current study illustrated that, there was a marked improvement in the total of burden domains (Interference in the caregiver's personal life, patient's dependence, irritation or intolerance, feelings of guilt, feelings of insecurity, and feelings of embarrassment domains) of the studied mothers post implementation of program with a highly statistically significant difference between pre and post intervention at $P \text{ value} = <0.01^{**}$. It indicates the effect of this program that achieved through increasing awareness, strengthening adaptive skills, reducing stress and anxiety, enhancing motivation, increasing self-confidence, expanding social activities, decrease feeling of insecurity and embarrassment and improving care skills in caregivers. This result was in accordance with the study conducted by **Balouchi et al., (2021)** who reported that the mean score of caregiver burden in families with epileptic children in the intervention group was significantly lower immediately after the intervention than before the intervention.

Concerning to total level of burden before and after program implementation, the result of the current study revealed that, more than half of mothers had severe burden before program implementation, while almost two thirds of them had mild burden and more than quarter of them had moderate burden post program implementation. It suggests that the program is successful in lessening the burden that careers experience; this could be because it is educating mothers, altering many of their attitudes, and improving their practices regarding epilepsy

through trial to improve their capacity to solve the issue, manage, and deal with their burden effectively. These results were in contrast to the study performed by **El Malky et al., (2016)** who illustrated that the majority of the studied caregivers have severe burden pre nursing intervention, nearly two thirds of them have moderate burden and less than one third have mild burden post intervention.

According to the effect of empowerment program on mothers` self-efficacy before and after implementation of program, the result of the current study revealed that there was a marked improvement in the total of self-efficacy domains (Obtaining respite, responding to disruptive patient behaviors, and controlling upsetting thoughts about caregiving) of the studied mothers post implementation of program with a highly statistically significant difference between pre and post intervention at P value = $<0.01^{**}$. This positive impact of the program on mother`s self-efficacy could be attributed to assisting mothers to learn skills to improving their self-efficacy as well as providing a booklet. This was encouraged by the interactive nature of the program, which allowed participants to freely talk about and ask questions concerning epilepsy. Nurses in healthcare facilities find that self-efficacy is a useful tool. By helping patients increase their self-efficacy, nurses can also increase the motivation of mothers to care for their children. Given that the treatment team's ultimate objective is to give the patient the skills necessary to increase self-efficacy. This result was consistent with the study

done by **Easom et al., (2020)** who found that meanwhile; statistically significant improvements were shown at the post intervention phase in all domains of self-efficacy. Also **Tan et al., (2020)** demonstrated that caregivers` self-efficacy was significantly improved by training.

As regard to total level of self-efficacy before and after program implementation, the result of study reported that, less than two thirds of mothers had low self-efficacy before program implementation, while almost three quarters of them had high self-efficacy post program implementation. This could be due to active participation of mothers in the program and strong desire of the mothers to receive the needed information about their children`s illness to be able to handle any related problems, which helps to increase their self-efficacy like (empowerment the mothers about how to implement emergency measures such as (first aids during child epileptic seizures and after the seizure, guidelines about antiepileptic drugs and precautions must follow for child safety and prevention methods from epileptic seizures). Mothers are encouraged to take charge of their lives as part of the program designed to empower them. In order to better their access to resources and alter their awareness through their ideas, values, attitudes, and practices, they must address their circumstances before acting. In order to improve developmental outcomes and pleasant transitions to care for their child, it makes it easier for parents to increase their self-efficacy and self-esteem.

This result was in agreement with the study performed by **Shahin & Hussien, (2021)** who reported that low scores were noted in all three aspects of self-efficacy as well as in total before the intervention, with the total mean score being less than half of the maximum attainable score. Also, that's came in the same direction with study carried out by **Hameed et al., (2021)** who found that, significant improvements in the self-efficacy scores of caregivers of children with epilepsy following the implementation of the educational intervention.

Meanwhile, this result similar to study conducted by **Hegazy & Dawood, (2021); Barani et al., (2021) & Abdel-Salam et al., (2023)** who found that, the mothers had elevated self-efficacy mean scores immediately after the educational intervention compared to before program. There were statistically significant differences regarding the total means scores of the mothers' self-efficacy before, immediately after and one month after application of the educational intervention. In addition, the result of the current study showed that increase frequency of seizures/ month had high frequency positive effect on burden level at p value $<0.01^{**}$. This suggested that the seizures were prolonged, requiring greater attention from the patient in terms of medication administration, multifaceted care, and protection. This also required more work and resulted in career (mothers) fatigue. These may lead to decreased bodily functions and psychological suffering.

Concerning to correlation between total burden and total self-efficacy among mothers after program implementation, the result of current study revealed that there was a highly statistically significant negative correlation between total burden and total self-efficacy among mothers after program implementation at $p = <0.01^{**}$. This could be due to providing empowerment program in this study promote caregivers' self-efficacy and consequently lower the burden. According to the self-efficacy theory, Higher and greater levels of self-efficacy may reduce the need for care. It also improves one's feeling of wellbeing. Encouraging and boosting self-efficacy can help caregivers cope better with the obstacles they face and avoid the negative effects of their burden.

Conclusion

The program has a positive effect on reducing the feeling of burden and improving the level of self-efficacy in mothers of children with epilepsy.

Recommendations:

1. Psycho-educational program should be part of care provided to mothers with epileptic children to promote their self-efficacy and decrease burden of them.
2. The implementation of a supportive educational program can help to raise maternal awareness about how to care, causes for recurrence, and actions carried out in the emergency stage of epilepsy by gradually increasing the self-efficacy of mothers of epileptic children.

3. More nursing interventions are needed around the time of the diagnosis with longitudinal assessment and follow up for both caregivers and their children.
4. Utilizing social media and additional of visual and auditory media to raise awareness of the epilepsy disease in our society, especially among young people.
5. Comparable studies should be carried out on a larger sample of children with different ages and regions for the results to be broadly applicable.

References:

- Abd El-Mouty, S.M., & Salem, N.M. (2019).** Burden and quality of life among caregivers to children with Epilepsy. *American Journal of Nursing Research*, Vol. 7, No. 5, 817-823.
- Abdel-Salam, A.A., Abd-El Aziz, S. M., El Arabie, M., & Sharshour, S.M. (2023).** Effect of implementing family empowerment model on the quality of life and self- efficacy of mothers of children with Systematic Lupus Erythematous. *Tanta Scientific Nursing Journal*. Vol. 29. No. 2. PP.2016-2044.
- Abo-a said, A. (2017).** The effectiveness of counseling program based on psychology in improving life satisfaction and hope among the school students with broken families in Kara. *Journal of Educational Studies*. (sup 2) 4, pp. 149-164. Available at: <https://search.emarefa.net/detail/BIM-846157>.
- Babalola, E.O., Adebawale, T.O., Onifade, P., & Adelufosi, A.O. (2020).** Prevalence and correlates of generalized anxiety disorder and depression among caregivers of children and adolescents with seizure disorders. *J Behav Health*;3:122-7.
- Balouchi, Z., Pahlavanzadeh, S., & Alimohammadi, N. (2021).** Efficacy of psycho-educational program on burden of caregivers of children with Epilepsy: A clinical trial. *Med Surg Nurs J.*; 10(2):e119961.
- Barani, M., Hassani L., Ghanbarnejad A. & Ali, M. (2021).** Effect of educational intervention based on self-Efficacy theory on tthe caring behavior of mothers having children with Cancer. Creative Commons Attribution International. Available at: DOI:10.21203/rs.3.rs-450017/v1.
- Bédard, M., Molloy, D.W., Squire, L., Dubois, S., Lever, J.A., & O'Donnell, M. (2001).** The Zarit Burden Interview: a new short version and screening version. *Gerontologist*; 41:652–7.
- Buelow, J., Miller, W., & Fishman, J. (2018).** Development of an Epilepsy Nursing Communication Tool: Improving the Quality of Interactions between Nurses and Patients with Seizures. *Journal of Neuroscience Nursing* 50(2):1.
- Bevan Jones, R., Thapar, A., Stone, Z., Thapar, A., Jones, I., & Smith, D. (2018).** Psychoeducational interventions in adolescent depression: A systematic review. *Patient Educ Couns.*; 101(5):804–16.
- Easom, L., Wang, K., & Alston, G. (2020).** Increasing self-efficacy and knowledge in carer training: Hispanic versus Caucasian. *Nurs Open*; 7:180-185.
- El Malky, M.I., Mohsen, M.M., & Amer, H.M. (2016).** The effectiveness of the nursing intervention program on feeling of burden and coping among caregivers of children with epilepsy. *International Journal of Advanced Nursing Studies*, 5 (1) 87-95.
- Foronda, C. L., Kelley, C. N., Nadeau, C., Prather, S. L., Lewis-Pierre, L., Sarik, D. A., & Muheriwa, S. R. (2020).** Psychological and socioeconomic burdens faced by family caregivers of children with asthma: An integrative review. *Journal of Pediatric Healthcare*, 34(4), 366–376.
- Gholami, S., Reyhani, T., Beiraghi, M., & Vashani, H. (2022).** Effect of a supportive educational program on self- efficacy of mothers with Epileptic children. *Evidence Based Care Journal*, 6 (2): 50-56.
- Hagemann, A., Pfäfflin, M., Nussbeck, F., & May, T. (2016).** The efficacy of an educational program for parents of children with epilepsy (FAMOSEs): Results of a controlled multicenter evaluation study. *Epilepsy & Behavior* 64;143–151
- Hameed, M., Alman, M., & Hussien, R. (2021).** Knowledge, attitude, practice, and self-efficacy

of caregivers of children with epilepsy: Impact of a structured educational intervention program. *Epilepsy & Seizure*; 13(1):1-16.

- Hasan, A.A. (2018).** The effectiveness of program based on psychological empowerment skills to improve adaptive perfectionism and life orientation among university students. *Journal of the Faculty of Education - Al-Azhar University, Issue (180)*.pp:13-72.
- Hegazy, S. M., & Dawood, B. M. (2021).** Effect of upgrading mothers' awareness regarding cardiovascular diseases on their self- efficacy to promote their children life style. *Egyptian Journal of Health Care*: 12 (1).
- Karakis, I., Cole, A., Montouris, G., San Luciano, M., Meador, K., & Piperidou.C. (2020).** Caregiver burden in epilepsy: determinants and impact. *Epilepsy Res Treat*; 808421.
- Lumbasi, R. (2020).**The effects of social support on self efficacy and self management of children living with epilepsy in Nairobi country. Published thesis.
- Pokharel, R., Poudel, P., Lama, S., Thapa, K., Sigdel, R., & Shrestha, E. (2020).** Burden and its predictors among caregivers of patient with Epilepsy. *Journal of Epilepsy Research*; 10(1): 24-30.
- Rahgoi, A., Sojoodi, T., Fallahi Khoshknab, M., Rahgozar, M., & Shahshahani, S. (2019).** Effects of empowerment program on the burden of care in mothers of children with Phenylketonuria. *Iran J Child Neurol. Spring*; 13(2): 53-60.
- Senthil, M. (2019).** Relationship between family interaction, family burden and quality of life among caregivers of patients with epilepsy, Vol.4 (Iss.4).
- Shahen, E.F. (2017).** The effectiveness of a short-term counseling program based on the discovery of benefit and goal setting in the development of psychological empowerment among a sample of graduate students. *Journal of Counseling Psychology. (52)*, pp 1-59.
- Shahin, M.A., & Hussien, R.M. (2021).** Knowledge, attitude, practice, and self-efficacy of caregivers of children with epilepsy: impact of a structured educational intervention program. *Journal of Japan Epilepsy Society. Vol. 13 No. 1*: pp. 1-16.
- Sheijani, M., Chehrzad, M., Reza Masouleh, S., Kazem Nezhad Leyli, E., & Bidabadi, E. (2020).** The effect of “Creating opportunities for parent empowerment” program on parents of children with Epilepsy and other chronic neurological conditions. *Iran J Child Neurol*; 14(1): 65-76.
- Steffen, A., McKibbin, C., Zeiss, A., Gallagher-Thompson, D., & Bandura, A. (2002).** The revised scale for caregiving self-efficacy: reliability and validity studies. *J Gerontol Ser B Psychol Sci Soc Sci*; 57(1):P74–P86.
- Tan, G.T.H., Yuan, Q., Devi, F., Wang, P., Ng, L.L., Goveas, R., Chong, S.A., & Subramaniam, M. (2021).** Factors associated with caregiving self-efficacy among primary informal caregivers of persons with dementia in Singapore. *BMC Geriatr*; 21: 13.
- Tan C-E, HiM-Y, Azmi, N.S., & Ishak, N.K. (2020).**Caregiving self efficacy and knowledge regarding patient positioning among Malaysian caregivers of stroke patients. *Cureus*; 12:e7390-7401.
- Wasilewski, T., Serventi, J., Ibegbu, c., Wychowski, T., Burke, J., & Mohile, N. (2020).**Epilepsy education in glomas: engaging patients and caregivers to improve care. *Support care cance*; 28:1405-1409.
- WHO, (2023).** Epilepsy. Available at: <https://www.who.int/news-room/fact-sheets/detail/epilepsy>. Retrieved on: 10/1/2023.