

# An Educational Intervention to Reduce the Burden on Family Caregivers of Patients with Schizophrenia

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## Abstract

**A. Background:** Schizophrenia is a chronic psychosis and experiences a high burden level of the family caregiver and consequent impairment in their health condition.

**B. Aim:** This study aimed to explore the effectiveness of an educational intervention program for decreasing the family caregivers' burden of patients with schizophrenia.

**C. The study design:** A quasi-experimental design was employed. The study was applied at the Psychiatric Outpatients Unit in Beni-Suef University Hospital. Forty-four family caregivers participated, 22 allocated to the experimental group and 22 in the control group.

**D. Tool of the study:** Demographic data and the Zarit Caregiver Burden Scale. The program was conducted once a week for four months in the experimental group. Results: the burden level diminished significantly in an experimental group; the mean scores of caregiver burden reduced from 84.05 pre-program into 53.24 post-program ( $P < 0.001$ ). However, the mean scores in the control group were slightly changed. The program was effective for family caregivers with low educational levels.

**E. Conclusion:** The majority of the studied family caregivers' burden was reduced after implementation of an educational program, with a highly positive significant statistical difference between parents and family caregivers with lower educational levels between before and after educational sessions.

**F. Recommendations:** Apply the components of this program in future studies, which emphasize to decline of burden levels of family caregivers of patients with schizophrenia and the mentally ill.

**Keywords** - Burden, Caregivers, Education, Family, Intervention, Schizophrenia.

## I. INTRODUCTION

Schizophrenia is a chronic psychosis in which the patient loses contact with reality. It is a distressing illness, often affecting a loss of social performance in affected persons [1]. Schizophrenia is a severe mental disorder, which is traumatic for the patients as well as for their family caregivers [2], [3]. Between 50% - 80% of patients live with or have regular contact with family members and depend on their families [4]. The family members remain the major source of care for the patient with schizophrenia and have a powerful effect on managing their illness. Schizophrenia is a family also affects the responsibilities and interactions within the family. They have lots of burdens, including care burden, fear, and humiliation around illness signs and symptoms, uncertainty about the course of the disorder, lack of social reinforcement, and stigma. The caregiver burden refers to the negative impact of the individual's mental disorders on the entire family [5]-[8].

The educational program attempt to create the following principles: the disorder is a brain disease; the pharmacological treatment is essential, the involvement of the family as the main rehabilitation agent, ensure a satisfactory emotional warmth in the family, caring for reducing the level of demands on the patient by allowing free expression and facilitating the reintegration into the social environment. However, these families' caregiver states great levels of burden related to caring for a member with schizophrenia [9]. The caregiver burden is a multidimensional concept reflecting emotional, social, physical, and financial concerns increasing from caring for an impaired family member. Several descriptions of the concept of caregiver burden have been attempted. The burden is escalating as a sign of being in close contact with a severely ill psychiatric family member [10], [11].

### A. The Significance of the Study

In Egypt, the primary care provider is usually the main source of support for the sick person and is commonly a family member [12]. Therefore, family caregivers who deliver care for family members with schizophrenia are at



potential risk for burden and consequent decline in health status[13]. There are multiple consequences of the caregiver burden, such as psychiatric-health problems (e.g., depression, anxiety, stress, and burnout disorder), physical health decline (e.g., diabetes and hypertension), and other negative things (e.g., social isolation, family dysfunction, excessive use of health facilities, and economic problems) [14].

The essential nursing intervention is prevention which focuses on reducing the stress and the stress response from having a harmful effect on the caregivers. For chronic schizophrenic patients with the leading professional care, nurses working at each stage; however, the family caregivers must have guidance from the nurses on dealing with this difficult situation and provide support for them. An understanding of the burden between family caregivers of people with schizophrenia may help identify areas of priorities that can be incorporated into an educational program based on their specific needs and how to diminish the burden level.

### **B. The Aim of the Study**

This study aimed to explore the effectiveness of an educational program to reduce the care burden on family caregivers of patients with schizophrenia.

### **C. The Study Hypotheses**

The family participants of patients with schizophrenia who attain the educational program will reduce their burden level.

## **II. METHODS**

### **A. Research Design**

The study adopted a randomized control trial (quasi-experimental) to examine the perceived burden level of the family caregivers of the patient with schizophrenia.

### **B. Setting**

The study was applied at the Psychiatric Outpatients Department in Beni-Suef University Hospital, which is affiliated with the Ministry of Higher Education, Egypt. The mental health services in this unit provide free services for rural and urban, all age groups, and all types of mental illness. Care is provided by a multidisciplinary team, psychiatrists, psychiatric nurses, social workers, and psychologists.

### **C. Subjects**

The family members who care for patients with schizophrenia; attending to the outpatient mental health department at Beni-Suef University Hospital and agree to participate in this study. Forty-four caregivers contributed to this research: 22 family caregivers were allocated to the experimental group, and 22 family caregivers were assigned to a control group.

### **D. Inclusion and Exclusion Criteria**

#### **a) Inclusion criteria for patient**

a. Patients who have schizophrenia, according to the Diagnostic and Statistical Manual of Mental Disorders "DSM-IV" edition and according to patients' sheet.

b. The patient has been diagnosed for a period not less than one year.

#### **b) Inclusion criteria for family Caregiver**

a. Caregivers were taking care of a relative who is providing management for a patient with schizophrenia and who attended the outpatient clinic.

b. The caregiver is a first-degree relative and living with the patient all time.

#### **c) Exclusion criteria for the family caregiver**

The caregiver will be ineligible for this study if he/she is:

a. Taking care of more than one chronically ill person within the family.

b. Caring for a patient with co-morbidity.

c. Unwilling to participate in the study.

### **E. Tools for Data Collection:**

**Part I: Demographic Data Sheet:** This was designed by researchers to collect general information about patients' caregivers. The information from caregivers will include gender, age, income, level of education, and average time spent in caring for the patient per day.

**Part II: Zarit Caregiver Burden Scale (ZCBS):** Developed by Zarit, Reever, and Bach-Peterson [15]. It was used to assess caregivers of patients with schizophrenia burden by Ribé et al., [16]. It is a self-administered scale comprising 22 items that explore the negative effects of the burden on caregivers in different areas of their life (mental, social, physical, and economic). It contains three subscales: 1) Burden, which indicates to the subjective influence of caring in the caregiver's life; 2) Rejection, which contains items related to feelings of rejection/hostility towards the patient; 3) Competence, which is associated with caregivers' self-assessment about their ability to preserve the relationship of care.

Each item is assessed on a 5-point Likert scale ranging from "Never" (0) to "Almost always" (4). Entire scores range from 0 to 88 (0 to 21 "No burden"; 22 to 40 "Moderate burden"; 41 - 60 "Moderate burden", and 61 to 88 "Intense burden"). The study tools were translated to Arabic language and translate back to English and to Arabic by a foreign person and submitted to a jury of five experts in the psychiatric nursing and medical fields to test content validity. Internal consistency was proven to be high (alpha 0.89), as is test-retest reliability (0.86).

### **F. Procedures**

Official permissions to carry out the study and collect data was obtained from the dean of the Faculty of Nursing, Beni-Suef University, and from the director of the identified study setting. Researchers explained the purpose of the study to participants. After giving oral consent, family caregivers were assessed individually. The participants were randomly assigned to the control or the experimental groups. The control group, the family of

patients who received the usual intervention, involving periodical meetings with psychiatry staff in order to prescribe the drug. The experimental group was distributed into four groups that received the family intervention program. Both control and experimental, the patients sustained to take an antipsychotic drug. The program was conducted through the period from the beginning of September to the end of December 2018 from the selected setting.

### **G. An Educational Family Program**

Involved four phases

**a) Assessment Phase:** The program was designed after reviewing the literature. The researchers were attention to the socio-cultural of Beni-Suef Governorate and the educational level of the caregivers to design the program to suitable for them. The program was conducted once a week for four months in psychiatric outpatient clinics of the Mental Hospitals in Beni-Suef Governorate.

**b) Preparation Phase:** According to the results accomplished from patients' records, interviewing, and observation, as well, review of the literature, a training instruction was established by the researchers. It was applied immediately after the pretest. The contents of the program: handouts were designed to meet the caregivers' needs and to fit into their interests and levels of understanding. Methods of teaching: all the experimental groups have given the same training program content and utilized the same instruction methods. These were: lectures/discussions, demonstration, and re-demonstration. Media of teaching: included handouts, pictures, videos, and the slide showed on the researchers' computer.

**c) Implementation Phase:** The researchers visited the psychiatric outpatient clinics of the Beni-Suef University Hospital once a week for 4 months from 9.00 a.m. to 2.00 p.m. immediately after completion of the assessment and the preparation phases, the training program was implemented. The sample of 44 patients was classified into two equal groups (control & experimental). The program was applied to the experimental group that was divided into four subgroups who took the program in a parallel manner. Each session continued 1.30 hours inside 10 minutes break.

### **The Researchers Divided the Implementation Phase of the Program into Two Parts:**

**Theoretical Part:-** It includes 6 educational sessions. It included information about the introduction of the program and disorder such as display of the members into the group, introduction to the program, an outline of the benefits from it. Exploring what relatives know about schizophrenia and modification of erroneous beliefs. Expressing feelings, experiences, and behaviors toward schizophrenia were notifying. It was giving information about the disease, causes and symptoms, and subtypes of schizophrenia. Explanation of medical treatment, types of drugs, and adverse effects.

**Practical Part:-**It includes 10 sessions for applying for the program through demonstration and redemonstration by the family caregiver under the observation of researchers. It included the skills and activities structured by the researchers for the family associations social implications of the disease. Applying the strategies to reduce the patient's distressing behaviors and discuss the objectives to reach with the patient, concepts of listening and empathy, the significance of self-care, and accepting the need for help. Improving the skills in the family to deal with the patient and understanding the need to reduce excessive stimulation. Applying problem-solving approaches and develops self-esteem. Training about deep breathing for relaxation and elimination of body tensions was applying.

### **d) Evaluation Phase:**

Evaluation of the program was accomplished promptly after the eventual application of the program functionality a post-test survey, which was the same as the pre-test to evaluate the effect of the program.

### **H. Ethical Considerations**

A verbal agreement from each caregiver who accepted to participate in the study was confirmed. The researchers explained the purpose of the study to the patients. The researchers assured privacy for participants, data that will be used for research purposes only. The caregivers were also informed that participation is voluntary, and they had the right to withdraw from the research work at any time without giving any reason.

### **I. Pilot Study**

In demand to determine that the tools of the study are feasible, clear, and applicable, a pilot study was done on 5 patients. No modifications were made; consequently, they were involved in the study sample.

### **J. Statistical Analysis:**

The statistical analysis of the data in the questionnaires was conducted through using the Statistical Package for Social Sciences (SPSS) software, version 22. Descriptive data were described as a percentage or frequency, and significance was determined using the Pearson's (r) test. Differences with P-values <0.05 were considered significant, and P-values <0.01 were highly significant. To assess the effectiveness of the program, the measures of ANOVA were used to compare the burden scores before and after the program in the experimental and control groups.

## **III. RESULTS**

Table1 shows the socio-demographic characteristics of caregivers in both groups. The studied sample comprised 44 family caregivers (31 women and 13 men). The mean age was 51.67 years (SD = 19.76) among the experimental group and 55.48 years (SD = 10.36) in the control group. There were 21 mothers, 6 fathers, 4 sisters, 5 daughters, 5 wives, and 3 other relatives. As regard residence areas, twenty-nine family caregivers were from rural. Twenty-two

family caregivers had not completed secondary school, and 14 were unemployed. As well, marital statuses of family caregivers were 11 single, 18 married, 8 divorced and 7 widows. There were no statistically significant differences between the experimental and control groups; this means that there was homogeneity between the studied groups.

Table 2 presents that, the patient characteristics of the studied sample among the experimental and control groups. The studied sample of 44 patients, 29 were men. The mean age was 34.72 years (SD = 6.24) among the experimental group and 32.09 years (SD = 9.74) in the control group. All patients had a diagnosis of schizophrenia and were receiving antipsychotic medication. Twenty-one patients had not completed secondary school. Thirty-seven patients were unemployed, but only 16 were receiving financial assistance from the Government. On average, patients had been hospitalized 3-4 times in the previous 3 years (SD = 1.2). The marital statuses of the studied patients were 20 single, 7 married, and 12 divorced and 5 widows. There were no statistically significant differences between an experimental and control groups; this means that there is homogeneity between the two main groups of the study sample.

Table 3 shows that the mean scores of family caregiver burden in the experimental and control groups before and after the program. There was a significant statistical change in the caregiver burden in an experimental group between before and after the intervention ( $t=16.5$  ( $P < 0.001$ )). As burden levels diminish from pre-program (Mean = 84.05, SD= 13.98) to post-program (Mean =53.24, SD= 12.18) in the experimental group, this means that the educational program had an important effect. There was no statistically significant change in the control group with a traditional treatment between before and after the program.

Table 4 states that the comparison of the mean scores of caregiver burden, rejection, and incompetence before and after application of the program in the experimental group. There was a significant statistical relation between the time of measurement (pre/post-intervention) and caregiver education program which caregiver burden ( $F = 211.61$ ;  $P < 0.001$ ); caregiver rejection ( $F= 81.63$ ;  $P < 0.001$ ), caregiver incompetence ( $F = 43.04$ ;  $P < 0.001$ ). This means that the family caregiver has benefited from the nursing program and reduces the level of burden.

Table 5 demonstrates that the comparison between burden levels in relation to caregivers' characteristics, before and after application of the program in the experimental and control groups. There was a significant statistical relationship between caregiver burden and educational level, and kinship. The reduction of the burden being significantly higher in parents ( $t = 15.32$ ;  $P < 0.001$ ), than other caregivers ( $t = 7.86$ ;  $P < 0.001$ ). The reduction of the caregiver burden being significantly higher in low educational levels ( $t = 12.98$ ;  $P < 0.001$ ) than among high educational levels ( $t = 12.25$ ;  $P < 0.001$ ). This is a good

indicator of the validity of the intervention program to reduce the family caregiver burden and accept them the ability to care for their relatives who have schizophrenia. There was no statistically significant change in the control group with the usual treatment between before and after conducting the program.

**Table (1): The Socio-demographic characteristics of Caregivers in the Experimental and Control Groups (n=44)**

Variables	Experimental group		Control group		X <sup>2</sup>	p
	N	%	N	%		
<b>Sex</b>						
Male	7	31.8	6	27.	0.066	0.52
Female	15	68.2	18	72.8		
<b>Age Mean (SD)</b>	51.67 (19.76)		55.48 (10.36)		t= -0.52	0.56
<b>Residence areas</b>					0.96	0.36
Rural	14	63.6	17	68.8		
Urban	8	36.4	5	21.2		
<b>Education level</b>					0.46	0.47
High	9	40.9	13	59.1		
Low	13	59.1	9	40.9		
<b>Kinship</b>					3.77	0.58
Mother,	11	50	1	45.		
Father,	2	9.1	0	4		
Daughter,	3	13.6	4	18.		
Sister,	2	9.1	2	2		
Wife,	3	13.6	2	9.1		
Other relatives	1	4.6	2	9.1		
<b>Marital status</b>					4.96	0.16
Single	6	27.3	5	22.		
Married,	7	31.8	1	7		
Divorced,	4	18.2	1	50		
Widow	5	22.7	4	18.2		
<b>Employment</b>					1.43	0.21
Yes	6	27.2	8	36.		
No	16	72.8	4	63.6		

**Table (2): Patient Characteristics of the Studied Sample among the Experimental and Control Groups. (n= 44)**

Variables	Experimental group		Control group		X <sup>2</sup>	p
	N	%	N	%		
<b>Sex</b>						
Male	14	63.6	15	68.2	0.84	0.33
Female	8	36.4	7	31.8		
<b>Age mean (SD)</b>	34.72 (6.24)		32.09 (9.74)		t 0.99	0.32
<b>Education level</b>						
High	10	45.4	13	59.1	0.78	0.43
Low	12	54.6	9	40.9		
<b>Government support</b>						
Yes	9	40.9	7	31.8	0.98	0.31
No	13	59.1	15	68.2		
<b>Number of episodes of 3 previous years (Mean + SD)</b>	3.9 (2.75)		3 (4.73)		t 0.75	0.32
<b>Marital status</b>						
Single	9	40.9	11	50	0.74	0.44
Married,	3	13.6	4	18.2		
Divorced,	8	36.4	4	18.2		
Widow	2	9.1	3	13.6		
<b>Employment</b>						
Yes	4	18.2	3	13.6	0.06	0.77
No	18	81.8	19	86.4		

**Table (3): Mean Scores of Family Caregiver Burden in the Experimental and Control Groups, Before and After the Program.**

Intervention Group	N	Mean	SD	t	P-value
<b>Experimental</b>					
Pre	22	84.05	13.98	16.8	0.001
Post	22	53.24	12.18		
<b>Control</b>					
Pre	22	86.75	12,31	0.64	0.42
Post	22	86.22	13.99		

\* Significant at p<0.05      \*\* highly significant at p <0.01

**Table (4): Comparison between Mean Score of Caregiver Burden, Rejection, and Incompetence, Before and After Application of the Program in the Experimental Group. (n=22)**

Variables	Pre-program		Post-program		F	p
	Mean	SD	Mean	SD		
<b>Burden</b>	47.22	7.89	25.50	7.96	211.61	0.001**
<b>Rejection</b>	17.84	3.45	9.51	2.99	81,63	0.001**
<b>Incompetence</b>	20.21	3.45	15.23	3.21	43.04	0.001**

\* Significant at p<0.05\*\* highly significant at p <0.01

#### IV. DISCUSSION

Previous studies reported that caregivers commonly don't have enough knowledge and skills for providing care to a patient with mental illness; therefore, family intervention has been established to intervene and teach effective coping strategies for families with mentally ill members[17], [18].The families' caregivers of patients with schizophrenia experience very high levels of burden, which has a negative effect on all areas of their lives. The family caregiver intervention program described here had a significant influence in reducing the general burden.

The contact between outpatients' unit staff and caregivers was more common in the experimental group than in controls. The greater reduction in burden observed in the experimental group may have been due in part to other non-specific effects deriving from increased contact with the hospital. Also, families' members and patients with schizophrenia need to be taught effective coping strategies moreover to enhance the quality of life of family caregivers. Therefore, the present study aimed to investigate the effect of family intervention on caregivers' burden.

Concerning caregivers' gender, the majority of the caregivers were females. In relation to the degree of relative to patients, mothers of the patients were the foremost caregivers. This is expected because females are accountable for caring for all family members, especially sick persons. In addition, the majority of the patients live in rural regions where extended families are common. Mothers as caregivers denote nearly half of the studied samples; this may be related to the nature of the extended families; more than one-third of the patients were married, which means that mothers are responsible for their caring, and this reflects the future of the females in Egyptian culture. These results are going in line with the previous studies by [19],[20]clarified that more than half of the caregivers were females, were married. In contrast, the studies were done in Portugal by [21], [22]displayed that the greatest of the caregivers were males.

The present study reported that more than one-third of the studied sample was receiving financial assistance from the Government. But, in the Arab culture, all people

give emotional support to each other. This reflects the importance of the role of families and friends in supporting patients according to Islamic teachings. In line with the foregoing, [23], [24] which highlighted that the significance of family and friends in supporting people mentally ill. The

results of the present study corroborate those reported by the World Federation of Mental Health [25] clarified that the problem of lower socioeconomic status is further compounded by the fact that greatest countries do not offer financial support for the care services that families provide

**Table (5): The Comparison between Burden Level in Relation to Caregivers' Characteristics, Before and After Application of the Program in the Experimental and Control Groups.**

	Pre	Post	Pre	Post
<b>Experimental group</b>				
<b>Level of educational</b>	<b>High educational level</b> 75.09 (10.0)	45.71(12.2)	<b>Low educational level</b> 97.47 ( 9.3)	63.23 (3.8)
	t = 12.25; P < 0.001		t = 12.98; P < 0.001	
<b>Kinship</b>	<b>Parents</b> 89.47 (12.6)	43.72 (14.4)	<b>Other caregivers</b> 67.20 (4.1)	52.67 (11.5)
	t = 15.32; P < 0.001		t = 7.86; P = 0.001	
<b>Control group</b>				
<b>Level of educational</b>	<b>High educational level</b> 79.29 (13.0)	78.29 (15.1)	<b>Low educational level</b> 92.85 ( 9.7)	93.54(9.9)
	t = 1.83; P = 0.13		t = -1.8; P = 0.07	
<b>Kinship</b>	<b>Parents</b> 91.00 (11.8)	90.47 (12.4)	<b>Other caregiver</b> 75.50 (8.3)	72.75 (11.0)
	t = - 1.38; P = 0.18		t = 1.38; P = 0.18	

\* Significant at p<0.05\*\* highly significant at p <0.01

For their mentally ill relative. The poor financial status in the family may further increase the risk or vulnerability for perceiving burden and the resulting distress and negative consequences such as mental health problems [26].

Regarding the level of caregiver burden was high, which pre-program (Mean = 84.05, SD= 13.98). This might indicate that the high level of caregiver burden in a family with a patient with schizophrenia. These results go in line with a study in Chinaby Chine, Chan and Morrissey revealed that the burden of caregivers of individuals with schizophrenia is high [27]. The caregivers of patients with mental disorders in Zimbabwe are suffering from a significant burden from care [28], while this is moderate to severe in Iran[29]. The study in Jamaican Africans, Alexander et al., presented that the burden of family caregiving is moderate in caring for persons with schizophrenia[30]. The burden of caregivers causes devastating effects not only for themselves but also for patients, other family members, and the health care system [31].

The current study showed that decreased burden level at the post-program in the experimental group (Mean =53.24, SD= 12.18). There was significant statistical relation in family caregiver burden in an experimental group between before and after the intervention (t=16.5; P < 0.001). This means that the intervention program was having a significant effect of reducing family caregiver burden; they need some skills to deal with patients' behavior and refresh their ability to give care for the patient with schizophrenia. These results were similar to the results revealed byTanriverdi, and Ekinci[32] Huis et al., [33] stated that caregivers who established the educational intervention estimated a decline of caregivers' burden. In

line with the foregoing, Yildirim et al. showed that the programs are effective in reducing the burdens on the family [34].

The result of the present study revealed that there was a significant statistical relation between the pre/post-intervention and caregiver educational program which caregiver burden (F = 211.61; P < 0.001); caregiver rejection (F = 81.63; P < 0.001), caregiver incompetence (F = 43.04; P < 0.001). This means that the family caregiver has benefited from the nursing program and reduces the level of burden. These findings were supported by Stam, and Cuijpers[35]presented that the components of the total burden score in which the program is greater effective. The result recommended that the program is effective in reducing the negative consequences for the family caregivers to provide good care for the patient and in reducing their feelings of contradiction, irritation, or rejection.

The present study demonstrated that there was a significant statistical relationship between caregiver burden and educational level, and kinship. The reduction of the burden being significantly higher in parents (t = 15.32; P<0.001), than other caregivers (t = 7.86; P<0.001). This might be due to the parents are the ones who take care of their children from young to adult, especially the patient one and those with mental illness in the Egyptian culture. This result is in agreement with [36], [37], which stated that the greatest of the caregivers were the parents of the patients with schizophrenia. This goes in line with [38] explained that the mothers had greater tension, upsetting, and complete burden, and fathers had higher distressing. In line with the studies carried out by [39]-[41]revealed that mothers were most of the caregivers. Mothers may perceive a greater care burden than fathers because mothers



may be in closer contact with their child, feel more responsible for the main part of the patient's care, or are more affected by their child's deteriorations.

The findings of the current study revealed that the reduction of the caregiver burden being significantly higher in low educational levels ( $t = 12.98$ ;  $P < 0.001$ ) than among high educational levels ( $t = 12.25$ ;  $P < 0.001$ ). This is a good indicator of the validity of the intervention program to reduce the family caregiver burden and accept them the ability to care for their relatives who have schizophrenia. According to the survey performed by [42] stated that the educational program demonstrated the greatest effect among family caregivers of low educational level. The results of the present study stated that the better effectiveness of the program in caregivers with low educational levels might be due to their higher burden level before the educational program.

The findings of the current educational intervention were supportive, and the caregivers in the experimental group directed a significant decrease in family burden. These results might be recognized to the strong desire of the participants to receive the needed information about their relatives' disorder, also the lack of caregiver skills to handle patient problems, allowing more interaction between each other's and sharing experiences, in addition to giving chances to express their held feeling related to caregiving duties and burdens. This result is in agreement with [43] suggested that there was an improvement in the greatest aspects of the behaviors of families' caregivers in the patients whom they took care of. Enhancement in the patient's clinical status and decreases in family burden may be related to the family's consciousness of strategies for dealing with daily challenging situations, in this respect [44], [45] who emphasized that the family caregivers should be involved as active members of the health care staff giving care for the patients with schizophrenia.

The family caregiver program was designed to develop skills to progress communication and self-management; thus, an enhancement in these aspects as a result of the intervention could also have contributed to reducing the burden. The effect of the presence in group therapy, as well as the better knowledge learned during the program and the increase of interactions between family caregivers and the psychiatric staff, are part of the therapeutic effect. The reduction in burden may be determined by factors such as recognition of the disorder, access to information about schizophrenia that may counteract the negative symptoms of incapacity and danger, learning about the use of problem-solving strategies, increased social support and community networks, and a greater appreciation of their own needs. This explanation was supported by [46].

In the findings of our control group, there was no statistical significance change from before to after the program. Which the patients were usually received care in an outpatient unit. These results were presented with a slight improvement in the patient's clinical status and family burden. It may reflect the fact that predictable services for clients with schizophrenia and their families' caregivers in Egypt do not meet their needs. These results

go in line with a study in Iran by Sharif et al., who stated that the control group, which established usual care, displayed little improvement in the patient's clinical conditions and family caregiver burden. These results may reflect the fact that usual management in the outpatient clinic for patients with schizophrenia and their families does not meet the patients' and families' needs [4].

## VI. IMPLICATION FOR NURSING PRACTICE

This study reveals the need to initiate nursing interventions that will ameliorate the burden of caregivers, however providing nursing care to patients with schizophrenia. Nurses being in direct contact with the patients and their caregivers need to constantly give education, advice, information, counseling, and motivation to the caregivers. This will help prevent real danger to the physical and mental health of the caregivers. The Nurse should provide caregivers with information on how to balance the important care role with their own health and well-being. Nurses should also advocate for the implementation of community mental health to bridge the gap between inpatient and outpatient services and to bring services closer to the people, and ensure adequate supervision to prevent recurrence and relapse. Nursing interventions that will be mindful of the role of the caregiver and the impact of illness on their wellbeing should be ensured, thus providing a comprehensive service that addresses caregivers' concerns as well as linking them to services that will improve their own health and lead to better health outcomes for the caregivers.

## VII. CONCLUSION

Based on the findings of the present study, it can be concluded that the effectiveness of the family caregivers program aimed to reduce the burden on the caregiver of patients with schizophrenia and reduced their burden in all three parts: burden, rejection, and incompetence. The program was effective in reducing the burden in parents and in caregivers with a low educational level in the experimental group and slight changes in the control group.

## VIII. RECOMMENDATIONS

Based on the findings of this study, the following recommendations are made in order to improve the burden experienced by relatives of patients with schizophrenia and mental illness.

- The psychiatric/mental health nurses should provide family focus programs can intervene to prevent the sufferings of the patients with schizophrenia and their relatives and improve their daily life and well-being
- Establishment and thorough supervision of mental health agencies, providers, policymakers, and educators to provide service, monitoring, supervision, and support for the mentally ill individuals and their caregivers.
- There is a need for the development of community mental health services under primary health care which will aim at focusing not only on the management of the patients but also to meet the needs of the caregivers.

- Locally based family support groups should be created for assisting caregivers and advocating for the promotion of their well-being in society.

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### REFERENCES

- Argermeyer, M., and Matschinger, H., The Stereotype of schizophrenia and its impact on discrimination against people with schizophrenia: Results from a representative survey in Germany. *Schizophrenia Bulletin*, 30 (2017) 1049 - 1061.
- Adewuya, A., and Makanuola, R., Subjective quality of life of Nigerian schizophrenia patients: socio-demographic and clinical correlates. *Acta Psychiatr Scand*, 120 (2009) 160 - 164. Available from: <https://doi.org/10.1111/j.1600-0447.2009.01395.x>.
- El-Azzab, S., Abu-Salem, E., Effective strategies for nurses empowering the life quality and antipsychotic adherence of patients with schizophrenia. *Journal of nursing education and Practice*, Sciedu Press, 8(10) (2018) 1 - 9. Available from: <http://www.jnep.sciedupress.com>.
- Sharif, F., Shaygan, M., and Mani, A., Effect of a psycho-educational intervention for family members on caregiver burdens and psychiatric symptoms in patients with schizophrenia in Shiraz, Iran. *BMC Psychiatry*, 12(48) (2012) 1-9. Available from: <http://www.biomedcentral.com/1471-244X/12/48>.
- Schulz, R., and Paula, R., Sherwood: physical and mental health effects of family caregiving. *Am J Nurs.*, 108(9) (2008) 23-27. Available from: <http://www.doi:10.1097/01.NAJ.0000336406.45248.4c>.
- Singh, P., and Prajapati, A., Burden of schizophrenia on caregivers in Nepal. *Nepal Med Coll J.*, 15 (2012) 140 - 143.
- Shamsaei, F., Khan, M., Kermanshahi, S., Vanaki, Z., Grosse, A., and Holtforth, M., Family caregiving in bipolar disorder: Experiences of stigma. *Iranian J Psychiatry*, 8 (2013) 188 - 194.
- Delgado, P., Overload of care, solidarity, and strategy of the experience of relatives of Psychosocial Care Centers. *PhysisRevista de SaúdeColetiva*, 24(4) (2014)1103 - 1126.
- Ran, M., Xiang, M., Chan, W., Leff, J., Simpson, P., Huang, M., Shan, Y., and Li, S., Effectiveness of psycho-educational intervention for rural Chinese families experiencing schizophrenia, A randomized controlled trial. *Social Psychiatry and Psychiatry Epidemiology*, 38 (2016) 69 - 75.
- Zegwaard, M., Aartsen, M., Grypdonck, M., and Cuijpers, P., Differences in impact of long term caregiving for mentally ill older adults on the daily life of informal caregivers: a qualitative study. *BMC Psychiatry*, 13 (2013) 103. Available from: <http://www.doi:10.1186/1471-244X-13103>.
- Wan, K., and Wong, M., Stress and burden faced by family caregivers of people with schizophrenia and early psychosis in Hong Kong. *Internal Medicine Journal*, 49 (2019) 9-15.
- Bayoumi, M., Lifestyle modification toward improving quality of life and effects on caregivers' burden: Development of new nursing theory. *Ann Nurs Primary Care*, 1(1) (2018) 1- 5.
- Chang, H.Y., Chiou, C.J., and Chen, N.S., Impact of mental health and caregiver burden on family caregivers' physical health. *Arch Gerontol Geriatr*, 50(3) (2010) 267 - 271.
- Ampalam, P., Gunturu, S., and the Padma, V., A comparative study of caregiver burden in psychiatric illness and chronic medical illness. *Indian J Psychiatry*, 54(3) (2012) 239 - 243.
- Zarit, S., Reever, K., and Back-Peterson, J., Relatives of the impaired elderly: correlates of feelings of burden. *TheGerontologist*, 20 (1980) 649 - 655.
- Ribé, J., Salamero, M., Pérez-Testor, C., Mercadal, J., Aguilera, C., Cleris, M., Quality of life in family caregivers of schizophrenia patients in Spain: Caregiver characteristics, caregiving burden, family functioning, and social and professional support. *International Journal of Psychiatry in Clinical Practice*, 22 (2018) 25-33, Available from: <http://www.doi:10.1080/13651501.2017.1360500>.
- Fallahi, K., Sheikhona, M., Rahgouy, A., Rahgozar, M., and Sodagari, F., The effects of group psycho-educational program on the family burden in caregivers of Iranian patients with schizophrenia. *Journal Psychiatric Mental Health Nursing*, 21 (2014) 438 - 446.
- Yazici, E., Karabulut, U., Yildiz, M., Baskant, T., Eda, N., Çakir, U., and Celaleddin, T., Burden on caregivers of patients with schizophrenia and related factors. *Turkish Association of Neuropsychiatry*, 53 (2016) 96 -101.
- Wong, D., Lam, A., and Chan, S., Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: Health and quality of life outcomes, 10(15) (2011) 2 - 9.
- George, S., and Sreekumaran, N., Effect of psycho-education on knowledge, attitude and burden among caregivers of persons with bipolar disorders: Randomized controlled trial. *International Journal of Advanced Research*, 3(7) (2015) 199 - 208.
- Goncalves, L., Costa, M., Martins, M., Nassar, S., and Zunino, R., The family dynamics of elder elderly in the context of Porto, Portugal, 19(3) (2011) 458 - 466.
- Ranjbar, F., Rahmani, F., Ebrahimi, H., Hosseinzadeh, M., The effects of group psycho-educational program on attitude toward mental illness in families of patients with schizophrenia. *Journal of Caring Sciences*, 4(3) (2015) 243 - 251.
- Griffiths, K., Crisp, D., Barney, L., and Reid, R., Seeking help for depression from family and friends: A qualitative analysis of perceived advantages and disadvantages. *BMC Psychiatry*, 11 (2011) 196. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3271042>.
- Akbari, M., Alavi, M., Irajpour, A., and Maghsoudi, J., Challenges of family caregivers of patients with mental disorders in Iran: A narrative review. *Iranian J Nursing Midwifery Res*, 23 (2018) 329 - 337.
- World Federation of Mental Health (WFMH)., *Caring for the caregiver: Why your mental health matters when you are caring for others.* Woodbridge VA: WFMH, (2010).
- Muralidharan, A., Lucksted, A., Medoff, D., Fang, L., and Dixon, L., Stigma: A Unique Source of Distress for Family Members of Individuals with Mental Illness. *J Behav Health Serv Res*, 43 (2016) 484-493.
- Chine, W., Chan, S., and Morrissey, J., The perceived burden among Chinese family caregivers of people with schizophrenia. *J Clin Nurs.*, 16 (2007)1151-1161.
- Marimbe, B., Kajawu, L., Muchirahondo, F., Marimbe, B., Cowan, F., Lund, C., Perceived burden of care and reported coping strategies and needs for family caregivers of people with mental disorders in Zimbabwe: Original research. *Africa J Disabil*, 5 (2016) 1 - 9.
- Padierna, A., Martín, J., Aguirre, U., González, N., Muñoz, P., and Quintana, J., Burden of caregiving amongst family caregivers of patients with eating disorders. *Soc Psychiatry Psychiatry Epidemiol*, 48 (2013) 151 - 161.
- Alexander, G., Bebee, C., Chen, K., Vignes R., Dixon, B., and Escoffery, R., Burden of caregivers of adult patients with schizophrenia in a predominantly African ancestry population. *Qual Life Res*, 25 (2016) 393-400.
- Boyer, L., Caqueo-Urizar, A., Richieri, R., Lancon, C., Gutiérrez-Maldonado, J., and Auquier, P., Quality of life among



- caregivers of patients with schizophrenia: A cross-cultural comparison of Chilean and French families. *BMC FamPract.*, 13(2012) 42- 50.
- [32] Tanriverdi, D., Mandakini, M., The effect psycho-education intervention has on the caregiving burden of caregivers for schizophrenic patients in Turkey. *International of Journal Nursing Practice*, 18 (2012) 281-288.
- [33] Huis, V., Verkaik, R., Mistiaen, P., Meijel, B., and Francke, A., The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; a systematic meta-review. *Biomed Central Geriatric journal*, 15(1) (2015) 147.
- [34] Yildirim, A., Buzlu, S., Hacıhasanoğlu, R., Camcıoğlu, T., Erdiman, S., and Ekinçi, M., The effect of family-to-family support programs provided for families of schizophrenic patients on information about illness, family burden and self-efficacy. *Turkish Journal of Psychiatry*, 25 (1) (2014) 31 - 37.
- [35] Stam, H., and Cuijpers, P., Brief report: Effects of family interventions on burden of relatives of psychiatric patients in the Netherland: A pilot study. *Community Mental Health Journal*, 37(2) (2001) 179 - 187.
- [36] Hsiao, C.Y., and Tsai, Y.F., Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia. *J Clin Nurs*, 24(11-12) (2015) 1546 - 1556.
- [37] Chen, L., Zhao, Y., Tang, J., Jin, G., Liu, Y., Zhao, X., Chen, C., and Lu, X., The burden, support, and needs of primary family caregivers of people experiencing schizophrenia in Beijing communities: a qualitative study. *BMC Psychiatry*, 19(75) (2019) 1 - 10. Available from: <http://www.doi: 10.1186/s12888-019-2052-4>.
- [38] Martín, J., Padierna, A., Aguirre, U., González, N., Muñoz, P., Wijngaarden, B., Anton, A., Quintana, J., Caregivers' consequences of care among patients with eating disorders, depression or schizophrenia. *BMC Psychiatry*, 15(124) (2015) 1-10. Available from: <http://www.doi:10.1186/s12888-015-0507-9>.
- [39] El-Mahdi, M., Kamel, F., Esmael, A., Lotfi, M., Kamel, A., and Elhosini, A., Burden of care on female caregivers and its relation to psychiatric morbidity, Department of Psychiatry, Faculty of Medicine, Al Azhar University, Cairo, Egypt, Middle East, (2010).
- [40] Abdel-kader, N., Shaheen, M., and Abdel-Aziz, E., Impact of the psychoeducational program on burdens among family caregivers of schizophrenic patients. *Mental Health Nursing, Faculty of Nursing, Cairo University, Cairo, Egypt*, 7(12) (2011) 822 - 830. (ISSN: 1545 - 1003). Available from: <http://www.americanscience.org>.
- [41] Souza, S., Ricardo, S., Mariane, A., and Jansen, K., Six-session caregiver psycho-education on bipolar disorder: Does it bring benefits to caregivers?. *International Journal of Social Psychiatry*, 62(4) (2016) 377 - 385.
- [42] Gutierrez-Maldonado, J., Caqueo-Uri'za, A., Effectiveness of a psycho-educational intervention for reducing burden in Latin American families of patients with schizophrenia, 6 (2007) 739-747. Available from: <http://ww.doi.10.1007/s11136-007-9173-9>.
- [43] Bandeira, M., Family burden interview scale for relatives of psychiatric patients: Reliability study of the Brazilian version. *Rev Bras Psiquiat* 29(1) (2007) 47 - 50.
- [44] Chang, K., Huang, X., Cheng, J., and Chien, C., The chronic sorrow experiences of caregivers of the client with schizophrenia in Taiwan: a phenomenological study. *Perspect Psychiatr Care*, 54(2) (2018) 281 - 286.
- [45] El-Azzab, S., The program for coping methods to improve auditory hallucinations among patients with psychiatric disorders: A randomized controlled trial, *American Journal of Nursing Science*, 7(6) (2018) 268 - 280. Available from: <http://www.doi: 10.11648/j.ajns.20180706.20>.
- [46] Ramírez, A., Palacio, J., Vargas, C., Díaz-Zuluaga, A., Duca, K., and Berruecos, Y., Expressed emotions, burden and family functioning of patients with schizophrenia and bipolar affective disorder type I of a multimodal intervention program: PRISMA, *Rev ColombPsiquiat*, 46 (2017) 2 - 11.