

**Research Article**

## **EFFECT OF PSYCHOEDUCATION ON REDUCING BURDEN AMONG PRIMARY CAREGIVERS OF PEOPLE WITH SCHIZOPHRENIA**

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### **ABSTRACT**

Schizophrenia is a serious psychological illness that needs long-term treatment. Family members, especially those who care for a patient at home, experience the burden of providing long-term care. Psychoeducational intervention may enhance the caregiver's outcomes. The major goal of the study was to explore the effect of psychoeducation on reducing the burden among primary carers of people with schizophrenia. In this study, thirty-two participants (32 caregivers) were purposefully selected based on the National Institute of Mental Health (NIMH). A personal information form and the Bangla version of the Zarit Burden Interview scale were administered. Total participants were divided by simple randomization into two groups (*i.e.*, experimental and control groups). Following the baseline evaluation by questionnaire, the experimental group of 16 caregivers received two sessions of psychoeducation, but the control group of the same number of caregivers did not. The effectiveness of psychoeducation was evaluated using a pretest-posttest control group design. Findings suggested that psychoeducation decreased the level of burden, and after the intervention, the mean score of the experimental group was lower than that of the control group. These findings found that the psychoeducation intervention had a positive outcome in reducing the burden on caregivers of patients who deal with schizophrenia.

**Keywords:** *Burden, Primary Caregivers, Psychoeducation, Schizophrenia*

### **Introduction**

Schizophrenia is recognized as one of the top 15 leading causes of disability globally and prevalence estimates range from 0.33% to 0.75% among non-institutionalized people worldwide (Moreno-Küstner, 2018). According to the National Institute of Mental Health Schizophrenia (2009) report, this illness is a complex, chronic, as well as long-lasting mental health condition characterized by an inclusive range of symptoms, such as hallucinations, delusions, disordered speech or behavior, and cognitive impairment. It may appear to have lost contact with reality due to the disorder's early onset and chronic duration, which have devastating impacts on both people with schizophrenia and their families (Lavretsky, 2008).

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In the field of family caregivers research the concept of caregiver burden is not uncommon but a clear definition of “caregiver burden” is lacking (Lee *et al.*, 2019). The concept of caregiver burden is often used interchangeably with terms such as “stress, problem, and negative effects” leading to a clear lack of understanding of the concept (Adelman *et al.*, 2014). Research shows that family caregivers experience a significant burden in providing care to patients with mental health illnesses (Cui *et al.*, 2014).

The primary carer is the closest person who provides special attention to people with schizophrenia. In Bangladesh, a common social function of family members (primary caregivers) is strongly connected, and providing care of a person who suffers from mental illness. Even so, during the times of treatment, rehabilitation, and recovery, families face several challenges and difficulties. An estimated 50 percent to 80 percent of people with schizophrenia stay with their families and maintain continuous interaction with them (Lehman and Steinwachs, 1998). These caregivers report a significant amount of burden associated with caring for a person with schizophrenia (Asen, 2002). Family caregivers often encounter difficulties and exhibit emotional reactions such as fear of violence, a great deal of burden, stigma, frustration, despair, and anger (Papastavrou *et al.*, 2010). They also experience financial difficulties and a lack of knowledge about schizophrenia (Small *et al.*, 2010). The quality of life, health, and functional status of the caregiver is also impacted by the burden of caring for an extended time (Caqueo-Urizar *et al.*, 2011). A long course of treatment, the severity of the condition, and the high cost of medication could be the risk factors for financial burden among caregivers (Darwin *et al.*, 2013). Family caregivers also face everyday obstacles that affect every aspect of their lives (World Federation of Mental Health, 2010). The burden on caregivers of patients with psychiatric disorders is enormous (Ukpong, 2012), and need for a comprehensive intervention to reduce (Inogho *et al.*, 2017; Okafor *et al.*, 2020).

For mental health service providers, reducing the strain of caring for carers of people with schizophrenia has been challenging (Chan *et al.*, 2011). To support caregivers of patients with mental disorders through all psychosocial interventions, psychoeducation has been described as an approach to educating patients and their families about illnesses, treatment options, coping mechanisms, and resources (Mary *et al.*, 2013). This intervention is considered one of the important techniques that have been used to lessen caregivers' stress and burden (Sin *et al.*, 2017) and can directly increase their knowledge regarding schizophrenia and other caregiving challenges (Birchwood *et al.*, 1992). Psychoeducational evidence-based treatment strategies focus on educating about the disorder, early warning signs, relapse prevention, and the development of coping, communication, and problem-solving skills (Dixon *et al.*, 2001; Sin *et al.*, 2017).

Literature suggests that psychoeducation intervention (PEI) has a positive effect and is beneficial on the family caregivers of the patient such as caregiver's burden (Chan *et al.*, 2009) and reducing deterioration (Dixon *et al.*, 2000). It may recommend and upgrade the knowledge level of caregivers, improving the quality of life by reducing psychological problems (Hogarty *et al.*, 1996). In a pre-posttest in India, regarding educating the primary caregiver a significant decrease in caregiver burden, was found between baseline and the final follow-up at 3 months (Devaramane *et al.*, 2011). Studies demonstrate that a relatively simple psychoeducation approach can be implemented in routine clinical settings and can have positive outcomes. Structured

psychoeducation intervention has emerged as superior to ‘care as usual’ in almost all studies (Droulout *et al.*, 2003).

In Bangladesh, the number of people who suffer from schizophrenia is increasing day by day (The Daily Star, 2023). Many institutions and organizations are working to give better treatment to them, but at a time ignoring the mental health issues of primary caregivers, which harm both the caregivers and the eventual recovery of those with the disorder. In this situation, psychoeducation may be helpful for them. Therefore, developing psychoeducational tools and evaluating their effectiveness on caregivers in the Bangladeshi setting are urgently needed at this time. However, limited research has been done earlier in the context of Bangladesh. These findings can guide efforts to preserve and promote an upgrade in the knowledge level of caregivers, strengthen their skills, and improve their quality of life by reducing psychological problems.

#### Objectives of the Study

The major objective of the study was to examine the effect of psychoeducation on reducing the burden among primary caregivers of people with schizophrenia. However, the specific objectives were:

1. To determine the level of severity burden among the primary caregivers of people with Schizophrenia;
2. To examine whether there is any effect of psychoeducation on reducing the burden among the primary caregivers of people with Schizophrenia;

#### Materials and Methods

##### Participants

A total number of 32 caregivers of people with schizophrenia were selected from the outdoors at the National Institute of Mental Health (NIMH), Dhaka. All the caregivers were selected based on the following inclusion and exclusion criteria. To select the caregivers a purposive sampling technique was used, and simple randomization techniques were used to divide the participants into two groups, i.e., experimental and control groups. The inclusion and exclusion criteria of the caregivers that were followed are displayed in Figure 1.

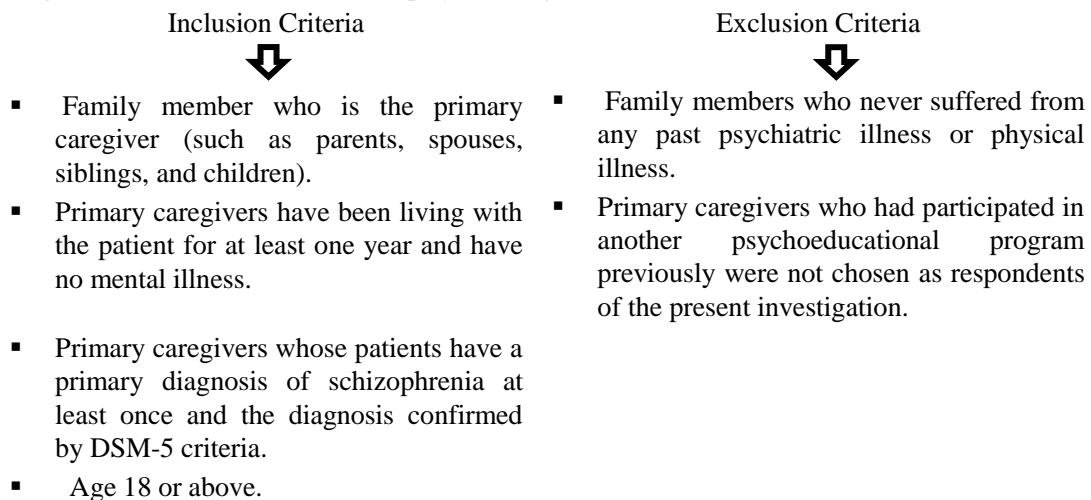


Fig. 1. Inclusion and exclusion criteria of caregivers.

## Demographic Characteristics of Sample

All the features of each caregiver (i.e., age, gender, education level, occupation, family income, marital status, etc.) were chosen and divided into groups following the research protocols (Table 1). Here selected demographic profiles are given below mentioning frequency and percent as additional information.

Table 1. Demographic profile of the caregivers

Variables	Experimental Group (n = 16)		Control Group (n = 16)		
	Frequency	Percent	Frequency	Percent	
Gender	Male	9	56.3	10	62.5
	Female	7	43.8	6	37.5
Age	18-35 years	10	62.5	10	62.5
	36-65 years	6	37.5	6	37.5
Educational Status	Below S.S.C	5	31.3	6	37.5
	S.S.C-H.S.C	7	43.8	8	50.0
	Graduation	4	25.0	2	12.5
Occupation	Housewife	5	31.3	5	31.3
	Job Holder	5	31.3	6	37.5
	Business	6	37.5	5	31.3
Family Income	Below 10,000 Tk	4	25.0	6	37.5
	11,000-20,000 Tk	5	31.3	6	37.5
	21,000-30,000 Tk	5	31.3	2	12.5
	Above 30,000 Tk	2	12.5	2	12.5
Marital Status	Married	9	56.3	9	56.3
	Unmarried	5	31.3	5	31.3
	Divorced/Widow	2	12.5	2	12.5
Family Structure	Nuclear Family	10	62.5	9	56.3
	Extended Family	6	37.5	7	43.8
Relationship with Patients	Parent-Children	5	31.3	6	37.5
	Siblings	5	31.3	6	37.5
	Spouse	6	37.5	4	25.0
Caregiver's Patient's Illness Duration	Less than 3 years	4	25.0	4	25.0
	3 years to 5 years	8	50.0	9	50.0
	Above 5 years	4	25.0	3	18.75

Measures

The following questionnaires have been administered here to determine and gather fundamental raw data from the respondents.

1. Personal Information Form (PIF).
2. Zarit Burden Interview (ZBI-B)- Bangla Version.

*Personal Information Form (PIF)*

Personal information needed in the study to collect data included the respondent's age, sex, educational status, marital status, occupational status, economic situation, relationship between patients and caregivers, duration of caregiving, and type of family.

*Bangla Version of Zarit Burden Interview (ZBI-B)*

The Bangla version of the Zarit Burden Interview (ZBI-22) (Zarit, Reever, and Peterson, 1980) was utilized was developed by Rabin *et al.*, (2016) to assess the level of burden on caregivers by taking care of a person with a particular medical condition. Here, the carer's burden was measured with the 22 items and participants reported each item on a 5-point Likert scale, ranging from 0 (not at all disruptive) to 4 (very disruptive). Item scores are added up to give a total score ranging from 0 to 88 with the higher score indicating a greater level of burden. Here, the scores range from 0-21 = little or no burden, 21-40 = mild, 41-60 = moderate, and 61-88 = severe burden. Cronbach's alpha value of the Bangla version (Rabin *et al.*, 2016) was found .84 for the test and .83 for retests. Test-retest reliability was .89 (When interpreting Cronbach's alpha or the intra-class *R*, a value > 0.7 reflects good reliability). The construct validity was highly correlated with the caregiver's burden score (Pearson's correlation coefficient,  $r = .90, p = 0.001$ )

Steps for Creating Psychoeducation Materials

In this study, the researcher herself developed psychoeducational materials by gathering data from numerous sources. The steps that were followed for the development of psychoeducation materials are in Table 2 (Ara and Chowdhury, 2014).

Table 2. Steps for developing psychoeducation materials

Steps	Developing Psychoeducation Materials
First	⇒ Information was taken from the primary caregivers of schizophrenia patients during outdoor service and psychotherapy sessions for patients at the National Institute of Health and Hospital to see what type of questions the caregivers asked about the illness of the patients;
Second	⇒ A range of sources, including books, research, and already published works, were used to gather materials and information;
Third	⇒ Further information was received after discussions with psychiatric professionals, professional psychologists, and nurses;
Fourth	⇒ The materials for psychoeducation's initial draft have been written;
Fifth	⇒ Professional psychologists, psychiatrists, and faculty from Jagannath University's psychology department evaluated this psychoeducational material;

Steps	Developing Psychoeducation Materials	
Sixth	⇒	The psychoeducational material's second draft has been revised and edited;
Seventh	⇒	Five caregivers of people with schizophrenia participated in a pilot study to understand the suitability of psychoeducational materials in a hospital context;
Eight	⇒	In the end, the materials were reviewed once more to determine their suitability and approval. From one judge evaluation to make-up, the final draft of psychoeducation was done.

### Design of the Study

The purpose of the study, which used a pretest-posttest control group design, was to see the effect of psychoeducation among the primary caregivers of people with schizophrenia. The design of the study is illustrated in Figure 2.

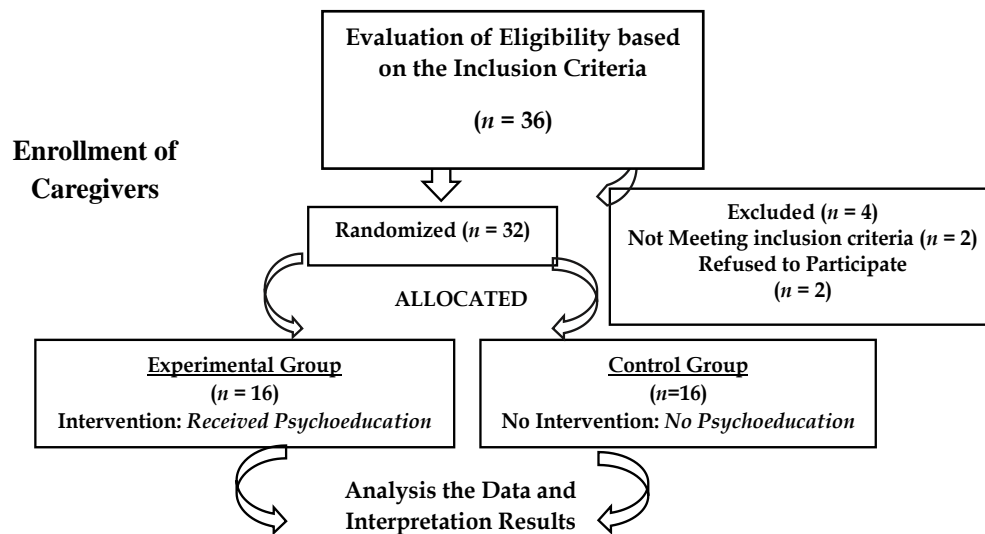


Fig. 2. Design and procedure of the present study.

### Procedure

A standard data collection method was followed for carrying out the research. The psychoeducational materials for family carers in the current study were created by the researchers themselves using the steps (Table 2) included gathering information and materials from sources, having them reviewed by an expert, creating a draught, and making sure the materials were appropriate before using them with the research participants. For data collection, cooperative services, and support from the concerned authority permission (i.e., receiving the required official approval for space, cooperation, and assistance from the authority) was approved by the NIMH. A total of 32 caregivers were screened for eligibility and selected for participation. At the pre-test session, all the instruments were given out. Participants were divided into two groups (e.g.,

experimental and control) by using simple randomization. Here, only 16 caregivers of the experimental group received the psychoeducational intervention. In a hospital setting the experimental group members individually received psychoeducation throughout two sessions(40 minutes). The participants were re-interviewed about seven days after the psychoeducation session ended, and all measurements were again administered in the post-test session. Here it is mentionable that a few conditions were also followed during the session. Before starting the data collection, a consent form (including the nature and aim of the study, probable risks and benefits, privacy, and the right to refuse or withdraw from participation) with necessary debriefing was also provided to the selected participants. After collecting information all participants were thanked.

The psychoeducation session structure is presented in Table 3.

Table 3. The content of psychoeducational intervention.

Session	Content	Session Goal
Pre Session	<ul style="list-style-type: none"> <li>• Overview of the psychoeducation intervention.</li> <li>• Discussion about the general purpose of the study and providing consent paper.</li> </ul>	To orient caregivers to the psychoeducational intervention.
	<ul style="list-style-type: none"> <li>• Completion of Personal Information Form by participants.</li> </ul>	To develop a relationship of trust between caregivers and instructors.
	<hr/>	
One	<ul style="list-style-type: none"> <li>• Describe the nature of schizophrenia, symptoms, and behaviors and their effects on the family.</li> <li>• Describe the etiology and treatments.</li> </ul>	To understand the disorder, such as symptoms, treatment, and its effects on patients and families.
	<hr/>	
Two	<ul style="list-style-type: none"> <li>• A review of the prior session.</li> </ul>	To improve the acceptance of the disorder adapt to new roles, and challenges, and improve skills in coping with the patient’s symptoms.
	<ul style="list-style-type: none"> <li>• Discuss the caregiving and take care of the people with Schizophrenia.</li> </ul>	
	<ul style="list-style-type: none"> <li>• Discuss the importance of effective communication skills in the family and with the patients when they have symptoms.</li> </ul>	To improve communication skills and oriented caregivers and relaxation for the family.
	<ul style="list-style-type: none"> <li>• Discuss how to cope with the patient’s negative emotions (for example, suicide) and discuss the warning signs of relapse.</li> </ul>	
	<ul style="list-style-type: none"> <li>• Discuss ways of reducing stress and practicing relaxation methods.</li> <li>• Question answer and summary of the session.</li> <li>• Termination.</li> </ul>	

### Data Analysis and Processing

The participants' responses were assessed following the criteria for each measure. Data were entered into the SPSS 26 software, which was used for both descriptive and inferential statistics. For describing the sociodemographic traits of the caregivers for people with schizophrenia, frequency and percentage were calculated. To determine whether there was a significant difference in the burden of the demographic factors, the independent sample *t*-test and one-way ANOVA were performed. The effect of psychoeducation on caregiver burden was examined using a paired sample *t*-test. This test was used because the primary interest was a between-group comparison of the change rate in the expected value of response variables over time. The statistical tests were run with a level of significance of .05.

## Results and Discussion

### Results

According to the objectives the collected data were analyzed using different statistical techniques.

#### Normality Test as Assumption Test

As a result, before conducting any statistical analysis of data, it is essential to confirm or verify this assumption. The following assumption test results are reported in the segment:

According to the caregiver's burden scores the visual inspection of the histograms, and box plots assumed that the data were normally distributed. Histogram indicates a classic bell-shaped, symmetric histogram with most of the frequency counts bunched in the middle and with the counts dying off in the tails. Further, the Box plot clearly shows the normal pattern of the data. It contains outliers and the data are symmetric.

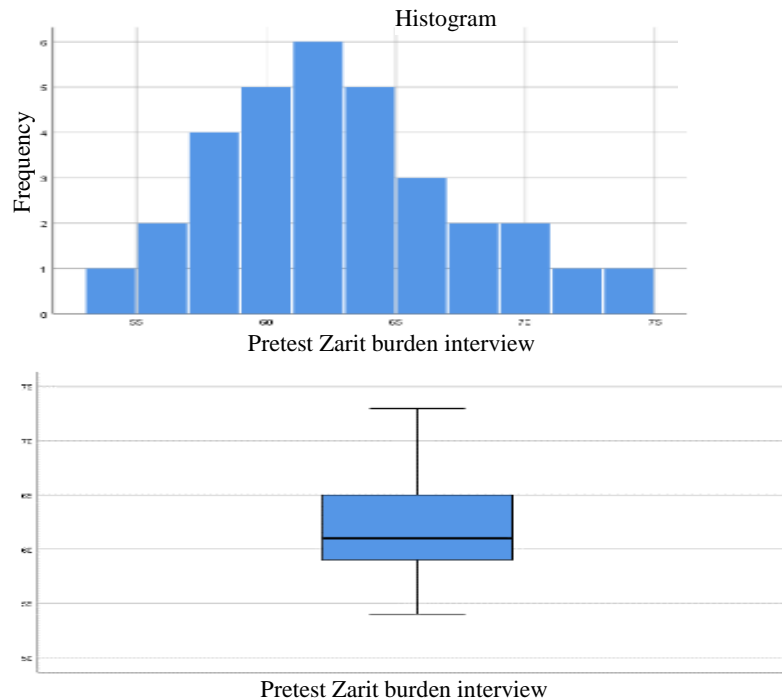


Fig. 3. Visual graph of pre-test Zarit Burden interview score as assumption test.



Table 4. Independent sample *t*-test of primary caregiver’s burden with the level of caregiver’s gender, age, and family structure

Variables	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i> -test	<i>p</i>
Caregiver’s Gender					
Male	19	62.26	5.38		
Female	13	61.15	4.12	.63	.54
Caregiver’s Age					
15-35 Years	20	61.05	5.19		
36-65 Years	12	63.08	4.19	-1.15	.26
Caregiver’s Family Structure					
Nuclear	19	62.53	4.54		
Extended	13	60.77	5.33	1.00	.32

Note. *N* = Number, *M* = Mean, *SD* = Standard Deviation, *p* = Probability

The above findings reveal no significant difference in burden between the levels of caregiver's gender, age, and, family structure.

Table 5. One-way ANOVA among different levels of education, occupation, family income, marital status, relationship with patients, and patient’s illness duration according to primary caregiver’s burden scores

Variables	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Caregiver’s Education					
Between Groups	15.94	2	7.97		
Within Groups	718.93	29	24.79	.32	.73
Total	734.87	31			
Caregiver’s Occupation					
Between Groups	85.90	3	28.63		
Within Groups	648.97	28	23.18	1.23	.31
Total	734.87	31			
Caregiver’s Family Income					
Between Groups	48.96	3	16.32		
Within Groups	685.91	28	24.5	.66	.58
Total	734.87	31			
Caregiver’s Marital Status					
Between Groups	10.09	2	5.05		
Within Groups	724.78	29	24.5	.20	.82
Total	734.87	31			

Variables	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>
<b>Caregiver's Relationship with Patients</b>					
Between Groups	27.43	2	13.71		
Within Groups	707.44	29	24.39	.56	.58
Total	734.87	31			
<b>Caregiver's Patient Illness Duration</b>					
Between Groups	28.17	2	14.08		
Within Groups	706.707	29	24.37	.59	.57
Total	734.87	31			

*Note.* *SS* = Sum of Square, *df* = Degrees of Freedom, *MS* = Mean Square, *p* = probability

Findings show that there is no significant difference among various levels of primary caregiver's educational status, occupation status, marital status, income of the family, relationship between patients and caregivers, and illness duration.

#### Intervention Effects

Table 6. Comparing descriptive statistics between the groups (experimental and control) based on the level of caregiver's burden scores

Group	Pre-test								Post-test							
	Little		Mild		Moderate		Severe		Little		Mild		Moderate		Severe	
	<i>Ss</i>	%	<i>Ss</i>	%	<i>Ss</i>	%	<i>Ss</i>	%	<i>Ss</i>	%	<i>Ss</i>	%	<i>Ss</i>	%	<i>Ss</i>	%
Experimental ( <i>N</i> =16)	0	0	0	0	5	31.25	11	68.75	0	0	4	25	10	62.5	2	12.5
Control Group ( <i>N</i> =16)	0	0	0	0	7	43.75	9	56.25	0	0	0	0	8	50	8	50

*Note.* *Ss* = Subjects

The results indicated that among the caregivers 31.25% had moderate and 68.75% had a severe level of burden in the pre-test or before intervention but in the post-test, the burden level decreased to 25% mild, 62.5% moderate and 12.5% had only a severe level of burden in the experimental group. But in the pre-test the control group, 43.75% had moderate and 56.25 had a severe level of burden and in the post-test 50% had moderate and 50% had a severe level of burden.

Table 7. Independent sample *t*-test of caregivers burden assessed by ZBI-22 in terms of the pre-assessment of the groups(experimental and control)

Group	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Experimental	16	62.38	4.06		
Control	16	62.25	5.64	.65	.52

*Note.* *M* = Mean, *SD* = Standard Deviation, *p* = Probability

The above table shows that there is no statistically significant difference in primary caregivers' burden between pre-test values in both control and experimental groups.

Table 8. Paired sample *t*-test of caregivers burden assessed by ZBI-22 between the pre and post-assessment of the experimental group

Group	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Experimental(Pre-test)	16	62.38	4.06	5.20	.000
Experimental (Post-test)	16	48.56	8.65		

Note. *M* = Mean, *SD* = Standard Deviation, *p* = Probability

The above table shows that there is a statistically significant difference in primary caregivers' burden between pre-test (*M* = 62.38) and post-test (*M* = 48.56) values in the experimental group.

Table 9. Paired sample *t*-test of caregivers burden assessed by ZBI-22 between the pre and post-assessment of the control group

Group	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Control (Pre-test)	16	61.25	5.64	-1.12	.28
Control (Post-test)	16	61.88	4.84		

Note. *M* = Mean, *SD* = Standard Deviation, *p* = Probability

The above results suggest that there is no statistically significant difference in primary caregivers' burden between pre-test (*M* = 61.25) and post-test (*M* = 61.88) values in the control group.

Table 10. Independent sample *t*-test of caregivers burden assessed by ZBI-22 in terms of the post-assessment of the experimental and control group

Group	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Experimental	16	48.56	8.64	-5.37	.000
Control	16	61.88	4.84		

Note. *M* = Mean, *SD* = Standard Deviation, *p* = Probability

The above findings suggest that there is a statistically significant difference in primary caregivers' burden between post-test values in both groups i.e., experimental and control groups.

## Discussion

The goal of the current study was to determine how psychoeducation affected primary carers of people with schizophrenia in terms of burden reduction. Results presented in Table 6 show (objective first) that in the post-test the severity level of burden among the primary caregivers in the experimental group was observed lower as compared to the pre-test session. But at the same time, no significant differences were observed in the control group. Usually, it was observed that caregivers of schizophrenia patients experience more burden (e.g., physical and mental stress) which reduces their daily functioning and the flow of their regular activities (Hjarthag *et al.*, 2010; Ukpung, 2012). To find out the second goal findings observed (Table 7) that at the pretest session, no significant difference between the groups was found. However, after the intervention

(Table 8) a significant difference was found in the experimental group. The mean scores of the post-test of caregiver burden were decreased after the psychoeducation session. Further, Table 9 shows that between pre and post-test values in the control group, no significant variation was found were at the same time the positive impact of the psychoeducation was observed from the findings of Table 10. The findings explained and concluded by the supporting evidence from Tabeleão *et al.*, (2018) that psychoeducational programs can be helpful for patients and carers, and give information about sickness and how to overcome it, as well as provide emotional support to carers (Sin *et al.*, 2017). Carers who get psychoeducational intervention programs no longer bear a heavy load (Mary *et al.*, 2013). It is appropriate to note that psychoeducation has consistently demonstrated positive effects in reducing caregivers' burden, improving knowledge, enhancing coping skills, and fostering family support (Devaramane *et al.*, 2011; Dixon *et al.*, 2000; Droulout *et al.*, 2003). It also contributes to better caregiver well-being and ultimately improves the overall quality of care provided to individuals with schizophrenia (Chan *et al.*, 2009; Hogarty *et al.*, 1996).

There were some drawbacks to the current study. The sample size was relatively small, and only one hospital in Dhaka city was selected. The long-term effects of psychoeducation could not be assessed, the number of psychoeducational sessions was confined only to two with a short follow-up period cause of the non-cooperative attitude of the respondents and hospital authorities. To overcome the drawbacks of the current study, further research may be needed to confirm the long-term effects of this psychoeducational intervention.

### **Conclusion**

From the foregoing discussion, it can be inferred that psychoeducational intervention, had favorable effects on reducing carers' strain. It also found that short-term psychoeducation increased the knowledge about the disorder, its symptoms, treatment options, and available resources, and improved of mental health status of caregivers.

Based on the current study discussion, the following recommendations are suggested:

1. The psychoeducation intervention resulted in a significant reduction of the primary caregiver's burden.
2. The long-term effects of psychoeducational intervention are recommended for better outcomes for primary caregivers.
3. Psychoeducation intervention may also apply to other mental disorders because the intervention was beneficial in decreasing the burden on family caregivers.

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