



# **“A STUDY TO ASSESS THE LEVEL OF PERCIEVED BURDEN AMONG PRIMARY CARE GIVERS OF CLIENTS WITH SCHIZOPHRENIA ATTENDING PSYCHIATRIC OUT PATIENT DEPARTMENT AT SHRI VINOBA BHAVE CIVIL HOSPITAL, SILVASSA, DADRA AND NAGAR HAVELI”**

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**ABSTRACT:** Schizophrenia is a mental disorder characterized by disruptions in thought processes, perceptions, and emotional responsiveness. It often involves symptoms such as hallucination, delusion, disorganized thinking, and impaired social functioning. Perceived burden among primary caregivers of individuals with schizophrenia refers to the subjective sense of strain, stress, or difficulty experienced by those who provide ongoing care and support to someone diagnosed with schizophrenia. This burden can manifest in various including emotional, financial and social challenges, and it reflects the impact of the care giving role on the well-being and quality of life of the caregivers.

**AIMS:** The study was aimed to assess the perceived burden among the primary caregivers of the client with schizophrenia.

**MATERIALS AND METHODS:** This descriptive study was conducted in 2023 among primary caregivers of the client with the schizophrenia. Structure interview questionnaire for the data collection. Data analysis was done through Descriptive and Inferential statistics.

**RESULTS:** Among 100 primary caregivers of schizophrenia patients 51% were having no burden,39% were having mild burden, 5% were having moderate and severe burden. In association age of caregivers(in years) have significant association with the socio

demographic variables  $\chi^2 = 0.0314$  and other variables was not significant association with the level of perceived burden among primary caregivers of the schizophrenia client.

**CONCLUSION:** The result of this study indicate that the family caregivers of the patients with schizophrenia encounter many problems related to multiple responsibilities in the caring process. Caregivers of schizophrenia patients experience enormous burden and are potential “high risk group” for mental disorder. Thus, they require comprehensive intervention in order to reduce the growing incidence of chronic enduring disease including mental disorders.

## INTRODUCTION:

According to the 39 Schizophrenia Statistics & facts (Steven Zauderer, June 30,2023) 24 million people have schizophrenia but less than 33% of them receive treatment. 0.30% of the worldwide population has schizophrenia.<sup>1</sup> According to WHO, there are 24 million people with schizophrenia or 1 out of 300 individuals in every country. this amounts to 0.32% of the worldwide population.<sup>2</sup>

In United states, according to National Alliance on Mental Illness, in 2019 the prevalence of schizophrenia among U.S adults is estimated to be 1.5 million people per year. National Institute of Mental Health, 2018, Schizophrenia is often diagnosed in young people during their late to early 30s with symptoms commonly presenting earlier in males than in females. JAMA Psychiatry, 2015, The average life lost for individual with schizophrenia in the U.S is 28.5 years.<sup>3</sup>

In India, where about 1.1 billion people reside, the prevalence of schizophrenia is about 3/1000 individuals (Gujrat, Girish & Issac, 2005). it is more common in men, and in terms of age of onset, men tend to be younger by an average of about Five Year than women when they develop schizophrenia.<sup>4</sup> National Mental Health Survey of India, 2015-2016, the report shows that 7.3 per cent of those in the 13-17 age group had mental disorders- nearly 9.8 million people. The rate was similar for boys and girls. Severe mental disorders, the report notes, include depression, schizophrenia and other psychotic disorders. Mental disorders were nearly twice as prevalent in urban areas (13.5 per cent) than in rural areas (6.9 per cent).<sup>5</sup>

According to DALYs relative to schizophrenia Indian states 2017 by SDI, in 2017, the highest rates attributed to schizophrenia was seen in Goa, categorized as a high SDI state with 210. DALYs or disability adjusted life years is a metric used to quantify the overall disease burden which is the number of years that are lost as a result of ill health, disability, or premature death, Arunachal Pradesh, a medium SDI state recorded a DALY rate of 177. By contrast, the lowest DALY rate relative to schizophrenia was seen in Bihar, which is a low SDI state with 133.<sup>6</sup>

## STATEMENT OF THE PROBLEM:

“A STUDY TO ASSESS THE LEVEL OF PERCEIVED BURDEN AMONG PRIMARY CARE GIVERS OF CLIENTS WITH SCHIZOPHRENIA ATTENDING PSYCHIATRIC OUT PATIENT DEPARTMENT AT SHRI VINOBA BHAVE CIVIL HOSPITAL, SILVASSA, DADRA AND NAGAR HAVELI”

## OBJECTIVES:

- To assess the level of perceived burden among primary care givers of clients with schizophrenia in attending Out Patient Department.
- To find out the association between perceived burden among primary care givers of client with schizophrenia and socio-demographic variables.

## HYPOTHESES:

**RH1:** There will be significant association between perceived burden among primary care givers and socio demographic factors among primary care givers of client with schizophrenia at 0.05 level of schizophrenia.

**NULL HYPOTHESIS**

**NH01:** There will be no significant association between perceived burden among primary care givers and sociodemographic factors among primary caregivers of client with schizophrenia at 0.05 level of significance.

**ASSUMPTION:**

- Care givers of schizophrenia patients may experience an amount of burden.
- Caregivers of schizophrenia patients may experience an amount of distress in their psychological status.

**METHODOLOGY:**

**STUDY DESIGN:** Descriptive design

**RESEARCH SETTING:** Out patient department of Shri Vinoba Bhave Civil Hospital, Silvassa.

**POPULATION:** primary caregivers of schizophrenia client.

**SAMPLE SIZE::** 100 primary caregivers of schizophrenia client.

**INCLUSION CRITERIA:**

- ✓ Above the age of 18-65 Years.
- ✓ Who will be able to speak and understand Hindi, Gujarati & English
- ✓ Who will be willing to participate for this study
- ✓ The Participants voluntarily agreed to participate in the study & signed informed consent

**EXCLUSION CRITERIA:**

- ✓ Who are not willing to participate for this study.
- ✓ Schizophrenia with other psychiatric disorder.

**DESCRIPTION OF THE TOOL****SECTION I: Socio-demographic variables**

It includes details such as: Age in years, Gender, Educational Qualification, Occupation, Religion, Marital status, Monthly income, Mode of journey

**SECTION II: Zarit burden interview Questionnaire scale.**

This was assessing the perceived burden among primary care givers of schizophrenia. It comprised 22 statements on perceived burden. The items were 5 point scale (never, rarely, sometime, frequently, nearly always). The total score 88

Total score range: 0 to 88

0-21: no to mild burden

21-40: mild to moderate burden

41-60: moderate to severe burden

≥ 61: severe burden

**ORGANIZATION OF THE DATA COLLECTION:**

The analysis of data was organized according to the objectives and presented under the following sections.

**SECTION-A:** Description of demographic variables of caregivers of schizophrenia client.

**SECTION-B:** Assessment of perceived burden among primary caregivers of schizophrenia.

**SECTION-C:** Association between perceived burden among primary care givers of client with schizophrenia and socio-demographic variables.

**SECTION-A: Description of demographic variables of caregivers of schizophrenia client.**

<b>SR. NO</b>	<b>SOCIODEMOGRAPHIC VARIABLES</b>	<b>FREQUENCY</b>	<b>PERCENTAGE %</b>
<b>1.</b>	<b>Age of caregivers (in years)</b>		
	18-29 years	29	29.0S
	30-39 years	20	20.0
	40-49 years	27	27.0
	50-59 years	21	21.0
	60-69years	3	3.0
<b>2.</b>	<b>Gender of the caregiver</b>		
	Male	55	55.0
	Female	45	45.0
<b>3.</b>	<b>Religion of caregivers</b>		
	Hindu	81	81.0
	Muslim	18	18.0
	Christian	1	1.0
<b>4.</b>	<b>Educational status of the caregivers</b>		
	Graduate or post graduate	18	18.0
	Intermediate or post high school diploma (12th pass)	28	28.0
	High school certificate (10th pass)	15	15.0
	Middle school certificate (8th pass)	13	13.0
	Primary school certificate (school dropout)	10	10.0
	Illiterate	16	16.0
<b>5.</b>	<b>Occupation of the caregivers.</b>		
	Legislators, senior officials and managers	4	4.0
	Professional	6	6.0
	Technicians and associate professionals	2	2.0
	Self-employed	18	18.0
	Skilled worker and shop and market sales worker	32	32
	Skilled agriculture and fishery workers	5	5.0
	Plant and machine operators and assemblers	5	5.0
	Elementary occupation	1	1.0

	Unemployed	27	27.0
6.	<b>Marital status of caregivers.</b>		
	Married	79	79.0
	Unmarried	20	20.0
	Divorced/ separated	1	1.0
7.	<b>Type of family</b>		
	Joint	59	59.0
	Nuclear	41	41.0
8.	<b>Is there any history of mental illness in your family/neighborhood other than patient.</b>		
	Yes	16	16.0
	No	84	84.0
9.	<b>Have you received information regarding mental illness?</b>		
	Yes	16	16
	No	84	84
10.	<b>Residencial area</b>		
	Urban	64	64.0
	Rural	36	36.0
11.	<b>Mode of journey</b>		
	Personal vehicle	36	36.0
	Walking	17	17.0
	Public transportation	47	47.0
12.	<b>Distance Travel each time to come for hospital visit (per month)</b>		
	<15km	40	40.0
	15-30km	28	28.0
	31-45km	15	15.0
	>45km	17	17.0
13.	<b>Caregivers Relationship with the Schizophrenia Patient.</b>		
	Mother	22	22.0
	Father	22	22.0
	Son	14	14.0

	Daughter	12	12.0
	Spouse	20	20.0
	Any other	10	10.0
<b>14</b>	<b>Income of the caregivers (per month)</b>		
	<9307	54	54.0
	9308-27882	41	41.0
	27883-46474	2	2.0
	46475-69534	3	3.0
<b>15.</b>	<b>Duration of illness of the client.</b>		
	<3months	74	74.0
	3months-6 months	20	20.0
	6months-1 years	3	3.0
	>1 years	3	3.0

### SECTION-II: Assess the perceived burden among primary caregivers of the schizophrenia patients.

Level of Burden	Frequency	Percent
No burden	51	51.0
Mild	39	39
Moderate	5	5
Severe	5	5
Total	100	100

The present study shows that among 100 samples of primary caregivers of schizophrenia patients 51% were having no burden, 39% were having mild burden, 5% were having moderate and severe burden.

### SECTION III: Association between perceived burden among primary care givers of client with schizophrenia and socio-demographic variables.

DEMOGRAPHIC VARIABLES	≤MEDIAN	>MEDIAN	TOTAL	$\chi^2$ VALUE	df	P VALUE	LEVEL OF SIGNIFICANCE
<b>Age in years</b>							
18-29years	18	11	29	10.601	df=8	0.031433	<b>S</b>
30-39years	11	9	20				
40-49years	21	6	27				
50-59years	7	14	21				
60-69years	0	3	3				
<b>Gender</b>							
Male	29	26	55	0.2551	df=2	0.613523	NS
Female	26	19	45				
<b>Religion</b>							
Hindu	33	48	81	3.1248	df=2	0.077109	NS
Muslim	12	7	19				
<b>Education</b>							
Graduate	8	10	18	7.1535	df=8	0.127996	NS
Intermediate	8	20	28				

High school	9	6	15				
Middle school	14	9	23				
Illiterate	9	7	16				
Occupation							
Professionals	6	4	10	5.9311	df=8	0.204356	NS
Self-employed	7	13	20				
Skilled worker and shop, market sales worker	19	13	32				
Skilled agriculture and fishery worker	3	8	11				
Unemployed	15	12	27				
Marital status							
Married	35	38	73	2.924	df=4	0.231777	NS
Unmarried	9	11	20				
Divorced/separated	1	6	7				
Type of family							
Joint	28	31	59	0.7226	df=2	0.395296	NS
Nuclear	23	18	41				
Is there any history of mental illness in your family/neighborhood other than patient.							
Yes	6	4	10	0.3601	df=2	0.54826	NS
No	45	45	90				
Have you received information regarding mental illness.							
Yes	11	7	18	0.2327	df=2	0.629508	NS
No	45	37	82				
Residencial area							
Urban	34	30	64	0.3212	df=2	0.570864	NS
Rural	17	19	36				
Mode of journey							
Personal vehicle	21	16	37	0.7929	df=4	0.672699	NS
Walking	6	7	13				
Public transport	24	26	50				
Distance travels each time to come for hospital visit.							
<15km	21	19	40	2.4761	df=6	0.479623	NS



15-30km	11	17	28				
31-45km	9	6	15				
>45km	10	7	17				
Relationship with the patient.							
Mother	11	11	22	4.0707	df=8	0.39652	NS
Father	15	7	22				
Son	7	7	14				
Daughter	6	6	12				
Spouse	12	18	30				
Income							
<9307	25	29	54	1.7855	df=6	0.618103	NS
9308-27882	24	17	41				
27883-46474	1	1	2				
46475-69534	1	2	3				
Duration of illness of the client.							
<3 months	26	15	41	4.7289	df=6	0.192759	NS
3-6months	4	4	8				
6-1years	7	12	19				
>1 years	14	18	32				

\*p<0.05 significant, \*\*p<0.01 &\*\*\*p<0.001 Highly Significant.

The table shows that the calculate chi-square value the demographic variables age of caregivers(in years) have significant association with the socio demographic variables  $\chi^2 = 0.0314$ , other socio demographic variables does not have association with the level of perceived burden among primary caregivers, Gender of care givers  $\chi^2 = 0.6135$ , religion of caregivers  $\chi^2 = 0.0771$ , educational level  $\chi^2 = 0.1279$ , occupation of the caregivers  $\chi^2 = 0.2043$ , Marital status  $\chi^2 = 0.2317$ , type of the family  $\chi^2 = 0.3952$ , any history of mental illness in their family/ neighbourhood  $\chi^2 = 0.5482$ , received information regarding mental illness  $\chi^2 = 0.6295$ , Residencial area  $\chi^2 = 0.5708$ , Mode of journey  $\chi^2 = 0.6726$ , distance travel each time to come for hospital visit  $\chi^2 = 0.4796$ , relationship with the client  $\chi^2 = 0.3965$ , income of the primary caregivers  $\chi^2 = 0.6181$ , Duration of illness of the client  $\chi^2 = 0.1927$ .

## DISCUSSION:

The present study shows that among 100 samples of primary caregivers of schizophrenia patients 51% were having no burden, 39% were having mild burden, 5% were having moderate and severe burden.

Various studies have been concluded to assess the perceived burden among primary caregivers of the schizophrenia patients. The present study has been discussed in reference with the objectives and hypotheses in accordance with other similar studies. The present study shows that among 100 samples of primary caregivers of schizophrenia patients 39% were having mild burden, 5% were having moderate and severe burden, and 51% were having no burden.

The similar study conducted on psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia in hospital setting in Thanjavur, India. In year 2017, quantitative cross-sectional design and survey methodology was used, data collected by standardized instruments from patients and their caregivers. This study reveals high perceived burden and



lower QOL were seen in the majority caregivers. They also have high anxiety and depression. Patient characteristics such as age, gender, symptoms and duration of illness did not influence the perceived burden of caregivers, while positive and negative symptoms and the duration of illness were correlated with their QOL.

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