"A Study to Assess the Burden of Care and Coping Strategies among Caregivers of Organic Brain Syndrome Patients"

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Abstract

Background: Organic Brain Syndrome (OBS) causes long-term dependency in patients, placing a heavy burden on family caregivers. Caregivers experience physical, emotional, social, financial, and time-related challenges. To developing supportive interventions caregivers' burden and coping strategies is essential. **Materials and Methods**: A qualitative phenomenological study with descriptive quantitative analysis was conducted among 60 caregivers of OBS patients at selected rehabilitation centers in Navi Mumbai using purposive sampling. Self-structured open-ended interviews were used. Chi square test and thematic analysis methods are used for the analysis. **Results:** Five burden themes emerged: physical, emotional, social, financial, and time burden. Prominent findings included fatigue (90%), emotional breakdown (70%), social isolation (70%), and financial stress (50%), and disrupted routines (90%). Problem focused, emotional focused, social support, spiritual support and self-care this are the approaches of the coping strategies. **Conclusion:** Caregivers of OBS patients experience multidimensional burden. Although various coping strategies are adopted, emotional distress remains high, indicating the need for structured psychosocial support programs.

Keywords: Assess, Burden of Care, Coping Strategies, Caregivers and Organic Brain Syndrome Patients

How to cite this article: Salunkhe R, Deshmukh PS, Kulkarni S, Jadhav J, Devika A. A Study to Assess the Burden of Care and Coping Strategies among Caregivers of Organic Brain Syndrome Patients. Int J Drug Deliv Technol. 2026;16(65s):1181-1188. DOI: 10.25258/ijddt.16.65s.121

Introduction –

Painful experience may often in life because of confusion and emotional instability however, individuals still have the ability to attain understanding and well-being. Organic brain syndrome refers to a multifaceted neuropsychiatric disorder that affects mental functioning, awareness, perception, attention, sleep–wake rhythm, and psychomotor responses. It commonly develops as a result of an underlying physical or medical condition. The clinical features can vary widely between patients and may also change periodically in the same individual. Due to these fluctuating symptoms and their resemblance to other psychiatric conditions, the disorder is frequently overlooked or diagnosed late. Even though the cognitive disturbances are often temporary, the condition demands prompt assessment and intervention, since early identification and appropriate treatment can greatly enhance recovery and patient outcomes.[1]

Rapid fluctuations in mental status and impaired cognitive functioning is the main characteristics of organic brain syndrome. In this syndrome patient receive strength and sore and recalling knowledge is damaged. The main cause of the organic brain syndrome is the withdrawal, acute metabolic encephalopathy, Trauma, central nervous system pathology, hypoxia, deficiencies, endocrine disorders, acute vascular insufficiency, toxins and drugs and this symptom is significant and scary.[2]

The incident rate in 2015 46.8 % people living with Alzheimer disease and living the organic brain syndrome. Dementia worldwide is expected to rise significantly over the coming years, with the figures likely to double approximately every 20 years. The estimated number may increase to 74.7 million by 2030 and further grow to 131.5 million by 2050. Noticeable variations in the elderly population

have been identified across different countries, particularly in Japan. In 2015, people aged older adults represented 26.3% of Japan's total population, which was considerably higher than the percentages reported in the European Union, the United States, and the global average. These statistics indicate that Japan is experiencing a fast-growing aging population. This increase in the elderly population is expected to continue, and by 2060, nearly two out of every five people in Japan may be above 65 years of age, while more than one-fourth could be older than 75 years.

The current incident rate of dementia in Europe country is 7.7 million. Alzheimer world incident rate reported in 2025 are 46.8 million people affected with dementia and probability increase cases 74.7 till 2030 and 131.5 million cases probability detected from 2030-2050. In japan 20265 26.5% cases is was detected and western countries 19% cases were reported and European union 15% cases was reported in USA and worldwide 8% patient living with the dementia. [3]

Providing health care facilities to individuals with organic brain syndrome creates subs individuals with dementia creates major burden of family caretaker, affecting not only economic resources but also work productivity and emotional health. The responsibilities associated with caregiving have wide-ranging effects on caregivers' psychological status and overall quality of life because of the mental health problems like a anxiety and depression challenges are increase. All research finding shows that all caretaker are in high risk because of heavy burden of care and not appropriate coping skill to reduce the present problem related to the mental illness. [3]

Recognizing the factors that contribute to psychological stress among caregivers is important to maintaining long-term mental health is necessary for providing health care facilities person with organic brain syndrome. Studies have identified various demographic characteristics associated with increased mental health difficulties among caregivers, such as lower levels of education, inadequate financial resources, being the spouse of the patient, female gender, and white ethnic background.[3]

Poor self-perceived health status, limited Family support systems, reliance on ineffective emotional coping strategies, stress, restriction, and caregiving burden are the major symptoms of the depressive symptoms. The level of burden experienced by caretaker is depend upon the patient condition. Increased behavioral disturbances, greater physical dependency in activities of daily living and declining cognitive abilities have all been identified as significant risk factors contributing to caregiver stress and depression.[4]

Materials and Methods

A qualitative phenomenological study with descriptive quantitative analysis was conducted among 60 caregivers of OBS patients at selected rehabilitation centers in Navi Mumbai using purposive sampling. Self-structured open-ended interviews were used. Chi square test and thematic analysis methods are used for the analysis.

Results

A total of 60 caregivers of Organic Brain Syndrome patients participated in the study. Most caregivers were aged 30–40 years (43.3%) and were female (53.3%). Nearly half had completed secondary education (46.7%), belonged to joint families (56.7%), and reported a monthly income between ₹15,000–30,000 (46.7%). With respect to caregiving duration, 43.3% had been providing care for 2–5 years. Analysis of caregiver burden revealed five major domains. Physical burden was prominent, with constant tiredness reported by 90% of caregivers and health problems such as headache (60%) and back pain (40%). Emotional burden was substantial; 50% experienced constant worry and uncertainty, while 70% reported emotional breakdown. Social burden was marked by lack of family support and limited community assistance (50% each), and 70% reported social isolation. Financial burden was evident, with 50% experiencing financial insecurity or no income and 70% reporting hospitalization costs as the primary financial stressor. Time burden was severe, as 60% reported no personal time and 90% experienced disruption of daily routines. Coping strategies adopted by caregivers were categorized into problem-focused, emotion-focused, social support, spiritual, and behavioral/self-care strategies. Problem-focused coping was commonly used, with 80% seeking professional help and 50% developing caregiving skills. Emotion-focused coping revealed higher negative emotional responses, as 70% expressed frustration and 80% reported hopelessness. Social coping strategies included seeking peer and community support (70%), while spiritual coping played a vital role, with 70% trusting in

God and 80% finding meaning or purpose in caregiving. Behavioral and self-care strategies such as energy management and leisure activities were reported by 60% of caregivers. Chi-square analysis demonstrated significant associations between burden of care and coping strategies with selected demographic variables such as age, education, income, occupation, and duration of caregiving ($p < 0.05$).

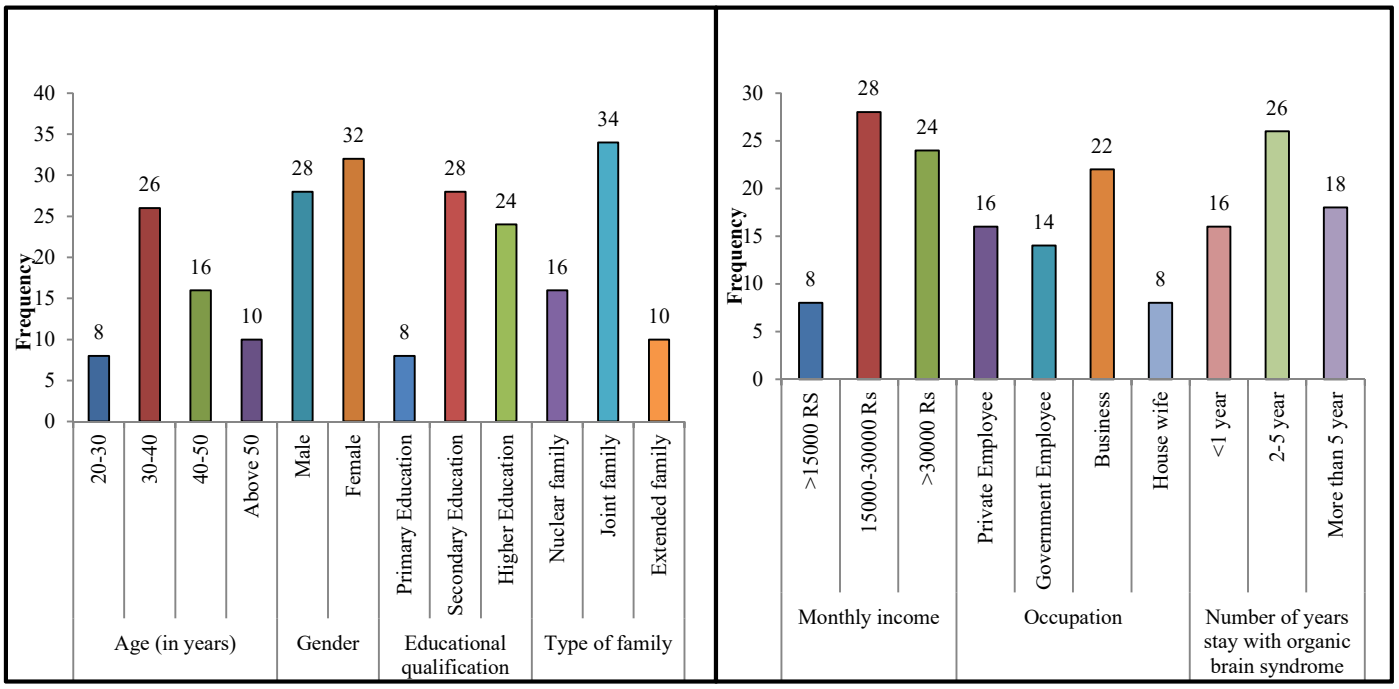
Demographic Profile Analysis:

Table 1 shows that caregivers of organic brain syndrome patient's majority of caregivers were 30–40 years old (43.33%), followed by 40–50 years (26.67%), with females slightly predominating (53.33%). Most caregivers had secondary education (46.67%) and belonged to joint families (56.67%). Nearly half reported a monthly income of ₹15,000–30,000 (46.67%), while 40% earned above ₹30,000. Common occupations included own business (36.67%) and private employment (26.67%). A substantial proportion had been caregiving for 2–5 years (43.33%), indicating prolonged caregiving responsibilities.

Table 1: Distribution of samples as a demographic profile (*n* = 60)

Variable	Groups	Frequency	Percentage
Age (in years)	20-30	8	13.33
	30-40	26	43.33
	40-50	16	26.67
	Above 50	10	16.67
Gender	Male	28	46.67
	Female	32	53.33
Educational qualification	Primary Education	8	13.33
	Secondary Education	28	46.67
	Higher Education	24	40.00
Type of family	Nuclear family	16	26.67
	Joint family	34	56.67
	Extended family	10	16.67
Monthly income	>15000 RS	8	13.33
	15000-30000 Rs	28	46.67
	>30000 Rs	24	40.00
Occupation	Private Employee	16	26.67
	Government Employee	14	23.33
	Business	22	36.67
	House wife	8	13.33
Number of years stay with organic brain syndrome Client	<1 year	16	26.67
	2-5 year	26	43.33
	More than 5 years	18	30.00

Fig.1: Distribution frequency and percentage of a demographic variable (*n=60)*



Qualitative Analysis: Burden of Care

Theme - Physical Burden

Subtheme I - Fatigue& Exhaustion

The physical burden among caregivers is reflected through two subthemes: fatigue & exhaustion and health problems. Under fatigue & exhaustion, a majority of caregivers reported constant tiredness 54 (90%), while a small proportion experienced physical burnout 6(10%) and none reported lack of rest 0(0%).

Subtheme II - Health problem

Health problems, headache 36(60%) was more commonly reported than back pain24 (40%). These findings indicate that caregivers predominantly suffer from severe fatigue and associated physical health issues due to prolonged caregiving responsibilities.

Theme - Emotional Burden

Subtheme I -Stress & Anxiety

Emotional burden is categorized into stress & anxiety and depression & sadness. In stress & anxiety, equal proportions of caregivers experienced constant worry 30(50%) and uncertainty 30(50%), while none reported fear about the future0 (0%).

Table 2: Distribution to Burden of Care under Theme and Sub theme.

Theme	Subthemes	Codes	f	%
Physical Burden	Fatigue & exhaustion	Constant Tiredness	54	90.00
		Physical Burnout	6	10.00
		Lack of rest	0	0.00
	Health Problems	Back Pain	24	40.00
		Headache	36	60.00
Emotional Burden	Stress and anxiety	Constant Worry	30	50.00
		Uncertainty	30	50.00
		Fear about future	0	0.00
	Depression & Sadness	Emotional Breakdown	42	70.00
		Feeling of hopeless	18	30.00

Social Burden	Lack of social support	No family help	30	50.00
		Limited community support	30	50.00
	Social isolation	Staying at home	18	30.00
		Withdrawal from society	42	70.00
Financial Burden	Dependency and financial stress	Financial insecurity	30	50.00
		No Income	30	50.00
	Direct medical costs	Medication expenses	18	30.00
		Hospitalization costs	42	70.00
Time Burden	Time constraints	No Personal time	36	60.00
		Constant Supervision	24	40.00
	Disruption of routine	Unpredictable daily routine	54	90.00
		constant supervision requirement	6	10.00

Subtheme II -Depression &Sadness

In depression & sadness, a large number experienced emotional breakdown 42(70%), whereas fewer reported feelings of hopelessness 18(30%). This shows that caregivers undergo significant emotional distress, particularly in the form of breakdown and persistent worry.

In social isolation, most caregivers reported withdrawal from society 42(70%), while fewer stayed at home 18(30%). These results suggest that caregiving leads to reduced social interaction and inadequate support systems.

Theme - Financial Burden

Subtheme I -Dependency and financial stress:

Financial burden includes dependency & financial stress under dependency & financial stress, caregivers equally reported financial insecurity 30(50%) and no income 30(50%).

Subtheme II -Direct medical costs

Regarding direct medical costs, hospitalization costs 42(70%) were more prominent compared to medication expenses 18(30%). This indicates that caregiving imposes a significant financial strain, especially due to high treatment costs.

Theme - Time Burden

Subtheme I -Time constraints

Time burden under the time constraints under time constraints, most caregivers reported no personal time 36(60%), while others required constant supervision 24(40%).

Theme - Social Burden

Subtheme I -Lack of social support

Lack of social support 30(50%), no family help 30(50%) and limited community support 30(50%).

Subtheme II -social Isolation

Subtheme II -Disruption of routine.

In disruption of routine, a majority experienced an unpredictable daily routine 54(90%), and a small proportion reported constant supervision requirements 06(10%). These findings highlight that caregiving significantly disrupts daily life and limits personal time.

Qualitative Analysis: Coping Strategies

Theme: Problem-Focused Coping

Subtheme I - Use of formal services

Problem-focused coping includes use of formal services Under use of formal services, most caregivers sought professional help 48(80%), while fewer utilized healthcare services 12(20%).

Subtheme II - Skill Development

In skill development, equal proportions reported learning caregiving skills 30(50%) and gaining medical knowledge 30(50%). This indicates that caregivers actively adopt practical approaches to manage caregiving challenges.

Table 3: Distribution of coping strategies under Theme and Subtheme

Theme	Subthemes	Codes	f	%
	Use of formal services	Seeking Professional Help	48	80.00

Problem-Focused Coping		Utilization of healthcare services	12	20.00
	Skill Development	Learning Caregiving skills	30	50.00
		Gaining medical knowledge	30	50.00
Emotion-Focused Coping	Emotional Expression	sharing feeling	18	30.00
		Expressing Frustration	42	70.00
	Positive Reframing	Feeling positives	12	20.00
		Hopelessness	48	80.00
Seeking Social Support	Peer Support	Talking to friends	42	70.00
		Sharing experiences	18	30.00
	Community Support	Support groups	42	70.00
		practical assistance	18	30.00
Religious / Spiritual Coping	Faith & Belief	Trust in God	42	70.00
		Inner strength from belief system	18	30.00
	Spiritual meaning making	Finding purpose in caregiving	48	80.00
		spiritual obligation	12	20.00
Behavioral/ Self-Care Coping	Physical Self-care	Taking rest	24	40.00
		Energy management	36	60.00
	Leisure Activities	Watching TV	36	60.00
		Listening Music	24	40.00

Theme: Emotion-Focused Coping

Subtheme I -Emotional Expression

Emotion-focused coping is categorized into emotional expression In emotional expression, most caregivers expressed frustration 42(70%), while fewer shared feelings 18(30%).

Subtheme II - Positive Reframing

Under positive reframing, a majority reported hopelessness 48(80%), while only a small number expressed positive feelings 12(20%). These findings suggest that emotional coping strategies are used, but negative emotions are more dominant.

Theme: Seeking Social Support

Subtheme I -Peer Support

This theme includes peer support under peer support, most caregivers talked to friends 42(70%), while fewer shared experiences 18(30%).

Subtheme II -Community support

In community support, support groups were utilized by many 42(70%), while fewer received practical assistance 18(30%). This shows that caregivers depend on social networks, though support may be limited in depth.

Theme: Religious / Spiritual Coping

Subtheme I - Faith &Belief

Religious coping under the faith & belief Under faith & belief, most caregivers trusted in God 42(70%), while fewer gained inner strength from their belief system 18(30%).

Subtheme II - Spiritual meaning-making

In spiritual meaning-making, a majority found purpose in caregiving 48(80%), while some

viewed it as a spiritual obligation 12(20%). This indicates that spirituality plays a vital role in coping.

Theme: Behavioral / Self-Care Coping

Subtheme I - Physical self-care

Behavioral coping includes physical self-care under physical self-care, more caregivers practiced energy management 36(60%) compared to taking rest 24(40%).

Subtheme II - Leisure activities

In leisure activities, watching TV (36; 60%) was more common than listening to music (24; 40%). These findings suggest that caregivers engage in self-care, though it may not be sufficient to fully reduce their burden.

Association of burden of care among caregivers with selected demographic variable

Result shows that Age had a significant association with depression and sadness, dependency and financial stress, time constraints, and disruption of routine. Gender showed a significant association only with time constraints. Educational qualification was significantly associated with fatigue and exhaustion, lack of social support, direct medical costs, and disruption of routine. Monthly income had a significant association with fatigue and exhaustion, lack of social support, dependency and financial stress, and time constraints. Occupation was significantly associated with fatigue and exhaustion, social isolation, and time-related burden. No significant association was observed between the remaining demographic variables and caregiver burden factors.

Association of coping strategies among caregivers with selected demographic variable

Age had a significant association with community support, faith and belief, and spiritual meaning-making. Educational qualification showed a significant association with use of formal services, positive reframing, peer support, community support, and spiritual meaning-making. Type of family was significantly associated with skill development, emotional expression, and faith and belief. Monthly income showed a significant association only with positive reframing. Occupation was significantly associated with emotional expression and physical self-care, whereas duration of caregiving had a significant association with emotional expression, peer support, and community support. No significant association was observed between the other demographic variables and coping strategies.

Discussion –

Present study highlights that caregivers of Organic Brain Syndrome patients experience a considerable multidimensional burden encompassing physical, emotional, social, financial, and time-related domains. Physical exhaustion and emotional distress were prominent, particularly among caregivers involved in long-term care, indicating the cumulative effect of sustained caregiving responsibilities. Significant associations between caregiver burden and demographic variables such as age, education, income, occupation, and duration of caregiving suggest that personal and socioeconomic factors strongly influence caregiver experiences. The widespread use of spiritual and social coping strategies reflects the cultural context of caregiving; however, the high prevalence of negative emotional coping indicates unmet psychosocial needs. These findings emphasize the importance of early identification of caregiver burden and the provision of structured support, education, and counseling services to promote adaptive coping and improve caregiver well-being.

Recommendation –

1. Qualitative research studies may be carried out to gain deeper insight into the lived experiences and emotional challenges faced by caregivers.
2. Studies may also examine the relationship between burden of care, quality of life, social support, and psychological stability outcomes among caretaker of organic brain syndrome patients.

Conclusion-

The study concludes that caregivers experience a high level of physical, emotional social and financial and also time-related burden. The prolonged caregiving by the caregivers significantly affects caregivers' wellbeing, particularly I term of fatigue, financial dependency, disruption of daily life and emotional distress. Although caregivers adopt various coping strategies such as spiritual, social. The association between demographic variables shows the need for targeted, caregivers-oriented interventions. Also strengthening caregivers through proper education and counseling and also awareness regarding community-based services to reduce

burden of care and to enhance the coping strategies.

Ethical consideration and the participants' consent-

Ethical approval was obtained for the present study from the Institutional Ethics Committee of Bharati Vidyapeeth (Deemed to be University) College of Nursing during the Ethics Committee meeting held on 04 October 2025 (Ethical Committee Approval Letter No. BVDU/CON/NAVI MUMBAI/EC/34/2025-2026. Written informed consent was signing from all the participants after explaining the aim of study. Confidentiality and anonymity of the collected data were strictly maintained throughout the research process.

Financial Support and Sponsorship

Nil

Conflicts of Interest

There are no Conflicts of Interest

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