

Caregiver burden among caregivers of hospitalized elderly

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ABSTRACT

Caregiver burden for hospitalized elderly patients is a complex phenomenon, characterized by physical, emotional, financial, and social challenges that significantly affect caregivers' well-being. Research highlights that caregiver often experience high levels of stress, anxiety, and physical strain due to the demands of supporting elderly patients with multiple health issues. Factors such as the elderly patient's comorbidities, length of hospital stay, and post-discharge care needs intensify the burden, particularly for those without adequate support systems or resources. Financial costs, including out-of-pocket expenses and lost income, further exacerbate the strain on caregivers.

Aim of Study: To study the caregiver burden among caregivers of hospitalized elderly people.

Research Methodology: Descriptive research design was used in this research study. 50 caregivers of hospitalized elderly were recruited through purposive sampling techniques from various hospital of Delhi.

Result and Conclusion: In present time caring of elderly people is big challenge for caregiver. The caring of the hospitalized elderly, caregivers often find themselves isolated from society. They have very little time to maintain social contacts, family responsibility, job related and daily routine work because they take the responsibility of the caring of elderly. Day by day this social isolation further increases with the problems of elderly since higher levels of care-giving and it create many Psychological and Behavioural problems like disturbed sleep, irritability, and aggression.

Keywords: Caregiver, Burden, Hospitalization, Elderly

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INTRODUCTION

The caregiver burden for those looking after hospitalized elderly individuals is a multifaceted challenge that encompasses physical, emotional, financial, and logistical strain. Caregivers take on critical roles, such as advocating for medical care, making healthcare decisions, managing patient's needs, and coordinating post-hospitalization care. These demands, while fulfilling, place significant stress on caregivers, affecting their health, financial stability, and relationships. George and Gwyther (1986) define caregiver burden as 'the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults'. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods; it involves tasks that may be unpleasant and uncomfortable, psychologically stressful, and physically exhausting. The role of caregivers for hospitalized elderly individuals is both essential and demanding, often placing a considerable burden on those providing care. With the ageing population on the rise, more families find themselves navigating the complexities of hospital care for elderly loved

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ones. Caregivers in this setting face various challenges, including physical strain, emotional stress, financial hardship, and managing complex healthcare needs. In addition to the time and energy devoted to advocating for and coordinating care, caregivers frequently balance these responsibilities with other family or work obligations, increasing the risk of burnout. Understanding the scope and impact of caregiver burden is critical, as it affects caregivers' health and well-being and has significant implications for the quality of care the elderly patient receives. This underscores the importance of developing resources and support systems to better

address and alleviate the burden on caregivers. Caregivers of hospitalised elderly people experience many problems during the care of the elderly in hospitals. They constantly worry about caring for the elderly, so they take all responsibility for the elderly. The caring caregiver started avoiding his health, family responsibilities, job and social interaction with friends and relatives. They do not participate in social gatherings and postpone or cancel family activities like watching movies, holiday tours, marriage ceremonies, etc. Sometimes, they do not celebrate festivals with family or friends because they care for the elderly in the hospital. After some time, the caregiver faces some Psychological and behavioural problems like disturbed sleep, low mood, aggression and irritability. These care giver burden can be grouped into four type (i) Health Burden(ii)Economic Burden(iii)Social Burden(iv) Family Burden.

Health Burden

Caregivers of the elderly have disturbed daily routine work because they engage in caring for hospitalised elderly at any time according to the situation of the elderly. They do not give proper time for his health because they think their main goal is caring for the elderly so they would not be disturbed. They take care of the medicine of the elderly regularly, but they find difficulty in taking their medicine regularly while suffering from chronic illness.

Economic Burden

The caregivers of hospitalized elderly people experience economic burdens. Family members spend a significant part of their money on medicine, hospital charges, and other necessary arrangements in the hospital and at home. Some caregivers borrow money from relatives, neighbours, friends, and money lenders. Due to caring for hospitalised older adults, caregivers take paid leave or absence, change jobs, or quit jobs, so their income decreases.

Social Burden

Caregivers tend to sacrifice their leisure pursuits and hobbies while restricting time with friends and family. Due to caregiving, they did not have proper time for their jobs and business. They do not participate in any functions or activities with neighbours, relatives, or friends. They avoid talking to any persons because they are busy caring for the elderly. Some people appreciate caring for the elderly, but others comment on this. The social burden on caregivers of hospitalized elderly individuals is substantial and often overlooked. Caregivers face significant changes in their social lives due to the time, energy, and emotional investment required to support their elderly loved ones. Hospital visits, coordinating care, and handling patient needs consume much of a caregiver's time, leaving little opportunity for socializing with friends and

family. Over time, this can lead to feelings of isolation and loneliness. Caregivers often sacrifice personal activities, hobbies, and interests, reducing opportunities to engage with others and negatively impacting their sense of identity.

Family Burden

Caregivers of hospitalized elderly face many problems in the family due to caregiving. There is a restriction on recreational activities in the family by the family members because of the hospitalized elderly. Family members may have to sacrifice their holidays and leisure time due to caregivers of the elderly. Sometimes, the family may have to postpone or cancel a planned function at home. There will be a destruction of routine activities due to hospitalized elderly people's needs and due to the care of elderly people. There is a reduction or even cessation of interaction with friends, relatives and neighbours. This eventually leads the family to become isolated from the rest of the community. Children and teens in caregiving families may feel neglected or stressed due to the time and attention their caregiver-parent must devote to the elderly family member. Some young family members may take on extra responsibilities at home, such as household chores or caring for younger siblings, to help support the primary caregiver. This can affect their academic and social lives, potentially impacting their overall development.

The costs associated with caregiving—such as medical expenses, transportation, and potential income loss—often impact the family budget. This can affect spending on other household needs and family activities, leading to stress and financial strain on the family. Suppose family members support the elderly individual's household and their own. In that case, this can significantly strain family resources and finances, creating stress for the caregiver and other family members. Caregiving responsibilities often restrict a family's ability to engage in social or recreational activities, as the primary caregiver may not be able to leave the elderly patient alone or have the time or energy. Family members may feel the loss of time for shared hobbies, family vacations, or even simple outings. This loss of togetherness can impact family cohesion and contribute to a disconnect among family members. The presence of a hospitalized elderly family member often shifts household routines, as family members prioritise caregiving responsibilities and hospital visits over usual activities. This disruption can be difficult, especially for younger family members or those with busy work schedules. Families may need to take on new roles to support caregiving. For instance, the primary caregiver may have to delegate some of their responsibilities to others, leading to shifts requiring patience and adaptation among family members. The family burden on caregivers of hospitalised elderly individuals is profound, affecting emotional well-being, financial

stability, and family cohesion. As caregiving responsibilities intensify, family members may experience conflict, isolation, and personal sacrifice. Addressing this burden requires a proactive, collaborative approach that involves open communication, shared responsibilities, and support systems to help the family navigate these challenges together. By fostering family resilience and accessing resources, caregivers can more effectively manage the burden, creating a healthier environment for the elderly patient and the family.

Problem to be Investigated

The study seeks to explore the multifaceted challenges faced by caregivers of hospitalized elderly individuals. Caregiving often places significant demands on individuals, encompassing emotional, physical, and financial stressors. These caregivers not only navigate the complexities of their loved one's health conditions but also juggle their own personal and professional responsibilities.

Aims & Objectives of the Study

To investigate the socio-demographic profile of caregivers of hospitalised elderly people.

- To understand the financial burden of caregivers.
- To assess the health problems of caregivers.
- To assess the family interaction of caregivers.
- To suggest means for caring to improve their situation as caregivers.

RESEARCH METHODOLOGY

This research aims to study caregiver burdens among caregivers of hospitalized elderly people. Therefore, a descriptive research design is used for the study. The descriptive research attempts to describe and explain the problems of caregivers of elderly people in hospitals. The study was conducted in Delhi, the Capital of India. In this study, 30 participants were selected through a purposive sampling technique from caregivers of hospitalised elderly people from the hospitals in Delhi.

Inclusion criteria for Respondents

- Caregivers of elderly people admitted to the hospital for at least one month.
- The caregiver should be over 25 years old.
- All those who can understand Hindi/English.
- Able to provide informed consent.

Exclusion criteria for Respondents

- There should not be any history of significant illness.
- Not related to family

RESULT

Table 1: Socio-demographic Variable of Caregiver

Variables		Frequency	Percent
Relationship	Son	20	40
	Daughter in law	10	20
	Daughter	20	40
Age	25-30	5	10
	31-35	10	20
	36-40	15	30
	41-above	20	40
Sex	Male	20	40
	Female	30	60
Residence	Rural	15	30
	Urban	20	40
	Semi-Urban	15	30
Marital Status	Married	45	90
	Unmarried	5	10
Education	Primary	10	20
	Middle	5	10
	Secondary	15	30
	Inter	10	20
	Graduate & above	10	20
Occupation	Government	10	20
	Private	15	30
	Business	10	20
	Other (Farmer, House wife, Labour, House Maid)	15	30
Income (Monthly)	Nil	10	20
	1-5000	15	30
	5001-10000	10	20
	10001-above	15	30
Family Income (Monthly)	0-5000	20	40
	5001-10000	15	30
	10001-above	15	30
Duration of caring (Months)	1-12	10	20
	13-24	20	40
	25-36	10	20
	37-above	10	20
Duration of caring per day (hours)	0-1	5	10
	2-3	20	40
	4-above	25	50

DISCUSSION

Regarding Socio-economic Status

Table 1 shows the socio-demographic variables of caregivers of the hospitalized elderly. Most of the respondents (80 per cent) were sons and daughters in relationships with the elderly. 70 per cent of respondents belong to the age range of 36 years and above. 60 per cent of respondents were female, and 40 per cent were male. 70 per cent of respondents belong to urban and semi-urban areas. 90 per cent of respondents were married, while 10 per cent were unmarried. 70 per cent of respondents were educated secondary and above. 70 per cent of respondents were involved in government, private, and business jobs. Half of the respondents were earning 10000 Rs. or below monthly, while 20 per cent of respondents had no source of income. 70 per cent of respondents had a family monthly income of 10000 Rs or below. 80 per cent of respondents' caregiving duration was above 12 months. The informal caregiver's strain is associated with caregiver income, education, and the care-recipient relationship. The caregiver had a higher level of education, so it influenced a greater level of family conflict in informal caring (Deimling et al., 2001). Interpersonal conflicts, role strain, family abuse and family disruptions affect both the caregiver and care receiver's well-being (Tobin & Kulys, 1980). Low income and poor health conditions were the negative predictors of caregivers' social support; strong social bonds, feelings of family abandonment, and sound health and wealth conditions were the strongest predictors of social support in elder caring (Pohl et al., 1994). The health burden on caregivers, particularly those looking after hospitalized elderly individuals, is considerable. This role often involves prolonged physical demands, emotional stress, and the need for sustained mental resilience, which can affect the caregiver's overall health and well-being. Caregivers frequently experience physical exhaustion due to long hours spent at the hospital, assisting with personal care, and fulfilling other caregiving duties. This persistent fatigue can weaken the immune system, making caregivers more susceptible to illness. Anxiety about the elderly patient's health and the unpredictability of caregiving needs can lead to poor sleep quality and insufficient rest, which in turn affects physical and mental health. Caregivers often help lift, transfer, or reposition the elderly patient, leading to physical strain and increased risk of musculoskeletal issues, particularly in the back, shoulders, and neck. Constantly attending to a hospitalised loved one, handling medical decisions, and coordinating with healthcare providers can create high levels of chronic stress. This stress can impact both mental clarity and overall resilience. Many caregivers face emotional exhaustion from the sustained demands of caregiving. The emotional toll of watching a loved one in distress or declining

health can lead to symptoms of depression and feelings of helplessness.

Regarding Health Burden of Caregiver of Hospitalized Elderly

40 per cent of respondents' perception of health was good, while 30 per cent of respondents think their health was poor (Table 2). 70 per cent of respondents were suffering from chronic disease. Regarding health issues, 34 per cent of respondents lost sleep and appetite. 70 per cent of respondents think their health was deteriorating very much or somewhat. 80 per cent of respondents accepted that they always become angry or sometimes. 40 per cent of respondents never gave their responsibility to others. The caregivers are at a greater risk level than the care receivers because when they devote themselves to someone else's needs, they tend to neglect their own needs. They may not recognise or ignore the signs of illness, exhaustion, or depression that they are experiencing. Stress may negatively impact the caregiver's physical health or cause the caregiver to be physically or verbally aggressive towards the care receiver (Gupta & Chaudhuri, 2008). Caregivers of the elderly have been highly correlated with mental and physical problems in comparison to those providing the care of others. The researchers' findings

Table 2: Health Burden of Caregiver of Hospitalized Elderly

Variables		Frequency	Percent
Perception about health	Good	15	30
	Average	20	40
	Poor	15	30
Suffering from Chronic Disease	Blood Presser	11	22
	Sugar	9	18
	Headache	5	10
	Both (BP & Sugar)	10	20
	No Chorionic Disease	15	30
Health Issues	Lost Sleep & Appetite	17	34
	Become Irritable	13	26
	Others (headache, bodily pain)	14	28
	Get Depressed	6	12
Deteriorating Health	Very much	15	30
	Somewhat	20	40
	Not at all	15	30
Become Angry	Always	18	36
	Sometime	12	24
	Never	20	40
Giving responsibility to other	Always	9	18
	Sometime	21	42
	Never	20	40

suggest that leisure time significantly impacts a caregiver's psychological well-being and appears to be an important issue for buffering caregiver distress (Losada et al., 2010).

Regarding Family burden of Caregiver of Hospitalized Elderly

30 per cent of respondents admitted that they always got support from family members, while 30 per cent never got support from family members. Half of the respondents accepted they were postponing religious activities due to caregiving of hospitalized elderly (Table 3). 40 per cent of spouses were impacted, 28 per cent of children, and 20 per cent of siblings were impacted in the family. In Indian families, people celebrate any function or organise activities with all family members. If anyone is hospitalized, someone takes care, and other family members take responsibility. Family members are worried about the hospitalised elderly, so they postpone or cancel any activities. Children are impacted by caring for the elderly because caregivers do not care for children and their education. Most caregivers said that due to the caregiving of the elderly, their children's academic performance was reduced in school. Female members in the house are more intimate with hands-on care needs, while men in the home are likely to do those tasks associated with household chores and out-of-home tasks (Quadagno, 2008). The informal caregiver got adequate social support within their family, Houde, (S.C.;1998). The caregiver strains directly influenced family conflict. The strain negatively influenced the caregivers' family members (Amirkhanyan & Wolf, 2003). The family members' support is an important indicator of informal caregivers' well-being (Burden, 1984). The elder illness and family members' involvement are associated with caregiver perception (Carriere & Mueller, 1997). Good communication, positive attitudes and family support were important factors in promoting the caregiver's quality of life and well-being (Geline et al., 2010). The family members' support strategy strengthens the caregiver's well-being (Marla Berg-Weger et al., 2000). Informal caregivers receive all kinds of social support from their family members, but the social support from their family members leads to an increase in the burden of a poor level of social relationships and responsibilities (Nur Fatimah et al., 2004). The caregiver strain is associated with the caregiver and care receiver relationship, family conflict, stress, quality of family relationship and family relationships and family members' attitudes (Yee et al., 1999).

Regarding Economic burden of Caregivers of Hospitalized Elderly

Half of the respondents accepted that they had taken complete financial responsibility for the elderly (Table 4). More than half of respondents (56 per cent) have taken loans from banks

or money lenders to cope with financial burdens. 60 per cent of respondents admitted that they have major financial issues in transportation and accommodation.

Table 3: Family Burden of Caregiver of Hospitalized Elderly

<i>Variables</i>		<i>Frequency</i>	<i>Percent</i>
Support from family members	Always	15	30
	Sometime	20	40
	Never	15	30
Family activities cancelled/postponed	Religious activities	25	50
	Picnics and tour	10	20
	Birthday Party/calibration	15	30
Impacted in Family	Spouse	20	40
	Children	14	28
	Siblings	10	20
	No one	6	12

Table 4: Economic Burden of Caregivers of Hospitalized Elderly

<i>Variables</i>		<i>Frequency</i>	<i>Percent</i>
Responsibility Economic Needs of Elderly	Complete	25	50
	Partially	20	40
	No at all	5	10
Cope with financial Burden	Borrow money from relatives, friends & neighbour	22	44
	Loan from money lenders	13	26
	Loan from bank	15	30
Major financial issues	Medicine	22	44
	Transportation	8	16
	Accommodation	10	20
	Food and diet	10	20

Table 5: Social Burden of Caregivers of Hospitalized Elderly

<i>Variables</i>		<i>Frequency</i>	<i>Percent</i>
Social life suffered	Complete	15	30
	Partially	20	40
	No at all	15	30
Social relationship affected	Not spent time	14	28
	No participation in social gathering	20	40
	Less Communication	16	32
Uncomfortable among friend	Always	14	28
	Sometime	26	52
	Never	10	20

Regarding Social burden of Caregivers of Hospitalized Elderly

70 per cent of respondents accepted that their complete or partial social life suffered (Table 5). 28 per cent did not spend time with others, 40 per cent did not participate in social gatherings, and 32 per cent started communicating less with others. Social support is a significant factor for caregivers of hospitalized elderly and influences the caregivers' health, behaviour, care skills, relationships and mental health. Due to a lack of social support, caregivers face many issues like caregiver burden, poor quality of life, disturbed behaviour, and problems in relationships. Low income and poor health conditions were the negative predictors of caregivers' social support; strong social bonds, feelings of family abandonment, and sound health and wealth conditions were the strongest predictors of social support in elder caring (Pohl et al., 1994). Social support influences many factors associated with a caregiver's health, attitude, behaviour, caring experience, strain, frustration and burden. Caregivers' social support is highly associated with their mental health. The lower level of caregiver's social support was influenced by the higher level of burden and depression (Chen & Greenberg, 2004), (Chiou et al., 2009), (Huang et al., 2006), (Daniel et al., 2009), (Lieberman & Fisher, 1999), (Nancy et al., 1995), (Parrish & Adams, 2003), (Katz-Saltzman et al., 2008).

CONCLUSION

The caregiver burden for those looking after hospitalized elderly individuals is a multifaceted challenge that encompasses physical, emotional, financial, and logistical strain. Caregivers take on critical roles, such as advocating for medical care, making healthcare decisions, managing patients' needs, and coordinating post-hospitalization care. These demands, while fulfilling, place significant stress on caregivers, affecting their health, financial stability, and relationships. Family caregivers may be motivated to care for the hospitalized elderly for several reasons: love or reciprocity, religious fulfilment, responsibility, guilt, and social pressure. Caregivers face many obstacles as they balance caregiving of hospitalized elderly with other demands of family, including child rearing, career and relationships with friends. Due to caregiving, caregivers are at increased risk for burden, stress, depression, irritability, aggression, and a variety of health complications. Caregivers tend to sacrifice their leisure pursuits and hobbies while restricting time with friends and family. Due to caregiving, they did not have proper time for their jobs and business. Addressing the caregiver burden requires a comprehensive approach that includes providing support systems, financial assistance, and resources to help caregivers navigate healthcare complexities. Accessible respite care, counselling services, and workplace flexibility

can also ease the burden on caregivers. Support from healthcare professionals, family members, and community organisations is essential to ensure that caregivers can sustainably provide quality care for their elderly loved ones while maintaining their well-being. Ultimately, a holistic and collaborative approach is necessary to mitigate caregiver burden and improve outcomes for elderly patients and their caregivers.

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