ASSESSING THE BURDEN ON FAMILY CAREGIVERS

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ABSTRACT

Family care giving has been recognized as a relatively challenging issue in the existing scenario of health in India. Literature indicates that the stress associated with care giving results in a number of long-term health effects for the family caregivers. This study examines the burden perceived by the caregivers of Alzheimer patients with regard to their severity of illness. To meet this objective, forty caregivers belonging to various levels of socio-economic status were assessed using a semi-structured interview schedule. The hypotheses underlying this study are (a) there will be a direct relationship between the average disease burden under each of the dimensions and the patients’ degree of illness; (b) different levels of severity impose an increasing degree of average disease burden on the family as a whole; and (c) there will be an inverse relationship between the patients’ degree of illness and the socio-economic status of the family. The data collected were descriptively analyzed. Results found support for hypotheses (a) and (b). This paper highlights the need for appropriate counseling services to the caregivers who experience immense stress along with social and emotional problems, while looking after their family members suffering from Alzheimer disease. This may further enhance their quality of life and empower them to care. Further implications of the study are discussed in the paper.

Keywords: Caregiver burden, degree of illness

“A touch, a loving voice, and the presence of a loved one help keep a person physically, and emotionally alive, even when he can no longer reach out to anyone.”

Howard Gruetzner

For the patient, the family is the microcosm of the whole world, i.e. accepting that a loved one is suffering from psychiatric illness, is a challenging task. These patients may feel more comfortable in a familiar environment among loved ones rather than in the strange, unfamiliar environment of the hospital. However, caring for such a patient at home is a tremendous responsibility and most often a burden, which takes its toll on the immediate caregiver - be it the spouse, child, or any other family member.

This study was an attempt to assess the burden experienced by caregivers of patients suffering from Alzheimer disease. It is one form of dementia and is considered a progressive, degenerative brain disease in which the nerve cells of the brain are destroyed and the brain substance shrinks. Consequently, the thinking and behavior pattern of an individual is impaired.

The existing literature suggests that care giving is associated with emotional and cognitive transformations. The most important predictors of burden were identified as problematic behavior, disability, and severity of symptoms (Ohaeri, et.al. 2003). Dementia doesn’t simply affect the person who has it. Rather, it profoundly changes the lives of those family members who are in close relation to that person. When someone they have loved and cared for gradually disintegrates as a person, the whole relationship changes and new and unexpected demands are placed on the caregiver. ‘Caring for the patient’ requires tremendous strength and patience. In the terminal stages of the disease, even
when the patient seemingly has lost contact with reality, human contact makes a real difference. It has been reviewed that throughout the process of caring for patients with AD, caregivers frequently experience social, emotional, physical, and financial losses, which become more significant as the disease progresses (Bullock, 2004). This is consistent with prior researches by Aupperie (2006), Aguglia et al. (2004), Connell et al. (2001), Karlin et al. (2001) and Annerstedt et al. (2000). In a study conducted by Juozapavicius & Weber (2001), an in-depth interview was used to explore caregiver issues. It was found that former Alzheimer’s caregivers remember their experiences vividly and can recount many stories regarding their successes, regrets, coping strategies, and barriers faced. Participants also shared how they coped with the death of their loved one, the major issues they had immediately following the death, and issues with which they are still dealing. Donaldson & Burns (1999) also explored that gender, availability of support systems, relationship to patient as well as the attitude of the caregiver plays a major role in determining how burdensome and stressful they find their role.

Previous clinical and pathological studies of dementia in India suggest that Alzheimer’s type dementia is rare and/or unrecognized in most clinical populations. Various clinical researchers observed that the prevalence and incidence of Alzheimer’s disease appear to be lower than in western countries. However, it is also possible that to explore the environmental risk and protective factors associated with the dementia in India.

As a part of overcoming the stress experienced by the family members of these patients, they can be provided with an opportunity to share their problems, to ventilate their feelings and to adopt various coping strategies to overcome their difficulties. The caregivers who are in need of individual attention are referred for appropriate counseling services. Community based services enable families to cope better with the increased responsibility of caring for such patients with complex functional disability. Such kind of services can moderate the stress associated with caring, thereby, reducing the possibility of neglect or abuse of the elderly. Thus, it is important to recognize that the caregivers are deemed to be deserving of help. Their move from invisible status to a visible one must bring benefit to them, improve their quality of life and empower them to care.

From an extensive review of the available literature, the following hypotheses are drawn:

(a) There will be a direct relationship between the average disease burden under each of the dimensions and the patients’ degree of illness.

(b) Different levels of severity impose an increasing degree of average disease burden on the family as a whole.

(c) There will be an inverse relationship between the patients’ degree of illness and the socio economic status of the family.

Objective:
To assess the burden experienced by caregivers of patients suffering from Alzheimer disease.

Methodology
Sample:
A semi structured interview was conducted in a hospital setting for a sample of 40 caregivers of Alzheimer patients with an age range of 55 to 85 years and above. These caregivers belonged to different levels of socio economic status ranging from Rs. 1000 to more than Rs. 15000 per month. Duration of the disease was recorded as ranging from less than one year to more than 10 years. The degree of severity of illness also varied from mild to severe.

Measures:
Caregiver Burden: The inventory used to assess caregiver burden is a semi structured interview schedule developed by Shaila Pai and R.L. Kapur (1981). This inventory has been specifically
designed to assess the burden placed on the families of psychiatric patients living in the community. It comprises 25 items, which are divided into 6 different dimensions of caregiver burden. They are enlisted as financial strain, effect on family routine, effect on family leisure, effect on family interaction, effect on physical health of other family members, and the effect on mental health of other family members. The caregivers’ perceived burden was rated on a 3 point scale. The responses of the family members varied from no burden (0) to severe burden (2).

Result

The purpose of the present study was to assess the burden experienced by caregivers of patients suffering from Alzheimer disease. The responses obtained by interviewing 40 caregivers were descriptively analyzed. **Graph 1** shows the average disease burden identified along different levels of severity. It can be seen that the magnitude of disease burden is ranged from 1.96 to 9.66. This finding supports our hypothesis (b) which states that different levels of severity impose an increasing degree of average disease burden on the family as a whole.

**Graph 1** shows the average disease burden score along different levels of severity of illness.

**Graph 2** shows the percentage of caregivers reporting different degree of burden on various dimensions. This reveals that 57.5% and 45% of caregivers reported that the effect of burden on the family interaction and physical health respectively was nil. Moderate burden was reported by 45% and 30% of caregivers on financial resources and family leisure time respectively. Moreover amongst all the dimensions, the family interactions were least affected and only 20% of caregivers were mentally exhausted throughout the process of caring for the patients.
Graph 2 shows percentage of caregivers reporting burden on various dimensions.

‘Financial strain’ perceived by the caregivers has also been found to be related to the socio economic status of the respective families. Graph 3 shows the average burden of the family under varied socio economic status. The graph reveals a direct relationship between levels of socio economic status and average burden of the family. This finding is contrary to our hypothesis (c) which states that there will be an inverse relationship between the patients’ degree of illness and the socio economic status of the family. Thus, our results doesn’t support hypothesis (c).

Graph 3 shows the average burden of the family over different levels of socio economic status.
Graph 4 shows the average disease burden along all the dimensions in terms of varied degree of severity. The line graphs represent a direct relationship of the burden with the severity of patients’ illness. This further suggests that the burden increases in a geometric fashion depending upon the reported degree of illness. This finding strongly supports our hypothesis (a).

Graph 4 showing the average disease burden on all the dimensions according to the severity of illness

Discussion

The purpose of the present study was to assess the burden experienced by caregivers of patients suffering from Alzheimer disease. Existing literature highlights the importance of care giving role in the treatment of people suffering from dementing illness. Research has also focused on how the process of care giving takes a dramatic emotional, physical and financial toll on the patients’ primary caregivers. Prior researchers in this area identified various combinations of treatment approaches to dementia and found that minimizing the unnecessary medication use may reduce the financial toll experienced by families of such patients (Grumbles et.al. 2005; Omelan, 2006). The following section elaborates each dimension of caregiver burden with respect to different degrees of severity of the illness.

Financial strain: The treatment process of the patients accounts for substantive costs. Medications are an integral part in the treatment of patients suffering from any form of neurological problem. It has been seen in many cases that medications given in the earlier stages of the said disease seem to be quite effective as compared to medications given in the later stages. It has been observed that the financial strain experienced by 52.5% of caregivers ranged from moderate severe. This suggests that as the severity of illness in the patient aggravates, requirement of medications also increases. The findings indicate a direct relationship with the financial strain experienced by the families considered in the sample. In the process of attending to the patients’ illness, they may not be able report to work due to the patient’s illness. Consequently, loss of income may occur in the family. The results also indicated a direct relationship between levels of socio economic status and average burden of the family. This finding is contrary to hypothesis (c) which states that there will be an
inverse relationship between the patients’ degree of illness and the socio economic status of the family. Thus, our results doesn’t support hypothesis (c). This is one of the limitations of this study. This may be attributed to the reason that we have not studied the relationship separately for all the three different levels of severity of the illness.

Effect on family routine: Severity of illness imposes a negative affect on the Alzheimer patients in the form of difficulties while performing daily living activities. These are also accompanied by several behavioural problems. As a result of attending to the patient’s illness and irrational demands, sometimes the family routine gets disrupted to the extent that they start perceiving the patient as a burden and there the family conflicts arise. It has been observed that 52.5% of cases reported moderate to severe burden of the disease on the family routine. It can also be inferred that the average disease burden reported is directly related to the severity of illness of the patient. The physical dependency of the patient may disturb the family’s routine life which in turn may add to the problem of not being able to report to work. As a result of the increase in absenteeism, the person may have to lose the job on account of providing care to the patient.

Effect on Family Leisure: The families may require devoting extra time and effort toward the rehabilitation of their family members suffering from the disease. Lack of participation by patient in leisure activity may result in their stopping of normal recreational activities, absorption of holiday and leisure time and abandonment of planned leisure activity. This is consistent with what most of the caregivers reported about their leisure time activities. They specifically said that due to the occurrence of illness in the family, their leisure time gets absorbed in caring for the patient. Moreover, the patients’ lack of interest in activities and unwillingness to participate in any social function leads their family to stop engaging themselves in their usual recreational activities. The findings also indicate a direct relationship between the average disease burden on family leisure time and the severity of illness among the caregivers. The results also show that moderate to severe burden on family leisure is experienced by 55% of caregivers interviewed.

Effect on family interaction: Literature shows that nearly 80% of the patients suffering from the disease become physically dependent upon their caregivers. The physical dependency of the patient reduces their interaction with friends, members and relatives and curtails their participation in social celebrations. All these factors take an internal toll on the general family atmosphere. It has been seen that patients suffering from moderate to severe degree of AD experiences a variety of hallucinations and delusions, which makes the family atmosphere unpleasant. Such kind of difficult behaviors are relatively common challenges that may occur throughout the natural progression of dementia. It has been observed that 42.5% of caregivers experience burden on the family interaction. The findings also reveal a direct relationship between the average disease burden and the severity of illness reported.

Effect on physical and mental health: The fifth and the last dimension of the caregiver burden is the effect on physical and mental health of the caregivers’. All the burden dimensions discussed above have an impact on both the physical and mental health of family members or caregivers. As far as the physical health is concerned, 90% of caregivers assessed reported to be physically unhealthy. With regard to the mental health of the family members, it has been observed that 25% of cases assessed are seeking professional help for their psychological illness. And 82.5% of cases observed were found to be weepy, depressed and irritable while disclosing information about their sick relatives. The findings revealed that the effect on physical and mental health of the caregivers of AD patients proves to be directly related to the patients’ severity of illness.

Management of dementia involves care for the cognitive, behavioral, functional and emotional changes that occur as part of the illness. The present study showed that the stress of caring for a family member with dementia has adverse effects on the caregivers. They develop anxiety and depressive
symptoms in the process of caring for the patient. Distressed individuals are more likely to have lifestyles that put them at greater risk, including poorer health habits such as a greater propensity for alcohol and drug abuse, poorer sleep, poor nutrition, less exercise, etc. This is consistent with Panza et.al. (2008).

Most of the caregivers interviewed found their sick relatives most burdensome with respect to the effect of illness on family finances, the disruption of normal family activities, and the production of stress symptoms in both the caregivers and the patients. They also reported as being affected in the form of getting tired, burnout, and easy fatigability.

There are certain limitations in this study. Firstly, the use of self report measure of the interview schedule may have been influenced by socially desirable answers which could have affected the results of the study. Secondly, the sample size is small. And finally, the relationship between the socio economic status and the financial strain perceived by the caregivers is not properly established.

Despite these limitations, the study provided new insight into the burden experienced by caregivers of Alzheimer patients. Future research should also be focused on studying the impact of burden on caregivers highlighting the gender differences. Also, the relationship between the socio economic status and the financial strain experienced by caregivers can be further studied separately according to the severity of illness. However, in view of high incidence of caregiver burden, there is a need for psychosocial intervention to minimize it. Alzheimer associations have been set up in India to offer support and advice to such families. Caregivers in order to overcome the stress related problems can practice yoga and meditation as a part of spiritual healing. “Spirituality” refers to our search for meaning and purpose in life and is not necessarily tied to any religious belief. It has a place for the person with dementia, their family and the clinician (Stuckey & Gwyther, 2003). Yoga is defined as a science of mental control. It not only helps one to control one’s mental state, but also to improve one’s personality and behavior. In meditation, random activity is restrained and directed into one direction. The goal of concentration in meditation is to focus the flow of thought by fixing the mind on a single object- the meditative object. If concentration is achieved by meditation, the mind is not only directed towards the object but becomes totally absorbed in it. To conclude, the significant caregiver burden has been empirically shown and supported by researchers. This burden can be reduced by providing them with appropriate counseling services which may further improve their quality of life and empower them to care.

References


Appendix:

### TABLE 1: SYMPTOMS OF ALZHEIMER’S DISEASE

- Gradual memory loss
- Decline in ability to perform routine tasks
- Disorientation in time and space
- Impairment of judgment
- Difficulty in learning
- Loss of language and communication skills
- Difficulty in learning
- An inability to verbalize the thought process
- Mental disorientation
- Impairment of working memory affecting job skills
- Personality change
- Problems with abstract thinking

*Source: Sadock BJ and Sadock VA. (eds.) Kaplan and Sadock's Comprehensive Textbook of Psychiatry. 9th edition.*

### TABLE 2: DSM IV DIAGNOSTIC CRITERIA FOR DEMENTIA OF THE ALZHEIMER’S TYPE

A. The development of multiple cognitive deficits manifested by both [(1) & (2)-A1 & A2].
   1) Memory impairment (impaired ability to learn new information and to recall previously learned information)
   2) One or more of the following cognitive disturbances:
      a) Aphasia (language disturbance)
      b) Apraxia (impaired ability to carry out motor activities despite intact motor function).
      c) Agnosia (failure to recognize or identify objects despite intact sensory function).
      d) Disturbance in executive functioning (i.e. planning, organizing sequencing, abstracting).

B. The cognitive deficits in criteria A1 and A2 each cause significant impairment in social and occupational functioning and represent a significant decline from the previous level of functioning.

C. The course is characterized by gradual onset and continuing cognitive decline.

D. The cognitive deficits in criteria A1 and A2 are not due to any of the following:
   1) Other central nervous system conditions that cause progressive deficits in memory and cognition (e.g. cerebrovascular disease, Parkinson’s disease, Huntington’s disease, subdural hematoma, normal pressure hydrocephalus, brain tumor).
   2) Systemic conditions that are known to cause dementia(e.g. hypothyroidism, vitamin B12 or folic acid deficiency, niacin deficiency, hypocalcaemia, neurosyphilis, HIV infection).
   3) Substance induced conditions.

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another Axis I disorder (e.g. major depressive disorder, schizophrenia).

*Source: Sadock BJ and Sadock VA. (eds.) Kaplan and Sadock's Comprehensive Textbook of Psychiatry. 9th edition.*
### TABLE 3: CLINICAL FINDINGS IN AD PATIENTS BY SEVERITY LEVEL

**MILD** (Duration: 1-3 years)
- Impaired registration and recent memory (early sign); remote recall mildly impaired.
- Defective temporal orientation.
- Mild impairment of thinking; bewilderment in the face of complexity.
- Impoverishment of language, naming problems.
- Mild apraxia for complex tasks
- Agnosia
- Difficulties in planning, sequencing and executing instrumental activities of daily living.
- Frequent personality changes; irritability, less apparent concern about issues of daily life and effects of their behavior on others.
- Depression in approximately 20% of patients, mild apathy, loss of initiative, and lack of energy.
- Frequent misinterpretations.
- Urinary incontinence in fewer than 10%.
- Other neurological signs and primitive reflexes rare.

**MODERATE** (Duration: 2-8 years)
- Recent memory and remote recall severely impaired.
- Severe temporal disorientation, and moderate spatial disorientation.
- Obvious impairment of thinking, catastrophic reactions if pressured.
- Fluent Aphasia, Anomia, paraphasic errors, empty quality of language, preservation.
- Praxic difficulties to manage dressing, feeding, manipulations.
- Agnosia evident: failure to identify objects, including familiar faces.
- Difficulties in planning, sequencing, and executing extended to basic activities of daily living.
- Evident personality changes: marked irritability, marked lack of concern about issues of daily life and effects of their behavior on others.
- Dysphoric mood, depression less frequent apathy, loss of initiative.
- Frequent psychotic phenomena (delusions/ hallucinations).
- Restlessness, pacing, wandering occasionally, agitation, sporadic aggressiveness.
- Urinary incontinence frequent, fecal incontinence rare.
- Gait disorder and frequent primitive reflexes.

**SEVERE** (Duration: 7-12 years)
- Memory: only earliest learned information retained.
- Total disorientation.
- Severe impairment of thinking, indifference in the face of failure
- Extreme impoverishment of language, communication impossible.
- Complete incapacity to manage eating, dressing and simple manipulations.
- Severe agnosia (inability to recognize close relatives)
- Total dependence for even basic activities of daily living.
- Total disconnection from environment.
- Affective indifference; severe apathy; loss of initiative.
- Double incontinence.
- Motor system rigidity and flexion contractures of all limbs; final stage of decortications.

TABLE 4

COURSE

Alzheimer's Disease can run its course from insidious onset to death in just a few years or it may progress over a period of 20 years.

AGE OF ONSET: After 60 years of age.

RISK FACTORS IN AD

Risk factors are those factors which are associated with the occurrence of dementia, i.e., they are more likely to have been present, prior to dementia onset, in people who then developed dementia than in those who did not develop dementia.

- Age - the risk of developing Alzheimer's disease increases with age. 1.0% of all people above 65 years & 50% of people over 85 years of age have Alzheimer's disease.
- Low education
- Small brain size
- Gender - affects women more than men.
- Genetic factors – early onset & family history.
- Down syndrome - causes early onset AD.
- Stroke
- Major depression.
- Head trauma with loss of consciousness.
- Diabetics.
- Heart disease.
- Hypertension

EPIDEMIOLOGY IN INDIAN CONTEXT

- Overall prevalence of dementia is between 5% to 10% among elderly population. It occurs within the age group of 60 - 65 years and older. The incidence of AD in India has been reported to be lowest in the world. This finding is supported by Chandra et al (2001), showed that incidence rates of AD in India is 3.2/1000 persons/years as compared to 4.7/1000 persons/years in western countries.
- Commonly, people suffer from Alzheimer disease for about 9 years. By the age of 80, about 1 person out of three has the disease. Women are twice as susceptible as men.
- Prevalence of dementia increases exponentially with age. More specifically, the prevalence this doubles with every five year increase in age; between ages 90-95 years, the prevalence may be as high as 30-40%.