



Comparative study of family burden and life satisfaction among care givers of the patients with dementia and schizophrenia

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Abstract

Background of the Study: Care giving has been acknowledged as a basic part of human nature and chief component of close relationship. A number of previous studies reveal a higher rate of depression and anxiety among the caregivers as compared to the general population. Regardless of the researches on caregivers, and particularly on their burden, their psychological well-being is not well known. Although the amount of research might suggest most caregivers are vulnerable of collapse, most cope and seem to cope quite well. The purpose of this study is to find out the level of burden and amount of life satisfaction among the caregivers of the patients of schizophrenia as compared to the caregivers of dementia patients.

Material and Method: A total number of 100 care givers 50 of schizophrenia patients and 50 of dementia patients from Jawaharlal Nehru Medical College, Aligarh Muslim University Aligarh were selected as sample of the present study. They were tested using The Satisfaction with Life Scale and Family Burden Interview Schedule.

Result and Discussion: There is not much difference in the level of burden and only a slightest difference is found between the level of life satisfaction among the caregivers of schizophrenia and dementia patients.

Keywords: caregivers, depression, schizophrenia, dementia, life satisfaction

Introduction

Caregiver burden has been defined as a multidimensional response to the negative evaluation and apparent stress resulting from taking care of an ill individual. Caregiver burden adversely affects physical, psychological, emotional and functional health of caregivers (Zarit *et al.* 1980, Parks & Novielli 2000, Eters *et al.* 2008, Carretero *et al.* 2009) [35, 17, 10]. Caregivers often suffer from depression; have maladaptive coping strategies and express concern about their poor quality of life (Serrano-Aguilar *et al.* 2006, Papastavrou *et al.* 2007, Molyneux *et al.* 2008) [47, 34, 27]. It leads them to report more physical and psychological symptoms and use more healthcare services and prescribed medicines as compared to non-caregivers. (Brodsky & Green 2002, Schulz & Martire 2004, Serrano-Aguilar *et al.* 2006) [8, 46, 47]. Because of lack of knowledge of the techniques helpful in dealing with the patient showing aggressive symptoms caregivers feel more burden and distress. Thus, the emotional well-being of the family, especially the primary caregivers, is affected on a large extent.

A stressful emotional climate, anxieties and practical burdens, can have harmful effects on the physical and mental health of both adults and children. Children as well as adults experience adverse effects on their health and this possibility has been studied extensively. Adversely affected mental and physical health of the children, with possible long-term consequences results in high social costs of having mentally ill people in the home (Rutter *et al.*, 1976) [42].

In chronic illnesses, the individual may have difficulty with his or her identity (what kind of person am I?) and with alterations in lifestyle (Charmaz, 1995) [12]. Prolonged or chronic illnesses also have negative impact on the rest of the family. Taking care of a chronically ill individual is demanding and stressful. The marital relationship may suffer (Woods & Lewis 1995) [55]. Family patterns may have to be warped and may be highly constrained by the sick member.

Serious illness precludes proper role functioning of the family and results in disruption of the normal family life. For example, those who are physically or emotionally ill may be incapable of adequately fulfilling the roles of spouse, parents, or, breadwinner. In extreme cases, most activities of family members reflect the ill person's needs and limitations. Poor interpersonal relationships can be a factor in the onset of a mental disorder, and mental disorders adversely affect interpersonal relationships (Palisi and Canning 1983) [33].

Although the amount of research might suggest most caregivers are at risk of collapse, most cope and seem to cope fairly well (Vitaliano 2000; Chappell 2001) [53, 11].

Among the contextual variables, gender plays an important role with female caregivers experiencing more burden than male caregivers (Barusch and Spaid 1989; Stuckey and Smyth 1997) [7, 50], although this finding is not supported by all the researchers (Miller and Cassafo 1992) [26]. Kramer and Kipnis 1995 [23] found that age of caregiver and burden were inversely related among employed informal caregivers. Jutras and Veilleux 1991 [21] reported an increase in burden with age

of caregiver. They also found that unemployed caregivers experienced higher levels of burden than did employed caregivers.

Caregivers burden consists of two dimensions, "objective burden" (effects on the household including financial loss; effects on health, on children, and family routine; and the abnormal behaviors shown by the patient) and "subjective burden" (the extent to which relatives felt they carried a burden). Some researchers though have mistakenly considered subjective burden as same as stress. The focus on patient's subjective sense of well-being is a fairly new phenomenon that has attracted professional attention only within the past two decade. Between 1850 and 1950, medicine was dominated by the quest for cures; treating chronic illness as well as helping patients manages long-term impairment received less attention.

Caregivers of patients having severe type of mental illnesses like schizophrenia, dementia, etc. face more issues than the caregivers of patients having other types of mental disorders because the patients of both the disorders needs complete assistance in daily functioning and are totally dependent on their caregivers. These disorders are of a very long duration and also the condition of the patients suffering from these illnesses gets worse with every passing day. Also the mood swings, aggressive behavior and worse mental and physical condition make it very difficult for the caregivers to cope with.

They say when you talk to god its prayer but when god talks to you its schizophrenia.
-Fox Mulder

According to the DSM-IV-TR, Schizophrenia is a persistent, often chronic and usually serious mental disorder affecting a variety of aspects of behavior, thinking, and emotion. Patients with hallucinations or delusions may be described as psychotic. Thinking may be disconnected and illogical. Peculiar behaviors may be associated with social withdrawal and disinterest (APA, 2000).

Schizophrenic patients occupy 50% of beds in mental hospitals. Caregivers of persons with schizophrenia experience more stress due to the nature of the symptoms as well as the prolonged duration of illness. The average prevalence of schizophrenia is 2-3/1000. The average incidence is 4.2/10,000 and 3/10,000 in the rural and urban areas, respectively. The prevalence rate of schizophrenia explains the magnitude of the issues involved in the process of caregiving. Subjective burden describes the psychological reactions which caregivers experience e.g., a feeling of loss, sadness, anxiety, and embarrassment in social situations, the stress of coping with disturbing behaviors, and the frustration caused by changing relationships.

Saunders in his review related to families living with schizophrenia found that there is general agreement in the literature that a multitude of variables affect families with a severe mental illness (SMI), such as schizophrenia. Among those various factors, the most frequently investigated variables were coping, psychological distress and caregiver burden, social support, caregiver resiliency and depression, and client behavioral problems. Shibre *et al.* found that

relatives of female patients suffered significantly higher social burden. Work and financial burdens affected female relatives more often than males.

On the other hand, Dementia is a major cause of disability and suffering among older people. The literature clearly documents that caring for a person with dementia can be associated with loss of mental health and subjective wellbeing. Studies have reported that 20-50% of dementia caregivers develop depression or high levels of depressive symptoms, and that these rates are stable or increasing over time. A recent prospective cohort study estimated the incidence of depression among spouses of persons with dementia to be more than fourfold higher than among spouses of persons without dementia. Caregivers of dementia patients also experience higher levels of depressive symptoms compared with caregivers of physically impaired older adults.

Family caregivers of people with dementia, often called the invisible second patients, are critical to the quality of life of the care recipients. The effects of being a family caregiver, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill-health, and financial hardship. There are an estimated 30 million people with dementia worldwide currently, and this figure is likely to double every 20 years. People with dementia generally require high levels of care, most of which is provided by informal or family caregivers. More than 60% of people with dementia live in developing countries. The 10/66 Dementia Research Group assessed the care arrangements of people with dementia in South-East Asia, China, India, Latin America and the Caribbean, and Nigeria.

In a research study the levels of emotional distress and strain were examined in two groups of relatives of psychiatric patients using standard instruments. The dementia group had more GHQ--30 cases than the schizophrenic group. Even though the schizophrenic relatives had higher distress and strain scores than the dementia relatives, they did not reach significant levels when the two groups were compared.

But there is not much research done in this field to compare the level of burden and satisfaction among the care givers of schizophrenia and dementia patients. The purpose to conduct present study is to evaluate and compare the difference between the level of family burden and life satisfaction among care givers of the patients with dementia and schizophrenia in order to prove fruitful for future research.

Methodology

Objectives

- To compare the level of family burden among care givers of the patients with dementia and schizophrenia.
- To compare the level of life satisfaction among care givers of the patients with dementia and schizophrenia.

Sample

A total number of 100 caregivers 50 of schizophrenia patients and 50 of dementia patients from Jawaharlal Nehru Medical College, Aligarh Muslim University Aligarh were selected as sample for the present study with the help of purposive sampling method. The age range of the caregivers was from 20-60 years.

Tools

- **The Satisfaction with Life Scale:** The Satisfaction with Life Scale (SWLS) was developed to assess satisfaction with the respondent's life as a whole. The scale does not assess satisfaction with life domains such as health or finances but allows subjects to integrate and weight these domains in whatever way they choose. Normative data are presented for the scale, which shows good convergent validity with other scales and with other types of assessments of subjective well-being. Life satisfaction as assessed by the SWLS shows a degree of temporal stability (e.g., .54 for 4 years), yet the SWLS has shown sufficient sensitivity to be potentially valuable to detect change in life satisfaction during the course of clinical intervention. Further, the scale shows discriminant validity from emotional well-being measures. The SWLS is recommended as a complement to scales that focus on psychopathology or emotional well-being because it assesses an individuals' conscious evaluative judgment of his or her life by using the person's own criteria.
- **The Family Burden Interview Schedule:** This scale was developed by Pai and Kapur in 1981 [32]. It is a culturally sensitive semi-structured interview schedule devised for assessment of perceived burden in the caregivers of subjects with psychiatric disorders. It has 24 items grouped under six areas of burden, namely: (i) financial burden; (ii) disruption of routine family activities; (iii) disruption of family leisure; (iv) disruption of family interactions; (v) effect on physical health of others; and (vi) effect on mental health of others. Each item is rated on a 3-point scale: zero indicating no burden, a score of 1 indicating moderate and a score of 2 indicating severe burden. The total score obtained for these six domains is termed as objective burden. It is a reliable and valid measure of burden and has been used in the past in many studies from India. The reliability and validity were found to be 0.87 and 0.72 respectively.

Procedure

The data was collected on 50 caregivers of the dementia patients and 50 caregivers of schizophrenia patients admitted in the psychiatry ward in Jawaharlal Nehru Medical College, Aligarh Muslim University Aligarh individually by administering different questionnaires that is The Satisfaction with Life Scale and The Family Burden Interview Schedule. The data was collected by purposive sampling method. Prior to data collection researcher had to establish a rapport with the subject that is caregiver of the patient. The purpose of the research was explained to the subject to develop the subject's

keen interest to cooperate the task and after the subject's readiness to support the purpose, they were asked to fill the questionnaires. The questions were translated in Hindi language to the caregivers if they found any difficulty in understanding the questions. The caregivers who were not willing or were not able to understand the purpose or outcome of the study were not included in the research study. After the completion of the questionnaires subject was told that his or her responses would be kept confidential and should be used for research purpose only. The data was analyzed using SPSS version 20.

Result

Table 1: showing the demographic details of the caregivers of Schizophrenia and Dementia patients

Variables		Dementia caregivers	Schizophrenia Caregivers
Age	20-40	23(46)	24(48)
	41-60	27(54)	26(52)
Gender	Male	22(44)	26(52)
	Female	28(56)	24(48)
Education	Illiterate	12(24)	09(18)
	Primary	16(32)	13(26)
	Secondary	14(28)	16(32)
	H.edu	08(16)	11(22)
Religion	Hindu	22(44)	23(46)
	Muslim	26(52)	26(52)
	Christian	02(04)	01(02)
Marital Status	Married	27(54)	26(52)
	Unmarried	23(46)	24(48)
Occupation	Employed	16(32)	18(36)
	Unemployed	34(68)	32(64)
Domicile	Rural	23(46)	24(48)
	Urban	27(54)	26(52)
SES	Upper	00(00)	00(00)
	Upper Middle	06(12)	08(16)
	Lower Middle	22(44)	20(40)
	Upper Lower	18(36)	20(40)
	Lower	04(08)	02(04)

Table-1 is depicting the demographic details of the caregivers of schizophrenic and dementia patients. Out of 100 caregivers 50 were of dementia patients and 50 were the caregivers of schizophrenia patients with age range of 20-60 years. Male caregivers were 22 for dementia patients and 26 for schizophrenia patients. Female caregivers for dementia and schizophrenia patients were 28 and 24 respectively. Majority of them were primary or secondary educated, unemployed, living in urban localities and were married.

Table 2: is showing the level of burden among caregivers of Schizophrenia and Dementia patients.

Groups	N	M	S.D	Standard Error Mean	t-value	95%Confidence interval of the Difference	
						Lower	Upper
Schizophrenia Caregivers	50	38.44	5.69	.80567	-.071	-2.32116	2.16116
Dementia Caregivers	50	38.52	5.59	.79140		-2.32116	2.16116

Table-2 is showing the mean scores of the carers of schizophrenia and dementia patients on Family Burden Interview Schedule. The mean scores of caregivers of

schizophrenia patients are 38.44 whereas the mean scores of carers of dementia patients are 38.52. There is a very minor difference in the scores of both the groups.

Pie chart showing the level of burden among caregivers of Schizophrenia and Dementia patients

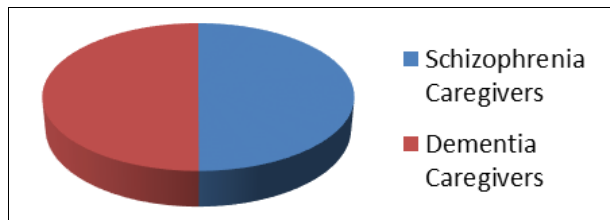


Fig 1

The pie chart is showing the difference between the level of burden among family caregivers of the patients of schizophrenia and dementia. It can be seen that there is very minute or no difference between the level of family burden. Caregivers of both the patients feel the same level of burden and depression.

Table-3 is showing the level of life satisfaction among caregivers of Schizophrenia and Dementia patients

Groups	N	M	S.D	Standard Error Mean	t-value	95% Confidence interval of the Difference	
						Lower	Upper
Schizophrenia Caregivers	50	9.32	2.61	.36971	2.209	.11186	2.08814
Dementia Caregivers	50	8.22	2.35	.33355		.11173	2.08827

Table-3 consists of the scores of life satisfaction of the caregivers of schizophrenia and dementia patients obtained by administering Satisfaction with Life Scale. The mean scores of schizophrenia patients' carers and caregivers of dementia patients are 9.32 and 8.22 respectively.

Pie Chart showing the level of life satisfaction among caregivers of Schizophrenia and Dementia patients

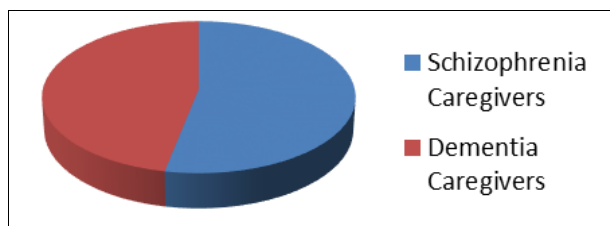


Fig 2

Second pie chart is showing the difference on life satisfaction among the caregivers of schizophrenia patients and dementia patients. The difference is not much but it is more than the difference in the level of burden. Schizophrenia patients' caregivers are showing more life satisfaction as compared to dementia caregivers.

Discussion

The present research study was done in order to examine and compare the level of burden and satisfaction with life among the caregivers of dementia and schizophrenia patients. It was

found that there was not much difference in the level of family burden as measured by Family Burden Interview Schedule on both the groups that are caregivers of schizophrenia and dementia patients. Both the illnesses are very distressing for both the patients and their caregivers. On one hand, schizophrenia is known as the cancer of mental illnesses and on the other side dementia is associated with long care hours and physically demanding care giving. Patients with mental illnesses required more assistance and higher level of care which is also distressing and time consuming which affects the personal life of the care givers as well. It can be well defined by the giving explanation of Archbold's concept.

Archbold's concept of care providers and care managers is useful. Care providers or care givers provide hands-on care, dressing, assisting with finances and other daily activities, and care managers arrange for others to provide care, for example a nurse for personal care, an accountant to assist with finances. Spouses tend to be care providers, and adult children and other relatives, care managers. Care providers tend to be more stressed than care managers (Archbold, 1981)^[4].

Many studies have found that caregivers of those with dementia (particularly care providers) have higher levels of burden than other caregivers (Gonzalez-Salvador, 1999, Ory, 1999 and Alzheimer's Association, 2007)^[18, 30, 1]. A 2003 survey of 227 US dementia caregivers found that nearly one quarter provided 40 hours of care or more per week (compared with 16% for non-dementia caregivers). This included personal care such as bathing, feeding, and assisting with toileting for 65% of caregivers. Over two thirds of caregivers sustained this commitment for more than 1 year and one third for 5 or more years (Alzheimer's Association, 2007)^[11].

The difference in the level of life satisfaction on Satisfaction with life scale can be understood from the above given description. Dementia caregivers are occupied in providing care almost whole day and they do not get any leisure time for their personal and social life. Though the condition is very much same with caregivers of schizophrenia patients this is reason why there is not much difference found in the level of life satisfaction. The schizophrenia patients have the possibility even though very minute but still have to get cure with the treatment and medicines or their condition may improve a little but dementia patients get worsen day by day and the disease goes with the patient's life.

In the Poulshock and Deimling (Poulshock and Deimling, 1984)^[40] model, dementia leads to a burden of care which can manifest as strain in a number of ways that can be exacerbated (eg, by behavioral disturbance, physical or psychological ill-health in caregiver) or ameliorated (eg, by support, mature coping mechanisms) (Figure 3).

Pearlin and colleagues' (Perlin, *et al.*, 1990)^[36] model of caregiver stress outlines four main areas that contribute to caregiver stress: the background context (such as level of support and impact of other life events), the primary stressors of the illness (such as the level of help required by the patient and behavioral and psychological problems in dementia [BPSD]), secondary role strains (such as family conflict and social life), and intra-psyche strains such as personality, competence, and role captivity of the caregiver (Figure-4) (Perlin, *et al.*, 1990 and Campbell, *et al.*, 2008)^[36, 9].

In Campbell and colleagues'(Campbell, *et al.*, 2008)^[9] review of the model, the strongest predictors of caregiver burden were sense of "role captivity" (carer feelings of being "trapped" in their role), caregiver overload (eg, fatigue and burnout), adverse life events outside of the caregiving role and relationship quality.

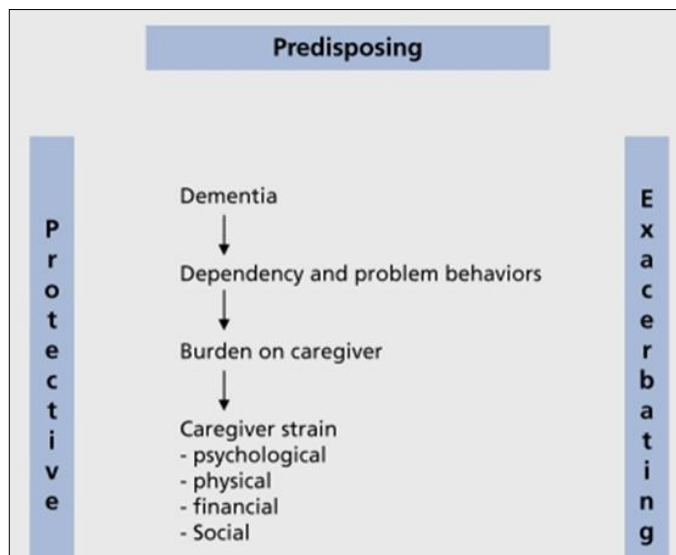


Fig 3

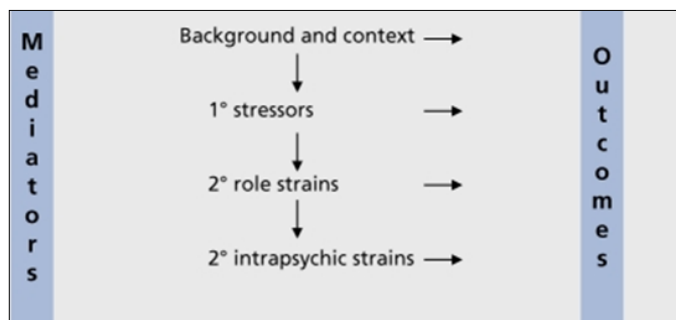


Fig 2

Conclusion

Caregivers of mental disorder patients report a greater number of physical health problems and worse overall health compared with non-caregivers or caregivers of physical illness patients. Those with psychological morbidity and greater strain are even more likely to have poor physical health and a higher risk of mortality.

Schizophrenia has a global prevalence of 0.3-0.7%, with 3 million Indians suffering from the same (Van and Kapoor, 2009)^[52]. Schizophrenia is a chronic psychiatric disorder, and its effects can be classified at three levels; first the patient who undergoes personal suffering, secondly the caregiver and/families for the burden of care along with the added responsibility of transitioning the relative from inpatient to the outpatient treatment, and thirdly the society as a whole for suffering from frequent hospitalizations and long-term financial and psychosocial support (Awad and Voruganti, 2008)^[51].

There are 30 million people suffering from dementia throughout the world. Dementia patients need full time

assistance even in regular simple activities. Caregivers of the dementia patients are always under the depression and their quality of life also gets worsen. They are called invisible second patients. Studies revealed that there are 20-50% of the caregivers who develop severe depression.

Family caregivers are essential to quality of life of people with schizophrenia or dementia. The high levels of burden and psychological morbidity are well documented, as are factors that predict which caregivers are vulnerable to these. Interventions can ameliorate these effects and thereby improve the quality of life of people with mental disorders as well as their caregivers. The management of the person having schizophrenia or dementia requires a comprehensive plan that includes a partnership between doctors, health care workers, and families. Caregivers susceptible to negative effects can be identified and could be targeted for interventions.

There are not many studies which have compared the burden in the families of patients with schizophrenia and dementia may be due to the stable phase of the illness. There is a need of future research in this field and also the interventions should be taken and training should be provided to the caregivers of mental illnesses' patients like those having dementia or schizophrenia so that caregivers are able to manage the patients as well as their personal, social and economic life efficiently.

The limitation of the present study was both the illnesses dementia and schizophrenia are of same severity. Both are stable in nature and the level of distress experienced by the caregivers is high because patients of both the illnesses required full time assistance in basic day to day activities. That is why there is not much difference found in the level of burden and life satisfaction among the caregivers of schizophrenia and dementia patients.

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