BURDEN AND QUALITY OF LIFE– A COMPARISON OF THOSE CARING FOR PSYCHIATRICALLY ILL AND MEDICALLY ILL

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ABSTRACT

BACKGROUND

Despite epidemiological transitions, communicable diseases are widely prevalent world over, concomitantly non-communicable diseases are also on the rise. Mental and behavioural disorders account for 12% of the global burden of disease. Caregiving for both groups of patients, rests with an identified primary caregiver. Caregiving lays a great deal of burden on the caregiver, adversely affecting his quality of life. These factors influence the quality of caregiving, and thereby the long-term well-being of the patient. Differences between the two groups of caregivers has not been studied, more so in the Indian context.

MATERIALS AND METHODS

60 caregivers of psychiatrically ill and 63 caregivers of the medically ill were studied. Burden of care was assessed using Elmstahl burden scale, and quality of life (QOL) using WHOQOL BREF.

RESULTS

The socio demographic profile of both groups was similar. All subjects experienced a burden of care, with those caring for the psychiatrically ill experiencing a greater burden. QOL was poorer in the care givers of the psychiatrically ill, especially in those married, employed, and in a lower income group. The female care giver, mostly the spouse, experienced a greater burden of care and a poorer QOL.

CONCLUSION

Chronicity, stigma, poor insight and disabling dependence of the psychiatrically ill, are probably contributory. A higher caregiver burden and a lower QOL will influence quality of caregiving, and have an adverse effect on the course and prognosis of the illness. There is thus a need for routine assessment of the caregiver, and planned intervention for the same.

KEYWORDS

Burden, Quality of Life, Mental Ill and Physical Illness.

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BACKGROUND

Despite epidemiological transitions, communicable diseases are still widely prevalent the world over. 'Infectious diseases of poverty' (neglected tropical diseases, HIV, tuberculosis, malaria) are on the rise, together being responsible for the death of more than 8.7 million people worldwide in 2008.[1] Non-communicable diseases (NCDs), also referred to as chronic diseases, are the leading causes of death worldwide. In 2008, 80 percent of NCD deaths were in developing countries, up from 40 percent in 1990.[2] NCDs accounts for 53 percent of deaths in India, and based on available evidence, cardiovascular diseases (26 percent), chronic respiratory diseases (13 percent), cancer (7 percent) diabetes mellitus (2 percent) and others (12 percent) are the leading cause of mortality.[3]

Psychiatric disorders constitute a major part of non-communicable diseases, the burden of which has risen over the past few decades. The World Health Organisation estimated that globally over 450 million people suffer from mental disorders.[4] Currently, mental and behavioural disorders account for about 12% of the global burden of disease. This is likely to increase to 15% by 2020.[5] At any given point in time mental and behavioural disorders are present in about 10% of the adult population.[6] In India, a systematic review of data on epidemiological studies published from 1960-2009 indicates the overall prevalence rates to be approximately 190-200 per 1000 population, translating to 20% of the population having one or the other mental disorder requiring professional intervention.[7]

Both in medical as well as in psychiatric illnesses, the role of care giving rests with an identified member of the family (primary care giver). This is seen more often in the non-western world. In 2009, nearly 66 million Americans (three in 10 U.S. households) reported at least one person providing unpaid care as a family caregiver.[8] In India, more

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than 90% of patients with chronic mental illness live with their families.[9] More adults with chronic conditions and disabilities are living at home than ever before, and family caregivers have an even higher level of responsibility.[10]

A caregiver has been defined as a family member who has been living with the patient, and has been closely involved in his/her activities of daily living, health care, and social interactions for more than a year.[11] The World Health Organisation defines Caregiver burden as the 'emotional, physical, and financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system.[12]

Caregiving lays a great demand of stress on the life of the care giver, giving rise to a significant burden, and adversely affecting his quality of life. WHO defines Quality of Life as individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.[12] Caregiving for the ill impinges on the well-being of the care giver, affecting his quality of life negatively.

A Caregiver thus needs to be assessed for perceived burden and quality of life, in order to plan interventions to reduce burden, improve quality of life, and enable a better quality of care to their respective wards. Care giver burden has been studied in the context of certain long term medical illnesses, such as stroke, dementia, and malignancies, and in the context of certain psychiatric disorders. As such studies that have compared the two groups of caregivers, and the differences between them in terms of caregiving burden, are sparse, more so in the Indian context, and hence the current study was undertaken.

MATERIALS AND METHODS

67 consenting primary care givers of patients admitted under the department of psychiatry over a three-month period were included in the study. Four of them withdrew their consent during the study, and three patients could not complete the study due to ill health. Hence, 60 patients were included. 63 consenting primary care givers of patients admitted under the department of general medicine over a three-month period were included in the study.

Sociodemographic data was elicited using a self-designed proforma for the purpose.

Burden of care was assessed using the Elmstahl care giver burden scale.[13] This is a 22-item scale developed by S. Elmstahl in 1996 to assess the Subjective Burden of care giving. The scale is divided into five indices – general strain, isolation, disappointment, emotional involvement, and environment, with each item being scored from 1 to 4. Total score ranges from 22 to 88, with higher scores indicating higher burden. This scale has been standardised for the study population and is widely used and quoted.

Quality of life of the care givers was assessed using the WHO-QOL BREF.[14] WHO-QOL 100 is a quality of life assessment that is applicable cross culturally, and is developed by the WHOQOL group in 1998.[15] It is based on a four domain structure covering physical health, psychological, social relationship, environment, with multiple facets with in each domain. WHO-QOL BREF is a short form that contains 26 questions, one item from each of the 24 facets contained in the WHO-QOL 100. Two questions from the overall quality of life and general health facet have been included.[16] The raw scores obtained on WHO-QOL BREF can be converted and made comparable with WHO-QOL 100. All the domains are scaled in a positive direction, with higher scores denoting a higher quality of life. It is standardised for the current study population and is widely used.

The study was approved by the Ethics committee of the Kempegowda Institute of Medical Sciences, Bangalore, where the study was conducted. Written consent was taken from the study sample.

RESULTS

Sociodemographic Profile- The care givers of both the psychiatrically and medically ill had an almost similar socio demographic profile. Majority of both groups were aged between 15 and 45 (75% and 78% respectively), with two thirds or more being female (66.6% and 73.7%). More than 85% of both groups were Hindus and were married (88% and 93%). They were educated formally for about ten years (76.6% and 82%), hailing mostly from an urban area (82%). 70% of caregivers of the psychiatrically ill and 57% of the care givers of the medically ill lived in nuclear families, with an income of less than Rs. 25,000 per month (85% and 93.4%).

Duration of Caregiving by the Primary Caregiver- Duration of care rendered by the primary care giver for the psychiatrically ill was less than a month in 11.6% of the cases, one month to one year in 30% of the cases, one year to six years in 40% of the cases, and for more than six years in 18.3% of the cases. Care rendered for by the primary care givers of the medically ill was less than a month in 47.5% of the cases, one month to one year in 30% of the cases, one year to six years in 13.1% of the cases, and for more than six years in 9.8% of the cases. The care giver was the spouse in 50% of those psychiatrically ill, and in 40% of those medically ill. Parents and grandparents constituted 30% of the caregivers of both groups. (Table 1)

Burden of Care- The burden among the care givers of psychiatry patients is much more than the burden among care givers of medical patients. The difference is found to be statistically significant (P=0.0001). (Table 2) This was found to be so, irrespective of age, gender, level of education, employment status, marital status, area of residence, type of family and income. (Table 3), as well as duration of care-giving. All the caregivers of the medically ill experienced burden of care. Majority of them experienced a mild burden of care, while a majority of those who cared for the psychiatrically ill experienced a moderate burden of care.

Quality of Life- Scores of individual domains of quality of life show that domain 2 (Psychological health) and domain 3 (Social relationships) are significantly better in care givers of medically ill patients. (Table 4). The overall domain scores are lesser in care givers of the psychiatrically ill patients (p=0.065) irrespective of age, gender, education, residence, type of family and duration of care-giving, though not statistically significant. However, married caregivers, employed caregivers, and those with a lower income, caring for the psychiatrically ill, had a significantly lower quality of life. (Table 5) Thus, married care givers, who constituted 88% of the care givers of the psychiatrically ill, had a higher burden, and a lower quality of life.

Psychiatric Diagnosis- Two care givers of the psychiatrically ill received a psychiatric diagnosis, one with dysthymia and one with a moderate depressive disorder.

	Psychiatrically Ill		**Medically Ill**	
Duration of Care				
<1 Year	25/60	41.6%	47/63	77%
>1 Year	35/60	58.4%	14/63	23%
Relationship				
Parent/grand parent	18/60	30%	19/63	30.1%
Spouse	30/60	50%	25/63	39.8%
Others	12/60	20%	19/63	30.1%

Table 1. Distribution of Care Givers according to Duration of Care giving and Relationship with the Patient

Caregivers	**Mean Score**	**Standard Deviation**	**T-value**	**P-value***
Psychiatry	46.78	13.39	7.11	0.0001
Medicine	32.59	7.91		

Table 2. Difference in the Total Burden of Care Experienced by the Two Groups

*P Value <0.05 Indicates Statistical Significance.

Socio Demographic Characteristic	**Mean Burden Score among Care Givers**		**T-value**	**P-value***
	Psychiatry PTS	**Medicine PTS**		
Age				
< 35 years	45.81	33.40	4.243	0.0001
>35 years	47.53	32.03	5.656	0.0001
Gender				
Male	45.50	33.04	5.128	0.0001
Female	49.35	31.31	5.127	0.0001
Marital Status				
Unmarried/widow	43.83	35.50	1.192	0.274
Married	47.11	32.38	7.018	0.0001
Education				
Uneducated	44.27	32.45	3.248	0.003
Educated	47.62	32.66	6.207	0.0001
Occupation				
Unemployed/student	44.50	32.81	3.70	0.0001
Employed	49.39	32.43	6.767	0.0001
Residence				
Rural	46.09	32.50	3.209	0.005
Urban	46.94	32.61	6.33	0.0001
Type of Family				
Nuclear	47.24	33.57	5.477	0.0001
Joint	45.72	31.27	4.188	0.0001
Income				
<25,000	45.96	29.71	5.237	0.0001
>25,000	47.37	33.70	5.238	0.0001

Table 3. Difference in the Burden Among Care Givers of Psychiatry and Medicine Patients According to Socio-Demographic Features

*P Value <0.05 Indicates Statistical Significance.

QOL Components	**Average Value of Component QOL of Care Givers of**		**T-Value**	**P-Value***
	Psychiatrically Ill	**Medically Ill**		
Question 1	3.25	3.57	-2.689	0.08
Question 2	3.36	3.49	-0.814	0.418
Domain 1	64.95	65.19	-0.091	0.928

Domain 2	55.82	61.25	-2.343	0.021
Domain 3	57.18	65.03	-2.703	0.008
Domain 4	63.17	61.90	0.681	0.497
Overall domains	60.20	63.34	-1.866	0.065

Table 4. Difference in the Quality of Life Among Care Givers of Psychiatry and Medicine Patients

*P Value <0.05 Indicates Statistical Significance.

Socio Demographic Characteristic	Average QOL Score Among Care Givers		T-Value	P-Value*
	Psychiatry PTS	Medicine PTS		
Age				
< 35 years	60.66	65.14	-1.779	0.083
>35 years	59.85	62.10	-0.997	0.322
Gender				
Male	60.54	63.46	-1.54	0.127
Female	59.53	63.02	-1.028	0.311
Marital Status				
Unmarried/widow	70.04	65.63	0.743	0.50
Married	59.11	63.18	-2.358	0.02
Education				
Uneducated	57.48	60.93	-1.063	0.296
Educated	61.11	64.52	-1.761	0.082
Occupation				
Unemployed/student	61.30	61.22	0.028	0.978
Employed	58.95	64.92	-2.890	0.006
Residence				
Rural	57.91	66.00	-2.163	0.043
Urban	60.72	62.82	-1.122	0.265
Type of Family				
Nuclear	59.56	63.28	-1.847	0.069
Joint	61.69	63.42	-0.574	0.569
Income				
<25,000	57.78	66.46	-3.079	0.004
>25,000	61.93	62.14	-0.103	0.918

Table 5. Difference in the Quality of Life (QOL) Among Care Givers of Psychiatry and Medicine Patients According to Socio-Demographic Features

*P Value <0.05. Indicates Statistical Significance.

DISCUSSION

The socio demographic profile of both groups was comparable in all parameters, considering that they were essentially from the same background and location. Both groups of care givers were young adults, from an urban background, educated up to high school levels, married, Hindus by religion, with a larger female representation. This appears to be the profile of the average care giver in an urban setting, in keeping with other studies.[17,18]

Research supports that care giver burden is perceived by those who give care to the mentally ill, as well as those who care for the medically ill. Many care givers (43.5%) of the mentally ill were found to have a more than average burden of care, with some having profound levels of burden (9.4%) in a Nigerian out-patient study.[19] Previous researches have shown that informal caregivers of patients with schizophrenia in Europe, America.[20] Australia.[21,22] Asia and Africa. experience moderate to high levels of caregiver burden. An Indian study conducted in a tertiary care hospital found all the caregivers of patients with schizophrenia included in their study to have a high (40%) or moderate (60%) burden of care.[23]

Caring for the medically ill involves a significant burden as well. Care givers of individuals who had suffered a stroke had a high burden of care with a negative correlation between burden and quality of life. In an 18 month prospective, naturalistic, observational cohort study reflecting the routine care of patients with Alzheimer's disease in France, Germany and the United Kingdom (GERAS) care giver burden was found to be high, with the Adult-Child care giver experiencing greater burden, and burden being higher more severe the disorder.[24]

A study comparing Caregiver burden found the caregiver of psychiatrically ill to perceive a significantly higher burden (schizophrenia, mood disorders, and substance abuse) as compared to caregiving for the physically ill (refractory tuberculosis, chronic bronchial asthma, diabetes mellitus, or rheumatoid arthritis) with increasing age of the care giver and greater duration of illness of their ward being important factors.[25] Care givers of mentally ill were found to have a higher burden of care than the caregivers of individuals diagnosed to have cancer.[26] Caregiving studied in three groups, one with physical illness (SLE, paralysis, cerebral trauma) one with mental illness (schizophrenia, OCD, mood disorders, anxiety disorders), and the third with both pathological conditions, found that the third group which consisted of individuals diagnosed to have Alzheimer's disease, faced the greatest burden of care compared to the other groups.[27] As opposed to the above studies, moderate to severe burden of care was found in both groups of care givers diagnosed to have schizophrenia or epilepsy.[28] Comparing both groups of care givers, the current study found care giver burden to be significantly higher among those caring for the psychiatrically ill, independent of all the sociodemographic features considered.

Perceived burden of care influences a care givers quality of life. Certain care giver factors have been found to influence the lower quality of life, such as age, gender, educational status of the caregiver, and chronicity of illness in their ward.[25,29] While care giving for both physical and mental disorders have been found to lower quality of life of the caregiver, it has been found that caring for the mentally ill results in a comparatively poorer quality of life. This was found to be lower in all domains, more so in the psychological domain, followed by social, environmental and physical domains.[30] Care givers attending to individuals with both physical disorders as well as mental disorders as opposed to any one of them, had a poorer quality of life in all areas.[27] Subjects caring for the mentally ill in the current study were found to have a poorer quality of life, mainly in the psychological and social relationship domains, and significantly so in the rural, employed, married and lower income groups.

The stress of care-giving for the mentally ill has been found to be associated with psychiatric morbidity in the care giver. Majority of literature has found that gender rather than age influences these phenomena. Higher levels of depressive symptomatology were found in women rather than in men, as also in wives rather than in husband caregivers.[31] Anxiety and depression were predominantly found in caregivers of mentally ill individuals with severe disabilities.[25,32] In the current study, one caregiver was diagnosed to have a major depressive disorder, and one with dysthymia. The lower rate of psychiatric morbidity in this study could be influenced by patient's illness related factors, environmental factors, family support systems, as well as the personality of the caregiver. These factors have not been examined in this study. The sample size being small and heterogeneous in their psychiatric diagnosis, an association between care giver burden and quality of life to diagnoses of the patients could not be made. However, the common factor for all the patients was that the severity of their current illness warranted admission for adequate care.

Thus, in our study, burden of care has been found to be higher in care givers of the mentally ill and they also had a lower quality of life. Psychiatric illnesses tend to be chronic and stigmatised. Patients with these disorders tend to be uncooperative, are at times abusive/assaultive, suspicious, and sometimes demand supervision in their day to day activities. They also tend to depend on their families for financial support. The rural, married caregiver belonging to the lower income group appears to be more susceptible to have a poorer quality of life. The spouse caregivers, mostly females, were found to have a greater burden and poorer quality of life, as they need to fulfil the demands of multiple roles.

The above factors do not play as significant a role in the caregivers of the medically ill. However, stigma, the need to aid in activities of daily living, and supporting a financially dependent patient, could well influence perceived burden in the caregivers of the medically ill. It was interesting to note in the current study that all the care givers of the medically ill do report care giver burden, even if the burden perceived is mild. This is to be taken cognisance of, as burden was perceived despite shorter illness duration.

CONCLUSION

Perceived burden of care and quality of life of the primary care giver directly translate to patient care. Interventions to reduce burden would improve quality of life, thereby positively influencing the quality of care rendered to the patient. Most psychiatric disorders require long term care, with a need for the care giver to stay in touch with the service provider, to ensure treatment adherence. The course and outcome of illnesses are dependent on the above factors, with better adherence translating to better outcome. This is also true of most medical illnesses, some of which run a chronic course. The need for care giver intervention has not been given adequate importance, and those that exist are mostly confined to tertiary centres. Burden of care givers is not routinely identified or addressed. There is thus a need for organised input to the caregivers of both groups, in terms of counselling sessions at primary intake. The spouse caregiver would probably require focussed intervention. These sessions must include input regarding nature of illness, need for long treatment, importance of adherence to the treatment protocols and regular contact with the treating team. Identifying psychiatric morbidity in the caregiver and treating the same, using both pharmacological and non-pharmacological measures, as well as enhancing their methods of coping would help them deal with the stress of caregiving. These measures would in turn ensure a better treatment adherence by the patient, and better long-term outcome.

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