

Caregiver's Burden on Patients with Neurological Disorders

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Abstract: Caregiver burden refers to considerable stressors who have been found to have worse emotional well-being, more difficulty with care giving tasks (Cochrane JJ, 2007) and more distress in general. The partner has an increased responsibility to provide support (which may be perceived as stressful), receiving support is particularly relevant for partners. The study was carried out in the Neurology out-patient setting in a tertiary care hospital. Thirty consecutive patients receiving in-patient care were included in the study. The anxiety and depression levels of these individuals were assessed using the Hospital Anxiety and Depression Scale (HADS). Caregiver Burden Inventory (CBI) is a 24-item multi-dimensional questionnaire was used to assess the caregiver burden. Time Dependence domain has the highest occurrence of burden based upon the aggregation of the scores of developmental, physical, social and the emotional burden from all study participants. The presence of depressive symptoms (HADS) in caregivers showed a strong positive correlation with the caregivers' level of burden (CBI) ($r = 0.978$, $p = 0.000$), while presence of anxiety symptoms correlated negatively with the caregivers' level of burden ($r = -0.472$, $p = 0.041$). The findings of this study show the need for the provision of accessible, affordable care for patients with neurological disorders and support for the family caregivers. It is important to explore caregiver's emotional turmoil as it helps in exploring their burden which can have impact on the patient's illness and functioning apart from their own.

Keywords: Caregivers, burden, Anxiety, Depression.

1. Introduction

Caregivers play an important role in supporting people with illness either acute or chronic. A larger number of studies have identified risk factors for greater caregiver burden. The importance of addressing the burden of care givers involved in care of patients with neurological disorders has been recommended. In spite of *neurological* conditions being one of the most common causes of disability very few studies have addressed the impact of these conditions on the care givers in Indian setting. It has been well documented that the family members are affected by the patient's illness from the outset. This burden of care can lead to a breakdown among the care givers themselves. The patients experience long-term impairments in physical, psychosocial, and cognitive function and rely mainly on the caregivers for practical and emotional support concerning activities of daily living. The three studies by Halm and colleagues (Halm & Bakas, 2007; Halm et al., 2006; Halm et al., 2007) indicated that male sex (or patient female sex) was associated with worse total caregiver burden. This was specifically for tasks such as personal care, mobility assistance and medical treatment, which may reflect generational role expectations. However, Halm and Bakas (2007) found female sex was an independent predictor of worse caregiver outcomes, highlighting the vulnerability of associations according to the method of conceptualizing and measuring caregiving factors. Only Stolarik et al (2000) identified age as a risk factor for caregiver burden; partners aged 31-50 and 71-80 had the highest caregiver burden, revealing both younger and older age to increase risk. The current study aims at assessment of the depression and anxiety levels among the care givers of the patients with *neurological* conditions. It is important to assess the mental health status and attend to the needs of care givers. Not only

do the care givers impact their own health and well being, their ill health impacts the care of the patients as well.

2. Objectives

- Assess the level of burden among caregivers of *patients with neurological* conditions.
- Associate the level of burden among caregivers with selected demographic variables

3. Methodology

The study was carried out in the *Neurology out-patient setting* in a tertiary care hospital. A total of 43 consecutive pairs of subjects and their principal caregivers were originally enrolled in the study. A principal caregiver was defined as –any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in the patient's care or is directly affected by the patient's health problem” All principal caregiver willing to participate in the study and giving informed consent were included in the study.

Eight of these pairs did not return the questionnaires, while another 5 were excluded because they ($n = 3$ patients, $n = 2$ caregivers) failed to complete them. Therefore, the final study participants were 30 pairs of caregivers and neuro out patients. All the caregivers accompanied the patients. All data were collected during scheduled time periods.

Socio-demographic questionnaire were collected from both of patients and of caregivers, namely patient's age, gender and diagnosis, caregiver's age, sex, education, and

relationship to the patient, and the presence of other persons who help care for the patient. The investigator explained the study to the patients and caregivers (reassuring them that their privacy would be strictly protected) and the questionnaires were administered to the participants. The self-report questionnaires were compiled in the waiting room. Caregiver Burden Inventory (CBI) is a 24-item multi-dimensional questionnaire in which 5 subscales explore 5 different dimensions of caregiver burden: it consisted of objective burden (which corresponds to the amount of time devoted to caregiving); the burden on the caregiver due to shortage of time (items 1–5); developmental burden: the caregiver's sense of being left behind, unable to enjoy the same expectations and opportunities as his or her peers (items 6–10); physical burden: feelings of fatigue and chronic health problems (items 11–14); social burden, which results from a perceived conflict of roles (items 15–19); emotional burden, which originates from awareness of negative feelings towards the patient that can be induced by the patient's bizarre and unpredictable behaviour (items 20–24). Subjects are asked to rate each item on a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive). The global score is obtained by summing the scores of each subscale; higher scores correspond to greater levels of perceived burden.

The anxiety and depression levels of these caregivers were assessed using the Hospital Anxiety and Depression Scale (HADS). HADS is a self-report questionnaire commonly used to assess levels of anxiety and depression. It was developed by Zigmond et al in 1983. The HADS comprises statements which the patient rates based on their experience over the past week. The 14 statements are relevant to generalised anxiety (7 statements) or 'depression' (7 statements), the latter being largely (but not entirely) composed of reflections of the state of anaerobia. Each question has 4 possible responses. Responses are scored on a scale from 3 to 0. The maximum score is therefore 21 for depression and 21 for anxiety. A score of 11 or higher indicates the probable presence of the mood disorder with a score of 8 to 10 being just suggestive of the presence of the respective state. The two subscales, anxiety (HADS-A) and depression (HADS-D), have been found to be independent measures. In its current form the HADS is now divided into four ranges: normal (0-7), mild (8-10), moderate (11-15) and severe (16-21).

Statistical analysis was performed using descriptive statistics for socio demographic variables and patient and caregiver measures, and Student's t-test for comparisons. Possible correlations between variables were tested using Pearson's correlation coefficients. The data was imputed and analysed using SPSS ver 20.0. The level of statistical significance was kept at $p < .05$.

4. Results

We recruited the care givers of 30 consecutive in-patients receiving out-patient care in the neurology ward of a tertiary care hospital. The sample included 16 male and 14 female care givers. Majority (89%) was married and employed

(76%). Around 65% of the subjects were literate. Around 64% of the subjects from a rural background and almost three fourth belonged to lower socio-economic status. Fifty six percent of the care givers were also the primary earning members of the family as well. All the caregivers that fulfilled the inclusion criteria agreed to participate in the study. The mean age of the participants was 46.23 ± 6.52 years. The mean age of the female caregivers was 42.04 ± 5.54 , while that of male caregivers was 47.21 ± 4.32 . There was no significant difference between the male and female caregivers ($t=3.12$, $p=0.19$). Twenty four percent of the caregivers were diagnosed with significant anxiety features. It included mild (16%), moderate (6%), and severe (2%). Eighteen percent of the caregivers met the criteria for depression using HADS-Depression scale. It included mild (14%), moderate (2%), and severe (2%). The mean anxiety and depression scores were 8.18 ± 2.76 and 8.21 ± 2.13 respectively. Male and female caregivers differed significantly on the total HADS score as well as the Anxiety and Depression subscale scores of HADS. Study found the prevalence of anxiety disorders was significantly higher in female caregivers than in males (26.1 vs. 10.9%; $p = 0.04$) as assessed by HADS.

The total score of each CBI subscale (Time Dependence, developmental, physical, social, emotional) was calculated and expressed as a relative percentage of the total CBI score: The 20 caregivers interviewed scored 54% in the Time Dependence burden; 34%, in the developmental burden; 21% in the physical burden, 16% in the social burden and 8 % in the emotional burden. The table shows that the Time Dependence domain has the highest occurrence of burden based upon the aggregation of the scores from all study participants. Gender differences were also examined: independent samples t-test analysis failed to reveal any statistical difference between caregiver burden perceived by men, mean value 29.51 SD 13.50 and by women, mean value 27.18 (SD 12.94) at the level of $p = 0.72$.

The relationship between the HADS scores and socio-demographic characteristics of the caregivers shown that the statistically significant correlations were found between the main study variables using Pearson's correlation coefficients. The presence of depressive symptoms (HADS) in caregivers showed a strong positive correlation with the caregivers' level of burden (CBI) ($r = 0.978$, $p = 0.000$), while presence of anxiety symptoms correlated negatively with the caregivers' level of burden ($r = -0.472$, $p = 0.041$). The multiple regression analyses did not identify any factors predictive of caregiver burden, either for the single domains of the CBI or for the total CBI score.

5. Nursing Implications

Quality of care and the health of the care-recipient are of vital importance. Several implications can be drawn from the findings of the present research. First, psychological burden of care-givers of patients with neurological disorders can be acknowledged by the health and social services. Initiation of comprehensive nursing strategies that deals with coping process, problem-solving strategies in order to reduce the

carers' distress. These coping strategies will help them to gain confidence that they care themselves as well as their partners also. The finding suggests that carers may benefit from efforts to mobilise their skills in coping strategies such as problem solving.

6. Conclusion

Care-giving is an exhausting task, and carers are reported to experience a very significant amount of strain. The study found high levels of emotional distress among caregivers, which is comparable to studies carried out in other parts of the world. Thus the well being of caregivers is important because the patients depend on them to uphold in the community.

References

- [1] Cochrane JJ, Goering PN, Rogers JM. The mental health of informal caregivers in Ontario: an epidemiological survey. *Am J Public Health*. 2002; 87 : 2002–2007.
- [2] WHO. Mental Health Gap Action Programme (mhGAP): scaling up care for mental, neurological and substance abuse disorders. World Health Organization, Geneva; 2008
- [3] Whiteford, HA, Degenhardt, L, Rehm, J et al. Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010. *Lancet*. 2013; **382**:1575–1586
- [4] Salomon, JA, Haagsma, JA, Davis, A et al. Disability weights for the Global Burden of Disease 2013 study. *Lancet Glob Health*. 2015; **3**: e712–e723
- [5] Lim, SS, Vos, T, Flaxman, AD et al. A comparative risk assessment of burden of disease and injury attributable to 67 risk factors and risk factor clusters in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet*. 2012; **380**: 2224–2260
- [6] Wilkinson R, Marmot M, eds. The solid facts: social determinants of health. Geneva, World Health Organization, 2003.
- [7] Herrmann C. International experiences with the Hospital Anxiety and Depression scale — a review of validation data and clinical results. *J Psychosom Res* 1997; 42 : 17-41. 14.
- [8] Ingrid Olsson, Arnstein Mykletun and Alv A Dahl. The hospital anxiety and depression rating scale: A cross-sectional study of psychometrics and case finding abilities in general practice. *BMC Psychiatry* 2005; 5 : 46. 15.
- [9] Das S, Hazra A, Ray BK, Ghosal M, Banerjee TK, Roy T, Chaudhuri A, Raut DK, Das SK. Burden among stroke caregivers: results of a community-based study from Kolkata, India. *Stroke*. 2010 Dec; 41 (12) : 2965-8. Janca A, Prilipko L, Saraceno B. A World Health Organization perspective on neurology and neuroscience. *Archives of Neurology*, 2000; 57:1786–1788.
- [10] Murray CJL, Lopez AD, eds. The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020.

- [11] Tannahill A. What is health promotion? *Health Education Journal*, 1985; 44:167–168.
- [12] The Bangkok Charter for Health Promotion in a Globalized World. Geneva, World Health Organization, 2005.
- [13] Leavell HR, Clark EG. Preventive medicine for the doctor in his community: an epidemiological approach, 3rd ed. New York, McGraw Hill, 1965.
- [14] The world health report 2002 – Reducing risks, promoting healthy life. Geneva, World Health Organization, 2002.
- [15] Rose G. The strategy of preventive medicine. Oxford, Oxford University Press, 1992.

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