Journal of the Neurological Sciences 358 (2015) 276–281

Contents lists available at ScienceDirect

Journal of the Neurological Sciences

journal homepage: www.elsevier.com/locate/jns

Burden among Parkinson's disease care givers for a community based study from India

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ARTICLE INFO

Article history:
Received 31 August 2015
Accepted 2 September 2015
Available online 4 September 2015

Keywords:
Burden
Caregiver
Caregiver burden scale
India
Parkinson's disease

ABSTRACT

Aim was to analyze predictors of burden among primary caregivers (CGs) of Indian Parkinson's disease (PD) patients. 150 PD patients were administered using Unified Parkinson's Disease Rating Scale (UPDRS), Hoehn and Yahr Scale (H&Y), Montgomery Asberg Depression Rating Score (MADRS) and Mini Mental State Examination (MMSE) in this cross-sectional evaluation study. CG burden was assessed by Caregiver's Burden Scale (CBS), Hospital Anxiety and Depression Scale (HADS), SF-36 and 20-item Burden Assessment Schedule (BAS). Linear regression methods were used to evaluate factors contributing to burden and stress. Mean age of CG was 50.38 ± 16.04 (range: 25-83 yrs). Marital status of CGs was noted to have significant relationship with CBS score ($F = 9.525$, $P < 0.0001$). Siblings (brother/sister) reported the highest CBS score while the wives reported the least. Correlations were strong between CBS and HADS anxiety ($r = 0.228$, $P = 0.0048$) and HADS depression ($r = 0.2172$, $P = 0.0076$). High correlations were found in caregiving duration, patients' stage of illness and motor disability among all the scales (CBS, HADS, SF36) determined. Step-wise regression analysis showed UPDRS (beta = 1.364–0.202 ranging among all scales) and H&Y stages (beta = 2.786–7.257) to have the strongest influence on CGs. CGs of patients with depression (MADRS: $P = 0.007$ (SF36 mental) and dementia (MMSE: $P = 0.01$) experienced greater stress. Social and financial status was disrupted in ~60% to 80% of the CGs. Motor imbalances with disability of PD patients and severity of disease are the main factors contributing to burden and stress in CGs.

1. Introduction

Family members comprise of an informal support system for most chronically ill patients. Caring for patients with such persistent disabling disease is associated with the caregivers experiencing physical and psychological distress, limiting their personal and social activities, and financial burden [1]. Parkinson's disease (PD) is a common neurodegenerative disorder characterized by increasing dependence on caregiving for activities of daily living that imposes a major burden upon the patient's caregiver (CG). The development of motor and non-motor complications in PD patients with time has serious consequences leading to the dependence on CGs for activities of daily living. Caregiver burden (CB) refers to the realm of physical, mental and socioeconomic problems experienced by caregivers of chronic disease patients [2]. This role becomes progressively important with disease progression, severity of their motor impairment increasing age of the patient, greater duration of the disease and other comorbidities such as depression, dementia, cramps, sleep fragmentation, nocturnal pain, etc. Research on informal caregivers of PD patients has been ignored as majority of the research into PD has focused on the PD patients themselves. Providing care to a family member with PD can have far-reaching effects on the caregiver's social activities, emotional health, and stress [3,4]. Even though medication is initially effective at controlling patients and allowing them to function normally while making little, if any, physical demands, the caregiver may experience emotional stresses related to uncertainty about the prognosis.

A similar situation is expected in India because of increasing PD incidence and negligible social support. There have been few studies into familial caregivers and the burden imposed on them by PD patients in India [5,6]. Assessment of the burden of CGs helps to develop broad managing strategies both for patients and their family members. Hence this study was undertaken to investigate for factors associated with increased feeling of burden and evaluate the impact of PD in West Bengal, India.

2. Materials and methods

2.1. Participants and procedure

This is a cross sectional descriptive study from a community based PD registry in Kolkata, India using interviewer-rated semi structured self-administered questionnaire among PD patients and their care-

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http://dx.doi.org/10.1016/j.jns.2015.09.009
0022-510X/

givers who attended the neurology outpatient Department of Movements Disorder Clinics of National Neurosciences Centre (NNC) and Nil Ratan Sircar Medical College (NRS) over a period of 3.5 years (2009–2013). Both are referral centers which also accept patients from other states in India. Primary caregivers of community-dwelling PD patients were informed about the study and invited to participate while visiting the clinic with the patients. Those who volunteered to participate completed the questionnaire at the outpatient clinic. A trained nurse in the clinic reviewed the patients' medical records and answered the questions regarding their medical condition. Forty-three caregivers who could not complete the questionnaire during the visit were given a stamped addressed return envelope, and twenty eight of them returned the questionnaire. Administration of the questionnaire through the interview process on the average took approximately 1–2 h.

2.2. Demographic information on the caregivers and features of the caregiving situation

Important demographic data together regarding caregivers and features of the caregiving situation (included gender, age, relationship with the patient, education level, occupational status, economic status, and family support were questioned, as were the caregivers' perception of the prognosis of the patient, the monthly medical cost, and the daily hours of caregiving), with clinically relevant information (disease status was determined using UPDRS (Unified Parkinson's Disease Rating Scale) [7] were gathered through face-to-face interview with the patients and their relatives. Diagnosis and staging of PD were done by the neurologists based on the Hoehn and Yahr Scale [8] which was the standard assessment tool at that time. Severity of depression and dementia was detected using Montgomery Asberg Depression Rating Score (MADRS) [9] and Mini Mental State Examination (MMSE) [10] respectively [11]. In the study, CG was defined as the unpaid person closely involved in physical (feeding, bathing, toileting, walking) and emotional care (empathic listening, encouragement and motivation to adhere to treatment), and CG was commonly a family member living with the patient. Health professionals included are doctors, nurses, and physiotherapists.

The study was approved by the Ethics committee, Directors and Heads of Department of Neurology of collaborating hospitals and completed in accordance with Declaration of Helsinki on Ethical Principles for Medical Research involving human subjects. Both written and verbal information about the aims of the study were explained to the patients and their caregivers before written consent obtained from both parties. Patients were under the supervision of legal guardian if necessary.

2.3. Caregiver burden assessment

A 20-item Burden Assessment Schedule (BAS), modified from a 40-item questionnaire [12] was used to study CG burden. Initially, three independent neurologists identified items appropriate for use in PD; a fourth neurologist selected common questions to constitute the final questionnaire, which was validated in the community.

The Caregiver's Burden Scale (CBS) [13] was used to assess burden of care among the caregivers. It is a 29-item scale designed to measure feelings of burden experienced by caregivers of elderly persons with senile dementia. The items for the CBS were selected based on clinical experience and prior research, and covered areas most frequently mentioned by caregivers as problems. The CBS provides opportunity for a systematic assessment of caregivers' perceptions of burden. For each item, caregivers have to indicate how often they have felt the suggested feeling or perception, from never (score 0) to nearly always (score 4). The CBS is scored on a 5-point sliding scale with the scores on the items summing the responses of the individual items as the total scores. A higher score indicates higher perceived CB. In this study a caregiver is defined as the patient's spouse, children or children-in-law, someone with kinship with the patient, who lived with and took care of patient almost every day (excluding domestic helpers or paid sitters). Although chiefly used on caregivers of dementia patients, the CBSI allows for broader application including PD.

The Hospital Anxiety and Depression Scale (HADS) is formed by 14 items, 7 measuring anxiety and 7 depression [14]. The item scoring ranges from 0 (No problem) to 3 (Extreme problem).

The SF-36 is a generic measure of Health related quality of life questionnaire (HRQoL) [15] that comprises of 36 items congregated into 8 dimensions. Each domain yields a score ranging from 0 (worse health state) to 100 (best health state). The summary of two scores, the so-called physical and mental components, is generated.

2.4. Data analysis

Data were collected through digital or pen and paper forms in English or local language (Bengali). All paper and electronic data were sent to the project investigator for entry into the study database and maintenance of records by the research team. Data collected from reported distributions to individual questions from CG of PD patients was analyzed using the SPSS (Statistical Package for Social Science version 16) computer program. Descriptive statistics were implemented to summarize the demographic information of caregivers, features of the caregiving situation, and information regarding patients' disease status. The relationships between the various study parameters were analyzed using one-way ANOVA and independent t-tests. The CB and level of patient care relationship were determined using Spearman rank correlation coefficient. The same analysis was used to explore the relationship between CGs CBS' association with the SF-36 and HADS parameters. Values of $P < 0.05$ were considered as statistically significant.

3. Results

3.1. Demographic characteristics

A total of 194 PD patients were approached for this study but only 150 were eligible to participate. Fig. 1 shows the different reasons for excluding some cases. Twenty-two of the patients came alone without caregivers, 9 came with non-caregivers while another 13 refused to participate in this study because of fatigue or lack of time (Fig. 1). All of the 22 patients who came alone were patients with early stage PD (stages 1 and 2). Three fourth of patients who refused to participate were in the advance stage of illness (stages 3 and 4). Four of the nine patients who came with the non-caregivers came from residential homes. They were accompanied by staffs who were not involved in caring and nursing for them at their homes. The remaining 5 patients came with family members who live separately from patients. The socio-demographic data of patients and their caregivers are displayed in Table 1.

46.7% patients belonged to H&Y staging I and II while 53.3% patients belonged to more advanced stages. The age of onset of PD patients ranged from 30 yrs. to 84 yrs. (mean: 57.62 ± 11.39). 109 (73%) patients were males and 118 (79%) of CGs were females. The majority ($n = 122$, 81%) of PD patients had tremor dominant PD, while only 28 patients had the akinetic rigid type of PD.

The mean age of CG was 50.38 ± 16.04 (range: 25-83 yrs). The CG relationship to patient included: Wife ($n = 61$), husband ($n = 11$), sons ($n = 18$), siblings ($n = 9$), daughter-in-law ($n = 31$), and daughter ($n = 20$). The no of other care/ill dependents (excluding the patient) in the family are presented in Table 1. Most of the CGs was either gainfully employed (31%) or housewives (59%). Approximately, 48% of the CGs was their spouse and 25% constituted patient's children.

3.2. Features of the caregiving situation and caregiver burden

The relationships between relationship/kinship and marital status of CG and CBS scores are as presented in Suppl. Table 1. Marital status of the caregivers was noted to have significant relationship with the CBS