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Factors related to Caregiver Burden in Caregivers of Patients with Parkinson's disease in Mumbai, India.

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ABSTRACT:

This study examined the relationship of caregiver burden with various patient and caregiver variables. 50 individuals with Parkinson's Disease were administered the Movement Disorder Society's Unified Parkinson's Disease Rating Scale (MDS-UPDRS), Hoehn and Yahr's Scale (HY), Mini Mental Status examination (MMSE), and their caregivers were administered the Zarit Burden Interview (ZBI). Kruskal Wallis ANOVAs and Mann Whitney U tests showed that caregivers suffering from ill health (U_x=402, p= 0.03) and the patients' MDS-UPDRS scores significantly affected caregiver burden. Simultaneous multiple regression analysis showed that MDS-UPDRS Part I,II and III were significant predictors of burden (R^2= 0.72, p<0.0001) of which the motor examination emerged as the most significant predictor of burden.

Keywords: Care giving, elderly, Parkinsonism

INTRODUCTION

Parkinson's disease (PD) is primarily a slowly progressive neurological disorder. People with PD experience both motor and non-motor symptoms that have a significant impact on their ability to carry out activities of daily living and which result in a progressive dependence on others to help them with various activities. While caregivers' responsibilities depend on the individual needs of the patient, often in the case of chronic and progressive diseases such as Parkinson's Disease, their responsibilities may keep increasing till at a certain point, caregiving may become their main or only activity (Martinez-Martin et al, 2007). A stable main caregiver has been defined by Martinez-Martin et al 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" (Martinez-Martin et al, 2007).

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The focus in this study is on informal caregivers, i.e. caregivers who are not compensated financially for their services and who are most often family members or friends (Vitaliano et al, 2003).

Although some studies have found that caregiving has positive aspects (e.g. Payne, 2001, cited MacRae, Fazio & Russell, 2009), caregiving has largely been studied with respect to the negative impact of the same (e.g.s. Aarsland, 1996, Schrag, 2009, cited MacRae et al, 2009). Caregivers may experience caregiver burden, which is "a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual" and refers to "the realm of physical, mental, and socio-economic problems experienced by the caregivers of chronic patients" (Zarit et al, 1980, cited Martinez-Martin et al, 2007). It has been found that caregivers of PD patients experience high subjective and objective burden, comparable to that experienced by caregivers of patients having experienced stroke and higher than that in general chronic disease. (Choi &Eun, 2000, cited Kim et al, 2007).

Caregiver burden is important to study as it has a significant impact on various aspects of the physical, psychological, emotional and functional health of caregivers (e.g.sZarit et al, 1980, Parks &Novielli 2000, Etters et al, 2008, Carretero et al. 2009, all cited Martinez-Martin et al, 2007). In addition, caregiver burden has been found to be related to patients' depression, quality of life, and incidence of falls (Schrag et al, 2006, cited Kim et al, 2007) and caregiver well-being in general has been found to have an impact on the course of the patient's disease and to determine the use of institutional placement (Dunkin & Anderson-Hanley, 1998, cited Kim et al, 2007).

Accounts of research on caregiver burden and protective and contributive factors among caregivers of patients with Parkinson's Disease in India are limited (Agrawal et al, 2012). In the current study, caregiver burden was studied in 50 caregivers of patients diagnosed with Parkinson's Disease, residing in Mumbai, India. The aim of the study was to understand the role of various patient and caregiver variables on caregivers' perceived caregiving burden.

METHOD

Sample

The sample was a convenience sample, with patients and caregivers recruited from among those attending the Parkinson's Disease and Movement Disorder Society's Support Centers that are situated throughout Mumbai. The sample consisted of 50 patients diagnosed with Parkinson's Disease based on the UK Parkinson's Disease Society Brain Bank criteria (Hughes, 1992) and their primary informal caregivers. Patients who had undergone Deep Brain Stimulation and those with Hoehn and Yahr (HY) stage 5 PD were excluded.

Procedure

Patients and their caregivers were informed about the study and gave their consent for participation. The assessment was conducted by a team of physiotherapists and clinical psychologists over the period of one year (August 2012 to July 2013). All ethical criteria were followed.

Patients were interviewed and demographic details related to their age, gender and duration of illness was noted. The severity of the patients' motor and non-motor symptoms were assessed using the Movement Disorder Society's Unified Parkinson's Disease rating Scale (Goetz et al, MDS UPDRS, Movement Disorder Society, 2008). Staging of the patients' disease was assessed using the Hoehn and Yahr's Scale (HY, Yahr&Hoehn, 1967) and the patients' cognitive functioning was assessed using the Mini Mental Status examination (MMSE, Folstein et al, 1975). Caregivers were also administered a brief questionnaire that assessed demographic variables such as their age, employment status, gender, relationship with the patient, number of caregivers available, family structure and the presence of ill health. Caregiver burden was assessed by administering the caregivers the revised version of the Zarit Burden Interview (ZBI, Zarit, Reever& Bach-Peterson, 1980).

Data Analyses

Data analyses were conducted using online software by Lowry et al (assessed 2013). Descriptive statistics were used for analysing the demographic data. Kruskal Wallis ANOVAs and Mann Whitney U tests were used to examine differences in the ZBI scores across various patient and caregiver variables. Non-parametric statistics were chosen because of the small and skewed sample distribution across various groups. Pearson's Product Moment Correlation coefficient was used to understand the relationship between the MDS UPDRS, the MMSE and the ZBI and this was followed by simultaneous multiple linear regression to see the contribution of each to the caregiver burden score.

RESULTS

Tables 1 and 2 depict the characteristics of the sample of patients as well as their caregivers, respectively. *(Insert Table 1 and 2).*Analyses of our data showed that patient age (Kruskal Wallis H= 0.66, p=0.487), stage of illness (Kruskal Wallis H= 6.84, p=0.145) and illness duration (Kruskal Wallis H= 2.2, p=0.699) were not found to be significantly related to ZBI scores. However MDS-UPDRS scores were found to be significantly related. Results of a multiple regression analysis indicated that the 6 predictors explained 73% of the variance (R^2= 0.73, p<0.01). Part I-MDS UPDRS scores (β=0.31, p<0.05), part II- MDS UPDRS scores (β=0.23, p<0.05), part III- MDS UPDRS scores (β=0.55, p<0.05) and total MDS UPDRS scores (β=-0.27, p<0.05) significantly predicted burden, but Part IV- MDS UPDRS scores (β=-0.09, n.s.) and MMSE scores did not (β=-0.01).

An analysis of the relationship between the various caregiver variables and the ZBI score showed that only ill health (Mann-Whitney U=402, p<0.05) of the caregivers had a significant relationship to the ZBI score. Other variables as mentioned in Table 2 showed no significant relationship with the ZBI scores.

DISCUSSION

This study aimed to find the factors related to caregiver burden among caregivers of patients with Parkinson's disease in an urban population in India. Interestingly, the mean score on the ZBI for the sample was 24.24, which is very low, (SD =16.67), and no one in the study reported high burden levels, with the highest score seen being 62 (with the maximum possible score being 88). In collectivistic Asian-Indian cultures, it is a cultural expectation that family members take up the care of other family members (Pillai et al, 2012) In India, offspring have traditionally been accepting the caregiving role as a natural course of life (Pillai et al, 2012) and the same is likely to hold for spouses of people who develop chronic health conditions. Spouses or offspring may see caregiving as a duty and may willingly undertake the same, and this attitude may lead to lower burden, or it could also prevent them from overtly acknowledging and reporting their burden accurately, even if they may be experiencing stress in the caregiving role.

Also, 76% of the caregivers identified were females. While in this case this was the outcome of convenience sampling, it is also likely to be reflective of general trends in the population.Caregiving is traditionally seen as being the responsibility of wives, daughters and daughters-in-law or the females in a family (Ozdilek&Gunal, 2012), which is particularly true in the Indian society. However, caregiver gender was not found to be related to burden in this study, and neither was caregiver age. Most of the caregivers in this study were spouses, and this could also be reflective of the changing nature of the Indian family unit, with elderly couples staying separately from their children. Inconsistent with Kim et al's findings (2007) but consistent with Shin etal's findings (2011), spousal and offspring caregivers showed similar levels of burden, as did other family members who took up the caregiving responsibility. As Shin et al had suggested, it may be that the burden is quantitatively similar but qualitatively different for the spouses, offspring and other family members.

Among the socio-demographic caregiver variables, interestingly, whether one is a sole or co-caregiver for the patient was found to be unrelated to caregiver burden, unlike previous research which suggested that the presence of multiple caregivers led to reduced burden (e.g.sAgrawal et al, 2012, Kim et al, 2011, Martinez-Martin et al, 2007). Also, burden levels were similar for caregivers in nuclear as well as joint families. Interviews with caregivers at the PDMDS support centers in Mumbai have brought to light the fact that even in the presence of multiple people available to care for a patient with PD, the primary caregivers are usually uncertain of the capability of other caregivers to care for the patient adequately and thus prefer to do it themselves, and this may nullify the potential benefits of having multiple caregivers.

In our sample since most of the caregivers were spouses of the patients and were elderly themselves (most of them in the 61- 70 age group), it follows that they may be likely to face

health problems of their own, which may interfere with their caregiving duties. This may be why in the current study, caregivers suffering from ill health, (though not as severe as PD), were found to show significantly more burden than those who did not experience any major personal health issues. Thus caregiver intervention programs must focus on educating caregivers about strategies to manage their own health.

Among the patient related variables, results of the multiple linear regression indicate that taken together, the various disease specific variables are significant predictors of caregiver burden. Since PD is a movement disorder characterized mainly by motor difficulties that lead to significant disability, it is natural that motor examination and motor experiences of daily living, which are indicators of symptom severity and functional impairment as a result of the same, were found to be the strongest predictors of burden, a finding that is in keeping with other research(e.g. Happe& Berger, 2002, cited D'Amelio, 2009). Non-motor experiences of daily living were also found to be modest predictors, similar to Carter et al (2008, cited D'Amelio, 2009). Motor complications such as dyskinesias and dystonias were not found to be significant predictors. This is an important finding and highlights the importance of improving patient health to indirectly decrease caregiver burden.

The level of cognitive functioning has previously been found to be a significant predictor of burden (Shin et al, 2012, Thommessen et al, 2002), but this was not found in the current study. This could be because severe cognitive impairment that may take the form of Parkinson's Disease Dementia typically occurs much later in the course of PD, and none of the patients in the sample had been diagnosed with the same.

Previous research has shown that the stage of the illness (Shin et al, 2012, Razali et al, 2011, D'Amelio et al, 2009) is related to caregiver burden, but no significant difference was seen in the present study. Not including H & Y Stage 5 patients in the present sample, therefore, may have been a limitation of the study. Patients in stage 5 are often home bound and their dependence on caregivers is typically high, and caregivers of these patients may show a different experience of burden than of those in other H & Y stages.

The current study indicates that while the PD patient's disabilities accounts for most of the caregiver burden, other factors related to the caregiver like their personal health status also plays an important role. Caregiver burden is not related to one specific key factor, but rather, may be the cumulative effect of a host of varied factors that come together. The patterns by which varied factors combine, and the effects that they have on each individual caregiver, may be qualitatively different, thus leading to different and varied experiences of burden among caregivers. Thus, further research can use qualitative models to understand these dynamics, including cultural attitudinal factors that may have led to low overall reported burden levels in this study. The study has implications in designing intervention programs that focus on helping individuals to cultivate protective factors against caregiver burden.

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TABLES

Table 1: Descriptive (frequency, percentages and means) of patient variables

Patient Variables	Number n	Percentage %	Mean(±SD)
Patient Age *<60 years* *61-70 years* *>70 years*	7 28 15	14 56 30	66.56 (± 6.91) years
Hoehn&Yahr Stage Stage 1 Stage 2 Stage 3 Stage 4	5 10 28 7	10 20 56 14	Stage 3(±0.82)
Illness duration *< 5 years* *5 to 8 years* *9 to 12 years* *13 to 15 years* *>16 years*	4 29 9 4 4	8 58 18 8 8	8.32(±4.72) years
Total MDS UPDRS score	-	-	64.6(±27.03)
MMSE score	-	-	24.82(±4.23)

Table 2: Descriptives (frequency, percentages) of caregiver variables

Caregiver Variables	Number	Percentage
	n	%
Caregiver Age		
< 40 years	9	18
41-50 years	3	6
51-60 years	10	20
61-70 years	23	46
> 71 years	5	10
Caregiver Sex		
Male	12	24
Female	38	76
Relationship to the patient		
Spouse	38	76
Children	6	12
Others	6	12
Employment Status		
Currently under formal employment	13	26
Non-formal employment (retired/housework)	37	84
Number of caregivers		
Sole	29	58
Multiple	21	42
Personal disability		
Present	22	44
Absent	28	56
Family Structure		
Nuclear	40	80
Joint	10	20