

Roles, experiences and needs of caregivers of people with Parkinson's disease in South Africa

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ABSTRACT

Parkinson's disease (PD) is a progressive, debilitating and demanding condition. Caregivers must continually cope with a variety of stressors due to changes resulting from the disease process. The aim of this descriptive study was to investigate the roles, experiences and needs of caregivers of people with PD in South Africa. A convenient sample of 400 people with PD was drawn from the Parkinson's Association of South Africa (PASA) address list. Questionnaires were sent to these people in the hope of identifying caregivers. There were 131 respondents (28.7% response rate). Most caregivers were spouses and the majority was not employed. Sixty percent felt they were adequately informed about PD and 61% felt they received adequate support. Caregivers experienced stress as a result of the disease and the financial burden it placed on the family. The main needs identified by caregivers were emotional support, strategies to ease care giving tasks, time to socialise and free time.

Key words: Needs, Caregivers, Parkinson's disease

Introduction

Much of the research on Parkinson's Disease (PD) is related to medical treatment and drug therapies. Despite the seriousness of PD and its obvious impact on caregivers, there is little research to quantify the experience of the caregivers of people with Parkinson's Disease. Pressures faced by caregivers are, for example, "decreased social status, role reversal, loss of peer and sexual partnership or worse, the triple functions of breadwinner, domestic manager and nurse attendant".¹ Furthermore, marital partners may experience conflict due to divided loyalties, economic limitations imposed upon the family, and time spent compensating for obligations not met. According to Sprinzel's¹ caregivers are warned against total immersion in patient care to the exclusion of other interests. Little information is available regarding the needs of caregivers in South Africa (SA). The need for further research to determine the needs of the caregivers of people with Parkinson's Disease emerged from the literature and the first author's own experience of participating in support groups.

Literature Review

Parkinson's disease is a chronic incurable neurological disorder primarily affecting people over 50 years of age. This condition results from chronic degeneration of cells in the basal ganglia that produce dopamine with no identifiable cause although genetic and environmental factors are thought to be important². The classic symptoms associated with PD are resting tremor, rigidity and bradykinesia. Secondary manifestations include gait, autonomic and postural disturbances^{3,4}. The management of the patient with PD is complicated by multi-system involvement and inconsistency in symptom presentation and severity⁵. Apart from a decrease in physical abilities, there are also limitations in social activities and emotional losses.⁶ People with PD also suffer from the side effects of medicine and fluctuations in performance because of the "wearing off" response to drug therapy⁵. Decline in cognition has important consequences in the management of people with PD and is an added burden on caregivers^{7,8}.

The Caregiver

Although little has been written about caregivers of people with PD in SA, Scherma⁹ describes the caregiver appropriately for the purpose of this study as: "One who, without monetary compensation, physically cares for an impaired relative, spouse, parent, child, other relative or significant other". A caregiver usually has been emotionally involved with the impaired person prior to their illness,

and is most frequently an older woman⁹.

Every help-relationship is unique. Caring for a person with PD is a demanding task, particularly considering that caregivers are often the spouse, elderly¹⁰ and non-professional in the task of caring¹¹. According to Waite¹⁰ more than 90% of people with PD in the United States live at home with their families and Caird¹², in turn, stresses the effects this may have on families and carers.

Literature has indicated that Parkinson's caregiver stress is strongly correlated with the degree of physical disability and mental limitation. Because the symptoms of PD change over the course of the disease, caregivers are required to adapt to these changes constantly. As a result, caregivers expressed "a need for the provision of easily accessible, trustworthy, competent, affordable and/or subsidised services"¹⁰.

Research on non-Parkinson's caregivers has shown that the negative impact of caregiving on the well-being of the caregiver is quite extensive¹⁰.

"As the world's population is ageing and people are living longer, it is becoming more important to ensure that older people enjoy a quality of life, and experience well-being, not just quantity of life"¹³. Quality of life for the elderly, according to Moller and Ferreira¹⁴ and Schrag et al¹⁵, can be described as the subjective experience of well-being. Moller and Ferreira¹⁴ identified five factors that contribute to the perception of well-being for the aged; namely, to be in control of one's own life, health, financial support, social integration and satisfactory life arrangements.

Aim

The aim of the study was to investigate the needs, roles and experiences of primary caregivers of people with PD in South Africa.

Methodology

Research design

A quantitative descriptive survey design was used. A descriptive study was considered appropriate for gathering information to develop appropriate services, allocate resources and determine priorities for the selected study populations¹⁶.

Study population and sampling

The research population included all caregivers of people with PD. As there was no comprehensive list of caregivers, the actual size



of the study population was unknown. The study sample therefore was one of convenience^{17, 18}. Four hundred potential participants were identified by selecting every fourth person with PD on an alphabetical address list supplied by the Parkinson's Association of South Africa (PASA). Information, letters, questionnaires and consent forms were sent to all these participants.

Measuring instrument

As no suitable instrument was available, a questionnaire was compiled by the first author after an extensive literature survey was conducted to identify the critical factors inherent in care giving. The questionnaire consisted of three sections. Questions in the first and second sections related to demographic information of the caregiver and medical information about the person they cared for. The third section pertained to the critical factors that specifically identified the roles, experiences and needs of the caregiver as indicated in *Table III*. Questions were mainly closed but some open-ended questions were included. The questionnaire was available in English and Afrikaans, in accordance with the language of communication specified by the PASA at that time. The questionnaire is available from the first author on request.

The questionnaire was piloted with two caregivers who were not included in the study. The aim of the pilot study was to ensure that the questions were clear, explicit and unambiguous¹⁸ and to determine the time the questionnaire took to complete. Based on feedback and suggestions from the pilot study, minor adjustments to the questionnaire were made to improve clarity of language, style and technical layout and the questionnaire was amended accordingly. The questionnaire was designed to be quick, easy to complete and user-friendly. It took approximately 25 minutes to complete.

Ethical aspects

The Ethics Committee of the Faculty of Health Sciences, University of the Free State, approved the study (ETOVS No. 2240/02). All respondents participated voluntarily and gave written informed consent. Confidentiality was ensured through the use of anonymous questionnaires.

Procedure

The informed consent letter and questionnaires were mailed to all identified participants. As participants were from all over SA, it was the most practical way of achieving the largest possible response rate. The participants were asked to return the questionnaires within three months using the enclosed, self-addressed, stamped envelope.

Analysis of data

The analysis of the data was done by means of SAS®. Frequencies and percentages were calculated for categorical variables, and medians and percentiles for continuous variables.

Limitations of the study

The communication language that was used at the PASA at that stage could have had an influence on the response rate of other culture groups. A low response rate may be due to various factors, such as: Not all persons with PD necessarily have caregivers, postal address changes, some persons with PD or caregivers may have passed away already, or people on the list may have been wrongly diagnosed with PD.

Results

One hundred and thirty-one (131) completed questionnaires were returned, yielding a response rate of 28.7%. The median age of caregivers was 67 years (range: 37 - 88 years). The median time period that caregivers had cared for the person with PD was 7 years (range: 0.2 - 45 years). Additional demographic information is given in *Table I*.

Demographic	Category	Frequency	Percentage
Gender (n=126)*	Male	29	23
	Female	97	77
Language (n=129)*	Afrikaans	54	42
	English	67	52
	Other**	8	6
Marital status (n=130)*	Married	116	89
	Single	2	2
	Divorced	4	3
	Widowed	8	6
Occupation (n=127)*	Employed	27	
	Unemployed	100	2179
Relationship to patient (n=127)*	Spouse	117	92
	Family member	5	4
	Friend	1	1
	Domestic worker	1	1
	Matrons at institutions	3	2

* Totals for these categories were not 131 due to missing information on questionnaires.

**Zulu, Dutch, German.

Table I: Caregivers' demographic information (=131)

Care (n=131)	Frequency	Percentage
Shopping	80	61
Transport	79	60
Dressing	65	50
Medication	54	41
Help with communicating	52	40
Lifting in/out of bed or wheelchair	46	35
Support when walking	46	35
Washing, bathing, showering	39	30
Eating	28	21
Blood pressure and heart rate measurements	12	9
Other#	30	23
Role (n=119)##		
Supervisory	18	15
Gives minimal physical support	46	39
Gives medium physical support (to person with PD)	33	28
Gives total physical support – (to person with PD completely dependent)	20	17
Other*	2	1
Caregivers' Perception of role (n=131):		
Overprotective	32	24
Too involved	21	16
Too responsible	35	27
Other**	35	27

Included: Cooking, supervising, reminding to take medication, and emotional support.
* Emotional support during "off" times when medication is at lowest functioning.
** Includes: protective, encouraging, accepting, trying to stay positive and act normally.
Total for this category was not 131 due to missing data.

Table II: Care provided, roles and perceptions of caregivers (n=131)

Most caregivers were not employed (79%; n=127) because they were either pensioned, had chosen to or were forced to leave their jobs to take on the caregiver role. Twenty-seven caregivers (n=127, 21%) pursued a profession. Of these some worked full-time (n=10, 37%) and some worked half-day (n=9; 33%).

Apart from their own personal day-to-day activities more than half the caregivers (n=123; 51%) spent time on additional activities requested by the person with PD. Twenty-eight percent spent a full day caring for the person with PD. The type of care given and the role of caregivers are presented in *Table II*.

Sixty percent of the caregivers felt that they were adequately informed about PD and 61% felt that they received adequate support. Support was given by family members (68%), support groups (46%), friends (45%), the church (20%), and others (e.g. nurses in old age homes, those who visited on a daily basis, doctors, neurologists and the PASA) (20%). Thirty-nine percent (39%) of caregivers felt support was insufficient and 34% ascribed this to

Experience	Frequency	Percentage
Social activities curtailed	75	57
Free time curtailed	62	47
Powerless feeling	59	45
Stress as a result of disease	56	43
Financial pressure as a result of disease	53	40
Physically drained as a result of responsibility to patient	42	32
No one understands responsibility and impact on life	35	27
Emotionally overwhelmed	32	24
Anger towards disease	32	24
Guilt feelings towards disease	28	21
Receives no acknowledgement	21	16
Rejection by patient as a result of disease	19	15
Other*	30	23

* e.g. No experience because person with PD was still independent; limited quality of life; faith can overcome emotional exhaustion.

Table III: Caregivers experience of the caregiver role (n=131)

the public's lack of knowledge. The caregivers' experience of the caregiver role is reflected in Table III.

Pressures brought about by the disease process as experienced by the spouse as caregiver, (n=117) included: social withdrawal as a result of the demands of being a caregiver (54%), decreased initiative by person with PD (47%), loss of communication with the person with PD (38%), decreased sexual contact (36%), frustration due to disinterest from person with PD (29%), loss of love/compassion (20%) and miscellaneous pressures, such as role changes in terms of patient/caregiver, handling stressful situations, patient depression, selfishness and tiredness (24%).

Discussion

Possible reasons for the low response rate could be the lack of caregivers in some cases, address changes, and the demise of patients or caregivers.

Most caregivers (90%) were spouses and were always available to take care of the patient's needs. The caregivers' emotional involvement with the patient was subsequently greater than that of an independent caregiver and professional distance could not be maintained. This may possibly be a reason why more than half of the caregivers expressed the need to learn how to manage their frustration and emotions and wanted strategies on easing the caregiving task. Brown et al¹⁹ emphasise that psychological tension is not limited to the patient, but transferred to the life partner. As a result, it should be recommended that both the patient and the caregiver be include in the occupational therapy programme.

Some caregivers felt that their social and free time activities were restricted. This finding is similar to that of Schrag et al¹⁵ who reported that 65% of caregivers stated that their social lives had suffered. They experienced stress as a result of the disease and the financial burden that the disease placed on the family. Caregivers felt that they were too responsible and overprotective and were thus partly to blame for their loss of independence, mobility, and own interest. Sprinzeles¹ stresses the importance of external help, especially where role changes take place and the caregiver is also the breadwinner and housekeeper. The scant finances available for external help seemed to be the limiting factor in most cases.

Most caregivers felt that they received support, mostly from family members. The primary support role that the family plays, is confirmed in the literature²⁰. Support groups and friends also offered a helping hand, but to a lesser extent. However, a third of the caregivers felt that they received no support and ascribed it to the public's lack of knowledge of both the disease itself and the burden of the disease on the caregiver.

The main needs expressed by caregivers of people with PD, that they felt would improve their quality of life, were to receive emotional support, acquire strategies to ease caregiving tasks, and have free time and time to socialise. The shift towards primary healthcare in the community^{21,22} necessitates public awareness, which requires more attention from healthcare workers and support groups²³. In turn, public awareness combined with increased support from healthcare

workers and support groups, could sufficiently address the needs of PD patients' caregivers.

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