

Published in final edited form as:

Parkinsonism Relat Disord. 2009 September ; 15(8): 554–557. doi:10.1016/j.parkreldis.2009.01.007.

Predictors of Loneliness in Caregivers of Persons with Parkinson's Disease

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Abstract

This study examined loneliness among caregivers of individuals with Parkinson's disease (PD). The sample included 70 caregivers (74% female; 96% spouses) who were currently living with the patient. A postal survey was sent to caregivers of persons with PD on the mailing list of a regional Parkinson association; response rate was 39%. Assessment instruments included the UCLA Loneliness Scale, Social Provisions Scale, Hoehn and Yahr (caregiver version), a perceived Self-Efficacy Scale developed previously for use with PD caregivers, and questions related to both patient and caregiver characteristics. Caregivers reported more loneliness than all similar normative groups except Alzheimer caregivers ($P < .001$ to $P = .011$). Hierarchical regression analyses were used to determine whether patient or caregiver characteristics were more predictive of loneliness. Results indicated that patient variables accounted for only 12% of the variance in loneliness, whereas caregiver variables accounted for an additional 46% of the variance ($P < .01$). Among the significant individual caregiver predictors of greater loneliness were less education, lower perceived self-efficacy (both $P < .05$) and poorer physical health ($P < .01$). It was also found that persons attending caregiver support groups reported less loneliness ($P < .05$) and more perceived support ($P < .05$) than those not attending support groups. Because loneliness was significantly predicted by caregiver rather than patient variables, it is possible that strategic interventions for caregivers could ameliorate loneliness.

Keywords

Parkinson's disease; caregivers; loneliness; social support; self-efficacy

INTRODUCTION

Parkinson's disease (PD) is a chronic neurodegenerative movement disorder. Due to increasing debilitation over time, persons with PD become less autonomous and more dependent on others for their care, often resulting in a reduction of quality of life for both the patient and the caregiver. Because PD is most often diagnosed among those 60 years of age and older, the demands placed on the caregiver are often compounded by their own aging process and physical decline, adding to the caregiver burden they already experience [1]. Almost every aspect of a

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caregiver's life can be affected, including daily routine, social activities, and emotional and physical health. Although some positive aspects of caregiving have been reported [2], in general, caregiving has been associated with increased feelings of depression, stress, and loneliness [3–9].

It is clear that “patient characteristics” such as stage of disease, duration of illness, or memory loss have an effect on caregivers' lives [3]. Because of the diminishing capacities of the person with PD, the relationship between the patient and caregiver may change gradually to the point that most interactions are centered on the act of caring for the patient [10]. Thus, loneliness, especially among spousal caregivers, often develops, putting caregivers at additional risk for mental and physical health consequences such as depression [3,5,7,9]. Although recent research has consistently demonstrated the link between loneliness and health outcomes [11], very little is known about caregiver characteristics that may either contribute to, or protect against loneliness. More information could potentially lead to strategies to reduce loneliness, which in turn, could reduce depression and contribute to better quality of life for both caregivers and patients.

Social support for the caregiver may help to ease feelings of loneliness and can be accessed in several ways. Although not uniformly positive, research on support groups has shown that groups are effective because they appear to serve as an enhancement and supplementation of current, but perhaps diminished social networks [12]. Although much is known about patient support groups and their benefits, there has been little research that has investigated the effectiveness of caregiver support groups specifically related to Parkinson's disease.

The purpose of this study was to learn more about predictors of loneliness in this sample of PD caregivers. In order to consider loneliness in the context of other research, preliminary analyses were conducted to determine relative levels of loneliness among PD caregivers and norm groups of caregivers and older adults. The primary aim of the study was to determine whether patient or caregiver characteristics were more predictive of loneliness in this sample. The secondary aim of the study was to investigate differences in degree of loneliness and perceived social support between those who attended caregiver support groups and those who did not attend.

METHODS

Participants

A postal survey was sent to caregivers of persons with PD on the mailing list of a regional Parkinson's association in the western United States. Recognizing there is no standard definition of “caregiver,” instructions solicited participation in the study even though the person with PD “may be functioning quite well and not appear to be a patient at all.” The response rate was 39%, which is well above the average return rate of 20% to 30% for surveys related to psychological issues sent to the general public [13]. Of the 87 responses received, only data from the 70 persons (74% female; 67 spouses and 3 other relatives) who were currently living with the individual with PD were included in analyses. Of those, 79% indicated their role had changed over time from being primarily a spouse or family member to caregiver. The Institutional Review Board of the University of Denver approved the study protocol. Return of the questionnaire was regarded as participants' consent to participate in the study.

Assessments

Patient characteristics—Caregivers were asked to report the age of the patient, their relationship to the patient, and duration of illness. In addition, participants rated the degree to which “you feel the patient's thinking or memory has been affected by PD or its medication.”

A 7 point Likert scale ranging from 1 (not at all) to 7 (extremely) was used. Finally, caregivers estimated the patient's stage of disease using an adapted version of the Hoehn and Yahr scale [14], the standard measure of disease severity in PD. This version of the scale was adapted specifically for use by caregivers and has been shown to correlate well with neurologist ratings ($\tau\text{-}b = 0.73$, $P < 0.001$) [15]. Descriptions of each stage were provided on the questionnaire and standard ratings ranging from 0 (no signs of disease) to 5 (wheelchair bound or bedridden unless aided) were used.

Caregiver characteristics—Participants were asked to report their age, gender, level of education (in years), ethnicity, employment status, and whether or not they attended a support group for PD caregivers. They were also asked to report the number of years as a caregiver, and number of hours per day spent providing personal care or supervising activities of the patient. Participants also indicated the degree to which “the patient is able to interact with you in the same way as always,” using a Likert scale ranging from 1 (not at all) to 7 (same as always). Finally, caregivers rated their own physical health on a Likert scale ranging from 1 (very poor) to 7 (excellent).

UCLA Loneliness Scale—Loneliness was assessed using the Revised UCLA Loneliness Scale [16]. Each item on this 20 item scale is rated on a 4-point Likert scale ranging from 1 (never) to 4 (often). Ten items are reverse scored, with total scores ranging from 20 to 80 and higher scores indicating more loneliness. Evidence of reliability and validity of this scale in samples of older adults has been presented in a number of other studies [17–18].

Social Provisions Scale (SPS)—The Social Provisions Scale [19] is a 24 item scale designed to measure perceived support. Each item is rated on a 4-point scale ranging from 1 (strongly disagree) to 4 (strongly agree). Reliability of the total SPS score is estimated to be .92 [19]. Validity has been established in a number of previous studies (see review by [19]). Total scores can range from 24 to 96, with higher scores indicating more perceived support.

Perceived Self-efficacy (S-E)—The five items developed to measure self-efficacy among Parkinson caregivers in this study were modeled on the items found in Lorig's work with arthritis patients and persons with a variety of chronic diseases [20]. The items were originally based on Bandura's theory and research related to self-efficacy [21]. According to this model, the question stem, “How certain are you that you can---,” is followed by the specific target behavior or attitude that is of relevance in the study. Examples of two questions included in this study are: “How certain are you that you can deal with the frustration that is sometimes part of being a caregiver?” and “How certain are you that you can manage your situation so that you can continue to do the things you enjoy doing?” Each item was rated on a 7 point Likert scale ranging from 1 (very uncertain) to 7 (very certain). Total scores could range from 5 to 35. In previous research with this scale, the estimate of reliability (coefficient alpha) was .89 [22].

Data Analyses

Descriptive analyses were conducted with the caregiver sample. One-sample t-tests were used to determine whether this sample of caregivers reported a similar degree of loneliness as other samples of older adults (e.g., persons with low vision and community dwelling samples) and caregivers of persons on dialysis and with Alzheimer's disease. Hierarchical regression analyses were used to investigate the relative contributions of patient and caregiver characteristics in the prediction of caregiver loneliness. T-tests were used to compare the levels of loneliness and perceived support of those attending and not attending caregiver support groups.

RESULTS

Descriptive Analyses

Results of descriptive analyses are presented in Table 1. In addition, caregivers reported spending an average of 3.3 (\pm 4.1) hours per day “providing personal care” for the patient, with scores ranging from 0 to 18 hours. Caregivers also indicated that they spent 6.1 (\pm 8.2) hours per day “supervising activities” for the patient. Scores ranged from 0 to 24 hours. Not surprisingly, the amount of time spent caring for and/or supervising patients was related to caregivers’ estimate of patient’s stage of disease (both $r = .40$; $P < .01$).

Level of Loneliness

Descriptive information related to the measures included in this study is presented in Table 2. Analyses related to skewness and kurtosis indicated that the UCLA Loneliness Scale and the SPS were normally distributed in this sample. In order to determine the degree of loneliness in this sample of caregivers relative to other groups of caregivers and older adults, several one-sample t-tests using average scores from other studies using the UCLA Loneliness Scale were conducted [17,23–27]. Results (see Table 3) showed that caregivers in the present study reported higher levels of loneliness than all comparison groups except Alzheimer caregivers [27].

Predictors of Loneliness

In order to determine whether patient or caregiver characteristics were more predictive of loneliness in this sample, a hierarchical regression analysis was performed. The following patient characteristics were included in the first block of variables: patient age, stage of disease, duration of illness, and “degree to which the patient’s thinking or memory has been affected by Parkinson’s disease or its medication.” The second block, consisting of caregiver variables, included: age, education, own physical health, Perceived Self-efficacy, and “degree to which the patient is able to interact with you in the same way as always.” The first block of patient variables did not significantly predict loneliness ($F [4, 54] = 1.836$, $R^2 = .12$), accounting for only 12% of the variance. However, the caregiver variables added in the second block contributed significantly to the equation ($F [5, 49] = 7.509$, R^2 change = .46), accounting for an additional 46% of the variance ($P < .01$). Individual predictors of loneliness are presented in Table 4.

Support Groups, Loneliness, and Social Support

Results of analyses determined that caregivers attending caregiver support groups reported less loneliness ($t = -2.38$; $P < .05$) and more perceived support ($t = 2.62$; $P < .05$) than those not attending support groups. In addition, it was found that caregivers attending support groups were older than those not attending ($t = 2.01$; $P < .05$).

DISCUSSION

This study investigated predictors of loneliness in a sample of caregivers of persons with PD. In order to explore the context of loneliness among similar groups of caregivers and older adults, preliminary analyses compared scores of the current sample on the UCLA Loneliness Scale with scores of similar groups from other studies. Results demonstrated that this group was lonelier than other samples that had used the UCLA Loneliness Scale (see Table 3), but was not significantly lonelier than the Alzheimer caregiver group. It should be noted that although the PD sample reported more loneliness than other groups, the average score of 40, given the scoring range of 20 to 80, does not objectively represent a high level of loneliness.

The primary aim of the study was to determine whether patient or caregiver characteristics were more predictive of caregiver loneliness in this sample. Results indicated that caregiver variables were more predictive of loneliness than patient variables. The directionality of the results for the significant individual predictors indicated that caregiver variables related to more education, better health, and greater perceived self-efficacy appeared to protect against loneliness. It is possible that with a larger sample size, the patient variable of duration of illness would have been a significant predictor of loneliness as it approached significance ($t = 1.948$, $P = .057$).

It is interesting that the significant individual predictors of loneliness were caregiver education, physical health, and self-efficacy. Education is often regarded as a surrogate variable for broader socioeconomic status. In this case results may indicate that more educated caregivers have more resources to deal with the challenges and demands of caregiving and thus, are less lonely. Physical health is also, apparently, a protective factor in regard to loneliness. Maintaining one's own physical health perhaps allows for more options in terms of dealing with loneliness. Finally, having a sense of self-efficacy, or confidence in one's ability to handle the day to day reality of being a caregiver, is also a predictor of less loneliness.

The secondary aim of the study was to determine whether there were differences in levels of loneliness and perceived support between those who attended caregiver support groups and those who did not. Results demonstrated that those who attended support groups were less lonely and reported more perceived support than those not attending support groups. These results are consistent with previous research, which has shown that support groups are beneficial in decreasing loneliness for caregivers [12]. An alternative explanation may be that some caregivers attending support groups may cope with the situation by reaching out to others, or helping others deal with similar circumstances. Because these analyses do not demonstrate causation, but only indicate differences between the two groups, future research is needed to investigate the characteristics of caregivers who attend caregiver support groups and the specific effects of groups on caregivers.

It is important to note that in this study caregivers were specifically asked whether they attend a support group for Parkinson caregivers. Support groups that include both patients and caregivers may be more psycho-educational in nature and focus on the effectiveness of current medications or the most recent information on management of disease. Support groups specifically for caregivers may assist in providing emotional support and help to enhance the person's coping skills in an environment that emphasizes sharing feelings, personal experiences, and coping strategies [28]. As one caregiver put it, "discussing my fear with my husband [the patient] puts that much more stress on him." Support groups for caregivers may allow people who are unable to discuss their experience with family members to have the type of support they need [29]. Support groups may also provide opportunities for altruism or social contact for caregivers who want or need to share their experiences with others in similar situations.

Results of this study indicated that caregivers who attended support groups were older than those not attending. It may be that younger caregivers were still working, and thus, were not able to attend daytime meetings, or they may find information and support in other ways. It may also be that older caregivers have less social support and experienced a greater need to be with other caregivers.

There are several limitations in this study. One limitation is related to the selection of participants. This sample was recruited from the membership of a regional Parkinson's association who voluntarily responded to a postal survey. It is possible that the individuals who chose to participate in this study were different in some ways from the total population [30].

For example, individuals who chose not to respond to the survey may have been more depressed, lonely or stressed than those who participated in the study, thus restricting the range and variability of the sample. In regard to demographic characteristics, however, the breadth and range of responses shown in Table 1 suggest that this was a demographically heterogeneous sample. Likewise, the range of scores for the assessment instruments presented in Table 2 indicates heterogeneity in responses in the sample. Additional research is required to assess the generalizability of these findings to other groups of caregivers, including a broader representation of participants with regard to ethnicity, gender, and familial relationship.

In conclusion, we found that caregiver characteristics were more predictive of loneliness than patient characteristics. Results suggest that it is important for caregivers of persons with Parkinson's disease to be mindful of their own physical health and to find ways to increase their sense of self-efficacy, or confidence related not only to caregiving, but to developing or retaining some activities apart from their role as caregivers. Because loneliness and depression are often strongly related [16,18], finding ways to ameliorate loneliness will probably also affect symptoms of depression.

In addition, participants who went to caregiver support groups reported less loneliness and more perceived support than those who did not attend. Although no causal explanations can be offered based on these analyses, it is possible that combining caregiver support groups with opportunities to enhance self-efficacy, or knowledge about how to care for the patient or oneself more effectively, could be helpful in decreasing loneliness.

Finally, this study can be regarded as an initial step toward learning more about loneliness among PD caregivers. Future research could include qualitative interviews and could explore relationships between caregiver data, patient self-reports of quality of life, and objective ratings of patients' physical and neurocognitive functioning. This approach would allow a fuller understanding of relationships among these important variables and perhaps lead to interventions that would be beneficial to caregivers, which could, in turn, be beneficial to patients.

Acknowledgments

CM was supported by a grant from NIH/NINDS R03 054992.

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TABLE 1
Demographic Characteristics of Caregivers and Patients

Caregiver Variables	Mean (SD) or percentage	Range
Gender		
Males	26%	
Females	73%	
Age (years)	65.5 (10.2)	40–85
Married	93%	
Education (years)	13.8 (2.8)	8–18
White	97%	
Employed	23%	
Own health ^a	5.2 (1.4)	1–7
Attend caregiver support group	30%	
<u>Patient Variables</u>		
Age of patient (years)	69.4 (9.1)	45–88
Hoehn & Yahr (caregiver version)	3.4 (.95)	1–5
Years since diagnosis (years)	9.2 (6.2)	1–26
<u>Caregiving Characteristics</u>		
Length of caregiving (years)	6.6 (4.9)	1–24
Interact same as always ^b	4.3 (1.8)	1–7
Memory affected by disease ^c	4.0 (1.9)	1–7

^a range = 1 (very poor) to 7 (excellent)

^b range = 1 (not at all) to 7 (same as always)

^c range = 1 (not at all) to 7 (extremely)

TABLE 2

Mean Scores, Reliability, and Scoring Range of Measures

Scales	M (SD)	alpha	Range
UCLA Loneliness Scale ^a	40.0 (10.6)	.90	22 – 64
Social Provisions Scale ^b	78.1 (10.3)	.86	51 – 96
Perceived Self-efficacy ^c	22.1 (6.8)	.89	5 – 35

^aPossible range = 20 to 80^bPossible range = 24 to 96^cPossible range = 5 to 35

TABLE 3

Rank Order of UCLA Loneliness Scores in Comparative Samples

Sample	N	Age Mean (SD)	Loneliness Mean (SD)	P [*]
Present sample	70	65.5 (10.2)	40.00 (10.6)	
Alzheimer caregivers [25]	40	74.0 (7.9)	37.35 (9.7)	.089
Older adults [23]	57	64.9 (5.0)	36.26 (8.2)	.011
Older adults [22]	161	60–80 (range)	34.52 (9.3)	<.001
Older adults with low vision [21]	93	75.1 (not given)	32.56 (6.9)	<.001
Older adults [17]	284	65+	31.51 (6.9)	<.001
Peritoneal dialysis caregivers [24]	65	43.9 (8.5)	28.30 (15.0)	<.001

* Significance level when compared to present sample in one-sample *t*-test.

TABLE 4
Regression Coefficients for Variables Predicting Loneliness in Caregivers

Variable	B	SE B	B	t
Step 1				
Patient age	-.150	.173	-.120	-.865
Stage of disease	-.237	1.588	-.021	-.149
Duration of illness	.543	.223	.326	2.431*
Thinking/memory affected	.122	.834	.022	.146
Step 2				
Patient age	-.036	.188	-.029	-.190
Stage of disease	-2.264	1.453	-.201	-1.558
Duration of illness	.346	.177	.208	1.948
Thinking/memory affected	-.516	.648	-.091	-.796
Caregiver age	-.176	.154	-.165	-1.140
Caregiver education	-.803	.376	-.215	-2.134*
Caregiver's physical health	-2.378	.844	-.325	-2.816**
Perceived self-efficacy	-.470	.202	-.304	-2.326*
Interact same as always	-1.278	.904	-.208	-1.413

Note. $R^2 = .12$ for Step 1; $\Delta R^2 = .46$ for Step 2 ($P < .01$).

* $P < .05$

** $P < .01$