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Neuropsychiatric problems in Parkinson's disease: Comparisons between self and caregiver report

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Introduction: This study examined the level of agreement between caregiver and Parkinson's disease (PD) patient reports of neuropsychiatric problems.
Method: Forty-three patients and 43 informants who knew the patient well (caregivers) participated in the study. Caregivers rated patients' behaviour, as well as their own stress, using the Neuropsychiatric Inventory (NPI). Information from patients was obtained using commonly used scales (Beck Depression Inventory, Apathy Scale, Unified Parkinson's Disease Rating Scale and the Hamilton Anxiety Depression Scale). Both the patients and the caregivers also completed the Frontal Systems Behavior Scale, which assesses behaviours associated with apathy, disinhibition and executive dysfunction.
Results: The level of agreement between these self and caregiver reports was low, with only 45.8% agreement for depression, 45.0% for apathy, 28.6% for hallucinations, 26.9% for sleep problems and 6.7% for anxiety.
Conclusions: Given this low level of agreement between self and other report, these two methods of assessment cannot be considered interchangeable.

Keywords: Parkinson's disease; NPI; depression; anxiety; apathy, neuropsychiatric symptoms

Introduction

A significant proportion of patients with Parkinson's disease (PD) are reported to experience a range of neuropsychiatric problems, including sleep disturbance, fatigue, depression and anxiety (Aarsland & Karlsen, 1999; Aarsland, Larsen, Lim, & Tandberg, 1999a; Bronnick, Aarsland, & Larsen, 2005; McKinlay et al., 2008; Shulman, Taback, Bean, & Weiner, 2001). These problems have been associated with reduced quality of life for the patient, increased caregiver distress, and early rest home placement (Aarsland et al., 1999a; Aarsland, Larsen, Tandberg, & Laake, 2000; Fernandez, Tabamo, David, & Friedman, 2001). Routine assessment for these problems should provide an opportunity for clinical interventions that will reduce caregiver distress and prolong independence for patients with PD. However, there is no widely accepted assessment methodology for these neuropsychiatric problems, and self-ratings and reports from caregivers have often been used interchangeably (Aarsland & Karlsen, 1999; Shulman et al., 2001) with the assumption that they are equally valid measures of the patients' symptoms. However, this assumption may not be correct. Thus, it is important to determine whether reports from patients and caregivers provide equivalent information.

There is extensive evidence regarding the level of agreement between self vs caregiver reports of neuropsychiatric symptoms for patients with dementia (for example, Ready, Ott, & Grace, 2004; Scocco, Fantoni, & Caon, 2006; Vogel, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006). However, this topic has only recently been to be addressed with regard to PD patients without dementia. Duenas and Serrano (2007) examined the level of agreement between self and carer report for 70 PD patients without dementia, compared with their caregivers using the Neuropsyciatric Inventory-short form (NPI-Q). These authors found little consistency between caregiver and patient reports of neuropsychiatric problems.

It is highly likely that these two means of reporting may provide very different information about the PD patient's neuropsychiatric status. Whereas caregivers' reports are based on their observations, the patient is describing their own symptoms based on personal experience that may or may not be accompanied by overt behaviours and which they may not have communicated with anyone else.

Even in the context of the healthy elderly, self and caregiver reports may not be interchangeable. For example, McAvay, Bruce, Raue, and Brown (2004) examined the frequency of depression reported by the elderly compared to that of an informant, and found that a number of elderly people who self-reported depressive symptoms were not identified by the informant and vice versa. Overall, informants tended to underestimate the presence of depression, identifying these symptoms in only 11% of individuals, compared to a self-reported frequency of 18% (McAvay et al., 2004).

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Both self and caregiver reports have potential problems. For example, self-report from patients with PD may be problematic because cognitive deficits that are frequently associated with this disorder may impair their ability to accurately describe problems. It is known that the agreement between caregiver and self-report decreased with more severe cognitive problems in Huntington's disease, suggesting that, as cognitive status becomes impaired, patient assessment is less accurate (Chatterjee, Anderson, Moskowitz, Hauser, & Marder, 2005). Conversely, the reports of caregivers may be influenced by their own level of distress. Mangone et al. (1993) reported that the best predictor of feelings of burden for the caregivers of patients with probable Alzheimer's disease was their report of perceived behaviour problems (Mangone et al., 1993).

Our primary objective was to examine the level of agreement between ratings of neuropsychiatric symptoms reported by PD patients and those reported by a caregiver. Rating scales were used that are commonly found in the literature and which separately examine either self-report or caregiver reports of neuropsychiatric symptoms in PD patients. Secondly, the relationship between the caregiver's own level of distress and his/her perception of neuropsychiatric symptoms in the patient was examined. As discrepancies in many commonly used neuropsychiatric measures could be explained by the fact that they represent different psychometric instruments and lack common measures, we also used the Frontal systems Behaviour Scale (FrSBe), which was completed by both the patient and their caregiver. This scale provided a method to directly compare the level of agreement between the two methods of reporting.

Methods

Approval for the study was obtained from the Upper South B Ethics Committee, and informed consent was obtained from the patients. Patients were also asked to nominate an informant (a 'caregiver' who knew them well, and in approximately 90% of cases this was the spouse) who would provide information regarding the patients' everyday functioning and general behaviour. Informed consent was obtained independently from all nominated caregivers.

Subjects

Patients in the Canterbury region of New Zealand with a confirmed diagnosis of idiopathic PD, identified by two experienced neurologists, were invited to take part. Inclusion criteria required no evidence of any other major medical illness, no evidence of dementia (Mini Mental Status Exam, MMSE $\geq$25), and being between 55 and 79 years of age. Of the 115 letters that were mailed out, 11/115 (9.6%) could not participate due to illness or dementia, 8/115 (9.6%) were deceased (6.9%), 8/115 (6.9%) declined and 34/115 (26.9%) did not respond. A total of 54 patients who met the inclusion criteria volunteered to take part (56% of the eligible patients). Five of the patients who volunteered did not complete all of the take home tests and six were unable to provide a caregiver. In total, 43 patients and their caregivers took part in the study.

Procedure

Patients were assessed while on PD medication. Information regarding current cognitive status, motor symptoms, hallucinations, sleep problems and depression were all collected during the session. Patients were also asked to complete self-report forms later at home regarding symptoms of apathy and anxiety. Details on how to complete these forms were explained during the session, and patients were asked to return these approximately 7 days later. Any questions or difficulties regarding the completion of the forms were addressed at that time. Patients were specifically requested to complete the self-report forms independently, unless they required help with writing. Information regarding the patients' everyday activities and general behaviour were collected during a face-to-face interview with the nominated caregiver. In the majority of cases, these were conducted by a second interviewer while the patients were themselves were being assessed.

Clinical and demographic characteristics

1. A semi-structured interview was used to gather demographic and clinical details including age [mean age of the patients was 66.5 years (SD) 6.8, range 52.0–77.0], and time since diagnosis of PD [mean of patients was 6.0 years (SD) 4.2 years, range 0.3–23.0].
2. The Mini Mental Status Exam provided information regarding current global cognitive status, with 30 being the maximum score that may be achieved (Folstein, Folstein, & McHugh, 1975). A variety of cut offs have been suggested for this instrument, but scores below 23–24/30 have been reported as having high sensitivity and specificity in identifying individuals with dementia (O'Connor et al., 1989). In this study, patients were included if they scored $\geq$25 [mean MMSE for the sample was 28.5 (SD) 1.3, range 25–30].

Neuropsychiatric information using self-report only

1. Symptoms of depression were assessed using the Beck Depression Inventory (BDI-II) (Beck, Steer, & Brown, 1996). The BDI-II consists of 21 items, each scored from 0 to 3. A threshold of 14 and above is recommended for detecting the presence of depression (probable depression),

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and 9 and above for screening purposes (possible depression). To be comparable with the Neuropsychiatric Inventory (NPI), which screens for both low mood (dysphoria) and depression, we used a cutoff of ≥9 as evidence of depressive symptoms.

(2) Anxiety was assessed using the Hospital Anxiety and Depression Scale (HADS), which consists of 14 items (Zigmond & Snaith, 1983). Of these, seven relate to anxiety and are each rated on a four point scale (0–3) with a maximum score of 21. A threshold of 10 has been recommended for detecting probable anxiety, with above 8 for possible anxiety. To aid comparison with the NPI, a score of ≥ 8 was taken as evidence of symptoms of anxiety (Zigmond & Snaith, 1983).

(3) Apathy was assessed using the Apathy scale (Starkstein et al., 1992), which is a 14 item self-report measure. Participants are asked to indicate the extent to which each of the 14 statements applied to them over the last month using a four-point scale: not at all, slightly, some, a lot. The recommended cut-off of >14 was used for this study (Starkstein et al., 1992).

(4) The frequency of sleep disturbance was assessed using a single screening item contained in the Unified Parkinson's Disease Rating Scale (UPDRS) (Fahn & Elton, 1987). Patients were asked to respond either Yes or No to the question, 'Do you have any problems with your sleep?'

(5) The presence of hallucinations was assessed by a single screening item from the UPDRS (Fahn & Elton, 1987). A five-point scale was used where 0 = none, 1 = vivid dreaming, 2 = 'benign' hallucinations with insight retained, 3 = occasional to frequent hallucinations or delusions without insight, 4 = persistent hallucinations, delusions or florid psychosis. For the purposes of this study, hallucinations were considered to be present if the patient scored 2 or higher on this scale.

Neuropsychiatric information from caregivers only

Patients' neuropsychiatric problems were assessed in a structured interview with the caregiver using the NPI (Cummings et al., 1994). The NPI covers 12 different areas of behavioral functioning: delusions, hallucinations, agitation, dysphoria/depression, anxiety, euphoria, apathy, irritability, disinhibition, aberrant motor behaviour, night-time behavior and appetite/eating change. Each question addressed changes in the person's behaviour since the onset of the illness. The interviewee was first asked whether the behavioral change was present or absent. If it was absent the interviewer continued to the next domain, otherwise the interviewer asked about the frequency of the problem (1 = occasionally, 2 = often, 3 = frequently, 4 = very frequently) and severity (rated 1 = mild, 2 = moderate, 3 = severe) using the script provided in the manual. Scores for each domain were generated by multiplying frequency by severity (maximum score = 12). A total NPI score was generated by adding together the scores from each domain (for this study the 12 item score was used). Each domain was also scored in terms of how emotionally distressing the caregiver found the behaviour (0 = no distress, 1 = minimal, 2 = mild, 3 = moderate, 4 = moderately severe, 5 = very severe or extreme). Information regarding caregiver's level of distress was also generated for each domain separately, and a total score was obtained by adding together the scores of the individual distress questions.

Neuropsychiatric information from both patients with PD and caregivers

Two versions of the The Frontal Systems Behaviour Scale (Grace & Malloy, 2001) were used, one for self-report and another for the caregiver to complete. This scale provided a method to directly compare the level of agreement between the two methods of reporting. The FrSBe assesses three areas of behavioral functioning: apathy, disinhibition and executive functioning. The scale consists of 46 questions describing possible behaviours, with each question being answered using a five-point scale (1 = almost never and 5 = almost always). Each question was answered in terms of how the patient was 'at the present time'. Raw scores were converted to age, gender and education adjusted *t*-scores (mean = 50; SD = 10), with higher scores indicating the presence of a greater number of problem behaviours. A score of 60–64 is considered borderline impairment, while >65 is considered to be clinically significant (Grace & Malloy, 2001).

Statistical analysis

The percentage of individuals with neuropsychiatric problems was calculated using previously validated cut-offs as described in the methods section. Data are also reported in terms of means and standard deviations. Pearson correlation and *t*-tests were used to examine the relationship between caregiver and self-report.

Results

Table 1 shows the percentage of patients reported by a caregiver as having neuropsychiatric problems. One or more problems were reported in over 80% of the patients. Symptoms consistent with depression (42.2%) and difficulty sleeping (44.2%) were the most frequently reported problems. Symptoms of agitation, anxiety, apathy and eating problems were each reported in over 20% of the patients.

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Table 1. Caregiver reports of the percentage of patients with different neuropsychiatric symptoms, and the percentage of caregivers reporting distress associated with patient symptoms, using the Neuropsychiatric Inventory.

	Patients with symptoms (%)	Mean (SD)[a]	Range	Caregivers reporting distress (%)	Mean (SD)	Range
Delusions	4.4% (2/43)	8.0 (5.7)	1–12	2.3% (1/43)	5.0 (–)	–
Hallucinations	8.9% (4/43)	5.3 (5.0)	1–12	7.0% (3/43)	3.0 (2.0)	1–5
Agitation	20.9% (9/43)	2.6 (1.7)	1–6	11.6% (5/43)	2.2 (1.1)	1–3
Depression	42.2% (19/43)	2.3 (2.0)	1–8	30.2% (13/43)	1.8 (0.7)	1–3
Anxiety	23.3% (10/43)	3.0 (2.1)	1–8	14.0% (6/43)	2.0 (0.9)	1–3
Euphoria	2.3% (1/43)	1.0 (–)	–	0.0% (0/43)	–	–
Apathy	27.9% (12/43)	4.2 (3.6)	1–12	20.9% (9/43)	2.1 (1.2)	1–4
Disinhibition	9.3% (4/43)	3.3 (2.2)	1–6	2.3% (2/43)	3.0 (1.4)	2–4
Irritability	11.6% (5/43)	3.8 (2.3)	1–6	2.3% (2/43)	3.0 (0.0)	–
Aberrant motor behavior[b]	4.7% (2/43)	2.5 (0.7)	1–3	0.0% (0/43)	–	–
Difficulty sleeping	44.2% (18/43)	6.2 (4.3)	1–12	23.3% (10/43)	2.6 (1.6)	1–5
Eating behaviour[c]	30.2% (13/43)	4.2 (3.4)	1–12	11.6% (5/43)	1.5 (0.5)	1–2
Total	81.4% (35/43)[d]	11.1 (12.8)	1–59	48.8% (21/43)[e]	5.9 (4.6)	1–16

[a] Mean scores presented here are calculated in terms of frequency × severity according to standard Neuropsychiatric Inventory scoring instructions. [b] Aberrant motor behaviour refers to pacing or unusually repetitive behaviours, e.g. opening closets or drawers. [c] Eating behaviour refers to change in food types preferred or appetite. [d] Total scores include night behaviour and eating problems. [e] Total caregiver distress is the sum of the sub-scores.

Table 2. Frequencies of caregiver and self-report of neuropsychiatric problems, and correlations between caregiver report and self-report, caregiver distress and self-report, and caregiver report and caregiver distress.

Correlations

	Frequency caregiver report	Frequency self-report	Level of agreement	Caregiver report vs self-report	Caregiver distress vs self-report	Caregiver distress vs caregiver report
Hallucinations	4 (9.3%)	5 (10.2%)	2 (28.6%)	0.51***	0.50**	0.99***
Depression	19 (44.2%)	16 (37.2%)	11 (45.8%)	0.37*	0.28	0.47**
Anxiety	7 (16.3%)	6 (14.0%)[a]	1 (6.7%)	−0.02	0.02	0.53***
Apathy	12 (27.9%)	17 (39.5%)	9 (45.0%)	0.22	0.16	0.47**
Sleep difficulties	18 (41.9%)	14 (32.7%)	7 (26.9%)	0.09	−0.02	0.63***

[a] Thirty-seven patients and their caregivers completed the self-ratings of anxiety, whilst correlations for all other measures are based on 43 patient and caregiver pairs. *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

Less frequently reported were symptoms of irritability, hallucinations, aberrant motor behaviour, delusions and euphoria (<12%).

The level of distress experienced by the caregiver regarding each of the neuropsychiatric problems he/she reported as present in the patient is also displayed on Table 1. Not all caregivers found the presence of neuropsychiatric problems distressing. Although over 80% of caregivers reported at least one neuropsychiatric problem, only 48% reported finding any of these problems distressing. However, for those who did, the presence of delusions, hallucinations, disinhibition and irritability were each reported as causing moderate to severe levels of distress. By contrast, the reported presence of agitation, anxiety, apathy and difficulty sleeping was associated with only mild to moderate distress in caregivers. Least distressing were the presence of eating problems and depression, which were reported as causing only minimal to mild distress.

Comparisons between the prevalence of neuropsychiatric problems using self (assessed using the BDI, HADS, Apathy Scale and the UPDRS) and caregiver reports (assessed using the NPI) were made for symptoms of apathy, anxiety, depression and the presence of hallucinations and sleep difficulties (see Table 2). Whereas reported frequency rates were similar for caregivers and patient, the agreement between an individual patient's report and that of their caregiver was not high. Indeed, there was a maximum of 45.8% (11/24) agreement for the presence of depression and a minimum of 6.7% (1/15) agreement for the presence of anxiety. Further, patients reported hallucinations that were not identified by the caregiver in 3/5 (60%) of cases. Higher levels of agreement were found for apathy (9/19; 45.0%) and sleep difficulties (7/26; 26.9%).

Overall, the correlations between caregiver versus self-report and caregiver distress vs self-report were low for ratings of apathy, anxiety and sleep problems. The only significant correlations were for the presence of hallucinations and depression (Table 2). By contrast, there was a significant positive association between the report of neuropsychiatric symptoms by a caregiver and their distress (see Table 2).

Table 3. Comparison between patient and caregiver reports for patients showing at least borderline impairment as rated by the FrSBe.

	Frequency caregiver	Frequency self-report	Level of agreement	Correlation Pearson's *r*
Apathy	21/43 (48.8%)	28/43 (65.1%)	17/32 (53.1%)	0.36*
Disinhibition	6/43 (14.0%)	19/43 (44.2%)	3/22 (13.6%)	0.16
Executive function	15/43 (34.9%)	26/43 (60.5%)	9/32 (28.1%)	0.00
Total Score	16/43 (37.2%)	27/43 (62.8%)	11/32 (34.4%)	0.09

*$p < 0.05$.

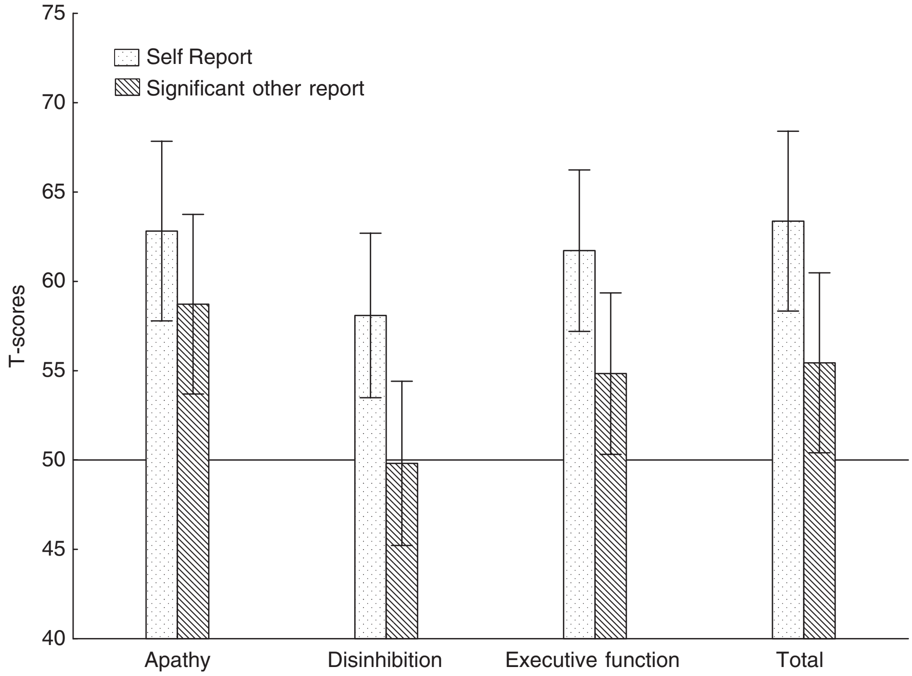

Figure 1. Comparisons between self-rating and caregiver rating using the Frontal systems Behavioral Rating Scale (line indicates mean t-score of 50 SD = 10; clinical range > 65).

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Ratings of sleep problems and hallucinations used a similar dichotomous scale for both self and caregiver reports. However, self-reports of depression, apathy and anxiety used continuous measures with set cut-offs, while caregiver report relied on a yes/no answer format. Thus, it was possible that the lack of agreement between caregiver and self-report of neuropsychiatric problems was due to the different measures used.

To overcome the difficulty outlined above, patients and caregivers also reported on the presence of neuropsychiatric problems using a rating scale that enabled both to report symptoms in the same manner, so that direct comparisons could be made. The FrSBe includes many of the same problem behaviours as the NPI. As shown in Table 3, even when the same rating scale was used, reported frequencies for caregivers and patient differed. Further, caregiver reports of neuropsychiatric problems did not correspond well with patient self-report, with a maximum of 53.1% agreement for the presence of apathy and a minimum of 13.6% agreement for the presence of disinhibition.

Figure 1 shows the mean self and caregiver ratings using the FrSBe. For each of the sub-scales, ratings by caregivers were lower than those by patients. This difference was significant for ratings of disinhibition ($t = 2.5$, d.f. = 84, $p < 0.02$), executive dysfunction ($t = 2.1$, d.f. = 84, $p < 0.05$) and overall score ($t = 2.2$, d.f. = 84, $p < 0.05$) but not for apathy ($t = 1.15$, d.f. = 84, $p > 0.20$). On average, patient ratings indicated borderline impairment in terms of the total score and for the subscales apathy and executive function, but not for disinhibition. However, caregiver ratings for the patients were all in the average range (average range = t 50 ± 10). The level of agreement between the two groups was also compared using Pearson correlation. The ratings of the two groups were significantly correlated for ratings of apathy only (Table 3).

Discussion

We compared caregiver and self-reports for neuropsychiatric symptoms (anxiety, depression, apathy, hallucination and sleep problems) experienced by PD patients. Although similar rates of symptoms overall were reported by patients and caregivers, the level of agreement within individual dyads was low. Thus our

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results show that reports of caregivers and patients cannot be regarded as interchangeable. This finding is consistent with a recent study conducted by Duenas and Serrano (2007).

One possible reason for the lack of agreement may be that caregivers were asked to report on problems that could not be identified based on observable behaviour, and thus relied on the patient having effectively communicated these problems to them. Moreover, the format of the measures used for ratings of self and caregiver reports differed. For example, for anxiety, depression and apathy, patients were endorsing a range of symptoms and the resulting score was classified in terms of a predetermined cut-off as having or not having one of these disorders. For the caregiver reports (using the NPI), all disorders were identified by a yes/no response. A yes/no format assumes that the informant has the relevant knowledge about indicative behaviours that are associated with the disorder, whereas for the patients, that knowledge is unnecessary because separate items on the scale are used for different behaviours.

It could be argued that the differences detected in this study were a result of different scales being used to assess the different neuropsychiatric problems. However, when caregivers and the patient were asked to report on the symptoms using the same scale (FsSBe), the relationship between the two reports was still low for ratings of disinhibition, executive dysfunction and in terms of the overall score. The only area for which the scores between the two raters were significantly correlated was apathy. On average, patients perceived themselves as having more problems than did the caregiver.

Previous research with Alzheimer's patients suggests that caregivers' reports can be influenced by the burden they perceive that the patient's behaviour places on them (Mangone et al., 1993; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). Moreover, caregiver reports may have been influenced by their own mental state. Many caregivers of patients with PD are themselves depressed, and this may cause them to view the patient's behaviour more negatively and endorse more neuropsychiatric symptoms (Caap-Ahlgren & Dehlin, 2002; Fernandez et al., 2001). Alternatively, patients might lack insight regarding their own behaviour (Leritz, Loftis, Crucian, Friedman, & Bowers, 2004). However, neither of these explanations seems credible given that the patients tended to rate themselves as more impaired on the FrSBe than their caregiver did.

In this study we found that the number of caregivers who reported particular neuropsychiatric behaviours as being distressing was much less than the number reporting the presence of these behaviours. One possible explanation for this is that caregivers' reported levels of distress were influenced by their own sense of loyalty to the patient and therefore tended to under-report levels of stress. Studies of patients with dementia have reported that caregivers are reluctant to be honest regarding a patient's behaviour because they do not want to upset them or they felt guilty doing so (Hughes, Hope, Reader, & Rice, 2002). Alternatively, caregivers may not report distress as a means of coping. Brandtstadter and Renner (1990) proposed that as individuals face the challenges of aging, they change their life expectations (update their goals) in an effort to preserve a sense of control. In the case of individuals who assist in the care of a patient, updating of goals may include an acceptance that PD may result in a number of neuropsychiatric problems and not allow this to cause distress.

There were a number of limitations with this study. First, only 56% of the patients eligible for the study volunteered to take part. Because patients with neuropsychiatric problems such as apathy, anxiety and depression are less likely to volunteer, the figures presented here may be an underestimation of the actual problems faced by this patient group. Further, comparisons would have been enhanced had the patient and caregiver reports been obtained using similar scales throughout. However, the measures we used are commonly used to assess either caregiver report or self-report of neuropsychiatric problems. Another potential shortcoming of the study is that we did not specifically collect information regarding the characteristics or mental state of the caregivers. Therefore, we could not examine differences between caregivers who found the presence of a particular disorder disturbing and those who did not.

Overall, our results suggest that there may be a low level of agreement between caregiver and self-reports of neuropsychiatric problems. Therefore, reports from these two sources cannot be considered interchangeable.

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