

The Parkinson fatigue scale

R.G. Brown^{a,*}, A. Dittner^a, L. Findley^b, S.C. Wessely^c

^aDepartment of Psychology, PO77, Institute of Psychiatry, De Crespigny Park, London SE5 8AF, UK

^bEssex Neuroscience Unit, Oldchurch Hospital, Romford, UK

^cAcademic Department of Psychological Medicine, Guy's King's and St Thomas' School of Medicine, London, UK

Received 12 March 2004; revised 8 July 2004; accepted 27 July 2004

Abstract

Background: In recent years several studies have highlighted the clinical significance of fatigue in Parkinson's disease. While we are becoming aware of its prevalence and impact on the lives of patient, little progress has been made in understanding its nature or aetiology, nor on finding ways to manage the problem clinically. One possible reason for the slow pace of progress is the lack of an appropriate instrument to measure fatigue in Parkinson's disease and related disorders. While assessment tools have been developed for assessing fatigue associated with other diseases, their use in patients with Parkinsonism can pose problems and their validity cannot be assumed.

Objectives: In an attempt to progress research and improve clinical management a new instrument is presented, the Parkinson Fatigue Scale.

Methods: This 16-item self-report instrument (the PFS-16) arose from statements by individuals with Parkinsonism experiencing fatigue. Initially tested on a sample of almost 500 patients, and subsequently on an independent sample of over 100.

Results: The PFS-16 scale was designed to tap a single construct encompassing the physical aspects fatigue and their impact on the patient's daily function. The scale deliberately excludes emotional and cognitive features that may occur as part of the fatigue experience but which may also occur independently in Parkinsonism. The scale has good intrinsic properties and satisfactory test-retest reliability. It shows reasonable associations with other measures of fatigue and is able to identify patients who self-report the presence of fatigue, and particularly those in whom fatigue is a problem. Cut-off scores are provided in both cases with good specificity and sensitivity.

Conclusion: While further evaluation is required, the scale is offered to facilitate clinical practice and future research. It is hoped that its use will enable the improved understanding and clinical management of this important problem.

© 2004 Elsevier Ltd. All rights reserved.

Keywords: Parkinson's disease; Patient; Clinical

1. Introduction

The subjective experience of fatigue, although lacking a standard definition, can be operationalised as a state of extreme tiredness, weakness or exhaustion, either mental or physical or both. Such fatigue is common in the general population [1] and particularly prevalent in patients with a wide range of psychiatric and physical disorders, including Parkinson's disease. Across a number of studies over the past 5 years fatigue has been reported in a third or more of

cases regardless of the Parkinsonian sample or method of assessment, with consistently higher mean levels than age matched healthy controls [2–10]. Although the presence of fatigue is widely recognized there is less consensus about its significance. It has been variously thought to reflect the presence of co-morbid depression, to be a subjective component of off-period or wearing off phenomena, or a direct consequence of nocturnal sleep disturbance. Although such factors may contribute to, or exacerbate, the experience of fatigue [8], recent evidence suggests that they cannot readily explain the high prevalence of the problem [2,3]. For example, fatigue is common in both depressed and non-depressed patients and experienced by patients who do not complain of sleep problems. Crucially

* Corresponding author. Tel.: +44 20 7848 0773; fax: +44 20 7848 5006.

E-mail address: r.brown@iop.kcl.ac.uk (R.G. Brown).

there appears to be no clear association between the presence or severity of fatigue and motor symptom severity or other indices of disease progression, or with the type, dosage or duration of anti-Parkinsonian medication.

Fatigue has a significant negative impact on patient quality of life (QoL) [11] and those experiencing it may describe it as being the worst, or amongst the worst, of all their Parkinsonian symptoms [3]. Despite this, fatigue tends to be under-diagnosed by clinicians [12]. Neither is there any indication from the literature of a systematic effort to improve the clinical management of this distressing problem, despite some encouraging reports from other conditions [13,14]. One reason for this clinical and scientific neglect may be that fatigue is not measured by existing PD symptom scales such as the Unified Parkinson's Disease Rating Scale (UPDRS) [15], and no separate measure has yet been developed specifically to assess fatigue in Parkinson's disease and related disorders. The majority of published studies have used one of two generic instruments, the Fatigue Severity Scale (FSS) [16] or Fatigue Assessment Inventory (FAI) [17]. The 9-item FSS is one of the best known and most commonly used fatigue scales in medical research. Studies of the FSS in a range of physical conditions have confirmed its psychometric properties, although findings from a study of patients with brain injury [18] suggest that its suitability in all populations cannot be assumed. The 29-item FAI, is an expanded version of the FSS. In general the FAI has good psychometric qualities, although it has only moderate test-retest reliability, and only two of its four factors demonstrate concurrent validity with other measures of fatigue and energy level. Conceptually it is very mixed scale including questions about factors that exacerbate (e.g. 'stress bring on my fatigue') or ameliorate fatigue (e.g. 'Resting lessens my fatigue') and more qualitative aspects such as 'my fatigue is worse in the morning' or 'my fatigue is worse in the afternoon'. While providing useful phenomenological information, it is not clear how endorsement of such items indicates greater fatigue severity.

Recently Lou and colleagues [8] adapted the FAI for use in Parkinson's disease patients, renaming it the Fatigue Severity Inventory (FSI). A number of items from the original FAI were removed, others reworded and additional items added relating to the nature of fatigue, its history and relationship to other Parkinsonian symptoms and its treatment (e.g. 'fatigue predated my other Parkinsonian symptoms' or 'when my antiparkinsonian medication is working my fatigue is less'). No clear rationale was given for these changes and, as with the FSS, the implication for fatigue severity of agreeing/disagreeing with some items is often unclear. Concurrent validity was demonstrated with other fatigue measures, although no other psychometric information was provided.

Thus, although a number of fatigue instruments exist to assess fatigue, their utility, reliability and validity in Parkinson's disease cannot be assumed. We chose therefore

to devise and evaluate a new instrument for use in patients with Parkinsonism. The aims were to develop a valid and reliable measure of the core construct of fatigue that was (a) derived from the personal experiences of people with Parkinsonism, (b) would have minimal overlap with other motor and non-motor symptoms of Parkinson's disease, and (c), be practical for use in clinical practice with individual patients and in research.

2. Methods and results

Several stages were involved in the construction and evaluation of the Parkinson Fatigue Scale (PFS). Initially, focus group methodology and qualitative analysis was used to derive a pool of fatigue-related questions for inclusion in a draft instrument. This was then administered to a large sample of people with Parkinsonism via a postal survey, and the results analysed to devise a shorter version. This was tested on a further sample of participants with a repeat testing to assess test-retest reliability. Additional data were collected at each stage to characterise the sample and assess some basic aspects of scale validity.

2.1. Focus groups and item generation

A series of focus groups were held with a total of 39 participants (23 male and 16 female), recruited from local branches of the Parkinson's Disease Society (UK). The mean age was 64.2 ± 9.6 years (range 38–82 years), with mean disease duration of 10.0 ± 7.6 years (range 2–28 years). Functional status was assessed using the Schwab and England Activities of Daily Living (ADL) scale [19] (mean 70.3 ± 15.5) (range 30–100). All were taking levodopa or a dopamine agonist, either alone or in combination.

The sessions were aimed at eliciting comments and discussion on all aspects of fatigue as perceived and experienced by the participants. The proceedings of the groups were video and audio recorded for subsequent transcription and coding using the software package QSR N5 [20]. A number of primary themes emerged from the transcripts: descriptions of the fatigue experience and its severity; its impact on the individual; its relationship to other Parkinsonian symptoms and their treatment, and factors influencing fatigue. The language used to describe the fatigue experience itself was limited. Apart from adjectives such as 'heavy' and 'drained', the most common constructs employed were 'tiredness' and 'lack of energy' and their extremes such as 'exhaustion'. However, there was a strong agreement that these feelings were qualitatively and quantitatively different from tiredness associated with activity or lack of sleep, or from feelings of somnolence. Abnormal tiredness thus emerged as the construct most typically used by sufferers in operationalising their fatigue.

A total of 57 statements relating to the symptoms and impact of fatigue were extracted from the transcripts for

inclusion in a draft scale. This addressed the question ‘How well do the statements describe your own feeling and experiences over the past two weeks?’ Based on feedback from users response options were ‘strongly disagree’, ‘disagree’, ‘do not agree or disagree’, ‘agree’ and ‘strongly strongly agreed’, scored 1–5, respectively. The overall PFS score was initially calculated as the mean response across all items (range 1.0–5.0).

2.2. Postal survey method

Questionnaire packs were sent to 1045 individuals, randomly selected from the membership of the Parkinson’s Disease Society (PDS) (UK) that had previously expressed a willingness to be contacted by third-parties. Of these 900 (86.1%) were returned with 598 (57.2%) completed or partially completed. A further 302 (28.9%) were returned uncompleted, with the reason provided in the majority of cases. In 172 the member of the PDS did not have Parkinsonism (typically they were a friend or relative), in 45 the person with Parkinsonism had died, and in 17 cases he/she had moved from the address. Together these 234 cases accounted for 77.5% of the questionnaires returned uncompleted. This number was removed from the denominator to give an adjusted response rate of 73.7%. A total of 145 questionnaires were not returned. If a similar proportion of these were individuals without Parkinsonism or who had changed address or died, a further 112 cases could be removed from the denominator to give a final estimated response rate of 85.6%.

Of the 598 questionnaires received, 184 had some missing data from the PFS. Of these, 103 had four or more items missing and were excluded from the subsequent analyses. These cases were significantly older (mean age 74.9 ± 7.6 years) with longer disease duration (11.3 ± 10.5 years) and worse ADL scores (57.3 ± 26.8) than the remaining 495 participants with complete or near complete PFS (see Table 1). The few items of missing data in the remaining cases were conservatively replaced with

the value 3 (neither agree nor disagree) to avoid missing values for the subsequent analyses.

In addition to the PFS, fatigue was assessed by two single item questions: ‘Do you experience fatigue?’ and ‘Is fatigue a problem for you?’ Answer options were ‘Yes’, ‘No’ and ‘Not sure’. Fatigue severity was rated on the Rhoten Fatigue Scale (RFS) [21] which taps the same core construct as the PFS with the question ‘How fatigued have you been over the past two weeks’, rated on an 11-point scale ranging from 0 (not tired (full of energy)) to 10 (totally exhausted). In addition, participants provided basic demographic (age and sex) and clinical details (time since diagnosis, a checklist of current antiparkinsonian medication, and a checklist of other physical health problems). The Schwab and England Activities of Daily Living (ADL) scale [19] was used to assess functional impairment and to provide an approximate index of disease progression.

2.3. Postal survey results

Details of sample are shown in Table 1. It comprised 36.3% females and 63.7% males. The two sexes did not differ in terms of mean age ($F(1,487) < 1$) or ADL score ($F(1,466) < 1$). However, the female participants reported having longer mean duration of Parkinsonism since diagnosis ($F(1,468) = 10.7$, $p < 0.01$). Fatigue was reported as present in 85.1% of cases, absent in 5.9%, while the remainder were uncertain. In subsequent analysis, the latter two responses were combined to allow the definition of two groups, one with and the other without fatigue. Fatigue was considered to be a problem by 67.4%, while 18.8% did not and the remainder were uncertain. The proportions of responses to the two questions did not differ between males and females. The mean score on the RFS was 6.3 ± 2.1 with no significant difference ($P > 0.05$) between the mean scores of males (6.5 ± 1.9) and females (6.1 ± 2.1). The mean PFS score was 3.41 ± 0.82 (males 3.48 ± 0.81 , females 3.36 ± 0.84 , $p > 0.10$).

2.4. Item analysis and reduction

A variety of approaches were taken to assess the properties of the 57-item PFS and to determine whether the number of items could be rationally reduced to produce a scale suitable for practical use. Item-level analyses failed to provide a basis for item deletion: (i) none of the items had an unusually large missing data rate, with the highest being less than 2%; (ii) individual means did not reveal any items susceptible to floor or ceiling effects: all lay in the range 2.56–3.94; (iii) the inter-item correlation matrix failed to reveal any pairs with extreme correlations that would indicate redundancy. Paired correlations ranged from 0.30 to 0.75, and (iv) the internal consistency of the total scale was high (Chronbach’s $\alpha = 0.98$) and unaltered by the deletion of any single item.

Table 1
First postal survey: characteristics of the respondents

	Male (N=315)	Female (N=180)	Total (N=495)
Age (years)	70.3 ± 10.2	70.4 ± 9.1	70.4 ± 9.5
Duration of parkinsonism (years)	7.2 ± 5.8	9.2 ± 7.7	7.9 ± 6.7
Schwab and England ADL score	67.2 ± 22.7	65.0 ± 23.4	66.4 ± 23.0
Antiparkinsonian medication			
No antiparkinsonian drug (%)	5.8	2.2	4.5
Non-dopa drug only (%)	2.2	2.2	2.2
Levodopa only (%)	50.6	53.4	51.6
Dopamine agonist only (%)	6.4	8.4	7.1
Levodopa + dopamine agonist (%)	34.9	33.7	34.5

The next approach was to explore the factorial structure of the scale to determine whether items could be removed while retaining a reliable and conceptually coherent scale. The data were subjected to factor analysis using principle components extraction with Varimax rotation. This produced an interpretable 6-factor solution accounting for 67.3% of item variance (Full details of the 57 item factor analysis can be obtained from the authors on request). The first factor (16.5% of variance) comprised 19 items with a factor loading of greater than 0.45, relating to the physical symptomatology (e.g. fatigue is one of my three worst symptoms) and its impact on general functioning (e.g. because of fatigue I do less in my day than I would like). Factor 2 (nine items, 11.9%) identified the social impact of fatigue (e.g. fatigue makes me reluctant to socialise). Factor 3 (seven items, 11.7%) identified symptoms of worry, anxiety, guilt and frustration associated with fatigue (e.g. I feel anxious in situations where I might feel fatigued). Factor 4 (eight items, 10.6%) comprised cognitive and motivational symptoms and impact (e.g. when I am fatigued I find it difficult to concentrate). Factor 5 (six items, 9.1%) identified a series of more severe or persistent physical symptoms (e.g. I feel completely shattered). Finally, Factor 6 (five items, 8.6%) identified additional symptoms of panic and anxiety, particularly in social situations (e.g. I cannot bear crowded places when I feel fatigued).

This factor structure supported the conceptual independence of the physical, cognitive and emotional aspects of fatigue, but did not support the separation of fatigue symptoms from their impact. A decision was made to select items from factors 1, 2 and 5 (physical symptoms and the impact of fatigue), but to omit items loading on factors 3, 4 and 6 (emotional, cognitive and motivational aspects). This was a result of the aim of a scale that minimized the contribution non-fatigue specific Parkinsonian symptomatology.

The remaining 34 items were still judged too many for a practical scale. A further reduction exercise was carried out, retaining those items loading most strongly on each of the factors to be used and excluding items with a high level of redundancy. The remaining 16 items addressed a balanced range of symptom type and severity and to assess the impact of fatigue on physical and social function (see Table 2). An exploratory factor analysis of these items revealed a single factor explaining 58.2% of variance with factor loadings in the range 0.64–0.83.

2.5. Assessing reliability and validity

The mean score of the 16-item PFS score (PFS-16) was 3.50 ± 2.94 . Internal consistency was high (Cronbach's $\alpha = 0.98$). A split-half analysis identified a correlation of 0.97 between the two parts and internal consistencies of 0.90 and 0.92. The PFS-16 score correlated by 0.68 with the RFS. This level of association is reasonable given that the latter scale is measuring a single dimension of fatigue, while

the PFS-16 is a multi-item scale. The PFS-16 score discriminated well between those patients who considered themselves to have fatigue (mean 3.56 ± 0.70) and those who did not (mean 2.37 ± 1.06) ($t(445) = 8.81$, $p < 0.001$). Within the fatigued group it also distinguished those where fatigue was considered a problem (3.83 ± 0.62) and those where it was not (2.48 ± 0.85) ($t(364) = 9.21$, $p < 0.001$).

To further assess the properties of the new scale, it was administered to an independent sample of 120 patients with Parkinsonism recruited from the same source and with the same methods as the initial sample. The purpose was to reassess the factor structure and internal consistency of the new scale administered as a separate entity, and to assess its test-retest reliability over an approximately 2 week period (mean interval 16.3 ± 3.5 days, range 12–34 days). Completed questionnaires on both occasions (T1 and T2) were received from 105 participants. Analysis was restricted to these cases.

Confirmatory factor analyses replicated the earlier result of a single factor for the 16-item scale, although with minor changes in the relative factor loadings of the different items. The factor explained 64.0% of scale variance at T1 and 63.2% at T2. Internal consistency for the T1 was 0.95 and for T2 0.96. The PFS-16 score correlated 0.71 with the RFS score at T1. The distribution characteristics of the mean PFS-16 score at T1 were as follows: mean 3.29 ± 0.78 , median 3.38, 25th percentile 2.84, 75th percentile 3.88, and at T2: mean 3.43 ± 0.81 , median 3.53, 25th percentile 2.86, 75th percentile 4.01.

An alternative simpler scoring method was also evaluated. In this, the responses 'agree' and 'strongly agree' were scored 1, and all other responses scored 0. A total score (range 0–16) was calculated for each subject with characteristics for T1: mean 8.51 ± 4.98 , median 9.0, 25th percentile 4.0, 75th percentile 13.0, and for T2: mean 9.06 ± 5.33 , median 9.0, 25th percentile 4.0, 75th percentile 14.0. The correlation with the RFS was 0.68 at T1.

The mean differences between T2 and T1 for the original and alternative scoring methods were 0.15 ± 0.47 (95% CI 0.24–0.05) and 0.55 ± 2.96 (95% CI 1.14 to -0.04) respectively. The T2 scores were higher than those at T1 scores for the original ($P < 0.01$), but not the alternative scoring method. The Pearson correlation coefficients between T1 and T2 were 0.83 for the original mean 5-point score and 0.82 for the alternative summed binary coded score.

Table 2 provides data on the individual PFS-16 items for the two assessments. Difference scores for the original scoring ranged from -0.03 to 0.38, being significantly higher at T2 only for item 12 ($p < 0.01$). Test-retest reliability (Spearman R) ranged from 0.52 to 0.72 (mean 0.63 ± 0.06). Using the binary scoring method, concordance rates (percentage of participants rating 0 or 1 on both occasions) was high (range 71.9–89.7%, mean $80.7\% \pm 5.2$). Cohen's coefficient kappa [22] was calculated as an alternative index of agreement in the two sets

Table 2
PFS-16 items statistics for assessments T1 and T2 (N=105)

Item	T1 mean (SD)	T2 mean (SD)	T2–T1 mean (SD)	Correl. <i>R</i>	Binary score (%)		Binary score concordance (%)	Cohen's kappa coef.
					T1	T2		
1. I have to rest during the day	3.78 (0.84)	3.75 (0.98)	–0.03 (0.87)	0.56	74.2	76.3	81.4	0.50
2. My life is restricted by fatigue	3.49 (1.12)	3.54 (1.08)	0.05 (0.92)	0.65	63.3	62.2	84.7	0.63
3. I get tired more quickly than other people I know	3.62 (1.01)	3.66 (0.99)	0.04 (0.82)	0.66	66.0	66.0	81.5	0.59
4. Fatigue is one of my three worst symptoms	3.42 (1.09)	3.60 (1.08)	0.18 (1.04)	0.54	56.3	65.6	71.9	0.41
5. I feel completely exhausted	2.73 (1.08)	2.95 (1.07)	0.21 (1.06)	0.52	27.1	33.3	79.2	0.51
6. Fatigue makes me reluctant to socialise	3.15 (1.07)	3.26 (1.12)	0.10 (0.83)	0.71	46.9	51.0	91.8	0.63
7. Because of fatigue it takes me longer to get things done	3.48 (1.02)	3.68 (0.98)	0.20 (0.92)	0.58	61.2	69.4	81.6	0.60
8. I have a feeling of 'heaviness'	3.17 (1.01)	3.35 (0.97)	0.17 (0.84)	0.64	47.4	52.6	74.2	0.49
9. If I wasn't so tired I could do more things	3.60 (0.97)	3.79 (0.93)	0.18 (0.87)	0.58	70.4	75.5	76.5	0.41
10. Everything I do is an effort	3.38 (1.05)	3.42 (1.00)	0.04 (0.91)	0.61	56.7	51.6	76.3	0.52
11. I lack energy for much of the time	3.30 (1.03)	3.44 (1.06)	0.13 (0.82)	0.69	54.1	53.1	82.7	0.65
12. I feel totally drained	2.70 (1.06)	3.08 (1.07)	0.38 (0.90)	0.64	26.8	39.2	77.3	0.50
13. Fatigue makes it difficult for me to cope with everyday activities	3.22 (1.02)	3.39 (1.09)	0.16 (0.81)	0.71	50.0	55.1	80.1	0.61
14. I feel tired even when I haven't done anything	3.31 (1.05)	3.5 (0.97)	0.19 (0.82)	0.67	55.1	58.1	78.6	0.56
15. Because of fatigue I do less in my day than I would like	3.70 (0.92)	3.89 (0.92)	0.18 (0.78)	0.68	77.6	77.6	83.3	0.50
16. I get so tired I want to lie down wherever I am	2.57 (1.06)	2.71 (1.09)	0.14 (0.80)	0.72	19.6	23.8	89.7	0.70

of ratings. The coefficients range from 0.41 to 0.70 (mean 0.55 ± 0.08). Generally, coefficients in the range 0.41–0.60 are considered 'moderate' and those in the range 0.60–0.80 'substantial'.

Of the 105 participants in the second sample, 86.6% reported experiencing fatigue and in 61.3% it was perceived to be a problem. An series of ROC analyses were undertaken to assess the PFS-16's ability to discriminate these subgroups. Using the full Likert scale, an average score of ≥ 2.95 optimally distinguished those who experienced fatigue from those who did not with a sensitivity of 81.0% and specificity of 85.7% (area under the curve: 87.5%). A slightly higher cut-point of ≥ 3.30 identified those perceiving fatigue to be a problem with a sensitivity of 84.7% with a specificity of 82.1% (area beneath the curve:

93.2%). For screening purposes the simpler binary coding scoring has computational advantages but has similar ability to distinguish subgroups. A score of ≥ 7 distinguished those who experienced fatigue from those who did not with a sensitivity of 73.8% and specificity of 76.9% (area under the curve: 87.1%), while a score of ≥ 8 identified those perceiving fatigue to be a problem with a sensitivity of 89.5% with a specificity of 83.3% (area beneath the curve: 93.4%).

3. Discussion

Growing evidence suggests that fatigue is a major cause of disablement and distress in people with Parkinsonism.

Despite this, the problem often goes unrecognised clinically and has been largely neglected scientifically. As with other non-motor aspects of Parkinsonism, clinical and scientific progress is dependent upon our ability measure the problem. The aim of the present study was to construct and undertake the preliminary psychometric evaluation of a new disease specific rating scale for assessing the physical aspects of Parkinsonian fatigue and its impact on the patient.

Unlike instruments already in use, the starting point was the direct experience of people with Parkinsonism. This initial stage confirmed that subjective fatigue is a complex, multifactorial problem. Although not reported here in detail, the focus group data revealed the diversity of personal experience of sufferers in their perceptions of fatigue, its concomitants and consequences. Nevertheless, we proceeded with the assumption that the core aspects of fatigue could be captured by a series of carefully selected questions suitable for both clinical and research use.

The initial 57-items tapped this range of the fatigue experience and its perceived consequences in the physical, emotional, cognitive and social domains. Factor analysis of the data from almost 500 participants indicated that the physical symptoms of fatigue were independent of the emotional features such as anxiety and depression, and of the cognitive and motivational aspects. In addition, items relating to the practical impact of fatigue were fundamentally enmeshed with those relating to physical symptoms and their severity. This argued against the separation of primary symptoms and their secondary consequences.

The PFS-16 has good intrinsic properties as evidenced by its high internal consistency and split-half reliability. The initial and confirmatory factor analyses also suggested that the scale is tapping a single coherent construct. Test–retest reliability was assessed over an approximately 2-week period. Such an assessment is a meaningful test of a scale's properties only if what is being assessed remains stable. Whether this is the case in Parkinsonian fatigue is not known. In practice, although the test–retest reliabilities of the individual items were modest, those based on the total scores were more robust ($r=0.82$ – 0.83). This suggests that the overall PFS-16 has reasonable reliability. However, these associations mask the fact that scores were slightly higher on the second occasion. The reason for the increase is unclear and further evaluation is necessary to determine whether it was a chance finding, or whether it is a reflection of the scale and its method of administration. In any event, the confidence intervals for test–retest change were narrow and provide a working basis on which to evaluate the statistical significance of change scores until further data become available.

Assessing the validity of the new scale was more complex. We sought to address the issue of face and content validity through the processes of scale construction and item selection already described. In terms of construct validity some decisions had to be made about the scale's scope. Through the focus groups, the core construct that emerged

in operationalising fatigue was a feeling of abnormal and overwhelming tiredness and lack of energy, distinct both qualitatively and quantitatively from normal tiredness. Another major decision lay in the inclusion or exclusion of the emotional and cognitive aspects of fatigue. While acknowledging their significance, there was the potential for contamination of the scale from non-motor symptoms unrelated to the experience of fatigue. For this reason, the conceptual focus of the scale was limited to the more physical aspects of fatigue and its impact on daily function. Researchers and clinicians interested in the wider aspects of fatigue and its concomitants would need to supplement the PFS-16 with additional instruments and measures.

Assessing the concurrent validity of the new scale is problematic as there is no 'gold standard' fatigue measure against which to compare the PFS-16. Rather than choosing one of the many multi-item scales, concurrent validity was assessed against the single-item RFS. Reasonably high correlations (0.68–0.71) were obtained suggesting good validity. Higher correlations would not be expected given the broad level of assessment undertaken by the PFS-16 versus the narrow focus of the RFS on the single dimension of 'exhaustion-energy'.

The study did not seek to assess the ability of the PFS-16 to distinguish between people with Parkinsonism and either healthy individuals or those with fatigue in different conditions. Rather, the focus was on the scale's ability to distinguish between (i) people with Parkinsonism who considered that they had fatigue and those who did not (or who were unsure), and (ii) between those with problematic and non-problematic levels of fatigue. ROC analyses suggested that scale has adequate utility in making these discriminations. The cut-offs have good sensitivity and specificity suggesting that they can be applied in a range of clinical or research situations. Further assessments of convergent, discriminant and predictive validity were beyond the scope of the present investigation but will need to be considered at a future stage. In relation to utility, the psychometric properties of the two scoring methods are broadly comparable. In terms of ease of use and scoring the binary coded method is probably preferable as a screening tool, although the full 5-point scale may have greater sensitivity in measuring change.

What of the possible shortcoming of the study methods? The main issue is the nature of the sample assessed. The Parkinson's Disease Society (PDS) UK is the largest patient organisation in the UK for individuals with Parkinsonism. With an estimated 60,000 individuals with Parkinson's disease in the UK, the PDS has a membership of over 20,000 individuals although, as seen, some of these are individuals without Parkinsonism but with an interest in the disease. The PDS thus provided the means to obtain a large convenience sample, even if it lacked the strength of a full population-based cohort. The high response rate in the present study increases the likelihood that the findings are representative of the study population. In practice,

the characteristics of the sample obtained appear to be reasonably representative of the general PD population in terms of age, gender, age at diagnosis and medication. Inevitably, the sample will have included individuals with other Parkinsonian syndromes. It is therefore safe to consider the present study as providing information on fatigue in Parkinsonism in general rather than idiopathic Parkinson's disease in particular. Finally, it is valid to ask whether the PFS-16 is 'superior' to existing scales. This cannot be judged from the present data, and it remains for future studies to explore its relative reliability, validity and utility, perhaps using and reporting the PFS-16 alongside other instruments such as the FSS or FAI.

In conclusion, although further evaluation is required, it is hoped that the PFS-16 will provide a useful tool in order to progress the study of Parkinsonian fatigue, and to encourage the development and evaluation of improved approaches to manage this common, distressing and disabling problem.

Acknowledgements

This work reported in this paper was supported by the Parkinson's Disease Society (UK).

References

- [1] Pawlikowska T, Chalder T, Hirsch SR, Wallace P, Wright DJ, Wessely SC. Population based study of fatigue and psychological distress. *BMJ* 1994;308(6931):763–6.
- [2] Herlofson K, Larsen JP. Measuring fatigue in patients with Parkinson's disease—the Fatigue Severity Scale. *Eur J Neurol* 2002;9(6):595–600.
- [3] Friedman J, Friedman H. Fatigue in Parkinson's disease. *Neurology* 1993;43(10):2016–8.
- [4] Friedman JH, Friedman H. Fatigue in Parkinson's disease: a nine-year follow-up. *Mov Disord* 2001;16(6):1120–2.
- [5] Abe K, Takanashi M, Yanagihara T. Fatigue in patients with Parkinson's disease. *Behav Neurol* 2000;12(3):103–6.
- [6] Erdal KJ. Depressive symptom patterns in patients with Parkinson's disease and other older adults. *J Clin Psychol* 2001;57(12):1559–69.
- [7] Karlens K, Larsen JP, Tandberg E, Jorgensen K. Fatigue in patients with Parkinson's disease. *Mov Disord* 1999;14(2):237–41.
- [8] Lou JS, Kearns G, Oken B, Sexton G, Nutt J. Exacerbated physical fatigue and mental fatigue in Parkinson's disease. *Mov Disord* 2001;16(2):190–6.
- [9] Scott B, Borgman A, Engler H, Johnels B, Aquilonius SM. Gender differences in Parkinson's disease symptom profile. *Acta Neurol Scand*. 2000;102(1):37–43.
- [10] Shulman LM, Taback RL, Rabinstein AA, Weiner WJ. Non-recognition of depression and other non-motor symptoms in Parkinson's disease. *Parkinsonism Relat Disord* 2002;8(3):193–7.
- [11] Herlofson K, Larsen JP. The influence of fatigue on health-related quality of life in patients with Parkinson's disease. *Acta Neurol Scand* 2003;107(1):1–6.
- [12] Shulman LM, Taback RL, Rabinstein AA, Weiner WJ. Non-recognition of depression and other non-motor symptoms in Parkinson's disease. *Parkinsonism Relat Disord* 2002;8(3):193–7.
- [13] Menza MA, Kaufman KR, Castellanos A. Modafinil augmentation of antidepressant treatment in depression. *J Clin Psychiatry* 2000;61(5):378–81.
- [14] Rammohan KW, Rosenberg JH, Lynn DJ, Blumenfeld AM, Pollak CP, Nagaraja HN. Efficacy and safety of modafinil (Provigil(R)) for the treatment of fatigue in multiple sclerosis: a two centre phase 2 study. *J Neurol Neurosurg Psychiatry* 2002;72(2):179–83.
- [15] Fahn S, Elton RL, Members of the UPDRS development committee. Unified Parkinson's Disease Rating Scale. . In: Fahn S, Marsden CD, Calne DB, editors. *Recent developments in Parkinson's disease*. Florham Park, NJ: Macmillan Health Care Information; 1987. p. 153–64.
- [16] Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol* 1989;46(10):1121–3.
- [17] Schwartz JE, Jandorf L, Krupp LB. The measurement of fatigue: a new instrument. *J Psychosom Res* 1993;37(7):753–62.
- [18] LaChapelle DL, Finlayson MA. An evaluation of subjective and objective measures of fatigue in patients with brain injury and healthy controls. *Brain Inj* 1998;12(8):649–59.
- [19] Schwab RS, England AC. Projection technique for evaluating surgery for Parkinson's disease. In: Gillingham FJ, Donaldson MC, editors. *Third symposium on Parkinson's disease*. Edinburgh: Livingstone; 1969.
- [20] QSR N5. QSR International Pty Ltd, 2000.
- [21] Rhoten D. Fatigue and the postsurgical patient. In: Norris C, editor. *Concept clarification in nursing*. Rockville: Aspen Systems Corporation; 1982. p. 277–300.
- [22] Cohen JA. A coefficient of agreement for nominal scales. *Educ Psychol Meas* 1960;20:37–46.