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The Comprehensive Anxiety and Parkinson's Scale (CAPS): co-development and initial validation of the long (CAPS-54) and short (CAPS-24) versions

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ABSTRACT

Purpose: Anxiety is a prevalent symptom of Parkinson's disease, but is often under-recognised and challenging to characterise. The present study aimed to develop a comprehensive new scale that characterised the specific and nuanced experience of anxiety in people living with Parkinson's disease. A shortened version of the scale was also developed. The psychometric properties of both versions of the scale were assessed for reliability and validity.

Methods: Secondary analyses were conducted on data from 254 people with Parkinson's disease and anxiety collected in a modified Nominal Group Technique ranking survey. Secondary analyses included exploratory factor analysis, reliability and validity analyses, and confirmatory factor analysis.

Results: A standardised scale of anxiety and Parkinson's disease, in its long Comprehensive Anxiety and Parkinson's Scale – 54 (CAPS-54) and short versions (CAPS-24), was developed. Reliability and validity analyses of the scales demonstrated excellent factorial and internal consistency, as well as good convergent validity.

Conclusions: The CAP Scales offer researchers and clinicians a more comprehensive means of assessing the experience of anxiety in the context of Parkinson's disease than is currently available. Initial validation of the scales is promising. Future validation and identification of clinical boundaries with an independent sample is recommended.

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KEYWORDS

Parkinson's disease; anxiety; measurement scale; measure development; patient and public involvement

► IMPLICATIONS FOR REHABILITATION

- Anxiety is a prevalent but under-recognised symptom of Parkinson's disease; current assessment measures focus on common anxiety presentations.
- The Comprehensive Anxiety and Parkinson's Scales (CAP-54 and CAP-24) offer a more comprehensive means of assessing the experience of anxiety in the context of Parkinson's disease than is currently available.
- Using the CAP Scales may allow therapists to better tailor their interventions to the specific form of anxiety that their patients with Parkinson's may experience.

Introduction

Anxiety is a commonly experienced symptom of Parkinson's disease [PD; 1], with an estimated prevalence of 31% [2]. The experience of anxiety among people living with Parkinson's (PLWP) is thought to be under-recognised and undertreated [3].


It is argued that a better understanding of anxiety experienced by PwP will lead to more timely identification and patients receiving more appropriate and effective intervention tailored to their specific needs [1,4,5]. A recent set of surveys identified that whilst anxiety in PwP shares many characteristics of anxiety in the general population, three quarters of anxiety factors were impacted by the experience of Parkinson's [6].

A review of anxiety measures for PwP highlighted that existing anxiety scales omitted fundamental clinimetric information and showed inadequate evidence of validity in this population [7]. This drove the development of the Parkinson's Anxiety Scale [PAS;

4]. It was claimed that this was an accurate and reliable measure of anxiety for use with PwP which could be administered quickly and easily [8,9]. Whilst this brief measure of only 12 items is quick to administer, it has since received significant criticism. A recent systematic review found that the PAS was less sensitive to anxiety in adults with Parkinson's, than the Geriatric Anxiety Inventory [GAI; 10]. Notably, the internal consistency of the avoidance subscale is relatively low [11]. Moreover, Pontone and colleagues [3] have suggested that the PAS focuses on common anxiety presentations and not the unique experience of anxiety for PwP. This supports the argument for the development of an accurate and reliable measure specifically for anxiety in PwP [8,12].

To characterise the experience of anxiety for PwP, Curran and colleagues [6] conducted a mixed-methods study, co-developed with two lay advisers with lived experience of Parkinson's and anxiety. Survey questions relating to the characterisation of anxiety

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experiences in PwP, were generated in a two-stage process using a modified Nominal Group Technique. Firstly, the qualitative accounts of anxiety from 205 PwP were collected and analysed (16,503 words). These accounts were coded into 137 unique statements. Finally, in a ranking survey, 341 PwP and anxiety rated these statements on a five-point Likert scale according to the representiveness or impact of their experience.

Aims

- To use the ranking survey data [6], to develop and validate a comprehensive standardised psychometric scale of anxiety for PwP that characterised the specific and nuanced experience of anxiety in PwP
- To develop a long and short form of this scale.
- To assess the psychometric properties of both versions of the scale in terms of reliability (e.g., internal consistency) and validity (e.g., factorial and convergent).

Methods

Design

Scale development and validation analyses were conducted on the modified Nominal Group Technique ranking survey data of anxiety experiences of PwP [6].

Participants

Curran and colleagues [6], collected ranking data from 341 participants recruited from the Research Support Network of Parkinson's UK and Parkinson's UK support groups. The inclusions criteria required participants to be 18 years old and above, able to read and write in English, and to have a self-reported diagnosis of Parkinson's. Participants self-identified as having experience of anxiety by agreeing with the statement "Since your Parkinson's diagnosis, [you] have experienced stress, worry or anxiety to an extent that has reduced your quality of life or sense of wellbeing." It was agreed with ethics that the ability of participants to

complete the survey effectively excluded those with any significant degree of dementia and demonstrated capacity to consent. PwP who had historic experience of anxiety were allowed to complete the ranking survey but 70% of participants exceeded the PAS threshold for a current anxiety disorder (>13) [4].

For the current study, 87 participants were excluded due to insufficient data for the purposes of scale development analysis. Data were deemed to be missing at random and were deleted listwise. Using this method, an entire case was excluded if any response value on any item was missing. Therefore, this study used data from 254 participants. Participant characteristics are described in Table 1.

Ranking survey data

This scale development study used the final dataset generated by Curran and colleagues [6]. This contained participant Likert ratings for each of the 137 unique statements (supplementary file 1) indicating the representativeness or level of impact of each statement in relation to their experience of anxiety. A 5-point Likert scale was used. Further details of the methodology and analysis are reported elsewhere [6].

Parkinson's Anxiety Scale (PAS)

Curran and colleagues [6] administered the PAS [4] as a standardised measure of anxiety in Parkinson's. This is a 12-item self-report measure with items reflecting three subscales; persistent anxiety (5 items), episodic anxiety (4 items) and avoidance behaviours (3 items). For each item participants respond using a 5-point Likert scale, ranging from 0 (not at all or never) to 4 (severe or almost always), with a total score of 48. The internal consistency for the PAS within a Parkinson's population is reasonable (Cronbach's $\alpha=0.87$) for the measure as a whole [4,8], and as follows for the sub-scales: persistent anxiety ($\alpha=0.88$), episodic anxiety ($\alpha=0.78$) and avoidance behaviour ($\alpha=0.67$) [5]. The PAS was used for assessing the convergent validity of both versions of the new scale as part of our scale development and validation process [13].

Ethical approval

The study by Curran and colleagues [6] received ethical approval from the University of East Anglia (UEA) Faculty of Medicine and Health Sciences Research Ethics Committee (FMH REC) on 10/01/2019, reference number: 2018/19-046. Additional ethical approval for the specific secondary analyses of the current study was subsequently confirmed by the FMH REC on 27/02/2020, reference number 2019/20-068. All stages of the research adhered to the British Psychological Society (2010) guidelines [14].

Steering group membership

Two lay advisors with lived experience of anxiety and Parkinson's, JM and RC, were recruited from Parkinson's UK Research Support Network. They were involved in the Curran et al. [6] study and in the development of the two versions of the scale described in this paper. JM and RC independently reviewed, completed and provided feedback on the content, design, presentation, and experience of completion. The steering group also included perspectives of a clinical neuropsychologist (CF), applied social psychologist (KB), cognitive behavioural therapist (CIC), trainee

Table 1. Characteristics of participants.

Variable	Frequency (%) N=254	Mean (SD)	Range
Age (Years)		65.7 (8.5)	38–83
Female	107 (42.1)		
Male	147 (57.9)		
Race			
White	251 (98.8)		
Black or Black British	1 (0.4)		
Other minority races*	1 (0.4)		
Other	1 (0.4)		
Sexual Orientation			
Heterosexual/Straight	243 (95.7)		
Bisexual	6 (2.4)		
Homosexual/Gay	1 (0.4)		
Other	1 (0.4)		
Prefer Not to Say	3 (1.2)		
Years Since Parkinson's Diagnosis		5.4 (4.4)	0–31
PAS (Total Score, Max = 60)		29.8 (8.8)	12–56
PAS: Avoidance Behaviour (Max = 15)		6.8 (2.7)	3–14
PAS: Episodic Anxiety (Max = 20)		8.1 (3.3)	4–20
PAS: Persistent Anxiety (Max = 25)		14.9 (4.3)	5–25

*Other minority races' included participants who identified as being from Asian, or Mixed/Multiple or Other racial groups.

clinical psychologists (DC, CIC) and a health researcher in Parkinson's research who has personal experience of a functional movement disorder (KD).

Data analysis

Data analysis was completed in three main phases:

1. Development of the scale and its underlying factor structure via exploratory factor analysis (EFA) and initial validation
2. Development of the shortened version of the scale via a scale reduction optimisation strategy and initial validation
3. Confirmation of the factor structure of the shortened version of the scale via confirmatory factor analysis (CFA) and initial validation

Scale development and initial validation

Scale development and initial validation was conducted using IBM SPSS Statistics software [Version 25.0; 15]. Firstly an EFA was carried out on the 137 items to identify underlying dimensions of anxiety experienced by PwP. Then a principal axis factor analyses were conducted with a direct oblimin rotation. An oblique rotation was adopted because it was predicted that the underlying dimensions of anxiety experienced by PwP would be interrelated. Next, factor extraction was based on an eigenvalue of greater than 2.0 and a confirmatory inspection of the scree plot. For the interpretation of the extracted factors, item loadings with a value of $< .30$ were considered for deletion [16,17]. All items with high cross-loadings, meaning those with secondary loadings with a value of $.30$ or more, were deleted. Items with primary factor loadings with a value of $.30$ or less were also deleted. The strength of the factor loadings was evaluated using Kline's recommendations [18], with loadings considered moderately high if above $.3$ and considered high if above $.6$.

Next the internal consistency of each factor was assessed using Cronbach's alpha [11], based on the criterion that alpha values of at least $.70$ represent good reliability. In line with Cronbach's [11] recommendation, reliability analyses were applied separately to each subscale, to ensure that the subscales are reliable measures of the components of anxiety they are assessing. This is particularly important if the subscales are to be used independently in future clinical practice or research. Applying reliability analyses to each subscale separately also accounts for a potentially inflated Cronbach's alpha value in relation to scales with a high number of items. Then to assess convergent validity, correlation analyses (Pearson's r) were performed on the overall and subscale scores of the Comprehensive Anxiety and Parkinson's Scale – 54 (CAPS-54) and the overall and subscale scores of the PAS. Correlations were evaluated as very weak ($r = .00 - .19$), weak ($r = .20 - .39$), moderate ($r = .40 - .59$), strong, ($r = .60 - .79$), or very strong ($r = .80 - 1.0$) [18].

Scale reduction and initial validation

Scale reduction was conducted using the Oasis application [19] in R [20]. Oasis offers an optimisation strategy for shortening scales which is more psychometrically defensible than previous methods of scale reduction, as it considers multiple important criteria simultaneously [19]. Previous methods have, either

assumed that all reliability and validity of a full-length scale is applicable to the shortened version [21], or only required a single criterion of a Cronbach's alpha value equal to, or larger, than $.7$ [20]. In contrast, the multiple criteria considered in Oasis include, Cronbach's alpha, Guttman's λ_2 , part-whole correlation and convergent validity. All subscale items from the CAPS-54, and the PAS for convergent validity, were inputted into Oasis. Oasis identified each possible way that the CAPS-54 items could be combined to make a shortened scale. The item combinations were then analysed and interpreted, to balance scale quality and internal consistency of the subscale scores, in order to establish the most robust combination, i.e., the shortened scale. Next scale quality and internal consistency were evaluated in accordance with a Cronbach's alpha value greater than $.70$ [11], a Guttman's (λ_2) value greater than $.75$, and a part-whole correlation (r_{pt}) value greater than $.90$ [19]. Then assessment of convergent validity was performed using correlation analyses (Pearson's r) were performed on the total PAS and CAPS-24 scores, as well as the total PAS and the CAPS-24 subscale scores. Correlations were evaluated as very weak ($r = .00 - .19$), weak ($r = .20 - .39$), moderate ($r = .40 - .59$), strong, ($r = .60 - .79$), or very strong ($r = .80 - 1.0$) [22].

Confirmation of factor structure of the shortened-version (CAPS-24)

The factor structure of the shortened scale was analysed *via* CFA using EQS 6.1 [23]. The robust maximum likelihood (ML) estimation procedure was used to account for multivariate non-normality of the data. Detection of multivariate non-normality in large samples (200-500 participants) [24] was corrected for, using a robust χ^2 statistic, the Satorra-Bentler scaled statistic (S-B χ^2) [25] and robust indices.

Next goodness-of-fit was assessed using the χ^2 goodness-of-fit index, Robust Comparative Fit Index (RCFI), the Robust Bentler-Bonett non-normed fit index (RNNFI), Robust Root Mean Square Error of Approximation (RRMSEA), and Standardised Root Mean Square (SRMR). Excellent model-to-data fit is typically evaluated in accordance with a RCFI value of $.90$ or greater, a RNNFI value of $.95$ or greater, a RRMSEA value of $.08$ or less, and a SRMR value of $.06$ or less [26-29].

Results

CAPS-54

Following examination of the pattern matrix, whilst employing the aforementioned criteria, a series of factor analyses removed 72 items from the original 137. Therefore, the final EFA included 65 items which loaded on to six factors and accounted for 48.5% of the total item variance. Eleven of these items were identified as having a poor conceptual fit and therefore low face validity and were removed from the EFA solution. This resulted in a simpler 6 factor solution which accounted for a greater amount of variance. The final clean solution included 54 items which loaded on to six factors and accounted for 49.4% of the total item variance. Item means ranged from 1.8 ($SD=0.9$) to 3.6 ($SD=1.2$) on the 5-point Likert scale, and strength of factor loadings ranged from moderately high $.30$ to high $.86$ (Supplementary file 1).

Inspection of item content confirmed that the extracted items could be represented by six dimensions (subscales). Subscale 1 was named "Impact of Parkinson's" and consists of 13 items that reflect concerns about the impact of Parkinson's in the present and future. For example; "my anxiety is triggered or made worse

when I see others at the later stage of Parkinson's," and "when I am anxious, I worry about the rate at which my Parkinson's symptoms progress and how I will cope at their worst." Subscale 2, named "Environment," consists of 11 items that reflect feared, problematic and avoided environmental settings. For example, "my anxiety is triggered or made worse when I am in crowded and/or noisy places," and "my anxiety is triggered or made worse if people are too close and I feel my movement is restricted." Subscale 3, named "Cognitions," consists of 9 items that reflect the content and process of generalised worry and rumination. For example, "there is no fixed focus to my worry; I worry about anything, including irrational things, things I have no control over," and "I blow things out of proportion and make mountains out of molehills." Subscale 4, named "Physical Sensations," consists of 7 items that reflect physiological symptoms of anxiety. For example, "when I am anxious, I experience changes to body temperature," and "when I am anxious, I experience increased sweating." Subscale 5, named "Physical Consequences," consists of 7 items that reflect the consequences, and feared consequences, of Parkinson's and/or anxiety on bodily functions. For example, "my anxiety is triggered or made worse when I am unsure if I can reach the toilet in time," and "when I am anxious, I worry about dribbling and that others will judge me negatively." Subscale 6, named "Anxiety Triggers," consists of 7 items that reflect situations triggering the experience of anxiety. For example, "my anxiety is triggered or made worse when I am alone," and "my anxiety is triggered or made worse when I am not occupied/busy."

The six subscales had excellent internal consistency, with alphas ranging from $\alpha = .84$ to $\alpha = .92$ (Table 2). Factor correlations ranged from weak ($r = .33$) to strong ($r = .65$; Table 2). A strong factor correlation was found between subscale 1 (Impact of Parkinson's) and subscale 5 (Physical Consequences). Correlations between subscale 3 (Cognitions) and subscale 4 (Physical Sensations), and between subscale 4 (Physical Sensations) and subscale 5 (Physical Consequences) were weak. All other subscale factor correlations were moderate.

Analysis of convergent validity found a very strong, positive correlation between the total overall scores on the CAPS-54 and the PAS ($r = .824$, $p < .001$; Table 3). Analysis of convergent validity between the total subscale scores of the CAPS-54 and the PAS ranged from moderate ($r = .43$) to strong ($r = .69$). The strongest correlations were found between the CAPS-54 subscales of "Cognitions" ($r = .69$), "Anxiety Triggers" ($r = .69$), and "Impact of Parkinson's" ($r = .61$), with the PAS subscale of "Persistent Anxiety." Another a strong correlation was found between the CAPS-54 subscale "Environment" and the PAS subscale "Avoidance Behaviour" ($r = .67$). All correlations were significant at $p < .001$ (Table 4).

The final 54 items were shared and discussed with the lay advisors (JM and RC) to establish the order of items, scale and subscale names and overall presentation. In addition, they completed the final scale and provided feedback on the experience

and completion time (mean = 5.5 min). The final measure was named the Comprehensive Anxiety and Parkinson's Scale (CAPS-54; supplementary file 2).

CAPS-24

The aforementioned criteria were used to evaluate the different combinations of the subscale items generated in Oasis. For each subscale, the item combination which scored optimally across the four indices (Cronbach's α , Guttman's λ_2 , part-whole correlation, and Pearson's r) was retained. Subscale 1 (Impact of Parkinson's) was reduced from 13 to 6 items. Subscale 2 (Environment) was reduced from 11 to 5 items. Subscale 3 (Cognitions) was reduced from 9 to 4 items. Subscale 4 (Physical Sensations) was reduced from 7 to 3 items. Subscale 5 (Physical Consequences) was reduced from 7 to 3 items. Subscale 6 (Anxiety Triggers) was reduced from 7 to 3 items. This resulted in a more parsimonious scale of 24-items which still had content validity and reflected the constructs encompassed by each subscale. To ensure content validity, larger subscales retained more items.

The six subscales demonstrated excellent internal consistency with Cronbach's alpha (α) ranging from .77 to .86, Guttman's (λ_2) ranging from .75 to .84, and a part-whole correlation (rpt) ranging from .90 to .94. Analysis of convergent validity between the total overall scores on the CAPS-24 and the PAS found a strong, positive correlation ($r = .820$, $p < .001$; Table 3). The six subscales also demonstrated good convergent validity (Pearson's r), with positive, and statistically significant ($p < .001$) correlations with the PAS subscales (Table 4). The strongest correlations were found between the CAPS-24 subscales of "Cognitions" ($r = .71$), "Impact of Parkinson's" ($r = .61$), and "Anxiety Triggers" ($r = .61$), with the PAS subscale of "Persistent Anxiety." Another a strong correlation was found between the CAPS-24 subscale "Environment" ($r = .67$) and the PAS subscale "Avoidance Behaviour."

The comparison between CAPS-54 and CAPS-24

Confirmatory factor analysis confirmed that the 24-item solution held the same six-factor structure as the 54-item solution. Examination of Mardia's normalised coefficient (14.33) indicated that the data departed from multivariate normality. Subsequently, the robust maximum likelihood (ML) estimation procedure was used. The model displayed a good fit to the data, $S-B \chi^2(51) = 475.35$, $p < .001$, RCFI = .92, RNNFI = .91, SRMR = .06, and RRMSEA = .06 (90% CI = .05–.07).

As with the CAPS-54, the final 24 items were shared and discussed with the lay advisors to establish the order of items and overall presentation. In addition, they completed the final scale and provided feedback on the experience and completion time (mean = 3 min). The final measure was named the Comprehensive

Table 2. CAPS-54 subscale factor correlations and internal consistency.

Subscale	Number of Items	α	Factor correlations						
			1	2	3	4	5	6	
Impact of Parkinson's	13	.92	1.00						
Environment	11	.91	.56	1.00					
Cognitions	9	.87	.54	.49	1.00				
Physical Sensations	7	.84	.45	.51	.33	1.00			
Physical Consequences	7	.87	.65*	.58	.44	.38	1.00		
Anxiety Triggers	7	.86	.58	.48	.52	.42	.48	1.00	

Key. α : Cronbach's Alpha. Good internal consistency was evaluated in accordance with a Cronbach's alpha value greater than .70 [11]. Factors: 1 = Impact of Parkinson's, 2 = Environment, 3 = Cognitions, 4 = Physical Sensations, 5 = Physical Consequences, 6 = Anxiety Triggers. *Factor correlations are considered strong if above .6.

Table 3. Correlations between CAPS-54, CAPS-24, and PAS total scores.

	CAPS-54 Total score	CAPS-24 Total score
PAS Total Score	.824*	.820*

Key. *Correlations are significant at $p < .001$. Correlations were evaluated as very strong ($r = .80 - 1.0$) [18]. A significant, very strong correlation was found between the CAPS-54 and CAPS-24 ($r = .980$, $p < .001$).

Table 4. Correlations between CAPS-54, CAPS-24, and PAS subscales scores.

Scale and subscale	CAPS-54						CAPS-24						
	1	2	3	4	5	6	1	2	3	4	5	6	
PAS													
Persistent anxiety	.61	.47	.69	.44	.47	.69	.61	.49	.71	.39	.38	.61	
Episodic anxiety	.51	.48	.45	.43	.50	.57	.54	.49	.49	.44	.40	.51	
Avoidance behaviours	.51	.67	.46	.48	.45	.43	.53	.67	.48	.41	.41	.39	

Key. CAPS-54 and CAPS-24: 1=Impact of Parkinson's, 2=Environment, 3=Cognitions, 4=Physical Sensations, 5=Physical Consequences, 6=Anxiety Triggers. All correlations are significant at $p < .001$. Correlations were evaluated as very weak ($r = .00 - .19$), weak ($r = .20 - .39$), moderate ($r = .40 - .59$), strong, ($r = .60 - .79$), and very strong ($r = .80 - 1.0$) [18].

Table 5. CAPS-24 subscale internal consistency.

Subscale	Number of items	α	λ_2	r_{pt}
Impact of Parkinson's	6	.85	.84	.94
Environment	5	.86	.84	.94
Cognitions	4	.77	.75	.92
Physical Sensations	3	.83	.78	.90
Physical Consequences	3	.84	.80	.91
Anxiety Triggers	3	.80	.76	.91

Key. α : Cronbach's Alpha; λ_2 : Guttman's; r_{pt} : part-whole correlation. Good internal consistency was evaluated in accordance with a Cronbach's alpha value greater than .70 [11], a Guttman's (λ_2) value greater than .75, and a part-whole correlation (r_{pt}) value greater than .90 [22].

Anxiety and Parkinson's Scale – Short Version (CAPS-24; [Supplementary file 3](#)).

Discussion

The aim of this study was to develop a new standardised psychometric scale that captured the unique and nuanced experience of anxiety in PwP, overcoming limitations of existing measures. Accordingly, the "Comprehensive Anxiety and Parkinson's Scale" was developed in its full (CAPS-54) and shortened (CAPS-24) versions. This offers a significant contribution to meeting the identified need for an accurate and reliable measure of anxiety for PwP [8,12].

For both the CAPS-54 and the CAPS-24, factor analyses confirmed that the extracted items could be represented by six subscales: anxiety triggers, physical sensations, physical consequences, cognitions, environment, and impact of Parkinson's. The psychometric properties of the two versions of the scale were assessed for reliability and validity. The overall scales, and each of the subscales, demonstrated excellent levels of reliability. The lowest subscale alpha value of the CAPS-54 was for "Physical Sensations" ($\alpha = .84$), and for the CAPS-24 was for "Cognitions" ($\alpha = .77$) (Table 5). In contrast, the internal consistency of the avoidance subscale of the PAS is relatively low ($\alpha = .67$) [4], and below the recommended Cronbach's alpha value ($\alpha = .70$) [11]. This supports that both the CAPS-54 and CAPS-24, and all subscales, demonstrated adequate reliability in the current sample.

The overall scales, and each of the subscales, demonstrated good levels of validity. Factorial validity, demonstrated by inter-factor correlations of the EFA, was good. Good convergent validity was demonstrated by a statistically significant, strong and positive correlation between the total scores on both the long and short form of CAPS with the PAS. Good convergent validity suggests that both the long and short forms of the CAPS and the PAS measure dimensions related to the same construct. Correlations between the long and short forms of the CAPS and PAS subscales were also all significant and positive. The CAPS-54 correlations ranged from moderate to strong, whilst the CAPS-24 correlations ranged from weak (borderline moderate) to strong. The stronger correlation coefficients were found between the long and short forms of the CAPS' individual subscales of "Anxiety Triggers," "Cognitions" and "Impact of Parkinson's" and the PAS subscale of "Persistent Anxiety." Another strong correlation was found between both the long and short form of the CAPS subscale "Environment" and the PAS subscale "Avoidance Behaviours." Again, good convergent validity suggests that both the long and short form of the CAPS and the PAS subscales measure related constructs. Further, weaker correlations suggest that both the long and short form of the CAPS may tap additional constructs of anxiety in Parkinson's not captured by the PAS. There were weak correlations between the CAPS-24 subscales "Physical Sensations," and "Physical Consequences" with the PAS subscale "Persistent Anxiety," as well as between the CAPS-24 subscale "Anxiety Triggers" and the PAS subscale "Avoidance Behaviours." This highlights that the CAPS-54 and CAPS-24 may offer a more comprehensive and nuanced understanding of the anxiety experienced by PwP.

The two versions of the scale begin to overcome the limitations of existing measures. Firstly, the psychometric properties indicate improved levels of reliability and good levels of validity. Secondly, the new scales focus on the unique and nuanced experience of anxiety in Parkinson's, as opposed to the PAS which focuses on common anxiety presentations [3]. Despite the comprehensive nature of the new scales, they remain quick and easy to administer (taking between 3 and 5.5 min to complete), in line with a principal strength of the PAS [8,9].

Strengths and limitations

Two comprehensive and nuanced versions of a new measure of anxiety in the context of Parkinson's have been developed, which demonstrate satisfactory clinimetric properties. A primary strength of these scales is that the overall content, design, and presentation were co-constructed by the target population, that is, people with lived experience of Parkinson's and anxiety. Specifically, the content of the scale items was derived from a rich, dataset collected as part of a large survey characterising anxiety in PwP [6], as well as benefiting from co-development through lay advisor input throughout. Lay advisors also provided significant contribution to the scale development process. This has resulted in the development of two versions of the CAPS scale which capture specific experiences of the population in a way not previously achieved. The involvement of lay advisors was instrumental in improving the relevance, quality, and impact of this research [30].

A significant strength of the empirical study relates to the opportunity of conducting secondary analysis on data collected by Curran and colleagues [6], enabling the development of a standardised scale. Strengths of secondary analysis on existing data include enhanced efficiency of research, cost-effectiveness [31,32], the generation of new knowledge [33], and reduction

in participant burden, which have become increasingly valued [32].

Another strength relates to the rigour employed in the development of the two scales. Recommended scale development procedures were adopted, including psychometric evaluation [13]. The rigour employed during scale reduction was achieved through the Oasis application, which offers psychometrically defensible methods compared to previous approaches [22]. Specifically, a range of reliability indices were considered simultaneously, as opposed to sole dependence on Cronbach's alpha.

A major limitation of the study is that the population that provided the data had limited representation of those with more severe disease or from ethnic minorities (Table 1). The length and complexity of the survey inevitably excluded those with poor English reading skills and those with dementia, so these findings are not generalisable to these populations.

Whilst the comprehensive nature of the CAPS-54 is clearly a strength, there are noticeably more items than the existing measure of Parkinson's and anxiety (i.e., PAS). An increased number of items will undoubtedly increase completion time slightly; it took our lay advisers 5.5 min to complete. This factor may be viewed as a limitation. However, Wechsler [34] advises that it is fundamental that, regardless of time constraints, clinicians find the time for comprehensive assessment. Whilst, we agree, it is also important that measures are as accessible as possible to patients and clinicians, and therefore a shortened version (CAPS-24) is offered in addition, which only took our lay advisers 3 min to complete. This provides researchers and clinicians the option to select the version most appropriate to their needs, knowing that each offers adequate reliability and validity. For example, a clinician may prefer to select the longer version (CAPS-54) to help inform comprehensive assessment and psychological formulation, whereas the short version may be preferred for briefer assessment or screening purposes.

Implications for practice and recommendations for future research

Given that the experience of anxiety among PwP is under-recognised and undertreated [3], it is hoped that this new scale will improve the assessment of anxiety in this population. As a result, this could lead to more timely identification and patients receiving more appropriate and effective intervention [1,4,5]. What is more, the comprehensive and rich nature of the information gathered by patients who complete either scale, could help guide psychological formulation and treatments. This may be of particular use to psychological or therapeutic practitioners who have limited knowledge of the character of anxiety experienced by many PwP.

It is recommended that future research further validates the CAPS-54 and CAPS-24 with independent samples. This is required to confirm the factor structure, as well as reliability and validity of both versions of the scale and their subscales. Additionally the threshold score for anxiety levels that impact significantly on quality of life could be identified. Future work should ensure more diverse populations are examined in order to ensure the measures are culturally relevant and robust. In the independent sample, appropriateness of the scales could be explored for subgroups of the Parkinson's population (e.g., people with different Parkinson's phenotypes, or at different levels of symptom severity). Findings from such research could inform clinical practice to better support PwP and anxiety. Whilst feedback from lay advisors has been encouraging, it is important to extend our understanding of the

acceptability of these scales in the wider Parkinson's population. This could be achieved through focus groups that include people with lived experience, their families, carers, and clinicians. Acceptability and utility of the new scales could also be explored in clinical settings.

Conclusion

This empirical paper generates and provides initial validation for two versions of a new psychometric scale of anxiety for PwP, overcoming limitations of existing measures. In doing so, it offers an exciting contribution to the field that may aid clinicians and researchers to capture the specific and nuanced experience of anxiety for PwP.

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References

- [1] Dissanayaka NNW, White E, O'Sullivan JD, et al. The clinical spectrum of anxiety in Parkinson's disease. *Mov Disord.* 2014; 29(8):967–975. doi:10.1002/mds.25937.
- [2] Broen MP, Narayen NE, Kuijff ML, et al. Prevalence of anxiety in Parkinson's disease: a systematic review and meta-analysis. *Mov Disord.* 2016;31(8):1125–1133. doi:10.1002/mds.26643.
- [3] Pontone GM, Dissanayaka N, Apostolova L, et al. Report from a multidisciplinary meeting on anxiety as a non-motor manifestation of Parkinson's disease. *NPJ Parkinsons Dis.* 2019;5(1):30. doi:10.1038/s41531-019-0102-8.
- [4] Leentjens AF, Dujardin K, Pontone GM, et al. The Parkinson Anxiety Scale (PAS): development and validation of a new anxiety scale. *Mov Disord.* 2014;29(8):1035–1043. doi:10.1002/mds.25919.
- [5] Weintraub D, Burn DJ. Parkinson's disease: the quintessential neuropsychiatric disorder. *Mov Disord.* 2011;26(6):1022–1031. doi:10.1002/mds.23664.

- [6] Curran D, Deane K, Ford C, et al. Characterisation of anxiety experiences in Parkinson's disease: a mixed methods investigation. *Disabil Rehabil.* (submitted).
- [7] Leentjens AF, Dujardin K, Marsh L, et al. Anxiety rating scales in Parkinson's disease: critique and recommendations. *Mov Disord.* 2008;23(14):2015–2025. doi:10.1002/mds.22233.
- [8] Dissanayaka NNW, Torbey E, Pachana NA. Anxiety rating scales in Parkinson's disease: a critical review updating recent literature. *Int Psychogeriatr.* 2015;27(11):1777–1784. doi:10.1017/S1041610215000885.
- [9] Martinez-Martin P, Rodriguez-Blazquez C, Forjaz MJ, et al. Measurement of nonmotor symptoms in clinical practice. *Int Rev Neurobiol.* 2017;133:291–345. doi:10.1016/bs.irn.2017.04.001.
- [10] Mele B, Holroyd-Leduc J, Smith EE, et al. Detecting anxiety in individuals with Parkinson disease: a systematic review. *Neurology.* 2018;90(1):e39–e47. doi:10.1212/WNL.0000000000004771.
- [11] Cronbach LJ. Coefficient alpha and the internal structure of tests. *Psychometrika.* 1951;16(3):297–334. doi:10.1007/BF02310555.
- [12] Martinez-Martin P, Leentjens AFG, de Pedro-Cuesta J, et al. Accuracy of screening instruments for detection of neuro-psychiatric syndromes in Parkinson's disease. *Mov Disord.* 2016;31(3):270–279. doi:10.1002/mds.26522.
- [13] Clark LA, Watson D. Constructing validity: new developments in creating objective measuring instruments. *Psychol Assess.* 2019;31(12):1412–1427. doi:10.1037/pas0000626.
- [14] British Psychological Society. Code of human research ethics. 2nd ed. Leicester (UK): British Psychological Society; 2014. <https://www.bps.org.uk/news-and-policy/bps-code-human-research-ethics-2nd-edition-2014>
- [15] IBM Corp. IBM SPSS statistics for windows (version 25.0) [Computer software]. New York: IBM Corp; 2017.
- [16] Nunnally JC. Psychometric theory. 2nd ed. New York: McGraw-Hill; 1978.
- [17] Tabachnick BG, Fidell LS. Using multivariate statistics. 2nd ed. New York: Harper and Row; 1983.
- [18] Kline P. The handbook of psychological testing. 2nd ed. Abingdon: Routledge; 2010.
- [19] Cortina JM, Sheng Z, Keener SK, et al. From alpha to omega and beyond! A look at the past, present, and (possible) future of psychometric soundness in the *Journal of Applied Psychology*. *J Appl Psychol.* 2020;105(12):1351–1381. doi:10.1037/apl0000815.
- [20] R Core Team. R: a language and environment for statistical computing [Computer software]. R Foundation for Statistical Computing; 2014. <https://www.r-project.org>
- [21] Smith GT, McCarthy DM, Anderson KG. On the sins of short-form development. *Psychol Assess.* 2000;12(1):102–111. doi:10.1037/1040-3590.12.1.102.
- [22] Evans JD. Straightforward statistics for the behavioral sciences. Boston: Thomson Brooks/Cole Publishing; 1996.
- [23] Bentler PM, Wu EJC. EQS 6 for windows: user's guide. Multivariate Software. Los Angeles: University of California; 2002.
- [24] West SG, Finch JF, Curran PJ. Structural equation models with nonnormal variables: problems and remedies. In: Hoyle RH, editor. Structural equation modeling: concepts, issues and applications. London: Sage; 1995. p. 56–75.
- [25] Satorra A, Bentler PM. Corrections to test statistics and standard errors in covariance structure analysis. In: Von Eye A, Clogg CC, editors. Latent variables analysis: applications for developmental research. London: Sage; 1994. p. 399–419.
- [26] Hooper D, Coughlan J, Mullen MR. Equation modelling: guidelines for determining model fit. *Electron J Bus Res Methods.* 2008;6:53–60.
- [27] Hu LT, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Eq Model Multidisciplinary J.* 1999;6(1):1–55. doi:10.1080/1070519909540118.
- [28] Marsh HW, Hau KT, Grayson D. Goodness of fit in structural equation modelling. In: Maydeu-Olivares A, McArdle J, editors. Contemporary Psychometrics. Abingdon: Routledge; 2005. p. 275–340.
- [29] Marsh HW, Hau KT, Wen Z. In search of golden rules: comment on hypothesis-testing approaches to setting cutoff values for fit indexes and dangers in overgeneralizing Hu and Bentler's (1999) findings. *Struct Eq Model.* 2004;11(3):320–341. doi:10.1207/s15328007sem1103_2.
- [30] Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf.* 2016;25(8):626–632. doi:10.1136/bmjqs-2015-004839.
- [31] Cheng HG, Phillips MR. Secondary analysis of existing data: opportunities and implementation. *Res Methods Psychiatr.* 2014;26:371–375.
- [32] Doolan DM, Winters J, Nouredini S. Answering research questions using an existing data set. *Med Res Arch.* 2017;5:1–14.
- [33] Magee T, Lee SM, Giuliano KK, et al. Generating new knowledge from existing data. *Nurs Res.* 2006;55(Supplement 1):S50–S56. doi:10.1097/00006199-200603001-00009.
- [34] Wechsler D. Manual for the Wechsler preschool and primary scale of intelligence. New York: Psychological Corporation; 1967.