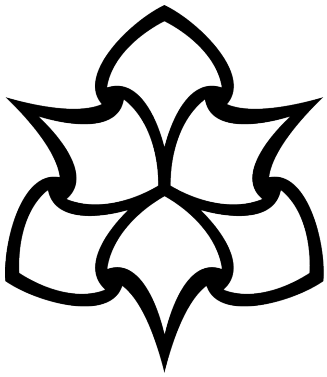

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A new scale measuring adaptive perceived control for people with Parkinson's: initial construction and further validation.

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Abstract

Introduction: Perceived control is an important concept in understanding adjustment to chronic conditions such as Parkinson's. While generic measures have been used to measure the construct in Parkinson's, no Parkinson's-specific scale currently exists. This study outlines the initial development and further validation of a free-to-use scale, the Parkinson's UK Scale of Perceived Control (PUKSoPC).

Method: Focus groups were used to create items for the new scale. Potential items were then subject to screening for readability and coherence by people affected by the condition. This left 49 items that were then completed, along with other measures, by 231 people with Parkinson's. Exploratory factor analysis then created a 15-item scale with five distinct subscales. This initial structure was then further tested using confirmatory factor analysis with 2032 people with Parkinson's. Structural equation modelling confirmed the acceptability of the total scale and subscale structures.

Results: The final scale is concluded to be a psychometrically robust measure of perceived control. It has good face validity, evidence of convergent and criterion (concurrent and divergent) validity, good test-retest reliability and is internally coherent, with a demonstrably solid factor structure. While further testing would be useful to assess the scale's predictive ability, it is currently considered robust enough for more widespread use.

Conclusion: The PUKSoPC is an appropriate scale to provide a more comprehensive measure of perceived control. It is preferable to single item, non-validated measures and can provide evidence of perceptions of control across a number of domains important in the measurement of the construct.

Highlights:

- Perceptions of control are important in determining psychological wellbeing
- No current scale exists to measure adaptive control in people with Parkinson's
- A new psychometrically valid scale is presented
- This scale has excellent psychometric properties and is free to use

Keywords: Parkinson's, control, scale, psychometric, validity, confirmatory factor analysis

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This work was supported by funding from Parkinson's UK [HRA7892]. Parkinson's UK's current 5 year strategy places a focus on 3 main themes: better treatments and a cure; quality services; and taking control. The charity commissioned Lancaster University to develop the control scale in order to create a tool with which to measure perceived levels of control amongst the Parkinson's community in the UK and to be able to measure the success of its strategic aim of increasing the community's reported sense of control. The scale, as a tool applied year on year through the strategic period, provides the charity with evidence of the effectiveness of its interventions within the Taking Control theme. Parkinson's UK coordinated the data collection, facilitated the focus groups and approved the decision to submit the article for publication. The funder was not involved in the analysis nor changed any substantive part of the draft.

Conflict of Interest:

Jane Simpson, Gerasimos Chatzidamianos, Ian Fletcher, Fiona Eccles: None

Luis Perpetuo: Employed by Parkinson's UK

1. Introduction

Perceived control is an important concept in influencing how people adapt to life with a chronic condition such as Parkinson's [1]. For example, higher levels of perceived control correlate with a range of more positive outcomes, such as better mood [2], and higher quality of life generally [3]. Control has been measured as a trait-like variable and this is what is most usually measured in more generic measures of perceived control [4]. However, perceived control can also be experienced over a number of illness-specific domains – e.g., belief in an individual's ability to control the progress of the condition generally and symptoms more specifically [5]. It is also a factor influencing how a condition affects lives outside the more narrow parameters of illness-defined symptomatic experience – e.g., how much control is experienced over access to health services in relation to a condition. In addition, when controlling the condition or symptoms is not possible, the control of emotional reactions and the ability to adapt to a new situation becomes important [6] as well as perceived control over other life domains and living well despite the condition [3]. Evidence also suggests that control can be manipulated therapeutically, with concomitant effects on psychological well-being [7].

However, despite its importance as a theoretical construct [1], no measure of control specifically created for people with Parkinson's currently exists. Previous research employing the theoretical concept has largely used general measures of control over illness [3]. Although these can be useful for making comparisons across patient groups, they are not as sensitive to the specific issues faced by people with such a diverse and unpredictable condition; in this sense they lack 'face validity' as they cannot include items which might not be relevant to a much wider population [8]. Moreover, scales need to be constructed so higher scores are indicative of adaptive levels of perceived control

and this is not possible with single item measures such as ‘how much control do you feel you have over your condition’. For example, a scale where stronger agreement on an item indicative of unrealistic aspirations of control (e.g. I have full control over the progress of my condition’) would result in a higher ‘perceived control’ score. However, this is unlikely to reflect a realistic (or adaptive) sense of control given the limitations faced by individuals with an unpredictable chronic condition [9]. Furthermore, such a scale would not correlate in meaningful ways with other scales where there should be some degree of concurrent validity, such as scales of well-being. Consequently, perceptions of adaptive levels of control are best measured using a range of outcomes considered important for demonstrating perceived control. However, this necessitates detailed preparatory work on a condition-specific basis to identify specific outcomes indicative of effective control across domains considered most important for those with the condition. The measurement of control from an individual perspective is also consistent with the move to incorporate patient reported outcomes (PROMs) in both assessment and outcome studies [10]. These measures privilege the view of the participant and in relation to measures that are concerned with views or perceptions of the self, they are seen as offering an important additional perspective to measures rated by others (e.g. family, other professionals) in PD research [11]. Moreover, condition specific PROMs have been increasingly developed for use with people with Parkinson’s [e.g. 12].

Consequently, this study reports the development of a psychometrically valid scale to measure individuals with Parkinson’s levels of their perception of the effectiveness of their control strategies with respect to their condition. It reports initial validation, with the creation of a provisional factor structure and further validation with a much larger sample.

2. Methods

2.1 Participants

For the scale creation, 49 potential scale items were sent by Parkinson's UK, a UK national charity for people with Parkinson's, to a group of around 1700 people affected by Parkinson's; 236 responses were received, with 231 retained for analysis (see demographic in Table 1). Smaller samples can also be acceptable when communalities are high and factors are strongly determined [13] and using MacCallum et al.'s [13] guidelines a sample of 200 was thought likely to be sufficient.

A second set of data for further validation was collected from 2032 members of Parkinson's UK (see Table 1). The age of participants was again wide-ranging, with 846 (42%) female. This participant number is appropriate given that the purpose of the second sample was to confirm the initial factor solution and is sufficient for asymptotically distribution-free (ADF) estimation.

[Insert Table 1 here]

2.2 Procedure

2.2.1 Initial item generation

The scale was created using best practice guidance for scale creation [14]. Focus groups of people with Parkinson's, recruited from Parkinson's UK, generated ideas to form the basis of the scale's items. Specifically, individuals were asked to consider how they would consider whether they had achieved appropriate and reasonable levels of control of their condition given that they had a chronic condition affecting multiple domains. A range of areas were cited as being potentially affected by perceptions of control – for example, the effects of control on their general well-being – i.e. their stress levels – and their level of external engagement. As already indicated, this much wider sampling of

areas related to control is more sensitive than research which has simply asked single item questions [e.g. 5].

This process led to the generation of an initial pool of 84 items with both positively and negatively worded questions (i.e. reverse scored items). People affected by Parkinson's reviewed these 84 items for face validity, and to ensure readability and acceptability. This resulted in changes to phrasing of some items. In addition, the negatively worded questions were removed as they were thought to be potentially problematic for those individuals who were experiencing difficulties in cognitive flexibility and perseveration. Reverse scored items can also cause contamination of data if respondents are inattentive or become confused. Items were also critically reviewed for length and possible overlap. These assessments led to a final pool of 49 items.

2.2.2 Scale creation

The 49 items, with other demographic and questionnaire items, were sent to potential participants. As part of this initial validation, other data also collected included: standard demographic details (gender, age, age at symptom onset, age at diagnosis, ethnicity, and living arrangements) and two previously validated measures of control to provide data on the new scale's concurrent validity. The two measures were:

General self-efficacy scale (GSE) [15].

This scale assesses individuals' sense of agency, i.e. how much they feel able to overcome difficulties and solve problems in life. It is a well-known scale of general (i.e. non health specific) control with good psychometric properties which has been validated internationally [16] with Cronbach alpha ranging from .75 to .91 [16]. In the current sample α=.94.

Self-efficacy for managing chronic disease-6 item scale [7,17].

This scale also assesses personal agency but in relation to managing a chronic health

condition and continuing with everyday activities despite the condition. It is a short form of the original 32 item scale and has a high internal consistency (α=.91) [17]. In the current sample α=.93.

In order to assess concurrent and divergent validity, we assessed the scale against the emotional well-being and stigma subscales of the Parkinson's Disease Quality of Life Scale (PDQ-39) [18]. This 39-item questionnaire assesses patient-reported quality of life across eight subscales. It is a widely used measure of the construct and has high internal consistency in both its total and subscale structures [19] and in this study, for the stigma subscale, α=.82 and for emotional well-being, α=.91.

Administration and completion of the scale (median completion=24mins) was conducted electronically aided by Smart Survey (https://www.smartsurvey.co.uk/). The work described has been conducted in line with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for studies involving humans. The analysis was reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee, Lancaster University (REF:S2014-72).

For the second stage of the validation, the same data collection and consent procedures were applied. This time, however, only the PUKSoPC was sent to participants.

2.3 Statistical analysis

Most statistical analyses were conducted using the Statistical Package for Social Sciences (SPSS) (version 22.0). Confirmatory factor analysis was conducted using AMOS (version 22.0; IBM Corp.) to fit the Structural Equation Model (SEM). Descriptive statistics (mean, standard deviation [SD]) were assessed. For all analyses, a two tailed p value of $\leq .05$ was used to denote statistical significance.

In order to develop the psychometric properties of the scale for the creation of the initial

solution, intra-item correlations between the 49 potential items of the new scale were examined. Items with mainly low correlations (<.30) with other items were removed as not representing the same underlying construct[20].

A principal axis exploratory factor analysis was then conducted on the remaining items with oblique rotation (direct oblimin, delta = 0). Exploratory factor analysis was chosen as this is suitable for identifying latent constructs [13,21,22] and the principal axis method was utilized as this does not have distributional assumptions [21] and certain items were negatively skewed. Oblique rotation was selected as the factors were expected to correlate and this approach permits examination of how the factors are related [21]. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy tests whether the patterns of correlations are likely to be appropriate for factor analysis. A score of >.8 is considered excellent [23].

Convergent, concurrent and divergent validity was measured using Pearson's r, with scores of ≥0.5 considered acceptable [24].

The confirmatory factor model was tested on the five factor solution previously identified, with a total score also viable and based on the total of the five individual subscales. Parameters were estimated with ADF estimates to yield optimal parameter estimates, due to non-normal distributions [25]. A chi-squared test was used to assess the fitness of the data to the hypothesized model, although it was noted that the chi-square test may report significant difference re model fit with sample sizes N>400 [26].

Model fit indices, such as the comparative fit index (CFI), the root mean square error of approximation (RMSEA), and the chi-squared statistic divided by the degrees of freedom (CMIN/df) were considered. An acceptable model is indicated by a CFI of ≥0.95, an RMSEA of ≤0.06 [27] and a CMIN/df of <3.0 [28].

Modification indices that made a significant contribution to the model (i.e. a modification index value of >10) were adjusted as appropriate; positively correlated error terms were the only modifications applied to the model.

Cronbach's alpha was used for testing the degree of the inter-relatedness among the items in the final solutions. A value above 0.7 is considered acceptable [22]. The presence of floor or ceiling effects were considered if 15% of respondents scored, respectively, the lowest or highest scores on the scale [29].

3. Results

For the initial validation, of the 236 responses received, 231 complete data sets were included.

3.1 Exploratory factor analysis

Eleven items with low correlations with other items were removed [23], reducing the total to 38. After this exclusion, for the data as a whole KMO=.94, with individual items also all above .8.

The remaining items were subject to an exploratory factor analysis. An initial analysis was conducted to obtain eigenvalues for each factor. Using Kaiser's criterion (retaining factors with eigenvalues greater than one), this generated a six factor solution which explained 61.6% of the variance (see Table 2). However, when deciding how many factors to extract, a number of considerations should be taken into account including the need to balance "parsimony" with "plausibility" [21].

[Insert Table 2 here]

Consequently, the number of factors was critically assessed and one of the factors (factor 5) was not felt to be robust enough to stand-alone. A five-factor model was felt to offer a more plausible model with factors that were separate enough to be meaningful.

Considering these various recommendations, the data indicate five clearly interpretable factors: 1) “do things”; 2) “get informed”; 3) “make plans”; 4) “think positive”; and 5) “be involved”.

3.2 Scale construction

When choosing items for the final scale from the structure reported above, items were chosen which had high factor loadings on the intended factor and which appeared to represent the breadth of each construct. To ensure a balanced final scale, three items were chosen from each of the five interpretable factors. As the final factor “get involved” only had two items with significant loadings, a third item was included from the original pool of items, which just missed being included in the initial analyses (see Appendix 1).

A principal axis exploratory factor analysis with direct oblimin rotation, forcing a five-factor solution generated the pattern matrix (see Table 3); the five factors explained 64.8% of the variance (a highly acceptable level of variance). As can be seen all items load ‘cleanly’ onto the expected factor, with no items cross loading.

[Insert Table 3 here]

Correlations were conducted between the final version of the scale with the two other measures of control. As expected, the total score of the new scale correlated highly with the general self-efficacy scale (r=.548; p<.01) and the condition specific measure (r=608; p<.01); this pattern was also replicated for the control scale subscales (all r>.269; all p<.01), indicating good concurrent validity. The correlation between the new control scale and the PDQ-39 subscale of emotional well-being was in the predicted direction (more control, less problems with emotional well-being) and significant (r=-.467; p<.01), indicating convergent validity. Control and stigma, as measured by the PDQ-39, also negatively correlated (r=-.351; p<.01) in the predicted direction (less

control, more problems with stigma), indicating divergent validity.

3.3 Confirmatory factor analysis

As the scale was created on a relatively small sample (*N*=231), it was important to test the model on a larger sample to assess the robustness of the initial factor solution.

Using confirmatory factor analysis, minimization was successful and the data were considered an acceptable fit to the model ([*N*=2031] χ^2=195.42 p<0.001; CMIN/df=2.96, RMSEA=0.03 [90% CI 0.03–0.04], CFI=0.96). Figure 1 (see supplementary material) displays the final model, including correlations, explained variance, and standardized path coefficients for each path. This confirms that the initial factor solution was valid.

No floor or ceiling effects were found for the PUKSoPC total score (percentages of patients achieving low scores, 1.5% and high scores, respectively, 9.9) and the subscales Think Positive (1.5/9.9), Get Informed (1.5/6.2), Make Plans (3.7/6.3) and Be Involved (9.6/5.8). Only the subscale Do Things showed some evidence of a ceiling effect (17.1).

The tests of internal reliability of the subscales (Cronbach alpha; Table 4) and total score were excellent (all α>.75). Test-reliability was also good (r=.80, *N*=84).

[Insert Table 4 here]

4. Discussion

The results of the scale construction reflect a robust approach to the development of the scale items in terms of an effective measurement of a complex construct and comprehensive testing of the initial solution through exploratory and confirmatory factor analysis. In relation to the different types of validity necessary to demonstrate a psychometrically robust scale, we would argue that because of the active input of people with Parkinson's, the scale has good face validity. It is also clear that from a psychometric perspective the initial factor solution held up well to further testing from

the confirmatory factor analysis stage indicating high construct validity. Furthermore, the scale has good concurrent, convergent and divergent validity – as indicated by its significant correlations with other measures of perceived control and other constructs with which it should positively and negatively co-vary – and strong test re-test reliability. Internal consistency on a total scale and subscale basis was excellent.

In terms of further work, clearly the scale would benefit from further validation; in particular its predictive validity – i.e. its ability to predict either psychological indices at a future time or other behavioral measures, such as increased use of health services, that would be expected to be predicted by higher baseline levels of perceived control. Although developed on a UK sample, the questionnaire can be used across population groups; the only possible modification would be to item 15, with the suggested addition of a more local patient support organization. While there is no reason to suggest that the scale would not be suitable for populations outside the UK, data from an international perspective would of course be useful.

Having an effective measure of perceived control means that interventions both on an individual and broader level with people with Parkinson's can now be effectively measured. For example, in some psychological interventions, e.g., cognitive behavioral therapy, control is specifically targeted given its mediating influence on other quality of life domains [30]. On a broader level, in the UK, Parkinson's UK is using the scale to track the change in control on an annual basis from surveys of its members. Finally, the scale is free to use and can be administered both online and in a more traditional paper format.

While the scale measures individuals' perceptions of effective levels of perceived control, it should not be assumed that lower scores necessarily reflect individual

difficulties. While attempts to increase control can be targeted at an individual level, it is more likely that systemic factors are equally or even more important [31]. Furthermore, while strategies for increasing control can be highlighted for individuals to adopt, difficulties reported by people with Parkinson's often relate to societal attitudes and constraints which limit their abilities to exercise control over their life [32]. Consequently, lower scores on this scale should be considered in light of individual and systemic factors even though the measurement of perceived control is at an individual level.

5. Conclusion

To conclude, this scale is a valid and reliable PROM that measures the successful exercise of control over a number of areas most affected by symptoms and also more general domains of control in people with Parkinson's. It shows high test – retest reliability, good convergent, concurrent and divergent validity and excellent construct validity. It is hoped that the scale can be used to measure this important construct and help provide evidence of interventions that can deliver meaningful change.

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Tables

Table 1: Characteristics of samples in first and second validation

	First sample		Second sample	
	Value	Percentage	Value	Percentage
Same size (n)	231		2032	
Mean age in years (SD)	65.9 (9.1)			
Age (n)				
25-34			2	<1
35-44			20	1
45-54			149	7
55-64			317	16
65-74			771	38
75 and over			693	34
Not known			80	4
Gender (n)				
Female	111	48	846	42
Male	118	51	1112	55
Other	0	0	1	<1
Not known	2	1	73	3
Ethnic group (n)				
White British	214	93	1895	93
White Irish	3	1	20	1
Any other white background	10	4	19	1
Asian British	1	<1	0	0
Asian/Asian British - Pakistani	0	0	3	< 1
Asian Chinese	1	<1	1	<1
Any other Asian background	1	<1	0	0
Black/Black British - Caribbean	0	0	1	<1
Mixed - White and Black	0	0	1	<1
Any other Mixed background	0	0	1	<1

Arab	1	<1	1	<1
Any other background	0	0	1	<1
Not known	0	0	89	4
Living arrangements (n)				
Alone	28	12	316	16
With others (partners, family &friends)	197	85	-	-
Live with spouse/partner	-	-	1476	73
Live with family/friends	-	-	94	5
Residential/nursing home	2	1	53	3
Other	-	-	21	1
Not known	4	2	72	4
Clinical data				
Mean age at symptom onset (SD)	57.9 (9.7)	-	-	-
Mean age when diagnosed (SD)	59.7 (9.5)	-	-	-
Time since diagnosis (n)				
Less than 2 years	-	-	271	13
2-10 years	-	-	1197	59
11-20 years	-	-	405	20
21 years and over	-	-	88	4
Not known	-	-	71	4

The category not known includes both those who left the item blank and those who ticked "prefer not to say" when this option was available.

Table 2: Item loadings on the 6 factors

	Factors					
	1	2	3	4	5	6
I try to focus on what I can do, rather than what I can't do				-.343		
When things aren't going well, I know how to make myself feel better				-.519		
I know what to do to stop myself worrying				-.829		
I know how to help myself feel calm in a stressful situation				-.781		
I try to focus on the positives in life				-.640		
I know how to manage my stress levels				-.797		
I know how to manage when I'm feeling down				-.805		
I feel I have accepted Parkinson's in my life				-.368		
I know what helps me manage my physical symptoms as much as possible		.613				
I know how Parkinson's affects me		.567				
I know where to go to find out more information about Parkinson's if I need it		.613				
I know about the different treatment options for Parkinson's		.719				
I know about what forms of exercise or other physical activities are best for me		.461				
I know what are the best foods for me to eat		.469				

I have worked out how to make my Parkinson's medication work best for me		.441		
I try to stay in touch with family and/or friends	.504			
I know who to go to for support when I'm feeling down			.467	
I feel I am a part of a community (local or online)	.307			.328
I know who to go to for help when I'm worried about Parkinson's		.407	.426	
I know I can get support from my family or friends when I'm struggling with Parkinson's				.315
I try to pursue hobbies and other activities I enjoy when I can	.878			
I try to engage in social activities with friends and family when I can	.839			
I try to take part in activities that are good for my physical health	.748			
I try to take part in activities that are good for my mental wellbeing	.777			
I try to keep my brain active	.769			
I try to find ways round challenges so that I can continue to pursue activities I enjoy	.773			
I try to stay as active as I can	.758			
I make time for activities that I enjoy	.822			
I try to pursue activities that I find worthwhile	.850			

I try to live life to the full as much as I can	.743			
I continue to set goals for things I would like to achieve	.405			
I plan how I will manage if my health deteriorates when I am out (e.g., I have an off period)		.535		
I have ways to help me remember to do things		.567		
I organise my diary to ensure that I can manage day-to-day activities		.675		
I ensure my plans are flexible so I can adapt them if I need to		.825		
I set myself targets for things I would like to do		.503		
I share my expertise in Parkinson's with others whenever I can			.773	
I help my family and friends to learn more about Parkinson's			.744	

Note: loadings <0.364 omitted [20]

Table 3: Item loadings on the final 5 factor solution with 15 items

	Final factors				
	1	2	3	4	5
Think positive					
I try to focus on the positives in life	.573				
I know how to manage my stress levels	.866				
I know how to manage when I'm feeling down	.903				
Get informed					
I know what helps me manage my physical symptoms as much as possible				.445	
I know where to go to find out more information about Parkinson's if I need it				.714	
I know about the different treatment options for Parkinson's				.653	
Do things					
I try to engage in social activities with friends and family when I can			.755		
I try to take part in activities that are good for my physical health			.849		
I try to take part in activities that are good for my mental wellbeing			.853		
Make plans					
I have ways to help me remember to do things					.548
I ensure my plans are flexible so I can adapt them if I need to					.949
I set myself targets for things I would like to do					.420
Be involved					

I share my expertise in Parkinson's with others whenever I can	.933
I help my family and friends to learn more about Parkinson's	.722
I am involved with a national organisation (e.g. Parkinson's UK)	.428

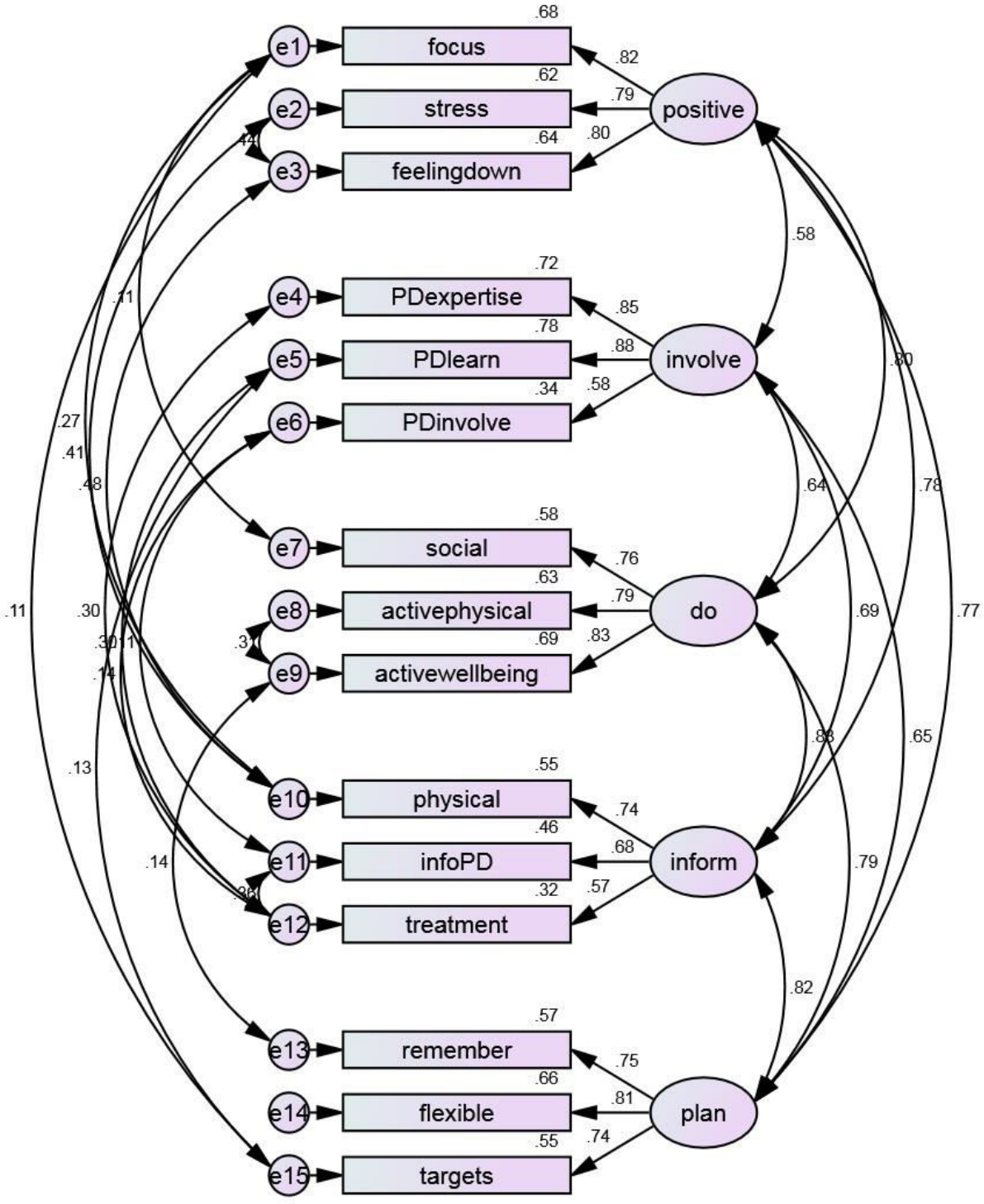
Note: loadings <0.364 omitted [26]

Table 4: Descriptive statistics and internal consistency values for subscales and scale total score in the second validation

	Mean	Standard Deviation	Cronbach alpha
Factor 1: Think positive	10.74	2.79	.87
Factor 2: Be involved	8.30	3.49	.80
Factor 3: Do things	10.84	3.18	.86
Factor 4: Get informed	10.23	2.86	.77
Factor 5: Make plans	9.64	3.01	.79
Total	49.76	12.28	.92

N = 2032: Note: each subscale total could range from 3 to 15 so the theoretical minimum and maximum of the total score are 15 and 75 respectively.

Figure showing final model including correlations, explained variance, and standardized path coefficients for each path.



Appendix 1: The Parkinson's UK Scale of Perceived Control (PUKSoPC)

Please think about how much each of the following statements applies to you and click the appropriate option.

		Not at all	**Only a little**	**Some what**	**Quite a lot**	**Very much**
1	I try to focus on the positives in life					
2	I know how to manage my stress levels					
3	I know how to manage when I'm feeling down					
4	I know what helps me manage my physical symptoms as much as possible					
5	I know where to go to find out more information about Parkinson's if I need it					
6	I know about the different treatment options for Parkinson's					
7	I try to engage in social activities with friends and family when I can					
8	I try to take part in activities that are good for my physical health					
9	I try to take part in activities that are good for my mental wellbeing					
10	I have ways to help me remember to do things					
11	I ensure my plans are flexible so I can adapt them if I need to					
12	I set myself targets for things I would like to do					
13	I share my expertise in Parkinson's with others whenever I can					
14	I help my family and friends to learn more about Parkinson's					
15	I am involved with a national organisation (e.g. Parkinson's UK)					

Scoring instructions

Each item is scored as follows

Not at all	1
Only a little	2
Somewhat	3
Quite a lot	4
Very much	5

To calculate the score for each subscale the answers to the following items should be summed

Think positive	1 2 3
Get informed	4 5 6
Do things	7 8 9
Make plans	10 11 12
Be involved	13 14 15

The total score is the sum of all items (or the sum of the subscales).