



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

Jane Simpson^{a,*}, Gerasimos Chatzidamianos^b, Ian Fletcher^a, Luis Perpetuo^c, Fiona J R Eccles^a

^a Division of Health Research, Lancaster University, Lancaster LA1 4YT, UK

^b Department of Psychology, Manchester Metropolitan University, Manchester M15 6GX, UK

^c Parkinson's UK, Vauxhall Bridge Road, London, UK

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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.

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

* Corresponding author.

E-mail address: j.simpson2@lancaster.ac.uk (J. Simpson).

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 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.

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

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)				
< 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.

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

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