

BACKGROUND

Parkinson's disease is a chronic, neurodegenerative disorder affecting around 145,000 people in the UK. Quality of life (QoL) and treatment satisfaction questionnaires were needed for a research programme on visual hallucination in people with Parkinson's, dementia, or eye disease (SHAPED-TF ID: ISRCTN14435750). Although individualised eye-condition specific QoL and eye treatment satisfaction questionnaires were already available, no such measures were available for Parkinson's¹ or dementia.² Comparable measures were needed to allow the three patient groups to be combined and compared. This poster describes the design of the individualised Parkinson's Dependent Quality of life (Parkinson'sDQoL) and the Parkinson's Treatment Satisfaction Questionnaire (Parkinson'sTSQ).

METHOD

Participants Nineteen people with Parkinson's disease, recruited from Cambridge and Newcastle services, were interviewed about the impact of Parkinson's on their QoL and their experience of treatment to inform the design of the two new questionnaires.

Parkinson'sDQoL A draft Parkinson'sDQoL was modelled on the questionnaire template from the Audit of Diabetes Dependent Quality of Life (ADDQoL).^{3,4} The ADDQoL is a disease-specific, individualised measure of the impact of diabetes on QoL, linguistically validated into 84 languages. The ADDQoL provides a template for new -DQoL instruments in numerous conditions, including the EyeDQoL used in SHAPED. Other -DQoLs include those for aortic aneurysm,⁵ kidney disease,⁶ macular degeneration,⁷ general eye conditions⁸ and HIV.⁹ These in turn have contributed to an item library of 60 items used to create new draft -DQoLs. The initial draft Parkinson'sDQoL included items selected from the item library, guided by the literature on the effects of Parkinson's on QoL.

16 (a)	If I did <i>not</i> have Parkinson's, I would be able to do things for myself:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much more	much more	a little more	the same	less
(b)	For my quality of life, my ability to do things for myself is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very important	important	somewhat important	not at all important	

Figure 1: Example item from the draft Parkinson'sQoL

Parkinson'sTSQ The Parkinson'sTSQ was modelled on a template from the Diabetes Treatment Satisfaction Questionnaire (DTSQ)¹⁰ and library of items from all condition-specific -TSQs. The DTSQ was developed to assess satisfaction with diabetes treatment, and has been used as a template to develop other measures of treatment satisfaction in other conditions, including renal conditions,¹¹ aortic aneurysms⁵ and HIV.¹²

1.	How satisfied are you with your current treatment for Parkinson's?								
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	very satisfied	6	5	4	3	2	1	0	very dissatisfied

Figure 2: Example item from the draft Parkinson'sTSQ

Procedure Participants were asked to complete draft versions of the Parkinson'sDQoL and Parkinson'sTSQ. They were asked to 'think aloud' and were encouraged to make any suggestions for changes to the questionnaires.¹ Draft items were modified, removed and added as needed within and between interviews until no further changes were required.

REFERENCES

- Jenkinson C et al. (1999). Health-related quality-of-life measurement in patients with Parkinson's disease. *Pharmacoeconomics*, 15(2):157-165.
- Smith SC et al. (2007). Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychol Med*, 37(5): 737-746.
- Bradley, C et al. (1999). The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: The ADDQoL. *Quality of Life Research*, 8(8): 79-91.
- Wee, HL et al. (2006). Usefulness of the Audit of Diabetes-Dependent Quality of Life (ADDQoL) questionnaire in patients with diabetes in a multi-ethnic Asian country. *Pharmacoeconomics*, 24(7): 673-682.
- Peach, G et al. (2016) Design of new patient-reported outcome measures to assess quality of life, symptoms and treatment satisfaction in patients with abdominal aortic aneurysm. *Br J Surgery*, 103(8), 1003-1011.
- Bradley, C (1997). Design of a renal-specific individualised quality of life questionnaire (RDQoL) *Perit Dial Int*, 17(S1): S72.
- Mitchell, J & Bradley, C (2004). Design of an individualised measure of the impact of macular disease on quality of life (the MacDQoL). *Qual Life Res*, 13(6): 1163-75.
- Brose, L et al. (2010). Development of the individualised eye-dependent quality of life questionnaire: EyeDQoL. *Qual Life Res*, 19(suppl 1): 29 Abstract #11837
- Romaine J et al. (2015). Design of the HIV Dependent Quality of Life (HIVDQoL) questionnaire and HIV Symptom Rating Questionnaire (HIVSRQ). *Qual Life Res*, 24(suppl 1): 162, Abstract #3035.
- Bradley, C (1994). The Diabetes Treatment Satisfaction Questionnaire: DTSQ. In Bradley C (Ed) (1994) *Handbook of Psychology and Diabetes: a guide to psychological measurement in diabetes research and practice*. Abingdon: Routledge ISBN 9783718655625, formerly published by Harwood Academic Publishers ISBN 3-7186-5562-4; p. 111-132.
- Barendse S et al. (2005). The Renal Treatment Satisfaction Questionnaire (RTSQ): A Measure of Satisfaction with Treatment for Chronic Kidney Failure. *Am J Kid Dis*, 45(3): 572-579.
- Woodcock A et al. (2006). Validation of the revised 10-item HIV Treatment Satisfaction Questionnaire status version (HIVTSQs) and new change version (HIVTSQc). *Value in Health*, 9(5): 320-333.

RESULTS

Participants included 8 women and 11 men ($M=73.17$ years, $SD=6.97$, range=64-83): 3 were single, 16 married. The 23-item Parkinson'sDQoL (see Figure 3) includes 15 items unchanged and 6 modified from the -DQoL library, and 2 new items (making myself understood and taking care of my health). The Parkinson'sTSQ (Figure 4) has 11 items, all from the -TSQ library with no modifications.

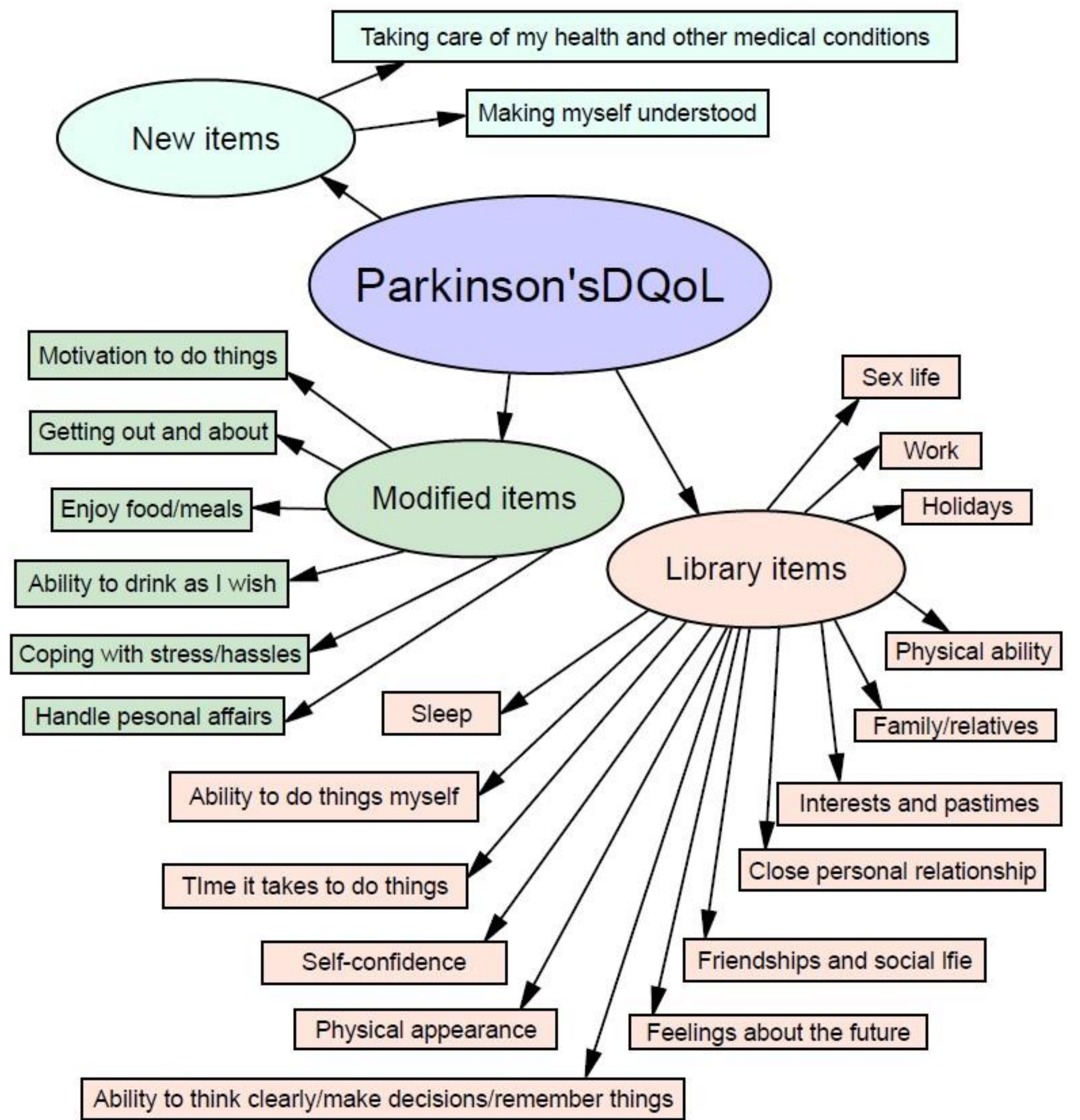


Figure 3: Diagram of items included in the Parkinson'sDQoL

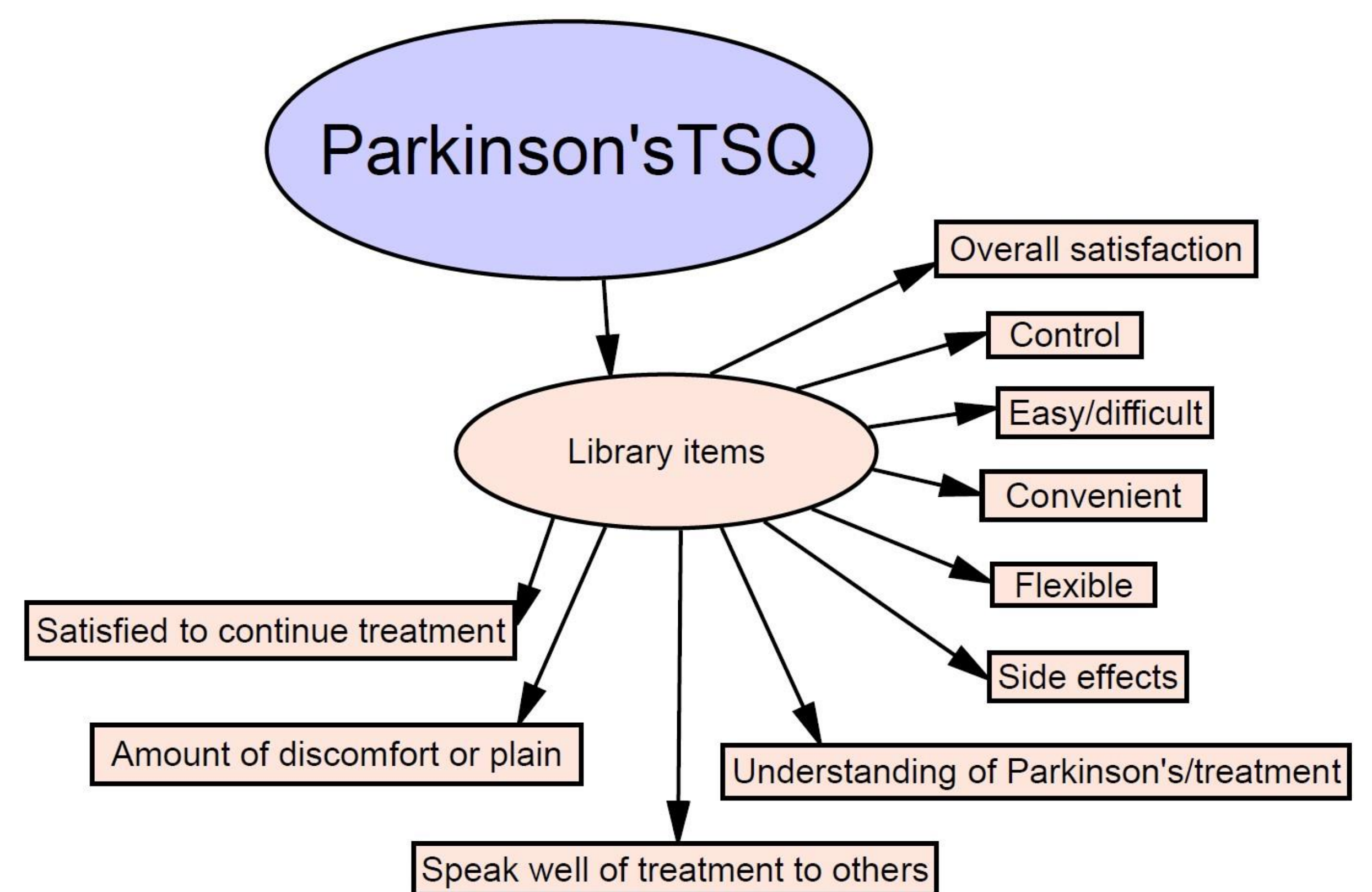


Figure 4: Diagram of items included in the Parkinson'sTSQ

CONCLUSIONS

The existing –DQoL and –TSQ templates and item libraries facilitated the design of new measures for people with Parkinson's with minimal, but important, additions needed. Psychometric analyses are underway to establish the optimal selection of items for scoring on common metrics to allow for comparison with –DQoL and –TSQ measures for other conditions.

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For access to questionnaires developed by Clare Bradley et al. please visit www.healthpsychologyresearch.com

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