

BACKGROUND

Dementia describes a group of illnesses causing progressive decline in cognitive functioning. Dementia affects 850,000 people in the UK. Lack of insight can impact people’s ability to make judgments about the decline in their cognitive ability and health.¹ However, people with dementia are expected to have a view about how good or bad they feel their life to be. This is the definition we use in measuring individualised quality of life (QoL) in the widely used Audit of Diabetes-Dependent QoL (ADDQoL)^{2,3} and sister –DQoL measures for other conditions.⁴⁻⁷ With notable exceptions such as the -DQoLs, existing questionnaires purporting to measure QoL often focus on health status and functioning⁸⁻¹⁰ rather than QoL. Here we wanted a -DQoL measure for dementia (MemoryDQoL) similar to the EyeDQoL measure already available for use in SHAPED (Study of Hallucinations in Parkinson’s, Eye Disease and dementia) and evaluate if an ADDQoL-derived individualised QoL template is suitable for people with mild-to-moderate dementia.

This research describes the design of the individualised MemoryDQoL and the Memory Treatment Satisfaction Questionnaire (MemoryTSQ), using templates and item libraries from the ADDQoL and Diabetes Treatment Satisfaction Questionnaire (DTSQ).^{11,12}

METHOD

MemoryDQoL Items in an initial draft of the MemoryDQoL were selected from the 60-item library from all condition-specific -DQoLs. Item selection was guided by the literature on the effects of dementia on QoL.

5	(a)	If I did <i>not</i> have memory / thinking problems, my friendships and social life would be:				
		☐	☐	☐	☐	☐
		very much better	much better	a little better	the same	worse
	(b)	For my quality of life, friendships and social life are:				
		☐	☐	☐	☐	
		very important	important	somewhat important	not at all important	

Figure 1: Example item from the MemoryDQoL

MemoryTSQ The MemoryTSQ was modelled on the Diabetes Treatment Satisfaction Questionnaire (DTSQ)^{11,12} and the item library stemming from development of this and other condition-specific -TSQs. e.g. 5, 13-14

1.	How satisfied are you with your current treatment for memory / thinking problems?								
	☐	☐	☐	☐	☐	☐	☐	☐	
	very satisfied	6	5	4	3	2	1	0	very dissatisfied

Figure 2: Example item from the MemoryTSQ

Participants Seventeen participants, diagnosed with dementia, were recruited from London and Newcastle as part of a larger UK research programme on visual hallucinations in people with Parkinson’s, dementia, or eye disease (SHAPED-TF ID: ISRCTN14435750).

Procedure Participants completed the Mini Mental State Exam (MMSE) to measure cognitive impairment. Design interviews first discussed the impact of memory problems on QoL and interviewees’ experience of treatment before draft questionnaires were completed while ‘thinking aloud’. Items were added, revised or removed as needed between sets of interviews, until no further changes were required. The wording of the items referred to memory/thinking problems, as some people were unaware that they had a formal diagnosis of dementia, and referred to their condition as ‘memory lapses’ or ‘a bad memory’.

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RESULTS

Four women and 13 men ($M=81$ years, $SD=8.86$, range=65-90) participated in interviews. The average MMSE score was 21.24 ($SD=4.04$, range=15-28), indicating mild-to-moderate cognitive impairment. The MemoryDQoL has 17 items (Figure 3); 11 items were unchanged and five items were modified from library items; one new item was created (making/keeping a plan). The MemoryTSQ has 7 items (Figure 4), all items unchanged from the TSQ library.

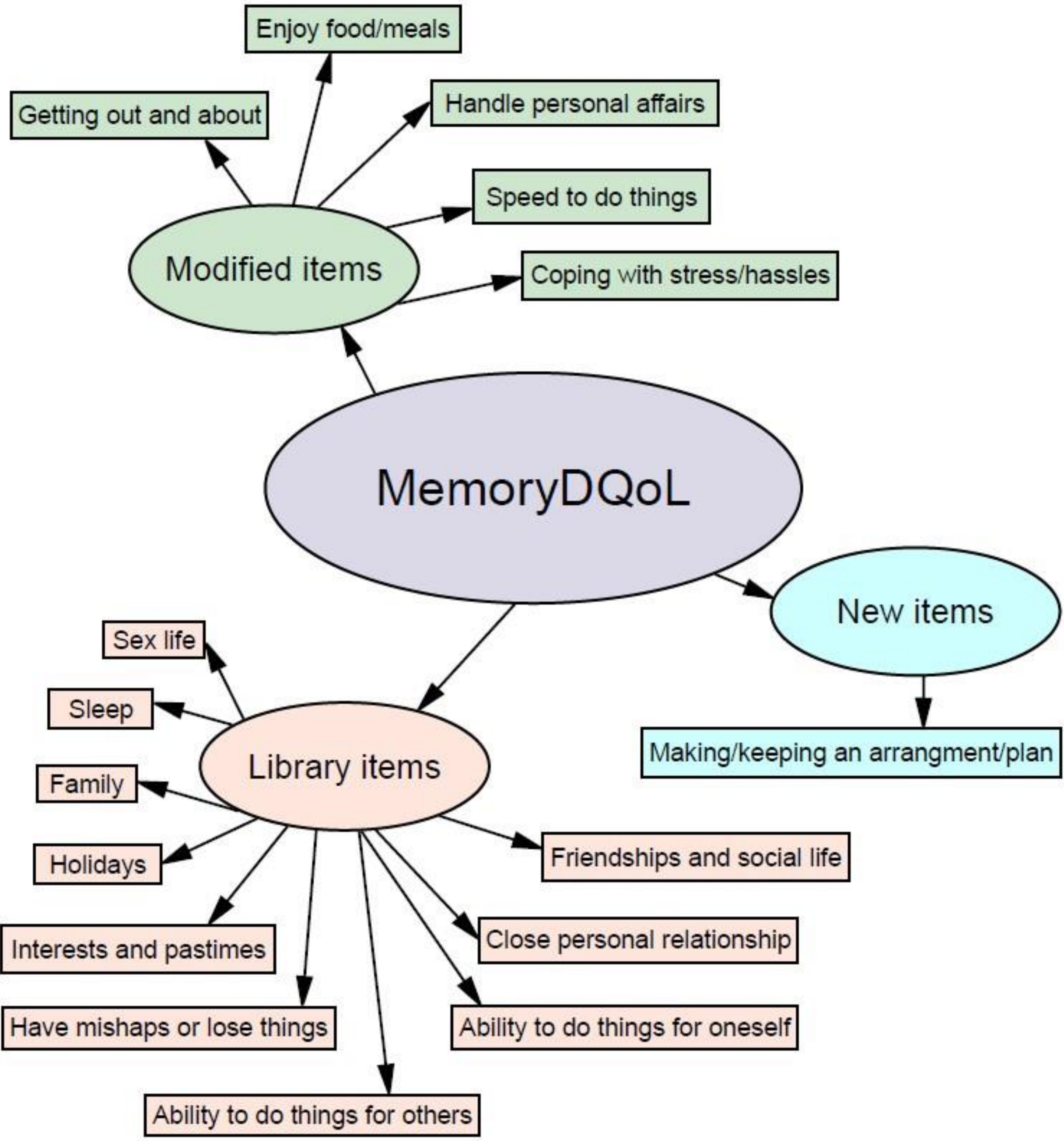


Figure 3: Diagram of items included in the MemoryDQoL

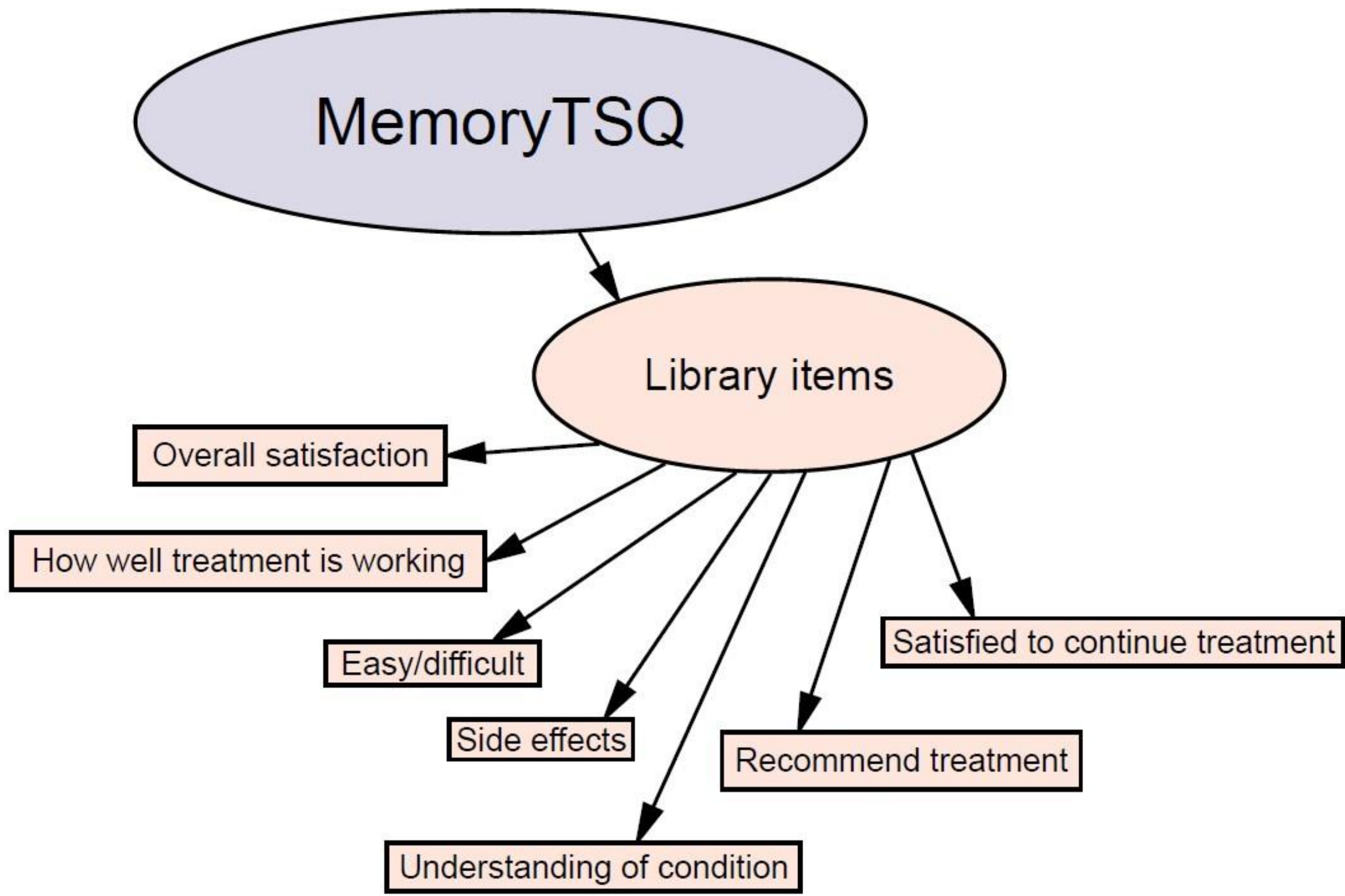


Figure 4: Diagram of items included in the MemoryTSQ

CONCLUSIONS

Although many participants needed help in reading the questionnaires, they were able to understand and respond to the questionnaire format without the need for revisions. Questionnaire design was facilitated by using existing item libraries and validated measures as templates. This allows for future comparisons across different conditions once psychometric analysis, now underway, has determined the optimal scoring of scales.

ENQUIRIES & ACKNOWLEDGEMENTS

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