

BACKGROUND

The Audit of Diabetes Dependent Quality of Life (ADDQoL) is an individualised questionnaire measuring generic QoL (single item) and diabetes-specific QoL (19 item pairs measuring impact of diabetes on 19 aspects of life, and the importance of each aspect for QoL).^{1,2} The ADDQoL is linguistically validated into 84 languages and provides a template for new –DQoL instruments.

11(a)	If I did <i>not</i> have diabetes, my self-confidence would be:				
	☐	☐	☐	☐	☐
	very much better	much better	a little better	the same	worse
(b)	My self-confidence is:				
	☐	☐	☐	☐	☐
	very important	important	somewhat important	not at all important	

Figure 1: Example item from the ADDQoL

To date this includes –DQoLs for retinopathy,³ kidney disease,⁴ macular degeneration,⁵ hypothyroidism,⁶ growth hormone deficiency,⁷ abdominal aortic aneurysms,⁸ general eye conditions⁹ and HIV.¹⁰ These in turn have contributed to an item bank of 60 items used to create new draft –DQoLs.

An ongoing research programme Study of Hallucinations in Parkinson’s, Eye disease and Dementia (SHAPED), provides an opportunity to compare QoL across conditions using different condition-specific -DQoLs.

METHOD

Design: Initial drafts of the AneurysmDQoL, HIVDQoL, Parkinson’sDQoL and MemoryDQoL were constructed using existing bank items, chosen following a review of relevant research and specialist websites and consultations with specialist clinicians. Drafts were refined through patient interviews.

Procedure: For the AneurysmDQoL, nine focus groups and 13 one-to-one interviews were conducted in the UK. For the HIVDQoL, 25 one-to-one interviews were conducted, 14 with UK participants and 11 in the USA. UK interviews with 19 patients were conducted for the Parkinson’sDQoL.. Fifteen patients with dementia and their carers were interviewed for the MemoryDQoL. Interviews were conducted in batches, and questionnaires refined between batches, until no further modifications were required.

RESULTS

The new AneurysmDQoL has 22 domains (16 existing bank items, 5 modified bank items, 1 new item) identified as impacting on the QoL of patients with, or following repair of, an abdominal aortic aneurysm. The HIVDQoL required 26 domains (10 existing, 12 modified and 4 new items). The Parkinson’sDQoL has 23 domains (15 existing, 6 modified & 2 new items). The MemoryDQoL has 17 domains (11 existing, 5 modified, and 1 new item). See Figure 2a,b,c,d for details. Though often few in number, the importance of the new additional items is demonstrated by the HIVDQoL, where the new items were rated as more important for QoL and detected more negative impact than existing/modified items.

CONCLUSIONS

Design of new condition-specific -DQoLs is expedited by using the existing template and item banks with minimal, but important, additions needed. During SHAPED we will be comparing across different condition-specific -DQoLs when evaluating the impact of interventions to prevent hallucinations.

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RESULTS

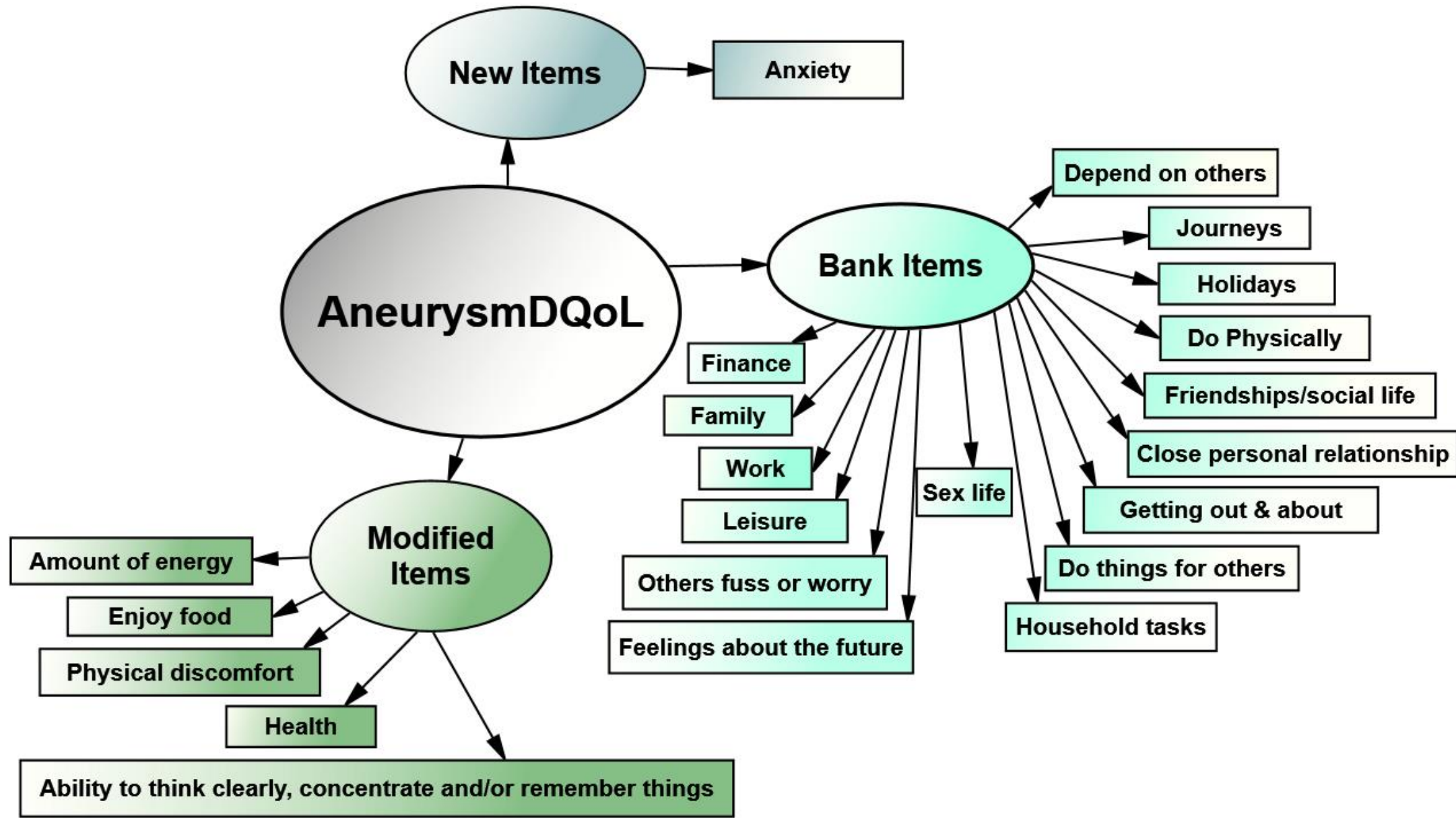


Figure 2a: Diagram of item included in the AneurysmDQoL

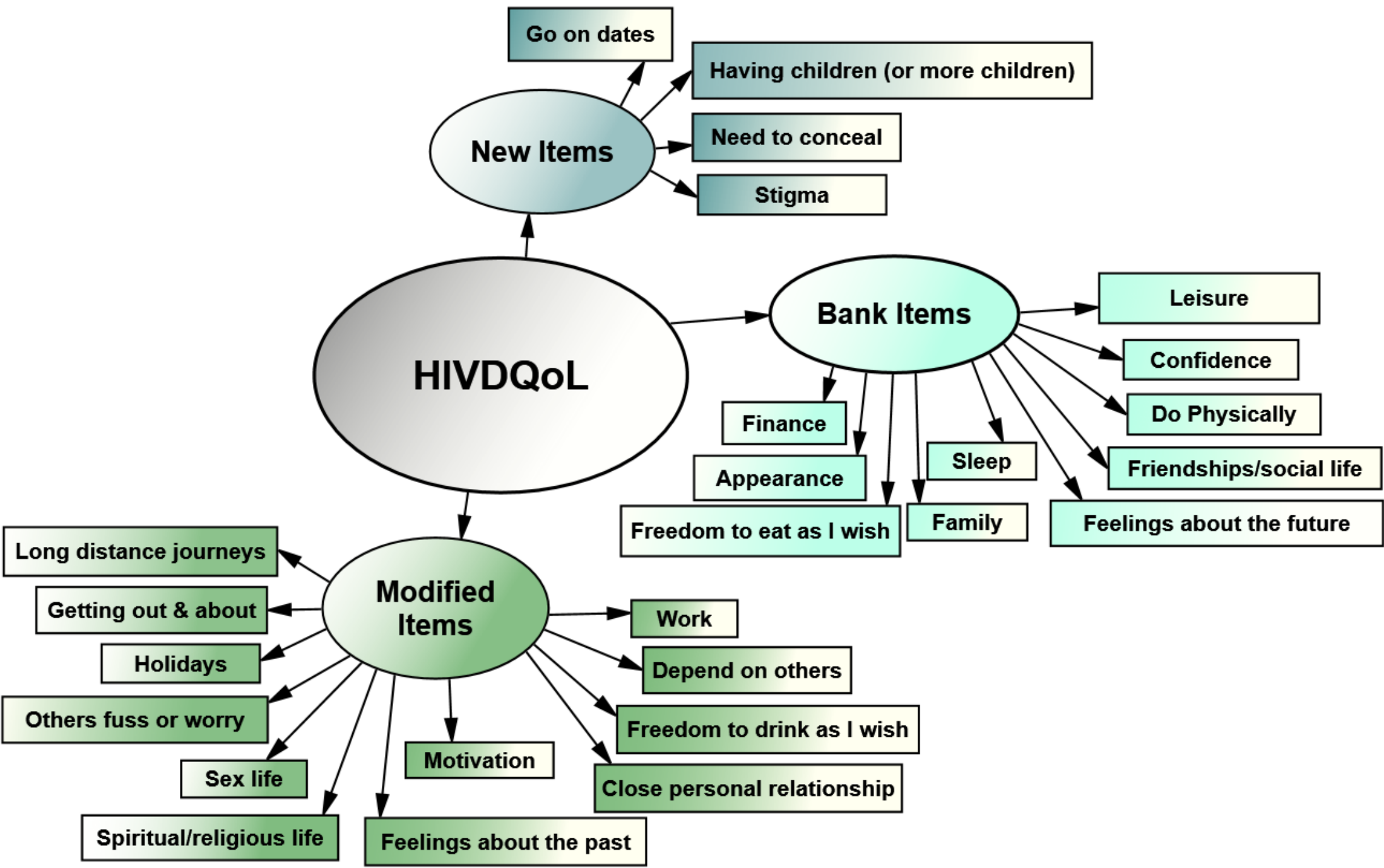


Figure 2b: Diagram of items included in the HIVDQoL

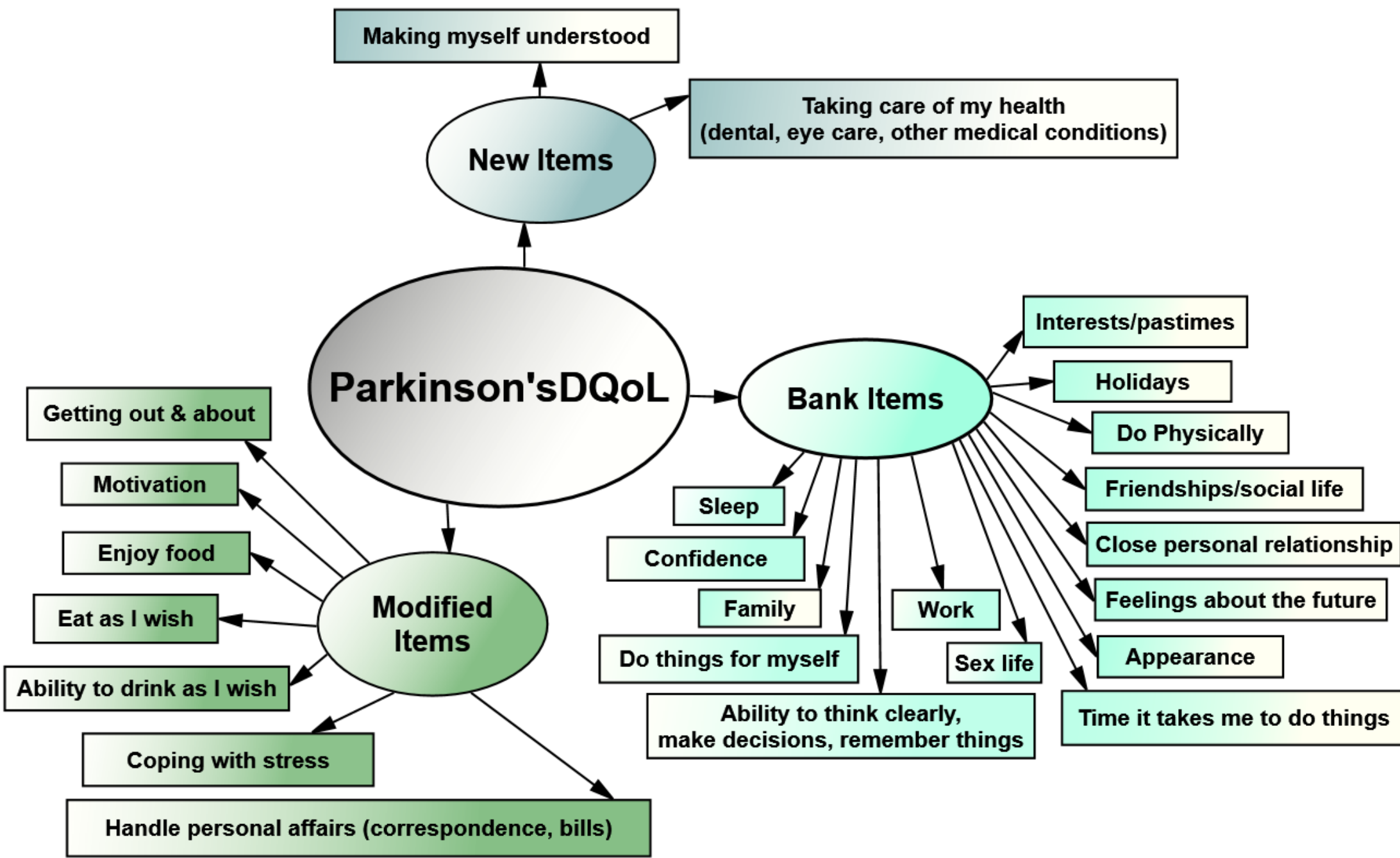


Figure 2c: Diagram of items included in the Parkinson'sDQoL

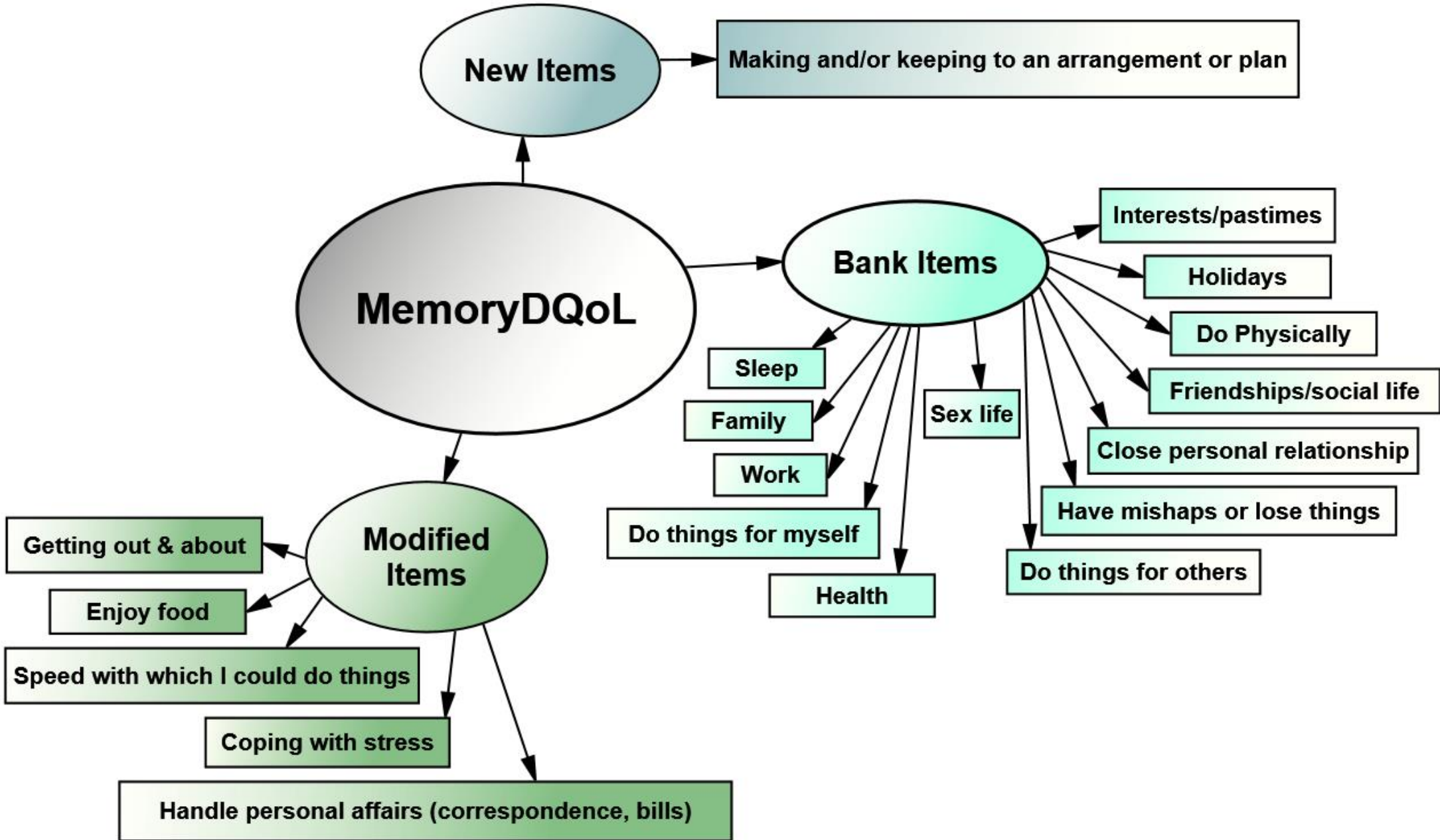


Figure 2d: Diagram of items included in the MemoryDQoL

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