

Design of three new condition-specific questionnaires to assess quality of life, symptoms and treatment satisfaction of patients with abdominal aortic aneurysms: The Aneurysm-DQoL, Aneurysm-SRQ and Aneurysm-TSQ.

George Peach^a, Alison Wilson^{b,c}, Rosalind Plowright^{b,c}, Jacquelyn Romaine^c,
Matt Thompson^a, Rob Hinchliffe^a, & Clare Bradley^{b,c}

^a St George's Vascular Institute, St George's Hospital London, UK ; ^b Health Psychology Research Ltd, UK; ^c Health Psychology Research Unit, Royal Holloway, University of London, UK

INTRODUCTION

An abdominal aortic aneurysm (AAA) occurs when the aortic wall weakens and dilates:¹ see Figure 1. In the UK, AAAs affect 5-10% of men and 1.5% of women between the ages of 65 and 79 and constitute a significant cause of mortality amongst this population.²

The general consensus is that aneurysms between 3.0 and 5.4 cm in diameter should be monitored regularly with ultrasonography and those 5.5 cm and over are repaired.

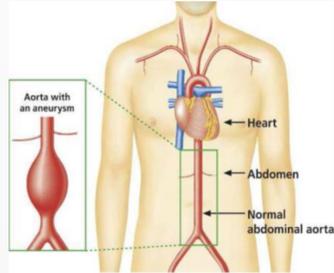


Figure 1: Abdominal Aortic Aneurysm
<https://www.stgeorges.nhs.uk/service/cardiovascular/aaa/>

There are currently two methods of repair: Open Repair (OR, Figure 2) or Endovascular Aneurysm Repair (EVAR, Figure 3).

OR is the traditional method and involves a midline incision and the insertion of a synthetic graft.

EVAR is a less invasive procedure and involves a small incision in the groin through which a stent is inserted. Although EVAR is associated with decreased mortality and inpatient stay it also involves life-long follow up with a potential need of reintervention.³

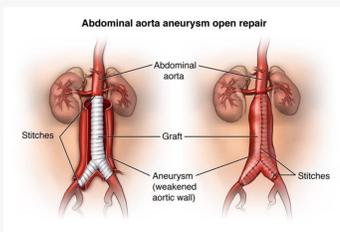


Figure 2: Open Repair

<https://www.urmc.rochester.edu/encyclopedia/content.aspx?ContentTypeID=92&ContentID=P08291>

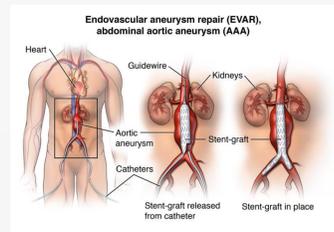


Figure 3: Endovascular Aneurysm Repair

Despite AAA being a diagnosis that may seriously affect patients' lives,⁴ a lack of any condition specific patient reported outcome measures (PROMs) has meant very little is known about the overall impact of AAA or AAA repair on quality of life (QoL) from the perspective of the patient. Additionally, very little is known about symptoms experienced or treatment satisfaction in this patient group.⁵

OBJECTIVES

The present work aimed to design three AAA-specific questionnaires: the Aneurysm-Dependent Quality of Life Questionnaire (Aneurysm-DQoL), Aneurysm Symptom Rating Questionnaire (Aneurysm-SRQ), and Aneurysm Treatment Satisfaction Questionnaire (Aneurysm-TSQ).

METHOD

Forty-one patients with AAA from five NHS Trusts participated in focus group discussions of experiences of AAA. This information guided inclusion of items in the questionnaires, supported by the clinical experience of vascular surgeon co-authors and a bank of items from existing questionnaires developed by CB and colleagues for other conditions.⁶⁻⁸ Initial questionnaire drafts were refined using 13 in-depth interviews with individual patients.

RESULTS

Table 1: Focus Group Participant Details

Details	Operation Type						Total
	OR		EVAR		Monitoring		
Number of focus groups	2		6		1		9
Number of participants: Focus groups	Male	Female	Male	Female	Male	Female	41
	6	2	28	1	4	0	
Number of participants: Interviews	Male	Female	Male	Female	Male	Female	13
	3	0	6	0	4	0	

The qualitative work revealed several previously unrecognised issues for patients with AAA, confirming the importance of AAA-specific PROMs. These included the impact on QoL of self-imposed restrictions on activity, notably patients' avoidance of sexual activity (rather than poor sexual function). Also, follow-up scans were reassuring rather than worrying for patients.

Focus Group / Interview Quotations

Self-imposed restriction of activity:

'I was terrified of doing anything'

Anxiety: 'waiting 18 months and it was getting bigger and bigger and I was on edge waiting for the results'

Scan as reassurance:

'It's a pleasure coming here and being told you're ok'

Anxiety: 'once you have one thing that was completely symptomless you wonder what else you might have wrong with you'

RESULTS

The **Aneurysm-DQoL** has 23 life domains (16 bank, 5 modified, 2 new items) identified as being important to the QoL of patients with AAA: see Figure 4.

The **Aneurysm-TSQ** has 11 items (2 bank, 6 modified, 3 new items): 7 are suitable pre- and post-intervention and 4 are suitable post-intervention only: see Figure 5.

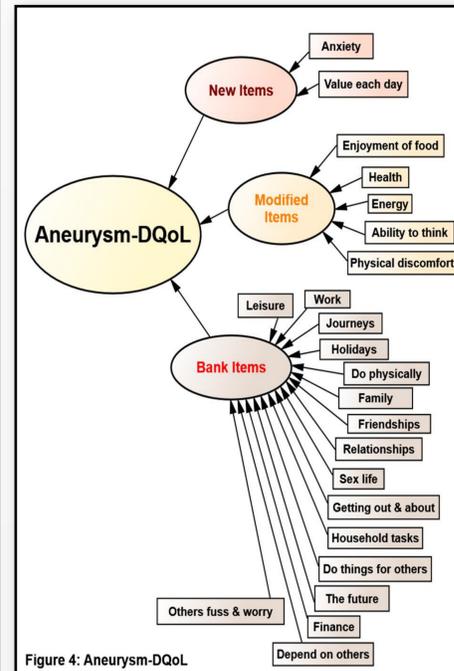


Figure 4: Aneurysm-DQoL

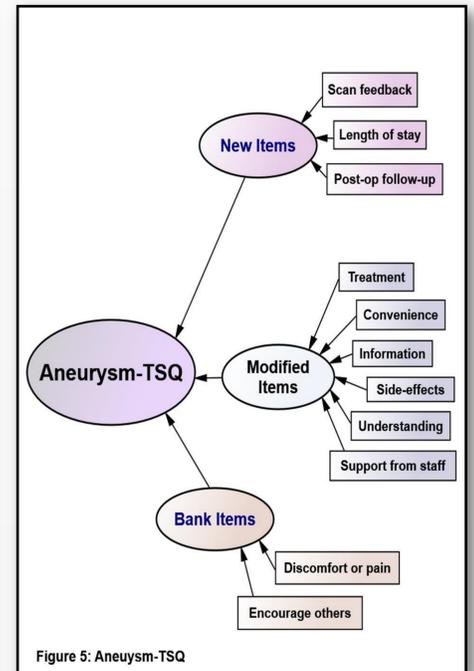


Figure 5: Aneurysm-TSQ

The **Aneurysm-SRQ** is a 44-Item measure, which assesses a wide range of physical and psychological symptoms (16 bank, 14 modified, 14 new items): see Figure 6 below.

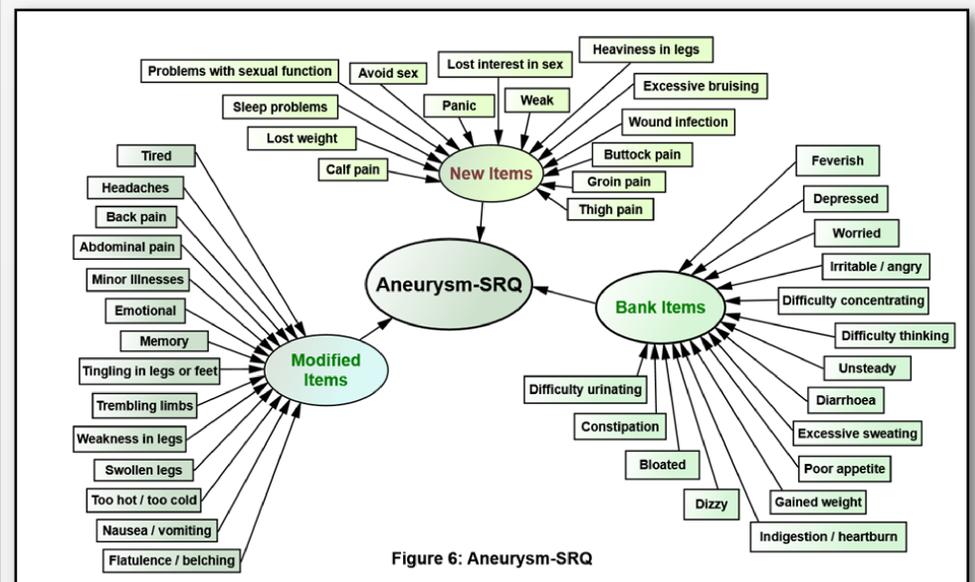


Figure 6: Aneurysm-SRQ

CONCLUSIONS

The detailed development process confirmed that the new tools have good face and content validity for patients with AAA. Item banks were valuable; few new items were needed for Aneurysm-DQoL and Aneurysm-TSQ. Psychometric analyses are reported elsewhere.⁹ The questionnaires are ready for wider clinical use and further validation.

REFERENCES

- Callanan, A., Davis, N.F., Walsh, M.T. & McGloughlin, T.M. (2011). Tissue-engineered extracellular matrices (ECMs) as adjuvant scaffolds for endovascular aneurysm repair (EVAR). In D Eberli (Ed.) *Regenerative medicine and tissue engineering - cells and biomaterials* (pp. 301-322). In Tech [on line] Available: <http://www.intechopen.com/books/regenerative-medicine-and-tissue-engineering-cells-and-biomaterials/tissue-engineered-extracellular-matrices-ecms-as-adjutant-scaffolds-for-endovascular-aneurysm-repair>
- Lucarotti, M., Shaw, E., Poskitt, K. & Heather, B. (1993). The Gloucestershire Aneurysm Screening Programme: The first 2 years. *Eur J Vascular Surg*, 7, 397-401.
- Karthikesalingam, et al., (2010) Risk of reintervention after endovascular abdominal aortic aneurysm repair *Brit J Surg*, 97, 657-663.
- Pettersson, M., Bergbom, I. & Mattsson, E. (2012). Health-related quality of life after treatment of abdominal aortic aneurysm with open and endovascular techniques: A two-year follow-up. *Surg Science*, 3, 436-444.
- Peach, G., Holt, P., Loftus, I., Thompson, M.M. & Hinchliffe, R. (2012). Questions remain about quality of life after abdominal aortic aneurysm repair. *J Vasc Surg*, 56, 520-527.
- Bradley, C., Todd, C., Gorton, T., Symonds, E., Martin, A. & Plowright, R. (1999). The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: The ADDQoL. *Qual Life Res*, 8, 79-91.
- McMillan, C., Bradley, C., Razi, S. & Weaver, J. (2008). Evaluation of new measures of the impact of hypothyroidism on quality of life and symptoms: The ThyDQoL and ThySRQ. *Value Health*, 11, 285-294.
- Woodcock, A. & Bradley, C. (2006) Validation of the revised 10-item HIV Treatment Satisfaction Questionnaire status version (HIVTSQs) and new change version (HIVTSQc). *Value Health*, 9, 320-333.
- Romaine, J., Peach, G., Thompson, M.M., Hinchliffe, R.J. & Bradley, C. (2015). Psychometric development of three new condition-specific questionnaires to measure quality of life (Aneurysm-DQoL), symptoms (Aneurysm-SRQ) and treatment satisfaction (Aneurysm-TSQ) of individuals with abdominal aortic aneurysms. *Qual Life Res*, 24 (suppl 1), 41-42, Abstract # 202.3 doi: 10.1007/s11136-015-1078-4

ENQUIRIES

Corresponding author: Dr Jacquelyn Romaine, Email: jackie.romaine@rhul.ac.uk
Postdoctoral Research Fellow in Health Psychology, Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK.

Access to Questionnaires: Visit www.healthpsychologyresearch.com