

Quality of life, symptoms and treatment satisfaction in patients with aortic aneurysm using new abdominal aortic aneurysm-specific patient-reported outcome measures

G. Peach¹, J. Romaine², P. J. E. Holt¹, M. M. Thompson¹, C. Bradley² and R. J. Hinchliffe¹

¹St George's Vascular Institute, St George's Healthcare NHS Trust, London, and ²Health Psychology Research Ltd, Royal Holloway, University of London, Egham, UK

Correspondence to: Mr G. Peach, c/o St George's Vascular Institute, 4th Floor St James' Wing, St George's Healthcare NHS Trust, London SW17 0QT, UK (e-mail: gpeach@doctors.org.uk)

Background: The aim of this study was to present preliminary data on quality of life (QoL), symptoms and treatment satisfaction gathered using three new abdominal aortic aneurysm (AAA)-specific patient-reported outcome measures (PROMs).

Methods: Patients with AAA were recruited from five National Health Service Trusts to complete the three new PROMs: the AneurysmDQoL, AneurysmSRQ and AneurysmTSQ. Patients were either under surveillance or had undergone AAA repair (open or endovascular) during the preceding 24 months. Data were initially collected as part of a study assessing the psychometric properties of the new measures, before being used in the observational analysis of outcomes presented here.

Results: Results, although largely non-significant, showed interesting trends. The impact of AAA repair on QoL appeared to worsen progressively after open repair (OR) and improve progressively after endovascular aneurysm repair (EVAR). Conversely, symptoms seemed to become progressively worse after EVAR and progressively better after OR. Information and understanding were key sources of dissatisfaction before the intervention, whereas postoperative dissatisfaction was related to bother from symptoms, follow-up and feedback about scan results.

Conclusion: Although a larger, prospective data set is necessary to explore outcomes more fully with the new AAA-specific PROMs, the observational data presented here suggest there may be clinically important differences in the symptoms, impact on QoL and treatment satisfaction associated with OR and EVAR.

Paper accepted 2 March 2016

Published online in Wiley Online Library (www.bjs.co.uk). DOI: 10.1002/bjs.10182

Introduction

Collection of patient-reported outcome data has been mandatory for four common surgical procedures in England since 2009 (hip replacement, knee replacement, hernia repair and varicose vein surgery)¹, but the use of patient-reported outcome measures (PROMs) in other areas of surgery is still not routine. Previous efforts to assess patient-reported outcomes for patients with abdominal aortic aneurysm (AAA) have been hampered by the absence of any truly suitable measures, and the impact of AAA on quality of life (QoL) and other outcomes remains unclear².

The aim of this study was to collect observational data on QoL, symptoms and treatment satisfaction in patients with AAA, during the validation of three new condition-specific questionnaires designed specifically for patients with AAA:

the Aneurysm-Dependent Quality of Life questionnaire (AneurysmDQoL); the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ); and the Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ)³.

Methods

All data presented here were collected as part of a study assessing the psychometric properties of the three new tools and validating them for use by patients with AAA (reported separately)⁴. Once that process had confirmed the structure and validity of the questionnaires and identified reliable subscales, data were used to compute patients' scores for QoL, symptoms and treatment satisfaction in this observational analysis of clinical outcomes in patients with AAA or following AAA repair.

Full details of the design and validation of the new aneurysm-specific PROMs are described elsewhere^{3,4}. In brief, the AneurysmDQoL (following psychometric validation) comprises two initial overview items relating to overall QoL and aneurysm-related QoL, followed by 22 items covering multiple specific aspects of QoL. Twenty of these items can be combined into a single scale (the two items relating to work and finances are excluded as they were found to be relevant only to a small number of patients with AAA). Importantly, the AneurysmDQoL is individualized in several ways. First, items that may not be applicable to everyone (such as sex life, family life) can be designated as not applicable, and not scored. For items that are considered applicable by an individual, part (a) concerns the impact of AAA on the aspect of life in question, with potential scores ranging from -3 (maximum negative impact) through 0 (no impact) to +1 (positive impact). Part (b) of each item concerns the importance of this aspect of life to their QoL, with potential scores ranging from +3 (very important) to 0 (not at all important)³. The score for each item – the weighted impact (WI) – is then calculated by multiplying the ‘impact score’ by the ‘importance score’. This provides a personalized assessment of the impact of AAA on each aspect of an individual’s life and the importance of that impact for QoL. An average weighted impact (AWI) score can then be calculated for each individual: the mean across all 20 applicable domains that can be combined in the scale, giving an indication of the overall impact of AAA on that individual’s QoL.

The AneurysmTSQ is an 11-item measure for assessing patients’ satisfaction with their aneurysm treatment. It has two subscales: the first is suitable both before and after intervention, and the second is applicable only after intervention. The AneurysmTSQ items are each scored on a scale from 6 (for example, ‘very satisfied’) to 0 (for example, ‘very dissatisfied’).

Finally, the AneurysmSRQ is a 44-item tool to assess whether patients experienced particular symptoms and how bothered they were by these symptoms. Bother scores for each item range from 1 (not at all) to 4 (a lot). A score of zero is given if the symptom was not experienced. The AneurysmSRQ contains a Composite subscale that combines 24 of the individual items to provide a broad indicator of overall bother from symptoms (*Appendix S1*, supporting information). It also contains six symptom subscales that focus on more specific areas/groups of symptoms: emotion, appetite, lower limb, cognitive, general malaise and gastrointestinal.

Patients were recruited from five UK National Health Service (NHS) Trusts: St George’s University Hospitals NHS Foundation Trust, North Bristol NHS

Trust, Worcester Acute Hospitals NHS Trust, Norfolk and Norwich University Hospitals NHS Foundation Trust, and University Hospital Southampton NHS Foundation Trust. St George’s Hospital was the lead centre, providing large numbers of patients who had undergone endovascular aneurysm repair (EVAR), whereas all other centres were chosen purposefully for the study on the basis that they perform significant numbers of both open aneurysm repair (OR) and EVAR. In each centre, members of the local clinical team retrospectively identified consecutive patients who had undergone AAA repair (OR or EVAR) within the preceding 12 months (or the preceding 24 months in the case of University Hospital Southampton) and invited them to take part in the study. Two centres (St George’s and Southampton) also identified a number of patients enrolled in preoperative surveillance of small AAAs. The number of patients was determined by the requirements for the psychometric validation study: numbers required to power detection of intergroup differences in outcome could not be calculated in advance of first use of these new tools. Participants were asked to complete a pack containing the three new condition-specific questionnaires (AneurysmDQoL, AneurysmSRQ and AneurysmTSQ) together with a basic demographic questionnaire. Each participant completed the questionnaires on a single occasion (without help from clinicians), providing cross-sectional data from patients at various points in the treatment pathway, before and after intervention.

Statistical analysis

Statistical analyses were carried out using SPSS[®] version 20.0 (IBM, Armonk, New York, USA). Intergroup comparisons were made using Mann–Whitney *U* tests, and multiple group comparisons with Kruskal–Wallis tests with Bonferroni correction as appropriate. Data from 6 weeks and 3 months after intervention were excluded from analyses owing to very small numbers in these groups.

Results

A total of 297 patients were sent packs for completion, of whom 197 (66.3 per cent) completed and returned the questionnaires. Three patients were excluded from the analysis of results due to being extreme outliers, having undergone initial surgery more than 3 years before questionnaire completion. Participant characteristics are shown in *Table 1*. If patients failed to answer any item, they were excluded from analysis of that item and means were calculated based on the number of valid responses.

Table 1 Patient characteristics

	Open repair (n = 69)	Endovascular repair (n = 103)	Surveillance (n = 19)	Total (n = 191*)
Mean (range) age (years)	72.7 (60.0–89.5)	76.6 (60.5–95.6)	78.0 (58.8–90.7)	75.3 (60.0–95.6)
Sex				
M	67	89	16	172
F	2	14	2	18
Missing	0	0	1	1
Centre				
St George's	5	55	17	77
North Bristol	3	8	0	11
Worcester	20	3	0	23
Norfolk and Norwich	18	13	0	31
Southampton	20	23	2	45
Missing	3	1	0	4
Time point				
Before surgery	–	–	19	19
After surgery				
6 weeks (4–8 weeks)	1	2	–	3
3 months (9–16 weeks)	2	5	–	7
6 months (17–39 weeks)	23	25	–	48
12 months (40–65 weeks)	27	52	–	79
>12 months (≥66 weeks)	16	19	–	35

*Three of the original 194 patients were excluded (1 at 6 months and 2 at 12 months) because of uncertainty regarding the surgical approach used.

Quality of life (AneurysmDQoL)

Broad differences in QoL at various points in the treatment pathway were initially examined using mean AWI scores, where a more negative score indicates greater negative impact on QoL.

In patients who had undergone OR, the negative impact of AAA repair on QoL was seen to worsen progressively over time. After EVAR, however, the negative impact on QoL was greatest 12 months after intervention (and similar to that seen in the OR group), but then improved markedly (*Fig. 1*). However, none of the apparent differences between mean AWI scores at different time points or between the two types of intervention were statistically significant. To assess the aspects of QoL that were contributing to this apparent trend, mean WI scores were also calculated for each item in the AneurysmDQoL (*Table S1*, supporting information). For patients who had undergone OR, the domains that appeared to contribute most to the worsening impact of AAA on QoL over time were holidays, ability to do things physically, impact on sex life, feelings about the future, general health, physical discomfort and anxiety. The trend was for all of these aspects of QoL to be more severely affected beyond 12 months after OR than at any other time point, including before intervention (*Fig. 2*).

The domains that contributed most to the negative impact of EVAR on QoL (and this was predominantly 12 months after intervention) were friends/social life, doing things for others, household tasks, overall health, feelings

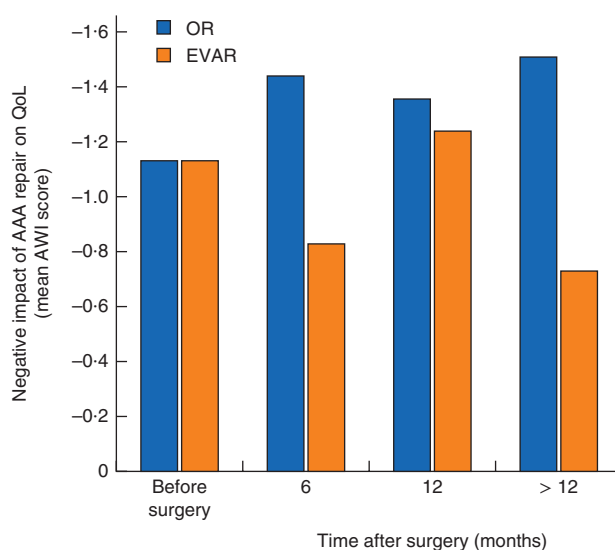


Fig. 1 Negative impact of abdominal aortic aneurysm (AAA) repair on quality of life (QoL) at different time points after open repair (OR) or endovascular repair (EVAR). AWI, average weighted impact

about the future, ability to think quickly and clearly, and physical discomfort.

Symptoms (AneurysmSRQ)

The overall impact of symptoms related to AAA and its treatment was initially examined using the AneurysmSRQ

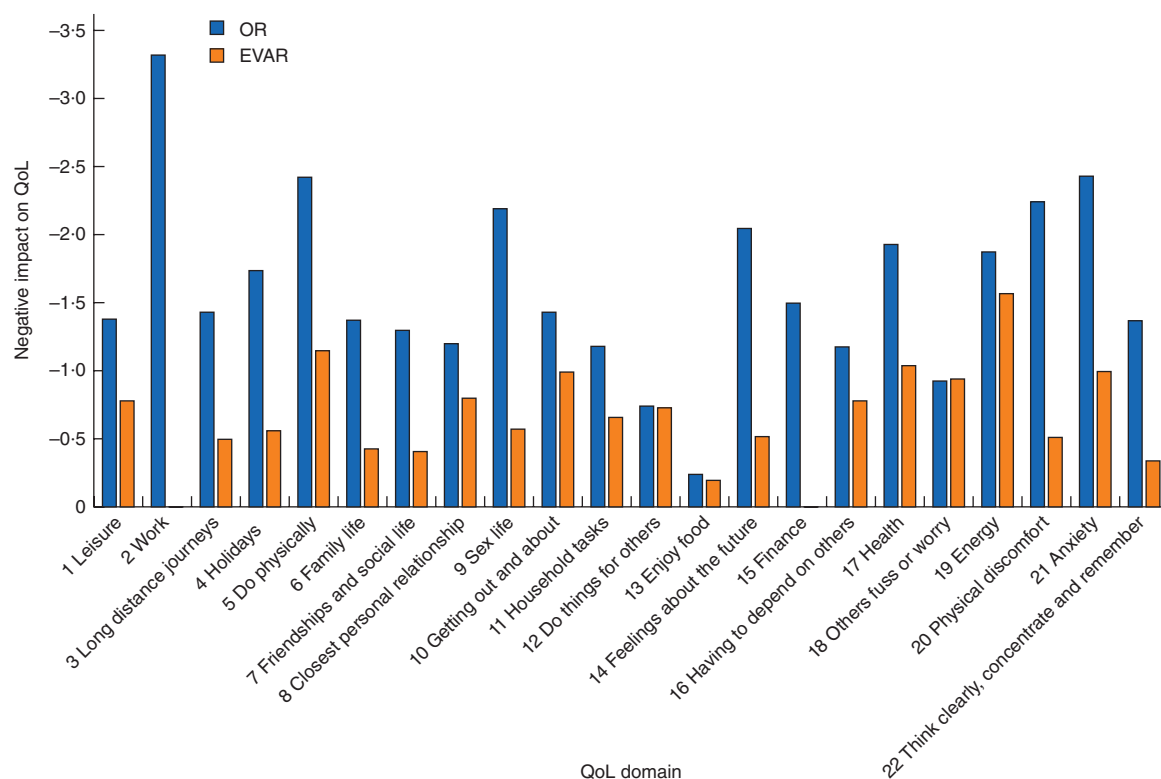


Fig. 2 Mean Aneurysm-Dependent Quality of Life (AneurysmDQoL) scores at over 12 months following intervention for the 22 weighted impact items in open repair (OR) and endovascular repair (EVAR) groups

Composite symptom subscale. Although this subscale does not contain all 44 items in the questionnaire (as psychometric validation demonstrated that it was not possible to group all 44 items legitimately into a single scale), it does contain 24 items and provides the broadest available overview of patients' experience of symptoms (*Appendix S1*, supporting information).

There was a general trend for those who had undergone OR to report less bother from symptoms at later time points, whereas those who underwent EVAR reported more bother from symptoms as time went on. At 6 months after intervention, patients reported a similar level of symptoms to that reported by patients before intervention, irrespective of whether they had undergone OR or EVAR (*Fig. 3*). At 12 months after intervention, patients in both groups reported slightly less bother from symptoms than had been reported by the preoperative group, but beyond 12 months those who had undergone EVAR were reporting more bother from symptoms (relative to the preoperative group), whereas those who had undergone OR were reporting less bother.

To explore the relative patterns in OR and EVAR more fully, the trends in scores for each of the six subscales of the

AneurysmSRQ were examined: emotion, appetite, lower limb, cognitive, general malaise and gastrointestinal. For three of these factors (emotion, lower limb and cognitive), the trends over time were similar to those seen with the Composite symptom subscale. For the factors reflecting appetite, general malaise and gastrointestinal symptoms, both from symptoms broadly reduced over time to well below preoperative levels.

Trends in mean scores for the individual items of the AneurysmSRQ were also assessed. Mean scores for the individual items showed few statistically significant differences across the different time points, with only 'tiredness or lethargy' (item 1) and 'indigestion or heartburn' (item 38) seen to cause significantly less bother over time in the OR group, and only weight loss (item 36) in the EVAR group.

However, analysis of the proportion of patients experiencing each symptom was more revealing. In the OR group, patients reported most bother 6 months after intervention, with more than 20 per cent of patients reporting moderate or severe bother from a large number of symptoms (*Table 2*). Far fewer symptoms were rated as causing moderate or severe bother at 12 months or more than

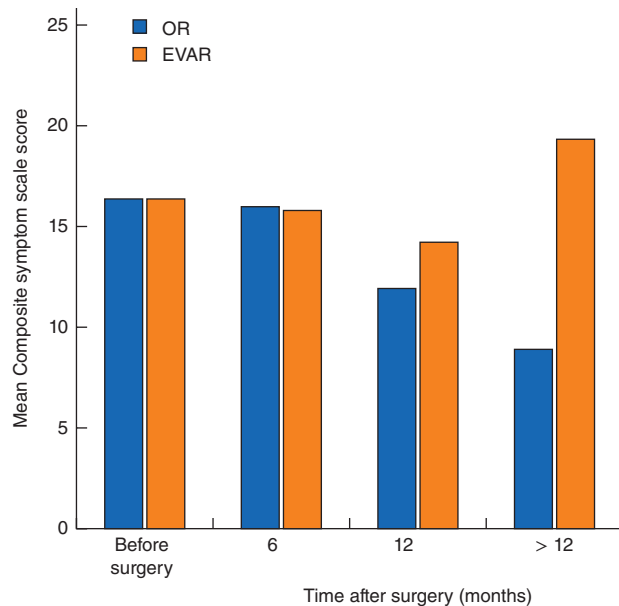


Fig. 3 Trends in mean scores for the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ) Composite symptom scale following open repair (OR) and endovascular repair (EVAR). A higher score indicates greater bother from symptoms

12 months after intervention. In the EVAR group the trend was largely reversed, with progressively more symptoms causing moderate or severe bother at later time points.

Treatment satisfaction (AneurysmTSQ)

Although there were no statistically significant differences in AneurysmTSQ item scores over time in either the OR or EVAR group, the use of mean or median scores may obscure clinically important areas of dissatisfaction when a majority of participants are reporting high levels of satisfaction. As the aim was to identify sources of dissatisfaction (and therefore potential targets for improvement), analysis of results from the AneurysmTSQ involved assessing the percentage of patients scoring 3 or less for each item at each time point. Possible scores for each item range from 6 (very satisfied) to 0 (very dissatisfied), so it was decided that a threshold score of 3 or less would indicate the proportion of patients who were not satisfied with that aspect of care.

Before intervention, more than 40 per cent of participants were dissatisfied with the information they had received about their aneurysm and its treatment, and also with their understanding of the treatment for the aneurysm. Furthermore, more than 20 per cent were dissatisfied with feedback about scan results and the amount of support they were receiving from healthcare professionals.

Table 2 Symptoms for which more than 20 per cent of patients reported moderate or severe bother before, and 6, 12 and more than 12 months after intervention

	Symptom	No. reporting bother	
Before OR/EVAR (n = 19)	Back pain/discomfort	9 (47)	
	Pain/discomfort calves	8 (42)	
	Weakness in legs	7 (37)	
	Tired/lethargic	5 (26)	
	Pain/discomfort/thighs	7 (26)	
	Tingle/numbness in legs	7 (26)	
	Heaviness in legs	7 (26)	
	Abdominal pain	4 (21)	
	Memory problems	4 (21)	
	Difficulty concentrating	4 (21)	
Difficulty thinking quickly	4 (21)		
OR 6 months (n = 23)	Tired/lethargic	9 (39)	
	Problems with sexual function	9 (39)	
	Weight gain	8 (35)	
	Back pain/discomfort	7 (30)	
	Memory problems	6 (26)	
	Abdominal pain	5 (22)	
	Heaviness in legs	5 (22)	
	Depressed/low	5 (22)	
	Worried/nervous	5 (22)	
	Irritable/angry	5 (22)	
	Emotional/upset	5 (22)	
	Episodes too hot/cold	5 (22)	
	Sleep problems	5 (22)	
	Indigestion	5 (22)	
	Flatulence/belching	5 (22)	
	12 months (n = 27)	Tired/lethargic	7 (26)
Problems with sexual function		7 (26)	
>12 months (n = 16)	Problems with sexual function	4 (25)	
	Episodes too hot/cold	4 (25)	
	Sleep problems	4 (25)	
EVAR	6 months (n = 25)	Weakness in legs	8 (32)
		Tired/lethargic	6 (24)
		Generally weak	6 (24)
		Episodes too hot/cold	6 (24)
	12 months (n = 52)	Flatulence/belching	6 (24)
		Tired/lethargic	16 (31)
		Pain/discomfort back	14 (27)
		Pain/discomfort thighs	14 (27)
		Pain/discomfort calves	13 (25)
		Tingle/numbness legs	12 (23)
	>12 months (n = 19)	Sleep problems	13 (25)
		Flatulence/belching	12 (23)
		Tired/lethargic	9 (47)
		Pain/discomfort back	7 (37)
		Weakness in legs	6 (32)
		Unsteadiness	6 (32)
		Generally weak	5 (26)
		Pain/discomfort calves	5 (26)
		Difficulty concentrating	5 (26)
		Lost interest in sex	5 (26)
Worried/nervous	4 (21)		
Irritable/angry	4 (21)		
Tingle/numbness in legs	4 (21)		
Difficulty thinking quickly	4 (21)		
Problems with sexual function	4 (21)		
Sleep problems	4 (21)		
Flatulence/belching	4 (21)		

Values in parentheses are percentages. OR, open repair; EVAR, endovascular repair.

By 6 months after intervention, less than 10 per cent of participants in either the OR or the EVAR group were reporting dissatisfaction in these areas, although dissatisfaction due to discomfort was more common (26 per cent after OR; 17 per cent after EVAR), as was bother from side-effects (32 per cent after OR; 8 per cent after EVAR). Nearly 20 per cent of patients in the OR group also expressed dissatisfaction with their follow-up at this time point.

At 12 months after intervention, a substantial number of patients in the OR group expressed dissatisfaction relating to discomfort (22 per cent), bother with symptoms (26 per cent) and follow-up (19 per cent). In the EVAR group, the most common areas of dissatisfaction were length of stay (15 per cent) and bother from side-effects (14 per cent).

Beyond 12 months after intervention, follow-up was the main source of dissatisfaction for patients in the OR group (25 per cent scored 3 or less), with feedback about scan results also (surprisingly) causing dissatisfaction (14 per cent). In the EVAR group, more than 15 per cent expressed dissatisfaction with feedback about scan results and the information they had been given about their treatment. Follow-up was also a cause of dissatisfaction for more than 10 per cent of the EVAR group at this time point.

Discussion

The aim of this study was to use three newly developed condition-specific instruments to assess symptoms, impact on QoL and treatment satisfaction associated with AAA and its repair. Although the data set analysed here was not collected primarily for the determination of outcomes (but rather to provide data for psychometric validation of the new questionnaires themselves), it provided a number of interesting preliminary findings that are contrary to previous assumptions about the experiences of this patient population.

The trends observed in AneurysmDQoL item scores suggested that the negative impact of AAA on QoL generally increased over time in the OR group and decreased over time in the EVAR group. Although there were no statistically significant changes in AneurysmDQoL AWI scores over time, the number of domains that were affected negatively at different time points is noteworthy. In the OR group, 17 of 22 domains were more severely affected over 12 months after intervention than in the preintervention group. Conversely, in the EVAR group, 15 of 22 domains were less severely affected more than 12 months after intervention than in the preoperative group. Furthermore, these trends were borne out by the trends in AWI score for the two groups.

Despite little clear evidence, it had long been assumed that patients undergoing OR experience greater negative impact on QoL in the early postoperative period than those who have EVAR (owing to the greater physical insult of OR), but then recover and surpass their EVAR counterparts as the physical aspects of the operation become less relevant and other factors such as concerns about the need for ongoing surveillance or reintervention begin to affect the EVAR group^{5,6}. These early data challenge this assumption.

The pattern for symptoms was opposite to that seen for QoL. Patients who had undergone EVAR reported more bother from symptoms as time went on, and those who had undergone OR reported less bother over time. Notably, at 12 months and beyond, patients who had EVAR were not only reporting increasing bother from symptoms, but these symptoms were almost exclusively physical, rather than the emotional or psychological issues that might have been expected, and were particularly related to pain and weakness of the legs and back. Even though clinicians might previously have predicted a certain amount of groin discomfort or even claudication following EVAR (particularly in those with coexistent peripheral arterial disease), few might have expected these symptoms to be experienced so commonly 1 year or more after intervention, unless there had been recognized iatrogenic occlusion of one or both internal iliac arteries. It was also notable, however, that a large number of patients under surveillance reported bother from back pain and calf pain before intervention. This raises the question of whether such symptoms are incidental in this elderly population, rather than being attributable to AAA or its repair. Nonetheless, their absence in the postoperative OR group would seem to contradict this suggestion, and it may be that these symptoms are indeed more common than previously recognized, even before surgery.

The fact that the trends for symptoms and QoL were contrary is interesting, as symptoms and QoL might be expected to show positive correlation. Detailed re-examination of the data demonstrated that when all patients (all time points, centres, operation types) are analysed as a single group, the expected relationship between symptoms and QoL can indeed be demonstrated, with a moderate ($r = 0.438$; $P < 0.005$) positive correlation between summary symptom score and AWI. It is a statistical phenomenon caused by disaggregation of the data into time-point groups (Simpson's paradox) that makes the overall trends in QoL and symptoms appear contrary to the underlying relationship, although the trends are nonetheless genuine^{7,8}.

The correlation between symptoms and QoL highlights the importance of identifying and addressing

postoperative symptoms where they exist, particularly after EVAR, which was previously thought to have very few postoperative symptoms. Nonetheless, it also seems clear that symptoms are far from the sole determinant of QoL, with feelings about the future and impact on social life, family life, travel and relationships all showing marked contributions. Although it may be difficult for clinicians to modify these aspects of life, their importance to patients means they should not be discounted, and better understanding of patients' broader QoL after aneurysm repair might ultimately influence both patient and clinician in their decision to proceed to repair, particularly for smaller aneurysms.

Assessment of mean item scores in the AneurysmTSQ provided little evidence of dissatisfaction, but analysis of the number of patients with a score of 3 or less for each item proved revealing. This identified a number of areas of dissatisfaction in both EVAR and OR groups, with patients being less than satisfied with information provision and understanding in the preoperative group, and side-effects, follow-up and feedback about scan results for postoperative patients. Perhaps surprisingly, the qualitative work conducted during the design of these new questionnaires suggested that dissatisfaction with follow-up was mostly related to the lack of follow-up after OR rather than excessive follow-up in the EVAR group². All of these areas represent potential targets for improvements in practice that may also have secondary effects on QoL.

There were some study limitations. Although the overall cohort included nearly 200 patients, separation of these patients by time point and operation type resulted in the largest group being only 52 patients and all other groups having fewer than 30. Indeed, the 6-week and 3-month after intervention groups were so small (largely for logistical reasons) that they were excluded from the analyses. This is particularly relevant as it may be in this early postoperative period that differences in trends for OR and EVAR are most marked. The small subgroups also prevented the intended between-centre comparisons. It is also notable that this work did not include any analysis of, or statistical adjustment for, age, co-morbidity, reintervention and other factors that might be related to QoL and symptom reporting. Controlling for these variables would strengthen future work on larger samples of patients and allow robust regression analyses to establish which patient or treatment factors are significant determinants of QoL.

The preliminary results presented here provide disease-specific assessments of QoL, symptoms and treatment satisfaction of patients with AAA. Although a larger data set is needed to explore the differences between OR and EVAR more fully and control for confounding

variables, observed trends suggest that there may be clinically significant differences in the pattern of symptoms and QoL experienced by these two groups. The findings also highlight the potential importance of distinguishing between health status and QoL when assessing outcome, as the two constructs (represented here by symptoms and QoL) do not necessarily follow the same pattern of change.

While it is perhaps information on QoL and symptoms that ultimately inform changes in treatment or health policy, data on treatment satisfaction provide much more immediate targets for improvements in clinical care. This study has identified several areas including information, follow-up and management of postoperative pain that might be the initial focus of such improvements. Ongoing use of the AneurysmTSQ would also allow evaluation of any improvement strategies that are implemented. Though understanding of the true nature of patient-reported outcomes for patients with AAA is still in the early stages, more detailed knowledge can now be gathered through wider routine use of these new AAA-specific measures.

Access to Questionnaires: To view samples of the questionnaires online, request review copies of the full questionnaires or request a license agreement to use the questionnaires, please visit www.healthpsychologyresearch.com. Alternatively, send requests for the aneurysm questionnaires directly to the dedicated email address: aaa@healthpsychologyresearch.com.

Acknowledgements

The authors thank the participating patients and the following colleagues who referred them to this study: D. Mitchell (North Bristol NHS Trust); M. Armon and M. Burrows (Norfolk and Norwich University Hospital NHS Foundation Trust); I. Nyamekye and W. Hayes (Worcestershire Acute Hospitals NHS Trust); I. Nordon (University Hospital Southampton NHS Foundation Trust); and J. Blundell (St George's University Hospitals NHS Foundation Trust).

This work was partly funded by a Medical Research Grant from the St George's Charitable Foundation. It was also supported by a Royal College of Surgeons Pump Priming Grant. P.J.E.H. is a Clinician Scientist, supported financially by the National Institute for Health Research (NIHR-CS-011-008). The NIHR had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

C.B. is the copyright owner of the AneurysmDQoL, AneurysmTSQ and AneurysmSRQ, which, together with other questionnaires designed by C.B. and her research team, are licensed to others to use through

Health Psychology Research (HPR) Ltd, of which she is Chief Executive Officer and majority shareholder. Licence fees are charged to commercial companies that license the questionnaires. Clinicians, academics and other non-commercial users are asked to pay a small administration charge, but no licence fee. Licence agreements are provided to students free of all charges.

Disclosure: The authors declare no other conflict of interest.

References

- 1 Department of Health. *Guidance on the Routine Collection of Patient Reported Outcome Measures (PROMs)*; 2008. http://web.archive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092625.pdf [accessed 3 February 2014].
- 2 Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992; **30**: 473–483.
- 3 Peach G, Romaine J, Wilson A, Holt PJE, Thompson MM, Hinchliffe RJ *et al.* Design of new patient-reported outcome measures to assess quality of life, symptoms and treatment satisfaction in patients with abdominal aortic aneurysm. *Br J Surg* 2016; **103**: 1003–1011.
- 4 Romaine J, Peach G, Thompson MM, Hinchliffe RJ, Bradley C. 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* 2015; **24**(Suppl 1): 41–42 (Abstract).
- 5 Wanhainen A, Svensjö S, Mani K. Screening for abdominal aortic aneurysm – areas where information is still inadequate. *Scand J Surg* 2008; **97**: 131–135.
- 6 Prinssen M, Buskens E, Blankensteijn JD; DREAM trial participants. Quality of life endovascular and open AAA repair. Results of a randomised trial. *Eur J Vasc Endovasc Surg* 2004; **27**: 121–127.
- 7 Simpson EH. The interpretation of interaction in contingency tables. *J R Stat Soc* 1951; **13**: 238–241.
- 8 Tu YK, Gunnell D, Gilthorpe MS. Simpson's Paradox, Lord's Paradox, and suppression effects are the same phenomenon – the reversal paradox. *Emerg Themes Epidemiol* 2008; **5**: 2.

Supporting information

Additional supporting information may be found in the online version of this article:

Appendix S1 Items in the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ) Composite symptom subscale (Word document)

Table S1 Mean weighted impact scores at various time points in the treatment pathway (Aneurysm-Dependent Quality of Life (AneurysmDQoL) questionnaire) (Word document)