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

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Preliminary data on quality of life, symptoms and treatment satisfaction in patients with aortic aneurysm using new AAA-specific PROMs

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Category: Original Article

Competing interests

Clare Bradley is the copyright owner of the AneurysmDQoL, AneurysmTSQ and AneurysmSRQ which, along with other questionnaires designed by CB and her research team, are licensed to others to use through Health Psychology Research (HPR) Ltd, of which she is CEO and majority shareholder. Licence fees are charged to commercial companies who 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.

Abstract

Introduction

Previous studies of quality of life (QoL) in patients with abdominal aortic aneurysm (AAA) have used generic measures and the impact of AAA remains unclear. There are also very few data on symptoms or treatment satisfaction for patients with AAA. The aim of this study was to present preliminary data on QoL, symptoms and treatment satisfaction gathered using three new AAA-specific patient-reported outcome measures (PROMs).

Methods

Patients with AAA were recruited from 5 NHS Trusts to complete 3 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, though largely non-significant, showed interesting trends. The impact of AAA repair on QoL appeared to worsen progressively after open aneurysm repair (OR) and improve progressively after endovascular repair (EVAR). Conversely, symptoms seemed to become progressively worse after EVAR and progressively better after OR. Information and understanding were key sources of dissatisfaction prior to intervention, whilst postoperative dissatisfaction was related to bother from symptoms, follow-up and feedback about scan results.

Conclusions

Though a larger, prospective dataset 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 open and endovascular aneurysm repair.

Introduction

Collection of patient-reported outcome (PRO) 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 PROs remains unclear.[4]

The aim of this study was to present preliminary observational data on QoL, symptoms and treatment satisfaction in patients with AAA, using data collected during the validation of three new condition-specific questionnaires designed specifically for patients with AAA: These are the Aneurysm-dependent Quality of Life questionnaire (AneurysmDQoL); the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ); and the Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ). [2][reference to design paper to be included here in place of the present references to abstracts if both are to be published simultaneously]

Methods

All data presented here were primarily 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).[3] Once that process had confirmed the structure and validity of the questionnaires and identified reliable sub-scales, 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,[2 3][reference to design and psychometric development paper to be included here in place of the present references to abstracts if published simultaneously or in advance of this paper] but in brief, the AneurysmDQoL (following psychometric validation) comprises 2 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 from this as they were only found to be relevant to a small number of patients with AAA). Importantly, the AneurysmDQoL is 'individualised' in several ways. First, those items that may not be applicable to everyone (e.g. sex life, family life) can be designated 'not applicable' and not scored. For those 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) - see design paper in this issue [ref to BJS as appropriate if this is published as companion to the design paper].[2] The score for each item – the Weighted Impact (WI) - is then calculated by multiplying the 'impact score' by the 'importance score' [Appendix 1]. This provides a highly personalised 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, i.e. the mean across all 20 applicable domains which 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 suitable for both pre- and post-intervention patients, and the second applicable only to post-intervention patients. The AneurysmTSQ items are each scored on a scale of 6 (e.g. 'very satisfied') to 0 (e.g. 'very dissatisfied').

Finally, the AneurysmSRQ is a 44-item tool to assess whether patients experienced particular symptoms and how bothered they were by symptoms experienced. 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 2]. It also contains 6 symptom subscales that focus on more specific areas/groups of symptoms: Emotion; Appetite; Lower limb; Cognitive; General malaise; and Gastrointestinal.

Patients were recruited from 5 UK 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), whilst all other centres were purposefully chosen 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 all patients (consecutive) 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 inter-group 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 (the AneurysmDQoL, the AneurysmSRQ and the 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, pre- and post-intervention.

Statistical analyses

Statistical analyses were carried out using SPSS v20.0 (IBM Corps, Armonk, NY). Inter-group comparisons were made using Mann-Whitney U tests, whilst multiple group comparisons were made using Kruskal-Wallis tests with Bonferroni correction as appropriate. Data from 6 weeks and 3 months post-intervention were excluded from analyses due to very small patient numbers in these groups (Table 1).

Results

A total of 297 patients were sent packs for completion, of whom 197 individuals (66%) completed and returned the questionnaires. Participant characteristics can be seen in Table 1. Three patients were excluded from the analysis of results due to being extreme outliers, having undergone *initial* surgery more than 3yrs prior to questionnaire completion. If patients failed to answer any item, they were excluded from analysis of that item and means calculated based on the number of *valid* responses to that item.

Quality of life (AneurysmDQoL)

Broad differences in QoL at various points in the treatment pathway were initially examined using mean Average Weighted Impact (AWI) scores, where more negative scores indicate 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. In EVAR patients, however, the negative impact on QoL was greatest at 12m post-intervention (and similar to that seen in the OR group) but then improved markedly by >12m post-intervention (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 'weighted impact' (WI) scores were also calculated

for each item in the AneurysmDQoL [Appendix 3]. 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 at >12m post-OR than at any other time-point, including pre-intervention (Fig. 2).

The domains that were seen to contribute most heavily to the negative impact of EVAR on QoL (and this was predominantly at 12m post-intervention), were friends/social life, doing things for others, household tasks, overall health, feelings 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 Aneurysm-SRQ 'Composite' symptom subscale. Although this subscale does not contain all 44 items in the questionnaire (since 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 2].

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

In order to explore the relative patterns in OR and EVAR more fully, we then examined the trends in scores for each of the 6 subscales of the AneurysmSRQ: 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, bother 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 very 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) seen to cause significantly less bother over time in the EVAR group.

However, analysis of the percentage of patients experiencing each symptom was more revealing: In the OR group, patients reported most bother at 6m post-intervention, with more than 20% 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 12m or >12m post-intervention. In the EVAR group the trend was largely reversed, with progressively more symptoms causing moderate or severe bother at later time-points (Table 2).

Treatment satisfaction (AneurysmTSQ)

Though there were no statistically significant differences in AneurysmTSQ item scores over time within either the OR or EVAR groups, 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. Since 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. Since possible scores for each item range from 6 (very satisfied) to 0 (very dissatisfied), it was decided that using a threshold score of 3 or less would indicate the proportion of patients who were not satisfied with that aspect of care.

Prior to intervention, more than 40% 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 their aneurysm. Furthermore, more than 20% were dissatisfied with *feedback* about scan results and the amount of *support* they were receiving from healthcare professionals.

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

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

Beyond 12m post-intervention, *follow-up* was the main source of dissatisfaction for patients in the OR group (25% scoring ≤3), with *feedback about scan results* also (surprisingly) causing dissatisfaction (14%). In the EVAR group, more than 15% 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% 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 issues associated with AAA and its repair. Though the dataset 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 has 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 items 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. Though there were no statistically significant changes in AneursymDQoL AWI scores over time, the number of domains negatively impacted at different time-points is noteworthy. In the OR group 17 of 22 domains were *more* severely impacted in the group that was >12m post-intervention than in the pre-intervention group. Conversely, in the EVAR group, 15 of 22 domains were *less* severely impacted in the group that was >12m post-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 to support the theory, it had long been assumed that OR patients experience greater negative impact on QoL in the early postoperative period than those who had undergone EVAR (due 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 impact on 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 12m post-intervention and beyond, EVAR patients were not only reporting increasing bother from symptoms, but these symptoms were almost exclusively physical - rather than the emotional or psychological issues which might have been

expected - and 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 would probably have expected these symptoms to be experienced so commonly a year or more post-intervention, unless there had been recognised iatrogenic occlusion of one or both internal iliac arteries. It was also notable, however, that a large proportion of patients under surveillance reported bother from back pain and calf pain prior to 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 preoperatively.

The fact that the trends for symptoms and QoL were contrary to one another is interesting in itself, since symptoms and QoL might be expected to show some positive correlation. Detailed re-examination of the data demonstrated that when all patients (i.e. 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 (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, though the trends are nonetheless genuine. [7 8]

The presence of *some* correlation between symptoms and QoL highlights the importance of identifying and addressing post-operative symptoms where they exist – particularly for EVAR patients who were 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 to the impact of AAA on QoL only some of which may be mediated by symptoms. Whilst it may be less easy 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 - particularly for smaller aneurysms.

Though assessment of mean item scores in the Aneurysm-TSQ provided little evidence of dissatisfaction,, analysis of the number of patients with a score of three or less for each item proved far more revealing. This identified a number of areas of dissatisfaction in both the 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 dissatisfaction with follow-up was mostly related to the *absence* of follow-up in the OR group rather than excessive or worrying follow-up in the EVAR group. [2] All of these areas represent potential targets for improvements in practice that may also have secondary effects on QoL, for example by reducing anxiety or pain or providing information about whether it is safe to travel by air or safe to resume sexual activity which may otherwise be avoided unnecessarily.

There were some study limitations. Though 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 6wk and 3m post-intervention groups were so small (largely for logistical reasons) that they were ultimately 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 sub-groups also prevented the intended inter-centre comparisons as these would have required the groups to be split still further. Consideration was given to grouping all patients from a particular centre together (irrespective of time-point) in order to allow inter-centre comparison, but with evidence suggesting there was quite marked variation in questionnaire scores over time, it was decided that this would be of little value. It is also notable that this work did not

include any analysis of, or statistical adjustment for, age, comorbidity, reintervention and other factors that might in themselves be related to QoL and symptom reporting, such as gender. It can be seen that the mean age of the EVAR group is, not surprisingly, several years older than that of the OR group and some of the trend to increased reporting of symptoms in the EVAR group at >12 months may be explained by increasing age and associated comorbidity. 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.

It should also be appreciated that the data presented here were cross-sectional rather than longitudinal, and data collected at each time-point were from different patients. Furthermore, a significant proportion of patients in the '>12m post-intervention' group were from a single centre (Southampton) and this could also have influenced the observed trends. Apparent changes in QoL, symptoms and treatment satisfaction over time must therefore be viewed with this in mind. Future work that follows individuals longitudinally will be able to gain a more detailed understanding of how QoL, symptoms and treatment satisfaction change for each individual over the course of their diagnosis and treatment.

The preliminary results presented here provide one of the first disease-specific assessments of QoL, symptoms and treatment satisfaction of patients with AAA. Though a larger dataset is needed to explore the differences between OR and EVAR more fully and control for confounding variables, our results have shown trends that suggest that there *may* be clinically significant differences in the pattern of symptoms and QoL experienced by these two groups. Our findings also highlight the potential importance of distinguishing between health status and QoL when assessing outcome, since the two constructs (represented here by symptoms and QoL) do not necessarily follow the same pattern of change.

Whilst it is perhaps information on QoL and symptoms that ultimately informs 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 Aneurysm-TSQ 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: visit www.healthpsychologyresearch.com

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Miss Jo Blundell (St George's University Hospitals NHS Foundation Trust)

Competing interests

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Table 1 – Patient subgroup characteristics

	Open repair	Endovascular repair	Surveillance	Total
Mean age (range)	72.7 (60 – 89.5)	76.6 (60.5 - 95.6)	78.0 (58.8 – 90.7)	-
Gender				
- Male	67	89	16	172
- Female	2	14	2	18
- Missing/unknown	-	-	1	1
Total	69	103	19	191
Centre				
- St George's	5	55	17	77
- North Bristol	3	8	-	11
- Worcester	20	3	-	23
- Norfolk & Norwich	18	13	-	31
- Southampton	20	23	2	45
- Missing/unknown	3	1	-	4
Total	69	103	19	191
Time-point				
- Pre-intervention	-	-	19	19
- 6wks postop (4-8wks)	1	2	-	3
- 3m postop (9-16wks)	2	5	-	7
- 6m postop (17-39wks)	23	25	-	48
- 12m postop (40-65wks)	27	52	-	79
- >12m postop (>66wks)	16	19	-	35
Missing details				3*
Overall total	69	103	19	194

* 1 patient excluded at 6months and 2 patients excluded at 12months (out of original 194 patients) due to being unsure about what type of operation they had undergone.

Table 2 - Symptoms for which more than 20% of patients reported moderate or severe bother

Pre-intervention (OR/EVAR) (n=19)		**6m** post-intervention (n=23)	**12m** post-intervention (n=27)	**>12m** post-intervention (n=16)
Back pain/discomfort (47%) Pain/discomfort calves (42%) Weakness in legs (37%) Tired/lethargic (26%) Pain/discomfort/thighs (26%) Tingle/numbness in legs (26%) Heaviness in legs (26%) Abdominal pain (21%) Memory problems (21%) Difficulty concentrating (21%) Difficulty thinking quickly (21%)	OR (%)	Tired/lethargic (39%) Probs with sex func. (39%) Weight gain (35%) Back pain/discomfort (30%) Memory problems (26%) Abdominal pain (22%) Heaviness in legs (22%) Depressed/low (22%) Worried/nervous (22%) Irritable/angry (22%) Emotional/upset (22%) Episodes too hot/cold (22%) Sleep problems (22%) Indigestion (22%) Flatulence/belching (22%)	Tired/lethargic (26%) Probs with sex func. (26%)	Probs with sex. func. (25%) Episodes too hot/cold (25%) Sleep problems (25%)
		6m post-intervention (n=25)	**12m** post-intervention (n=52)	**>12m** post-intervention (n=19)
	EVAR (%)	Weakness in legs (31%) Tired/lethargic (24%) Generally weak (24%) Episodes too hot/cold (24%) Flatulence/belching (24%)	Tired/lethargic (31%) Pain/discomfort back (27%) Pain/discomfort thighs (27%) Pain/discomfort calves (25%) Tingle/numbness legs (23%) Sleep problems (25%) Flatulence/belching (23%)	Tired/lethargic (47%) Pain/discomfort back (37%) Weakness in legs (32%) Unsteadiness (32%) Generally weak (26%) Pain/discomfort calves (26%) Difficulty concentrating (26%) Lost interest in sex (26%) Worried/nervous (21%) Irritable/angry (21%) Tingle/numbness in legs (21%) Difficulty thinking quickly (21%) Probs with sex func. (21%) Sleep problems (21%) Flatulence/belching (21%)

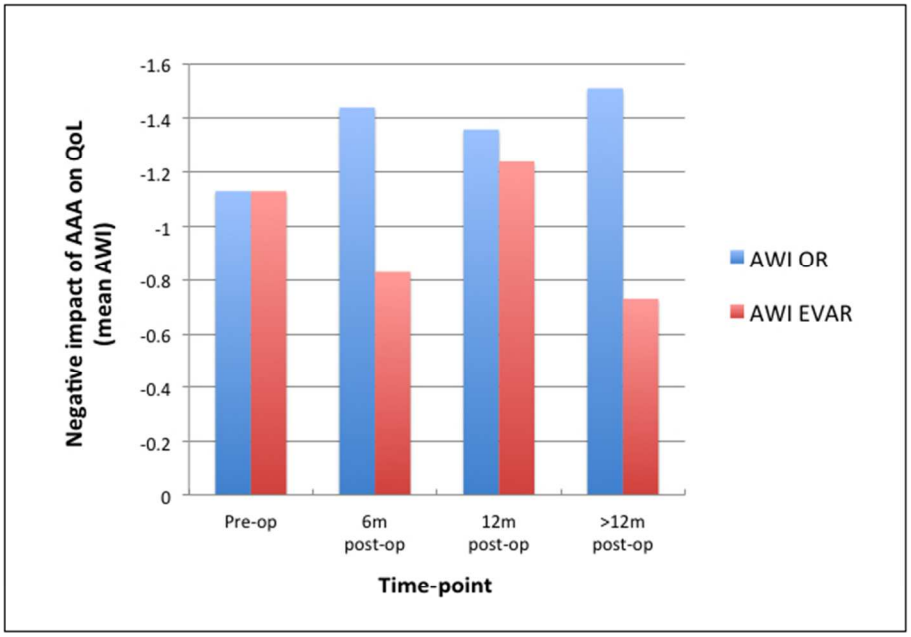


Figure 1 – Negative impact of AAA on QoL at different time-points following open repair (OR) or endovascular repair (EVAR).

254x190mm (72 x 72 DPI)

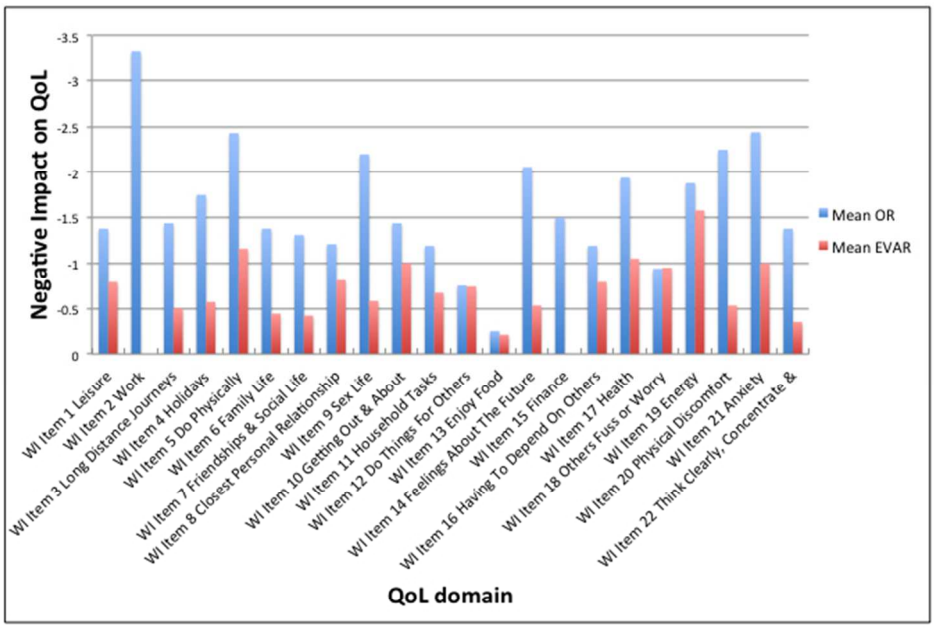
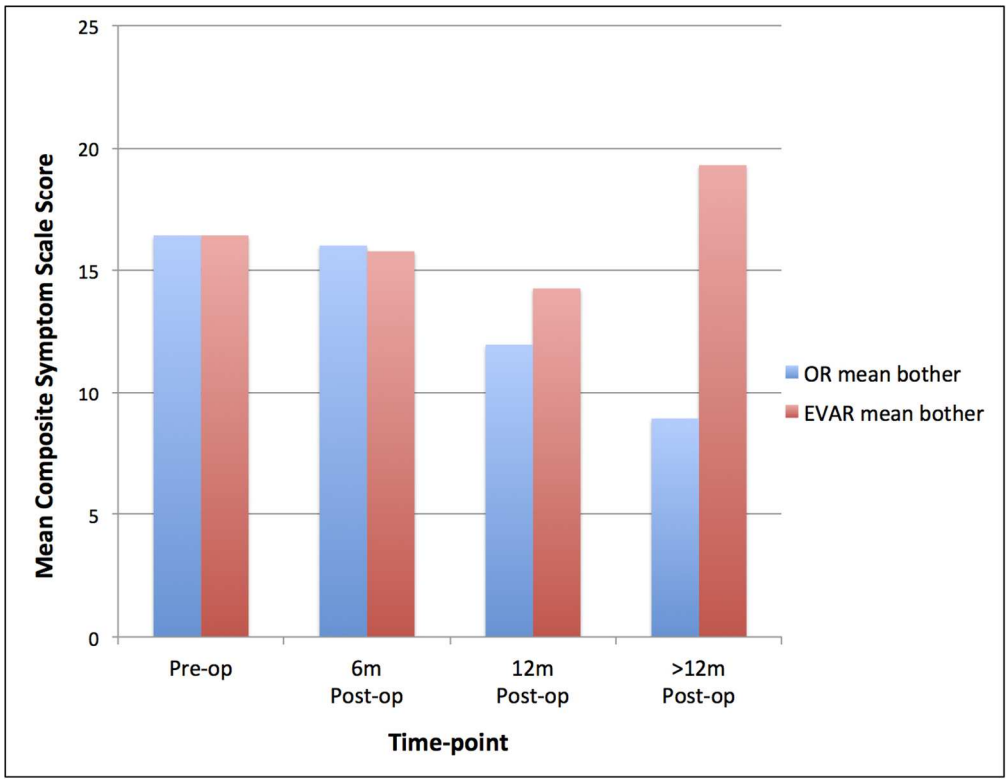


Figure 2 – Aneurysm-Dependent Quality of Life (AneurysmDQoL) item scores at >12m post-intervention.
254x190mm (72 x 72 DPI)



Caption : Figure 3 – Trends in mean scores for the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ) 'Composite' symptom scale. Higher score indicates greater bother from symptoms.
241x186mm (150 x 150 DPI)

Appendix 1 – Example of question format and scoring for the Aneurysm-Dependent Quality of Life Questionnaire (AneurysmDQoL) (scoring shown information only – not usually visible)

5 (a)	**If I had never had an aneurysm, physically I could do:**				
	☐-3 very much more	☐-2 much more	☐-1 a little more	☐0 the same	☐+1 less
(b)	**For me, how much I can do physically is:**				
	☐+3 very important	☐+2 important	☐+1 somewhat important	☐0 not at all important	

Appendix 2 – items in the AneurysmSRQ 'Composite' symptom subscale

Q1b Tired or Lethargic
Q2b Headaches
Q3b Feverish
Q6b Pain discomfort groin
Q8b Pain discomfort back
Q9bAbdominal pain
Q13b Depressed or low
Q14b Feelings of panic
Q15b Worried nervous
Q16b Irritable angry
Q17b Emotional upset
Q18b Difficulty concentrating
Q19b Memory problems
Q20b Difficulty thinking quickly clearly
Q21b Unsteady uncoordinated
Q22b Dizzy/lightheaded
Q24b Heaviness in legs
Q25b Trembling e.g. limbs
Q26b Weakness in legs
Q29b Avoided sexual activity
Q31b Excessive sweating
Q32b Episodes too hot or too cold
Q34b Generally weak
Q40b Flatulence or belching

Appendix 3 – Mean Weighted Impact scores at various time-points in the treatment pathway

(AneurysmDQoL

	Preop mean		6m mean				12m mean				>12m mean			
	OR/EVAR (n=19)	SD	OR (n=23)	SD	EVAR (n=25)	SD	OR (n=27)	SD	EVAR (n=52)	SD	OR (n=16)	SD	EVAR (n=19)	SD
WI Item 1 Leisure	-1.26	2.10	-1.5	2.39	-0.54	1.25	-1.77	2.64	-1.02	1.65	-1.38	2.34	-0.79	1.03
WI Item 2 Work	-1.5	2.12	-0.57	1.51	-0.5	1.23	-0.4	0.89	-0.57	0.98	-3.33	0.58	0	0.00
WI Item 3 Long Distance Journeys	-0.94	1.96	-0.91	1.83	-0.92	2.10	-1.07	1.80	-1.06	2.13	-1.44	2.50	-0.5	1.10
WI Item 4 Holidays (NA=0)	-1	1.56	-1.65	2.72	-1.3	2.54	-1.24	2.20	-1.63	2.25	-1.75	2.62	-0.57	1.22
WI Item 5 Do Physically	-0.94	1.39	-2.5	2.99	-1.22	2.35	-2	2.35	-1.52	2.24	-2.43	3.16	-1.16	1.46
WI Item 6 Family Life (NA=0)	-1.53	2.50	-1.64	3.00	-1.04	2.84	-1.65	2.76	-1.28	2.19	-1.38	2.50	-0.44	0.92
WI Item 7 Friendships & Social Life	-0.89	2.26	-0.91	2.41	-0.64	2.20	-1.54	2.53	-1.47	2.54	-1.31	3.09	-0.42	0.77
WI Item 8 Closest Personal Relationship (N=0)	-0.67	1.78	-1.25	3.07	-0.65	1.95	-0.68	1.32	-0.49	1.34	-1.21	2.78	-0.81	1.68
WI Item 9 Sex Life (NA=0)	0	0.00	-2.31	2.98	-1	3.03	-1.19	2.75	-1	1.81	-2.2	2.57	-0.58	0.90
WI Item 10 Getting Out & About	-0.68	2.21	-1.14	2.46	-1.12	2.33	-1.37	1.88	-1.54	2.24	-1.44	2.66	-1	1.67
WI Item 11 Household Tasks	-1.32	2.38	-1.41	1.97	-0.8	2.16	-1.52	2.31	-1.29	2.07	-1.19	2.40	-0.67	1.19
WI Item 12 Do Things For Others	-1.05	2.25	-1.52	2.09	-0.36	1.22	-0.81	1.42	-1.31	2.12	-0.75	1.73	-0.74	1.66
WI Item 13 Enjoy Food	-0.79	1.51	-0.52	1.90	0.04	0.74	-0.35	0.94	-0.46	1.15	-0.25	1.00	-0.21	0.92
WI Item 14 Feelings About The Future	-1.79	3.05	-1.17	1.80	-0.88	2.28	-1.63	2.99	-1.23	2.15	-2.06	2.89	-0.53	0.84
WI Item 15 Finance	-0.11	0.46	-0.14	0.83	-0.17	0.82	-0.15	0.53	-0.29	1.32	-1.5	2.45	0	0.00
WI Item 16 Having To Depend On Others	-0.63	1.34	-1.61	2.33	-1.13	2.33	-1	1.90	-1.16	2.28	-1.19	2.48	-0.79	1.90
WI Item 17 Health	-1.84	2.52	-1.83	2.89	-1.04	2.09	-1.42	2.10	-1.67	3.12	-1.94	3.02	-1.05	1.31
WI Item 18 Others Fuss or Worry	-0.83	2.28	-1.26	1.84	-0.79	1.77	-1.04	1.82	-0.61	1.82	-0.94	1.29	-0.95	2.12
WI Item 19 Energy	-1	1.56	-2.5	3.05	-1.24	2.45	-1.59	2.10	-1.92	2.82	-1.88	2.47	-1.58	2.27
WI Item 20 Physical Discomfort	-0.68	1.34	-1.39	2.39	-0.84	2.06	-1.7	2.61	-1.43	2.67	-2.25	3.38	-0.53	1.31
WI Item 21 Anxiety	-1.53	2.57	-1	1.57	-1.2	2.61	-1.63	2.47	-1.31	2.26	-2.44	3.33	-1	2.19
WI Item 22 Think Clearly, Concentrate & Remember	-1.26	2.45	-1.43	2.15	-0.32	1.25	-1.04	2.16	-0.87	1.90	-1.38	3.32	-0.35	1.46