Original article

Design of new patient-reported outcome measures to assess quality of life, symptoms and treatment satisfaction in patients with abdominal aortic aneurysm

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Background: **No condition-specific patient-reported outcome measures exist for patients with abdominal aortic aneurysm (AAA). The aim of this work was to develop three questionnaires to assess quality of life (QoL), symptoms and treatment satisfaction in patients with AAA.**

Methods: **Semistructured interview techniques were used to explore patients' experiences of having an AAA in a series of focus groups and in-depth interviews. The information gathered was used to inform design and selection of items for the new tools; the overall structure of the new questionnaires was based on tools developed previously for patients with diabetes and other conditions.**

Results: **Fifty-four patients (51 men, 3 women; mean age 71·9 years) were recruited from four NHS Trusts to participate in focus groups or interviews, either while under surveillance, or following AAA repair (using open or endovascular techniques). The Aneurysm-Dependent Quality of Life Questionnaire (AneurysmDQoL) is an individualized measure of the impact of AAA on patients' QoL. Twenty-three domains were chosen specifically for their relevance to patients with AAA, with a further two overview items to assess overall QoL and the impact of AAA on QoL. The Aneurysm Symptom Rating Questionnaire (AneurysmSRQ) is a 44-item measure assessing physical and psychological symptoms reported by patients with AAA. The Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ) contains 11 items, suitable for patients before and after surgical intervention.**

Conclusion: **The iterative development process reported here has confirmed that these three new tools have good face and content validity for patients with AAA.**

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Introduction

In the UK, abdominal aortic aneurysm (AAA) affects 5–10 per cent of men and 1·5 per cent of women between the ages of 65 and 79 years, and constitutes a significant cause of death in this age group[1]. Owing to the risk of rupture, patients diagnosed with AAA usually undergo elective repair once the aneurysm reaches threshold size (5·5 cm). Techniques of AAA repair have evolved significantly in recent years, with large numbers now treated with endovascular aneurysm repair (EVAR) rather than open repair (OR). As a result of these advances and rigorous quality improvement programmes, surgical morbidity and mortality rates have fallen dramatically, and these parameters are therefore less useful than previously as the markers of surgical quality[2]. Additionally, and importantly, measures of quality of life (QoL), symptoms and treatment satisfaction allow evaluation of outcomes from the patient's perspective. This allows clinicians to target the issues that are most important to patients and strive for even higher-quality care rather than simply avoiding adverse outcomes. For this reason, the past few years have seen the UK Department of Health embark on a nationwide initiative to encourage the use of patient-reported outcome measures, both in the surgical specialties generally and more specifically in aortic aneurysm surgery[3,4].

In the absence of a validated aneurysm-specific QoL measure, all previous studies of QoL in patients with AAA have used generic tools. A systematic review[5] of these studies demonstrated that there was no clear consensus about the overall impact of AAA (or AAA repair) on QoL. A meta-analysis[6] of existing data did provide some additional clarification, suggesting that QoL may be affected negatively after AAA repair. However, the pattern of change over time (particularly beyond 12 months after intervention) and any differences between OR and EVAR may have been obscured by the use of generic tools and the heterogeneity of the data in the included studies. It is important to note that health and QoL do not necessarily improve or deteriorate in tandem[7]. Furthermore, little is known about symptoms experienced or treatment satisfaction in these patients.

The aim of this work was to design three new condition-specific questionnaires based on the experiences of patients with AAA to provide robust, separate assessments of QoL, symptoms and treatment satisfaction for use in clinical practice, audit and research.

Methods

Recruitment of patients

Patients were recruited from four English NHS Trusts: St George's University Hospitals NHS Foundation Trust (London), North Bristol NHS Trust, Norfolk and Norwich University Hospitals NHS Trust and Worcestershire Acute Hospitals NHS Trust. All participants had undergone AAA repair (OR or EVAR) within the preceding 24 months, or were enrolled in preoperative surveillance with an aneurysm that was below the threshold size for intervention. Men and women were invited, and there was no age constraint. Only English-speaking patients were invited.

Focus groups

Patients were identified using a purposive sampling technique (maximum variation) and assigned to focus groups with similar patients (all preintervention, or all OR or EVAR). This was done to prevent confusion between participants who had experienced different forms of treatment. The National Research Ethics Service (NRES Committee – London Chelsea – 11/LO/1416) approved the process of patient recruitment before the study and patients provided written consent at each stage.

The number of focus groups was determined using a theme-saturation model, which dictates that no further focus groups are necessary once there are no new themes being presented by participants[8]. Focus groups were moderated by a trainee vascular surgeon and a health psychologist with extensive experience in questionnaire design. A semistructured format was used to explore patients' experiences in relation to QoL, symptoms and treatment satisfaction at each stage in the treatment pathway using open-ended questions. The discussion included diagnosis, surveillance, preoperative investigations and, where applicable, intervention, recovery and follow-up. More sensitive topics (such as bowel or sexual function) were not broached by the facilitators during focus groups to avoid causing embarrassment, but were discussed during in-depth interviews. Written notes and audio recordings were made during each session to allow subsequent transcription.

Transcripts underwent content analysis to allow identification of the themes raised by group participants. Individual issues were listed and grouped into themes, with continual re-evaluation after each group and addition of new issues/themes as they emerged. Newly identified themes were then re-explored in greater depth at subsequent focus groups. This process clarified when theme saturation had been reached, and resulted in a single list of all aspects of QoL, symptoms and treatment satisfaction that had been raised by the participants. (*Table S1*, supporting information).

Questionnaire design

The themes identified during the focus groups then determined the aspects of QoL, symptoms and treatment satisfaction that were included in drafts of the three new questionnaires. To minimize the need for linguistic validation, the wording and structure of questions in the new tools was based on items from existing questionnaires previously developed with other patient groups, and validated as described below. The number of items in each of the new questionnaires was not predetermined, but instead resulted from selection of suitable items from a pre-existing item bank to address the domains relevant to patients with AAA. If no previous bank item existed (or could be adapted) to cover a QoL domain raised in the focus groups, a new item was created with specialist linguistic input (to facilitate future translations into other languages) before being tested in interviews.

Aneurysm-Dependent Quality of Life Questionnaire

The overall format of the Aneurysm-Dependent Quality of Life Questionnaire (AneurysmDQoL) and many of the individual items were based on those in the Audit of Diabetes-Dependent Quality of Life (ADDQoL) and associated questionnaires designed for use by people with other conditions. The ADDQoL was designed to improve on previous condition-specific measures that were not individualized, and often contained a mixture of items

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	

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

measuring symptoms, functional status and treatment satisfaction, with a minority including items genuinely measuring QoL. The ADDQoL is the most widely used of the various –DQoL measures and has been validated linguistically in more than 60 languages[9–17]. The design of the ADDQoL was influenced by the principles underpinning the Schedule for the Evaluation of Individual QoL (SEIQoL) interview methodology[18]. The guiding definition of QoL provided by the ADDQoL, as with the SEIQoL, is 'How good or bad you feel your life to be?'. The SEIQoL allows respondents to select the important aspects of their life for their QoL before rating them for quality, thereby providing an individualized measure of QoL. The –DQoLs differ from the SEIQoL by being condition-specific and questionnaire measures rather than a generic interview tool, but are similarly individualized in two different ways: first, a not applicable option is provided for items that may not apply to everyone (such as working life); and, second, a rating of the importance of each aspect of life is elicited as well as a rating of the impact of the condition on that aspect of their life (*Fig. 1*). Thus each item consists of two rating scales to measure impact and importance, and the two scores are multiplied to give a weighted impact score. The AneurysmDQoL thereby provides a personalized assessment of the impact of AAA on an individual's QoL

In addition, the AneurysmDQoL also includes two broad overview items. The first asks respondents to rate their present QoL and the second asks how their QoL would be if they had not had an aneurysm.

Aneurysm Symptom Rating Questionnaire

The question format of the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ) was based on tools developed for patients with a number of long-term conditions[19,20].

In the first part of each question, respondents are asked to indicate whether they had experienced a particular symptom at all in recent weeks (defined as 'about 4 weeks'). For those who had experienced that symptom, the second part of the question asks how much it had bothered them. Responses to the second part of the question are given using a four-point scale from 'not at all' 'to 'a lot' (*Fig. 2*).

1 (a)	Have you felt **unusually tired or lethargic** in recent weeks? No ☐ If *no*, go to next symptom Yes ☐ If *yes*, complete (b)			
(b)	If ***yes***, how much has this bothered you?			
	☐ not at all	☐ a little	☐ moderately	☐ a lot

Fig. 2 Example item from the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ)

5. How satisfied are you with feedback about scan results?
very satisfied 6 5 4 3 2 1 0 very dissatisfied

Fig. 3 Example item from the Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ)

Aneurysm Treatment Satisfaction Questionnaire

The Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ) was based on the Diabetes Treatment Satisfaction Questionnaire and associated questionnaires for other conditions[21–26]. For each question in the AneurysmTSQ, patients are asked to respond using a seven-point scale, where a higher score indicates greater satisfaction with treatment (*Fig. 3*).

As questionnaires were to be tested in patient interviews, all patient-identified issues were included in the initial drafts even if they were considered to be uncommon or unrelated to having an aneurysm, or had been mentioned by only one or two participants. Several additional items were also incorporated into the drafts to assess more sensitive symptoms including bowel function and sexual function, which may not have been mentioned by patients in a focus-group setting, but where there is evidence to suggest that AAA or its repair may have a negative impact[27–29].

Pilot interviews and questionnaire refinement

In the next stage of development, the draft questionnaires were refined through in-depth interviews. In these interviews, participants were asked to work through each of the questionnaires in turn, reading the questions out and thinking aloud so that interviewers could see when they were having difficulty reading or comprehending an item. This technique has been well proven over many years of developing similar tools[9,30]. Participants were also given the opportunity to identify any additional issues that they felt had not been covered in the new tools.

Table 1 Patient demographics

	Open aneursym repair	Endovascular aneurysm repair	Surveillance
No. of focus groups	2	6	1
No. of focus group participants (M : F)	8 (6 : 2)	29 (28 : 1)	4 (4 : 0)
No. of interviewees (M : F)	3 (3 : 0)	6 (6 : 0)	4 (4 : 0)
Age (years)*	74·9 (65·3–86·3)	72·9 (61·4–88·2)	73·7 (64·9–84·2)
Time since intervention (months)*	8·0 (3–20)	5·7 (2–13)	–

*Values are mean (range).

Results

Nine focus groups were held during the initial phase of development (6 EVAR, 2 OR, 1 surveillance). In total, these involved 41 patients with AAA, with between three and six participants in each group. For logistical reasons the majority of groups involved patients who had undergone EVAR, but theme saturation suggested no further groups were necessary for patients who had had either OR or surveillance. Thirteen in-depth interviews were then carried out during the subsequent refinement process (*Table 1*).

Aneurysm-Dependent Quality of Life Questionnaire

In all of the focus groups for patients who had already undergone aneurysm repair (OR or EVAR), there were reports of AAA-related issues that could have affected QoL negatively (*Table S1*, supporting information). Preoperative anxiety was particularly prevalent, with participants mentioning this spontaneously in eight of the nine focus groups, and describing feelings of having a ‘ticking time-bomb inside’. Anxiety about surgical intervention was also noted.

Participants in two groups (both EVAR) reported feelings of relief once their aneurysm had been repaired, using phrases such as ‘I felt happy to be alive’, ‘I had a near miss’ and ‘it was as if the bomb had been defused’. One patient (EVAR group) also said that they valued each day more since having the aneurysm repaired. However, relief of anxiety following intervention was certainly not universal. With many having experienced no preoperative symptoms, participants in four groups (3 EVAR, 1 OR) expressed concerns about the possibility of other occult illnesses and how they would ever know if any problem were to arise with their aneurysm repair.

Another common theme was the impact of lifestyle restrictions on QoL. This was mentioned in six groups (all EVAR) and related largely to patients feeling that they had to limit their physical activity (as opposed to being physically incapable of doing things). In a small subset of patients (for example commercial drivers) there were financial implications resulting from being prohibited from working with an untreated aneurysm. Other notable QoL themes raised by participants included failure of well-being to return to preoperative levels following intervention, impact on relationships with family members, and the fact that some patients felt unprepared for the severity of the operation, or complications when they arose.

The initial draft of the AneurysmDQoL contained 25 items in total. Following the first two overview items, there were 23 domain-specific items addressing the impact of AAA on multiple patient-identified aspects of life of importance for QoL (*Table S2*, suppporting information). The final item on the questionnaire was a free-text question, to allow patients to identify any other ways in which QoL was affected by having had an AAA.

In-depth interviews resulted in several minor modifications to the AneurysmDQoL. To improve patients’ understanding of the stem question, the wording was changed from ‘If I had not had an aneurysm, my quality of life would be … ’ to ‘If I had never had an aneurysm … ’. This was because a number of participants misinterpreted this to be about how their QoL would be if they had not had an aneurysm repair, rather than the actual condition. For example, some patients commented that they would be dead if they had not had an aneurysm repair. The change to the wording improved participants’ understanding that the item was asking them to consider their QoL at the time of questionnaire completion, and how they felt this would be different if they had never had an aneurysm (whether repaired or not). Wording of the discomfort item was also changed, with participants finding the words ‘physical discomfort’ easier to understand than ‘bodily discomfort’.

In a draft version of the AneurysmDQoL, there were three items relating to cognitive function, which asked about ‘memory’, ‘ability to concentrate’ and ‘ability to think quickly and clearly’. However, a composite form of this question ultimately proved to detect as much impact as the three separate items taken together, and the composite item was therefore retained in their place (item 22; *Table S2*, supporting information).

None of the participants identified any additional aneurysm-related QoL issues that were not already covered by the questionnaire. The final version contained

23 domain-specific items plus two overview items and a single free-text question about any other ways that QoL is affected. One domain-specific item ('The amount I value each day') was ultimately removed during validation, resulting in 22 domain-specific items.

Aneurysm Symptom Rating Questionnaire

During focus groups, patients reported a wide range of symptoms that they attributed to their aneurysm or its repair (*Table S1*, supporting information). The most common of these was pain, with leg pain, lower back pain, abdominal pain and buttock pain being the most common (reported in 7, 5, 4 and 4 groups respectively). Other lower limb symptoms included swelling, numbness, weakness and heaviness. In addition to pain and limb symptoms, a number of more generalized symptoms were frequently mentioned. Participants in seven of the eight postoperative groups (all 6 EVAR groups and 1 OR group) commented on a feeling of marked lethargy for many months after intervention. Low mood and weight loss were also noted in four groups each, with general weakness, decreased activity, profuse sweating, significant bruising and poor appetite each mentioned in at least two groups.

The initial draft of the AneurysmSRQ comprised 43 items asking about the specific physical, mental and psychological symptoms that were identified during focus groups, plus three free-text items allowing patients to identify any additional symptoms that had not been covered elsewhere. Interviews provided the opportunity to discuss more sensitive topics that were not raised during focus groups. The interviews confirmed that these issues were experienced by patients and warranted inclusion in the AneurysmSRQ, with more than 40 per cent of interviewees reporting some upset in gastrointestinal function and over 60 per cent reporting symptoms related to sexual dysfunction. The interview stage also resulted in the amendment or removal of several items that participants found difficult to understand or were not deemed relevant. These included items relating to general muscle pains, hallucinations, lumps under the skin and wound infection. A number of completely new items were also added after being identified as important by interviewees. These included avoidance of sexual activity (as distinct from problems with sexual function and loss of interest in sex, which were in the original draft), feeling faint/lightheaded, difficulty thinking quickly and clearly, and changes in bowel function. Furthermore, items were reordered to group symptoms into themes (such as gastrointestinal symptoms or pain) so that the questionnaire followed a more logical sequence. The final version contained 44 items (*Table S3*, supporting information) and two blank items for free text describing any additional symptoms.

Aneurysm Treatment Satisfaction Questionnaire

When it came to discussion of treatment satisfaction, a range of issues were highlighted, although the most frequently reported concern was that patients did not feel it had been made clear to them how serious their condition was (*Table S1*, supporting information). This related to a lack of information about likely side-effects (as opposed to complications covered in the preoperative consent process), and how much intervention might affect them both mentally and physically. Similarly, patients in six of the nine focus groups felt that they had been given insufficient information about whether they should avoid physical exertion and whether certain activities, such as air travel, were safe before or after aneurysm repair. Patients also frequently commented (6 of 9 groups) that they had not been given any choice about the type of intervention they would have (OR or EVAR); one elderly woman was distressed that she had had an OR and would have preferred EVAR. Some appeared not to be concerned by the lack of choice, however, and felt that the surgeon knew best and that they would not have minded what sort of operation they had. Other reported factors reducing satisfaction included insufficient time for consent, little contact with the surgeon and a lack of feedback about scan results. Interestingly, however, patients generally described feeling positively reassured by follow-up scans and clinic visits, rather than seeing them as a burden or source of anxiety.

In the AneurysmTSQ, patients are asked to evaluate their experiences of AAA treatment (including any monitoring or surveillance) over the preceding few weeks. The initial draft contained 15 items related to specific elements of treatment and monitoring, including overall treatment, convenience, discomfort, information, feedback, support, follow-up, demands of treatment and monitoring, understanding and satisfaction with type of operation (OR or EVAR). As in the AneurysmDQoL and AneurysmSRQ, there was also a final open question to allow respondents to mention any particular areas of satisfaction or dissatisfaction that had not already been covered.

Four items were removed from the AneurysmTSQ following in-depth interviews. Three of these were poorly understood by patients or unnecessarily repetitive, and related to demands of treatment, flexibility of treatment and how well they felt the operation had worked. The fourth item to be removed asked about whether patients would choose to undergo the same type of intervention again should it become necessary. Unfortunately, this was found to cause concern among participants as they felt it was suggesting that further intervention was likely. It was also decided that this aspect of satisfaction was covered in a separate item that asked whether patients would encourage others to have the same kind of aneurysm treatment.

Once again, despite prompting, none of the interviewees highlighted any sources of satisfaction or dissatisfaction that had not already been covered by the questionnaire. The final version therefore contained 11 items (*Table S4*, supporting information) and a single open question about any unmentioned issues.

Discussion

The focus groups and interviews provided significant new qualitative data relating to patients' experiences of AAA and AAA repair. This identified the aspects of QoL, symptoms and treatment satisfaction that are most relevant to these patients and led to the design of three comprehensive new outcome measures.

Over and above the health status outcomes described elsewhere in the literature, patients involved in this study identified a number of previously unrecognized QoL issues associated with AAA. These included persistent postoperative anxiety in both EVAR and OR cohorts, restrictions of activity, avoidance of sexual activity, impact on family life and loss of financial independence. Importantly, with the exception of anxiety, these newly identified themes are not addressed at all by the generic measures of health status (such as the Short Form 36 (QualityMetric, Lincoln, Rhode Island, USA) and EuroQol 5D (EuroQol Group, Rotterdam, The Netherlands) that have commonly been used to assess these patients[31,32].

Patients described a wide range of symptoms and aspects of treatment that might influence their QoL. Although some of these symptoms may not be related directly to AAA or its repair, a conscious decision was made to retain all symptoms that had been mentioned by patients in the questionnaire until a much larger data collection had been undertaken. At that point it may be possible to remove items if there is robust evidence that they are unrelated to AAA.

Postoperative pain – particularly affecting the lower limbs – has been described previously, but what was unexpected here was that persistent pain and lethargy seemed to be reported as frequently after EVAR as after OR. This differs from previous evidence suggesting that OR has a greater long-term physical impact than EVAR[33]. Even though the data presented here are qualitative rather than quantitative, they certainly suggest that this aspect of recovery after AAA repair warrants further investigation.

The suggestion that AAA is a largely asymptomatic condition before intervention[34] is supported by the fact that most of the patients in the present cohort did not describe overt physical symptoms before surgery. However, that is not to say that having an aneurysm had no negative impact on their QoL during surveillance. In the absence of major physical symptoms, the impact of AAA on QoL appears to be centred around anxiety in the preoperative phase. Although this may have been anticipated, what was less expected was that patients in both OR and EVAR groups reported persistent anxiety after intervention. In the OR group, a number of patients also expressed concerns about the relative lack of follow-up and felt that they had been left to cope alone very soon after a major operation. Indeed, patients who had undergone EVAR generally reported feeling reassured by follow-up scans, rather than seeing them as a burden or a source of anxiety. This is contrary to previous assumptions that repetitive follow-up after EVAR might cause patients to worry that their aneurysm was not fixed, or that CT surveillance might lead to concerns about radiation exposure[35,36]. It also highlights the need for more detailed study of this area, as awareness of such patient views might influence the current trend towards more rapid hospital discharge and early cessation of follow-up. At the very least it might allow clinicians to guide patients' expectations more effectively.

Managing patients' expectations about treatment is clearly a very important part of the patient–doctor interaction, and the treatment satisfaction issues described by participants were often related to communication and the provision of information. Patients were often unclear about the nature and severity of their condition, whether they should restrict their day-to-day activity, and the likelihood of side-effects and complications. Although communication issues are a common source of dissatisfaction in healthcare[37], the identification of specific deficiencies in this setting has highlighted clear targets for improvements in practice.

Although a small number of changes were made to the newly designed questionnaires during the interview phase, they were generally well understood from the outset. They were acceptable to (and welcomed by) patients, and proved to have good face validity and content validity. Items relating to the more sensitive topics little discussed in the focus groups also proved to be highly relevant, and these topics therefore warrant further quantitative investigation in a larger group of patients. The QoL and symptom measures are suitable for all patients with AAA investigated to date, and psychometric validation has confirmed that the AneurysmTSQ has separate subscales suitable for patients before or after intervention and at any of the time points studied (while under preoperative surveillance, and from 6 weeks to well beyond 12 months after surgery)[38].

Significant efforts were made to include a representative sample of patients by involving multiple centres and patients having OR and EVAR, both before and after intervention. However, it is recognized that the ratio of men to women was higher than might be expected based on the natural prevalence of the condition. This was partly because more men than women had undergone AAA repair within the preceding 2 years at the centres involved in the study. The number of women participants was also limited by simple logistic considerations, such as whether they were readily contactable or available on the dates of the focus groups or interviews. Nonetheless, the deliberate retention of free-text items in the final versions of each questionnaire will ensure that patients have the opportunity to raise any issues that have not been covered within the questionnaires to date.

This paper reports the design of three new questionnaires to assess QoL (AneurysmDQoL), symptoms (AneurysmSRQ) and treatment satisfaction (AneurysmTSQ) among patients with AAA. Having been developed with patient involvement at every stage, these new questionnaires are believed to be highly representative of the issues experienced by these patients. Psychometric evaluation (to be reported separately) has confirmed their structure, reliability and suitability for use in this patient group and they are now ready for wider clinical use in order to improve our understanding of the impact of AAA and AAA repair[38].

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.

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Supporting information

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

Table S1 Aspects of quality of life, symptoms and treatment satisfaction identified during focus groups (Word document)

Table S2 Domains covered in the final version of the Aneurysm-Dependent Quality of Life Questionnaire (AneurysmDQoL) (Word document)

Table S3 List of symptoms covered in the final version of the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ) (Word document)

Table S4 Aspects of treatment covered in the final version of the Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ) **(**Word document)