

A Novel Quality of Life Instrument for Patients with an Abdominal Aortic Aneurysm

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WHAT THIS PAPER ADDS

This study provides a new instrument to measure quality of life in patients with an abdominal aortic aneurysm. It quantifies the impact of ongoing aneurysm surveillance on quality of life in aneurysm patients. The ability to objectively measure disease specific quality of life in aortic aneurysm patients provides a novel patient-centred outcome measure for varying aneurysm repair techniques and better informs the decision making process regarding aneurysm repair options and timing.

Objective: The surveillance and treatment of abdominal aortic aneurysms (AAAs) may impact patient quality of life (QOL). A novel AAA specific QOL instrument was developed and validated to quantify the impact of AAA surveillance on QOL.

Methods: The study was performed in two phases: development (2011–2013) and validation (2013–2014) of a survey instrument. Content was informed by focus groups at three centres (22 patients) and two multidisciplinary physician focus groups (6 vascular surgeons, 7 primary care providers). Cognitive interviews (17 patients) ensured questions were understood as intended. The final survey was mailed to AAA patients at six US institutions. Patients were scored on two AAA specific domains of QOL: emotional impact (EIS) and behavioural change (BCS), range 0–100 with higher scores indicating worse quality of life. Test retest reliability and internal consistency were assessed. Discriminant validity was determined by comparing scores between patients under surveillance vs. those who had undergone AAA repair. Scores were externally validated by correlation with the Short Form (SF)-12.

Results: A total of 1,008 (73%) of 1,373 patients returned surveys: 351 (35%) were under surveillance, 657 (65%) had undergone repair (endovascular, 414; open, 179; unsure, 64). Median EIS was 11 (range 0–95; IQR 7–26). Median BCS was 13 (range 0–100; IQR 9–47). To test reliability, 337 patients repeated the survey after four weeks with no significant differences between scores over time. EIS and BCS demonstrated good internal consistency (Cronbach's Alpha 0.85 and 0.75 respectively). There was strong correlation between scores ($r = 0.53$) and both related moderately to SF-12 scores ($r = 0.45$ and $r = 0.39$, respectively). Patients under AAA surveillance had worse EIS than repair patients (22 vs. 13; $p < .001$). Patients with a higher perceived rupture risk had a worse EIS (45 vs. 12; $p < .001$) and BCS (30 vs. 13; $p < .001$).

Conclusions: An AAA specific QOL instrument was successfully created and validated. The range of impact on QOL by AAA surveillance is broad. For most patients the impact is minimal, but for some, especially those with a greater perceived rupture risk, it is severe.

Keywords: Abdominal aortic aneurysm, Quality of life

Article history: Received 26 March 2018, Accepted 18 January 2019, Available online 23 February 2019

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[☆] This paper was presented at the Society for Vascular Surgery Annual Meeting June 18, 2015, National Harbor, MD, 2015.

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<https://doi.org/10.1016/j.ejvs.2019.01.018>

INTRODUCTION

Ruptured abdominal aortic aneurysm (AAA) is the 14th leading overall cause of mortality in the United States, accounting for over 4,500 deaths annually.^{1,2} The incidence of

AAA is about 8% in men over the age of 65 years.³ A majority of new AAA diagnoses are made through incidental findings on imaging studies obtained for other reasons, and as the number of imaging studies performed has risen precipitously, so has the number of AAAs diagnosed.^{4,5} In addition, the United States Preventive Services Taskforce has recommended that men over the age of 65 who have smoked should be screened for an AAA,⁶ a guideline that has been vetted via systematic review and been shown to decrease aneurysm related mortality.^{7,8} As a result, more patients are receiving aneurysm repair at smaller sizes and many undergo serial surveillance imaging studies awaiting repair at a future time.^{4,9}

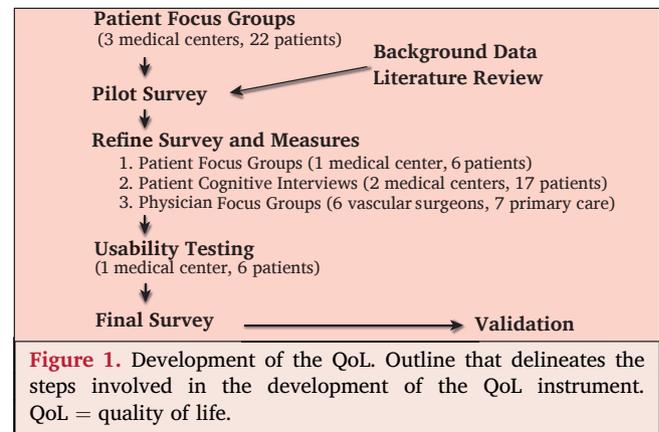
However, the psychological impact on the patient that is imparted by a new diagnosis of AAA remains poorly described. Some suggest that screening and surveillance can have a negative impact on patient quality of life.¹⁰ Since the majority of newly diagnosed aneurysms are small, most AAA patients enter surveillance rather than undergoing repair, and the anxiety of living with this diagnosis has been described by some as similar to “living with a ticking time bomb.”¹¹ Such assessments are generally limited to qualitative descriptors and are poorly defined by the existing generic quality of life surveys. Furthermore, patients who have undergone aneurysm repair have been assessed for changes in quality of life using existing quality of life measures, but no clear conclusions can be drawn because of the lack of specificity of the instruments. A recent review article on quality of life after AAA repair declared that “there exists a paucity of good quality data” and that “no clear conclusions can be drawn about the relative quality of life benefits of AAA repair.”¹²

The lack of good quality data on quality of life in AAA patients directly relates to the absence of a disease specific quality of life measure for this patient population. The purpose of this study, therefore, was to develop, refine, and validate an instrument that can reliably quantify and measure quality of life in patients with an AAA. This instrument was devised in the form of a survey among patients who were under surveillance for AAA and to validate it by comparing quality of life scores with patients who have undergone either open or endovascular repair of an AAA.

METHODS

Survey development

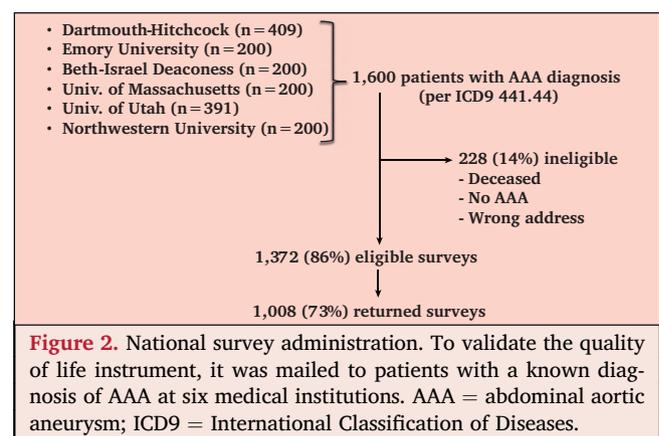
The work involved in the creation of the AAA Quality of Life survey instrument has in part been reported previously.¹³ Fig. 1 highlights the steps involved in the development of the survey. First, three independent focus groups were organised with 22 AAA patients at three different medical centres to ascertain what key domains influence their quality of life. A comprehensive literature review on this subject was performed. Combining the findings from the literature and the AAA patients, a pilot survey was devised with questions that addressed each of the key domains identified. This work was performed in close collaboration with survey creation experts from the Centre for Survey Research (CSR)



at the University of Massachusetts, Boston. This pilot survey was then presented to a six patient focus group for refinement. Two physician focus groups, one comprising of six vascular surgeons and one seven primary care providers, assessed the pilot survey and draft measures for sensibility and clarity. Survey experts then revised the pilot survey based on the feedback obtained and presented the revised survey to AAA patients one on one in 17 separate cognitive interviews. These served to ensure that the questions were understood as intended and that the survey was feasible to complete for the average patient. Further revisions were made along every step of the derivation process based on quantitative and qualitative analyses under the direction of CSR that involved adding and removing questions/answer choices, rewording, and reordering of items based on cluster and correlation analyses. Once complete, the final revised survey was deemed ready for validation.

Validation

Validation of the final survey was performed via mailed administration of the instrument on a national scale. At six institutions, 1,600 patients were identified who had visited clinic with an AAA diagnosis per ICD-9 code 441.44 (Fig. 2). Patients were included whether they were under surveillance of an AAA or had already had an AAA repair, be it open or endovascular, emergency or elective. The survey was created in such a way that it would distinguish between



patients who had a repair and those who had not. Questions were tailored to each group through the development process explained above. A copy of the final survey and how it distinguishes between surveillance and repair patients is available in Supplementary material, [Appendix I](#). Along with the survey, each patient was initially mailed a \$5 cash incentive, a postmarked return envelope, a copy of the Short Form 12 (SF-12) generic survey, and a covering letter describing the nature and purpose of the study. This letter clearly instructed that participation in the study was voluntary and that consent for participation and the utilization of the patient's answers was implied by their returning the completed survey. Thus, a separate consent form was not necessary and the need for such was waived by the Institutional Review Board at each participating site. Patients who did not return the initial survey were sent a reminder postcard two and four weeks after initial mailing.

All patients were asked to complete all components; otherwise they were excluded from analysis. Validity of the survey was assessed on multiple levels. First, to assess for test re—test reliability and reproducibility of responses, the first 200 respondents under AAA surveillance and the first 200 respondents who had an AAA repair were each sent another copy of the survey at least one month later with instructions as to why they were asked to complete the same survey again. Next, summary scores were created by combining responses for questions that assessed similar domains. For example, answers to questions about emotional impact or behavioural change were combined into a summary score for each category. The emotional impact score (EIS) was obtained by summing the responses to the questions listed in [Table 1](#), which deal with topics such as worry about AAA rupture, anxiety about interventions, worry about cost, fear of death, etc. Similarly, [Table 2](#) lists the questions that were used to calculate the summative behavioural change score (BCS), which focuses on how patients altered their physical and character behaviour after being diagnosed with an AAA or having undergone a repair. Answers to each question were graded

Question
1 How often did AAA related thoughts cross your mind?
2 How often did these thoughts about your AAA bother you?
3 How often did you have trouble sleeping because of your AAA?
4 How worried were you that your AAA might rupture?
5 How worried were you about medical bills you might have because of your AAA?
6 How worried did people close to you seem about your AAA?
7 How worried are you that you might need surgery for your AAA?
8 How worried are you that you might have side effects from surgery for your AAA?
9 How worried are you that you might die from your AAA?
10 How anxious have you been because of your AAA?

These questions of the survey were used to calculate the emotional impact score. AAA = abdominal aortic aneurysm.

Question
1 Compared with before your AAA diagnosis, how often do you do strenuous activity now?
2 Is this change in activity directly related to your AAA?
3 Compared with before your AAA diagnosis, how often do you travel now?
4 Is this change in activity directly related to your AAA?
5 Compared with before your AAA diagnosis, how often do you do heavy lifting now?
6 Is this change in activity directly related to your AAA?
7 Compared with before your AAA diagnosis, how often do you engage in sexual activity now?
8 Is this change in activity directly related to your AAA?

These questions of the survey were used to calculate the behavioural change score. AAA = abdominal aortic aneurysm.

from 0 to 100, where the higher numbers indicate worse or more negative answer choices with regards to quality of life. The EIS and BCS are each an average of the individual answer scores for the questions in each category. Each question with its respective answer received equal weighting in the summary score.

The survey was measured for internal consistency by ascertaining Cronbach's alpha statistic for each summary score group, compared according to repair type. Construct validity of the survey was measured by testing the hypothesis that quality of life scores would be worse for those patients who have a higher perceived aneurysm rupture risk. In addition, it was hypothesised that summary scores would correlate loosely with quality of life scores obtained by the validated generic SF-12 survey, yet yield more discriminatory power. Lastly, to test discriminant validity, the hypothesis that patients who were under aneurysm surveillance would have worse quality of life scores than those who had undergone AAA repair was tested.

To eliminate bias in the interpretation of the results, all survey responses were collected by the Centre for Survey Research at the University of Massachusetts, Boston, and de-identified for analysis. Responses were compared using the chi-square or the independent/Student *t* test when applicable, and $p < .05$ was significant. Analytical work was performed using STATA software (College Station, TX, USA).

Ethics approval

The Dartmouth Geisel School of Medicine's Centre for the Protection of Human Subjects as well as the Institutional Review Board (IRB) at Dartmouth and at each participating site granted IRB approval for the study. IRB review and approval were performed in compliance with the Declaration of Helsinki. All subjects enrolled in this study provided informed consent to participate.

RESULTS

Of the 1,600 mailed surveys, 228 were deemed ineligible since the patient was either dead, did not in fact have an

AAA diagnosis, or the mail was undeliverable due to a wrong address. Of the 1,372 eligible surveys, 1,008 (73%) were returned complete and usable for analysis (Fig. 2). About one third of the patients ($n = 351$) were under surveillance for AAA, while 593 patients had undergone repair of their AAA (414 had an endovascular repair and 179 an open repair). Sixty-four patients were unsure of what type of repair they had. These patient groups were defined by patient responses on the survey alone; the medical records were not accessed to verify patient responses as to their repair type. Demographics of the survey respondents are shown in Table 3. There were no significant differences in age, gender, race, education, or smoking history among the surveillance, endovascular repair (EVAR), or open repair groups.

Fig. 3 demonstrates the distribution of both the EIS and BCS. About half of the patients cluster around the low end of the scoring spectrum. This suggests that about 50% of patients have minimal emotional impact from their AAA diagnosis and don't significantly change their behaviour as a result of their diagnosis. In other words, these patients have fairly good quality of life as it relates to their AAA. However, for the other half, the scores have a wide range across the higher (i.e. worse) quality of life spectrum. Therefore, about 50% of AAA patients have a significant and varied impact of their quality of life in relation to their AAA. One can see that the EIS and BCS for these 50% of patients are broadly distributed, rather than clustered around a certain score. This suggests more variance among patients with worse summary scores, underlining the need for the instrument to be able to discriminate among these patients and the variables that influence their AAA related quality of life.

In order to assess test re-test reliability, 400 survey respondents were asked to complete the same survey a second time, one month later. Of 200 initial respondents who indicated that they were under AAA surveillance, 169 (85%) completed and returned a second survey. Of 200 respondents who indicated that they had had an AAA repair, 186 (93%) returned a complete second survey. For all of these patients, the mean EIS on the first survey was 16.6 (95% CI 14.8–18.4). In comparison, the mean EIS on the

repeat survey for the same group was 16.2 (95% CI 14.4–18.0, $p = .42$), indicating no significant difference in mean summary score between sets of surveys. The mean BCS also did not differ significantly between the initial and re-test survey one month later. The initial mean BCS was 20.6 (95% CI 17.8–23.4) compared with the re-test mean BCS of 22.2 (95% CI 19.3–25.0, $p = .2$). On sub-analysis, no difference in mean scores was noted for each individual question that contributed to the summary scores, indicating good correlation of results. This suggests that patients responded to questions similarly on the re-test survey as on the initial one.

The internal consistency of responses was determined by calculating Cronbach's alpha statistic for the summary scores. Table 4 shows the results of these calculations, comparing each patient group of AAA surveillance vs. repair type. In general, a Cronbach's alpha of greater than 0.7 is good with a maximum acceptable value of 1.¹⁴ Therefore, it was found that patient responses on the survey were very consistent for both EIS and BCS across all repair groups, indicating that the same patient would answer similar questions in a similar way.

The hypothesis that patients with a perceived high rupture risk would have worse quality of life scores was tested in order to determine the construct validity of the survey. Among the survey questions, one of the questions was "What is your best guess of how likely it is that your AAA will rupture in the next 12 months?" Table 5 shows the mean EIS and BCS for patients compared with how they responded to this question. It can be seen that patients who felt their AAA was not likely to rupture had a mean EIS of only 12 while those who felt their AAA was somewhat likely to rupture had a mean EIS of 31 and those who thought their AAA very likely to rupture had a much higher mean EIS of 45. This trend of worse quality of life score correlating with a worse perceived chance of rupture was highly significant ($p < .001$) and was replicated for the BCS. Furthermore, the EIS and BCS for all patients were compared with their overall scores obtained on the SF-12 generic quality of life survey. Correlation between both the EIS (correlation coefficient $r = 0.45$) and BCS (correlation coefficient $r = 0.39$) was found with the SF-12 scores, further validating the construct that higher EIS and BCS indicate worse quality of life.

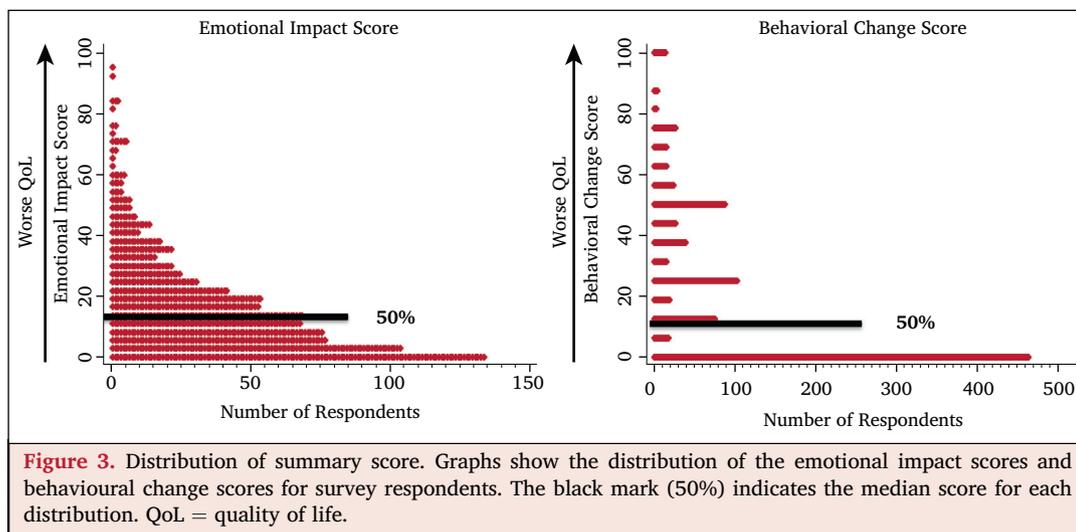
Lastly, the survey's discriminant validity was confirmed. To do so, quality of life scores between patients who were under AAA surveillance were compared with those who had undergone AAA repair. The hypothesis was that quality of life would be worse for those under surveillance because of anxiety and worry. In Table 6 the mean EIS and BCS for the various repair groups are shown, broken down for patients who had received their AAA diagnosis or AAA repair less than one year prior to taking the survey vs. those who had been diagnosed or repaired more than one year previously. First, the EIS did not significantly change for surveillance patients who had their diagnosis less than a year ago (mean EIS 23) or more than a year prior to taking the survey (mean EIS 23). This suggests a persistent emotional impact of the

Table 3. Demographics of survey respondents

	Surveillance ($n = 351$)	EVAR ($n = 414$)	Open ($n = 179$)	Unknown ($n = 64$)
Age (mean), years	76	76	75	78 *
Female gender, %	25	23	25	36 *
Non-white race, %	8	6	7	10
Graduated high school, %	55	53	52	33 *
Any smoking history, %	86	86	86	83

Demographics of those who returned completed surveys.

* $p < .05$. EVAR = endovascular repair.



AAA diagnosis regardless of timing. Compared with the surveillance patients, however, patients who had an EVAR have a comparatively lower EIS in the short term (17 vs. 23) with an even more marked improvement in EIS by more than one year after repair (12 vs. 22). For open repair patients, the mean EIS in the short term did not significantly differ compared with surveillance patients (22 vs. 23); however, it also markedly improved in the long term to a mean score similar to the EVAR patients (13 and 12, respectively). This implies that anxiety, worry, fear, and other emotional components of quality of life related to AAA improve after AAA repair, and they do so in the long term regardless of repair type. On the other hand, change in behaviour as indicated by the BCS is essentially improved across all groups in the long term, with a more dramatic improvement in patients who had undergone aneurysm repair.

DISCUSSION

Over the course of several years, the group successfully devised, refined, and then validated a disease specific quality of life survey for patients with an AAA. Through meticulous AAA patient interviews, the domains that determine their quality of life have been determined, and then this subjective data has been turned into a tangible instrument that reliably and succinctly measures AAA

related quality of life. This instrument is able to individually assess the emotional impact of an AAA diagnosis and the resultant change in patient behaviour. Specifically, there is minimal impact on quality of life after diagnosis in about half of the aneurysm patients. However, for half of aneurysm patients it was found that the impact is more pronounced along the spectrum of severity. This level of discrimination has not been attained previously by generic or other quality of life instruments when applied to AAA patients.^{12,15-18} It therefore highlights the necessity of a disease specific measure, the lack of which has been the major critique of the heterogeneity in prior quality of life studies among AAA patients.¹²

This instrument may also offer a role in the informed decision making process of patients with aneurysm disease. To date, most decision making regarding aneurysm repair revolves around anatomical features, such as maximum diameter, rate of expansion, and morphology among others, and patient level risk calculations based on comorbid medical conditions.^{19,20} For some patients, the addition of patient derived concerns, anxiety, and impact on quality of life may help guide a decision to repair or delay repair of an aneurysm. The application of this tool in such a matter will require prospective trialling of patients and is among future

Patient group	Cronbach's alpha statistic	
	EIS	BCS
Surveillance	0.87	0.75
EVAR	0.79	0.79
Open Repair	0.86	0.73
Unknown Repair Type	0.7	0.78

Note. The Cronbach alpha statistic is shown as an assessment of internal consistency of the emotional impact score and behavioural change score for the various patient groups. EIS = emotional impact score; BCS = behavioural change score; EVAR = endovascular repair.

"What is your best guess of how likely it is that your AAA will rupture in the next 12 months?"		
Answers	EIS	BCS
Not likely to rupture	12	13
Somewhat likely to rupture	31	33
Very likely to rupture	45	30
Not answered	22	15
	<i>p</i> < .001	

Note. The mean EIS and BCS are listed for patients who selected each answer choice as a measure of construct validity. In other words, patients who felt that their aneurysm was more likely to rupture had higher, or worse, EIS and BCS. EIS = emotional impact score; BCS = behavioural change score; AAA = abdominal aortic aneurysm.

Table 6. Discriminant validity

Patient groups	EIS		BCS	
	< 1 year	> 1 year	< 1 year	> 1 year
Surveillance	23	22	22	18
EVAR	17	12	35	18
Open repair	22	13	35	28
	$p < .001$	$p < .001$	$p < .001$	$p < .001$

Note. Mean EIS and BCS are shown for patients who were under aneurysm surveillance, had an open surgical repair, or an EVAR, compared according to whether they entered surveillance/had their repair less than or more than one year prior to completing the survey. EIS = emotional impact score; BCS = behavioural change score; EVAR = endovascular repair.

planned work. The aim of this study was to develop and validate the quality of life instrument and not to measure the outcome of how quality of life scores may impact repair options. Such an effort will require a prospective trial that can reliably assess quality of life as an outcome measure.

In addition to aiding the decision making process, this instrument may serve to quantify outcomes of patients enrolled in registries, trials, and long-term surveillance following repair or monitoring of growth of aneurysms. Prior work has indicated that some of the survey questions (Supplementary material, Appendix II, Surveillance Survey, Questions 33–39) can also determine patient knowledge about their AAA and therefore direct education efforts that may improve health related quality of life.¹³ While prior analysis found that baseline patient knowledge about their aneurysm disease does not appear to correlate with quality of life, perhaps education of a patient, i.e. the improvement in their knowledge, may alleviate anxiety and ultimately prevent repair of small aneurysms due to anxiety. Future efforts will use this novel instrument to measure emotional impact scores before and after patient education to prospectively ascertain how provider education could relieve patient anxiety and fear.

The multicentre survey that was performed among aneurysm patients to validate the instrument constitutes the largest survey study performed among vascular patients in general. In addition, it is by far the largest quality of life study undertaken among AAA patients.¹⁸ Patients who are under aneurysm surveillance have, in general, a worse quality of life than those who have undergone repair. Further, the negative impact of an aneurysm diagnosis appears to be persistent for more than a year among surveillance patients without significant change over time. Repair does appear to be associated with improvement in quality of life. EVAR patients appear to demonstrate this improvement earlier on, while after more than one year open repair patients appear to catch up and mirror the marked improvement in quality of life. Patients also appear to alter their behaviour in the early stages after an aneurysm diagnosis. This behavioural change appears to diminish over time. Further work will be required to delineate how the change in behaviour may be influenced by education vs. repair.

Another implication of this novel instrument is that it could screen for patients who suffer high anxiety about aneurysm surveillance. Rather than “fix” the anxiety of a patient with a small aneurysm by offering repair, improved communication between provider and patient, as well as potentially psychiatric or cognitive therapy, could be employed to improve anxiety and thus QoL in AAA surveillance patients. In a prospective fashion, this survey could measure anxiety before and after such an intervention to inform of the intervention’s effectiveness. Additionally, since recent AAA imaging surveillance guidelines have become less stringent,²¹ another therapy for high anxiety patients may be closer imaging surveillance rather than jumping to repair.

The recently updated European Society for Vascular Surgery Clinical Practice Guidelines on the Management of Abdominal Aorto-iliac Artery Aneurysms summarise that the current decision making process regarding when to repair an aneurysm is framed by the balance between risk of aneurysm rupture and risk of operative repair.²² Multiple factors, such as patient comorbid conditions, aneurysm diameter, operative complexity based on anatomy, and so forth play into this decision making process and therefore the process of deciding when and how to perform an aneurysm repair remains complex. As outlined in the practice guidelines, especially as novel repair techniques are rapidly advancing for complex aneurysms such as juxtarenal aneurysms, there remains a lack of patient specific data to guide decision making. “None of the studies on the treatment of juxtarenal abdominal aortic aneurysms have focused on the patient’s perspective or quality of life.”²² The outcome measure in this study will be able to fill this void and allow for investigators to assess aneurysm specific quality of life before and after multiple varying techniques of aneurysm repair, be that chimney grafts, fenestrated grafts, or open repair. This will hopefully inform the advantages and patient perceived outcomes of each repair option and help guide future management of complex abdominal aortic aneurysm disease.

There are several limitations inherent to the study design. First, all responses are derived from the patients via the survey. Medical records were not assessed to verify their repair type, repair status, or aneurysm size. However, in anticipation of this item, the ability to determine if a patient had a repair and what repair they had were addressed in the cognitive interviews and as a result a survey was created with specific questions and terminology that helps patients make a clear and reliable choice. Plus, this scenario indicates the real world setting in which the survey will be used the majority of the time. The goal was to develop an instrument that will be cost effective and consume minimal time in its administration. While the inclusion of patient level variables such as exact aneurysm size, rate of growth, insurance status, etc., may add more sensitivity to the overall instrument, very good discriminatory power of the instrument has already been seen and the additional time and staff time used by abstracting such data would outweigh the potentially minimal increase in refinement.

Second, while trends can be assessed of quality of life of patients who had an aneurysm repair vs. those who are under surveillance, these comparisons at this stage serve the primary purpose of instrument validation. While these retrospective responses potentially indicate better quality of life scores in patients who had AAA repair, the study was not designed to assess this level of granularity. A dedicated analysis and separate survey administration will be required to better understand the impact of AAA repair on quality of life. Lastly, with qualitative analytic work, there remains a potential for bias introduced by patient comments and preferences. In an attempt to diminish this potential, a heterogeneous patient population was ensured by drawing on patients from multiple institutions and by creating a large survey pool of over 1,000 patients.

CONCLUSIONS

Quality of life assessments among AAA patients have thus far been inconclusive, in part due to the lack of a disease specific quality of life instrument. Through meticulous psychometric analysis, such an instrument in the form of a survey was devised and subsequently refined. This was successfully validated on multiple constructs via a large, national survey administration. From the survey, it was learned that a significant portion of AAA patients have a profound and varied impact on quality of life from their diagnosis, with significant emotional impact and change in behaviour. The validation effort provided responses from patients who had undergone AAA repair and might suggest that repair may improve quality of life in these patients. Prospective work is required to better delineate and understand the link between AAA repair and impact on quality of life.

CONFLICT OF INTEREST

None.

FUNDING

This work was funded by the following, directed toward the primary investigator, Brian W. Nolan, MD, MS. None of these entities had any involvement in study design; collection, analysis, and interpretation of data; manuscript writing; or the decision to submit the manuscript for publication: NHLBI K23 Career Development Award (1K23HL092160-01A2); American College of Surgeons Career Development Award; SVS Clinical Research Grant; PVSS Academic Award; Hitchcock Foundation Award.

APPENDIX A. SUPPLEMENTARY DATA

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ejvs.2019.01.018>.

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