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Towards Patient Centred Outcomes for Elective Abdominal Aortic Aneurysm Repair: A Scoping Review of Quality of Life Scales

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WHAT THIS PAPER ADDS

This paper adds an inventory of available literature on quality of life (QoL) assessment in elective abdominal aortic aneurysm repair and points out the missing aspects that should be addressed in further research to adequately implement the patient's perspective on QoL in treatment outcomes.

Objective: In order to better incorporate the patient's perspective in medical decision making, core outcome sets (COS) are being defined. In the field of abdominal aortic aneurysm (AAA), efforts to capture the patient's perspective focus on generic quantitative quality of life (QoL) scales. The question arises whether these quantitative scales adequately reflect the patient's perspective on QoL, and whether they can be included in the QoL aspect of COS. A scoping review of QoL assessment in the context of elective AAA repair was undertaken.

Data Sources: PubMed, Embase, Web of Science, and the Cochrane Library.

Review Methods: A scoping review was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines. Articles reporting QoL assessment in the context of elective AAA repair were identified. Quantitative studies (i.e., traditional QoL scales) were aligned (triangulation approach) with qualitative studies (i.e., patient perspective) to identify parallels and discrepancies. Mean Short Form 36 item survey (SF-36) scores were pooled using a random effects model to evaluate sensitivity to change.

Results: Thirty-three studies were identified, of which 29 (88%) were quantitative and four (12%) qualitative. The 33 studies reported a total of 54 quantitative QoL scales; the most frequently used were the generic SF-36 (16 studies) and five dimension EuroQol (EQ-5D; eight studies). Aneurysm specific scales were reported by one study. The generic quantitative scales showed poor alignment with the patient's perspective. The aneurysm specific scales better aligned but missed "concerns regarding symptoms" and "the impact of possible outcomes/complications". "Self control and decision making", which was brought forward by patients in qualitative studies, was not captured in any of the current scales.

Conclusion: There is no established tool that fully captures all aspects of the patient's perspective appropriate for a COS for elective AAA repair. In order to fulfil the need for a COS for the management of AAA disease, a more comprehensive overview of the patient's perspective is required.

Keywords: AAA, Aneurysm, Core Outcome Set, COS, Patient's perspective, Quality of life

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INTRODUCTION

Efforts to establish more patient centred health care have led to the increasing integration of the patient's perspective in medical decision making. To achieve this, disease specific core outcome sets (COSs) are defined together with patients for a wide range of diseases.^{1,2} It is recommended that COSs are reported in all studies concerning a specific

patient cohort in order to allow for systematic evaluation of study outcomes.^{3,4}

In the process of developing the new European Society for Vascular Surgery guidelines on the management of abdominal aortic aneurysms (AAAs), it was discovered that outcomes considered important by vascular surgeons may substantially differ from the patient's perspective on treatment outcomes.^{5,6} In order to better incorporate the patient's perspective, the vascular society called for definition of a COS for the management of AAA disease.⁷ COSs are collections of key outcomes, such as mortality, morbidity, and the patient's perspective.⁷ The focus of this study was on the patient's perspective in the context of elective AAA repair.

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Studies addressing the patient's perspective generally rely on "quality of life" (QoL) as a quantitative equivalent. This umbrella term includes concepts such as QoL, health related QoL, or health status.⁸ Underlying these concepts are generic and disease specific (quantitative) questionnaires. Generic questionnaires, such as the Short Form 36 item survey (SF-36) and five dimensional EuroQol (EQ-5D), are applicable across a broad variety of diseases, and allow for comparison across patient groups, as well as with the general population.⁹ Disease specific questionnaires provide more detail and allow for a more focussed evaluation.¹⁰ It is generally recommended that both generic and disease specific questionnaires are used to best evaluate the QoL of a patient cohort.¹⁰ A limitation of quantitative scales is that they are based on questions defined by health professionals, which may not reflect the patient's perspective. Moreover, quantitative scales provide limited information and do not allow for an in depth examination of the patient's view.¹¹ To better assess the patient's perspective, qualitative research (semi-structured interviews and focus groups) is needed.¹²

In the field of AAAs, most studies addressing the patient's perspective on treatment outcomes rely on quantitative QoL questionnaires.^{13–15} With the knowledge that quantitative QoL scales do not, or only partially, capture the patient's perspective, the question arises whether current QoL scales adequately reflect the perspective of patients with AAA, and can be included in the QoL aspect of a COS for AAA. To address this question a scoping review was performed. Unlike a (regular) systematic review that addresses one specific question, a scoping review broadly identifies and maps all the available evidence to inform practice.¹⁶ The aim of this review was to (1) summarise the available reports of QoL assessment in elective AAA repair; (2) evaluate possible discrepancies between established (quantitative) QoL questionnaires and qualitative research (patient's perspective); and (3) estimate the sensitivity of QoL scales to changes in QoL in the context of elective AAA management.

METHODS

Literature search

This review was undertaken according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines (Supplementary Material 1).^{17,18} The study protocol uses the methodological framework proposed by Arksey and O'Malley,¹⁹ and additional recommendations made by Levac.^{20–22} The study protocol is available upon request from the corresponding author. Studies were identified through a systematic search in PubMed, Embase, Web of Science, and the Cochrane Library (updated 25 January 2021). The search strategy was based on QoL/patient perceptions and AAA (Supplementary Material 2).

Study inclusion

The review included all studies reporting QoL in the context of elective open AAA repair or endovascular aneurysm repair (EVAR). Studies that exclusively focussed on patients with small AAAs (< 5.5 cm); patients under surveillance; or studies that exclusively evaluated pre-operative QoL were excluded, as were studies that focussed on ruptured AAA, thoracic abdominal aneurysm, or aortic dissection. Letters, comments, reviews, or studies not available as full texts were also excluded. Studies evaluating cost effectiveness by estimation of quality adjusted life years (QALYs) were also excluded, because QALYs are based on mortality and re-intervention rates, rather than patient reported outcomes (PROs). Two authors (R.B. and J.L.) reviewed the results of the search strategy. Titles and abstracts were reviewed for eligibility. When eligibility was uncertain or unclear, the full texts were reviewed.

Data extraction

Data concerning year of publication, years of patient inclusion, number of included patients, patient characteristics (age and sex), treatment by open repair or EVAR, and timing of follow up were collected for all study types.

For quantitative studies, data extraction included type of QoL assessment tool(s), timing of QoL assessment, and key results. For qualitative studies data extraction included method of data collection (interview or focus groups), and key results. Data extraction was done by three independent researchers (R.B., J.L., and J.S.).

Quality assessment

Owing to the heterogeneity of study design the quality of quantitative studies was assessed by a descriptive review (age, sex, patient background, and responsiveness rate) (Table 1). The Critical Appraisal Skills Programme (CASP) qualitative research checklist was used to evaluate the methodological quality of qualitative studies.²³ Quality assessment was done by three independent researchers (R.B., J.L., and J.S.). In line with the guidelines for scoping reviews, the methodological quality of studies was not included in the analysis.²¹

Outcome assessment

The primary outcomes were (1) identification of quantitative QoL scales and their outcomes; and (2) comparison between items included in quantitative QoL scales and items emerging in qualitative research. Secondary outcomes included average follow up duration, and outcomes with respect to follow up.

Mean QoL scores were pooled at predefined time points: pre-operative, one, six, 12, and 24 months after intervention.

Table 1. Review articles reporting quality of life (QoL) assessment in elective abdominal aortic aneurysm (AAA) repair

First author (year of publication)	Inclusion years	Type of repair	Male/female ^a	Age (range) – y	QoL tool	Attention for re-interventions	Follow up timepoints	Study type	Response rate – %	Patient characteristics
<i>Quantitative research</i>										
Magee (1992) ²⁹	1998–99	OR	78/8	71 (48–84)	Rosser index	–	Pre-op, 30 (18–42) mo	P Single	80	–
Sandstrom (1996) ³⁰	1993–94	OR	16/6	69 (49–81)	SIP HI	–	6–12 mo	P Single	100	–
Mangione (1997) ³¹	1990–93	OR	78/17	72 ± 8	SF-36	–	Pre-op, 1, 6, 12 mo	P Single	86	No differences responders vs. no responders
Hennessy (1998) ³²	†	OR	11/3	71 (56–88)	Rosser index HSCL GHQ	–	13 (3–28) mo	R Single	–	–
Perkins (1998) ³³	†	OR	50/9	74 (51–83)	SF-36 Rosser index	–	Pre-op, 6 w, 3 mo, 6 mo	P Multi	95	–
Lloyd (2000) ³⁴	†	EVAR, OR	EVAR: 34 OR: 48 ^b	EVAR: 73 (59–82), OR: 73 (59–86)	SF-36	–	Pre-op, 6 mo	P Single	–	–
Malina (2000) ³⁵	1997–98	EVAR, OR	EVAR: 17/4, OR: 16/5	EVAR: 74 (53–81), OR: 74 (46–80)	NHP score	–	Pre-op, 5, 30, 90 d	P Single	100	–
Aquino (2001) ³⁶	1997–99	EVAR, OR	EVAR: 23/2, OR: 19/7	EVAR: 71 ± 2, OR: 70 ± 6	SF-36	–	Pre-op, –1, 4, 8, > 52 w	P Single	100	100% white (EVAR), 96% white (OR)
Ballard (2004) ³⁷	2000–03	EVAR, OR	EVAR: 20/2, OR: 81/26	EVAR: 77 (51–87), OR: 72 (33–89)	SF-12	–	Pre-op, 3 w, 4 mo, 1 y	P Single	100	–
Lottman (2004) ³⁸	1996–99	EVAR, OR	EVAR: 54/3, OR: 16/3	EVAR: 69 (52–82), OR: 68 (52–81)	SF-36 EQ-5D	–	Pre-op, 1, 3 mo	RCT Multi	95	–
Soulez (2005) ³⁹	1998–2002	EVAR, OR	EVAR: 19/1, OR: 20/0	EVAR: 70 ± 6, OR: 71 ± 7	SF-36 Karnofsky score Pain scale	–	Pre-op, 1, 3, 6, 12, 18, 24 mo; 24, 48 h; 7, 30 d (pain scale)	RCT Single	–	–
Vogel (2005) ⁴⁰	1998–2003	EVAR, OR	EVAR: 80/12, OR: 86/40	EVAR: 72 ± 0.7, OR: 71 ± 0.7	SF-36	–	Pre-op, 2 w–3 mo + 3–12 mo	P Single	70	–
Aljabri (2006) ⁴¹	†	EVAR, OR	EVAR: 37/6, OR: 25/8	EVAR: 76 ± 7, OR: 67 ± 9	SF-36	–	Pre-op, 1 w, 1 mo, 6 mo	P Multi	100	88% self-dependent (EVAR), 97% self dependent (OR)
Kurz (2010) ⁴²	1997–2003	EVAR	213 (<80 y)/ 19 (<80 y), 31 (>80 y)/ 7 (>80 y)	<80 y: 70 (43–79); >80 y: 83 (80–93)	NHP score	–	<80 y: 55 (29–78) mo; >80 y: 34 (4–71) mo	P Single	96–53	–
Ehlers (2011) ⁴³	1989–2007	OR	327/0	72 ± 5	SF-12 EQ-5D EQ-VAS	–	5 ± 3.5 y	R Registry	87	No differences between responders and no responders, except time since surgery (shorter in responders)
Khan (2011) ⁴⁴	2006–08	EVAR, OR	EVAR: 17/4, OR: 86/16	EVAR: 78 ± 1, OR: 74 ± 7	Study specific questionnaire (based on: review + focus group)	–	23 (6–40) mo	P Registry	89	–
Kisis (2012) ⁴⁵	2008–10	EVAR, OR	EVAR: 17/3, OR: 16/4	EVAR: 78 ± 1, OR: 74 ± 7	SF-36	–	Pre-op, 1 mo, 1 y	P Single	100	–
Hinterseher (2013) ⁴⁶	1995–2006	EVAR, OR	EVAR: 47, OR: 98 ^b	EVAR: 71 (68–92), OR: 69 (52–86)	WHOQOL-BREF SF-36	–	30 (4–53) mo (EVAR), 67 (18–153) mo (OR)	R Single	76	–
Mouawad (2013) ⁴⁷	†	EVAR, OR	EVAR: 18/2, OR: 14/1	EVAR: 71 ± 8, OR: 69 ± 4	SF-36	–	Pre-op, 30 d, 90 d, 1 y	P Single	75	75% married (EVAR), 87% married (OR)
Pol (2014) ⁴⁸	2009–11	EVAR	880/93 (<80 y), 250/40 (>80 y)	70 ± 7 (<80 y), 83 ± 3 (>80 y)	EQ-5D	–	Pre-op, 1 w, 30 d	R Registry	96	–
Tocher (2013) ⁴⁹	†	OR	19/3	69 (58–80)	Pain score Interview (pain expectations)	–	Pre-op, post-op (0, 24, 48, 96 h)	P Single	–	–
De Bruin (2016) ⁵⁰	1999–2002	EVAR, OR	EVAR: 161/12, OR: 161/17	EVAR: 71 ± 7, OR: 70 ± 7	SF-36 EQ-5D	–	Pre-op, 3 w, 6 w, 3 mo, 6 mo, 12 mo + every 6 mo until 5 y	RCT Multi	90	–
Peach (2016) ⁵¹	†	EVAR, OR	EVAR: 89/14, OR: 67/2	EVAR: 77 (61–96), OR: 73 (60–90)	AneurysmDQoL AneurysmSRQ AneurysmTSQ	–	6, 12, >12 mo	R Multi	66	–
Kato (2017) ⁵²	2011–13	EVAR, OR	EVAR: 24/1, OR: 28/2	EVAR: 76 ± 8, OR: 73 ± 8	SF-36	–	Pre-op, 1, 3, 6, 12 mo	P Single	100	Patients with additional surgical procedures were excluded

Table 1-continued										
First author (year of publication)	Inclusion years	Type of repair	Male/female [†]	Age (range) – y	QoL tool	Attention for re-interventions	Follow up timepoints	Study type	Response rate – %	Patient characteristics
Dijkstra (2019) ⁵³	2009–11	EVAR	175/22 (endoleak), 803/90 (no endoleak)	74 ± 8 (endoleak), 73 ± 8 (no endoleak)	EQ-5D	Yes	Baseline, 1 y	R Registry	–	Patients with concomitant or another type (I/III) of endoleak were excluded
Pettersson (2019) ⁵⁴	†	EVAR, OR	EVAR: 32/4, OR: 31/9	EVAR: 75 (65–85), OR: 68 (52–80)	SOC-questionnaire Malina's 5 6ESQ	–	1 mo, 1 y, 2 y	P Single	84	–
EVAR 2 (2005) ⁵⁵	1999–2003	EVAR, no repair	EVAR: 141/25, No intervention: 147/25	EVAR: 77 ± 6, No intervention: 76 ± 7	SF-36 EQ-5D	–	EVAR: 1, 3, 12 mo; no intervention: 2, 4, 13 mo	RCT Multi	96	Patients who are considered non-eligible for OR
Lederle (2012) ⁵⁶	2002–08	EVAR, OR	EVAR: 441/3, OR: 435/2	EVAR: 70 ± 8, OR: 71 ± 8	SF-36 EQ-5D IIEF-5	–	6 mo, 30 d, 12 mo + every year until 8 y	RCT Multi	67–85	87% white (EVAR), 87% white (OR)
EVAR 1 (2005) ⁵⁷	1999–2003	EVAR, OR	EVAR: 494/49, OR: 489/50	EVAR: 74 ± 6, OR: 74 ± 6	SF-36 EQ-5D	–	Pre-op, 0–3 mo, 3–12 mo, 12–24 mo	RCT Multi	99	100% white (EVAR), 100% white (OR)
<i>Qualitative research</i>										
Dubois (2014) ⁵⁸	†	EVAR, OR	EVAR: 18, OR: 18 [‡]	72 (58–85)	Focus group	Yes	2–12 mo	P Single	34	Patients primarily declined owing to difficulty travelling to the hospital
Lee (2017) ⁵⁹	†	EVAR, OR	EVAR: 31, OR: 21 [‡]		Focus group: questionnaire	Yes	Experience of peri-op and post-op care (1 y)	P Registry + single	32	–
Letterstal (2010) ⁶⁰	2005	OR	6/4	73 (55–83)	Semi-structured interviews	–	< 3 mo	P Single	100	–
Peach (2016) ⁶¹	Before 2016	EVAR, OR	EVAR: 28/1, OR: 6/2	EVAR: 73 (61–88), OR: 75 (65–86)	Focus groups	–	EVAR: 6 (2–13) mo, OR: 8 (3–20) mo surveillance	P Single	–	–

Data are presented as *n*, median interquartile range, or mean ± standard deviation, unless stated otherwise. OR = open repair; pre-op = pre-operative; P = prospective study; Single = single centre study; SIP = Sickness Impact Profile; HI = health index; SF-36 = Short Form 36 item survey; HSCL = Hopkins Symptom Checklist; GHQ = General Health Questionnaire; R = retrospective study; Multi = multicentre study; EVAR = endovascular aneurysm repair; NHP = Nottingham Health Profile; SF-12 = Short Form 12 item survey; EQ-5D = EuroQoL 5D; RCT = randomised controlled trial; EQ-VAS = EuroQoL visual analogue scale; WHOQOL-BREF = World Health Organisation Quality of Life Questionnaire – BREF; post-op = post-operative; Pre-op = pre-operative; AneurysmDQoL = Aneurysm-Dependent Quality of Life; AneurysmSRQ = Aneurysm Symptom Rating Questionnaire; AneurysmTSQ = Aneurysm Treatment Satisfaction Questionnaire; SOC = Sense of Coherence; ESQ = Experience of Service Questionnaire; IIEF-5 = International Index of Erectile Function – 5; peri-op = peri-operative.

* If sex of patients was not specified, it was assumed that sex was 100% male.

† Year of inclusion not stated in the article.

‡ Only men.

To explore outcomes emerging from qualitative research, qualitative studies were analysed in several phases. Firstly, key findings were sorted by their original themes and subthemes (Supplementary Material 3). Secondly, similar findings were identified and sorted into common themes and subthemes using the framework analysis (Supplementary Material 4).²⁴ The findings were compared with the original texts to confirm that the correct meaning was comprehended.

To evaluate the alignment between qualitative and quantitative studies, items that emerged from the qualitative synthesis were mapped against items from quantitative

studies. A triangulation approach was used to evaluate whether the items overlapped (+), partially overlapped (+/–), or did not overlap (–).^{25,26}

Three authors (R.B. [PhD student], J.L. [vascular researcher], and J.S. [vascular surgeon]) independently extracted and analysed the data. When the researchers disagreed, outcomes were discussed and consensus on the findings was reached.

Statistical analysis

Mean QoL scores of quantitative questionnaires were pooled using a random effects model of DerSimonian and

Laird.²⁷ Heterogeneity was assessed by I^2 statistics.²⁸ All analyses were performed with Stata/SE, version 12.0 (StataCorp, College Station, TX, USA).

RESULTS

Literature search

The literature search identified 4 446 non-identical articles, of which 2 921 were excluded after title review. Eighty-eight abstracts and 47 full texts were read to assess eligibility. The final review included 33 articles that reported aspects of the QoL of patients with AAA who underwent elective repair (Fig. 1).

Study characteristics

Of the 33 articles, 29 (88%) were quantitative studies and four (12%) were qualitative studies. Most studies included both EVAR and open repair (OR) patients. Eight studies exclusively included OR patients, and four studies focussed on EVAR patients. An overview of included articles can be found in Table 1.^{29–61}

In total, this review included data for 7 223 patients: 2 610 treated by OR and 4 613 by EVAR. All patients were included between 1989 and 2013. Patient age ranged from 67 to 83 years (OR group: 67 – 83 years; EVAR group: 69 – 78 years). The proportion of males was 91% in both the OR

and EVAR groups. The median follow up was one year. Only one study reported a follow up period of > 6 years (Fig. 2).

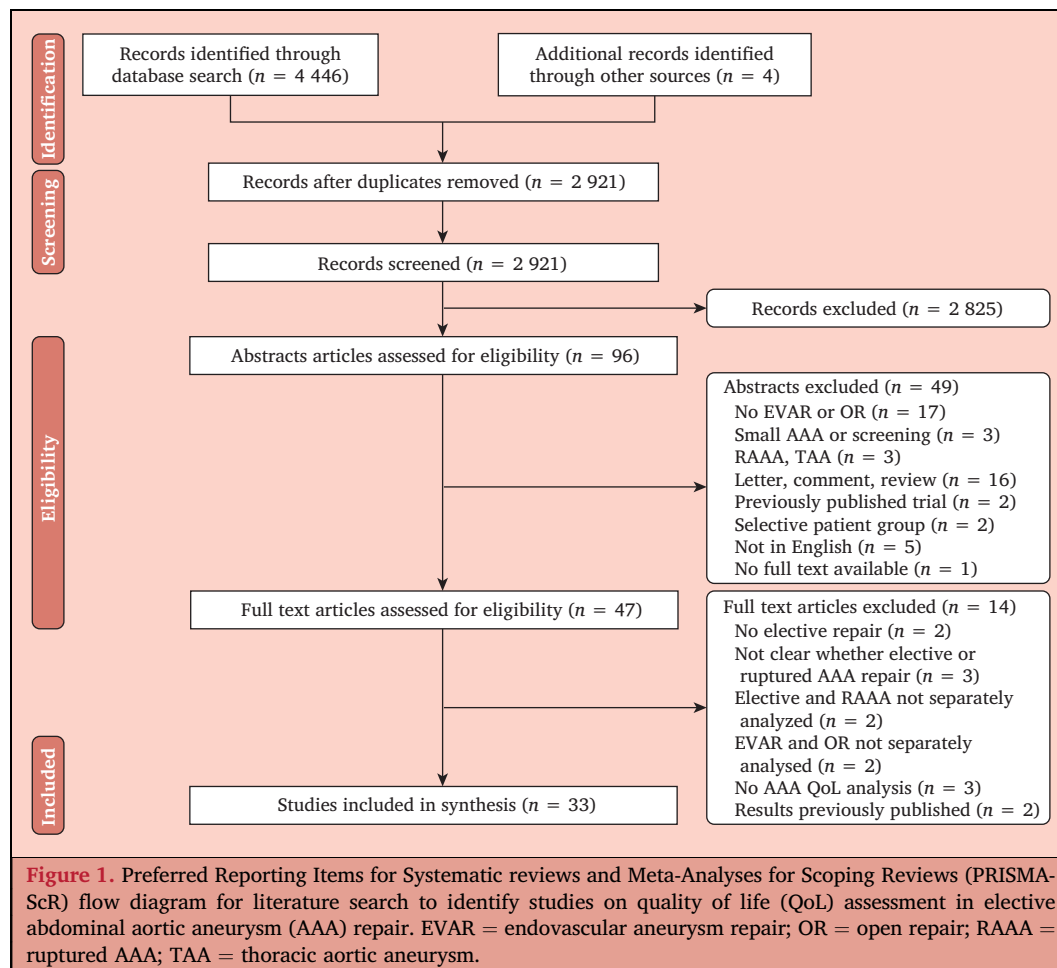
The overall quality of qualitative studies was good (Supplementary Material 5). The methodology of studies reporting quantitative QoL measurements varied. Descriptive data regarding the patient population and response rate are reported in Table 2.

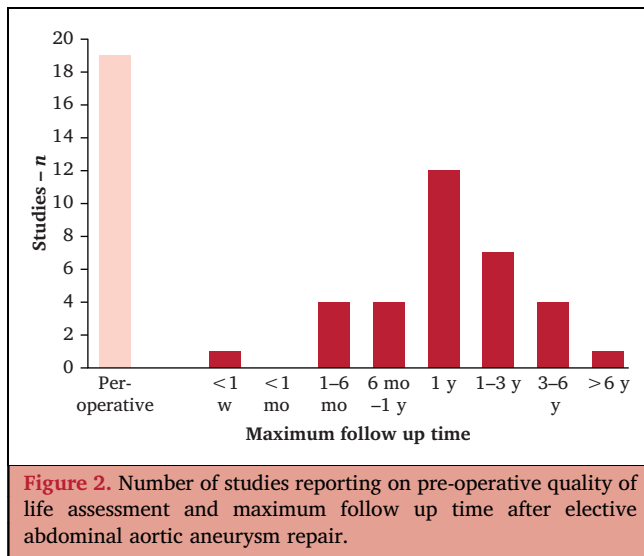
Quality of life assessment in quantitative and qualitative studies

The 33 studies reported a total of 54 QoL scales, the majority of which were quantitative. A detailed overview of all scales used is provided in Fig. 3.

The most frequently used quantitative scales were the generic SF-36 (reported in 16 studies or 30% of all reported scales) and the EQ-5D (reported in eight studies or 15% of all reported scales). The aneurysm specific scales, AneurysmDQoL (Aneurysm Dependent Quality of Life), AneurysmSRQ (Aneurysm Symptom Rating Questionnaire), and AneurysmTSQ (Aneurysm Treatment Satisfaction Questionnaire), were only reported by Peach *et al.* (Figure 3).⁵¹

As the SF-36 was reported in 16 studies, it allowed for a meta-analysis of its sensitivity to changes in QoL following elective AAA. The mean SF-36 scores were pooled for pre-defined time points (Fig. 4). It was concluded that SF-36 scores did not vary over time, with the exception of a





transient drop in the scores of two questionnaire items (role physical and vitality) following OR. Pooling of the EQ-5D and aneurysm specific scales was not possible owing to insufficient data and study heterogeneity.

Four studies applied a qualitative approach, of which three relied on focus groups and one on semi-structured interviews (Fig. 3).^{58–61} A comprehensive overview of aspects identified in the qualitative studies is provided in [Supplementary Material 4](#). In summary, qualitative evaluation of the patient's perspective on QoL identified six main themes: functional outcomes; (physical) symptoms; psychological symptoms; social outcomes; communication; and self control (Table 2).

Comparison of aspects covered in quantitative scales vs. qualitative studies

Aspects emerging from qualitative research (patient's perspective) were mapped against aspects covered by the most used quantitative QoL scales (generic and aneurysm specific) to evaluate parallels and discrepancies (Table 2). The comparison revealed poor alignment of the generic QoL questionnaires with the patient's perspective as reported by the four qualitative studies included in this review. The SF-36 and EQ-5D covered few of the aspects that patients in the qualitative studies reported as being important (i.e., functional outcomes and pain [Table 2]). The three aneurysm specific questionnaires were better aligned with aspects considered relevant by patients but still missed "concerns regarding symptoms" and "the impact of possible outcomes/complications". "Self control and decision making", which was brought forward by patients in all four qualitative studies, was not captured in any of the quantitative questionnaires.

The impact of follow up on quality of life

Three of 33 studies (10%) addressed the QoL with regard to follow up and/or re-interventions. One quantitative study

evaluated the impact of a re-intervention in the first year after EVAR due to endoleaks.⁵³ It found similar mean EQ-5D scores at the one year follow up for patients both with and without endoleaks (endoleak 0.88 ± 0.18 ; no endoleak 0.88 ± 0.16 ; $p = .94$). Two qualitative studies addressed the patients' attitudes towards the possibility of a re-intervention in elective repair.^{58,59} It was concluded that the possibility of a re-intervention influenced the choice of repair (i.e., patients preferred to not have a re-intervention). No qualitative study specifically addressed the impact on QoL of an actual re-intervention.

Qualitative studies found that patients have a positive attitude towards follow up visits, and generally feel reassured by follow up scans. Quotes from patients reported in qualitative research are summarised in [Table 3](#), to illustrate the findings regarding re-interventions.

DISCUSSION

This scoping review shows that there is currently no established tool that fully captures all aspects of the patient's perspective on QoL appropriate for the QoL aspect in a COS for elective AAA repair. In order to fulfil the need for a COS for the management of elective AAA disease, a more comprehensive overview of the patient's perspective is required.

The medical field is rapidly changing from hierarchically structured to shared forms of decision making. The development of a COS provides the opportunity to put patients at the centre of care, by ensuring that outcomes important to patients are included, monitored, and assessed in clinical studies and practice.^{1,2} Moreover, consistent reporting of a disease specific COS enables systematic evidence synthesis, and reduces study heterogeneity and reporting bias.^{3,4}

In the context of AAA, improvements in peri-operative care, patient selection, and surgical techniques (such as the introduction of EVAR) led to marked reductions in procedural complications and death.⁶² As a result, traditional (surgical) outcome measures such as peri-operative mortality and/or complication rates became less discriminatory parameters, especially in the case of EVAR, to evaluate patient care, and patient derived outcomes gained in importance.⁶³ So far, most studies that have addressed the patient's perspective in the context of elective AAA repair have relied on generic quantitative QoL questionnaires. A critical question is whether these questionnaires adequately capture the patient's perspective. For example, health status, a dimension included in many quantitative QoL questionnaires, is different from perceived QoL, and does not truly reflect the patient perspective.⁸ The question arises to what extent the generally applied quantitative QoL questionnaires reflect the patient's perspective on QoL.

Based on this scoping review it was concluded that quantitative QoL questionnaires lack the sensitivity to detect changes in QoL associated with elective AAA repair, and do not capture several important dimensions identified in qualitative studies of what patients consider to be

Table 2. Items from qualitative research categorised in six main themes and their alignment in the generic, quantitative quality of life questionnaires in assessment for elective abdominal aortic aneurysm (AAA) repair

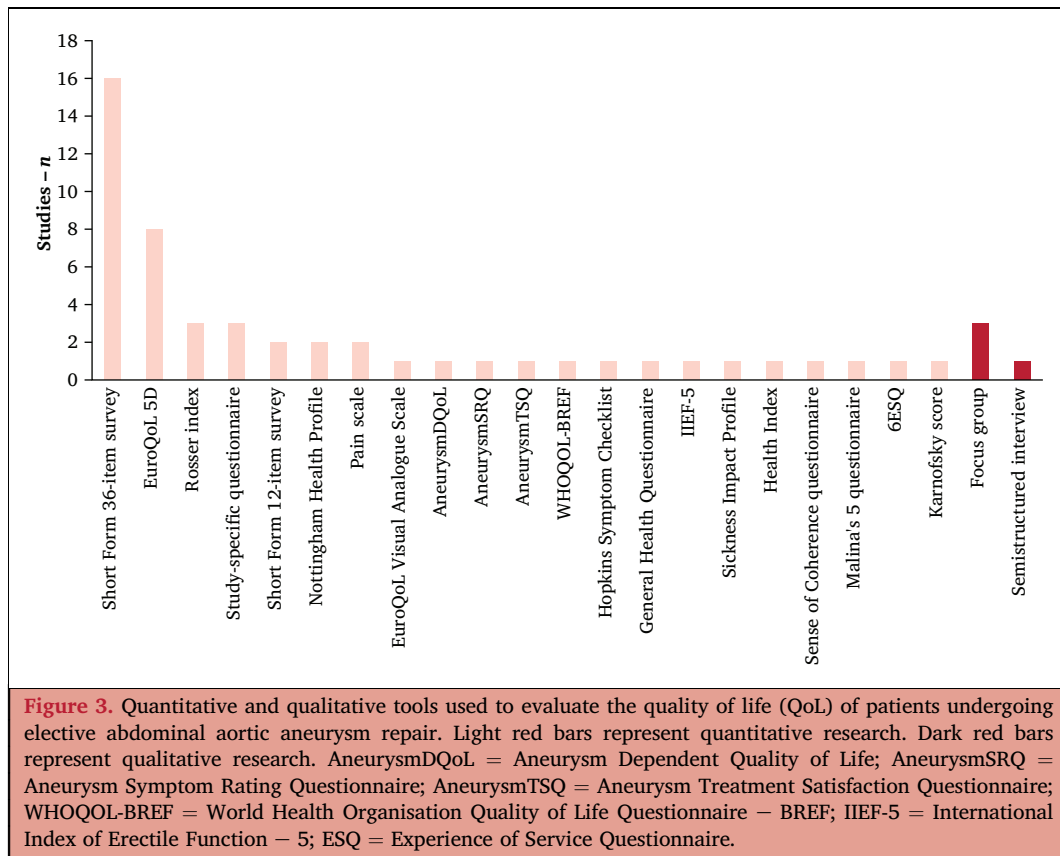
Aspects emerging from qualitative research	Generic		AAA specific		
	SF-36	EQ-5D	AneurysmDQoL	AneurysmSRQ	AneurysmTSQ
<i>Functional outcomes</i>					
Recovery time	–	–	–	–	–
Being able to go home	–	–	–	–	–
Being able to work	–	+/-	+	–	–
Financial implications	–	–	+	–	–
Energy	+	–	+	–	–
Restrictions of activity	+	+	+	–	–
Self care/dependence on others	+	+	+	–	–
Sex life	–	–	+	–	–
Household tasks	+/-	–	+	–	–
Able to go on holiday	–	–	+	–	–
<i>(Physical) symptoms</i>					
Pain	+	+	–	+	–
Leg numbness	–	–	–	+	–
Problems walking	+	+	–	+	–
Loss of appetite	–	–	–	+	–
Weight loss/gain	–	–	–	+	–
Urination problems	–	–	–	+	–
Bowel problems	–	–	–	+	–
Nausea	–	–	–	+	–
Lethargy	+	–	–	+	–
General weakness	–	–	–	+	–
Tiredness	+	–	–	+	–
Sleep/sleeping disturbances	–	–	–	+	–
(Night) sweats	–	–	–	+	–
Fever	–	–	–	+	–
Bruising	–	–	–	+	–
Swelling	–	–	–	+	–
Headaches	–	–	–	+	–
Wound problems	–	–	–	+	–
<i>Psychological outcomes</i>					
Concerns about outcomes/complications	–	–	–	–	–
Concerns about symptoms	–	–	–	–	–
Anxiety	+	+	+	–	–
Angry/upset	–	–	–	+	–
Cognitive function	–	–	+	–	–
Depression/feeling down	+	+	+	–	–
Fear of the future/unknown	–	–	+	–	–
<i>Social outcomes</i>					
Impact on family members	+/-	+/-	+	–	–
The amount people worry about me	+/-	–	+	–	–
Social life	+	+/-	+	–	–
<i>Information</i>					
Need for information	–	–	–	–	+
Lack of information	–	–	–	–	+
Opportunity to gather information	–	–	–	–	+
<i>Self control</i>					
Decision making	–	–	–	–	–

SF-36 = Short Form 36-item survey; EQ-5D = EuroQoL 5D; AneurysmDQoL = Aneurysm Dependent Quality of Life; AneurysmSRQ = Aneurysm Symptom Rating Questionnaire; AneurysmTSQ = Aneurysm Treatment Satisfaction Questionnaire; + = included; +/- = partially included; – = not included.

“quality of life”. This latter aspect may reflect the fact that the SF-36 and EQ-5D (cost utility analysis) are primarily designed to evaluate the health status of patients rather than the full spectrum of QoL.⁶⁴

In contrast to quantitative research, qualitative research strategies allow for in depth evaluation of patient thoughts, and are therefore more suitable to evaluate QoL.^{12,65} Based

on qualitative research, Peach *et al.* designed AAA specific questionnaires to assess QoL (AneurysmDQoL), symptoms (AneurysmSRQ), and treatment satisfaction (AneurysmTSQ).^{51,61} While these questionnaires largely cover the aspects emerging from other qualitative studies, they do not address themes such as the “ability of self control and decision making” and “concerns about symptoms”.



Moreover, these AAA specific scales designed by Peach et al. are based on the data of a single study.⁶¹ Hence, it cannot be ruled out that the aspects addressed are incomplete, and/or that cultural interferences impact the conclusions. In addition, these AAA specific questionnaires have not been widely validated in clinical practice. So, while these AAA specific questionnaires take an important first step towards the inclusion of PROs in AAA management, they require further refinement.

Perceptions of “quality of life” influence medical decision making. In the case of elective AAA repair, the impact of follow up and re-interventions on “quality of life” is a recurring point in the debate regarding EVAR vs. OR.^{5,66} From a health provider’s perspective, it is generally assumed that mandatory follow up and risk of late graft failure and re-interventions after EVAR negatively affect QoL.^{5,66} However, there is limited evidence to support these assumptions. This review shows that only three studies specifically address the impact of follow up and potential re-interventions on a patient’s perspective of QoL.^{53,58,59} One emerging conclusion is that, in contrast, to general assumptions, patients experience follow up as reassuring. In fact, patients report that dissatisfaction with follow up was due to a lack of follow up after OR rather than to excessive follow up after EVAR. Similar conclusions are drawn from the qualitative PREFER study (Preferences of Patients, Their Family Caregivers and Vascular Surgeons in the Choice of Abdominal Aortic Aneurysms Treatment Options), which

explored patients’ motivations to decide on EVAR or OR.^{67,68} In the current study, it was found that patients and caregivers were not concerned about a more intense follow up. Therefore, the general notion that intensive mandatory follow up negatively impact QoL is not correct.

A critical finding of this review is that the median follow up of all QoL assessments of elective AAA repair was one year (Fig. 2). As the majority of re-interventions occur after one year, information on the impact of actual re-interventions on aspects of the QoL of patients with AAA is missing.^{69,70} To address this knowledge gap, longer follow up times and more qualitative research is needed to more adequately explore the patient’s perspective with regard to elective repair and its possible complications.⁷¹ Addressing long term aspects is vital, as elective AAA repair is a purely prophylactic procedure and does not come with additional benefits. Hence, elective AAA repair should not harm patients over their life expectancy.

A challenge in the evaluation of the QoL of patients with AAA is the asymptomatic nature of aortic aneurysm disease.⁷² In contrast to symptomatic diseases that result in discomfort or are directly life threatening and therefore likely to gain significant improvement in QoL after intervention, treatment of asymptomatic AAA will most likely not lead directly to tangible benefits and consequent clear improvements in QoL. This aspect may explain the apparent unresponsiveness of the generic quantitative QoL scales. In fact, a study of subjective outcomes following open surgical

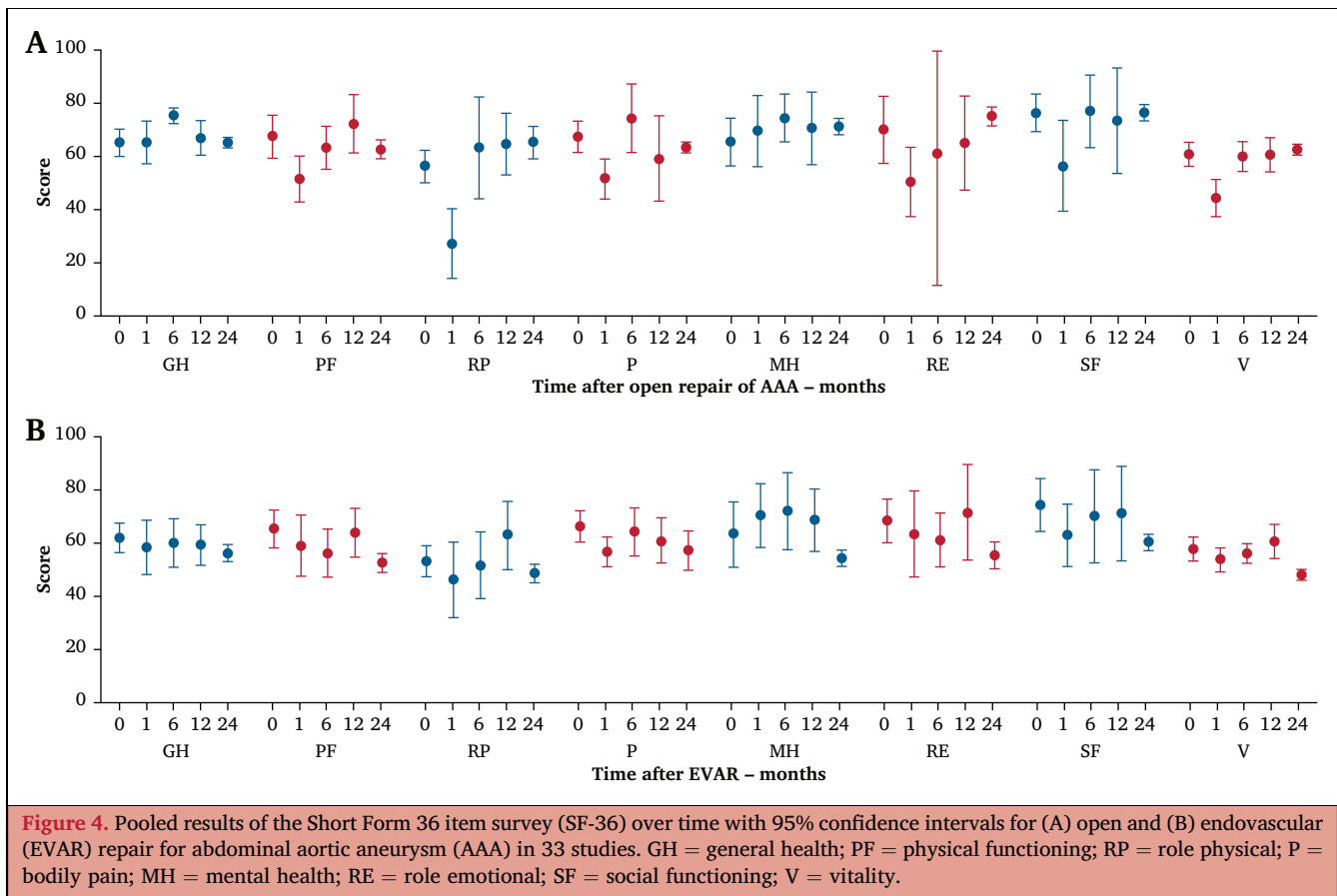


Table 3. Impact of re-interventions and follow up on quality of life	
Impact of re-intervention and follow up	Patient quote
The possibility of re-interventions influenced the choice of repair	“I looked at both procedures and I recognised that there was a slightly higher chance of not making it through with the incision in my stomach, but I didn’t think it was significant enough to go for the through the groin, and possibly having to redo it.” ⁵⁸ “For me it was the longevity of the stents. The stability of the stent as far as it dropping out of position, no follow up in my case [was most important].” ⁵⁸
Experience lack of information about follow up	“Recovery time. Didn’t realise monitoring would be continued, thought I was cured.” ⁵⁹ “I was surprised that I needed another stent and balloon after the first trouser stent.” ⁵⁹
Feeling reassured by follow up scans	“It is a pleasure coming here and being told you’re OK.” ⁶¹

repair reported that 18% of patients indicated that they would not undergo AAA repair again knowing the recovery process, even though they fully understood the implications of AAA rupture.⁷³ Therefore, instead of focusing on improvement of QoL after repair, the aim should be to minimise deterioration in QoL during follow up and following elective repair.

In summary, there are currently no scales that cover all aspects of QoL in the context of elective AAA repair. In order to meet the need for a AAA specific COS,⁷ existing scales should be optimised to include more aspects that patients consider to be important regarding their QoL than is currently the case. Table 2 provides a list of items that should be included in future studies. This is a comprehensive list and a more condensed set of outcomes would be useful in the light of AAA surgery trials. In fact, information on critical outcome

aspects that emerged from the qualitative studies, such as “recovery time” and “the ability to go home”. Outcomes related to self control are generally missing from most study protocols. In line with the concept of a COS, definition of outcome sets should be performed in consultation with patients (i.e., representative focus groups should be conducted in order to define a COS for future studies). In addition, pre-existing (validated and non-validated) tools, such as the Hospital Anxiety and Depression Scale, can be used to provide further input. Owing to the lack of qualitative data, the question remains whether all aspects that patients report as important are captured. The aneurysm specific scales defined by Peach *et al.* provide a promising first step but must be further validated and expanded.^{51,61} Moving forward, a more comprehensive tool that enables the detection of changes in QoL following AAA repair must be developed. Such a tool

should also include the individual patient motives and priorities, which are often influenced by age and context in time.^{74,75} In other words, patients should not only be asked to report on specific items, but also on how they feel about and prioritise different items. Sanderson *et al.* provides a methodological strategy to develop a prioritised patient derived COS.⁷⁶

Although QoL is mostly subjective in nature, its measurement should meet scientific criteria, such as validity and reliability. Therefore, during the development of a QoL COS, extensive validation of both qualitative and quantitative research is needed.⁷⁷

Limitations

The focus of this study was on QoL aspects of a COS, as QoL is most widely used to evaluate the patient's perspective. Yet, COSs are not exclusively about QoL and other aspects need to be considered when designing a COS. The evaluation of possible outcome differences between EVAR and OR, and aspects beyond elective AAA repair (e.g., AAA surveillance) were beyond the scope of this review. Inclusion of studies with different methodologies and sample sizes resulted in considerable heterogeneity between the studies pooled in the meta-analysis. Consequently, only the SF-36 scores could be pooled. Finally, women were under represented. To design a COS that represents the entire patient population, efforts must be made to adequately address sex specific aspects.

Conclusion

Exclusive reliance on generic QoL questionnaires cannot be recommended in the development of a COS to evaluate the QoL of patients undergoing elective AAA repair. They are poorly aligned with the patient's perspective and are insufficiently sensitive to change. Aneurysm specific questionnaires provide an important first step in the understanding and incorporation of the patient's perspective but require extension and further validation. Despite efforts to evaluate care from a patient's perspective, there is a paucity of data in this field. Therefore, more qualitative research should be conducted, and stronger patient involvement is required to allow for the development of a disease specific COS that adequately incorporates the patient's perspective on treatment outcomes. This way, a COS can provide clinicians with a tool to evaluate and target issues important to patients, and ultimately to strive for higher quality of care.

APPENDIX A. SUPPLEMENTARY MATERIAL

Supplementary material to this article can be found online at <https://doi.org/10.1016/j.ejvs.2021.06.026>.

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