

# Decision-Making in Thoracic Aortic Aneurysm Surgery—Clinician and Patient View



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Treatment decision-making in thoracic aortic aneurysms of the ascending aorta is complex both with regard to the timing of surgery and with regard to the invasive treatment strategy. From a clinician perspective, it is seen as important to balance the risks of watchful waiting versus preventive surgery and to choose a surgical treatment strategy that will result in the lowest early and late event occurrence. The current clinical practice guidelines and reported outcomes after surgery suggest that there are many gray zones in determining the optimal timing and the type of intervention. From a patient perspective, quality of life and in particular minimization of anxiety and depression due to the fear of aortic rupture or the potential occurrence of complications related to the different treatment strategies are important to consider. Quality of life studies and evidence on the importance of patient participation in decision-making make a strong case for evidence-based shared treatment decision in this complex patient group.

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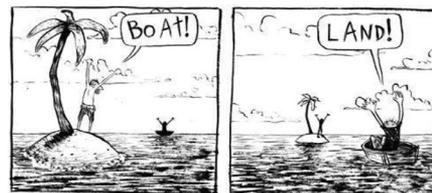
Thoracic aortic aneurysms (TAA) result from progressive dilatation of the thoracic aorta and confer a risk for aortic dissection or rupture, which is associated with significant morbidity and mortality. The incidence of TAAs in the general population is difficult to estimate because the disease is usually “silent.” The main concern of TAA is an acute dissection of the aorta, which represents an emergent condition associated with an exceptionally high mortality rate in the first 48 hours after symptom onset, particularly in patients who are not immediately referred for surgical treatment to centers with expertise in this procedure. The goal of treatment is to prevent aortic dissection, because this is associated with poor outcome. The indication for preventive surgery is presently based on the underlying diagnosis (reflecting the “frailty” of the vessel wall) and aorta diameter size (representative of the wall tension). It is crucial that the risk for “prophylactic” aortic replacement

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Boat vs land.

## Central Message

Treatment decision-making in thoracic aortic aneurysms of the ascending aorta is complex both with regard to the timing of surgery and with regard to the invasive treatment strategy.

should be no greater than the risk for dissection. Also, longer term complications associated with surgery should be taken into account in the decision on timing of surgery and on the preferred surgical strategy.

Many TAA patients experience high levels of stress, afraid that their aorta might rupture. Treatment decision-making is often complex, both when it comes to deciding on the timing of intervention and on the preferred surgical strategy. Better consideration of patient preferences in these treatment decision-making processes and reliable patient information conveyance may greatly enhance patient’s quality of life (QOL) and participation in treatment decision-making.

This perspective will focus on treatment decision-making in TAA of the ascending aorta, first focusing on *the clinician perspective*: the current guidelines and reported outcomes after surgery. Second, *the patient perspective* will be addressed including QOL outcomes and the importance of patient participation in decision-making. Finally, the case for *evidence-based shared treatment decision-making* in TAA is made.

## THE CLINICIAN PERSPECTIVE

Treatment decision-making from a clinical perspective is built upon evidence on outcomes after different treatment options and application of this knowledge to the unique state and circumstances of the patient. The internationally most

**Table 1.** Pooled Characteristics and Outcomes of VSRR and Bentall Procedure

	VSRR		Bentall	
	Pooled Data	Range	Pooled Data	Range
Total patient number	4777	32–430	7629	40–675
Surgical period	1988–2012		1968–2012	
Mean age (years)	51	29–63	49.8	29–65
Gender, male (%)	71	57–85	76.3	55–91
Type A dissection (%)	10.5	0–33	15.3	0–39
Connective tissue disease (%)	23.9	0–100	22.6	0–100
Bicuspid aortic valve (%)	14.1	0–33	24.9	4–100
Prior cardiac operation (%)	4.49	2–12	16.2	1–7
	Pooled Data	95% CI	Pooled Data	95% CI
Early mortality (%)	2.2	1.7–2.6	5.6	5.0–6.0
Overall late mortality (%/y)	1.53	1.19–1.96	2.02	1.77–2.31
Late reoperation (%/y)	1.32	1.0–1.74	0.30	0.22–0.41
Late hemorrhage (%/y)	0.23	0.13–0.42	0.64	0.47–0.87
Late thromboembolism (%/y)	0.41	0.22–0.77	0.77	0.60–1.00
Late endocarditis (%/y)	0.23	0.11–0.51	0.39	0.33–0.46
Late MAVRE (%/y)	1.66	1.24–2.23	2.66	2.17–3.24

Bentall, Bentall procedure; y, patient-years; VSRR, valve-sparing root replacement; MAVR, major adverse valve related event. Early: <30 days; Late >30 days; Late reoperation: reoperation on aortic valve.

recognized guidelines on aortic disease are the 2010 American Heart Association (AHA) and American College of Cardiology Foundation “Guidelines for the Diagnosis and Management of Patients with Thoracic Aortic Disease”<sup>1</sup> and the 2014 European Society of Cardiology (ESC) “Guidelines on the diagnosis and treatment of aortic diseases”.<sup>2</sup> The AHA guidelines recommend surgery at an ascending aortic or aortic sinus diameter >5.5 cm, the ESC guidelines >5.0 cm. Both recommend surgery at smaller diameters in case of genetically mediated disorders; the AHA guidelines also include patients who require aortic valve surgery or progression of aortic diameter >0.5 cm/y. The ESC guidelines add that lower thresholds for intervention may be considered (IIB) according to small BSA, rapid progression, aortic valve regurgitation, planned pregnancy, or patient preference. Most of the recommendations in both guidelines have level of evidence C. In the 2014 ESC guidelines, 80% of the recommendations are consensus based. The 2014 ESC guidelines also provide an overview of the major knowledge gaps. These include the accuracy and reproducibility of aortic measurements, data on female patients, randomized studies for the optimal timing for preventive intervention, epidemiological data on acute aortic syndrome, and the value of biomarkers. This reflects the lack of knowledge on thoracic aortic disease and the urgent need for more research.

In recent years, systematic reviews on reported outcomes after aortic root surgery have been published in an effort to improve scientific quality of data and identify the knowledge gaps. Mookhoek et al performed a systematic review including meta-analysis of reported results of mechanical Bentall operations over a surgical period of 44 years, including 46 studies in

their analysis.<sup>3</sup> Arabkhani et al performed a systematic review including meta-analysis of reported results of valve-sparing aortic root replacement, including 31 studies in their analysis.<sup>4</sup> The pooled characteristics and outcomes of these 2 studies are displayed in Table 1. Both studies report that heterogeneous reporting in the included studies limits the meta-analyses and argue the need for standardizing data reporting, and collaboration of centers worldwide.

A systematic review and meta-analysis on aortic root surgery in patients with Marfan syndrome was reported by Flynn et al.<sup>5</sup> It compared pooled outcomes of valve-sparing root replacement (VSRR, N = 1352) with the Bentall procedure (N = 1624) from 23 studies (published 1999–2017). Pooled early mortality was 0.3%/patient-year (95% confidence interval [CI] 0.2–0.5%/patient-year) for Bentall, and 0.1%/patient-year (95% CI 0–0.2%) for VSRR. Pooled late mortality was 1.8%/patient-year (95% CI 1.1–2.5%) in Bentall, and 0.5% (95% CI 0.3–0.7%) in VSRR. Although it was reported that in comparison to the Bentall procedure VSRR was associated with reduced risk of thromboembolism, late hemorrhagic complications and endocarditis and no significant difference in reintervention rates between VSRR and the Bentall procedure, these results need to be interpreted with caution as no details were given about potential differences in patient characteristics between the populations and the follow-up duration of the studies was limited.

Worth mentioning is a new, lesser invasive preventive treatment modality has been developed for aortic root aneurysm in the last decade: Personalised external aortic root support (PEARS). PEARS is a polymer mesh sleeve for the prevention

of aortic root dilatation in Marfan syndrome patients, and is individually manufactured for each patient using 3D imaging. PEARS is employed at smaller aortic root diameters than contemporary surgery in patients who do not require intervention on the aortic valve, and is wrapped around the patients' aortic root and ascending aorta without opening the aorta. Cardiopulmonary bypass can be omitted, making the procedure less invasive than contemporary aortic root surgery. Izgi et al reported a prospective series of 24 consecutive Marfan syndrome patients who received PEARS. MRI measured aortic growth during a mean follow-up of 6.3 years showed no increase in aortic root and ascending aorta diameters, but a significant increase in descending aorta diameter (which is not covered by PEARS).<sup>6</sup> A histologic study of PEARS-covered aorta in a Marfan syndrome patient who died 4.5 years after implantation showed that the supported part of the aorta had a normal histologic appearance.<sup>7</sup> Although still in the pioneer phase and lacking long-term outcome data, PEARS represents a promising treatment modality that toward the future will allow patients and doctors to choose for a lesser invasive surgical procedure earlier on in the disease process.

The evidence on clinical outcomes after different invasive treatments as described above illustrates that morbidity and mortality after aortic root surgery are considerable and that both the occurrence and the nature of the complications differ between the different surgery options. After mechanical Bentall anticoagulation-related complications are more common while bioprosthetic Bentall and valve-sparing aortic root surgery the hazard of reinterventions prevails. In case of PEARS, it remains uncertain whether preventive and less invasive surgery earlier on during disease progression provides a durable solution. There are still a lot of knowledge gaps to be filled. International collaboration and standardized outcome reporting are required to fill these gaps. The international AVIATOR registry that was initiated in 2013 will be of great value in this respect.<sup>8</sup>

### THE PATIENT PERSPECTIVE

To come to a truly patient-centered treatment decision, it requires consideration of evidence on outcomes, the patient's unique state, and circumstances but to also taking the patient perspective into account and involving the patient in decision-making. This sounds logical but clinical practice shows that this is not easy. It requires consideration of patient QOL, patient values and goals in life, and eliciting patient preferences in relation to the available treatment options. What do we know about QOL in patients with TAAs? And how can we elicit patient preferences and involve patients in decision-making?

In a previous review by De Heer et al, QOL after thoracic aortic surgery was discussed in detail.<sup>9</sup> It illustrated that limited and only observational data are available concerning QOL after thoracic aortic surgery. Although an older study by Olson in 1999 showed significantly worse health-related QOL outcomes for patients who had thoracic aortic surgery compared to the general population, an updated study in 2013 showed comparable QOL.<sup>10,11</sup> This may be due to advances in

cardiac surgery and quality of cardiovascular care throughout the years and is in line with other contemporary studies including a systematic review by Jarral et al that found QOL in thoracic aortic surgery patients to be comparable to the general population.<sup>12–14</sup>

There may however be differences in QOL between aortic root surgery strategies: observational evidence suggests that QOL after surgery is significantly worse in most of the domains of the SF-36 in patients with composite graft root replacement versus valve-sparing surgery. Additionally, composite graft patients report to be significantly more disturbed by valve sound, more afraid that their valve would fail and assign a lower score to their overall condition.<sup>15</sup> This is in line with findings from a study by Aicher et al that compared QOL in mechanical aortic valve recipients versus valve-sparing and pulmonary autograft replacement.<sup>16</sup> There is no evidence that there is a difference between mechanical versus biological composite root replacement.<sup>17</sup>

For patients with Marfan syndrome, there seems to be a significantly reduced QOL compared to the general population. Goldfinger et al recently reported on QOL in the GENTAC cohort and showed that health-related QOL is below the norm in patients with Marfan syndrome, confirming previous observations.<sup>18</sup> Interestingly, determinants of health-related QOL in this US cohort are mostly related to health insurance and socioeconomic factors and not to aspects of Marfan. Moon et al reported anxiety and depression in 64% and 72%, respectively, of Marfan syndrome patients visiting a tertiary care hospital in Seoul, South Korea.<sup>19</sup> They also found that QOL (SF-36) is affected significantly by social support, disease-related factors, and biobehavioral factors, and underline the need for comprehensive interventions addressing these factors.

Given these observations, the notion arises that it is important to consider QOL as a factor in treatment selection for TAA surgery—in particular for those with Marfan syndrome—and elicit patient preferences with regard to treatment selection in order to come to an evidence-based and patient-centered treatment decision that best reflects the patient's values and goals in life.

### THE CASE FOR EVIDENCE-BASED SHARED TREATMENT DECISION-MAKING IN THORACIC AORTIC ANEURYSM

The ESC guidelines mention the consideration of patient preferences in aortic aneurysm treatment decision-making,<sup>2</sup> and of course patients should be fully informed about the indications for and the timing of the surgery, risks of anticoagulant therapy, and the potential need for and risk of reoperation in a shared decision-making process that accounts for the patient's values and preferences. Both patients and clinicians are reported to find shared decision-making important but it is not yet well implemented in clinical practice.<sup>20,21</sup> The use of patient decision aids to support the shared decision-making process may be helpful in this regard. A recent randomized trial showed that the use of a patient decision aid to support

prosthetic heart valve selection results not only in improved patient knowledge, patients also feel better informed, less anxious and depressed, and experienced a better mental quality of life at the time of the decision-making.<sup>22</sup>

A recent study in *Heart* investigated through an online questionnaire Marfan patient and physician preferences for timing of an intervention and the consequences of choosing valve-sparing or valve-replacing strategies.<sup>23</sup> They found that the most important reported preferences were retaining an active and participatory lifestyle, avoiding anticoagulation, and maintain as normal a life as possible. Patients were leaning toward getting the surgery over with as soon as possible, while doctors took a more conservative approach. The authors conclude that people anticipating root replacement surgery should have ample opportunity to express their viewpoints and to have them acknowledged ahead of a consultation when they can then be fully explored in a mutually informed forum. In line with these observations, the Rotterdam group is in the process of developing an information portal and decision aid for patients with TAA (ZonMW project number 849200014).

### EVIDENCE-BASED AND SHARED TREATMENT DECISION-MAKING IN THORACIC AORTIC ANEURYSM: THE HOLY GRAIL?

From a clinician and a patient point of view, it seems that combining (1) clinical evidence on outcomes, (2) the unique clinical state and circumstances of the individual patient, and (3) informed patient preferences in treatment decision-making for TAA patients results in optimal clinical decision-making. Given the value sensitive nature of the decisions that need to be made regarding both the timing and the preferred surgical treatment strategy in TAA patients, ample consultation time is required. Unfortunately, in many health care systems, reimbursement is still largely based on the number of procedures rather than the time spent in consultation concerning treatment decision-making. However, times are slowly but surely changing, with increasing emphasis in medicine on patient-reported outcome measures and the implementation of patient information portals and decision aids to support shared decision-making. It requires a different role pattern: for doctors to take a more guiding role, and for patients to be proactive and become a member of their own heart team. In this respect, the introduction of decision aids in cardiovascular clinical practice is not only effective in empowering patients, but may also help to instruct clinicians on optimal implementation of shared decision-making in their clinical practice.<sup>24</sup> Especially for TAA patients who face so many challenges related to their disease, this will make a world of difference and allow for optimal tailoring of both the timing and the preferred treatment strategy from a clinical and a patient perspective.

### REFERENCES

- Hiratzka LF, Bakris GL, Beckman JA, et al: 2010 ACCF/AHA/AATS/ACR/ASA/SCA/SCAI/SIR/STS/SVM guidelines for the diagnosis and management of patients with thoracic aortic disease: A report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines, American Association for Thoracic Surgery, American College of Radiology, American Stroke Association, Society of Cardiovascular Anesthesiologists, Society for Cardiovascular Angiography and Interventions, Society of Interventional Radiology, Society of Thoracic Surgeons, and Society for Vascular Medicine. *Circulation* 121:e266–e369, 2010
- Erbel R, Aboyans V, Boileau C, et al: 2014 ESC guidelines on the diagnosis and treatment of aortic diseases: Document covering acute and chronic aortic diseases of the thoracic and abdominal aorta of the adult. The task force for the diagnosis and treatment of aortic diseases of the European Society of Cardiology (ESC). *Eur Heart J* 35:2873–2926, 2014
- Mookhoek A, Korteland NM, Arabkhani B, et al: Bentall procedure: A systematic review and meta-analysis. *Ann Thorac Surg* 101:1684–1689, 2016
- Arabkhani B, Mookhoek A, Di Centa I, et al: Reported outcome after valve-sparing aortic root replacement for aortic root aneurysm: A systematic review and meta-analysis. *Ann Thorac Surg* 100:1126–1131, 2015
- Flynn CD, Tian DH, Wilson-Smith A, et al: Systematic review and meta-analysis of surgical outcomes in Marfan patients undergoing aortic root surgery by composite-valve graft or valve sparing root replacement. *Ann Cardiothorac Surg* 6:570–581, 2017
- Izgi C, Newsome S, Alpendurada F, et al: External aortic root support to prevent aortic dilatation in patients with Marfan syndrome. *J Am Coll Cardiol* 72:1095–1105, 2018
- Pepper J, Goddard M, Mohiaddin R, et al: Histology of a Marfan aorta 4.5 years after personalized external aortic root support. *Eur J Cardiothorac Surg* 48:502–505, 2015
- de Heer F, Kluin J, Elkhoury G, et al: AVIATOR: An open international registry to evaluate medical and surgical outcomes of aortic valve insufficiency and ascending aorta aneurysm. *J Thorac Cardiovasc Surg* 157:2205–2211, 2019
- de Heer F, Gökalp AL, Kluin J, et al: Measuring what matters to the patient: Health related quality of life after aortic valve and thoracic aortic surgery. *Gen Thorac Cardiovasc Surg* 67:37–43, 2019
- Olsson C, Thelin S, Stahle E, et al: Thoracic aortic aneurysm and dissection: Increasing prevalence and improved outcomes reported in a nationwide population-based study of more than 14,000 cases from 1987 to 2002. *Circulation* 114:2611–2618, 2006
- Olsson C, Thelin S: Quality of life in survivors of thoracic aortic surgery. *Ann Thorac Surg* 67:1262–1267, 1999
- Jarral OA, Kidher E, Patel VM, et al: Quality of life after intervention on the thoracic aorta. *Eur J Cardiothorac Surg* 49:369–389, 2016
- Lohse F, Lang N, Schiller W, et al: Quality of life after replacement of the ascending aorta in patients with true aneurysms. *Tex Heart Inst J* 36:104–110, 2009
- Stalder M, Staffelbach S, Immer FF, et al: Aortic root replacement does not affect outcome and quality of life. *Ann Thorac Surg* 84:775–780, 2007. discussion 780–781
- Franke UF, Isecke A, Nagib R, et al: Quality of life after aortic root surgery: Reimplantation technique versus composite replacement. *Ann Thorac Surg* 90:1869–1875, 2010. <https://doi.org/10.1016/j.athoracsur.2010.07.067>
- Aicher D, Holz A, Feldner S, et al: Quality of life after aortic valve surgery: Replacement versus reconstruction. *J Thorac Cardiovasc Surg* 142:e19–e24, 2011
- Lehr EJ, Wang PZ, Oreopoulos A, et al: Midterm outcomes and quality of life of aortic root replacement: Mechanical vs biological conduits. *Can J Cardiol* 27:262.e15–262.e20, 2011
- Goldfinger JZ, Preiss LR, Devereux RB, et al: Marfan syndrome and quality of life in the GenTAC registry. *J Am Coll Cardiol* 69:2821–2830, 2017
- Moon JR, Cho YA, Huh J, et al: Structural equation modeling of the quality of life for patients with Marfan syndrome. *Health Qual Life Outcomes* 14:83, 2016
- Korteland NM, Bras FJ, van Hout F, et al: Prosthetic aortic valve selection: Current patient experience, preferences and knowledge. *Open Heart* 2:e000237, 2015

21. Korteland NM, et al: Cardiologist and cardiac surgeon view on decision-making in prosthetic aortic valve selection: Does profession matter? *Neth Heart J* 22:336–343, 2014
22. Korteland NM, Ahmed Y, Koolbergen DR, et al: Does the use of a decision aid improve decision making in prosthetic heart valve Selection? A multicenter randomized trial. *Circ Cardiovasc Qual Outcomes* 10:e003178, 2017
23. Treasure T, King A, Hildago Lemp L, et al: Developing a shared decision support framework for aortic root surgery in Marfan syndrome. *Heart* 104:480–486, 2018
24. Coylewright M, O'Neill ES, Dick S, et al: PCI choice: Cardiovascular clinicians' perceptions of shared decision making in stable coronary artery disease. *Patient Educ Couns* 100:1136–1143, 2017