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Prosthetic aortic valve selection: current patient experience, preferences and knowledge

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ABSTRACT

Objective: Current clinical practice guidelines advocate shared decision-making (SDM) in prosthetic valve selection. This study assesses among adult patients accepted for aortic valve replacement (AVR): (1) experience with current clinical decision-making regarding prosthetic valve selection, (2) preferences for SDM and risk presentation and (3) prosthetic valve knowledge and numeracy.

Methods: In a prospective multicentre cohort study, AVR patients were surveyed preoperatively and 3 months postoperatively.

Results: 132 patients (89 males/43 females; mean age 67 years (range 23–86)) responded preoperatively. Decisional conflict was observed in 56% of patients, and in 25% to such an extent that it made them feel unsure about the decision. 68% wanted to be involved in decision-making, whereas 53% agreed that they actually were. 69% were able to answer three basic knowledge questions concerning prosthetic valves correctly. 56% were able to answer three basic numeracy questions correctly. Three months postsurgery, 90% (n=110) were satisfied with their aortic valve prosthesis, with no difference between mechanical and bioprosthetic valve recipients.

Conclusions: In current clinical practice, many AVR patients experience decisional conflict and suboptimal involvement in prosthetic valve selection, and exhibit impaired knowledge concerning prosthetic valves and numeracy. Given the broad support for SDM among AVR patients and the obvious need for understandable information, to-be-developed tools to support SDM in the setting of prosthetic valve selection will help to improve quality of decision-making, better inform and actively involve patients, and reduce decisional conflict.

Trial registration number: NTR3618.

KEY MESSAGES

What is already known about this subject?

- Shared decision-making (SDM) receives more and more attention in healthcare. Prosthetic aortic valve selection concerns a value sensitive decision. The 2014 ACC/AHA Valvular Heart Disease Guidelines and 2012 ESC/EACTS guidelines highlight the importance of SDM.

What does this study add?

- However, the attitude of patients towards SDM in prosthetic aortic valve selection remains unexplored. Therefore, we conducted a prospective multicentre cohort study among elective adult aortic valve replacement (AVR) patients.

How might this impact on clinical practice?

- We are convinced that our observations provide an important information base on which we can build effective tools for the implementation of SDM in prosthetic aortic valve selection. This will result in better informed patients who feel more responsible for their own health and disease management, and it will hopefully lead to better informed decision-making and better quality of care.

INTRODUCTION

For most patients who require aortic valve replacement (AVR), two options exist: mechanical or bioprosthetic valve replacement. Each prosthetic valve has specific risks and benefits. Mechanical valves are thrombogenic and therefore require lifelong anticoagulation. Bioprosthetic valves carry a higher risk of reoperation due to valve degeneration.[1 2] There is no apparent difference in survival for adult patients with a mechanical or bioprosthetic valve.[3 4] Therefore, prosthetic valve choice is mainly driven by valve-specific risks and benefits. Given the different nature of these risks and benefits for mechanical and bioprosthetic valves, informed patient preferences deserve consideration in decision-making.

The 2014 ACC/AHA Valvular Heart Disease Guidelines state that prosthetic valve choice should be a shared decision process,[2] while the 2012 ESC/EACTS guidelines highlight the importance of considering informed patient preferences (Class 1 recommendations).[1] We previously showed that the majority of the Dutch cardiothoracic surgeons and cardiologists are of the opinion that

prosthetic aortic valve selection should ideally be done together with the patient and they report to communicate to the patient most important risks of the different prosthetic valve types. Nevertheless, only half of them actively involves patients in prosthetic valve selection.[5] Although the guidelines advocate shared decision-making (SDM), clinicians do not have any tools to engage this activity.

In order to engage in SDM, both the clinician and the patient should be able and willing to participate. It is unknown how patients experience decision-making in prosthetic aortic valve selection and what their attitude is towards SDM. The purpose of this prospective study was to assess among adult patients accepted for AVR: (1) experience with current clinical decision-making regarding prosthetic valve selection, (2) preferences for SDM and risk presentation and (3) prosthetic valve knowledge and numeracy.

METHODS

This study was approved by the institutional review board of all three participating centres (Erasmus MC MEC nr. 12-323). Written informed consent was obtained. Participants were adult patients who were accepted for elective AVR in one of the three hospitals between September 2012 and June 2013. Patients had to be legally capable. Two surveys were conducted, one preoperatively after preoperative outpatient counselling, and another 3 months postoperatively.

Preoperative survey

Patient experience with prosthetic valve selection

Multiple choice (MC) questions assessed which clinician (surgeon, cardiologist, both or other) performed the preoperative consultation with regard to prosthetic valve choice, if a friend or family member was involved in prosthetic valve choice, patient opinion on the amount of time available for prosthetic valve choice, and how patients valued their participation in prosthetic valve choice.

The Decisional Conflict Scale (DCS) was used to measure the degree of uncertainty about which course of action to take and the main modifiable factors contributing to uncertainty. It is a 16-item questionnaire with five subscales: uncertainty, informed, values clarity, support and effective decision. Total scores <25 are associated with no decisional conflict and implementation of decision. Scores exceeding 25 are associated with decisional conflict, with higher scores indicating higher decisional conflict. Scores ≥37.5 are associated with decision delay or feeling unsure about implementation.[6]

A 1–5 Likert scale was used to assess how patients value the importance of the different risks and benefits associated with a mechanical and bioprosthetic valve.

Patient preferences for SDM and risk presentation

A 1–5 Likert scale and a Control Preferences scale were used to assess patient view on participation in decision-making.[7]

Patient preference for presentation of scientific evidence was assessed by asking patients to rate four graphical formats of scientific evidence: a horizontal bar, pie chart and two pictographs (a visual presentation of data).[8]

Patient prosthetic valve knowledge and numeracy

Information that patients perceived from the treating physician with regard to prosthetic valve selection and patient knowledge regarding the risks and benefits associated with mechanical and bioprosthetic valves was assessed by MC questions and a 1–5 Likert scale.

Patient numeracy was assessed using the Numeracy Scale.[9]

For a detailed description of the preoperative survey, see online supplementary appendix 1.

Postoperative survey

Patient experience with prosthetic valve selection

MC questions and a 1–5 Likert scale were used to assess patient opinion on the amount of time available for prosthetic valve choice, how patients value their participation in prosthetic valve choice, and patient satisfaction with the type of prosthetic valve they received.

Valve-specific quality of life (QoL) was measured with a valve-specific questionnaire.[10]

Patient preferences for SDM

Patient view on participation in decision-making was assessed by a 1–5 Likert scale and a Control Preferences scale.

Patient prosthetic valve knowledge

Information that patients perceived from the treating physician with regard to prosthetic valve selection was assessed with MC questions and a 1–5 Likert scale.

For a detailed description of the postoperative survey, see online supplementary appendix 2.

Statistical methods

Continuous variables were displayed by the mean, SD and range. Discrete variables were displayed as counts or proportions. Multiple imputations (5 iterations) were used to impute missing DCS values. To compare DCS group responses, the Mann–Whitney U test or Kruskal-Wallis test was used. To compare group responses between patients with a mechanical and bioprosthetic valve, the Mann–Whitney U test or Fisher exact test was used. Patients were allocated to the mechanical or bioprosthetic subgroup according to their survey answer. To compare group responses presurgery and postsurgery, the Wilcoxon signed-rank test was used. All tests were two-sided, and a p value of 0.05 or less was considered statistically significant. All statistical analyses were performed using IBM-SPSS V.20 (IBM Corp., Armonk, New York, USA).

RESULTS

Preoperative survey

One hundred and thirty-two elective adult patients scheduled for AVR in three academic Dutch hospitals participated. Twenty-nine patients reported that they were to receive a mechanical valve, 74 a bioprosthetic valve, 2 a valve repair, and 29 did not know which valve they were going to receive. Table 1 displays patient characteristics. Patients with a bioprosthetic valve were significantly older than patients with a mechanical valve (p=0.000).

Patient experience with prosthetic valve selection

The preoperative consultation with regard to prosthetic valve choice was performed by the cardiologist (48%), the surgeon (18%), the surgeon and cardiologist together (16%) or other, for example a resident or physician assistant (19%). More than half of the patients (57%) involved a friend or family member in prosthetic valve choice. Sixty-four per cent of patients felt they had sufficient time to make a deliberate prosthetic valve choice and 64% felt they had a prosthetic valve choice.

Table 2 displays the results of the DCS.

There were no significant differences in the total DCS score between patients from the three different hospitals, and between patients with a mechanical versus bioprosthetic valve. The type of medical professional who performed the preoperative consultation did not influence the patient total DCS score. Patients who involved a friend or family member in prosthetic valve choice experienced significantly less decisional conflict than patients who made the decision alone (p=0.001).

Table 3 displays the patient's valuation of the importance of the different risks and benefits associated with mechanical and bioprosthetic valves.

Patient preferences for SDM and risk presentation

Patient preference for the final decision in prosthetic valve choice is displayed in figure 1. Sixty-eight per cent of patients wanted to be involved in decision-making, whereas 53% agreed that they were actually involved.

The majority of patients (68%) preferred scientific evidence presentation in a pie chart, followed by the horizontal bar, and the two pictographs.

Table 1 Patient characteristics

	n=132
Age, mean (SD), years	66.7 (12.8)
Age, range, years	23–86
Male sex, n (%)	89 (67)
Educational level, n (%) (n=130)	
<High school	45 (35)
High school graduate	55 (42)
College graduate	27 (21)
Other	3 (2)
Hospital, n (%)	
1	57 (43)
2	55 (42)
3	20 (15)
Referral to academic hospital, n (%) (n=129)	
Other hospital	114 (88)
General practitioner	15 (12)

Table 2 Preoperative score on Decisional Conflict Scale (DCS)

N (%) with total score on DCS	
<25	58 (44)
25–37.5	41 (31)
>37.5	33 (25)
Mean (SD) score on DCS subscales:	
Uncertainty	33.6 (24.9)
Informed	22.3 (25.3)
Values clarity	29.3 (23.5)
Support	24.0 (23.5)
Effective decision	13.0 (18.4)

Total score <25: no decisional conflict and implementation of decision.
Total score ≥25: decisional conflict.
Total score ≥37.5: decision delay or feeling unsure about implementation.

Patient prosthetic valve knowledge

Ninety-nine per cent of patients were aware that there are different types of aortic valve prostheses and 80% reported knowing which valve they were going to receive. Fifty-nine per cent were of the opinion that they had sufficient knowledge about the different types of aortic valve prostheses.

Table 4 displays patient prosthetic valve knowledge and numeracy.

Ninety-eight per cent of patients (n=129) answered all three questions concerning prosthetic valve knowledge. Of these, 5% were not able to answer any of the three questions correctly, 9% were able to answer one question correctly, and 16% and 69% were able to answer two and three questions correctly, respectively. There were no significant differences between patients with a mechanical and bioprosthetic valve. Sixty-four per cent of patients (n=84) answered all three numeracy questions. Four per cent were not able to answer any of the three questions correctly, 12% were able to answer one question correctly, 29% were able to answer two questions correctly and 56% were able to answer three questions correctly. There were no significant differences between patients with a mechanical and bioprosthetic valve.

Postoperative survey

One hundred and ten patients responded to the postoperative survey. Reasons for loss to follow-up included death (n=4), inability to complete the survey due to morbidity (n=5), cancelled operation due to comorbidity (n=2) or non-response (n=11). At the time of the postoperative survey, 86% of patients (n=95) were in NYHA class I or II, and 14% of patients (n=15) were in NYHA class III or IV. Twenty-eight patients reported that

Table 3 Patient valuation of the importance of the different risks and benefits associated with a mechanical (MP) and bioprosthetic (BP) valve

	Total (%)	MP (%)	BP (%)
I am concerned about a possible bleeding			
(Totally) agree	23	24	21
Not agree/disagree	18	28	16
(Totally) disagree	27	31	24
Do not know*	31	17	39
I am afraid of blood clots			
(Totally) agree	24	21	23
Not agree/disagree	20	24	23
(Totally) disagree	32	45	26
Do not know	24	10	29
I have problems with taking medication			
(Totally) agree	9	7	7
Not agree/disagree	6	7	4
(Totally) disagree	75	82	72
Do not know	11	4	17
I am afraid that I may need another valve operation			
(Totally) agree	23	45	20
Not agree/disagree	13	21	9
(Totally) disagree	41	31	44
Do not know*	23	3	28
I am afraid that my valve may fail			
(Totally) agree	13	28	11
Not agree/disagree	11	21	8
(Totally) disagree	55	45	54
Do not know*	22	7	26
I am afraid that I will be limited by my new heart valve in my daily activities			
(Totally) agree	12	24	6
Not agree/disagree	10	14	6
(Totally) disagree	58	52	64
Do not know	20	10	25
I am afraid that my new heart valve will negatively influence my social life			
(Totally) agree	5	3	7
Not agree/disagree	12	24	4
(Totally) disagree	65	62	67
Do not know	18	10	22
It bothers me that I have to use oral anticoagulation lifelong			
(Totally) agree	53	45	57
Not agree/disagree	9	7	6
(Totally) disagree	27	38	23
Do not know	12	10	14
I am afraid that the valve sound will bother me			
(Totally) agree	34	38	34
Not agree/disagree	14	21	10
(Totally) disagree	28	34	24
Do not know*	24	7	31

*p<0.05 proportion of patients answering 'do not know' in mechanical versus bioprosthetic valve groups.

they received a mechanical valve, 81 a bioprosthetic valve and 1 a valve repair.

Patient experience with prosthetic valve selection

Seventy-seven per cent of patients felt they had sufficient time to make a deliberate prosthetic valve choice, which was significantly higher than preoperatively (p=0.001). Seventy-four per cent of patients felt they had a prosthetic valve choice (p=NS compared with preoperative).

Ninety per cent were satisfied with their valve prosthesis, 7% did not have an opinion and 4% were unsatisfied. There was no difference between patients with a mechanical and bioprosthetic valve.

The results of the valve-specific questionnaire are displayed in table 5.

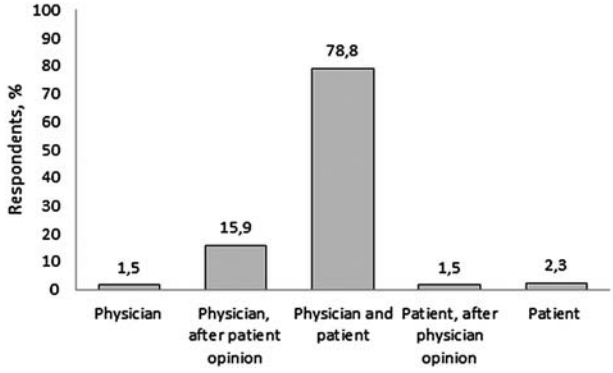

Figure 1 Preoperative patient preference for final decision in prosthetic aortic valve choice (n=132).

Patient preferences for SDM

Eighty-seven per cent of patients wanted to be involved in decision-making, whereas 74% agreed that they were actually involved. This was significantly higher than preoperatively (68% vs 87%; p=0.000, and 53% vs 74%; p=0.000, respectively). Seventy-nine per cent preferred the final prosthetic valve choice to be a shared decision process (p=NS compared with preoperative).

Patient prosthetic valve knowledge

Ninety-nine per cent of patients were aware that there are different types of aortic valve prostheses and 100% reported knowing which valve they received. Seventy-four per cent were of the opinion that they had sufficient knowledge about the different types of aortic valve prostheses (p=NS compared with preoperative).

DISCUSSION

In current Dutch cardiovascular clinical practice, patients who require AVR often experience decisional conflict and suboptimal involvement in prosthetic valve selection, and exhibit impaired numeracy. The majority of patients want to be involved in prosthetic valve selection, while only half of the patients actually feel involved. Given the limited patient knowledge of prosthetic valves and numeracy, there is an obvious need for improved information conveyance on prosthetic valve options and their associated risks and benefits.

Patient experience with prosthetic valve selection

The quality of decision-making does not appear to be influenced by the physician who discusses prosthetic

Table 4 Preoperative prosthetic valve knowledge and basic numeracy

	Correct (%)
Prosthetic valve knowledge (n=129)	
1. Which valve type is most durable?	84
2. Which valve type is associated with increased risk of blood clots?	72
3. Which valve type requires lifelong anticoagulation?	88
Basic numeracy questions (n=84)	
1. Convert 1% to 10 in 1000	87
2. Convert 1 in 1000 to 0.1%	61
3. How many heads in 1000 coin flips?	89

valve selection, but our study results suggest that it is important for patients to involve a friend or relative, as this will reduce decisional conflict. This is in alignment with the 2014 ACC/AHA Valvular Heart Disease Guidelines that highlight the importance of involving family members in decision-making.[2]

Table 5 Postoperative answers to a valve-specific questionnaire

	Total (%)	MP (%)	BP (%)
If I had to do it over again, would I make the same decision to have surgery?			
Yes/probably	85	85	85
I do not know	11	7	13
Probably not/absolutely not	4	7	3
Is there a valve sound that bothers me?*			
Frequently/always	6	22	0
Occasionally	11	32	4
Never/rarely	83	47	96
Following my valve surgery, the frequency of doctor visits and blood tests bothers me			
Frequently/always	8	14	6
Occasionally	25	29	24
Never/rarely	67	57	70
The possibility of complications due to my implanted valve concerns me			
Frequently/always	4	4	4
Occasionally	26	29	25
Never/rarely	70	68	71
I am concerned about possible bleeding caused by my anticoagulant medication			
Frequently/always	7	11	5
Occasionally	25	32	23
Never/rarely	69	57	73
I am afraid that my valve may fail			
Frequently/always	3	4	3
Occasionally	16	18	15
Never/rarely	82	79	83
I am afraid that I may need another valve operation			
Frequently/always	5	4	5
Occasionally	22	7	27
Never/rarely	74	89	68

*p<0.05 MP versus BP groups.
BP, bioprosthetic valve; MP, mechanical valve.

Preoperatively, one-third of patients in this study felt they did not have sufficient time to make a deliberate prosthetic valve choice, and/or felt like they did not have a choice at all. This observation indicates room for improvement in decision-making, allowing for sufficient time and adequate information conveyance. Postoperatively, significantly more patients felt they had sufficient time than preoperatively. It is possible that preoperative stress may have influenced patient perception regarding the amount of time needed for prosthetic valve choice.

More than half of the patients experienced decisional conflict, and one in four patients to such an extent that it made them feel unsure about the decision. Decisional conflict was most evident in the uncertainty and values clarity subscales, suggesting that particular measures aimed at reducing patient uncertainty and improving value clarification will be effective in improving decision-making quality.[6] Patient satisfaction with the selected prosthetic valve did not appear to be affected by the suboptimal decision-making. This may be caused by the phenomenon of choice closure: the process by which people come to perceive a decision to be resolved and complete. As choice closure results in greater satisfaction, it can explain at least in part why most patients were satisfied with their prosthetic valve.[11]

Preoperatively, the most common patient concerns about complications were related to the use of lifelong oral anticoagulation, the risk of bleeding or blood clot, valve sound and the need for a reoperation. Therefore, these topics require particular attention in the preoperative consultation. Interestingly, patients with a bioprosthetic valve more often answered 'do not know' when they were asked about complications. This may be due to their older age as it is known that older patients usually have a more passive role in decision-making and more difficulties understanding medical information.[12 13]

Patient preferences for SDM and risk presentation

A common misperception among clinicians is that many patients do not want to be involved in decision-making.[14] The current study shows the contrary: most of the patients who require AVR do want to be involved. Previous studies in different medical fields also show that patients prefer to be involved in decision-making.[15 16] In our study, more patients felt involved in decision-making postoperatively than preoperatively. The preoperative survey was conducted after preoperative outpatient counselling, on average 2 weeks before the operation. It is possible that patients received more information about prosthetic valve selection in the remaining time prior to and following the operation.

SDM receives more and more attention in healthcare. It can be described as a meeting of experts, the clinician as an expert on the medical issues and the patient as an expert on their values and preferences.[14] SDM has several advantages, like increased patient knowledge, less

patient anxiety, improved health outcomes, reductions in care and cost variation and more alignment of care with patient values.[17] Therefore, it is not surprising that the 2014 ACC/AHA Valvular Heart Disease Guidelines and the 2012 ESC/EACTS guidelines state that SDM is a Class I recommendation for prosthetic valve selection.[1 2] Nevertheless, despite the advantages of SDM and the fact that the guidelines advocate SDM, informed SDM is not often applied in daily clinical practice.[18 19] SDM can be time-consuming and requires extra effort, which can be a barrier for cardiovascular professionals. In this respect, the use of a decision aid (DA) may be useful to support SDM. It has been shown that patients who use a DA have improved knowledge, more accurate risk perception, reduced decisional conflict and are more likely to receive care that is in line with their personal values.[17] In the setting of prosthetic valve selection, a DA can inform patients about the different prosthetic valves and associated risks and benefits, help them clarify their preferences and guide them through the decision-making.

In order to participate in decision-making, patients should be able to understand what the available prosthetic valve options and their associated risks and benefits are. The way risks and benefits are presented influences the ability of the patient to understand the given information. Presenting statistical information in a graphical instead of numerical format increases people's understanding and may affect their decision-making.[20] Previous studies show that a pictograph is the preferred option to present probabilistic information to patients.[8] In this study, however, most patients preferred a pie chart. Of note, this study only investigated patient preference for the presentation of scientific evidence, while previous studies investigated which graph format achieved the best accuracy of risk perception. Therefore, although most patients in our study preferred a pie chart, this does not necessarily imply that it is the most effective way to communicate risks.

Patient prosthetic valve knowledge and numeracy

Almost half of the patients in our study felt that they had insufficient knowledge of prosthetic valves and almost one-third were unable to answer three basic knowledge questions about prosthetic valves correctly. We can only hypothesise that they either were not informed about the different prosthetic valves or received information that they were unable to comprehend. This observation nevertheless calls for the development of information provision on prosthetic valves that is tailored to the needs of patients.

Besides testing patient knowledge, we also deliberately tested numeracy. Since numbers are an inherent part of weighing risks and benefits,[9] numeracy is of great influence on the capacity of patients to engage in SDM. One-third of the study patients did not answer any basic numeracy question. It could be that the questions were perceived too difficult and patients were afraid to answer them. Additionally, nearly half of the patients who did answer all numeracy questions exhibited impaired numeracy. These observations underline the importance of recognition among physicians that many patients have difficulties understanding numbers and need help in understanding the risks and benefits of treatment options.[21]

Given their limited basic knowledge regarding prosthetic valves and limited numeracy, many patients will experience difficulties in weighing the risks and benefits associated with mechanical and bioprosthetic valves. A DA with plain language, absolute risks presented as frequencies, and pictographs used to communicate risks and benefits[20] may therefore be helpful in the setting of prosthetic valve selection. Building on this study and a previous survey concerning SDM in prosthetic valve selection among Dutch cardiovascular professionals,[5] an information portal and DA for prosthetic valve selection has been developed and is currently being tested in a multicentre randomised controlled trial (RCT) to assess whether the use of the DA indeed improves the quality of decision-making and patient outcome in the setting of prosthetic valve selection.

Study limitations

This study population represents Dutch academic cardiovascular clinical practice. A limitation of the study was the relatively small sample size. Furthermore, surveys were completed at home and patients may have been influenced by family members or friends. Finally, it is possible that only the more motivated patients may have completed the questionnaire, which could introduce selection bias.

In conclusion, this study illustrates that in current Dutch cardiovascular practice, patients who require AVR experience suboptimal involvement in prosthetic valve selection, and exhibit impaired knowledge concerning prosthetic valves and numeracy. Given the broad support for SDM among patients and the cardiovascular community, and the obvious need for understandable information, implementation in clinical practice of the concept of SDM would be a major step forward in improving clinical decision-making in prosthetic valve selection. This will result in better patient involvement in decisions, increased patient knowledge, involvement and satisfaction and perhaps even a better QoL.

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Appendix 1 Preoperative survey

Original version

1. Bent u ervan op de hoogte dat er verschillende soorten aortakleppen zijn?
   - Ja
   - Nee

2. Is de keuze voor een bepaald type aortaklep al gemaakt?
   - Ja
   - Nee
   - Weet ik niet

3. Wat voor aortaklep krijgt u?
   - Mechanische klep
   - Biologische klep
   - Anders, namelijk…
   - Weet ik niet

4. Welk type aortaklep gaat het langst mee?
   - Biologische klep
   - Mechanische klep
   - Weet ik niet

5. Welk type aortaklep geeft het grootste risico op het ontstaan van bloedklontjes?
   - Biologische klep
   - Mechanische klep
   - Weet ik niet

6. Met welk type aortaklep moet je je leven lang bloedverdunners slikken?
   - Biologische klep
   - Mechanische klep
   - Weet ik niet

7. Hebt u het idee dat u voldoende kennis hebt over de voor- en nadelen van de verschillende typen aortakleppen?

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

8. Met wie heeft u het gesprek over de keuze voor een bepaald type aortaklep gehad?

- Met de cardioloog
- Met de hartchirurg
- Anders, namelijk…

9. Hebt u voor uw gevoel genoeg tijd gehad om een weloverwogen beslissing te kunnen nemen?

- Ja
- Nee
- Weet ik niet
- Ik heb zelf geen beslissing hoeven nemen

10. Is er nog iemand anders betrokken geweest bij het maken van de keuze voor een bepaald type aortaklep?

- Ja, een familielid
- Ja, een goede vriend(in)
- Ja, …
- Nee

11. De arts heeft mij betrokken in het maken van een keuze voor een bepaald type aortaklep.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet
- Niet van toepassing

12. Ik vind het belangrijk betrokken te worden bij het kiezen van een aortaklep.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet
- Niet van toepassing

13. Hebt u het gevoel een keuze te hebben gehad bij uw beslissing voor een bepaald type aortaklep?

- Ja

- Nee
- Weet ik niet

14. De uiteindelijke keuze voor een aortaklep zou moeten gebeuren door:
    - De arts alleen
    - Voornamelijk de arts
    - De arts en de patiënt samen
    - Voornamelijk de patiënt
    - De patiënt alleen

15. Ik vond het moeilijk om deze beslissing te nemen.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

16. Het was me duidelijk wat voor mij de beste keuze is.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

17. Ik wist niet zeker wat ik moest beslissen.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

18. Ik was mij bewust van de keuzes die ik had in de behandeling van mijn aortaklepaandoening.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

19. Ik had het gevoel dat ik de voordelen van de verschillende typen aortakleppen wist.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

20. Ik had het gevoel dat ik de nadelen van de verschillende typen aortakleppen wist.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

21. Ik had meer advies en informatie willen hebben over de keuzemogelijkheden.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

22. Ik wist hoe belangrijk de voordelen van de verschillende typen aortakleppen voor mij waren bij het nemen van deze beslissing.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

23. Ik wist hoe belangrijk de nadelen van de verschillende typen aortakleppen voor mij waren bij het nemen van deze beslissing.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

24. Ik vond het moeilijk om te beslissen of de voordelen of de nadelen voor mij belangrijker zijn.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

25. Ik voelde mij, bij het nemen van deze beslissing, door anderen onder druk gezet.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

26. Ik kreeg voldoende steun van anderen bij het maken van deze keuze.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

27. Ik heb het gevoel dat ik goed geïnformeerd een keuze heb gemaakt.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

28. Mijn beslissing laat zien wat voor mij het meest belangrijk.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

29. Ik verwacht dat ik bij mijn beslissing zal blijven.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

30. Ik ben tevreden over mijn beslissing.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

31. Ik ben bang voor een bloeding.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

32. Ik ben bang voor trombose.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

33. Ik heb problemen met het slikken van medicatie.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

34. Ik ben bang voor een mogelijke heroperatie.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

35. Ik ben bang dat mijn nieuwe hartklep zal falen.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

36. Ik ben bang dat ik hinder bij dagelijkse activiteiten ervaar door mijn nieuwe hartklep.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

37. Ik ben bang dat mijn nieuwe hartklep mijn sociale leven negatief beïnvloedt.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

38. Ik vind het vervelend om levenslang antistolling te slikken.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

39. Ik ben bang dat ik last heb van het tikken van de klep.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

- Weet ik niet

40. Een patiënt die medicijn A gebruikt heeft 1% kans op een allergische reactie. Als 1000 patiënten medicijn A gebruiken, van hoeveel patiënten verwacht u dan dat ze een allergische reactie krijgen?

… patiënten van de 1000.

41. Een patiënt die medicijn B gebruikt heeft een kans van 1 op 1000 om een allergische reactie te krijgen. Hoeveel procent van de patiënten die medicijn B gebruiken zal een allergische reactie krijgen?

… %

42. Stel dat een euro 1000 keer wordt gegooid. Hoe vaak zal de euro op ‘kop’ vallen bij 1000 keer gooien?

… keer van de 1000.

43. Stel, het risico op een heroperatie na een hartklepvervanging is 5 procent (%). In de figuren op de volgende bladzijdes is dit weergegeven. Wij willen u vragen de figuren te rangschikken op duidelijkheid. Ieder figuur krijgt één cijfer. Hierbij geldt: 1 = meest duidelijk en 4 = minst duidelijk.

Figuur 1	1	2	3	4
Figuur 2	1	2	3	4
Figuur 3	1	2	3	4
Figuur 4	1	2	3	4

Translated version

1. Are you aware that there are different types of aortic valve prostheses?
   - Yes
   - No

2. Has a decision been made regarding a specific type of aortic valve prosthesis?
   - Yes
   - No
   - I don't know

3. What kind of aortic valve prosthesis will you receive?
   - Mechanical valve
   - Biological valve
   - A different valve prosthesis, namely…
   - I don't know

4. What type of aortic valve prosthesis is the most durable?
   - Biological valve
   - Mechanical valve
   - I don't know

5. Which type of aortic valve prosthesis has the highest risk of causing blood clots?
   - Biological valve
   - Mechanical valve
   - I don't know

6. With which type of aortic valve prosthesis does one have to use lifelong anticoagulation?
   - Biological valve
   - Mechanical valve
   - I don't know

7. Do you think you possess sufficient knowledge on the risks and benefits that come with the different types of aortic valve prostheses?

Strongly disagree 1 2 3 4 5 Strongly agree

8. With whom did you have the consultation regarding the choice for a specific type of aortic valve prosthesis?
- Cardiologist
- Cardio-thoracic surgeon
- Other

9. Do you feel like you have been given enough time to make a well thought through decision?
- Yes
- No
- I don't know
- I did not have to make the decision by myself

10. Has someone else been involved with the decision making for this specific type of aortic valve prosthesis?
- Yes, a family member
- Yes, a close friend
- Yes,…
- No

11. The doctor has included me during the decision making process for a specific type of aortic valve prosthesis.

Strongly disagree 1 2 3 4 5 Strongly agree
- I don't know
- Inapplicable

12. I think it is important to be included in the decision making process for a specific type of aortic valve prosthesis.

Strongly disagree 1 2 3 4 5 Strongly agree
- I don't know
- Inapplicable

13. Do you feel like you had a voice in the decision making process for a specific type of aortic valve prosthesis?
- Yes
- No
- I don't know

14. The final decision in prosthetic aortic valve choice should be made by:
- The physician
- The physician, after considering the patients opinion
- The patient and physician together
- The patient, after considering the physicians opinion
- The patient

15. This decision was difficult for me to make.

Strongly disagree 1 2 3 4 5 Strongly agree

16. I was clear about the best choice for me.

Strongly disagree 1 2 3 4 5 Strongly agree

17. I was not sure about what to choose.

Strongly disagree 1 2 3 4 5 Strongly agree

18. I was aware of which types of aortic valve prostheses were available to me.

Strongly disagree 1 2 3 4 5 Strongly agree

19. I was aware of the benefits of each type of aortic valve prosthesis.

Strongly disagree 1 2 3 4 5 Strongly agree

20. I was aware of the risks and side effects of each type of aortic valve prosthesis.

Strongly disagree 1 2 3 4 5 Strongly agree

21. I would like to have had more advice and information on the different types of valve prostheses.

Strongly disagree 1 2 3 4 5 Strongly agree

22. It was clear which benefits of the different types of valve prostheses applied most to me.

Strongly disagree 1 2 3 4 5 Strongly agree

23. It was clear which risks and side effects of the different types of valve prostheses applied most to me.

Strongly disagree 1 2 3 4 5 Strongly agree

24. It was difficult for me to decide what was more important to me (the benefits or the risks and side effects).

Strongly disagree 1 2 3 4 5 Strongly agree

25. I felt pressure from others during the making of this choice.

Strongly disagree 1 2 3 4 5 Strongly agree

26. I received enough support from others while making a choice.

Strongly disagree 1 2 3 4 5 Strongly agree

27. I feel I have made an informed choice.

Strongly disagree 1 2 3 4 5 Strongly agree

28. My decision shows what is important to me.

Strongly disagree 1 2 3 4 5 Strongly agree

29. I expect to stick with my decision.

Strongly disagree 1 2 3 4 5 Strongly agree

30. I am satisfied with my decision.

Strongly disagree 1 2 3 4 5 Strongly agree

31. I am afraid of possible bleeding.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don’t know

32. I am afraid of getting thrombosis.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know

33. I have a problem with taking medication.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know

34. I am afraid of possibly needing another valve operation in the future.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know

35. I am afraid of the possibility of my valve failing.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know

36. I am scared that my new heart valve will limit me in my daily activities.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know

37. I am scared that my new heart valve will influence my social life negatively.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know

38. It bothers me that I have to use oral anticoagulation for the rest of my life.

Strongly agree 1 2 3 4 5 Strongly disagree

- I don't know

39. I am scared that the valve sound might bother me.

Strongly agree 1 2 3 4 5 Strongly disagree

- I don't know

40. A person taking Drug A has a 1% chance of having an allergic reaction. If 1,000 people take Drug A, how many would you expect to have an allergic reaction?

… person(s) out of 1,000

41. A person taking Drug B has a 1 in 1,000 chance of an allergic reaction. What percent of people taking Drug B will have an allergic reaction?

… %

42. Imagine that I flip a coin 1,000 times. What is your best guess on how many times the coin would come up heads in 1,000 flips?

… times out of 1,000

43. Imagine the risk of a reoperation after heart valve replacement is 5 percent. This is represented in the following figures. Please order the figures based on how clear they are to you. 1 = most clear, 4 = least clear.

Figure 1	1	2	3	4
Figure 2	1	2	3	4
Figure 3	1	2	3	4
Figure 4	1	2	3	4

Appendix 2 Postoperative survey

Original version

1. Bent u ervan op de hoogte dat er verschillende soorten aortakleppen zijn?
   - Ja
   - Nee

2. Wat voor aortaklep heeft u gekregen?
   - Mechanische klep
   - Biologische klep
   - Anders, namelijk…
   - Weet ik niet

3. Hebt u het idee dat u voldoende kennis hebt over de voor- en nadelen van de verschillende typen aortakleppen?

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

4. De arts heeft mij betrokken in het maken van een keuze voor een bepaald type aortaklep.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

   - Weet ik niet
   - Niet van toepassing

5. Ik vind het belangrijk betrokken te worden bij het kiezen van een aortaklep.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

   - Weet ik niet
   - Niet van toepassing

6. Hebt u voor uw gevoel genoeg tijd gehad om een weloverwogen beslissing te kunnen nemen?
   - Ja
   - Nee
   - Weet ik niet
   - Ik heb zelf geen beslissing hoeven nemen

7. Hebt u het gevoel een keuze te hebben gehad bij uw beslissing voor een bepaald type aortaklep?

- Ja
- Nee
- Weet ik niet

8. De uiteindelijke keuze voor een aortaklep zou moeten gebeuren door:

- De arts alleen
- Voornamelijk de arts
- De arts en de patiënt samen
- Voornamelijk de patiënt
- De patiënt alleen

9. Hebt u last van kortademigheid?

- Ja
- Nee

Zo ja,

- Bent u kortademig bij inspanning (meer dan normaal), maar niet in rust?
- Bent u kortademig bij geringe inspanning, maar niet in rust?
- Bent u kortademig in rust?

10. Wanneer ik nogmaals zou moeten beslissen, zou ik dan opnieuw kiezen om een aortaklepoperatie te ondergaan?

- Ja, zeker
- Waarschijnlijk wel
- Weet ik niet
- Nee, waarschijnlijk niet
- Nee, absoluut niet

11. Is er een geluid van mijn aortaklep wat ik vervelend vind, waar ik last van heb?

- Altijd
- Vaak
- Soms
- Zelden

- Nooit

12. Ik vind de hoeveelheid doktersbezoeken en bloedonderzoeken die ik sinds mijn aortaklepoperatie moet hebben vervelend.
- Altijd
- Vaak
- Soms
- Zelden
- Nooit

13. Ik maak mij zorgen over de mogelijke complicaties van mijn aortaklep.
- Altijd
- Vaak
- Soms
- Zelden
- Nooit

14. Ik maak mij zorgen over mogelijke bloedingen als gevolg van het gebruik van bloedverdunners (anti-stollings medicatie).
(ook beantwoorden indien u geen bloedverdunners gebruikt)
- Altijd
- Vaak
- Soms
- Zelden
- Nooit

15. Ik ben bang dat mijn aortaklep zal falen.
- Altijd
- Vaak
- Soms
- Zelden
- Nooit

16. Ik ben bang dat ik mogelijk nog een aortaklepoperatie moet ondergaan.

- Altijd
- Vaak
- Soms
- Zelden
- Nooit

17. Ik ben tevreden met mijn nieuwe aortaklep.

Helemaal mee eens 1 2 3 4 5 Helemaal mee oneens

Translated version

1. Are you aware that there are different types of aortic valve prostheses?
   - Yes
   - No

2. What kind of aortic valve prosthesis did you receive?
   - Mechanical valve
   - Biological valve
   - A different type, namely…
   - I don't know

3. Do you think you possess sufficient knowledge on the risks and benefits that come with the different types of aortic valve prostheses?

Strongly disagree 1 2 3 4 5 Strongly agree

4. The doctor has included me during the decision making process for a specific type of aortic valve prosthesis.

Strongly disagree 1 2 3 4 5 Strongly agree

5. I think it is important to be included in the decision making process for a specific type of aortic valve prosthesis.

Strongly disagree 1 2 3 4 5 Strongly agree

   - I don't know
   - Inapplicable

6. Do you feel that you have been given enough time to make a well thought through choice?
   - Yes
   - No
   - I don't know
   - I did not have to make the decision by myself

7. Do you feel like you had a voice in the decision making process for a specific type of aortic valve prosthesis?

- Yes
- No
- I don’t know

8. The final decision in prosthetic aortic valve choice should be made by:
- The physician
- The physician, after considering the patients opinion
- The patient and physician together
- The patient, after considering physicians opinion
- The patient

9. Do you sometimes experience a shortness of breath?
- Yes
- No

If yes,

- Do you experience shortness of breath during exercise (more than normal), but not in rest?
- Do you experience shortness of breath during minor exercise, but not in rest?
- Do you experience shortness of breath in rest?

10. If I had to do it over again, would I make the same decision to have surgery?
- Yes, for sure
- Yes, probably
- I don’t know
- No, probably not
- No, absolutely not

11. Is there a valve sound that bothers me?
- Always
- Frequently
- Occasionally
- Rarely
- Never

12. Following my valve surgery, the frequency of doctor visits and blood tests bothers me.

- Always
- Frequently
- Occasionally
- Rarely
- Never

13. The possibility of complications due to my implanted valve concerns me.

- Always
- Frequently
- Occasionally
- Rarely
- Never

14. I am concerned about possible bleeding caused by my anticoagulant medication.

- Always
- Frequently
- Occasionally
- Rarely
- Never

15. I am afraid that my valve may fail.

- Always
- Frequently
- Occasionally
- Rarely
- Never

16. I am afraid that I may need another valve operation.

- Always
- Frequently
- Occasionally
- Rarely
- Never

17. I am satisfied with my new aortic valve.

Strongly agree 1 2 3 4 5 Strongly disagree