

Appendix Table of Content

Appendix 1 = MOOSE Checklist.

Appendix 2 = Search strategy example – MEDLINE.

Appendix Table 1 = Excluded studies, with reasons.

Appendix Table 2 = Additional study and participant demographics.

Appendix Table 3 = Qualitative study quality.

Appendix Table 4 = Quantitative study quality.

Appendix Table 5 = Qualitative results – CERQual Summary of Findings.

Appendix 1. MOOSE Checklist for Meta-analyses of Observational Studies

Item No	Recommendation	Reported on Page No
Reporting of background should include		
1	Problem definition	3
2	Hypothesis statement	N/A
3	Description of study outcome(s)	4
4	Type of exposure or intervention used	4
5	Type of study designs used	4
6	Study population	4
Reporting of search strategy should include		
7	Qualifications of searchers (e.g., librarians and investigators)	3,4
8	Search strategy, including time period included in the synthesis and key words	3, 25-27
9	Effort to include all available studies, including contact with authors	3,4
10	Databases and registries searched	4
11	Search software used, name and version, including special features used (e.g., explosion)	N/A
12	Use of hand searching (e.g., reference lists of obtained articles)	4
13	List of citations located and those excluded, including justification	16, 28-30
14	Method of addressing articles published in languages other than English	N/A
15	Method of handling abstracts and unpublished studies	4
16	Description of any contact with authors	4
Reporting of methods should include		
17	Description of relevance or appropriateness of studies assembled for assessing the hypothesis to be tested	5
18	Rationale for the selection and coding of data (e.g., sound clinical principles or convenience)	5
19	Documentation of how data were classified and coded (e.g., multiple raters, blinding and interrater reliability)	5

20	Assessment of confounding (e.g., comparability of cases and controls in studies where appropriate)	N/A
21	Assessment of study quality, including blinding of quality assessors, stratification or regression on possible predictors of study results	5
22	Assessment of heterogeneity	N/A
23	Description of statistical methods (e.g., complete description of fixed or random effects models, justification of whether the chosen models account for predictors of study results, dose-response models, or cumulative meta-analysis) in sufficient detail to be replicated	N/A
24	Provision of appropriate tables and graphics	16-22
Reporting of results should include		
25	Graphic summarizing individual study estimates and overall estimate	N/A
26	Table giving descriptive information for each study included	17
27	Results of sensitivity testing (e.g., subgroup analysis)	N/A
28	Indication of statistical uncertainty of findings	N/A
Reporting of discussion should include		
29	Quantitative assessment of bias (e.g., publication bias)	N/A
30	Justification for exclusion (e.g., exclusion of non-English language citations)	N/A
31	Assessment of quality of included studies	33, 34
Reporting of conclusions should include		
32	Consideration of alternative explanations for observed results	12-14
33	Generalization of the conclusions (i.e., appropriate for the data presented and within the domain of the literature review)	14
34	Guidelines for future research	14
35	Disclosure of funding source	16

From: Stroup DF, Berlin JA, Morton SC, et al, for the Meta-analysis Of Observational Studies in Epidemiology (MOOSE) Group. Meta-analysis of Observational Studies in Epidemiology. A Proposal for Reporting. *JAMA*. 2000;283(15):2008-2012. doi: 10.1001/jama.283.15.2008

Appendix 2. Search strategy example – MEDLINE.

Database searched = OVID Medline Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

1. *Attitude to Health/
2. *Patient Participation/
3. preference*.ti,ab.
4. *Patient Preference/
5. choice.ti.
6. choices.ti.
7. value*.ti.
8. health state values.ti,ab.
9. valuation*.ti.
10. expectation*.ti,ab.
11. attitude*.ti,ab.
12. acceptab*.ti,ab.
13. knowledge.ti,ab.
14. point of view.ti,ab.
15. user participation.ti,ab.
16. users participation.ti,ab.
17. users' participation.ti,ab.
18. user's participation.ti,ab.
19. patient participation.ti,ab.
20. patients' participation.ti,ab.
21. patients participation.ti,ab.
22. patient's participation.ti,ab.
23. patient perspective*.ti,ab.
24. patients perspective*.ti,ab.
25. patients' perspective*.ti,ab.

26. patient's perspective*.ti,ab.
27. patient perce*.ti,ab.
28. patients perce*.ti,ab.
29. patients' perce*.ti,ab.
30. patient's perce*.ti,ab.
31. health perception*.ti,ab.
32. user view*.ti,ab.
33. users view*.ti,ab.
34. users' view*.ti,ab.
35. user's view*.ti,ab.
36. patient view*.ti,ab.
37. patients view*.ti,ab.
38. patients' view*.ti,ab.
39. patient's view*.ti,ab.
40. or/1-39
41. patient*.ti.
42. user*.ti.
43. men.ti.
44. women.ti.
45. or/41-44
46. exp *Decision Making/
47. decision mak*.ti,ab.
48. decisions mak*.ti,ab.
49. decision*.ti.
50. mak*.ti.
51. 49 and 50
52. avoidance learning/
53. 46 or 47 or 48 or 51 or 52
54. 45 and 53
55. discrete choice.ti,ab.
56. decision board*.ti,ab.

57. decision analy*.ti,ab.
58. decision-support.ti,ab.
59. decision tool*.ti,ab.
60. decision aid*.ti,ab.
61. discrete-choice*.ti,ab.
62. decision*.ti,ab.
63. 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62
64. 45 and 63
65. 54 or 64
66. decision support techniques/
67. (health and utilit*).ti.
68. gamble*.ti,ab.
69. prospect theory.ti,ab.
70. preference score.ti,ab.
71. preference elicitation.ti,ab.
72. health utilit*.ti,ab.
73. (utility and (value* or score* or estimate*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
74. health state.ti,ab.
75. feeling thermometer*.ti,ab.
76. best-worst scaling.ti,ab.
77. best worst scaling.mp.
78. best worst.ti,ab.
79. TTO.ti,ab.
80. time trade-off.ti,ab.
81. probability trade-off.ti,ab.
82. or/66-81
83. Choice Behavior/

84. or/66-83
85. preference based.ti,ab.
86. preference score.ti,ab.
87. multiattribute.ti,ab.
88. multi attribute.mp.
89. EuroQoL 5D.mp.
90. EuroQoL5D.ti,ab.
91. EQ5D.mp.
92. EQ 5D.ti,ab.
93. SF6D.ti,ab.
94. SF 6D.ti,ab.
95. HUI.ti,ab.
96. 15D.ti,ab.
97. or/85-96
98. SF36.ti,ab.
99. SF 36.ti,ab.
100. SF12.ti,ab.
101. SF 12.mp.
102. HRQoL.ti,ab.
103. QoL.ti,ab.
104. quality of life.ti,ab.
105. "Quality of Life"/
106. or/98-105
107. 40 or 65 or 84 or 97 or 106
108. Aortic Stenosis.mp. or exp Aortic Valve Stenosis/
109. (aortic valve implantation or TAVR or transcatheter or transfemoral or transapical or transaxillary or SAVR or heart valve replacement or surgical aortic valve replacement or surgical AVR or SAVR or TAVI or aortic valve replacement or transvascular).af.
110. 107 and 108 and 109
111. limit 110 to humans

Appendix Table 1. Excluded studies, with reasons.

#	Title	First author	Year	Reason for exclusion
1	Toronto Aortic Stenosis Quality of Life Scale (TASQ): Development and quality of life in aortic stenosis and TAVI patients	Styra	2019	Abstract only
2	Rapid-cycle development of decision support tools for patients with symptomatic aortic stenosis	Knoepke	2018	Abstract only
3	Risk willingness and survival in patients with severe aortic stenosis	Hussain	2019	Abstract only
4	A learning curve for shared decision making: The impact of physician experience on decision aid efficacy in severe aortic stenosis	Coylewright	2018	Abstract only
5	Subjective preferences and goal among the patients treated with transaortic valvular replacement	Sugiura	2019	Abstract only
6	Patients and their physicians do not agree on shared decision making in transcatheter aortic valve replacement	Coylewright	2016	Not about values and preferences elicitation
7	Is it worth it? A collaborative clinical decision making exercise using an old-school debate	Wright	2016	Not about values and preferences elicitation
8	The medically managed patient with severe symptomatic aortic stenosis in the TAVR era: Patient characteristics, reasons for medical management, and quality of shared decision making at heart valve treatment centers	Dharmarajan	2017	Not about values and preferences elicitation
9	Patients' Decision Making About Undergoing Transcatheter Aortic Valve Implantation for Severe Aortic Stenosis	Olsson	2016	Not about values and preferences elicitation
10	Determinants and Outcome of Decision Making Among Patients with Severe Aortic Stenosis	Hussain	2017	Not about values and preferences elicitation

11	Patients' self-reported function, symptoms and health-related quality of life before and 6 months after transcatheter aortic valve implantation and surgical aortic valve replacement	Olsson	2017	Not about values and preferences elicitation
12	Self-reported health status, treatment decision and survival in asymptomatic and symptomatic patients with aortic stenosis in a Western Norway population undergoing conservative treatment: a cross-sectional study with 18 months follow-up	Oterhals	2017	Not about values and preferences elicitation
13	[ANMCO/SIC/SICI-GISE/SICCH Consensus document: Risk stratification in elderly patients undergoing cardiac surgery and transcatheter aortic valve implantation]	Pulignano	2016	Not about values and preferences elicitation
14	Patients and informal caregivers' experience of surgical and transcatheter aortic valve replacement: Real-world data contributing to establish value-based medicine in Denmark	Rosseeel	2019	Not about values and preferences elicitation
15	Current decision making and short-term outcome in patients with degenerative aortic stenosis: the Pooled-Rotterdam-Milano-Toulouse In Collaboration Aortic Stenosis survey	Van Mieghem	2016	Not about values and preferences elicitation
16	Factors influencing the choice between transcatheter and surgical treatment of severe aortic stenosis in patients younger than 80 years: Results from the OBSERVANT study	Tarantini	2020	Not about values and preferences elicitation
17	Transforming the experience of aortic valve disease in older patients: A qualitative study	Kirk	2019	Not about values and preferences elicitation
18	Long-term outcomes of transcatheter versus surgical aortic valve replacement in low risk, elderly patients with severe aortic stenosis	Kang	2019	Not about values and preferences elicitation

19	Reasons for choosing conservative management in symptomatic patients with severe aortic stenosis - Observations from the CURRENT AS registry	Ishii	2019	Not about values and preferences elicitation
20	Patient disposition and clinical outcome after referral to a dedicated TAVI clinic	Gorecka	2019	Not about values and preferences elicitation
21	Validation of a Heart Team Performance for Patients with Severe Aortic Stenosis	D'Aronco	2019	Not about values and preferences elicitation
22	The Learning Curve for Shared Decision-making in Symptomatic Aortic Stenosis	Coylewright	2020	Not about values and preferences elicitation
23	Pilot Study of a Patient Decision Aid for Valve Choices in Surgical Aortic Valve Replacement	Anaya	2019	Not about values and preferences elicitation
24	Exploring the experience of early discharge after transcatheter aortic valve implantation for older adults and their informal caregivers (Dissertation)	Knoll	2018	Not about values and preferences elicitation
25	Living with Aortic Stenosis: A Phenomenological Study of Patients' Experiences and Subsequent Health Choices (Dissertation)	Hagen-Peter	2015	Not about values and preferences elicitation
26	Low Gradient Aortic Stenosis: Who Benefits From Intervention?	Baumgartner	2019	Not primary study
27	TAVR in Patients With End-Stage Renal Disease and Critical Aortic Stenosis: Hard Choices	Bayliss	2019	Not primary study
28	Quality of life after transcatheter aortic valve replacement	Bonow	2017	Not primary study
29	TAVR: A Good Fix, But It Cannot Fix Everything	Carabello	2016	Not primary study
30	Treating of aortic valve stenosis in real-life: A multifaceted decision-making challenge	Franken	2017	Not primary study
31	Are transcatheter procedures the treatment of choice for all patients with severe aortic stenosis?	Hernandez-Vaquero	2017	Not primary study

32	The less complex the case is, the more complex is it to choose? The case of lower risk patients with aortic valve stenosis	Lemos	2018	Not primary study
33	Elevating Aortic Stenosis Treatment?	McCabe	2018	Not primary study
34	Transcatheter aortic valve implantation in patients with severe aortic stenosis: Does lower-risk profile mean a young patient?	Michel	2019	Not primary study
35	Transcatheter aortic valve replacement: Suitable for all?	Minakata	2018	Not primary study
36	Aortic stenosis: Treat the patient not the numbers	Otto	2018	Not primary study
37	Surgical or transcatheter aortic-valve replacement	Reyes	2017	Not primary study
38	From knowledge to wisdom	Sousa-Uva	2018	Not primary study
39	TAVR - The future of aortic stenosis management	Ullah	2016	Not primary study

Appendix Table 2. Additional study and participant demographics.

Study	Data collection period	Setting	Funding source	Conflicts of interest
Quantitative studies				
Marsh 2020	July-August 2018	Not applicable (online survey)	Edwards Lifesciences	Two authors are employees of Edwards Lifesciences. Three studies are employees of Evidera. Evidera received funding from Edwards Lifesciences to conduct the study and develop the manuscript.
Hussain 2016	May 2010-April 2014	Large university hospital	Norwegian Health Association and Inger and John Fredriksen	No conflict of interest
Qualitative studies				
Coylewright 2015	June 2012-August 2014	Tertiary academic medical institution	No funding sources	No conflict of interest
Olsson 2016	May 2010-June 2011	Large university hospital	Vasterbotten's County Council, Umea University, and The Heart Foundation of Northern Sweden	No conflict of interest
Skaar 2017	February 2014-April 2015	Large university hospital	Grieg Foundation, Department of Heart Disease, Haukeland University Hospital and Kavli Research Centre for Geriatrics and Dementia, Haraldsplass Deaconess Hospital, Bergen.	NR
Lauck 2016	NR	Provincial cardiac TAVI center	Providence Health Care Nursing Research Competition	Four authors are consultants to Edward Lifesciences. One author is a consultant for Edward Lifesciences, St. Jude Medical and Abbott Inc., HearthWare, and Norvasc.
Ontario Health Technology Assessment Series 2018	NR	Not applicable (phone interview)	Health Quality Ontario	NR

Frank 2019/Styra 2019	2015-2017	Tertiary academic medical institution	Partially funded from Edwards Lifesciences (manufacturer of TAVI valves)	NR
-----------------------------	-----------	--	--	----

NR = Not reported.

Appendix Table 3. Qualitative study quality.

Study	Coylewright 2016	Ontario Health Technology Assessment Series 2018	Lauck 2015	Olsson 2019	Skaar 2019	Styra/Frank 2019
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	No	Can't tell	No	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Can't tell
6. Has the relationship between researcher and participants been adequately considered?	Can't tell	No	No	No	Yes	No
7. Have ethical issues been taken into consideration?	Yes	Can't tell	Yes	Yes	Yes	Yes
8. Was the data analysis sufficiently rigorous?	No	Can't tell	Yes	Yes	Yes	Can't tell
9. Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes
Overall methodological limitations	Moderate	Serious	Moderate	No or very minor	No or very minor	No or very minor

Appendix Table 4. Quantitative study quality.

Risk of bias criteria		Hussain 2016	Marsh 2020
Selection of participants into the study	Was an appropriate study sample selected from the sampling frame?	Moderate risk of bias	Serious risk of bias
Completeness of data	Was the attrition sufficiently low to minimize the risk of bias?	Moderate risk of bias	Serious risk of bias
Measurement Instrument: Choice of the methodology	Was the instrument used for eliciting relative importance of outcomes valid and reliable?	Moderate risk of bias	Low risk of bias
Measurement Instrument: Administration of the methodology	Was the instrument administered in the intended way?	Low risk of bias	Moderate risk of bias
Measurement Instrument: Outcome presentation	Was a valid representation of the outcome (health state) utilized?	Moderate risk of bias	Serious risk of bias
Measurement Instrument: Understanding of the methodology	Did the researchers check the understanding of the instrument?	Moderate risk of bias	Low risk of bias
Data analysis	Were the results analyzed appropriately to avoid influence of bias and confounding?	Moderate risk of bias	Serious risk of bias

Appendix Table 5. Qualitative results - CERQual Summary of Findings

Summary of Qualitative Review Findings	Reference	Explanation of CERQual assessment
Values and preferences concerning perioperative mortality risk of procedure		
Patients with severe aortic stenosis viewed declining treatment to be worse than accepting the risk related to the procedure	²³	Limited, thin data to support this finding, only one study that did address both TAVI and SAVR
Risk willingness varied considerably, but many patients were generally willing to accept a high perioperative mortality risk when undergoing aortic valve replacement	^{21 23}	Limited, thin data to support this finding, not enough studies, not enough settings, and studies did not address both TAVI and SAVR.
Values and preferences concerning health-related quality of life when deciding on treatment		
<i>Function/ activities of daily living</i>		
Patients aimed for improved body function, better health and activities of daily living when deciding on treatment.	^{21 27 23 22}	Studies with methodological limitations, limited, thin data to support this finding, not enough studies, not enough settings and all but one study did not address both TAVI and SAVR, and when it was reported it was separate
Patient-defined goals central to decision-making included specific activities and hobbies.	^{21 27 23 24}	Studies with methodological limitations, limited, thin data to support this finding, not enough studies, not enough settings and studies did not address both TAVI and SAVR.
Patients emphasized importance of managing by oneself or be independent as reasons to undergo treatment.	^{21 27 24 22}	Studies with methodological limitations, limited, thin data to support this finding, not enough studies, not enough settings and studies did not address both TAVI and SAVR.
<i>Improve quality of life</i>		
Patients hoped the procedure would improve their quality of life, and spoke of their desire to get back to 'normal', have a 'good life' or have a 'new lease on life' when deciding on treatment.	^{27 22 23 24}	Studies with methodological limitations, limited, thin data to support this finding, not enough studies, not enough settings and studies and studies did not address both TAVI and SAVR
<i>Maintaining independence/ obligations</i>		
Patients reported their sense of responsibility to maintain the best possible health condition to be able to fulfill their obligations, including on financial management, maintaining one's home and participating in day-to-day activities.	^{21 27 24 22}	Studies with methodological limitations, limited, thin data to support this finding, not enough studies, not enough settings and all but one study did not address both TAVI and SAVR, and when it was reported it was separate

Some patients reported that they felt an obligation to their relatives to accept a treatment that was recommended.	^{27 23}	Studies with methodological limitations, limited, thin data to support this finding, uncommon, but important finding, not enough studies, not enough settings and all but one study did not address both TAVI and SAVR, and when it was reported it was separate
Values and preferences concerning pain and risk of stroke		
Some patients were concerned about pain or getting a stroke after the procedure.	²²	Study with methodological limitations, uncommon, but important finding, only one study and TAVI and SAVR was reported separately
Values and preferences related to decision-making guidance on treatment and practical issues		
Patients stressed the importance of a trusting relationship with their physician(s) as essential sources of information, decision-making guidance and facilitators of referral and decision-making	^{21 27 23}	Studies with methodological limitations, thin data to support this finding, not enough studies, not enough settings and studies did not address both TAVI and SAVR, and when it was reported it was separate
There was a high degree of variability on the reliance on informal social support provided by family, friends and community members on their decision making.	^{21 27 23}	Studies with methodological limitations, thin data to support this finding, not enough studies, not enough settings and studies did not address both TAVI and SAVR, and when it was reported it was separate
Patients and caregivers noted that the costs involved with travel and a longer hospital stay were an additional burden and a potential barrier to receiving SAVR.	^{22 21 23 27}	All but one study did not address both TAVI and SAVR, and when it was reported it was separate