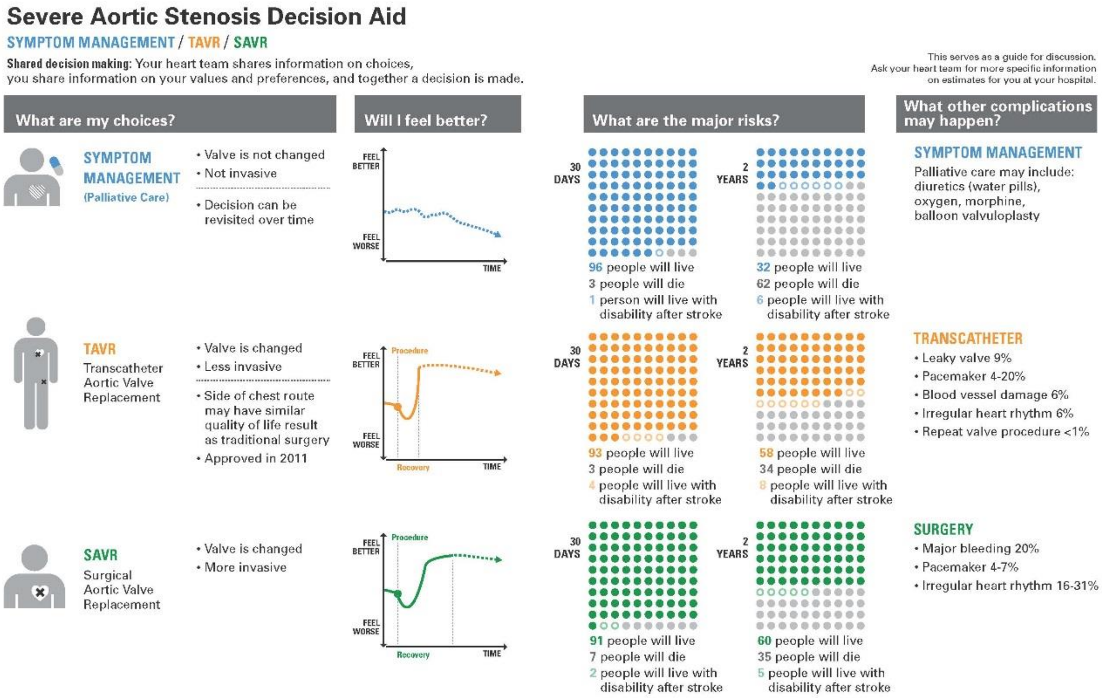
Supplementary Online Content

Coylewright M, O'Neill E, Sherman A, et al. The learning curve for shared decision-making in symptomatic aortic stenosis. *JAMA Cardiol.* Published online January 29, 2020. doi:10.1001/jamacardio.2019.5719

eAppendix 1. Development of Severe Aortic Stenosis Decision Aid

The Severe Aortic Stenosis Decision Aid was developed iteratively with input from stakeholders as part of a national initiative by the American College of Cardiology named “Championing Care for the Patient with Aortic Stenosis.” Content was informed by contemporary guidelines and evidence, reviewed systematically and assessed by an expert panel. User-centered testing occurred at nine high-volume U.S. TAVR centers, with clinician, patient and family input leading to design modifications (prior version displayed below). Patients favored a paper-based tool with large font, with focus on quality of life. Clinicians strongly objected to internet-based log on requirements and manual entry of data, limiting individualized risk display. Patients’ adult children preferred mortality data remain included in the decision aid, even as patients highly prioritized quality of life data. Prompts for values elicitation were added when testing revealed this was missing from encounters (i.e. “What matters most to you?”). The decision aid is available at sharedcardiology.org/tools.

eFigure 1. Prior Version of Severe Aortic Stenosis Decision Aid



Severe Aortic Stenosis Decision Aid

SYMPTOM MANAGEMENT / TAVR / SAVR

Shared decision making: Your heart team shares information on choices, you share information on your values and preferences, and together a decision is made.

This serves as a guide for discussion. Ask your heart team for more specific information on estimates for you at your hospital.

What are my choices?

SYMPTOM MANAGEMENT (Palliative Care)

- Valve is not changed
- Not invasive
- Decision can be revisited over time

TAVR Transcatheter Aortic Valve Replacement

- Valve is changed
- Less invasive
- Side of chest route may have similar quality of life result as traditional surgery
- Approved in 2011

SAVR Surgical Aortic Valve Replacement

- Valve is changed
- More invasive

Will I feel better?

What are the major risks?

	30 DAYS	2 YEARS
SYMPTOM MANAGEMENT	96 people will live 3 people will die 1 person will live with disability after stroke	32 people will live 62 people will die 6 people will live with disability after stroke
TAVR	93 people will live 3 people will die 4 people will live with disability after stroke	58 people will live 34 people will die 8 people will live with disability after stroke
SAVR	91 people will live 7 people will die 2 people will live with disability after stroke	60 people will live 35 people will die 5 people will live with disability after stroke

What other complications may happen?

SYMPTOM MANAGEMENT

Palliative care may include: diuretics (water pills), oxygen, morphine, balloon valvuloplasty

TRANSCATHETER

- Leaky valve 9%
- Pacemaker 4-20%
- Blood vessel damage 6%
- Irregular heart rhythm 6%
- Repeat valve procedure <1%

SURGERY

- Major bleeding 20%
- Pacemaker 4-7%
- Irregular heart rhythm 16-31%

Versions developed in 2012-2014 when surgery was offered routinely to high surgical risk patients, included a third option of surgical aortic valve replacement. Based on evolving care patterns and stakeholder engagement, this option was removed from the final decision aid.

eFigure 2. Shared Decision-Making Checklist for Severe Aortic Stenosis Choice

Dartmouth-Hitchcock
HEART & VASCULAR
CENTER

THE
Dartmouth
INSTITUTE
FOR HEALTH POLICY & CLINICAL PRACTICE

Defining the learning curve for decision aids: *Aortic Stenosis Choice*

Shared Decision Checklist

1. Name the choices

   ☐ "We have a choice to make today."

   SYMPTOM MANAGEMENT / TAVR

2. Explain shared decision making

   ☐ "I am the expert on the choices that are appropriate for you and you are the expert in how you weigh those choices. We make a decision together."

3. Describe the choices using the decision aid

   ☐ Check understanding: "Tell me what you understand about the choices."

   Will I feel better?

4. Listen to what matters most to the patient

   What other complications may happen?

   ☐ There are many ways to do this: "What do you hope to do that you cannot do now?" or "What matters most to you?"

5. Make a decision together, using what the patient said matters most

   ☐ "What I hear you saying is…, and it sounds like *option X* matches your goals."

eAppendix 2. Patient Surveys

Pre-Visit Survey

Participant ID: ……………………………..

About this survey:

Before your visit today, we would like to learn more about you and what you know about treatments for your heart valve disease (severe aortic stenosis).

1. How old are you?

………………………………………………

2. What is your gender?

☐ Male

☐ Female

☐ Other

3. What is your highest level of education? (Please mark only one choice.)

☐ Some high school

☐ High school graduate, diploma, or GED

☐ Some college or associate’s degree

☐ 4-year college degree (bachelor’s degree)

☐ Graduate / professional school degree

4. My family doctor or my other cardiologist taught me about treatment choices before I came to this visit. (Please mark only one choice.)

☐ Disagree ☐ Neither agree nor disagree ☐ Agree ☐ I don’t know / not applicable

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Some of the statements below are true and some are false. Please mark only one box after each statement.

5. One choice is to take medicines and not have a valve replacement.

☐ True

☐ False

☐ I don’t know

6. Medicines alone will help me live longer.

☐ True

☐ False

☐ I don’t know

7. I am more likely to feel better with a valve replacement compared to medicines.

☐ True

☐ False

☐ I don’t know

8. One of the risks of a transcatheter valve (TAVR) is that it may leak.

☐ True

☐ False

☐ I don’t know

Thank you for your time. We will ask you to complete a second survey after your doctor’s appointment.

Post-visit Survey

Participant ID: ……………………………..

Patient Survey

About this questionnaire:

We would like to ask you a few questions about the visit you just had. Please circle one number or check one box for each question. If you have questions, please ask the researcher.

1. How much effort was made to help you understand your health issues?

0 1 2 3 4 5 6 7 8 9

No effort
was made

Every effort
was made

2. How much effort was made to listen to the things that matter most to you about your health issues?

0 1 2 3 4 5 6 7 8 9

No effort

Every effort

was made was made

3. How much effort was made to include what matters most to you in choosing what to do next?

0 1 2 3 4 5 6 7 8 9

No effort
was made

Every effort
was made

4. Did this provider explain things in a way that was easy to understand?

☐ Yes, definitely

☐ Yes, somewhat

☐ No

5. Did this provider listen carefully to you?

☐ Yes, definitely

☐ Yes, somewhat

☐ No

6. Did this provider give you easy-to-understand information about your health questions or concerns?

☐ Yes, definitely

☐ Yes, somewhat

☐ No

7. Did this provider seem to know the important information about your medical history?

☐ Yes, definitely

☐ Yes, somewhat

☐ No

8. Did this provider show respect for what you had to say?

☐ Yes, definitely

☐ Yes, somewhat

☐ No

9. Did this provider spend enough time with you?

☐ Yes, definitely

☐ Yes, somewhat

☐ No

10. Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate this provider?

0	1	2	3	4	5	6	7	8	9	10
Worst provider possible										Best provider possible

Now that you have had your appointment with your heart doctor, we would like to ask again about treatments for your heart valve disease. Some of the statements below are true and some are false. Please mark only one box for each statement.

11. One choice is to take medicines and not have a valve replacement.

☐ True

☐ False

☐ I don’t know

12. Medicines alone will help me live longer.

☐ True

☐ False

☐ I don’t know

13. I am more likely to feel better with a valve replacement compared to medicines.

☐ True

☐ False

☐ I don’t know

14. One of the risks of a transcatheter valve (TAVR) is that it may leak.

☐ True

☐ False

☐ I don’t know

Lastly, we would like to know about the decision you and your heart doctor talked about today.

15. Are you clear about which benefits and risks matter most to you?

☐ Yes

☐ No

16. Do you know the benefits and risks of each option?

☐ Yes

☐ No

17. Do you have enough support and advice to make a choice?

☐ Yes

☐ No

18. Do you feel sure about the best choice for you?

☐ Yes

☐ No

19. Right now, which treatment option are you most likely to choose? (Please mark only one.)

☐ Medical therapy (medicines without a procedure)

☐ TAVR (newer, less invasive procedure to replace the valve)

☐ I don’t know

Thank you very much for completing this survey.

eTable 1. Shared Decision-Making (Observer OPTION^5) Score Scale

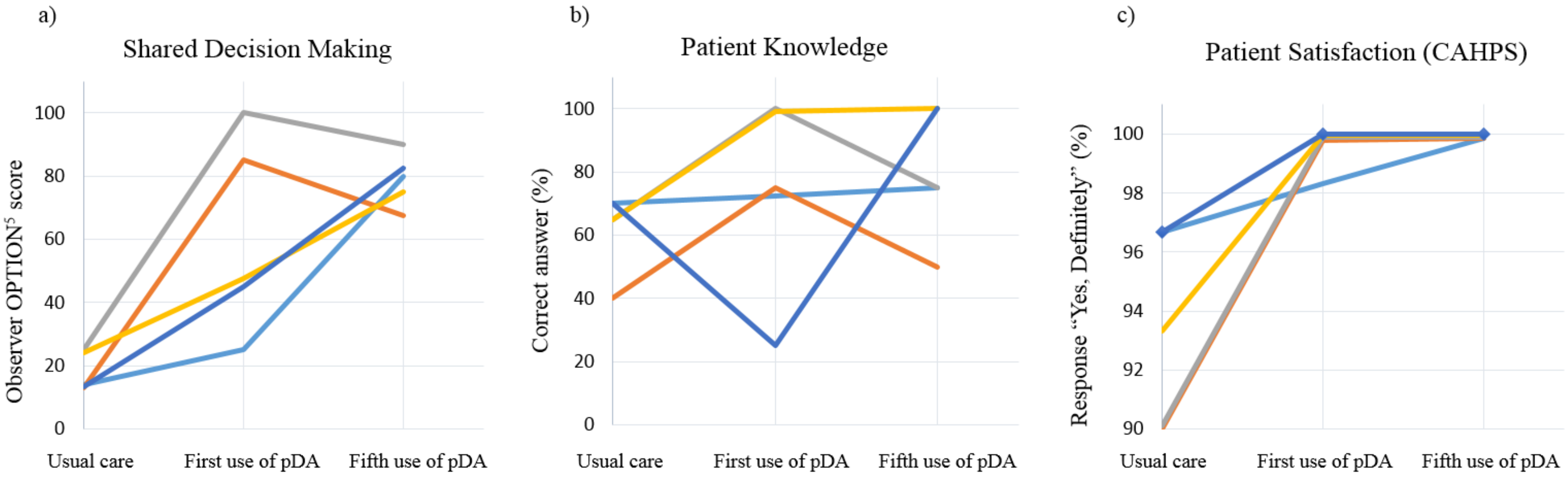
Observer OPTION^5 scale [1-3]

1. The provider draws attention to, or re-affirms, a problem where alternate treatment or management options exist and which requires the initiation of a decision making process. If the patient draws attention to the availability of options and the provider responds by agreeing that the options need consideration, the item can also be scored positively.	0 1 2 3 4
2. The provider reassures the patient, or re-affirms, that the provider will support the patient to become informed. The provider supports/explains the need to deliberate about the options.	0 1 2 3 4
3. The provider gives information, or re-affirms/checks understanding, about options that are considered reasonable (including taking 'no action'), to support the patient in understanding/comparing the pros and the cons.	0 1 2 3 4
4. The provider supports the patient to examine, voice, and explore his/her personal preferences in response to the options that have been described.	0 1 2 3 4
5. The provider makes an effort to integrate the patient's preferences as decisions are either made by the patient or arrived at by a process of collaboration/discussion.	0 1 2 3 4
Other notes on the Observer OPTION^5 scale:	

Observer OPTION^5 scale score descriptions

Score	**Description**
0	The behavior is not observed
1	A minimal attempt is made to exhibit the behavior
2	The behavior is observed and a minimum skill level achieved
3	The behavior is exhibited to a good standard
4	The behavior is exhibited to a very high standard

eFigure 3. Changes in Decisional Quality Outcomes With Multiple Uses of Patient Decision Aid



Each line represents a unique clinician over time. a) Shared decision making as measured by Observer OPTION^5; b) Patient knowledge using a four-item survey; c) Patient satisfaction using the Consumer Assessment of Healthcare Providers and Systems (CAHPS).

eTable 2. Raters' Agreement for Observer OPTION^5

Raters	Correlation coefficient [a]	Mean difference [b]	95% limits of agreement
KA&SG	0.1 (CI[c]: -0.4 to 0.5)	-8.6	-33.5 to 16.2
MG&SG	0.4 (CI: -0.2 to 0.7)	-2.9	-24.5 to 18.8
RM&LG	0.3 (CI: -0.2 to 0.7)	15.5	-45.3 to 76.3

[a] Lin concordance correlation coefficient
[b] Bland Altman Analysis
[c] CI= Confidence interval

The table summarizes the results of Lin concordance correlation coefficient and Bland-Altman analysis. The small sample size of patients hampered the ability to test the assumption of normality for the paired t-test and was also reflected by the wide intervals of the 95% limits of agreement of the Bland-Altman analysis. The wide intervals indicate the great variation of the differences, which could be due to small sample size or to rater level of experience scoring Observer OPTION^5. The psychometric properties of Observer OPTION^5 were evaluated where the majority were observations were based on video data.[4] All the clinical encounters in our study were audiotaped.

eTable 3. Themes Generated From Qualitative Analysis of Clinician Semi-Structured Interviews, With Supportive Quotes

Prior to DA use: Usual care	
Clinicians shared a common goal of educating their patients about the risks and benefits of different treatments; most felt they already did this well. They identified patients as visual learners, and reported making their own visual aids. Clinicians also used posters illustrating diseased aortic valves and TAVR models.	*"I do the education and …draw a survival curve that shows patients what happens in real time." – Clinician 1* *"The visual cues are typically drawings."* - *Clinician 2* *"I do a visual with my hand...."* - *Clinician 5*
One clinician discussed how shared decision making may be distinct from current practice.	*"I think many surgeons feel that shared decision making is something that we do every time we consent someone for surgery…(but) it isn't necessarily part of the consent process…there are other components to it." – Clinician 4*
Clinicians interpreted that patients were most interested in outcomes data, specifically data on quality of life, stroke, and mortality. However, there was uncertainty how much patients understood the content of the discussions; techniques such as teach-back or other mechanisms to assess patient and family level of understanding were not mentioned.	*"No one cares about bleeding or pacemaker or length of stay. They care about stroke and death."- Clinician 5* *"I speak to (risk) verbally, with proportions…I have no idea how well they can interpret information like this. Something we find second nature…" – Clinician 1*
Clinicians felt the idea of shared decision making was consistent with usual practice… but that a DA may take up time. Clinicians were unified in reporting the content and process promoted by the DA merely replicated their current practice. Clinicians expressed concerns that the DA may be difficult to integrate into clinical workflow. There was a sense from some clinicians that the DA would take too much time, especially compared to a more traditional, paternalistic approach. Others acknowledged the potential for a learning curve and even need for specific training.	*"… (I)t has the potential to add some time…hopefully, it will be meaningful time." – Clinician 3* *"I would need training (about)…how people have used it effectively…and how it has helped people." – Clinician 3* *"If you want to be very paternalistic and sort of take control…you can feel the frustration or the temptation when (the discussion) is going round and round to say, 'Let's make a plan,' and be very directive." – Clinician 3*
After first use of DA	
After first use of DA, clinicians felt the DA did not contribute significantly to the clinical encounter. Many clinicians felt uncomfortable the first time they used the DA with a patient in a real-world setting. Each clinician suggested that deviating from their own routine was challenging.	*"I purposely made it clunky so I didn't miss anything…whereas (otherwise) I think we organically hit the five points (of shared decision making)." – Clinician 2*

	"It's like when I get into my car: I know I have to put my seatbelt on…I don't have a checklist to tell me to do (it). I feel like this… is stuff that we do all the time." – Clinician 3
At the same time, clinicians felt that the DA helped patients learn about their treatment options. Some clinicians saw the DA primarily as a way to convey information to the patient rather than prompting a conversation about patient values; others acknowledged the prompts to elicit patient preferences and goals.	*"I think it's more helpful for the patient to be able to visualize things as opposed to the physician because obviously, we know these numbers. It's more for them." – Clinician 4*
	"I didn't get into... what his values and preferences were because…I feel that is going into his decision making." – Clinician 4 *"I think it's great to have a stopping point that says, 'What matters most?' as a reminder to physicians to elicit that conversation." – Clinician5*
Several clinicians described the DA as easy to use, without impeding the clinical workflow. The tool was seen as advantageous if it addressed frequently asked questions from patients and families.	*"I think it might actually allow things to go a little bit smoother because most of these…are things that patients ask." – Clinician 4*
Clinicians wanted more time with the DA beforehand: both for themselves, and their patients. Clinicians felt they must be facile with the DA for patients to understand it, and appreciated a learning curve after using the tool. Clinicians also stressed that patients must be prepared before the visit for a discussion of values and preferences.	*"If I'm a little bit confused when I first see it, (the patients) certainly are… (it should be) introduced …when the decision is made to send them surgery." – Clinician 1* *"I would definitely get somebody to get the tool in their hands before they come and see me." – Clinician 1* *"We have a single office visit and…you say to patients, 'What matters most to you?' and two weeks from now that might change because (they) haven't come into the office prepared to answer that." – Clinician 5*
Clinicians emphasized that patients may not understand all of the DA; in contrast, the information was seen as very helpful for the patients' family members.	*"I think this can be awkward to integrate into an initial visit…unless you're just talking to the family (and not the patient)…this is what they like to see." – Clinician 3*
After fifth use of DA	
After fifth use of DA, some of the clinicians felt that the DA may be a useful tool that could be used to reveal gaps in patient understanding.	*"I can see how (the DA) crystallized a very complex issue…it enables you to get your arms around it…It gives some uniformity, some standardization. I think it's going to*

There was a greater comfort in DA implementation once it was used multiple times.	*benefit the patients…and the doctors, make us better." – Clinician 6* *"I think early on, I would try to introduce it and…get a little frustrated and I would say, 'Well, you can take this with you and you can look at it when you get home.'" – Clinician 3*
Others continued to believe the DA could be confusing, particularly for their most vulnerable patients; family members were still seen to benefit, however.	"*You need…small bites (of information)…The sheet itself is overwhelming in its current format." – Clinician 1* *"The questions I got back from patients implied to me that they weren't necessarily grasping everything." – Clinician 3* *"To be honest, the people who really liked it were the family members that were with the patients." – Clinician 3*

eReferences

1. Barr PJ, O'Malley AJ, Tsulukidze M, Gionfriddo MR, Montori V, Elwyn G. The psychometric properties of Observer OPTION(5), an observer measure of shared decision making. *Patient Educ Couns.* 2015;98(8):970-976.
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3. Elwyn G, Hutchings H, Edwards A, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expect.* 2005;8(1):34-42.
4. Barr PJ, O'Malley AJ, Tsulukidze M, Gionfriddo MR, Montori V, Elwyn G. The psychometric properties of Observer OPTION(5), an observer measure of shared decision making. *Patient Educ Couns.* 2015;98(8):970-976.