



Exploring experiences associated with aortic stenosis diagnosis, treatment and life impact among middle-aged and older adults

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ABSTRACT

Background and purpose: Although multiple studies have examined the clinical aspects of diagnosis, treatment, and management of patients with aortic stenosis (AS), limited data exist regarding patient experiences related to symptoms, diagnosis, treatment, and personal impacts of living with AS.

Methodology: Adults aged \geq 40 years diagnosed with AS were recruited and separated into three cohorts: medically managed, surgical aortic valve replacement (SAVR), and transcatheter aortic valve implantation (TAVI). Forty-five semi-structured interviews were conducted (15 per treatment group) via teleconference using open-ended questions and probes. Interview recordings were transcribed, and inductive thematic analyses were conducted.

Results: The majority of participants were male (55.6%), White (95.6%), and non-Hispanic (93.3%). Participants noting longer times to diagnosis also reported mild symptom onset and experiences of misdiagnoses. Participants described a strong reliance on their health care professionals (HCPs) to guide them through their treatment decisions, which were influenced by the effects of anticoagulation, future valve interventions, and recovery. Medically managed participants reported having to make lifestyle modifications to manage symptoms, while participants who underwent TAVI or SAVR reported positive sentiments in their ability to return to normal life following their treatment.

Conclusions and implications: Due to the varied experiences of AS patients, there is a need to improve patient resources to advance patient understanding and facilitate informed treatment decisions. Reported experiences also indicate a need for additional HCP education on early referral to a multidisciplinary heart valve team.

Keywords: Aortic stenosis; patient experience; transcatheter valve.

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Introduction

Aortic stenosis (AS) is the most common valvular heart disease in developed countries, with estimated

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prevalence as high as one in eight in the 75 or older population (Osnabrugge et al., 2013). The progression of AS varies considerably among diagnosed patients, and presentation of AS can range from asymptomatic to severely symptomatic (Otto et al., 2021). If left untreated, symptomatic severe AS is an important cause of heart failure and sudden death. Options for treatment of AS include surgical aortic valve replacement (SAVR), transcatheter aortic valve implantation (TAVI), and medical management (MM). Professional guidelines recommend a shared decision-making approach to treatment as incorporating this into the care of AS patients increases both knowledge regarding treatment choices and satisfaction in their care (Coylewright et al., 2020).

A diagnosis of symptomatic severe AS may significantly impact an individual physically, emotionally, mentally, and socially. Beyond the physical symptoms and functional limitations associated with AS, patients with AS have also described the diagnosis of AS as mentally and emotionally challenging due to decreased ability to conduct daily

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activities, increased dependence on family, and anxiety about the increased risk of sudden death (Olsson et al., 2016). To provide better care to patients living with AS and identify the barriers to effective diagnosis and treatment, it is imperative to understand their personal experiences and perspectives. In addition, describing the effects of AS on patient quality of life and the strategies used for selfmanagement can provide essential knowledge into gaps in patient resources.

Purpose of this investigation

While several studies have explored patient treatment decisions and highlighted different treatment approaches to AS (Olsson, 2016; Smith & Argaez, 2019). and others have explored patient experiences specific to recovery from TAVI (Kirk et al., 2019) the literature is lacking a description of the personal experiences of patients living with AS, their discussions with health care providers around their treatment decisions, and their methods for self-management, especially among the medically managed population. The purpose of this investigation was to outline the patient experiences related to AS diagnosis, treatment, self-management, and overall personal feelings and psychological impact of the disease.

Methods

Adults aged \geq 40 years with a previous diagnosis of AS from a health care professional (HCP) were recruited in 2020 from national patient networks and through professional recruiters from a database of patients diagnosed with AS. Participants were separated into one of three cohorts: patients currently being treated by MM, patients with previous TAVI, and patients with previous SAVR.

Participants were emailed the informed consent form and a screening survey to collect demographic information and medical history specific to AS. With consent from participants, qualitative interviews were conducted via teleconference by two trained staff members lasting 30–75 minutes. Three semi-structured interview guides specific to each cohort were developed using open-ended questions and probes (Supplement A, Supplemental Digital Content 1, http://links.lww.com/JAANP/A150).

Data analysis

Interviews were recorded and precisely transcribed. Thematic analysis was used to analyze the text in NVivo 12 (QSR International, LLC). After an initial review of the data, codes were developed, and transcriptions were coded for themes using a data-driven inductive approach. A codebook defining key terms was developed to identify patterns and themes regarding patient experiences.

The study was reviewed by Western IRB (Puyallup, WA) and deemed exempt under 45 CFR § 46.104(d)(2).

Results

Participant demographics

Our study cohort included 45 participants with AS (15 per treatment cohort). Among interview participants, 55.6% were male, 57.8% were aged 65 years or older, 95.6% were White, 93.3% were non-Hispanic, 55.6% had a household income \geq \$100,000, and 93.3% reported educational attainment of at least some college (**Table 1**).

Themes and findings

The primary themes identified describe patient experiences with AS symptoms, diagnosis, treatment, shared decision making and influence on daily life and are delineated below:

Symptom presentation. Interview participants reported experiencing diverse symptoms prior to receiving a diagnosis of AS, including heart murmurs, fatigue/weakness, shortness of breath, chest pain/angina, flutters/arrhythmias, light-headedness/dizziness, arm/back pain, high blood pressure, and head rush symptoms. While some patients reported having no signs or symptoms of AS prior to their diagnosis, most participants expressed that they experienced at least some symptom presentation. Some participants reported that they attributed their symptoms to advancing age.

"And when I'm doing things, ordinary things, it might be housework, like mopping the floors or something, I'm noticing that I have more shortness of breath and I can't do it like I used to without becoming sort of winded by the exertion. So it's a gradual thing, and all of a sudden one day it dawns on you, this, this, and this is happening, and maybe I should tell my doctor about it and check it out." (-MM)

"I didn't think I had symptoms. I was just getting out of breath a lot, but I thought that was just because I'm getting older." (-MM)

"The symptom I noticed that sort of pushed me to have something done about the aortic stenosis was I began to have pain, I guess it's angina. I never got it in my chest, it was always in my back. And so that's when I began to think that I needed more help. And I saw my heart doctors again." (-TAVI)

Diagnosis experience. Participants were asked to describe their experiences prior to receiving an AS diagnosis and their reasons for initially seeking medical attention. While some participants described a reluctance to pursue diagnostic testing out of fear or denial, others were proactive about scheduling a cardiology visit or echocardiogram because of their symptoms. **Table 2** outlines five common diagnosis experiences described by participants. Participants were often referred to a cardiologist by a primary care physician. Participants commonly

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	All Participants (n = 45)	Medical Management (n = 15)	SAVR (<i>n</i> = 15)	TAVI (n = 15)
Sex				
Male	25 (55.6%)	6 (40.0%)	7 (46.7%)	12 (80.0%)
Age				
65+ years	26 (57.8%)	5 (33.3%)	6 (40.0%)	15 (100%)
Race				
Asian	1 (2.2%)	1 (6.7%)	0 (0%)	0 (0%)
Black	1 (2.2%)	1 (6.7%)	0 (0%)	0 (0%)
White	43 (95.6%)	13 (86.7%)	15 (100%)	15 (100%)
Ethnicity				
Hispanic	3 (6.7%)	1 (6.7%)	1 (6.7%)	1 (6.7%)
Education				
High school graduate	3 (6.7%)	1 (6.7%)	0 (0%)	2 (13.3%)
Some college	8 (17.8%)	2 (13.3%)	3 (20.0%)	3 (20.0%)
Associates degree	6 (13.3%)	2 (13.3%)	3 (20.0%)	1 (6.7%)
Bachelor's degree	15 (33.3%)	6 (40.0%)	3 (20.0%)	6 (40.0%)
Graduate degree	13 (28.9%)	4 (26.7%)	6 (40.0%)	3 (20.0%)
Income				
\$25,000-\$49,999	6 (13.3%)	2 (13.3%)	2 (13.3%)	2 (13.3%)
\$50,000-\$99,999	11 (24.4%)	4 (26.7%)	4 (26.7%)	3 (20.0%)
\$100,000-\$149,999	11 (24.4%)	4 (26.7%)	4 (26.7%)	3 (20.0%)
\$150,000-\$249,999	11 (24.4%)	4 (26.7%)	3 (20.0%)	4 (26.7%)
\$250,000 or more	3 (6.7%)	1 (6.7%)	0 (0.0%)	2 (13.3%)
Prefer not to answer	3 (6.7%)	0 (0.0%)	2 (13.3%)	1 (6.7%)

Note: AS = aortic stenosis; SAVR = surgical aortic valve replacement; TAVI = transcatheter aortic valve implantation.^aRepresented as n (%).

reported having visits with their cardiologist 1–2 times per year for monitoring, blood tests, electrocardiograms, echocardiograms, and review and adjustment of medications.

Accuracy of diagnosis and time to diagnosis. Participants had varied perceptions regarding the way they received an AS diagnosis from their HCP. The time to receive an accurate diagnosis of AS from the first HCP visit for symptoms, concern about family history, or the detection of a heart murmur, also ranged widely among participants lasting as short as one month to as long as 30 years. However, median time from symptom onset to diagnosis among participants was 6 months (interquartile range: 1–12). Participants noting longer times to diagnosis also reported mild symptom onset and experiences of misdiagnoses. Some participants described that HCPs explained the AS diagnosis clearly and understandably, while others left the encounter confused with unanswered questions.

"I'm very fortunate to have a doctor that will take the time to explain things and will also give me information about where I am with my condition, and the options I have." (-MM)

"The doctors, they talk down to you like you're supposed to know everything. I tried to do my own research on it. I tried as best I could. I went on to the American Heart Association. I did get some info, but it wasn't what my doctors were telling me." (-MM)

Table 2. Five experience types related to AS			
Diagnosis Experience Type	Description		
Heart murmur	Individuals previously diagnosed with a heart murmur by a HCP with no other concerning symptoms. Some were referred to cardiologists after heart murmur detection (commonly older patients). Many individuals with a heart murmur were not referred to cardiologists at the time of detection. Murmur was simply noted in charts or "watched" by HCPs.		
Symptoms and scheduled an office visit	Individuals who went to see an HCP after concerning symptoms, oftentimes referred to cardiologists (or self-referred directly to cardiologists), diagnosed with aortic stenosis by HCP or cardiologist.		
Symptoms but waited until annual office visit	Individuals that noticed symptoms but waited until an annual HCP office visit to discuss symptoms. Diagnosed by HCP or referred to a cardiologist for diagnosis.		
Symptoms led to emergency department visit	Individuals that noticed prior symptoms but did not schedule a doctor's visit. Severe symptoms resulted in an emergency department visit and subsequent diagnosis.		
Proactive scheduling of cardiology visit/echocardiogram	Individuals that proactively scheduled a cardiology appointment and received an echocardiogram because of age, family history of heart disease, or extra health savings account money, resulting in diagnosis.		
Note: AS = aortic stenosis: HCP = health care prot	iessional.		

"I strictly remember him using the word tight valve, I don't remember if he said it was aortic stenosis, but as I told you, I'm an engineer. I have patents on biomedical products. So I immediately did my own research on it. It was clear to me what was going on. Now 'Joe Schmoe' might not have been able to do that, but I was." (-SAVR)

Communication in shared treatment decision

making. Although several participants mentioned difficulties communicating or sharing in the decision-making process with cardiologists and surgeons, most participants described a strong reliance on their HCPs to guide them through their treatment decisions. Most participants reported honest and open communication about procedures, risks, eligibility, and longevity after treatment. The decision for a procedure or a specific valve type was strongly influenced by patient preferences, which were informed by answers to patient questions provided by HCPs. Treatment decisions were influenced by the effects of anticoagulation, future valve interventions, and recovery time. Some medically managed patients reported they had not discussed treatment options yet, after HCPs indicated they would continue to be monitored.

"At the beginning, I actually went to like two different cardiologists. The first one was kind of negative. He was like, "You'll probably need a [catheterization] and this is going to cut your life short. You have very high cholesterol. How come you're not on statin medication?" He was really not very kind. I didn't like his entire approach. He was just awful." (-MM) "When I went to go for the consultation with the surgeon, because of my age, they wanted to put the mechanical valve, because of longevity and stuff. I didn't really want that. I wanted the cow, artificial, and he said, the surgeon said, "Okay, that's fine." I told him, "You know what?" I go, "You're the expert at this. You do what you feel is right," and he said, "Okay." Because of the diet and everything that goes with the mechanical valve, I really didn't want that restriction. [Interviewer: Did the surgeon listen to your request?] Participant: Oh yeah, oh yeah." (-SAVR)

"Because if you're healthy enough to undergo the surgery, it will be a more complete procedure if you let them do it open heart because they get to go in there and they get to see everything. They're not limited. [My doctor said], "You'll have a better result."" (-SAVR) **Sources to inform treatment decisions.** Participants also turned to resources outside of their health care team for support and guidance when making treatment decisions, including printed materials received at office visits, internet sources, support groups (virtual and in-person), and friends in the medical field or with a history of cardiac treatment. Less often reported sources of information included books, television, hospital information sessions and published academic research. From the TAVI and

"Well, as far as I can remember, I mean, after I'd read up on TAVI, then there was no doubt in my mind. So when I went in there, I wanted TAVI. And so [he]

SAVR cohorts, most interview participants were treated

within 1-2 years from diagnosis.

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didn't really give me much on the pros and cons. And I'd had surgery. I mean, I know what that involves. So wasn't much for him to tell me." (-TAVI)

"[Advice for making treatment decisions] Avail yourself of everything, whether your surgeon likes a support group or not, and don't put all your eggs in one basket, find a surgeon you trust, listen to people who've been through it because that was really big for me to talk to people who'd been through it." (-SAVR)

Experiences living with AS. Medically managed participants reported making more lifestyle modifications to manage AS symptoms, including chronic anxiety and fatigue. Subsequently, medically managed patients were more likely to report negative feelings and attitudes including exhaustion, anxiety about the future, and depression. In contrast, participants who underwent TAVI or SAVR described feelings of gratitude, optimism, and freedom to live life normally following the procedure. Most patients had positive feelings and better psychological impacts after having valve replacement. An infographic characterizing the personal feelings expressed by patients living with AS are described in **Figure 1**.

"Well, I wish I didn't have it obviously. It's something that, I mean, everybody in their life, this is the way I look at. Everyone has some kind of challenge during the course of their life, whether it be mental or physical or sometimes, unfortunately both, but by nature, I'm a pretty optimistic person. I think positive. I think positive thinking really helps. To answer your question, yeah. It could be depressing of course and it's always on my mind, so I wish it wasn't, but I try not to think about it. Of course, I have to because that's how I stick to stick to... How I stay on course, because if the alternative, if I don't do what I'm supposed to, then I won't be here for my family. That's what keeps me going and keeps me positive." (-MM)

"I think when you first get your diagnosis, it's scary. It's not like they're telling you have cancer, which is even scarier to me, but when you don't know you have the condition and you get that diagnosis, it is kind of unnerving and upsetting, especially if you don't know that much about it." (-MM)

"I'm a real positive person, so I just feel like I'm lucky that I had something that they could fix. They fixed it, and when this becomes more calcified or whatever, then maybe then can put another valve on the inside. I have to think positively, because there's no reason to be "doom and gloom." (-SAVR)

Influence of AS on daily life and required

adaptations. Receiving a diagnosis of AS was a surprise to some participants as they associated heart disease with

unhealthy personal behaviors. While most participants described making no changes to their life following a diagnosis, some participants developed increased stress and anxiety about their future and made changes to their everyday lives. Participants indicated they made changes to self-manage or avert the progressive symptoms they were experiencing. Participants reported reducing their physical exertion, including quitting sports, taking shorter walks and hikes, and increasing their breaks while exercising. They also reported a desire to reduce stressful situations due to anxiety about their symptoms and made more time for rest, hired an assistant at work, or cancelled future travel plans. The majority of valve replacement participants in the TAVI and SAVR cohorts reported no residual symptoms of AS following their valve replacement after sufficient recovery time.

"My body says, stop, take a rest. So I listen to it now. But before surgery, [I would] keep going." (-TAVI)

"I wasn't *paddle* boarding as much at all. In fact, I stopped riding my bike. I just couldn't get the oomph to get up and do walks. I'm still a very energetic person. That's just my personality. I run up and down stairs, but just was slower. I just felt tired and I just didn't do as much." (-SAVR)

"[Any changes to your life after surgery?] No. I would say it's better. You know, I have more energy, for sure. I feel like the bionic woman, right?" (-SAVR)

Discussion

Due to the varied experiences of patients in the diagnosis, treatment, and control of AS, there is a need to improve patient resources and increase awareness to advance patient understanding and facilitate informed treatment decisions. Reported patient experiences also indicate a need for additional HCP education on early referral to a multidisciplinary heart valve team.

Our study provides several important insights. Awareness of AS, including the causes, symptoms, disease trajectory, and treatment options, was low among patients. Although many patients were diagnosed prior to symptom development due to auscultation of a heart murmur, those patients with symptoms that prompted evaluation, particularly those with indolent onset, often had delays in diagnosis of AS. Patients also reported surprise that they were at risk for AS, as they associated heart disease with unhealthy behaviors. Given the vague symptoms that patients with AS exhibit (e.g., fatigue, exercise intolerance), patient-facing public health campaigns aimed at increasing awareness of symptoms of AS and when to seek medical care should probably not be the only focus. However, once diagnosed, there may be opportunities to better educate patients about how the disease will progress and potential treatment options.

Medically managed patients reported more negative feelings and attitudes about having aortic stenosis compared to TAVR and SAVR patients. normally. (SAVR) Most patients had positive feelings and outlooks after valve replacement. (SAVR) Challenging (MM), mentally challenging (MM) Just living my life. (TAVR) Scary (MM) A bit concerned over the life of the valve. (TAVR) Feel depressed sometimes (MM) (SAVR) Feel like aortic stenosis is controlling my life at times. (MM) stenosis. (SAVR) Can't do what I want to do. (MM) Draining (SAVR) Don't feel fixed. (SAVR)

One more thing to worry about. (MM)

Negative

- Now I know why I'm out of breath and I don't press myself. (MM)
- I don't think about it at all. I'm living
- Feels like it never happened. (SAVR)
- Aware but don't worry about it. (SAVR)
- I actually forget I have a different valve.
- I try to be positive. (MM)
- Now I don't sweat the small stuff.
- I don't consider myself as having aortic
- Appreciation that valve replacement was so easy. (TAVR)
- Grateful (TAVR) and lucky (SAVR) it was found and fixed.

Figure 1. Negative and positive descriptions of how it feels to live with aortic stenosis provided by adults 40+ years.

Implications for practice

Patients noted a strong reliance on HCPs in treatment decisions as opposed to a model of shared decision making. Within this structure, patients identified the need for HCPs to have additional training and education on explaining the diagnosis, disease trajectory, and treatment options, including visual aids, and paper pamphlets or other reading materials to take home and read later, in addition to encouraging patients to do their own research and return with additional questions. Furthermore, even when patients felt that HCPs provided clear information, there appeared to be a desire for more peer-to-peer education. Similar patient- and caregiver-support groups in conditions such as spontaneous coronary artery dissection and cancer have been greatly valued by patients with new diagnoses with public knowledge gaps. More education through multiple mechanisms (e.g., peer support groups, educational materials from professional groups and HCPs) and a willingness for HCPs to engage in more open communication could enable patients to participate in true shared decision making more fully.

This study also highlights several important issues surrounding diagnosis, management, and treatment of AS, as well as the patient's perception of their condition. There remains an important lack of recognition of the disorder as well as a lack of an understanding of natural history of the disorder amongst some HCPs. This is completely understandable in the modern era of medicine, as the average clinician must have knowledge in a multitude of areas in medicine. While AS is a common condition, there are many nuances to the management of the disease that may not be evident to HCPs who are not routinely caring for patients with valvular heart disease. This may result in delays in diagnosis or a sense of concern by patients when faced with the diagnosis, especially if the condition is untreated and the reasons for not pursing treatment are not clear to the patient. Additionally, the indications for treatment, recommendations for the timing of treatment, and available modalities of treatment are in rapid evolution, making it difficult for even cardiovascular specialists to remain current in the management of AS.

Therefore, it is critical to consider early referral to valve centers of excellence for a formal multidisciplinary heart team evaluation for all patients with valvular heart disease, regardless of the severity of the valve disease or the presence of symptoms. Such centers of excellence can provide a formal multidisciplinary heart team evaluation where patients can be evaluated by cardiovascular specialists with expertise in valvular heart disease, including interventional cardiologists, cardiac surgeons, cardiac imagers, cardiac anesthesiology, cardiovascular nursing, and cardiac critical care. The multidisciplinary heart team can determine the severity of the disease, whether treatment is warranted, and provide a recommendation for the optimal treatment strategy. It is important that this multidisciplinary heart team can also provide routine surveillance for patients who do not yet require intervention as well as vital education for these patients regarding the natural history of the disorder. Powered with a greater understanding of their disease by experts in the management of AS, medically treated patients may have a greater degree of confidence and

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security regarding the diagnosis and may have a more positive outlook on their condition having been educated on their present state and knowing that they will be followed closely. Referral to the multidisciplinary heart team should not only be limited to patients who are clearly in need of a procedure but to all patients with AS, as many patients with lesser degrees of AS may be candidates for clinical trials that may provide more valuable information regarding optimal timing of treatment.

Limitations

There are several potential limitations to our study that merit further discussion. First, patients included in our study were more educated and likely more engaged and informed than a general population of patients with AS. It is possible the drive for more information and education evident in our study would not generalize to all patients with AS nor would the desire for shared decision making. Second, our study cohort did not include a broad spectrum of patients of different races, ethnicities or socioeconomic status. Patients were recruited from national patient networks and through professional recruiters from a database of patients diagnosed with AS, which are inherently less diverse as underrepresented racial and ethnic groups (UREGs) have a lower prevalence of AS relative to White participants. Even so, there remains a gap in the research on the experiences of UREGs with AS and more research is needed to understand their experiences with diagnosis and treatment (Wilson et al., 2020; Czarny, et al., 2021). Finally, while the focus of this study was the patient experience with diagnosis and treatment of AS, all data were self-reported, thus details such as time to diagnosis and symptoms of AS may not be accurate, particularly in the MM group which likely included patients with mild forms of AS.

Conclusions

These findings indicate that middle-aged and elderly patients with AS have varied experiences with AS symptom presentation, diagnosis, treatment, treatment decisions, feelings about AS, and lifestyle modifications. The results suggest a need for increased education on AS disease progression and treatment options for patients, especially after diagnosis, whether through HCPs or peerto-peer channels. The negative patient experiences due to delayed diagnoses or lack of information surrounding treatment decisions indicate the importance of professional education on the early referral of patients to a multidisciplinary heart valve team.

The data underlying this article will be shared on reasonable request to the corresponding author.

Authors' contributions: K. Picou and D. Heard developed the qualitative interview guide, conducted the interviews, and performed the analyses. K. Picou wrote the initial draft of the manuscript. P. Shah and S. Arnold provided medical expertise and insights and drafted the discussion. All authors developed the research project and revised the manuscript for final submission.

Competing interests: K. Picou and D. Heard are employed by the American Heart Association. P. Shah is a proctor/consultant for Edwards Lifesciences, and has received educational grants from Edwards Lifesciences, Medtronic, and Abbott. The remaining authors report no conflicts of interest.

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