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SUMMARY WITH CRITICAL APPRAISAL

Experiences and Perspectives of Treatments for Heart Valve Disease: A Rapid Qualitative Review

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Abbreviations

AS	aortic stenosis
SAVR	surgical aortic valve replacement
TAVI	transcatheter aortic valve implantation

Context and Policy Issues

Heart valve disease happens when any of the heart's valves either cannot open well enough to let blood flow through (stenosis) or cannot close well enough to prevent backflow of the blood (regurgitation). Heart valve disease can affect any of the four heart valves in different ways, including a combination of stenosis and regurgitation.¹ It can be degenerative due to “wear and tear” on the valve or be functional due to the internal structure of the valve. People with heart valve disease, particularly aortic and mitral valve disease, can experience heart failure symptoms including chest pain, shortness of breath, and fatigue as the heart works harder to pump blood through the body.¹ Untreated, this condition can lead to heart failure and the inability to perform activities of daily life.

Multiple surgical procedures for valve replacement or repair exist. Open heart procedures have traditionally been the gold standard of care for heart valve disease.² However for patients who are at high risk of complications or death due to open heart surgery, minimally invasive techniques are an emerging alternative option.³ For example, MitraClip is an emerging health technology that enables the repair of the mitral valve. It is placed in the heart via a catheter inserted in the femoral artery, and holds segments of the valve together to reduce regurgitation.⁴ Similarly, transcatheter aortic valve implantation (TAVI) is an established procedure for those at high surgical risk.⁵

Minimally invasive procedures tend to be delivered in specialist cardiac centres. Patients who undergo minimally invasive procedures tend to have shorter hospital stays than those who undergo open heart surgery.¹ As minimally invasive procedures, using technologies such as MitraClip, become more common there is a need to understand how people with heart valve disease navigate and experience treatment of their condition.

The purpose of this report is to describe how people with heart valve disease and those who treat them understand and experience treatment and care, including open and minimally invasive surgical techniques.

Research Questions

Two sets of research questions guided this review:

- How do people with heart valve disease understand and experience treatment options (open or minimally invasive surgical procedures and/or medical management) for their condition? What are their perspectives on and expectations of treatment? What are their experiences of accessing, receiving, and recovering from treatment for their heart valve disease?
- How do health care providers who care for people with heart valve disease understand and experience treatment options? What are their perspectives on and expectations of communicating and supporting decision making around treatment options for heart valve disease?

Key Findings

People with heart valve disease struggled with breathlessness, fatigue and pain that limited their ability to live independent and full lives, and left some feeling depressed, lonely and worthless. They saw surgery (either minimally invasive or open heart) as offering hope to live longer and fuller lives. The burden of their symptoms and the trust they placed in their doctors and the procedure were key factors in deciding whether to undergo heart valve surgery, whether either minimally invasive or open heart. Some viewed minimally invasive procedures specifically as being preventative, or pre-empting future health problems, while heart valve surgery in general was seen as potentially opening the door to other treatment options for other health problems or comorbidities.

People who were not eligible for minimally invasive surgery felt they were left managing their heart failure symptoms as best as they could, but confronted the inevitable worsening of their symptoms and death. Others decided against minimally invasive surgery, for example due to comorbidities or religious beliefs. Some who decided against the procedure did so because they felt coping with heart failure symptoms was better than living longer with their comorbidities or the potential complications of surgery.

Waiting for surgery was hard, involving fear over a potentially worsening condition and requiring coping skills and support. People with heart valve disease had to deal with travel and logistical challenges, including out of pocket expenses, while being assessed and undergoing minimally invasive surgery.

People undergoing heart valve surgery expressed appreciating being offered minimally invasive surgery because of the anticipated shorter recovery time. People's recovery after heart valve surgery varied, however. For some who underwent minimally invasive procedures, it was an immediate and dramatic change; for others, it was a slower struggle to return to "normal". Family caregivers were seen by people who had heart valve surgery as playing a vital role in their recovery. Those who noticed an improvement in their symptoms following surgery reported appreciating a return of their breathing the most, describing once again being able to walk and engage in activities they had missed, leading to increased independence.

One study was identified that described health care providers' perspectives on heart valve surgery (i.e., TAVI). Cardiologists and cardiac surgeons expressed that they appreciated the short recovery time of minimally invasive procedures, but described their uncertainty around using the procedure in younger patients because of the lack of long-term data on valve durability. They described TAVI as a highly complex procedure with a steep learning curve, needing a dedicated heart team as a key success factor for implementation in a hospital.

Methods

Literature Search Methods

A limited literature search was conducted by an information specialist on key resources including Ovid MEDLINE/PsycInfo and SCOPUS. The search strategy was comprised of both controlled vocabulary, such as the National Library of Medicine's MeSH (Medical Subject Headings), and keywords. An initial search returned zero qualitative studies on mitral valve disease. As a result, the main search concept was expanded to valvular heart disease. Search filters were applied to limit retrieval to qualitative studies. The search was

also limited to English language documents published between January 1, 2008 and May 7, 2020.

Selection Criteria and Methods

One reviewer screened citations and selected studies. In the first level of screening, titles and abstracts were reviewed and the full-text of potentially relevant articles were retrieved and assessed for inclusion. The reference lists of included articles were hand searched to identify any further potentially eligible citations, and for these the full-text were also retrieved. The final selection of full-text articles was based on the inclusion criteria presented in Table 1. The final included literature included studies on both aortic and mitral valve heart disease because of the similarities between the conditions, specifically for heart failure symptoms (e.g., breathlessness and fatigue), the range of surgical options (i.e., minimally invasive and open surgeries for the replacement or repair of valves) available, and decision-making considerations such as surgical risk from a patient's perspective.

Table 1: Inclusion Criteria using SPIDER⁶

Sample	Adults being treated for aortic or mitral heart valve disease Clinicians who treat adults with aortic or mitral heart valve disease
Phenomena of Interest	Treatment options for aortic or mitral heart valve disease: including open or minimally invasive surgical procedures and medical management
Design	Any qualitative design that uses qualitative data collection and analysis methods; mixed method designs that have a qualitative component that uses qualitative data collection and analysis methods
Evaluation	Perspectives on and experiences with: <ul style="list-style-type: none"> • treatment options for aortic or mitral heart valve disease • treatment expectations • treatment decision-making • accessing and receiving treatment • recovering and impact of treatment on the lives of people with the condition
Research Type	Qualitative studies; qualitative component of mixed method studies

Exclusion Criteria

Articles were excluded if they did not meet the inclusion criteria outlined in Table 1, were duplicate publications reporting on the exact same data and the same findings or were published prior to 2008.

Critical Appraisal of Individual Studies

One reviewer assessed the quality of the included publications guided by the ten items from the Critical Appraisal Skills Programme (CASP) Qualitative Checklist.⁷ Results of the critical appraisal were not used to exclude studies from this review; rather they were used to understand the methodological and conceptual limitations of the included publications in specific relation the purpose of this review. The critical appraisal contributed to the analysis by identifying the limits of transferability of the results of included studies to this review in terms of differences in setting, study populations and interventions.

Data Analysis

A framework analysis was used to organize and analyze results of the included studies.³ The a priori framework consisted of orienting concepts identified through project scoping, which included reading background materials on surgical (open and minimally invasive) options for heart valve replacement and repair. The initial framework included concepts related to the pathway of the condition and accessing the procedure, from experiencing symptoms to being potentially eligible for surgical treatment, to undergoing treatment and to recovery.

One reviewer conducted the analysis. Included primary study reports were read and re-read to identify key findings and concepts that mapped on the framework, which was modified as new and relevant concepts emerged. During the reading and re-reading of study reports, memos were made, noting details and observations about the study's methodology, findings, and interpretations, and connections to other studies and concepts in the framework. Diagramming was used to explore how emerging concepts mapped across study findings and across concepts. Using these techniques, concepts were re-ordered and organized into thematic categories. Re-reading, memoing and diagramming continued until themes were appropriately described and supported by data from the included publications. During the analysis, issues with transferability and the results of the critical appraisal were reflected on to aid with interpretation. The objective of the analysis was to describe the perspectives and experiences of people with heart valve disease and the clinicians who care for them on deciding on, undergoing, and recovering from treatment for heart valve disease.

Summary of Evidence

Quantity of Research Available

A total of 679 citations were identified in the literature search. Following screening of titles and abstracts, 656 citations were excluded and 23 potentially relevant reports from the electronic search were retrieved for full-text review. One additional potentially relevant publication was identified through hand searching reference lists of potentially included studies and was retrieved for full text review. Of these 24 potentially relevant articles, nine publications were excluded because the focus was an irrelevant population or intervention, and one was excluded because it was not reporting on qualitative research. Fourteen publications, representing 13 unique studies, met the inclusion criteria and were included in this report. Two publications used the same interview data but reported on different findings.^{8,9} Appendix 1 presents the PRISMA¹⁰ flowchart of the study selection process.

Summary of Study Characteristics

Details regarding the characteristics of included publications and their participants are provided in Appendix 2 and Appendix 3.

Study Design and Data Collection

Authors of six publications did not report the study design used.^{8,9,11-14} The study design reported in three publications was described as qualitative description,¹⁵⁻¹⁷ and three as phenomenology.¹⁸⁻²⁰ One publication reported a mixed methods study design,²¹ and another was reported as a grounded theory study.²² Twelve studies reported in 13 publications collected data using semi-structured interviews,^{8,9,11-13,15-22} and one study used

focus groups.¹⁴ In one study reported in two publications, participants were interviewed prior their eligibility assessment for TAVI,^{8,9} two while participants were waiting for TAVI,^{12,15} and one after participants were told they were ineligible for TAVI.¹⁶ In eight studies data were collected from participants after they had undergone heart valve surgery,^{11,14,17-22} and in one study data were collected from health care providers who had experience with TAVI.¹³

Country of Origin

Four of the 13 included studies, reported in five publications, were conducted in Sweden.^{8,9,16,18,22} Two studies each were conducted in Denmark^{19,20} and Canada,^{15,17} and one each in the United Kingdom,²¹ United States,¹² Germany,¹³ Norway,¹¹ and Australia.¹⁴

Study Population and Interventions

Eleven studies reported in 12 publications included people who were older adults with aortic stenosis.^{8,9,11,12,15-22} One study included patients and their family caregivers,¹⁷ and one study included physicians who had experience with TAVI.¹³ One publication did not report a description of the participants' health condition or severity.¹⁴ Over half of the participants in six studies, reported in seven publications, were assessed as being level III or higher on the New York Heart Association Functional Classification, meaning that they experienced symptoms of breathlessness with any activity.^{8,9,15-17,21,22} In two studies, over half the participants experienced level II or higher symptoms, meaning that they experienced mild symptoms with physical activity.^{11,19} Two studies described participants as having severe aortic stenosis,^{12,18} and two studies did not state the severity of participants' symptoms or condition.^{14,20}

Eight studies reported in nine publications included participants who were eligible for or were to undergo TAVI,^{8,9,11,12,15,17,19,21,22} and three studies included people who had undergone either open or minimally invasive valve surgery.^{14,18,20} One study included people who were only eligible for medical management,^{15,16} one included people who were referred for assessment of their eligibility for TAVI,¹⁵ and one study included patients who chose medical management.¹² One further study included physicians who had at least one year of experience with TAVI.¹³

Summary of Critical Appraisal

Overall the included studies were assessed to be of high quality. A high level summary of the results of the critical appraisal can be found in Appendix 4.

The key methodological issue affecting the assessment of quality of the included studies was whether the analysis was sufficiently rigorous. Four studies were judged to have issues that affected this assessment.^{12,14,20,21} This was because there were limited data presented that supported the findings, the findings were not richly described, and some interconnections between data and themes were judged as not being adequately explored.

Transferability of the included studies was judged to be high, as all addressed the treatment experiences of people with heart valve disease in high income countries. One study focused narrowly on the experience of delirium post-surgery in elderly patients,¹⁸ which limited its relevance to the questions guiding this review.

Summary of Findings

People with heart valve disease struggled with breathlessness, fatigue and pain that limited their ability to live independent and full lives. They saw surgical treatment (either minimally invasive or open surgery) as offering hope to live longer and fuller lives

People who experienced heart failure symptoms as a result of their valve disease described living in a “shrunk world.”^{15,21} The experience of heart failure symptoms – primarily breathlessness, fatigue, and pain – affected all aspects of their lives: their sleep, their memory, and their ability to socialize and live independently.^{8,9,15,21} People reported feeling lonely and lacking a source of pleasure in their life, being unable to engage in the daily activities that once gave them joy and pleasure.^{12,15,21}

With the inability to be active, that is to physically move without experiencing breathlessness, people with heart valve disease described that they felt they had become increasingly dependent upon others.^{8,11,15,21} They relied upon their spouses or domestic partners, and their family and friends, for help with cleaning, food preparation, and errands including transportation.^{9,15,21} Their emotional connection to family was described as deepening with their increased need for help,²¹ but so did changes in social roles.^{9,15,21} For instance, the demands of caregiving shifted peoples’ relationships from being a spouse to being someone cared for by, and dependent upon, the other.^{15,21} One male participant described how this affected him: “I get disgusted with myself because I can’t do anything. I’m a guy that used to do everything, everything.”¹⁵ This reveals how heart valve disease and the symptoms of heart failure can impact peoples’ sense of self and self-esteem.⁹

The toll of breathlessness and fatigue on the lives of people with heart valve disease left some describing they felt depressed, lonely, and worthless.^{9,15,21} For some, a life with extreme breathlessness was a life not worth living.^{15,21} As one participant put it, “some days I wished it was all over, I really did, because it was so painful to breathe and well, your life isn’t the same, you can’t get out, can’t go shopping you see on my own, or anything.”²¹

It was in this backdrop of a limited life – both in terms of perceived duration and quality – that people with severe heart failure symptoms framed the surgical option presented to them (whether minimally invasive or open) as being the only treatment option that would address their symptoms and enable them to continue to live.^{11,14,15,21,22} “If I would have turned it [TAVI assessment] down, I mean, who knows how long I would last? Not much longer, probably, you know.” (p. 489)¹⁵

Many articulated that they were confronting their mortality and the possibility of death, and they placed hope in surgery to extend their life: ^{12,14,15,21} “I didn’t have any expectations.... except to live another year.”¹⁴ But, having a longer life alone was not seen as sufficient for some. With the return of their breath, people hoped that post-surgery they would once again be able to be active and independent.^{12,14,15,21} One participant described how she wanted “to be able to garden, walk, do household chores... I want to live in my home independently.”¹² People often pointed to specific activities, like gardening and walking, that they hoped to be able to do as they did before their symptoms of heart failure prevented them. ^{8,12,14-16,21} These activities were described as integral to experiencing a full and meaningful life. Having a quality of life that involved being active, social and independent was often at the heart of people’s hopes for treatment, as articulated by someone as: “Well quality for me is that I can, I’m living in my own home as long as I’m suited for that, I have

friends, I have interests, I'm interested in what's going on in the world, good family about me... that's what I want..."¹⁴

Peoples' decision to undergo surgery (either minimally invasive or open) for their heart valve disease was driven by the burden of their symptoms and the trust they placed in their doctors and the procedure

People with heart valve disease weighed the risk of the surgery against the burden of their symptoms and their ability to live a full and long life.^{11,12,14,15} For some, the decision was almost a non-decision, in that not choosing surgery was seen as choosing a decline in their ability to live a longer and more active life: "It was not difficult at all to decide. I reckoned that if I said no, I wouldn't live much longer."¹¹ This links back to the ways in which people with heart valve disease describe surgery as the only treatment option that offers hope for alleviating their heart failure symptoms. Some described that they did not recall having a choice presented to them.^{14,15,21}

People described weighing the risks against the benefits of surgery, returning to worries about how their heart failure symptoms affected their lives.^{8,14,15} For instance, one participant described how when she brought her symptoms in view, it changed her thoughts on the importance of surgery, in this case TAVI:

But I am in full swing doing things, so because of that I wonder if it's worth the risk to take a chance. I don't know the outcome of the operation, but it is a difficult operation, so sometimes you feel that perhaps you should leave off the whole thing and try to go on living, but when it hurts the most, you realize that perhaps this isn't so funny.⁸

Similarly, people described that the risk of dying during surgery (either minimally invasive or open) was worth the potential benefit of improved symptoms:^{11,14} "...there is always the possibility of being left paralysed or brain dead or vegetabilised... and no one wants that... it was better to risk living or dying with the operation and having an improved quality of life."¹⁴ Some found the information provided during the initial consultation on treatment options made them anxious, and felt like there was "too much information" and too great an emphasis on the risk.^{11,15}

Those who had already experienced heart surgery reflected on their past experiences and the health benefits they experienced afterwards when deciding to undergo heart valve surgery.^{15,16,22} The experiences of family and friends who had undergone heart surgery were also used to inform their decision in terms of risk and benefits of a particular procedure.^{8,15} People with heart valve disease often referred to the ways in which their family and friends were an important source of information and support during treatment decision-making.^{8,11,15}

Some saw the surgery, specifically minimally invasive procedures, as being preventative or pre-empting future health problems.^{11,15} One participant described how their decision to undergo TAVI was primarily to avoid further problems: "...although they told me that being only 50% blocked, my aortic valve, it can take two years before it fully blocks. But why wait two years, you know, when you can have something to prevent it, something new stuck in there?"¹⁵ Older adults, in particular, worried about regretting a choice to decline surgery should their condition worsen and they no longer be eligible for minimally invasive surgery.¹¹ In some instances, participants described how , for example, hip replacement surgery.^{12,21}

By and large, people with heart valve disease described how their trust in their doctor and their doctor's treatment recommendations influenced their decision to undergo surgery, whether minimally invasive or open.^{11,14,15} Some put it simply as "I go by what the doctors tell me."¹⁵ Others pointed to the way their doctor had consulted them, taking the time to provide information and make a decision.^{11,15}

People who were not eligible for minimally invasive surgery felt they were left managing their heart failure symptoms as best as they could but confronted the inevitable worsening of their symptoms and death

Where surgical intervention offered hope to those eligible for it, people who were ineligible for any form of heart valve surgery were left feeling hopeless.^{15,16} Some described being under surveillance for many years for their heart conditions, and did not understand how they did not have the opportunity to have heart valve surgery and felt missed:¹⁶

I've been on check-ups for 10-years, but there has never been any talk of surgery and that's what I'm wondering about, because I cannot be the one who knows. Yes, there should have been a doctor earlier saying: now we are going to operate before it gets to be too late.¹⁶

Non-surgical medical treatment was viewed as accepting the inevitable decline of their condition.^{14,16,21} As one participant put it: "[t]here's no doctor who can help me, so I have to manage by myself."¹⁶ While people with heart valve disease who lacked minimally invasive surgical options felt despair, others put their energy and focus into maintaining as best as they could, and found hope in their ability to relieve their symptoms in daily life.¹⁶

People who decided against minimally invasive surgery did so because they felt coping with heart failure symptoms was better than living longer with their comorbidities or the potential complications of surgery

Some decided against surgical treatment and opted for medical management due to comorbidities or religious beliefs.¹² One person described how, as someone who had Parkinson's disease, he did not want to extend his life through TAVI: "I would rather die quickly of heart failure... Knowing what my options are with Parkinson's, I don't want to face a prolonged, debilitated life."¹²

Others chose to avoid minimally invasive surgery (in this study, TAVI) and potential complications such as stroke, dialysis or ventilation, which could have drastically affected their remaining quality of life. Avoiding the risk of complications was seen as allowing a focus on end-of-life planning, put by one participant as: "I want to go home and get my affairs in order. I don't want anything else."¹²

Waiting for surgery was hard, and people with heart valve disease had to deal with travel and logistical challenges while being assessed and undergoing minimally invasive surgery

People with heart valve disease described waiting for surgery as a trying time, where they were trying to manage and cope as best as they could.^{9,21} They worried about their condition deteriorating to the point that they would no longer be eligible for minimally invasive surgery,⁹ and felt "scared, lonely and short-tempered."²¹

Those who lived away from specialized treatment centres, which offered surgical treatment, described the inconvenience of travel for assessment and surgery.^{15,17} One participant said:

We get by, but that's about it. So it's a little bit of a bind having to arrange things to get down from [home town] of course. And the second visit, we'll have to overnight the night before because the appointments are early in the morning. But it's part of the price you pay for living up here.¹⁵

Travel required out-of-pocket expenses, such as for gas or transit fare and accommodation, for themselves and their spouse or adult children. Other logistics, including coordinating their travel with their caregiver were a challenge: "I've gotta depend on my daughter. She's retired, but she's busier than a three-armed paper hanger."¹⁵

People undergoing heart valve surgery expressed appreciating being offered minimally invasive surgery because of the anticipated shorter recovery time

Many of the participants were already experienced heart surgery patients and had previously had open heart surgeries, in some cases multiple. They compared their prior experience with open heart surgery to their upcoming minimally invasive surgery, and hoped that they would have a shorter recovery time undergoing minimally invasive surgery.^{15,22}

It's [TAVI] easy by comparison to an open heart surgery. That is just a big plus. Can you imagine having your chest cut right open and taking months to recover? I've had about six surgeries in the last six, seven years, and I'm still recovering from pretty much all of them.¹⁵

Additionally, some participants pointed to their familial obligations as a reason why a shorter recovery time would be a benefit to them.¹⁵

While it was not raised as a concern related to decision making on treatment for heart valve surgery, people who had undergone open heart surgery did raise their experience adjusting to the scars. Some described trying to cover it up, and were worried about how others, particularly sexual partners, would view it.²⁰ Others grew to accept their scar and watched as it faded over time.²⁰

People's recovery after heart valve surgery varied. For some who underwent minimally invasive procedures, it was an immediate and dramatic change; for others, it was a slower struggle to return to "normal"

Some participants described undergoing and recovering from TAVI as surprisingly easy and fast.^{17,19,21,22} These accounts included how people with heart valve disease noted an immediate improvement in their breathing and their energy levels after surgery:^{17,19,21,22} "[TAVI] made all the difference in the world. I mean, I didn't realize it but everybody said I looked grey. My colour was terrible, I had no energy, I could hardly move. And then as soon as I had the operation, I felt great."¹⁷ Some people who had minimally invasive surgery noted that they experienced unexpected pain at the incision site.¹⁷

Those who noticed an improvement in their heart failure symptoms following surgery (either (minimally invasive or open) reported that the thing they appreciated the most about having surgery was how their breathing had improved.^{17,20,21,17} They described finding themselves once again as able to walk and engage in activities they had missed: as one participant put it: "Well I do exactly what I used to do ten years ago. You know I do my garden, go shopping, go the gym, you know."²¹ Many reported feeling hopeful for the future and the sense of having a longer life ahead:^{17,19-22}

I remember that last year, when I took out the Christmas candle holders, I thought it was for the last time. Now, when we took them out again last week, I thought: my God, I believe I can use these several more years. I can't be sure but I imagine that I have some years left.²²

People found with improved breathing and increased ability to be active, they become more independent and their relationships with others upon whom they were dependent changed.²¹

Not all experienced this rapid improvement in symptoms. Complications after minimally invasive surgery that led to longer recovery time conflicted with people's expectation of a fast recovery.^{17,22} Those who had open heart surgery described how the surgery physically affected them, including their sleep and pain.²⁰

For those who experienced a slower recovery, they described that they continued to feel weak, isolated and dependent.^{17,20} Some people who had heart valve surgery held out hope for eventual improvement, and described that they felt relief that something had been done for their heart valve condition.^{19,21,22} Others reported they struggled with feelings of disappointment when they did not experience the improvement in breathing they had hoped for:^{16,17,20} "I just feel worn right out, like, I sleep a lot. I have no strength, I'm always feeling like I'm not living. [After TAVI] I expected to be more alive, be able to move faster, to be able to do a little bit more than I do."¹⁷ When people had worse symptoms after TAVI, they expressed regrets about undergoing surgery.²²

After heart valve surgery, people described that they paid greater awareness to their bodily sensations. This attention led some to feel confident and safe in their body, and to worry less about potential complications and symptoms affording them peace of mind.^{17,19,21} For others, the awareness of their body and sensations led them to feel anxious about further complications and symptoms.²⁰

People with heart valve disease often experienced recovery in the context of aging and other health conditions

People experienced the change in their heart failure symptoms post-surgery in the context of aging and comorbidities.^{17,19,22} Where they felt improvements, it sometimes drew attention to their other health condition and the impact they had on their lives.^{17,19,21} For instance, one woman described how she still was dependent upon her daughter, because of her other health conditions: "My daughter follows me everywhere. I cannot drive anymore because I have poor vision and hearing and I have diabetes."²²

As these other conditions gained prominence in people's life, they affected how they viewed the outcome of their heart valve surgery.^{17,21} As one participant put it: "I have severe rheumatoid arthritis and if you remember my medications, I'm actually on 100 milligrams of morphine twice a day. So if you want to know if I'm satisfied with that, no, I'm not."¹⁷ This points to the ways in which the impact of heart valve surgery on people's health and their quality of life is, perhaps unexpectedly, constrained by their health as a whole.

Family caregivers were seen by people who had heart valve surgery as playing a vital role in their recovery

People who underwent heart valve surgery described how their family caregivers were critical in enabling their recovery.^{17,20,21} One participant put it bluntly: "I would say every patient should certainly have someone look after them for a good three weeks."¹⁷

Some who underwent minimally invasive heart surgery described they were not prepared for the early discharge, and relied on family to help them return home.¹⁷ One participant described their experience as:

The next morning I woke up about 6:30 and at 7:00 the doctor came in and says, 'Oh, you can go home.' And I said, 'What?' He said 'We can't do any more for you, everything went fine. Do you want to go home?' And I said, 'Well, I'd like to but I didn't make any arrangements to get picked up or anything.'¹⁷

Caregivers' knowledge about and ability to identify potential complications gave people a sense of security as they recovered.¹⁷ Others talked about how they perceived their family caregivers as invaluable: "If it wasn't for my husband it would not have gone so well."²⁰ This included a need for mental health support, where people could process the experience of heart valve replacement.²⁰ As one participant put it, "I bothered my friends with it, so I got a kind of processing, psychologically."²⁰

Physicians' perspectives on minimally invasive surgery for heart valve disease

One study was retrieved that explored physicians' experiences with and views on heart valve surgery. This study explored cardiologists' and one cardiac surgeon's views on TAVI to describe the diffusion of the procedure across hospitals in Germany.¹³ Physicians expressed that they saw TAVI as having an advantage over SAVR, in particular due to the quick recovery period:

But it is an intervention in which the patient is basically walking around the next day. And with heart surgery that is, of course, very, very different. That's it, especially for older persons... And I think the 80-year-old patient must quickly get out of the hospital and back into his environment and considering this, such a method has, of course, a huge advantage.¹³

Given uncertainty around the duration of implanted valves, physicians in this study worried about the use of TAVI in patients under than 75 years of age.

Physicians described TAVI as a highly complex procedure with a steep learning curve, needing a dedicated heart team.¹³ Adopting TAVI within hospitals was seen as challenging because it caused a renegotiation of the roles of interventional cardiologists and cardiac surgeons. The negotiation of these relationships and roles was described as being key to successfully implementing TAVI in a hospital.

Limitations

The limitations of this review stem from the transferability of the review findings in terms of the range of treatments and populations captured in the included studies. While the individual included studies were judged to be highly transferable, taken together they did not capture all aspects of the population and interventions of interest to the review question. For example, there was limited specific information on the experiences of those who had undergone open heart valve surgery, mitral valve surgery, or medical management for their heart valve disease. No information was available on those who had the choice of either open or minimally invasive heart valve surgery, and how decisions might be made between each.

The included studies focused on elderly people with aortic stenosis, the majority of whom were experiencing severe heart failure symptoms. As a result, the findings of this review

may not be a comprehensive description of the experiences of people with heart valve disease who have few symptoms or are asymptomatic. Related, younger adults may experience heart valve disease and its treatment differently given their stage in their life course, where experiences around, for example, caregiving for their family (e.g., children, adult parents) and employment may figure more prominently.

One included study explored health care providers' experiences and perspectives on treatments for heart valve disease. This did not allow for a synthesis of health care providers' perspectives, and therefore a more fulsome description of their perspectives remains unexplored.

Within the included studies, there was no analysis or reporting of differences by population, for example, sex and gender, racialized persons, and people living in urban, rural and remote locations. It is possible that experiences in accessing and receiving care for heart valve disease differ by these, or other characteristics, which are not well understood.

Conclusions and Implications for Decision or Policy Making

Using a framework analysis, this review synthesized the findings of 14 included publications describing the perspectives and experiences of people with heart valve disease, and the clinicians who care for them, on deciding on, undergoing, and recovering from treatment for heart valve disease.

People with heart valve disease struggled with breathlessness, pain and fatigue that limited their ability to feel like they were able to live independent and full lives, and left some feeling depressed, lonely and worthless. They saw heart valve surgery, both minimally invasive and open heart, as offering them hope of a longer and fuller life. With this perception, some people with heart valve disease saw medical management as an option that was unlikely to offer any improvement in their heart failure symptoms. Thus, when making treatment decisions, many appear to see surgical options in a positive light and as a form of "active" treatment, as compared to medical management. Based on the findings of this review, minimally invasive heart valve procedures that are suitable for elderly persons and people with comorbidities, who are typically not candidates for open heart surgery, are likely to be viewed as affording new hope. Some people described minimally invasive procedures likewise as being preventative, or helping to pre-empt future health problems.

Some people, however, chose medical management for their heart valve disease, as opposed to surgery, particularly when living with the potential complications of surgery or existing comorbidities, such as Parkinson's disease, was viewed as undesirable. People who made this choice also expressed that it allowed them to make end-of-life preparations and get their personal affairs in order. When people were deemed ineligible for either open or minimally invasive surgery, it left them feeling hopeless and having to cope as best as they could in the face of worsening symptoms and impending death. As such, shared decision-making that involves accounting for individuals' personal situations, including their health status, remains important in the treatment of heart valve disease. Related, when people were faced with making a decision whether to undergo any form of surgery, trust in their physician and their recommendation helped guide their choice.

Once they had decided on heart valve surgery, people found waiting difficult. This was especially true for those who were to undergo minimally invasive valve surgery as they worried about their condition worsening and becoming ineligible for the procedure. As much as is possible, shorter waiting times would likely contribute to reduced anxiety. People

undergoing assessment and surgery typically faced logistical and financial challenges of arranging travel to larger urban centres where specialized facilities were located, and accommodations to account for their stay. Having flexibility in appointment times to minimize the need for overnight stays and opportunities to support out-of-pocket costs would likely enhance the support, and experiences, of people with heart valve disease access treatment.

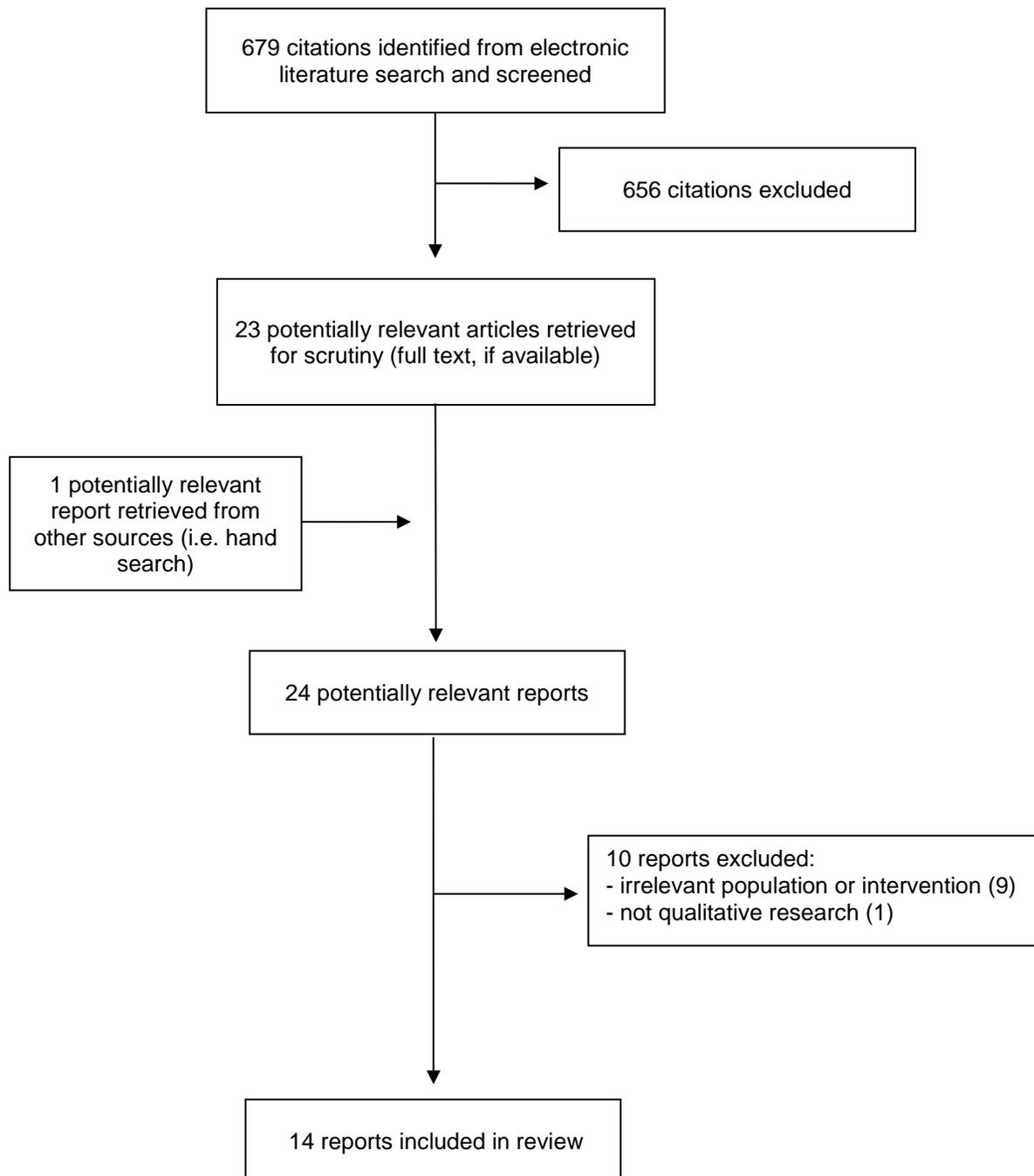
Minimally invasive valve surgery was typically anticipated as leading to a shorter recovery time, and many eligible people with heart valve disease expressed being grateful for this option, particularly where they had already experienced other forms of heart surgery. Physicians expressed a similar appreciation of the short recovery time, but also worried about using the procedure in younger patients because of the lack of long-term data on valve durability.

People's recovery time after heart valve surgery varied. For some who underwent minimally invasive procedures, it was an immediate and dramatic change, while for others it was a slower struggle to return to "normal". For some, the recovery time was even quicker than expected, leaving them unprepared for an early hospital discharge, for example. Given the different pace at which people recover from heart valve surgery, including information on the process of recovery during decision making can help align patients' expectations with their post-surgical experiences. Similarly, ensuring patients have a recovery plan that includes family support at discharge, and during recovery, may be an important facet of discharge planning.

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Appendix 1: Selection of Included Studies



Appendix 2: Characteristics of Included Publications

Table 2: Characteristics of Included Publications

First Author, Publication Year, Country	Study Design	Study Objectives	Sample Size	Inclusion Criteria	Data Collection Strategy
Kirk, 2019, Denmark ¹⁹	Phenomenology	To explore patients' lived experiences of daily life and coping with recovery after TAVI	10 patients	Patients with AS who had been treated with TAVI	Interviews three to four months post-TAVI
Olsson, 2019, Sweden ¹⁶	Qualitative description	To explore patients' experiences of being evaluated and ineligible for TAVI	8 patients	Patients who were assessed for TAVI but were judged to be ineligible	In-depth interviews one to four weeks after being told they were ineligible for TAVI
Baumbusch, 2018, Canada ¹⁷	Qualitative description	To describe older adults' and their family caregivers' perspectives on undergoing TAVI	31 patients 15 caregivers	Patients who underwent TAVI and had attended their one-year follow-up appointment, and their family caregivers	Semi-structured interviews one year after undergoing TAVI
Instenes, 2018, Sweden ¹⁸	Phenomenology	To explore how octogenarian patients experience postoperative delirium after TAVI or SAVR	10 patients	Patients aged 80 and older who had experienced postoperative delirium after undergoing TAVI or SAVR	Semi-structured interviews at six to 12 months post-discharge
Olsson, 2018, Sweden ²²	Grounded theory	To explore how patients experienced the recovery process from TAVI	19 patients	Patients who had undergone TAVI	In-depth interviews at six months post-TAVI
Astin, 2017, UK ²¹	Mixed methods: qualitative ethnographic design	To describe patients' views on how TAVI impacted their quality of life during early recovery	89 patients	Patients who underwent TAVI	In-depth semi-structured interviews at one and three months post-TAVI
Skaar, 2017, Norway ¹¹	NS	To describe older adults' experiences of decision-making around TAVI	10 patients	Patient who underwent TAVI and were ineligible for SAVR	Semi-structured interviews two to four weeks after TAVI
Coylewright, 2016, US ¹²	NS	To elicit and report patient-defined goals from elderly	46 patients	Elderly patients (not defined) with severe AS and	Responses to one open-ended question during clinical

First Author, Publication Year, Country	Study Design	Study Objectives	Sample Size	Inclusion Criteria	Data Collection Strategy
		patient making treatment decisions for severe AS		who were either at high surgical risk or were inoperable and who were assessed for TAVI	evaluation (pre-assessment for TAVI)
Lauck, 2016, Canada ¹⁵	Qualitative description	To explore factors influencing patients' decision-making to undergo eligibility assessment for TAVI	15 patients	Patients who were 75 years old or older and referred for assessment of their eligibility for TAVI	Semi-structured interviews before assessment for eligibility for TAVI
Olsson, 2016, Sweden ^{9*}	NS	To describe patients' experiences of coping with severe AS while waiting for TAVI	24 patients	Patients who were eligible for and awaiting TAVI	Semi-structured interviews prior to TAVI
Olsson, 2016, Sweden ^{8*}	NS	To describe patients' decision making to undergo TAVI	24 patients	Patients who were eligible for and awaiting TAVI	Semi-structured interviews prior to TAVI
Merkel, 2015, Germany ¹³	NS	To describe factors influencing the uptake of TAVI in hospitals in Germany	10 clinicians (9 cardiologists and 1 cardiac surgeon)	Cardiologists and cardiac surgeons working in hospitals and who have at least one year of experience with TAVI	Problem-centered interviews
Oldroyd, 2014, Australia ¹⁴	NS	To describe how octogenarians decided to proceed with cardiac surgery	21 patients	Patients aged 80 or older who had undergone elective cardiac surgery in the past three to 13 months	Focus groups with patients post-surgery
Berg, 2013, Denmark ²⁰	Hermeneutic phenomenology	To describe the experiences of people recovering from heart valve replacement	10 patients	Patients who had undergone either TAVI or open surgical valve replacement in the previous six to nine months	Semi-structured interviews six to nine months post-heart valve replacement

AS = aortic stenosis; NS = not specified; SAVR = surgical aortic valve replacement; TAVI = transcatheter aortic valve implantation

*Olsson 2016⁹ and Olsson 2016⁹ use the same interview data

Appendix 3: Characteristics of Study Participants

Table 3: Characteristics of Study Participants

First Author, Publication Year, Country	Sample Size	Sex (% female)	Age (range in years or average age)	Condition; average severity	Surgery or intervention
Kirk, 2019, Denmark ¹⁹	10 patients	60%	72-87	Aortic stenosis; 50% experienced NYHA level II symptoms	TAVI
Olsson, 2019, Sweden ¹⁶	8 patients	25%	77-93	Aortic stenosis; experienced NYHA level III or IV symptoms	Patients were denied SAVR and TAVI
Baumbusch, 2018, Canada ¹⁷	31 patients 15 caregivers	Patients: 58% Caregivers: 67%	Patients: 58-96 Caregivers: 56-95	Aortic stenosis; median NYHA classification was Level III	TAVI
Instenes, 2018, Sweden ¹⁸	10 patients	50%	81-88	Severe aortic stenosis; NS	40% underwent TAVI, 60% underwent SAVR
Olsson, 2018, Sweden ²²	19 patients	42%	60-90	Aortic stenosis; 42 experienced NYHA level III symptoms, 58% experienced level IV symptoms	TAVI
Astin, 2017, UK ²¹	89 patients	60%	Mean of 82 years	Aortic stenosis; 67.9% experienced NYHA level III symptoms	TAVI
Skaar, 2017, Norway ¹¹	10 patients	60%	70% between 80-89, 30% between 70-79	Aortic stenosis; 70% experienced NYHA level II symptoms	TAVI
Coylewright, 2016, US ¹²	46 patients	63%	Mean of 84 years	Severe aortic stenosis; NS	Assessment for TAVI; 85% underwent TAVI, 15% of patients chose medical therapy/palliative care
Lauck, 2016, Canada ¹⁵	15 patients	40%	75-92	Aortic stenosis; 73.3% experienced NYHA level III symptoms	Assessment for TAVI

First Author, Publication Year, Country	Sample Size	Sex (% female)	Age (range in years or average age)	Condition; average severity	Surgery or intervention
Olsson, 2016, Sweden ^{8,9*}	24 patients	37%	Mean of 81 years	Aortic stenosis; 46% experienced level III NYHA symptoms, 54% experienced level IV symptoms	Awaiting TAVI
Merkel, 2015, Germany ¹³	9 cardiologists, 1 cardiac surgeon	NS	NS	NA	NA
Oldroyd, 2014, Australia ¹⁴	21 patients	38%	80-88 (mean of 84 years)	NS	52% had undergone CABG + valve replacement (either aortic or mitral), 10% had undergone valve replacement alone (either aortic or mitral)
Berg, 2013, Denmark ²⁰	10 patients	50%	20-85 (mean of 66 years)	80% had aortic valve disease, 20% had pulmonary valve disease; NS	50% had TAVI, 50% underwent open valve replacement surgery

CABG = coronary artery bypass grafting; NA = not applicable; NS = not specified; NYHA = New York Heart Association Functional Classification; SAVR = surgical aortic valve replacement; TAVI = transcatheter aortic valve implantation

*Olsson 2016⁹ and Olsson 2016⁹ use the same interview data

Appendix 4: Critical Appraisal of Included Publications

Table 4: Critical Appraisal of Included Publications

Qualitative Studies Assessed Using CASP Qualitative Checklist ⁷										
First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Kirk, 2019 ¹⁹	+	+	+	+	+	+	+	+	+	+
Olsson, 2019 ¹⁶	+	+	+	+	+	+	+	+	+	+
Baumbusch, 2018 ¹⁷	+	+	+	+	+	+	+	+	+	+
Instenes, 2018 ¹⁸	+	+	+	+	+	+	+	+	+	-
Olsson, 2018 ²²	+	+	+	+	+	+	+	+	+	+
Astin, 2017 ²¹	+	+	+	+	+	+	+	-	+	+
Skaar, 2017 ¹¹	+	+	+	-	-	+	+	+	+	+
Coylewright, 2016 ¹²	+	+	-	+	-	-	+	-	+	+
Lauck, 2016 ¹⁵	+	+	+	+	+	-	+	+	+	+
Olsson, 2016 ⁹	+	+	+	+	+	+	+	+	+	+
Olsson, 2016 ⁸	+	+	+	+	+	+	+	+	+	+
Merkel, 2015 ¹³	+	+	+	-	+	+	+	+	+	+
Oldroyd, 2014 ¹⁴	+	+	+	+	-	+	+	-	+	+
Berg, 2013 ²⁰	+	+	+	+	+	+	+	-	+	+

+ = yes; - = no