National Institute for Health and Care Excellence

Final

Heart valve disease presenting in adults: investigation and management

[L] Evidence review for information and advice

NICE guideline NG208

Evidence reviews underpinning recommendations 1.9.1 to 1.9.5 and the research recommendation in the NICE guideline

November 2021

Final

These evidence reviews were developed the National Guideline Centre, hosted by the Royal College of Physicians

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1.1. Review question

1.1.1. What information and advice is useful and valuable to adults with heart valve disease and their family and carers? Introduction

Patient choice is essential for clinical decision making in heart valve disease; informed choice is desirable, so patient education regarding disease characteristics, assessment, monitoring and valve intervention options is very important. Furthermore, the central role of onset of symptoms in timing of intervention, makes it essential for patients, family and carers to develop awareness of symptoms and observe decline in exercise tolerance. Information regarding preparation for intervention and the subsequent recovery is also essential.

1.1.2. Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: characteristics of review question

Objective	To determine what information and advice is useful and valuable to adults with heart valve disease and their family and carers
Population and setting	Adults aged 18 years and over with diagnosed heart valve disease and their family and carers.
Context	To identify qualitative interview and focus group studies that include views, opinions and experiences relating to information, education or support. Themes will be derived from the evidence identified for this review and not pre-specified. Themes may include: • Decision making • Preferred format of information provision • Content of information • Impact of treatment on lifestyle • Information sources other than healthcare professionals (e.g. support groups, online resources) • Psychological support • Delivery of support (e.g. nurse, peer groups)
Review strategy	Synthesis of qualitative research. Results presented in narrative format. Quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

1.1.3. Qualitative evidence

1.1.3.1. Included studies

We searched for qualitative studies that would inform recommendations on information and support needs of patients with heart valve disease. Although the search was not limited to any specific subpopulation of heart valve disease, the majority of relevant studies we found were on patients with aortic stenosis and their experiences with transcatheter aortic valve replacement (TAVI).

One study, reported in two papers,[10, 11] instead covered a population with aortic stenosis or mitral regurgitation that underwent valve surgery, another covered those undergoing either surgical valve replacement or TAVI, with 20% having pulmonary valve replacement and 80% having aortic valve replacement,[3] and an additional study covered those with aortic stenosis that underwent either surgical replacement or TAVI and experienced delirium.[13]

Fourteen qualitative studies (from fifteen papers) were included in the review[1-3, 5, 10, 11, 13, 19, 23, 27, 40-43, 50] these are summarised in Table 2 below. Key findings from these studies are detailed in Section 1.1.5 below. Quality assessment for each specific subtheme within each of these findings was also performed.

See also the study selection flow chart in Appendix C study evidence tables in Appendix D, qualitative evidence summary for each subtheme within each finding in Appendix E and excluded studies lists in Appendix F.

1.1.3.2. Excluded studies

See the excluded studies list and reasons for exclusion in Appendix F.

1.1.4. Summary of studies included in the qualitative evidence

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Astin 2017[1] (UK)	Semi-structured interviews	Purposive sample of adults awaiting transcatheter aortic valve replacement (TAVI) recruited from a regional centre N=53 39% male; mean age 81.7 years >80% NHYA III or IV	To provide an in-depth understanding of patients' views about the impact of transcatheter aortic valve implantation on self-reported quality of life	In-person interviews 1 and 3 months post-TAVI in the home setting
Baumbusch 2018[2] (Canada)	Semi-structured interviews	Purposive sample of patients and 15 family caregivers from a TAVI programme N=31 patients and 15 family members Median age of patients 81 (range: 58-96); 42% male; median NYHA III Mean age of caregivers 76 (range: 56-95); 33% male	To describe older adults and family caregivers' perspectives on undergoing TAVI at one year post-procedure.	Most interviews were conducted by telephone
Berg 2013[3] (Denmark)	Semi-structured interviews	Purposive sample of patients who had valve surgery in the previous 6-9 months N=10 (2 pulmonary valve replacement; 8 aortic (SAVR or TAVI) 5 men Mean age 66 years (range 20-85)	To describe the experience of recovery at home after heart valve replacement.	Interviews conducted in person, either at the patients' home or in the hospital.
Coylewright 2016[5]	Retrospective qualitative analysis of	Elderly and either high-risk for surgical aortic valve	To report patient-defined goals from elderly patients facing treatment	Retrospective analysis – unclear where information was collected but

Study	Design	Population	Research aim	Comments
(USA)	patient responses to a single question asked prior to TAVI to assess patient goals	replacement or inoperable, and eligible for TAVI following initial heart team evaluation between June 2012 and August 2014 N=46 (7 of those eligible chose not to undergo TAVI) 25 males, 21 females Mean age 84 years (89% ≥75 years)	decisions for severe aortic stenosis (AS) and at high surgical risk.	likely within the centre the procedure was performed at as was obtained as part of a clinical assessment and reviewed retrospectively
Hansen 2016[11]; Hansen 2018[10] (Denmark)	Semi-structured interviews	Recruited from the intervention arm of a trial N=9 6 males, 3 females 2 age 40-49; 2 50-59, 3 60-60 and 2 70-79 years	To gain insight into patients' experiences in cardiac rehabilitation, after isolated heart valve surgery.	Interviews conducted in person, either at the patients' home or in the hospital according to patient preferences.
Instenes 2019[13] (Norway)	Semi-structured interviews	Adults aged 80 years or over recruited from a prospective cohort study treated either with SAVR (n=6) or TAVI (n=4), who had experienced postoperative delirium. N=10 5 males, 5 females Mean age 83 (2.2) years	To explore and describe how octogenarian patients with post-aortic valve replacement delirium experience interactions with healthcare professionals and relatives within the first year and four years later.	Interviews conducted in person, either at the patients' home or in the hospital.
Kirk 2019[19] (Denmark)	Semi-structured interviews (phenomenological-hermeneutic analysis)	A purposive sample of patients treated with TAVI for AS were interviewed 3-4 months after treatment. 5 patients had experienced NYHA class II symptoms and 5 NYHA class III	To explore factors influencing patients' decision making to undergo TAVI eligibility assessment to inform practice, programme development, health policy and future research	Interviews conducted in participants own homes

Study	Design	Population	Research aim	Comments
		n=10 4 males and 6 females Mean age 79 years (range 72-87)		
Lauck 2016[23] (Canada)	Semi-structured interviews	A purposive sample of adults 75 years and older recruited at the time of their referral for assessment of eligibility from the TAVI clinic. Most participants experienced NYHA class III symptoms. n=15 9 males and 6 females Median age 86 years (range 75-92)	To explore factors influencing patients' decision-making to undergo assessment for TAVI eligibility to inform practice, programme development, health policy and future research	Interviews conducted at a provincial cardiac TAVI centre. Authors had conflicts of interest. They were consultants for companies that manufacture or sell cardiac devices. The study was not funded by these companies.
Lysell 2020[27] (Sweden)	Semi-structured interviews	Adults with severe AS and planned TAVI procedure between 2016 and 2017 interviewed at 2-3 months following TAVI procedure. 64% had moderate symptoms and 36% had severe symptoms according to NYHA class. n=14 5 males and 9 females Mean age 86 years	To explore patients' experiences during everyday life before and after TAVI.	Interviews were conducted at the hospital or in participants' homes/nursing home.
Olsson 2019[41] (Sweden)	Semi-structured interviews	A purposive sample of patients with severe AS who were being considered	The aim of this study was to explore patients' experiences of being considered for transcatheter aortic	Single-centre study with a small number of participants

Study	Design	Population	Research aim	Comments
		for TAVI but judged ineligible. The median Society of Thoracic Surgeons predicted risk of surgical mortality was 6.4% (range 2.6–16.3%) Participants were considered high risk for surgery due to other illnesses and their age. All were NYHA class III and IV. n=8 6 males and 2 females Mean age 82 years (range 74-93)	valve implantation but judged ineligible.	Interviews conducted in the patient's home or in the county hospital
Olsson 2016[40] (Sweden)	Semi-structured interviews	Adults with severe AS and planned for TAVI. Participants had either NYHA class III and or NYHA class IV. n=24 15 males and 9 females Mean age (SD) 80.7 years (7.4)	To describe patients' experiences of coping with severe AS while waiting for TAVI	Interviews were conducted on the ward the day before having TAVI. The timing and setting of the interviews may have had an influence on participants' thoughts and ability to describe their situation. They may have been anxious and not able to recall events clearly.
Olsson 2016[42] (Sweden)	Semi-structured interviews	Adults with severe AS and planned for TAVI. Participants had either NYHA class III and or NYHA class IV. n=24	To describe the decision-making process about undergoing TAVI treatment in people with severe AS	This is a sub-study of Olsson 2016[40] and presents the same issues of participants being interviewed in hospital the day before their procedure which may have influenced their ability to describe their thoughts and situation.

Study	Design	Population	Research aim	Comments
		15 males and 9 females Mean age (SD) 80.7 years (7.4)		
Olsson 2018[43] (Sweden)	Semi-structured interviews	Consecutive patients treated by TAVI at a single centre. Population was said to represent a variety of people. N=19 11 males, 8 females Median (range) age: • Males, 80 (65-89) • Females, 82 (60-90)	To explore how patients experienced the recovery process from TAVI	Interviews performed in outpatient clinic or in participants' homes.
Skaar 2017[50] (Norway)	Semi-structured interviews	Purposive sample of adults 70 years and over who underwent elective TAVI due to severe symptomatic AS and high risk for complications to SAVR. n=10 4 males and 6 females; No mean or median age values reported 3 patients were aged 70-79 years and 7 aged 80-89	To explore conditions for an autonomous choice experienced by older adults who recently underwent TAVI, with a special focus on relational and cognitive aspects.	Interviews were conducted 2 to 4 weeks after TAVI (except for three patients who were interviewed after 9, 41 and 52 days due to practical reasons)

See Appendix D for full evidence tables.

1.1.5. Summary of the qualitative evidence

Interpretations and explanations from the original studies were synthesised to gain an insight into themes present across the body of evidence as a whole. The main concepts found in each individual study which were relevant to our review question were drawn together to inform understanding of overarching themes, with subthemes identified within each of these main findings, which are summarised in Figure 1.

Table 3: Review findings

Main findings (themes)	Statement of finding
Impact of the illness 11 studies (from 12 papers)[1, 5, 10, 11, 19, 23, 27, 40-43, 50]	Living with aortic stenosis (AS) had a significant physical and psychological impact on participants. The loss of control was difficult to accept. Coping strategies such as trying to gain control over symptoms, preserving social networks and managing social limitations were essential for restoring hope.
Formal and informal support 12 studies (from 13 papers)[1-3, 10, 11, 13, 23, 27, 40-43, 50]	Health care professionals play an important part in supporting AS patients and are the most trusted source for obtaining information about the illness and treatments. Informal support from families and friends also plays an important role, which was also highlighted for those dealing with delirium following transcatheter aortic valve replacement (TAVI) or surgical aortic valve replacement There is an urgent and important need for information about the disease, treatments and how to take control of one's health to help support patients and restore hope.
Factors influencing the decision to undergo TAVI or surgery 10 studies (from 11 papers)[1, 2, 5, 10, 11, 23, 27, 40, 42, 43, 50]	One of the most important factors that influences AS patients to undergo TAVI is the burden of symptoms, particularly breathlessness and fatigue, which have the greatest impact on their daily activities. Other factors include expectations from the procedure, influence of healthcare professionals, influence of and obligations to family (particularly children) and patient experience. A hope of returning to 'normality' was commonly mentioned for those having TAVI and was also reported for patients undergoing surgery for AS or mitral regurgitation. For those deciding against having a TAVI procedure, avoiding invasive procedures and the possible complications of these procedures was the most cited reason for their decision.
Impact of TAVI or surgery on daily life 8 studies (from 9 papers)[1-3, 5, 10, 11, 19, 27, 43]	Although TAVI or surgery relieves symptoms and enhances physical abilities for many participants, the speed and extent of improvement differs for different participants and for some their expectations prior to the procedure were not met in reality and they felt disappointed. Despite some feeling disappointed with their progress and experiencing complications, very few regretted having the procedure. Comorbidities were often highlighted as limiting improvements in health and their ability to perform activities as these could not be treated by TAVI or surgery and remained, for example arthritis or lung disease.

Main findings (themes)	Statement of finding
	Self-intervention and taking health initiatives are seen by many participants as important to help improve recovery.

1.1.5.1. Narrative summary of review findings

Overall review findings and subthemes identified within these findings are discussed below, as well as an explanation of the quality assessment for both. Quality assessment for overall review findings is presented in Table 4 below. A similar quality assessment table for subthemes within each finding is presented in Appendix E.

Review finding (theme) 1: Impact of illness

Explanation of quality assessment for overall finding (theme) of 'impact of illness':

There were 11 studies (from 12 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Coping with physical symptoms and anxiety

Symptom burden/loss of control - subtheme:

Severe and overwhelming fatigue and shortness of breath were prominent and were associated with limitations on activities of daily living, such as maintain hygiene, cooking and housekeeping, and reduced mobility, as well as preventing them from participating in hobbies such as gardening or travelling. Dizziness and fainting, which made the disease unpredictable, were particularly troublesome and led to feelings of loss of control and security.

Symptoms often led to anxiety and difficulty sleeping. Participants felt that the disease caused a sense of insecurity and despair for the loss of functions and strength they had before, with a short temper also being reported. They grieved the loss of independence in daily life and did not want to be a burden on their relatives. Social limitations often occurred as a result of the physical restrictions caused by their illness, with many feeling unable to leave their homes and be as socially active as before, including enjoying time with their spouse and grandchildren as well as other social situations. This led to feelings of loneliness, isolation and depression.

Participants commonly expressed thoughts about death, which increased their anxiety, despair and insecurity and included a fear of dying alone as well as the effect their death would have on their spouse. It was difficult to live with bad prognoses since they did not know how much time they had to live. They asked themselves if death would come suddenly or cause extended suffering and some wondered whether death due to the disease or on the operating table was preferable. Stressful thoughts and life-threatening symptoms were described as eventually becoming part of life.

Explanation of quality assessment for this subtheme: There were 11 studies (from 12 papers) that contributed to this subtheme. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Coping with losses and struggling for control:

Trying to take control and reducing anxiety - subtheme:

Participants described having to adapt previous activities such as household work to lighter forms which had to be planned around severe symptoms such as breathlessness, fatigue and fainting. Participants had to rearrange their housing, learn to use new technology and rely on support from relatives, friends and healthcare professionals.

The responsibility of having to fulfil obligations including financial management, maintaining one's home and participating in day-to-day activities increased the sense of responsibility to maintain the best possible health. Therefore, participants sought methods to create a sense of control and to improve their condition through, for example, fluid restrictions, training programmes and diet. Relief of their symptoms, whether they were related to heart failure or not, inspired hope.

Getting necessary support from healthcare and knowing who to get in touch with if needed provided an important sense of security and strengthened hope.

Explanation of quality assessment for this subtheme: There were 10 studies (from 11 papers) that contributed to this subtheme. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Preserving important social relationships - subtheme:

Participants felt the necessity of being of use socially and taking part in the community and attempted to hold on to their previous activities to make life meaningful. Those who were able to accept taking a new, less strenuous role while still participating, expressed a feeling of hope and satisfaction.

Explanation of quality assessment for this subtheme: There were 5 studies (from 6 papers) that contributed to this subtheme. There were minor concerns about methodological limitations, minor concerns about relevance, minor concerns about adequacy and no concerns about coherence. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection. There were also some concerns about adequacy as fewer studies touched on this subtheme compared to other subthemes within the main finding of 'impact of illness'. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Managing social limitation by shifting focus - subtheme:

Participants described how the illness meant they had to handle dependency, social limitations and a new, less important role in the family, especially men with severe symptoms and decreased capacity who grieved over their altered or lost roles. Family and friends helped in maintaining social life in which they could be the people they were before.

Participants had to shift focus by reflecting on the activities they had previously considered to be important.

Explanation of quality assessment for this subtheme: There were 9 studies (from 10 papers) that contributed to this subtheme. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Review finding (theme) 2: Formal and informal support

Explanation of quality assessment for overall finding (theme) of ‘formal and informal support’: There were 12 studies (from 13 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants. It was also noted that evidence was limited to those with aortic stenosis in most studies, though one study also included some undergoing replacement for pulmonary valve disease and another included some undergoing replacement for mitral regurgitation.

Health care professionals – subtheme:

Primary care physicians and specialists were perceived as essential sources of information and some patients were solely reliant on information provided by physicians who cared for them through previous health issues. Participants wished health care professionals to be honest and optimistic but still not concealing risk. They appreciated physicians informing them about the procedure and giving them enough time to think it through. Participants had great trust when they had the same physician for many years and those who didn’t struggled for years. Patients who were doubtful about their decision on whether to undergo TAVI or not particularly relied on and listened to those with expert knowledge. The effect that health care professionals had on the expectations of patients undergoing a TAVI procedure, and their family members, was highlighted. Health care professionals were also noted to have an important role in maintaining hope when recovery from a TAVI procedure was slower than the patient had expected.

Participants who were not eligible to have TAVI had great confidence that the decision made by their physician was carefully substantiated, especially when they had been thoroughly examined and provided clear explanations. This made the decision easier to accept and brought on feelings of hope because they really believed that the doctors had their best interests in mind. They trusted that doctors, were truly concerned for their lives and did not want them to undergo a treatment that was too risky.

While some appreciated the honest approach of clinicians, others reported that information from the physician could be frightening, in terms of what was being said and how it was being said, including the physicians body language and expressions and the emphasis on the risks of the TAVI procedure. One patient tried to avoid finding out about the risks of the TAVI procedure as a way of managing fear and when complications they had not expected occurred, they commented that had they known this may have affected their decision to undergo it, further highlighting the need for a full discussion of risks and benefits of the procedure.

Those who had their own doctor or specialist nurse whom they relied on reported that this provided an important sense of security and strengthened hope. In some cases, support from private psychologists was sought in order to help with psychological issues.

Following a valve intervention, patients required guidance when trying to explain symptoms and sensations following discharge from hospital and while some reported good contact with healthcare professionals, others did not feel supported enough when transitioning from the ‘safe’ hospital environment back to a home environment and felt uncertainty, for example due to fragmented care or inconsistent information. The offer of physical rehabilitation was seen as useful for many participants and some that were not offered it regretted this, though the intensity and content of the programmes were not well-suited to all participants and some struggled to maintain the regime after it was complete.

The importance of having healthcare professionals close by specifically in those suffering from delirium following TAVI or surgical aortic valve replacement was highlighted, as it increased feelings of security and confidence. Some commented that they felt that their constant need for reassurance was bothersome for the nurses and that the tone of voice used towards them was sometimes distressing and disrespectful, which was something that stayed with them years after the experience.

Explanation of quality assessment for this subtheme: There were 12 studies (from 13 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants. It was also noted that evidence was limited to those with aortic stenosis in most studies, though one study also included some undergoing replacement for pulmonary valve disease and another included some undergoing replacement for mitral regurgitation.

Caregivers/families/informal - subtheme:

Participants who had physical and emotional support from partners and children found their support very valuable and those who were alone had difficulty, especially with daily activities and decision making. Some participants sought information from the internet. Others reported that stories from trusted sources, such as friends who have had the procedure, gave them confidence and helped with decision making. Family caregivers were also described as having an important role during the recovery period following valve intervention, including TAVI and surgical valve replacement (majority aortic valve intervention in the form of TAVI). Others reported that some relatives did not handle the changed situation well and spoke of relationships having to be rebuilt. In the context of those suffering from episodes of delirium following TAVI or surgical aortic valve replacement, patients appreciated the involvement of their relatives and though some reported relatives to be very reassuring and helpful, others recalled insensitive comments and laughter towards the behaviour or a refusal to talk about the situation which made a lasting impression on the patients.

The importance of informal caregivers having an understanding of the possible complications of the procedure was also emphasised.

Explanation of quality assessment for this subtheme: There were 10 studies (from 10 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection and data richness. It was also noted that evidence was limited to those with aortic stenosis in most studies, though one study also included some undergoing replacement for pulmonary valve disease.

Content/type of information sought - subtheme:

Participants said they needed more knowledge about the disease and treatment options but had varying experiences of such support. Information given about TAVI was sometimes confusing. They asked many disease-related questions about how to take control of their health and participants also described their own attempts to gain control of their health for example through physical activity, which was seen as an indication of having an urgent need for information and support to restore hope. Patient education, particularly prior to a TAVI procedure, was highlighted as important in order to prepare patients for the experience, for example the possibility of pain at the incision site following the procedure as well as the likely timing of discharge so that appropriate support can be arranged ahead of time. Caregiver knowledge about the possible complications of the procedure was also emphasised as important.

Explanation of quality assessment for this subtheme: There were 8 studies (from 8 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance, minor concerns about adequacy and no concerns about coherence. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection and data richness. Although 8 studies still report on some aspects of this subtheme, there were concerns about adequacy as each tends to touch on slightly different elements rather than confirming statements seen in the other studies. It was also noted that evidence was limited to those with aortic stenosis in most studies, though one study also included some undergoing replacement for pulmonary valve disease.

Review finding (theme) 3: Factors influencing the decision to undergo TAVI or surgery

Explanation of quality assessment for overall finding (theme) of ‘factors influencing the decision to undergo TAVI or surgery’: There were 10 studies (from 11 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants. It was also noted that that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Symptom burden – subtheme:

Increasing fatigue and breathlessness which were limiting daily activities and were associated with rapid progression of severe aortic stenosis were the most commonly reported symptoms that influenced the decision to undergo TAVI. Participants felt that these symptoms were life limiting and therefore the decision to undergo TAVI was no longer a choice but a necessity. They were aware of the extreme gravity of the situation and understood that their lives were threatened. They had also lost fortitude and could no longer cope with their life situation.

Explanation of quality assessment for this subtheme**:** There were 11 studies (from 12 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Expectations – subtheme:

Most participants believed that TAVI would relieve their symptom burden, extend their life and improve their quality of life. The shorter recovery time and the potential benefits of the procedure were seen as an advantage. Participants believed that TAVI would allow them to return to 'normal' activities sooner, including hobbies and chores as well as spending time with family and friends, and this was particularly important for those who had obligations that they wanted to resume following the procedure. Some noted that successful TAVI would allow them to worry less about their symptoms and improve their mental wellbeing.

Another expectation of TAVI that some had was that it would also improve their quality of life indirectly, as it was seen as a bridge towards being able to undergo other life-improving operations, such as hip replacements.

A similar expectation of returning to normality was highlighted in those undergoing surgery for aortic stenosis or mitral regurgitation, rather than TAVI, as reported by one study. Most expected to return to normal life as it was before the onset of illness and though the definition of 'normality' differed between participants, it often involved multiple aspects such as improving symptoms and being able to return to 'normal' activities (for example, returning to work) sooner.

Explanation of quality assessment for this subtheme**:** There were 10 studies (from 11 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection and data richness. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

The 'experienced' patient – subtheme:

Some participants perceived themselves as being 'experienced' patients due to their advanced age, complex health histories and previous cardiac procedures. They framed their decision to pursue a new minimally invasive treatment option within their previous experiences of cardiac care. Participants weighed up risks and benefits and understood that not having the procedure would be worse than accepting its risks. They also understood that as symptoms got progressively more serious there may no longer be hope for recovery without the procedure. They were aware that if they declined to have TAVI, it might not be an option later. They felt it was a necessity and thus, barely experienced being in a situation where they should make a choice. They reported little doubt or anguish about having to make the decision. Participants were aware that due to them being at high surgical risk or surgery not being an option that their alternative options were limited and were grateful to have the option of TAVI.

Explanation of quality assessment for this subtheme**:** There were 8 studies (from 8 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection and data richness. It was also noted that evidence was limited to those with aortic stenosis.

Influence of healthcare system and informal support – subtheme:

Participants relied heavily on health care professionals in their decision making and perceived them as essential (and sometimes the sole) sources of information, decision making guidance and facilitators of referral for TAVI. Trust and medical guidance were required both when they were sure and unsure of the decision. The strong effect that health care professionals had on the expectations of patients in terms of their health following the procedure was highlighted.

Informal social support resources provided by family, friends and community members were noted as having an influence on decision making. Stories from trusted friends gave participants confidence and hope that TAVI would help alleviate some of the symptom burden. Sharing the decision was easier when the responsibility for the decision could be shared with others, such as a husband or wife. Those who didn’t have this support described how demanding it was for them to be alone with their concerns.

Explanation of quality assessment for this subtheme**:** There were 10 studies (from 10 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection. It was also noted that evidence was limited to those with aortic stenosis.

Obligations and responsibilities – subtheme:

Many participants were concerned about the burden of their health-related needs on their caregivers, or the effect that their death might have on them, and this had motivated them to try to maintain health and to undergo TAVI. This was closely intertwined with participants’ ability to fulfil other obligations and maintain or improve their current level of independence, including financial management, maintaining one’s home and participating in day-to-day activities (e.g. chores, cleaning, grocery shopping).

Obligation to close family members, fulfilling their children’s wishes and not wanting to let them down often determined the decision. Some participants were so passive in their decision that they accepted TAVI simply because their children wanted them to.

Explanation of quality assessment for this subtheme**:** There were 10 studies (from 11 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection. It was also noted that evidence was limited to those with aortic stenosis in all but one study, where a mixture of participants with aortic stenosis and those with mitral regurgitation was included.

Logistical barriers and facilitators – subtheme:

The practicalities of pursuing specialised treatment at a TAVI centre located far from their homes and the expected personal costs and burden of travel was a concern for some participants.

Explanation of quality assessment for this subtheme**:** There were 2 studies (from 2 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance, moderate concerns about adequacy and no concerns about coherence. Overall, there was low confidence in this finding. The main reason for downgrading was that most of the evidence came from studies that did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection and richness. There were moderate concerns about adequacy as only two studies touched on this specific subtheme. It was also noted that evidence was limited to those with aortic stenosis undergoing TAVI.

Deciding against having TAVI – subtheme:

Some patients from one study eventually decided against undergoing the TAVI procedure, with avoiding invasive procedures and the possible complications of these procedures being the reason most cited for this decision. Another patient did not want to suffer over a long period of time having been diagnosed with Parkinson's disease and this contributed to their decision not to accept TAVI.

Explanation of quality assessment for this subtheme**:** There was 1 study (from 1 paper) that contributed to this finding. There were moderate concerns about methodological limitations, minor concerns about relevance, moderate concerns about adequacy and no concerns about coherence. Overall, there was low confidence in this finding. The main reason for downgrading was that the study did not address the role and influence of the researchers and their relationship with participants, there were concerns about the retrospective nature of the study and methods of data analysis were poorly described. There were moderate concerns about adequacy as only a single study mentioned factors involved in the decision not to have TAVI. It was also noted that evidence was limited to those with aortic stenosis undergoing TAVI.

Review finding (theme) 4: impact of TAVI or surgery on daily life

Explanation of quality assessment for overall finding (theme) of 'impact of TAVI or surgery on daily life': There were 8 studies (from 9 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and minor concerns about coherence. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most studies did not address the role and influence of the researchers and their relationship with participants and there were some concerns about coherence as one study suggested all experienced improvements following TAVI whereas other studies reported some with improvements and some being disappointed following TAVI or surgery. It was also noted that most of the evidence was limited to those with aortic stenosis.

Varying effects on bodily sensations and symptoms – subtheme:

After TAVI or surgery, many participants felt a noticeable change in their bodies described as a clear before and after distinction, particularly regarding improvement in respiratory distress. Being able to breathe better made patients happy and confident that they would be able to live a daily life with meaningful activities, which was described as life-changing by many. Some patients also experienced improved sleep following TAVI, which gave them more energy and the feeling that they could participate in activities they couldn't previously participate in and consequently renewing their enjoyment of life. The feeling of having a longer life-span was also reported for those with successful TAVI procedures. A feeling of safety and having peace of mind was also described, with reduced thoughts of imminent death.

Body soreness, weakness and feeling tired after TAVI was reported by many but this dissipated over time. Some reported concerns about bodily signals such as 'galloping' heart beats and were able to find a way to cope with these concerns.

Most studies highlighted that experiences post-TAVI differed across participants in terms of the degree and speed of improvements observed, with some experiencing immediate relief and improvement, others experiencing a more gradual improvement and others experiencing no improvement or even a feeling of deterioration. However, overall the majority did experience some degree of improvement in symptoms over time or were considered to have achieved their goals, for example increasing their ability to walk or participate in hobbies.

Some evidence was also obtained from one study that returning to normal living and regaining physical strength was a struggle for all participants undergoing pulmonary or aortic valve replacement by TAVI or surgery, and that the feeling of weakness remained following the intervention and made them feel unsafe when trying to return to activities. This meant that rebuilding networks and their role in society was difficult and they still relied heavily on others to care for them and help them with daily activities. However, improvements in shortness of breath and increased energy were described by some of these participants, meaning they had the ability to participate in physical activities. A feeling of an extended life was also reported by some participants in this study.

For a group that all underwent surgery for aortic stenosis or mitral regurgitation, all experienced fatigue and some had pain immediately following the procedure. Some subsequently recovered quickly with improvements in their physical and mental health and the ability to resume previous physical and social activities. However, others struggled with the speed and extent of their recovery and did not experience 'normality' by the end of the interviews, with daily living still restricted and feelings of uncertainty present.

Explanation of quality assessment for this subtheme**:** There were 8 studies (from 9 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and minor concerns about coherence. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most studies did not address the role and influence of the researchers and their relationship with participants and there were some concerns about coherence as one study suggested all experienced improvements following TAVI whereas other studies reported some with improvements and some being disappointed following TAVI or surgery. It was also noted that most of the evidence was limited to those with aortic stenosis.

A changed bodily attention and complications – subtheme:

Participants experienced increased bodily awareness following TAVI or surgery. This was described as similar to an out-of-body experience and they felt like they were not really "inside their own bodies". For example, patients were now noticing and registering the rhythm of their heart more. This was not necessarily brought on by anxiety but rather an increased awareness of the importance of their heart's function. A consequence of this increased attention on the importance of the heart for some was that they were anxious and fearful about how to be active in a safe way as they viewed keeping the heart safe a major concern.

Some patients that underwent TAVI had other illnesses that needed treatment and were concerned about how the body would cope with this. These worries made the participants feel a new kind of bodily awareness where they had to stop and really think about whether what they were feeling was physically a sign of illness. They described this as feeling well but something still lurking. On the one hand they noted the familiar signs of bodily functioning but on the other they noticed their bodies in a way that made them feel unsure. The continuing need to take diuretics after TAVI led to worries about needing further treatment and whether they could trust their bodies or should expect a life with the limitations they had prior to treatment. This illustrated that previous experiences could lead to uncertainty months after having TAVI. Some patients that had surgery for aortic stenosis or mitral regurgitation also described difficulty in interpreting bodily symptoms.

Some patients experienced stressful complications following TAVI or surgery which affected them physically and mentally as they feared further complications such as stroke and some feared dying. For some patients following pulmonary or aortic valve replacement by surgery or TAVI, the scar from the procedure was a source of psychological stress as they were aware of it themselves and worried about what others thought of it. For some, thinking about the seriousness of their condition and what could have happened was emotionally distressing. Sleeping problems were also reported for some that had TAVI or surgery and pain was reported to be a major issue for those that had open heart surgery.

Explanation of quality assessment for this subtheme**:** There were 7 studies (from 8 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and minor concerns about coherence. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most studies did not address the role and influence of the researchers and their relationship with participants and there were some concerns about coherence as one study suggested all experienced improvements following TAVI whereas other studies reported some with improvements and some being disappointed following TAVI or surgery. It was also noted that most of the evidence was limited to those with aortic stenosis.

Changes in physical possibilities and the ability to cope with life – subtheme:

Although the degree of improvement differed, many participants talked about how their bodies were able to do more than before they had TAVI. They were happy that their physical fitness had improved after treatment and this was reflected in their daily activities. They were pleased to be able to resume normal activities that they were no longer able to do before TAVI, consequently renewing their zest for life and improving their mood. They described becoming stronger and being able to do more as time passed. Going for walks was of particular significance as this represented how they were feeling and was a measure of their progress after treatment. In addition, it enabled them to participate in social activities which in turn improved their sense of confidence, wellbeing and control over their own lives. Some participants also expressed relief at being able to continue caring for partners that were dependent on them following TAVI.

Similar improvements in physical capacity were described by some of those undergoing pulmonary or aortic valve replacement by surgery or TAVI as improvements in shortness of breath and increased energy meant they had an increased ability to participate in physical activities and return to ‘normal’ life such as going to work. A gradual improvement was described for most, with being able to walk on their own in the street seen as a great achievement.

Another benefit of the TAVI procedure described was the opportunity to undergo subsequent procedures to improve quality of life, for example hip replacements.

Participants were aware of the necessity of self-intervention after TAVI or surgery. They knew that although relief of symptoms, improved physical abilities and renewed energy did come about on their own, an independent effort on their part was crucial to their recovery. Participants who were offered rehabilitation programmes found them helpful but others who were experienced felt that setting their own goals for walking or using an exercise bike helped them manage on their own. Those not offered physical rehabilitation often regretted this. Having the ability to improve their physical fitness proved to be motivational in itself and requiring physical rehabilitation was an opportunity for those who were not previously physically active to do so. After rehabilitation programmes, some continued to be physically active, but others returned to a more inactive way of life. Some were uncertain and concerned about what level of activity was safe for them, either because of complications they suffered following their intervention or due to an increased awareness of the importance of the heart.

Explanation of quality assessment for this subtheme**:** There were 8 studies (from 9 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and minor concerns about coherence. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most studies did not address the role and influence of the researchers and their relationship with participants and there were some concerns about coherence as one study suggested all experienced improvements following TAVI whereas other studies reported some with improvements and some being disappointed following TAVI or surgery. It was also noted that most of the evidence was limited to those with aortic stenosis.

Meeting expectations and disappointment – subtheme:

Some were surprised not to experience the physical discomforts of the illness following the procedure after discharge as they had anticipated and experienced an immediate, positive change post-TAVI, with some comparing their experiences to previous surgery they or other people had undergone and finding TAVI to be a more preferable experience in terms of the speed of their recovery. while others were disappointed with their recovery in terms of the speed and/or extent of improvement and their ability to perform normal activities and hobbies. Among those that were disappointed with their progress, some commented that their expectations of life after the procedure were very different to the reality. Some that had previously had coronary artery bypass grafting were disappointed as they had expected recovery from the TAVI procedure to be similar and not slower, though the fact they were now older and in a worse condition was appreciated. Similar experiences were also identified by some participants undergoing pulmonary or aortic valve replacement by surgery or TAVI and some undergoing surgery for aortic stenosis or mitral regurgitation, with some being very disappointed in not feeling the improvements in their health they had hoped for following the procedure and limitations in their abilities still being present.

Despite many not achieving the improvements they had expected prior to the TAVI procedure or experiencing complications, very few participants expressed regret at their decision to have the procedure. Some commented that even though their symptoms had not improved as much as they had hoped, having the procedure had still allowed them to have subsequent operations to improve their quality of life indirectly, such as hip replacements. For others the knowledge that all that was possible had been done to improve their health was some improvement. An absence of regret at having had the procedure was also identified for those that underwent pulmonary or aortic valve replacement by surgery or TAVI and had not experienced the expected improvement in their condition, even for those that experienced life-threatening complications.

Relatives sometimes helped participants to reflect on their improvements by reminding them to compare their current condition to that immediately before the TAVI procedure, rather than to their health before they became ill or at a much younger age. When participants did this, they often accepted that they did experience some improvement in their condition compared to immediately before the procedure, even if not to the extent that they had anticipated.

The strong influence that health care professionals had on the expectations of patients following the TAVI procedure was highlighted, with one relative commenting that his mother had high expectations as the clinician said she would be able to return to her walking and ‘be able to climb mountains’ following the procedure. When the expected level of improvement was not realised it led to disappointment.

As well as patient expectations, the expectations of family caregivers and other relatives had to be managed as some relatives had expected more of an improvement in the condition of participants and their ability to do things following the TAVI procedure. The unmet expectations of relatives were also highlighted in one study that included participants undergoing pulmonary or aortic valve replacement by surgery or TAVI.

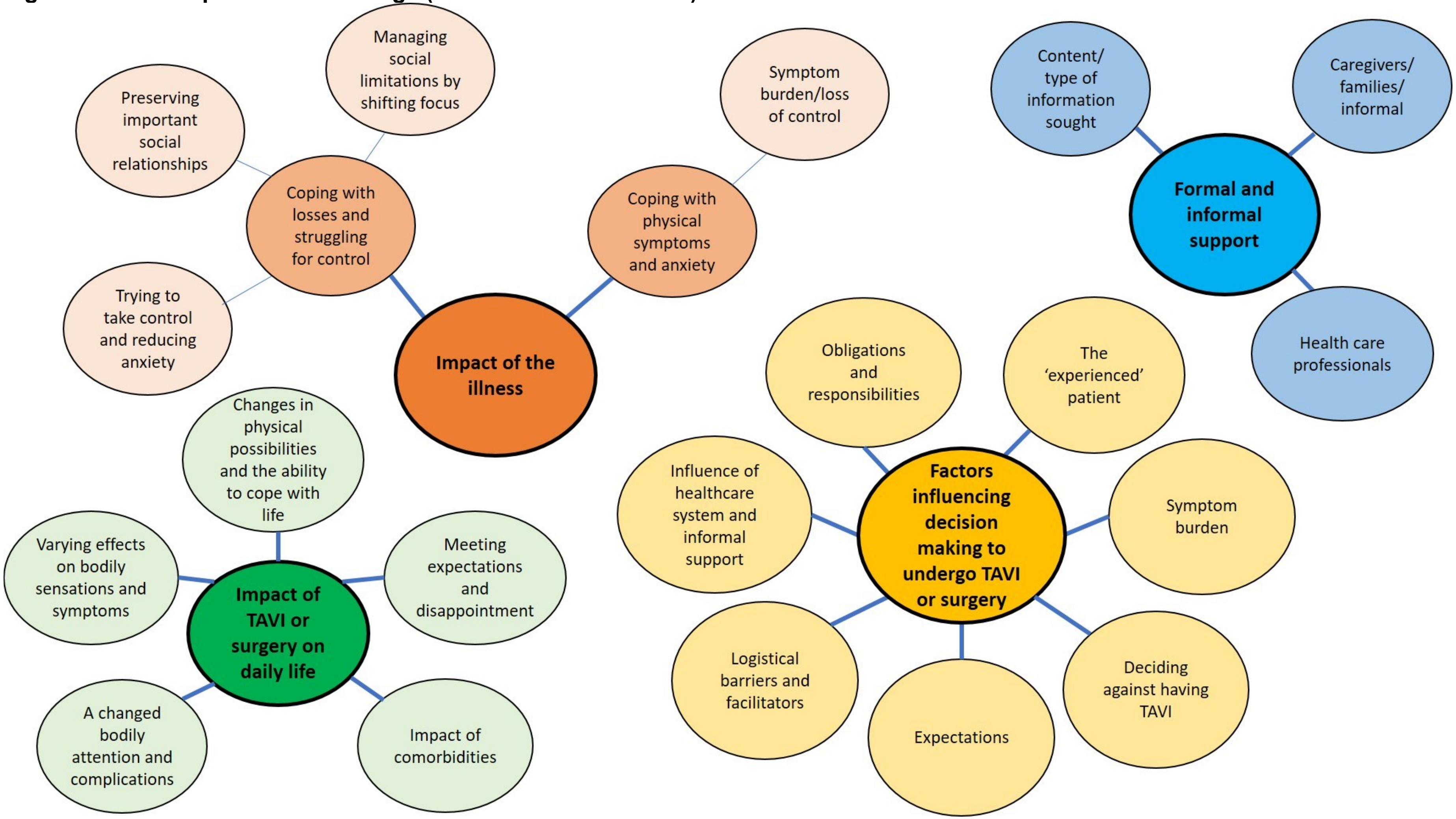
Explanation of quality assessment for this subtheme**:** There were 8 studies (from 9 papers) that contributed to this finding. There were minor concerns about methodological limitations, minor concerns about relevance and minor concerns about coherence. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most studies did not address the role and influence of the researchers and their relationship with participants and there were some concerns about coherence as one study suggested all experienced improvements following TAVI whereas other studies reported some with improvements and some being disappointed following TAVI or surgery. It was also noted that most of the evidence was limited to those with aortic stenosis.

Impact of comorbidities – subtheme:

The existence of other health conditions mediated the scale and speed of improvement, meaning some experienced less of an improvement than they had hoped in terms of symptom improvement or took longer to recover. For example, comorbidities such as COPD or morbid obesity appeared to counteract any improvements in their symptoms due to their heart condition as symptoms associated with their comorbidities were not relieved by the TAVI procedure and conditions such as arthritis meant some were still limited in the extent and type of activities they could participate in. It was often difficult for those living with multiple comorbidities to assess the impact of TAVI on their own symptom burden and quality of life, explaining that it was difficult for them to understand which physical symptoms were attributed to which condition. However, many participants understood that their ongoing health issues would not be cured by TAVI.

Explanation of quality assessment for this subtheme**:** There were 4 studies (from 4 papers) that contributed to this finding. There were moderate concerns about methodological limitations, minor concerns about relevance and no concerns about coherence or adequacy. Overall, there was moderate confidence in this finding. The main reason for downgrading was that most studies did not address the role and influence of the researchers and their relationship with participants, and there were some concerns about data collection and adequacy. It was also noted that the evidence was limited to those with aortic stenosis undergoing TAVI.

Figure 1: Mind map of review findings (themes and subthemes)



Bold text indicates the main findings (themes) and branches from these main findings are subthemes.

1.1.6. Qualitative evidence summary

Table 4: Summary of evidence for overall findings (see Appendix E for summary table for subthemes)

Study design and sample size			**Quality assessment**		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Impact of the illness					
10 studies (from 11 papers)[1, 5, 10, 11, 19, 23, 27, 40-43, 50]	Semi-structured interviews (n=9 studies) or responses to a single question (n=1 study)	Aortic stenosis (AS) has a significant physical and psychological impact. Coping strategies are essential for restoring hope.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Formal and informal support					
12 studies (from 13 papers)[1-3, 10, 11, 13, 23, 27, 40-43, 50]	Semi-structured interviews	Healthcare professionals are the most trusted source of information and together with patients' family and friends form an important support system.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Factors influencing decision to undergo transcatheter aortic valve replacement (TAVI) or surgery					
11 studies (from 12 papers)[1, 2, 5,	Semi-structured interviews (n=10	Symptom burden is a significant factor in deciding to undergo TAVI. Influence of healthcare professionals and obligations to family also play an important role, as do	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	

Study design and sample size			**Quality assessment**		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
[10, 11, 23, 27, 40-43, 50]	studies) or responses to a single question (n=1 study)	expectations from the procedure and patient experience A hope of returning to 'normality' was commonly mentioned for those having TAVI and was also reported for patients undergoing surgery for AS or mitral regurgitation. For those deciding against having a TAVI procedure, avoiding invasive procedures and the possible complications of these procedures was the most cited reason for their decision.			
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Impact of TAVI or surgery on daily life					
8 studies (from 9 papers)[1-3, 5, 10, 11, 19, 27, 43]	Semi-structured interviews (n=7 studies) or responses to a single question (n=1 study)	Although TAVI or surgery relieves symptoms and enhances physical abilities for many participants, the speed and extent of improvement differs for different participants and for some their expectations prior to the procedure were not met in reality and they felt disappointed. Despite some feeling disappointed with their progress and experiencing complications, very few regretted having the procedure. Comorbidities were often highlighted as limiting improvements in health and their ability to perform activities as these could not be treated by TAVI or surgery and remained, for example arthritis or lung disease.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	Minor concerns about coherence[3]	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

Study design and sample size		Finding	Quality assessment		
Number of contributing studies	Design		Criteria	Rating	Overall assessment of confidence
		Self-intervention and taking health initiatives are seen by many participants as important to help improve recovery.			

[1] Downgraded if there were concerns about methodological limitations. Most of the evidence comes from studies that did not address the role and influence of the researchers and their relationship with participants

[2] Downgraded due to concerns on the relevance and extent to which the body of evidence from the included studies is applicable to the context of the review as the majority of studies are limited to the AS population rather than heart valve disease in general.

[3] Downgraded as there were some concerns about coherence as one study suggested that all patients experienced improvements following TAVI whereas the others suggest a more balanced experience with some experiencing large improvements and others being

1.1.7. Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

1.1.8. The committee's discussion and interpretation of the evidence

1.1.9.2 The quality of the evidence

Most of the evidence was from studies that did not address the role and influence of the researchers and their relationship with participants and was from a limited subset of the overall heart valve disease population, older-adults with aortic stenosis being considered for TAVI. Therefore, the overall confidence in the main findings was moderate in all cases. There was however some insight into those that underwent surgery as one study that included those with aortic stenosis or mitral regurgitation undergoing surgery and another that included those undergoing pulmonary or aortic valve replacement by surgery or TAVI. Looking at individual subthemes within each finding, there were two within the 'factors influencing the decision to undergo TAVI or surgery' finding (logistical barriers and facilitators, and deciding against TAVI) where confidence in the evidence was considered to be low. This was because there were additional concerns about adequacy as fewer studies touched on these specific subthemes.

There was no evidence for tricuspid valve disease, and only a small proportion of patients in one study had mitral valve disease. There was also no evidence about the information and support needs of those with mild/moderate valve disease. However, it was considered appropriate to make general recommendations covering all severities and types of valve disease, by extrapolating the evidence identified and using experience of the committee, rather than limiting to the populations covered in the evidence.

Differences in the strength of recommendations made were based on potential resource or cost implications and not the quality of the evidence, as there was moderate confidence in all of the main findings reported and for the majority of subthemes identified within these findings.

1.1.9.3 Findings identified in the evidence synthesis

The key themes that emerged from the evidence were: the impact of the illness, formal and informal support, factors influencing the decision to undergo TAVI or surgery and the impact of TAVI or surgery on daily life. Recommendations were not made for people deciding between TAVI or surgery and these themes are therefore not considered further.

There was clear and consistent evidence of the negative impact of symptoms and loss of control on participants that led to feelings of despair and insecurity. In this context, a point of contact for advice between appointments, as reported in the evidence and in the experience of the committee, increases hope and security. The committee agreed that this may need to be considered for all people with heart valve disease and not just those at the stage of needing or having had valve intervention. Based on the fact that this may not always be done in current practice and therefore would represent increased resourcing and subsequent cost, a consider rather than offer recommendation was made.

The committee agreed that it was important to list what areas of information and advice are important to people with heart valve disease. The list of areas included in the recommendation was compiled from the evidence and the experience of the committee and a strong recommendation was made as it was agreed to be important that this information is provided to all of those diagnosed with heart valve disease and that it should not be associated with an increased cost. The main focus was to ensure that the expectations of people with heart valve disease accurately match the likely course of their condition, as the evidence on factors influencing the decision to undergo intervention (surgery or TAVI) identified expectations as one of these factors. The full list included the expected progression and prognosis of their condition (including the likely length of an asymptomatic stage), any need for intervention (including the type of intervention), pregnancy (if appropriate), the impact of comorbidities on recovery, rehabilitation and long-term outcomes and palliative care, if appropriate (including how to access this). All of those areas listed were based on the evidence reviewed combined with experience. Providing people with information on the expected progression and prognosis, possible interventions (or palliative care if appropriate), pregnancy (where applicable), rehabilitation and long-term outcomes was agreed to be useful in order to help patients understand their condition and options better with the aim of reducing the impact heart valve disease has on their lives, which was identified as a key finding in the review. The impact of comorbidities on recovery was also included in this list as evidence demonstrated that comorbidities often influenced the expectations patients had of their recovery following intervention and it is important people are informed about this so that they do not have unrealistic expectations. Having the information that is listed in this recommendation will be beneficial for planning appropriately, reducing anxiety, and supporting shared decision making.

The committee noted from the evidence and their experience the psychological impact of heart valve disease, whether or not symptoms are currently being experienced. It was agreed and recommended that clinicians should be aware of the potential psychological impact of receiving a diagnosis of heart valve disease and consider providing appropriate additional advice and support to those receiving a heart valve disease diagnosis. Based on the fact that this may not always be done in current practice and therefore would represent increased resourcing and subsequent cost, and that it may not be deemed necessary based on each individual, a consider rather than offer recommendation was made. It was noted that specialist heart valve nurses may be a good source of additional support where available. It was also noted that clinicians should approach discussions with an appreciation of this possible psychological impact of heart valve disease. Support could also be provided by establishing a support network of expert patients.

The committee stressed the importance of individualised care and shared-decision making in heart valve disease, particularly as the evidence reported the influence of healthcare professionals as one of the factors influencing their decision to undergo TAVI and it was therefore important to ensure that shared-decision making is emphasised. Cross referral to the relevant NICE guidelines was therefore recommended. Also, as with other conditions in which surgery is undertaken in older adults, delirium was reported in the evidence as being prevalent after valve surgery. The committee were aware of the recommendations in the NICE guideline on delirium on information.

1.1.9.4 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this is a qualitative review question.

The committee noted the increased hope and security afforded by having a point of contact for advice between appointments. It could also lead to the timely reporting of symptom change that might indicate disease progression. This could result in more timely intervention. Overall, the committee thought that the benefits would outweigh the potential resource implications of the time needed by healthcare professionals to provide this service. The cost effectiveness of a single point of contact to provide support for patients with heart valve disease is not certain and so a ‘consider’ recommendation was made.

The committee agreed that this applied to all people with heart valve disease, and not just those at the stage of needing or having had valve intervention.

A similar issue regarding resource implications exists for the recommendation to consider providing psychological support for those receiving a diagnosis of heart valve disease, as this may not always be done in current practice, which is why a ‘consider’ recommendation was made.

The other recommendations arising from this review relate to the content of information and so are not expected to have resource implications.

1.1.9.5 Other factors the committee took into account

The committee noted the limitations of the available evidence, which was mostly from those being considered for TAVI. This population is not fully generalisable to all people with heart valve disease, as such patients typically have more complex comorbidities, and their older age means that hopes and fears experienced would be different to those of younger adults. Therefore, a research recommendation was made to seek evidence of the information and advice needs of all adult age groups with heart valve disease of all severities and stages (see Appendix G.1 for details). It was noted that this should include patient-reported outcomes and experiences of decision aids. Furthermore, this research would inform when to give information and further detail on the themes that need to be included. The research recommendation may also lead to a stronger ‘offer’ recommendation on the point of contact.

The committee noted that specific information may need to be provided, as appropriate on wound care, valve care, the surveillance regime post-intervention and mental health support.

The committee discussed the information and support needs of people who live some distance from specialist services. They noted that some people will want to travel to these services whereas other will prefer care nearer to home. The committee therefore signpost to the recommendations on tailoring healthcare services for each patient in the NICE guideline on patient experience of adult services.

The committee highlighted the need to ensure that people are involved in decisions about their care including people for example with dementia and learning disabilities. The committee noted the importance of providing information on advocacy services and, if the person needs it and consents to it, providing an independent advocate who will attend appointments. The committee were aware of the recommendations on involving people living with dementia in decisions about their care in the NICE guideline on dementia and on communicating and making information accessible in the NICE guideline on care and support of people growing older with learning disabilities.

The committee highlighted the importance of providing information and support to young adults regarding transition from paediatric to adult services. They made a recommendation signposting to the NICE guideline on transition from children’s to adults’ services for young people using health or social care services.

1.1.9. Recommendations supported by this evidence review

This evidence review supports recommendations 1.9.1-1.9.5 and the research recommendation on patient information.

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Appendices

Appendix A Review protocols

Table 5: Review protocol for information and support

ID	Field	Content
0.	PROSPERO registration number	CRD42020182872
1.	Review title	What information and advice is useful and valuable to adults with heart valve disease and their family and carers?
2.	Review question	What information and advice is useful and valuable to adults with heart valve disease and their family and carers?
3.	Objective	To determine the subject areas, information and kinds of discussions that are useful and valuable to adults with heart valve disease, their family and carers.
4.	Searches	The following databases (from inception) will be searched: • Embase • MEDLINE • CINAHL • PsycINFO Searches will be restricted by: • English language • Human studies • Letters and comments are excluded

		Other searches: • Inclusion lists of relevant systematic reviews will be checked by the reviewer. The searches may be re-run 6 weeks before the final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Diagnosed heart valve disease in adults aged 18 years and over: Aortic (including bicuspid) stenosis, aortic regurgitation, mitral stenosis, mitral regurgitation and tricuspid regurgitation.
6.	Population	Inclusion: Adults aged 18 years and over with diagnosed heart valve disease and their family and carers. Information concerning people with different stages of heart valve disease will be reported separately if available, as follows: • Mild • Moderate • Severe • Post-valve intervention Exclusion: Children aged less than 18 years. Adults with congenital heart disease (excluding bicuspid aortic valves). Tricuspid stenosis and pulmonary valve disease. Mixed population with <75% heart valve disease
7.	Intervention/Exposure/Test	Views, opinions and experiences relating to information, education or support

8.	Comparator/Reference standard/Confounding factors	N/A
9.	Types of study to be included	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches, including survey data or other types of questionnaires only if they provided analysis from open-ended questions). Quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified. This will be decided in discussion with the guideline committee.
10.	Other exclusion criteria	Exclusion criteria: • Non-English language studies • Conference abstracts will be excluded because they are unlikely to contain enough information to assess whether the population matches the review question in terms of previous medication use, or enough detail on outcome definitions, or on the methodology to assess the risk of bias of the study.
11.	Context	Heart valve disease (HVD) in adults can have a notable effect on the person's quality of life and has key points where shared-decision making must be optimised. Adequate face-to-face discussions, support and information provision for a person with HVD and their family and/or carer can aid care planning and management, improve understanding and accuracy of expectations, and can influence quality of life. As such, this information for a person with HVD and their family and/or carer, provided both from direct contact with healthcare professionals and in the community, can be invaluable. Any type of information and support described by studies will be included with no restriction by country or setting.
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and may include: • Decision making • Preferred format of information provision (e.g. face-to-face discussion, paper, electronic) • Content of information (e.g., symptom reduction, timing of intervention)

		• Impact of treatment on lifestyle and lifestyle on treatment • Information sources other than healthcare professionals (e.g. support groups, online resources, telephone helpline, Apps) • Psychological support e.g., for support with anxiety, fear, confidence) • Delivery of support (e.g. patient's GP, specialist cardiac nurse, peer groups, cardiac chatrooms) • Greater understanding of own condition • Confidence in self-management • Resilience
13.	Secondary outcomes (important outcomes)	N/A
14.	Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract information from studies (see Developing NICE guidelines: the manual section 6.4). Once saturation is considered to have been reached (all the themes are already covered in the data extraction) data from other included papers will not be extracted or critically appraised, but the paper will still be read to check for any additional themes and will be noted in the included studies. The point at which data saturation is reached will be noted within the review.10% of the sifting and extractions will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third party.
15.	Risk of bias (quality) assessment	Appraisal of methodological quality: The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) qualitative

		checklist Evidence will be analysed using thematic analysis; findings will be presented narratively and diagrammatically where appropriate. Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes. 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: • papers were included /excluded appropriately • a sample of the data extractions • correct methods are used to synthesise data • a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary.
16.	Strategy for data synthesis	The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings. GRADE CERQual will be used to synthesise the qualitative data and assess the certainty of evidence for each review finding.
17.	Analysis of sub-groups	**Groups that will be analysed separately (strata):** Information concerning people with different stages of heart valve disease will be reported separately if available: • mild • moderate

		- severe - post-valve intervention Severity will be reported as defined in the studies. **Subgroups that will be investigated if heterogeneity is present:** Not applicable		
18.	Type and method of review	☐	Intervention	
		☐	Diagnostic	
		☐	Prognostic	
		☒	Qualitative	
		☐	Epidemiologic	
		☐	Service Delivery	
		☐	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	09/05/2019		
22.	Anticipated completion date	17/06/2021		
23.	Stage of review at time of this submission	Review stage	Started	Completed

		Preliminary searches	☑	☑
		Piloting of the study selection process	☑	☑
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		Data analysis	☑	☑
24.	Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail HVD@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre		
25.	Review team members	From the National Guideline Centre: Sharon Swain [Guideline lead] Eleanor Samarasekera [Senior systematic reviewer]		

		Nicole Downes [Systematic reviewer] George Wood [Systematic reviewer] Robert King [Health economist] Jill Cobb [Information specialist] Katie Broomfield [Project manager]
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10122
29.	Other registration details	None
30.	Reference/URL for published protocol	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication

		• publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords	Aortic regurgitation; aortic stenosis; carers; family; heart valve disease; information; mitral regurgitation; mitral stenosis; qualitative; patient information; tricuspid regurgitation	
33.	Details of existing review of same topic by same authors	N/A	
34.	Current review status	☐	Ongoing
		☒	Completed but not published
		☐	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information	N/A	
36.	Details of final publication	www.nice.org.uk	

Appendix B Literature search strategies

Heart valve disease – search strategy 12 – patient information

This literature search strategy was used for the following review:

- What information and advice should adults with heart valve disease and their family and carers receive?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[36]

For more information, please see the Methodology review published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 6: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 - 14 October 2020	Exclusions
Embase (OVID)	1974 - 14 October 2020	Exclusions
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 14 October 2020	
PsycINFO (ProQuest)	Inception – 14 October 2020	

Medline (Ovid) search terms

1.	exp Heart Valve Diseases/
2.	exp heart valves/
3.	((primary or secondary) adj valv* disease*).ti,ab.
4.	((valv* or flap* or leaflet*) adj1 (heart or cardiac) adj (disease* or disorder* or failure or failed or dysfunction* or insufficien* or repair* or replace* or damage* or leak*)).ti,ab.
5.	((mitral or aortic or tricuspid or pulmon*) adj (valv* or flap* or leaflet*) adj (disease* or disorder* or failure or failed or dysfunction* or insufficien* or repair* or replace* or damage* or leak*)).ti,ab.
6.	((mitral or aortic or tricuspid or pulmon*) adj3 (prolapse or regurgitation or stenos?s or atresia or insufficienc*)).ti,ab.
7.	exp Heart Murmurs/
8.	((heart or cardiac) adj murmur*).ti,ab.
9.	or/1-8
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.
18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.
20.	18 not 19
21.	animals/ not humans/
22.	exp Animals, Laboratory/
23.	exp Animal Experimentation/
24.	exp Models, Animal/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27

29.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
30.	28 not 29
31.	limit 30 to English language
32.	"patient acceptance of health care"/ or exp patient satisfaction/ or consumer health information/ or needs assessment/
33.	Patient Education as Topic/ or exp patients/ or exp family/ or caregivers/ or patient preference/
34.	((client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)).ti,ab.
35.	((educat* or learn* or support*) adj3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
36.	((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) adj3 (service* or information* or material* or virtual*or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
37.	or/32-36
38.	31 and 37

Embase (Ovid) search terms

1.	exp valvular heart disease/
2.	exp heart valve/
3.	((primary or secondary) adj valv* disease*).ti,ab.
4.	((valv* or flap* or leaflet*) adj1 (heart or cardiac) adj (disease* or disorder* or failure or failed or dysfunction* or insufficien* or repair* or replace* or damage* or leak*)).ti,ab.
5.	((mitral or aortic or tricuspid or pulmon*) adj (valv* or flap* or leaflet*) adj (disease* or disorder* or failure or failed or dysfunction* or insufficien* or repair* or replace* or damage* or leak*)).ti,ab.
6.	((mitral or aortic or tricuspid or pulmon*) adj3 (prolapse or regurgitation or stenos?s or atresia or insufficienc*)).ti,ab.
7.	exp heart murmur/
8.	((heart or cardiac) adj murmur*).ti,ab.
9.	or/1-8
10.	letter.pt. or letter/
11.	note.pt.
12.	editorial.pt.
13.	Case report/ or Case study/

14.	(letter or comment*).ti.
15.	or/10-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animal/ not human/
19.	Nonhuman/
20.	exp Animal Experiment/
21.	exp Experimental animal/
22.	Animal model/
23.	exp Rodent/
24.	(rat or rats or mouse or mice).ti.
25.	or/17-24
26.	9 not 25
27.	(exp child/ or exp pediatrics/) not (exp adult/ or exp adolescent/)
28.	26 not 27
29.	limit 28 to English language
30.	patient attitude/ or patient preference/ or patient satisfaction/ or consumer attitude/ or needs assessment/
31.	*patient information/ or *consumer health information/ or *family/ or *caregivers/
32.	*patient education/
33.	((client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)).ti,ab.
34.	((educat* or learn* or support*) adj3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
35.	((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) adj3 (service* or information* or material* or virtual*or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
36.	or/30-35
37.	29 and 36

CINAHL (EBSCO) search terms

S1.	(MH "Heart Valve Diseases+")
S2.	(MH "Heart Valves+")
S3.	TX (primary or secondary) AND TX valv* disease*

S4.	TX (valv* or flap* or leaflet*) AND TX (heart or cardiac) AND TX (disease* or disorder* or failure or failed or dysfunction* or insufficien* or repair* or replace* or damage* or leak*)
S5.	TX (mitral or aortic or tricuspid or pulmon*) AND TX (valv* or flap* or leaflet*) AND TX (disease* or disorder* or failure or failed or dysfunction* or insufficien* or repair* or replace* or damage* or leak*)
S6.	TX (mitral or aortic or tricuspid or pulmon) AND TX (prolapse or regurgitation or stenosis or stenoses or atresia or insufficienc*)
S7.	(MM "Heart Murmurs")
S8.	TX (heart or cardiac) AND TX murmur*
S9.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8
S10.	TX (client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) AND TX (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)
S11.	TX (educat* or learn* or support*) AND TX (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster* or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)
S12.	TX (patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) AND TX (service* or information* or material* or virtual*or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster* or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)
S13.	S10 OR S11 OR S12
S14.	S9 AND S13

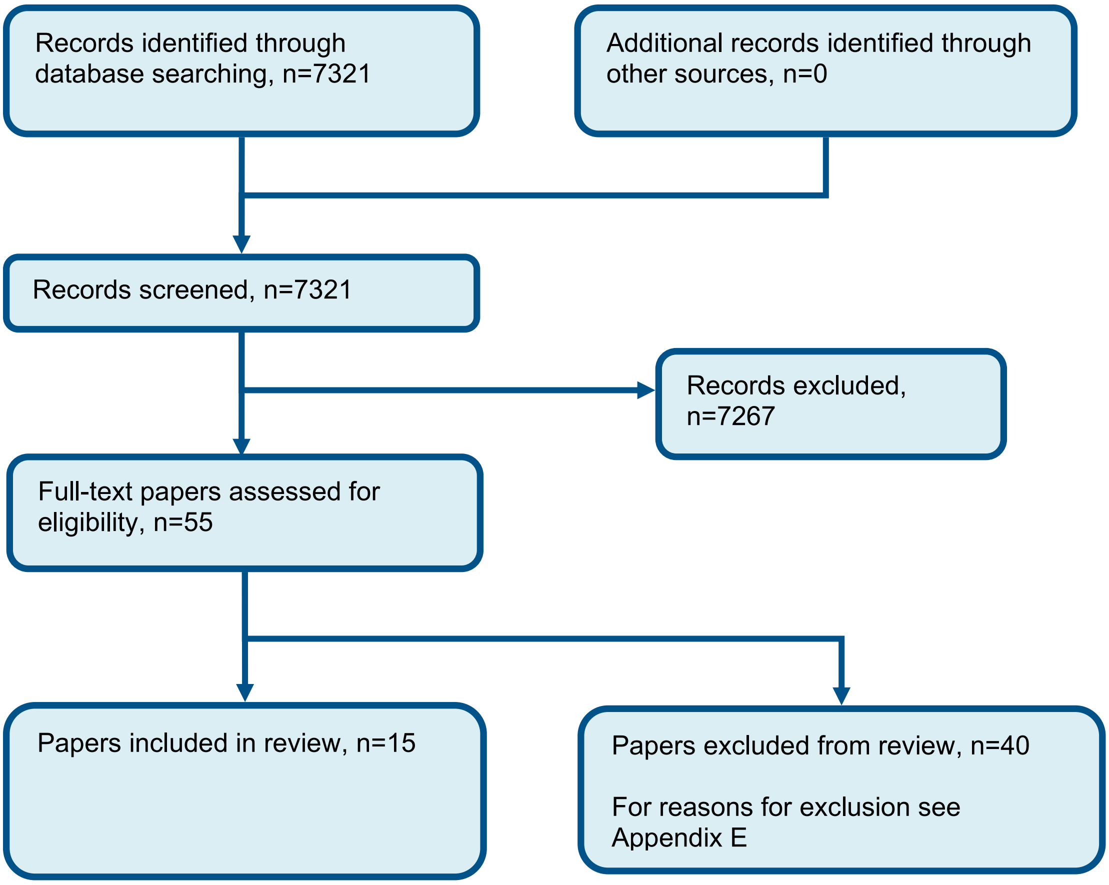
PsycINFO (ProQuest) search terms

1.	((MAINSUBJECT.EXACT("Heart Valves") OR (heart valve disease*) OR ab(primary OR secondary NEAR/2 valv* diseases*) OR ti(primary OR secondary NEAR/2 valv* diseases*) OR ab(((mitral OR aortic OR tricuspid OR pulmon*) NEAR/1 (valv* OR flap* OR leaflet*) NEAR/1 (disease* OR disorder* OR failure OR failed OR dysfunction* OR insufficien* OR repair* OR replace* OR damage* OR leak*))) OR ti(((mitral OR aortic OR tricuspid OR pulmon*) NEAR/1 (valv* OR flap* OR leaflet*) NEAR/1 (disease* OR disorder* OR failure OR failed OR dysfunction* OR insufficien* OR repair* OR replace* OR damage* OR leak*))) OR ab(((valv* OR flap* OR leaflet*) NEAR/1 (heart OR cardiac) neaer (disease* OR disorder* OR failure OR failed OR dysfunction* OR insufficien* OR repair* OR replace* OR damage* OR leak*))) OR ti(((valv* OR flap* OR leaflet*) NEAR/1 (heart OR cardiac) neaer (disease* OR disorder* OR failure OR failed OR dysfunction* OR insufficien* OR repair* OR replace* OR damage* OR leak*))) OR ab(((mitral OR aortic OR tricuspid OR pulmon*) NEAR/3 (prolapse OR regurgitation OR stenosis OR stenoses OR atresia OR insufficienc*))) OR ti(((mitral OR aortic OR tricuspid OR pulmon*) NEAR/3 (prolapse OR regurgitation OR stenosis OR stenoses OR atresia OR insufficienc*)))) OR (MJMAINSUBJECT.EXACT("Heart Disorders") OR ti(((heart OR cardiac) NEAR/1 murmur*)) OR ab(((heart OR cardiac) NEAR/1 murmur*)))) AND (ab(patient* OR carer* OR caregiver* OR famil* OR parent* OR

	father* OR mother* OR spouse* OR wife OR wives OR husband* OR next of kin OR significant other* OR partner* OR guardian* OR inpatient* OR outpatient* OR in patient* OR out patient*) OR ti(patient* OR carer* OR caregiver* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR next of kin OR significant other* OR partner* OR guardian* OR inpatient* OR outpatient* OR in patient* OR out patient*))

Appendix C Qualitative evidence study selection

Figure 2: Flow chart of qualitative study selection for the review of information and support



Appendix D Qualitative evidence tables

Study	**Astin 2017**[1]
Aim	To provide an in-depth understanding of patient's views about the impact of transcatheter aortic valve implantation on self-reported quality of life during early recovery (up to 3 months post-TAVI)
Population	A total of 53 participants that were on the waiting list for TAVI were included. All participants scheduled to undergo TAVI at a single regional centre in the North of England were invited to participate. English-speaking participants with a Mini Mental State Examination score ≤17 and able to provide consent were included. Maximum variation approach used to purposefully select a sample to capture a variety of patient experiences by age and gender. Eligible patients were identified by clinical staff not involved in the study. n=53; 21 male: 32 female; mean (SD) age 81.7 (7.36) years; all of Caucasian ethnicity; 39.6% had a carer; 81.1% NYHA class III or IV
Setting	Interviews were conducted for all patients in their homes.
Study design	Mixed methods, including qualitative interviews and quantitative assessment of quality of life scores.
Methods and analysis	Each participant completed a series of up to two in-depth, face-to-face interviews that were semi-structured and qualitative. Interviews were performed in their own homes. Time-points for data collection (1 and 3 months post-TAVI) were selected as cardiac patients and their carers find the early post-discharge period of recovery challenging. Open-ended questions were used, for example 'tell us about your experience of TAVI', 'have any aspect of your life changed because of TAVI treatment', 'do you think TAVI has influenced your quality of life' and 'if yes then how has this happened and what has changed?' One experienced researched trained in qualitative methods performed all of the interviews supplemented by field notes until data saturation was confirmed. Framework analysis was used to explore emerging concepts on a case-by-case basis. An initial coding framework was developed by three researchers after the coding of the first five transcripts. Themes representing unifying concepts or statements about the impact of TAVI on quality of life during a 3 month recovery period are presented. Authentication of data interpretation was through a series of audiorecorded team meetings where decisions about analysis strategy were discussed, disconfirming cases were reviewed and potential sources of researcher bias considered. Disagreement between reviewers was resolved by revisiting raw data and reviewing the fit of interpretations. Quantitative data on quality of life were also collected by using the SF-12 and EQ-VAS instruments. These were not extracted for analysis as this review focused on qualitative data. At the 1-month follow-up, 1 patient had died, 5 had withdrawn and 1 could not be contacted but participated in a later interview. By 3 months, a further 3 patients had withdrawn from the study.
	Shortened life

Study	**Astin 2017**[1]
Findings	1. **Facing mortality:** a primary concern for participants as their aortic stenosis progressed was the feeling of impending death and the effect this may have on their family, this included fear about dying alone or concern about the impact of their death on their spouse. Others felt they had lived their life and thought there was little point worrying about things out of their control. Those with extreme breathlessness commented that death may be preferable to their current situation. While waiting for TAVI, feelings of fear and loneliness and a short temper were reported. Most participants were in their eight or ninth decade of life and had experienced the death of family members and friends that had led to changes in their personal relationships and social networks. Living with a life-limiting condition often increased the emotional closeness of remaining family members. 2. **Deciding to have TAVI:** pre-TAVI consultation involved a patient-doctor discussion about the risks and benefits of TAVI and potential outcomes, as well as the prognosis if no treatment was given. Responses to the consultation varied. Some appreciated the candid and honest approach while others found the information distressing and felt the risks were emphasised more than the benefits. All participants were aware that their heart condition meant their life expectancy was shortened and for many TAVI was a source of hope as they had a treatment option that could improve their life where they had thought there wasn't one.
	Limited life: the health of participants was severely affected by aortic stenosis and comorbidities. Symptom burden limited their opportunity to live what was described as a 'full life' and day-to-day life was a 'struggle' for many. 1. **Symptom burden:** prior to TAVI most reported moderate-severe breathlessness leading to physical restrictions, which negatively impacted day-to-day life. Breathlessness severity affected energy levels and fatigue. Common complaints were shortness of breath, dizziness, fainting, falls, fatigue, pain, sleep disturbance, memory loss, concentration and appetite. Extreme breathlessness was reported by some patients and they reported this to be frightening (one participant had to sleep in a chair because of breathlessness, was unable to talk to family on the phone and fearful to go anywhere alone). An increased dependence on others to manage daily activities meant some participants reported feeling a burden and worthless. 2. **Functional and social restrictions:** symptom burden and associated physical limitations led to restrictions in many areas of participants' lives but leisure/social activities were reported to be most affected. Participants often described themselves as having lost their independence and many felt unable to leave their homes, leading to functional and social restrictions. Being confined to the home led to reduce social contact, which caused feelings of loneliness, isolation, boredom, loss of control and depressive symptoms. Many reported a loss of pleasure in life and a lack of motivation. Others highlighted restrictions on driving and taking holidays and inability to be involved in day-to-day activities of normal life, for example hygiene needs, housework, meal preparation, gardening and caring for family members such as grandchildren. These were either not possible or took much longer than before, which led to feelings of frustration and misery. Accounts highlighted the link between physical

Study	**Astin 2017**[1]
	functioning and psychological well-being as reduced functioning led to more restrictions in physical ability and reduced psychological well-being.
	Extended life: TAVI was viewed as an intervention that could treat their life-threatening heart condition and was preferable to surgical aortic valve replacement 1. **Survival:** all participants were aware of their life-limiting condition and the possible risks associated with having TAVI. Relief of having survived the TAVI procedure was expressed as well as gratitude at being able to have this procedure. Those with a successful TAVI reported the feeling of having a longer life-span.
	Changed life: reduced symptom burden and prospect of a longer life following the TAVI procedure was reported as 'life-changing' by many participants. They appreciated the availability of a procedure that could offer the potential for a better life, particularly at an advanced age. Post-recovery a change in the nature of relationships with significant others was evident for many participants. Participants were more focused on these connections and wanted to change from the feeling of being a burden to being 'of use'. 1. **Symptomatic relief:** for most, TAVI impacted on quality of life by reducing the burden of physical symptoms that were experienced daily. Many reported the improvement in breathing to be the best thing about TAVI. The magnitude and pace of improvement varied, with some experiencing an immediate improvement in their physical health and others having a more gradual improvement. The existence of other health conditions mediated the scale of improvement, meaning some experienced less of an improvement than they had hoped in terms of symptom improvement. For example, comorbidities such as COPD or morbid obesity appeared to counteract any improvements in their symptoms due to their heart condition as symptoms associated with their comorbidities were not relieved by the TAVI procedure. It was often difficult for those living with multiple comorbidities to assess the impact of TAVI on their own symptom burden and quality of life, explaining that it was difficult for them to understand which physical symptoms were attributed to which condition. Reduced symptom burden changed the views of some participants about their desired length of life. Others reported a less dramatic change in symptoms but still reported some improvement. Many reported reduced fatigue following TAVI. Others reported less shortness of breath and that they could go about their daily activities faster. Health improvements led to improved mood, with participants and family members reporting that participants less short-tempered. No participants openly expressed regret about having the TAVI procedure, though one acknowledged that the procedure had extended their life but commented that it had not improved their symptom burden as they much as they had hoped. For those not achieving the improvement in symptoms they had hoped, an improvement in quality of life was still experienced. For some TAVI was a bridge to other procedures that they had not been well enough for previously. One example was access to elective surgical procedures, such as hip surgery, which would potentially benefit quality of life. For others the knowledge that all that was possible had been done to improve their health was some improvement. Another participant mentioned the potential

Study	Astin 2017[1]
	health improvement following TAVI would enable them to continue caring for their spouse. When successful, TAVI often allowed participants to regain a level of functional capacity they had experienced at a younger age. A number of participants described 'the turning back of time' or having 'a new lease of life'. 2. **Feeling safe:** many said that TAVI led to feelings of them 'being safe', 'more confident' and having 'peace of mind'. The feeling of imminent death was removed and their 'repaired' heart meant they could participate more in daily activities. The significant reduction in symptoms most participants expected they felt signalled a tangible improvement in their heart function and contributed to feelings of security. Even for those not experiencing large improvements there was a feeling that everything had been done for their health. Increased confidence regarding physical health enabled participants to return to some activities they had previously stopped, such as taking holidays. This allowed a fuller life and increased participation in social activities.
Limitations and applicability of evidence	Minor limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis; however, there were concerns about data richness as only limited data was provided, with only few quotes and the number of participants contributing to each theme not being clear. In addition, although potential researcher bias was discussed in meetings, a discussion of how this may have affected results was not provided in the report and it was unclear whether ethical approval was obtained. The study was specifically on AS patients undergoing TAVI and not general HVD patients. The evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Baumbusch 2018[2]
Aim	To examine in-depth experiences and perspectives of patients and family caregivers at one year after TAVI
Population	Recruitment materials mailed to patients that underwent TAVI between August 2013 and October 2014 and who had completed 1 year follow-up care. Purposive sampling performed to ensure maximum variation in terms of gender and geographical distance from the site where procedures were performed. Patients that consented were then asked if they had a family caregiver who supported them during the procedure and recovery procedure and materials were then sent to them to invite them to participate. n=31 patients (13 male: 18 female; median, range age: 81, 58-96 years) and n=15 family caregivers (5 male: 10 female; mean, range age: 75.93, 56-95 years). Among patients, mean (range) proximity to procedure site was 244 (1-1225) km, with the majority living >100 km from the site and requiring road, ferry or air travel from their home. 32% lived alone, 36% lived with their spouse only, 23% lived with their spouse and other family members, 3% with a friend and 6% lived with other. Medical history data was missing for 2 participants, but median NYHA class was III, mean ejection fraction was 59%, 10% had previous percutaneous coronary intervention and 17% had previous coronary artery bypass grafting.

Study	Baumbusch 2018[2]
	Among family caregivers, 7% worked full-time, 20% worked part-time and 73% were retired. The person they were caring for was their spouse in 87% of cases and parent/in-law in 13% of cases. 87% of caregivers lived with the person they were caring for and 13% did not.
Setting	Recruited from a centre in western Canada where >300 procedures are performed annually, and which provides specialty services across a large area with dispersed populations. Telephone interviews for most patients (n=29) due to geographical spread of patients, though 2 were interviewed in person due to hearing impairment.
Study design	Qualitative interviews
Methods and analysis	Semi-structured interviews conducted between April and November 2015 with patients and caregivers. Most interviews were held over the telephone due to patients being spread over a large geographical area. Patients and caregivers were could be interviewed together or separately as previous research had indicated a preference to be interviewed together, and all apart from one family chose to be interviewed together. This was felt to be appropriate as patients and caregivers had a shared experience of TAVI recovery. Open-ended questions were asked about the experience of undergoing TAVI as well as the current health status of patients. Data analysis took place concurrently with data collection and continued until informational redundancy was achieved. Interviews were transcribed verbatim and transcripts were used to analysis. General inductive approach used for coding and generation of themes. Patient and caregiver perspectives as a whole were analysed. A clear audit trail was used to address dependability through documenting team meetings, memos through research process and reporting study procedures.
Findings	**Recovery in the context of aging and comorbidities** **1. Limited options:** TAVI was the only option for the patients due to other cardiac issues, comorbidities or frailty making them not eligible for surgery. The wife of one participant explained the limited options her husband had due to his health, explaining that they were aware that a fourth surgical intervention would not be possible and that TAVI may have to be performed. In the absence of alternatives, patients and family caregivers were grateful for the possibilities that TAVI offered. This feeling was said to be shared by all participants. **2. Post-procedure symptom burden:** some participants described an immediate, positive change post-TAVI, with three quotes given to support this from different patients. However, some found they did not experience the improvement they had expected following TAVI, with a quote from one participant highlighting some disappointment in not being able to do as much as they used to but recognising that they can still do some things at a slower pace. 3. **Recovery in relation to other comorbidities:** some participants recognised and ascribed ongoing health issues to other diagnoses and increasing frailty. For example, one participant highlighted that their arthritis stops them from doing a lot of the things they would like to do even post-TAVI. Comorbidities affected how participants felt about their quality of life post-TAVI and often overshadowed the symptom relief experienced due to TAVI, with one participant explaining that their severe rheumatoid arthritis still requires them to be on morphine and is something they are not satisfied with.

Study	Baumbusch 2018[2]
	Sometimes family caregivers helped participants to reflect upon changes related to TAVI and those related to other, ongoing, health conditions. For example, the wife of one patient helped them to reflect on what they could do immediately before the procedure and to compare that with what they could do post-TAVI, rather than comparing to when they were years younger. Patients reported relief from aortic stenosis symptoms but struggled with ongoing health issues and frailty that affected their wellbeing.
	Reconciling expectations with reality 1. **Unexpected reality:** while some reported immediate positive effects following the procedure, over time they had to reconcile improved aortic stenosis symptoms with the reality that they still had complex and challenges health issues. Some participants shared the feeling that their expectations of life after the procedure were very different to the reality, with one commenting that they thought they would not be cured but be healthy again and would not deteriorate, and another saying that they felt worn out and like they were not living even after TAVI and that they expected to be able to move faster and do more than they are able to currently. Some participants compared their life pre- and post-procedure as a way of reconciling the reality that they still had frailty and other comorbidities to consider, for example, one participant reflected that if they had not had the procedure they might not be doing the interview now as they were aware that they could have deteriorated rapidly and so they were happy with the outcome of the procedure. They had also been able to return to their hobby following the procedure, which their condition prior to TAVI had prevented them from doing. 2. **Influence of providers on expectations:** the expectations of participants in terms of the TAVI procedure were partly shaped by information given to them from clinicians prior to the procedure. One caregiver described how this shaped his mother's recovery, as the clinician commented that she would be able to return to her walking and 'be able to climb mountains' following the procedure. They explained that this certainly wasn't the case and that they should not have said that, but that she is aware of her health now and doesn't push herself too much as she realises her limitations. 3. **Expectations of others:** caregivers had to manage their own expectations. For example, one husband had expected his wife to be in a better shape than she was following the procedure, though acknowledging he didn't think it would be a miracle reaction. Expectations of others also had to be managed, for example other relatives. One participant described the reaction of her brother when she got home from the hospital, with him being surprised that she was not able to do more immediately after the procedure. The participant commented that this may have been because it was not open heart surgery there was the expectation that it would not be as draining. She also commented that other people made similar comments.
	Recommendations for recovery 1. **Information needs:** several participants highlighted patient education, particularly before the procedure, as an important aspect. With one participant explaining that they realised the more information patients can get before the procedure the better. Others shared that they had not expected to experience pain at the incision site during the immediate recovery period and that this information should be emphasised more to prepare them for it.

Study	Baumbusch 2018[2]
	2. **Keeping patients and caregivers informed of evolving care practices:** the shift towards minimising hospital stay, part of evolving care processes, resulted in an unanticipated information gap between pre-procedure teaching and the time of the procedure. Though participants had arranged support at home following the procedure, based on information provided to them in the pre-admission clinic, some were not prepared for discharge potentially as early as the next day. 3. **Address unique needs of patients living at a distance from the procedure site:** some had to travel long distances to the procedure site and several participants commented on the need for systems in place to assist with transportation. One participant commented on this gap in support, explaining that there was no set procedure day or time and that it was up to the doctor. His wife described that it felt emotional and like being in a cattle car when travelling by bus to the procedure site. 4. **Emphasise need for informal support during initial recovery:** family caregivers had a central role during the recovery period. One participant that lived alone said that every patient should have someone there for them for at least 3 weeks. Caregiver knowledge during the recovery period, in order to be vigilant about possible complications, was also emphasised as important by participants. One caregiver described their situation following the procedure where they were told to be aware of bleeding at the groin site but were not made aware of how this may or may not present and what would be normal following TAVI procedure. As the patient had woken up in the night very concerned that they were bleeding and the caregiver could feel some hardness or a lump and saw bruising, the patient was taken back to hospital. On arrival they said this was nothing abnormal and was to be expected.
Limitations and applicability of evidence	Moderate limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis; however, there were concerns about data richness as only limited data was provided, with lot of quotes but the number of participants contributing to each theme and sharing the same thoughts not being clear. In addition, the role of the researcher and the potential impact of this was not discussed. There were some concerns about the method used for interviews as most had telephone interviews and patients and family caregivers were interviewed together rather than separately, which may have affected the responses people were willing to give. In addition, 2 participants received face-to-face interviews due to hearing impairments, meaning interview method differed between participants. It was also unclear who performed the interviews and how this may have affected results. The study was specifically on AS patients undergoing TAVI and not general HVD patients. The evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Berg 2013[3]
Aim	To explore patient experiences of recovery at home following heart valve replacement, including traditional open-heart surgery and transcatheter valve replacement. This aimed to include aspects such as current health problems and thoughts about the future.

Study	**Berg 2013**[3]
Population	A total of 10 participants who had a heart valve replacement within 6-9 months previously were included. This time-frame was chosen to ensure sufficient time to experience recovery from the procedure. Of those included, 2 had pulmonary valve replacement and 8 had aortic valve replacement either by traditional surgery or TAVI. Ten patients were thought to provide good insight into how the recovery could be experienced with the knowledge that more patients would add to the level of insight. Participants were identified from hospital database and selected to represent both genders, different age groups and types of replacement (surgery or TAVI) to achieve maximum variation, though they were said to be consecutively included. A research assistant initially approached participants via letters, followed by phone calls, to ask if they would participate. An informed consent form was sent prior to interviews to be signed. Study performed in a single hospital in Denmark. n=10; 5 male: 5 female; mean (range) age: 66 (20-85) years; 8/10 lived with a partner; 3/10 were employed; 5/10 had open surgery and 5/10 had TAVI; and 5/10 had rehabilitation at their local setting.
Setting	Interviews were performed either in an office at the hospital or in their homes. Some opted for interviews to be performed at home to avoid transportation to the hospital.
Study design	Qualitative interviews
Methods and analysis	Phenomenological-hermeneutic frame dealing with human perception and experiences of recovering from heart valve replacement. Interviews aimed to answer the following questions: 'what are the experiences of returning home after a heart valve replacement?'; 'what are the new experiences in daily living following the procedure?'; 'which health problems are experienced?'; and 'what are the thoughts about the future?'. The questions were used as an interview guide to fulfil the purpose of the study. Semi-structured interview guide developed allowing for open-ended questions asking patients to describe experiences freely and openly and to ensure consistency. Though it provided a frame it was not followed step-by-step. Patients had time to read through and familiarise themselves with the guide beforehand. Authors were nurses and their pre-understanding was that recovery would be smooth but long and that patients were not closely followed by the health care system. These thoughts were set aside at interviews as no closed questions were asked and patients were allowed to talk about the topics they felt were important. Interviews lasted 30-50 minutes on average. Two researchers, who were not known to the patients beforehand, were present during interviews with one being the primary interviewer. Interviews were tape-recorded and transcribed by a secretary. Data was kept confidential and reported anonymously. Patient statements were repeated to them during the interview to ensure the interpretation was correct. Analysis consisted of three levels (naïve reading, structured analysis and critical interpretation and discussion). Two interviewers analysed separately and then discussed the findings on each level. **Naïve reading** involved reading text several times to understand meaning in a way that requires them to be open and put pre-understanding aside. **Structured analysis** involves moving from what the text says to what it speaks about and aims to validate or invalidate the naïve reading. All units of meaning were identified and patterns were identified, which were used to produce themes. Contradictory data were included in perspectives on the same area. **Critical interpretation and discussion** involved comparing and contrasting themes to other research findings and discussing the meaning.

Study	Berg 2013[3]
	Use of two researchers and the possible effect on results is described, highlighting that it is possible it could be overwhelming for some patients, though they justify their reasoning and how two researchers appeared to benefit the interview process.
Findings	**Suffering weakness, struggling to resume normality:** overall concept emerging from the analysis. Patients felt weak since before they needed the intervention and was very present, though in a more physical form, following the procedure, with some experiencing extreme tiredness and deconditioning. All struggled to resume normal living in terms of regaining physical strength and re-establishing balance in overall living, meaning they struggled to re-establish their role in society and networks and emotional and physical balance. 1. **Disturbed network:** being in a fragile situation following valve surgery, network became of great importance. Patients often could not look after themselves following release from hospital and spoke about relatives being invaluable. Relationships changed for a while with parents, friends and partners having new roles as helpers both physically and emotionally. Examples of tasks patients required assistance with were preparing food, assisting in heavy lifting and driving. Some commented that they would not have been able to return home so soon without the help of their spouse. Patients also needed friends and family to listen and share views to process all of their experiences. Many were grateful for their relatives; however, some did not handle the altered situation well often due to broken expectations and some relationships had to be repaired and rebuilt after recovery. Patients needed guidance and answers when understanding symptoms and sensations following hospital release. Some had good contact with healthcare staff while others felt rejected and lost. There was often insecurity about how to handle illness and recovery, particularly at the beginning when going from a safe hospital environment to a home environment, which also applied to spouses. Some participants felt confused about whether follow-up took place at the treating hospital or local hospital. Some were offered rehabilitation while others were not or were offered it but came to late and did not fit their working hours. Resuming a normal life was important. Those not offered rehabilitation regretted this. One participant turned it down and tried to make her own way ahead. Needing physical rehabilitation was an opportunity for some who were not previously physically active to do so. Some remained physically active after the programme, but others returned to a more inactive way of life. 2. **Disturbed body:** stressful complications were experienced by many patents, including brain, kidney or leg thrombosis, pericardial exudates, pseudo-aneurism or anaemia. These affected them physically but also meant they feared further complications such as stroke. Some were anxious and fearful about how to be active in a safe way. Keeping the heart safe was a major concern and participants became very aware of the body, paying attention to signals and sensations. **Increased bodily attention** also included the scar resulting from the procedure. This was a source of psychological stress for some, but others compensated for this by training more to develop a more fit body. Comments were made about how others would look at and see the scar and how they wished to cover it up, both to protect it from the sun and also make a partner feel more comfortable during intimacy. Differences in **physical capability** following the procedure were observed, with some feeling they had benefitted greatly from the procedure in terms of shortness of breath and increased energy in physical activities and others being very disappointed in

Study	Berg 2013[3]
	not feeling improvements, despite health care professionals sometimes measuring an improvement. Many were physically affected, experienced large weight loss and were affected by the procedure. Strange metallic tastes in the mouth were reported to be confusing and connected to ongoing food loathing. Severe sleeping problems in the first 1-2 months were also reported and pain was a major issue for those that had open heart surgery. **3. Recovery:** patients saw the operation as inconvenient as it led to interrupted living meaning that plans and hopes for the future had to be changed, for example travelling and family planning. The weakness and illness that patients experienced also disturbed normal living. **Suffering weakness** meant they felt incapable, were not able to do normal activities or resume normal life. Extreme tiredness overwhelmed many patients. They also felt weak when walking the streets and were worried about people bumping into their chest and taking the bus and it suddenly braking. Patients underestimated how long usual activities required (for example riding a bike or how much work they could do), meaning they had not recognised their own poor physical state. Most patients experienced **gradual recovery**. Walking the street on their own was seen as a great achievement. Some experienced fast recovery while others were affected for many months. Patients described colour returning to their cheeks after a few weeks and how they struggled their way back to **achieve normality**, including returning to work. Feeling normal and not ill was the goal and included regaining independence and a normal relationship to relatives. Demonstrating normality was important to some participants as they did not want to be labelled as being disabled. Feelings of pride and relief were experienced when they were able to return to normal activities. **4. Reflections:** patients experienced relief in doing everyday activities and felt being able to do more without being out of breath was an important result of the intervention; however, some were disappointed that they did not feel any difference. Despite some experiencing life-threatening complications, patients did not regret the procedure. Some expected to have to have the procedure again further down the line but accepted that, though those that had open heart surgery hoped for a less invasive procedure next time. Some participants felt their life was prolonged following the procedure. Thinking about the seriousness of the procedure could lead to them feeling sad and fragile. Thoughts about what really happened in hospital and what could have happened occurred during recovery. Thinking about how close they might have been to death and the disturbing experiences of relatives was heart-breaking. Some were described as very depressed and almost gave up at times when trying to achieve physical and emotional recovery. Others did not find the experience too stressful and quickly achieved emotional closure.
Limitations and applicability of evidence	Minor limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis; however, there were concerns about data richness as only 10 participants were included. Though the sample was said to be purposeful to obtain variation, it was also described as a consecutive sample. Sufficient data was provided to support the findings; however, participants differed with regard to the type of valve operated on (aortic or pulmonary valve) and type of procedure (open heart surgery or TAVI) and this was not explored in order to explain any differences in perspectives between patients, for example the effect of scarring may have been different for those undergoing TAVI and those having surgery. In addition, there were some differences in the methods between patients as the setting differed, with some attending the hospital to be interviewed and others having it at home. The role of

Study	Berg 2013[3]
	the researcher was discussed in terms of how the presence of two researchers in the interview may have affected results and it was highlighted that the background of the researchers as nurses would not have affected the responses as they did not use close questions. The study included those undergoing aortic valve or pulmonary valve replacement not general HVD patients. The evidence is still applicable to the review question but relevance is limited to these sub-populations. There is also indirectness as pulmonary valve disease was not included in the guideline but are combined with results for aortic valve disease in this study.

Study	Coylewright 2016[5]
Aim	To report patient-defined goals from elderly patients facing treatment decisions for severe aortic stenosis and at high surgical risk.
Population	Patients included were elderly and either high risk for surgical aortic valve replacement or inoperable. All had severe AS and were eligible for TAVI following initial heart team evaluation between June 2012 and August 2014. n=46; 25 male: 21 female; mean age 84 years; 89% ≥75 years; STS score: 3-9 (63%), 10+ (32.6%) or not reported (4.3%). 52.2% were discharged to home, 8.7% to home with visiting nurse association, 4.3% to rehabilitation, 28.3% rehabilitation to home, 2.2% rehabilitation to assisted living and 4.3% were deceased before discharge. Seven of those eligible for TAVI chose not to undergo the procedure and had medical management/palliative care. Mean age in this group was 86 years and over half were female.
Setting	Unclear, but likely within the centre the procedure was performed at as was part of a clinical assessment
Study design	Retrospective qualitative analysis of patient responses to a single question asked prior to TAVI to assess patient goals
Methods and analysis	Conducted by members of multidisciplinary heart team at single centre in Northern New England, USA. Heart team broadly includes interventional cardiologists, cardiac surgeons, valvular heart disease clinicians, multimodal imaging experts, palliative care physicians and nurses and other administrative and clinical support staff. TAVI programme coordinator, a master's level nurse in the heart team, usually responsible for assisting in assessment of patient eligibility for TAVI and facilitating discussions with the patient and family concerning processes of care, met with every patient considering TAVI and asked about patient goals by asking the following during the initial evaluation: 'what do you hope to accomplish by having your valve replaced?'. When family members answered for the patient the question was redirected to the patient for further elaboration. These patient-defined goals were documented within a spreadsheet and discussed at heart team conferences in the context of patient risk profiles. Information on perceptions of having met these goals following the procedure were recorded as 'yes' or 'no'. Detailed review of medical records was performed by the TAVI coordinator for those with missing data to assess and categorise goals for therapy. Range of themes identified by patients were used to formulate four descriptive groups to categorise patient-defined goals. These were adapted from prior work in a similar population: **1. Maintaining independence**, **2. Staying alive**, **3. Reducing/eliminating pain or symptoms** and **4. Ability to do a specific activity**. Patient-defined goals were categorised by three independent reviewers and

Study	**Coylewright 2016**[5]
	categorisations compared. Discrepancies were resolved by discussion between reviewers. Whether or not goals were attained post-TAVI was assessed by the team through reviewing electronic medical records. 1-month follow-up visit notes were reviewed as well as notes written by TAVI coordinator at time of follow-up visit. Follow-up visit occurred 3-6 weeks after the procedure. Audio-recording was not performed due to the retrospective nature
Findings	**Maintaining independence:** for 14 patients (30%) improving or maintaining their current level of independence was their desired outcome when thinking about TAVI. Many were previously living alone and due to their condition could not maintain their homes or do chores such as cleaning, gardening, chopping wood or grocery shopping. Most wanted to continue living in an independent setting or to stay in their homes.
	Staying alive: 3 patients said that the primary goal for them was to remain alive. They acknowledged the mortality associated with medical therapy in terms of the natural history of AS and this played a large role. This was often expressed in clear and concise statements such as 'I want to live'. Increasing the length of life for patients was often the preference of adult children and not by the patients themselves. Where this was first stated by family members this was redirected to the patients for further clarification.
	Reducing/eliminating pain or symptoms: 7 patients (15%) highlighted a reduction in pain, symptoms and suffering was their primary aim when considering TAVI. Of these, 3 indicated that treatment for AS was a prerequisite to undergo further procedures to reduce suffering, such as orthopaedic surgery and tumour resection. Of those wanting relief of suffering from AS symptoms, profound and persistent fatigue and a lack of energy was the most consistent complaint. One patient commented on how restricting the limitations were due to them feeling unwell.
	Ability to do a specific activity: 48% expressed their desire to be able to do a specific activity again. This included daily hobbies that they had not been able to do because of their illness and most of the activities involved how patients interacted with their loved ones. This included the ability to regain their stamina to enjoy activities that defined their persona, such as dancing or fishing. Resuming volunteer work and enjoying time spent with their spouses, grandchildren and pets were also mentioned, as well as activities such as hiking, biking or walking, while others enjoyed arts and crafts. Several patients also wanted the ability to travel again. This highlighted specific activities with others as well as personal hobbies that were central to decision-making for each patient.
	Patients that decided against TAVI: seven patients decided against TAVI despite being eligible, choosing to continue with medical therapy and additional support from palliative care. One of these had early Parkinson's disease and this contributed to the decision as they said they would rather die quickly from heart failure than have a prolonged and debilitated life with Parkinson's. The remaining patients wanted to avoid invasive procedures and possible complications. One patient was concerned about the need for blood transfusion during the procedure, while others feared stroke, the possible need for dialysis and prolonged need for ventilation. A focus on maintaining control around end-of-life planning was also apparent.
	Follow-up and achieving goals: of those that underwent TAVI, 87% were determined to have met their goals at 1 month, based on descriptive visit notes and documented NYHA functional status. For example, two patients with goals of becoming more active quantified goal achievement by accomplishments, with one mentioning she was walking around 4 times the distance than before the procedure and another acknowledging a newfound ability to exercise. It was concluded that 6 patients (13%) did not meet their goals, with 2 of them dying in the hospital before discharge and 2 with severe symptoms at 1 month follow-up and passing away within 4 months of discharge. One patient continued to feel debilitated and fatigued,

Study	Coylewright 2016[5]
	which limited the ability to do his favourite activities. Another patient whose goal was to enjoy outdoor hobbies was not met as he continued to feel fatigued at follow-up.
Limitations and applicability of evidence	Moderate limitations. The retrospective nature of this study means that data had been collected before inclusion of the patients and may have led to selection bias. The details surrounding data analysis were also vague with not much detail provided and there was no discussion of the role of the researcher and how this may have affected results. The study appeared to be rich in terms of data with 46 participants included and a good level of detail and examples provided within the text. The study was specifically on AS patients considering TAVI and not general HVD patients. The evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Hansen 2016[11] and Hansen 2018[10]
Aim	To explore structure and content of narratives concerning the recovery process in those undergoing heart valve surgery and participating in cardiac rehabilitation and to identify whether/how these changed within the first 9 months following surgery
Population	Recruited from intervention group of 147 patients in a randomised clinical trial (CopenHeart$_{VR}$) comparing cardiac rehabilitation with usual care. Rehabilitation was started 4 weeks post-surgery and involved a physical exercise training programme tailored to the individual three times weekly for 12 weeks, as well as psychoeducational nurse-led interventions at monthly consultations. The aim of the psychoeducational intervention was to improve coping strategies and disease management, and to provide information to help resume daily life following surgery. Recruited at index valve surgery hospital admission (single hospital in Denmark). Participants had to be at least 18 years old and able to speak and understand Danish, and having elective right- or left-sided heart valve surgery. Exclusion criteria were ischaemic heart disease, diseases complicating physical activity, individuals performing strenuous physical exercise and pregnancy and/or breastfeeding. n=9; 6 male: 3 female; age: 40-49 (n=2), 50-59 (n=2), 60-69 (n=3) and 70-79 (n=2); 5 were employed and 4 retired; surgery was for aortic stenosis in 5 patients and mitral regurgitation in 4 patients; a biological valve was received in 6 patients and a mechanical valve in 3 patients; 4 patients had prior heart disease, 8 patients had symptoms prior to surgery and 6 patients had a comorbidity; 4 patients were readmitted <1 month post-surgery; rehabilitation was home-based in 6 patients, at the local hospital in 2 patients and at the hospital where surgery was performed in 1 patient; the rehabilitation nurse consultations were at the hospital in 5 patients and at the hospital/by telephone in 4 patients.
Setting	Interviews were performed at home (7 patients) or at the hospital (2 patients) according to participant preferences
Study design	Qualitative, prospective narrative interview study
Methods and analysis	Patients were evaluated on entering the trial and 10 consecutive patients were contacted by the first author (PhD student at Department of Cardiology) at the hospital or by telephone after discharge when they represented characteristics needed to ensure high heterogeneity: sex, age, type of surgery, asymptomatic vs. symptomatic prior to surgery and the context for physical exercise training (hospital, municipality or home). One was subsequently excluded due to onset of a severe mental disorder.

Study	Hansen 2016[11] and Hansen 2018[10]
	Aim was to obtain detailed descriptions rather than saturation so priority of resources was given to fewer participants having several interviews rather than interviewing more patients only once. Three consecutive semi-structured interviewed with cardiac rehabilitation patients following heart valve surgery were performed. Interviews were performed by a researcher with previous experience interviewing patients with heart disease. They were performed between April 2013 and October 2014, including at 2-3 weeks, 3-4 months and 8-9 months following discharge. The same interview guide was used to all interviews with only minor modifications. Subsequent questions were adapted to the participants' responses to the first questions. Interviews were 45 minutes long on average and were audio-recorded and transcribed verbatim. Before the later interviews, summaries of the previous interviews were read to ask follow-up questions and clarify any uncertainties. All interviews were conducted in Danish. Adapted an interactionist perspective, which emphasises thematic content and narrative structure of participants' stories and the interaction of creating the stories. Summaries were used to develop initial ideas about participants' perspectives using coding. Changes with the same participant in terms of subsequent interviews were analysed. Preliminary analysis and stages were discussed with co-authors until consensus was reached. Two papers using almost identical methods and using the same data are included, with the second focusing more on the aspects related to the rehabilitation programme.
Findings	**From the primary qualitative study (Hansen 2016)** Immediately following the procedure most expected to return to normal life before the onset of illness. Concepts of normality differed between participants and often involved multiple aspects, such as absence of symptoms, not having to take medication or returning to work. The relative importance of each also varied over time for each participant. 1. **The restitution narrative:** only 2 patients followed the narrative of illness followed by surgery, recovery and returning to normality. Having valve surgery was compared to taking a vehicle to a professional 'repair facility' and neither were worried about undergoing surgery. One participant reflected that the idea of having valve surgery had been less troublesome for her than the idea of having her teeth removed. On discharge, these participants felt tired and had a lack of energy, with one having trouble concentrating. Both felt well-informed and safe and soon became active and competent in the recovery process as they slowly re-established their former identity by resuming activities. At 6-8 weeks post-discharge, initial symptoms had gone and there were improvements in physical and mental health. Cardiac rehabilitation helped physical well-being but also seen as 'nice to have' rather than something they needed to have. Between the second and third interviews both participants had resumed all previous physical and social activities, with one planning an overseas journey further indicating a return to normality for them. 2. **The frustrated struggle to resume normality:** 3 participants pursued normality at each interview. These narratives highlighted a positive progression with fewer and less severe factors opposing their overall goal of normality over time. However, despite the positive progression, these participants did not experience normality at the third interview. Before experiencing heart valve disease symptoms, participants said they felt health and expected to recover easily. Throughout

Study	Hansen 2016[11] and Hansen 2018[10]
	interviews they considered themselves as not normal but not ill, despite feeling ill due to the medications they had to take (particularly anticoagulants) and as their daily living was restricted, partially caused by feelings of uncertainty. Feelings of tiredness and pain were reported at the first interview but were reported to be as expected. One was bothered by the valve sounds. All experienced severe complications following surgery and had acute readmission, which led to uncertainty and a fear of dying, further complications, being alone, concerns about being physically active and of difficult in interpreting bodily symptoms. They saw themselves as active at this stage and wanted to take responsibility for their recovery but experiencing these complications made them feel uncertain as to which actions were safe. They considered planned and unplanned contacts to healthcare professionals when they had difficulty interpreting bodily symptoms but noted that this dependence on healthcare professionals maintained their feeling of being ill. Uncertainty was increased by experiences of fragmented care, inconsistent information and the feeling of not being taken seriously by physicians on some occasions. They felt they needed to be very active and to be reassured of normal progression. At the second interview participants had gradually experienced physical improvement but had expected more. The sense of uncertainty and fear of being physically active had reduced. Rehabilitation was seen as helpful to get fit and reduce insecurity. One was diagnosed with depression, became socially isolated and began seeing a psychologist which contributed to the feeling of positive progression. Contact with healthcare professionals diminished and was replaced by self-surveillance techniques, which allowed participants to be more active but also hindered their ability to return to normality. For example, one participant explained they could not sleep thinking about strong heart beats they could hear in their right ear and that they check their blood pressure too often. At the third interview, participants had learned to trust their bodies and stopped self-surveillance techniques, however one participant explained they were very alert to their body at 8-9 months post-surgery. They had returned to previous activities and normal living but despite positive progression they still experienced reduced energy, tension and becoming easily stressed and overloaded. They continued to believe in returning normality and struggling to get there, but also became impatient and still worried about their health and future. 3. **The challenged expectation of normality – being in a limbo:** two participants that pursued normality at each interview experienced positive progression by the second interview. However, at the third interview this was replaced by experiencing regression in their condition. Prior to surgery, they were used to taking medication but did not feel ill. They were aware recovery may take time. Their view of themselves changed over time from ‘not normal but not ill’ to ‘not normal and not well’. Tiredness, dyspnoea, low energy and disrupted sleep were prominent at the first interview. These were expected and gradual progress was experienced. One participant was readmitted with complications and feared wound rupture, felt low emotionally, had an ill temper and lacked information about normal recovery pathways. Both looked forward to starting rehabilitation and felt that following the advice of healthcare professionals would lead to normality being resumed. At the second interview, although experiencing physical improvement there was an expectation of more. Rehabilitation was seen as useful to reach their current physical shape and emotional status was stable. Most activities had been resumed, with one returning to work and becoming more active in the recovery process.

Study	Hansen 2016[11] and Hansen 2018[10]
	At the third interview, normality was not achieved due to symptoms resuming, including tiredness, pain, dyspnoea, swollen legs and frustration. One had a pacemaker implanted and the other was seeing a heart failure nurse. Both struggled in terms of normal life, with one only having energy for work and sleep and struggling to maintain his job and the other sleeping 11-12 hours a day and struggling to keep his house. One had started to see a psychologist. Both expressed disappointment at their regression and contrasts with their expectations prior to having the procedure. Frustrations included feeling of restriction, experiencing a deterioration after having considered themselves cured and disappointment. They maintained hope for the future, however the gap between their experience and expectations both physically and mentally led to a fear of the future and of becoming chronically ill. They felt in limbo and experienced their old self fading away and were not yet able to develop new images of themselves. 4. **Becoming a heart patient:** two patients changed their recovery goal between first and third interview, changing from aiming for normality to learning to accept themselves as heart patients and have hope for the future. They experienced overall progression towards their goals at different times. Before their heart valve disease was diagnosed, they felt healthy. This changed from ‘not ill after surgery’ to ‘not feeling ill but having become heart patients’. Feelings of tiredness were experienced at the first interview but they felt safe and well-informed despite sever pre-surgery complications. They contacted healthcare professionals often but considered the system cohesive. They took active involvement after discharge, with one performed physical training at home and the other resuming part-time work. Both felt well at the second interview but expected to improve further. They saw themselves as heart patients due to lifelong medication, valve sounds and reduced heart functioning for one patient. Maintaining the social appearance of being normal was seen as very important, which was particularly important in terms of spouses and close friends. Taking active responsibility became important to compensate for their identity change, though they found it difficult to obtain information about how they could strengthen their hearts. Rehabilitation training helped as improving physical shape was one way of taking active responsibility. Use of pulse watches and repetitive exercise were also used as self-surveillance techniques. One felt a fear of what was next and of dying as traumatic events occurring prior to surgery as a result of a high pulse faded into the background due to the successful surgery; seeing a psychologist helped to accept his new identity and to regain faith in the future. Both participants saw this time-point as a turning point when they were more focused on the future and gradually resumed daily living. At the third interview, they were physically well and had resumed prior activities, though one felt his work-related and physical performance were below the pre-surgery level. Having become heart patients had fallen into the background despite still taking medication and the time horizon felt longer but still was not as stated earlier on in the illness. People in their social network considered them cured and this made participants happy.
	From the secondary qualitative study (Hansen 2018): following heart valve surgery, participants expected to return to normal and thought rehabilitation would help them achieve this goal.

Study	Hansen 2016[11] and Hansen 2018[10]
	1. **Reducing insecurity:** participants felt cardiac rehabilitation would improve security and allow them to become physically active again, leading to increased courage to take part in daily activities again. Following discharge, there was uncertainty about which activities were safe to do as they feared complications or overworking the heart. Insecurities about being alone, and being fearful of engaging in daily activities, complications and death were common. a. **Feeling safe about becoming physically active:** all felt the physical training programme helped increase their courage to be more physically active and re-engage in everyday activities. Starting supervised training in hospitals was reassuring and using a pulse watch made those choosing home-based training feel safe. Meeting other peers during training in hospital or municipality setting was also seen as reassuring as they were able to exchange experience and see how they could improve if complying with the programme, though meeting peers in a better condition than them could also lead to a sense of increased insecurity initially. Home-based training was preferred overall as it allowed flexibility of combining training with work, though it also made some feel like they had a debilitating disease. Some expressed concern about how to interpret bodily symptoms, despite feeling secure to engage in regular physical activity after completing the rehabilitation. b. **Feeling cared for:** those benefitting from psychoeducational intervention said they felt it helped them to feel less insecure and to view life in new ways. They commented that nurses had time to listen to their concerns. Participants often felt they received conflicting information from different healthcare professionals and were unsure who was in charge of their treatment following surgery (for example when experiencing atrial fibrillation). They described how nurses provided comprehensive answers to their questions based on extensive knowledge. The role cardiac rehabilitation nurses had in coordinating was appreciated, particularly as they saw the healthcare system as fragmented and confusing at times. Those with relatively few concerns found sessions with no specific agenda to be too unstructured, in contrast to those who found open patient-centred dialogues meaningful. c. **Consulting other healthcare professionals:** despite the psychoeducational intervention, the input of other healthcare professionals before and during rehabilitation was sought. This included emergency department visits, multiple contacts with general practitioners and direct telephone-based contract with nurses in their local outpatient clinic. Private psychologists were also employed by some either through workplace of insurance, which was most common in those undergoing home-based exercise training. Psychologists helped them deal with psychological and existential issues. 2. **Taking active personal responsibility:** taking responsibility for their current recovery and future was important among all participants. Though the rehabilitation programme provided them with tools to do so, taking this responsibility was difficult to some extent.

Study	**Hansen 2016[11] and Hansen 2018[10]**
	a. Getting in better physical shape: improving physical capacity through cardiac rehabilitation was an extremely important way of taking personal and active responsibility. They felt it would improve the strength of their heart, extend the valve life and improve prognosis as well as mental health. Preferences around when this should be started, its duration and content differed. In general it was felt that the programme focused too much on the lower body. Views on the programme varied, ranging from those finding it to be repetitive and a lack of a challenge and others who appreciated the nature of the exercises. **b. Feeling challenged:** taking active responsibility could be challenging. The rehabilitation was challenging to complete in some cases, for example struggling to combine the training with a physically demanding job or due to pain. Some also discontinued physical training after the programme due to upper back or neck pain or tension and saw private physiotherapists. Most had learnt that their valve disease was not a typical lifestyle disease with multiple risk modifiers and risk factor management was not an explicit part of the intervention. Participants highlighted that this left them with limited options for personal responsibility for their health, reinforcing the importance of increasing their physical activity. **c. Alternative help-seeking strategies:** there was an agreement that one nurse consultation post-discharge was important but those with few concerns felt that five consultations was too many, with a suggestion that rather than a fixed number of sessions there could be an open-door access to valve experts for up to 6 months post-surgery instead. Despite the psychoeducational intervention, some pursued additional strategies to obtain more information about their condition and to manage their health, such as researching physical training online. Others also consulted alternative therapists (such as acupuncturists, healers, reflexologists and dieticians) in the hope of improving well-being and prognosis.
Limitations and applicability of evidence	Minor limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis; however, the role of the researcher and the effect this may have had on the results was not discussed and there were some concerns about the rigour of data collection, with saturation not being mentioned and some interviews taking place in hospitals and others at home. The study focused on those undergoing valve replacement and receiving cardiac rehabilitation, with all having either AS or MR, and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population. The population were obtained from part of a randomised controlled trial and the authors note that the age of those included in the study was lower than the typical patient that would be undergoing valve replacement in reality, which may reduce its applicability. It also only covers those undergoing standard surgery replacement and not newer technologies such as TAVI and all of them also had cardiac rehabilitation which may not be the case in practice.

Study	Instenes 2019[13]
Aim	To explore and describe how octogenarian patients with post-aortic valve replacement delirium experience interactions with healthcare professionals and relative within the first year and at four years
Population	Recruited from prospective cohort study (CARDELIR). Had been treated for severe aortic stenosis with either surgical aortic valve replacement or TAVI and experienced postoperative delirium. They were included 6-12 months following the valve replacement for this qualitative study. Inclusion criteria were: ≥80 years, ability to speak and understand Norwegian, no cognitive impairment, ability to remember the delirium experience and provided consent to participate. Delirium was assessed for 5 postoperative days using the CAM scale. n=10; 5 male: 5 female; mean age 83 years; 5 were living alone, 4 living with their spouse and 1 living with others; 4 had received TAVI and 6 had received surgical replacement; mean Mini-Mental State Examination score 27.4. At 6 months, all 10 patients were available and at 4 years only 5 patients were available.
Setting	Cardiac surgical ward in a tertiary hospital in western Norway – first interview: seven interviews took place in the home of the patient and three in an office at university hospital; follow-up interview: four took place in the patients' home and one in an office at the university hospital
Study design	Qualitative study with inductive explorative design
Methods and analysis	Recruitment was by an experienced cardiovascular nurse at the 6-month follow-up at a cardiac outpatient clinic. 13 were identified at the initial interview; however, 9 were excluded or withdrew due to not remembering the delirium, withdrawal of consent and 2 declining to participate. Four consented, but due to the small number of participants recruitment was continued up to 12 months post-AVR. Detailed letters inviting them to participate were sent to 9 patients, with 6 of these agreeing to participate. For the 4-year follow-up interview, 1 patient had died, 1 was no longer eligible for inclusion and 3 did not respond to the letter, meaning 5 patients consented to participate in this interview. In-depth interviews structured around predetermined open-ended questions were performed for the first interview, which covered patient experiences of postoperative delirium. A pilot interview was used to troubleshoot and refine questions, which formed the final guide for the first set of interviews. All patients were interviewed by the same researcher and were encouraged to talk freely about their experiences. Interviews were audio-recorded and transcribed verbatim and lasted 30-40 min. Based on responses in the first interview, a new interview guide was developed for the 4-year follow-up interview, which focused on healthcare professionals' and relatives' presence and reactions. One researcher (different to the one who conducted the first set of interviews) conducted and transcribed these interviews. Transcribed interviews formed the data for analysis. Qualitative content analysis was used to analyse delirium experiences, using an inductive and open-minded approach. Similarities and differences were identified and formally described. Disclosure of context occurred after completing all interviews. Transcribed text from 6-12 month and 4-year interviews was read multiple times and steps in qualitative analysis were followed to identify themes and subthemes using coding. The process was repeated iteratively until consensus was achieved among authors.
Findings	**The need for close supportive care:** the delirium made the patients feel vulnerable. Feelings of being frightened and anxious were consistently described, as well as the memory of having hallucinations. A soothing effect was found when healthcare professionals and relatives were close by, increasing the feeling of security and confidence. Patients described wanting their relatives to be nearby during

Study	Instenes 2019[13]
	their hospitalisation, with their fear and confusion being so great that they needed constant supporting care. Situations where relatives had to arrange a change of patient rooms (to a single-patient room or a place in the corridor) due to the delirium meaning it wasn't suitable for them to share a room were highlighted. The importance of support from relatives during the hospital stay was repeated at the 4-year follow-up interview, including the effect they had on helping them get moving. When in a state of disorientation and fear, supportive care from healthcare professionals was seen as essential. Some felt that they were denied access to a safe environment (nurses' room) instead of being comforted. The delirium meant they confused the hospital with their own home, which led to difficulties such as with accepting they had limited freedom when walking around. Others recalled episodes where they felt compelled to use the alarm-clock to call for help but felt from nurses' reactions that the repeated calls were bothersome for the staff. However, the patients commented that their delirious behaviour excused this response.
	Disrespectful behaviour created a barrier: difficult interactions between patients and healthcare professionals were described during delirious episodes. The hallucinations created a barrier between them and their surroundings. Harsh tones and orders by healthcare professionals did not help with the emotional stress and insensitive comments towards them made them feel disrespected, creating barriers in the relationship. These memories were still clearly recalled at the 4-year follow-up interview and they clearly remembered their distressed emotions and the need they had for a comforting hand. Negative reactions were also described, mostly in a humorous way but with a clear serious tone.
	Insensitive comments made lasting impressions: patients appreciated their relatives being involved; however, insensitive comments and laughter towards the delirious behaviour were noticed and made an impact. Reactions of family members differed, with some being very reassuring, particularly when patients started questioning their own behaviour, and some responding with silence and avoiding talking about the delirium afterwards. It was clear in the follow-up interview at 4-years that patients clearly recalled how relatives still struggled with accepting the delirium and did not want to be reminded of it.
Limitations and applicability of evidence	Moderate limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis; however, although the role of the researcher was briefly mentioned, this was very vague and the effect this may have had on the results was not well described. There were also some concerns about data collection as a different researcher performed the first and follow-up interview, the location of the interview differed for different patients and data saturation was not mentioned. There were further concerns about data richness as it was small sample of 10 participants at the first interview and only 5 at the follow-up interview, with no apparent attempt to obtain a heterogeneous sample and it being unclear throughout how many shared a particular thought or theme. The study was specifically on AS patients experiencing delirium following TAVI or surgical replacement of the valve. The evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Kirk 2019[19]
Aim	To explore patients' lived experiences of living and coping with recovery in daily life after TAVI
Population	A purposive sample of 10 patients treated with TAVI for aortic stenosis were included 3-4 months after treatment. Patients were identified through records at one hospital in Copenhagen Denmark. Variation was sought in relation to sex, age, New York Heart

Study	Kirk 2019[19]
	Association classification (5 NYHA class II and 5 NYHA class 3 pre-TAVI) and type of TAVI (i.e trans-femoral (n=8), trans-subclavian (n=1) or trans-apical access (n=1) to achieve maximum variation. All patients were able to speak and understand Danish. n=10; 4 male: 6 female; mean age 79 years (range 72-87)
Setting	The interviews were conducted in the patients' own homes (Denmark). This place was deliberately chosen as the aim was to explore the patients experience of living and recovery in daily life.
Study design	Qualitative research design
Methods and analysis	A semi structured interview guide was developed based on existing knowledge trying to capture the gaps and used to ensure consistency. The questions facilitated openness and flexibility during interviews (e.g. what are the experiences of returning home after TAVI?). The interview guide provided a framework but was not followed step by step. The interviewer used an open approach and allowed the patients to talk about the experiences they found important. The interviews were 30-80 minutes long, were recorded and transcribed verbatim, resulting in rich descriptions. A phenomenological-hermeneutic approach. Interpretation involved a spiral process consisting of 3 levels: **1) naïve understanding**: text read several times with an open mind to achieve an overview of the overall story, an initial understanding was established and reflections noted; **2) structural analysis:** the text was divided into units of meaning (what is said) and units of significance (what is being talked about). To ensure coherence, the various units were compared to naïve reading and were considered separately to ascertain additional themes; **3) comprehensive understanding**: resulted in an interpretation of the entire text taking into account the themes extracted from structural analysis. Two researchers analysed and discussed the findings on each of the 3 levels.
Findings	**Transformation of bodily sensations** Prior to TAVI patients had experienced bodily changes which they attributed to age. These included reduced physical strength and overwhelming fatigue which affected their level of activity and limited their everyday activities. Respiratory distress was also prominent in patients before undergoing TAVI. After TAVI patients felt a noticeable change in their bodies described as a clear before and after distinction particularly regarding improvement in respiratory distress. Being able to breathe better made patients happy and confident that they would be able to live a daily life with meaningful activities. Patients also experienced improved sleep which gave them more energy and feeling that they could participate in activities they couldn't previously participate in, renewing their enjoyment of life.
	A changed bodily attention After TAVI, the patients experienced increased bodily awareness. This meant they felt like they were having an out-of-body experience and they were not really "inside their own bodies". For example, patients were now noticing and registering the rhythm of their heart. Many patients had other illnesses that needed treatment which played a role in undergoing TAVI. For example, the continuing need to take diuretics after TAVI led to worries about needing further treatment and whether they could trust their bodies or should expect a life with the limitations they had prior to TAVI. On the one hand they noted the familiar signs of bodily functioning but on the other they noticed their bodies in a way that made them feel unsure. This illustrated that previous experiences could lead to uncertainty months after having TAVI.
	Enhanced physical possibilities to cope with life

Study	Kirk 2019[19]
	Patients talked about how their bodies were able to do more than before TAVI. They were surprised that their physical fitness had improved within a short space of time after treatment and this was reflected in their daily activities. They were pleased to be able to resume normal activities they were no longer able to do during before TAVI, consequently renewing their zest for life. Being able to walk was particularly important as this represented how the they were feeling and was a measure of their progress after treatment. In addition, being able to walk meant that they were able to participate in social activities thus improving their sense of wellbeing and control over their own lives. Participants were conscious that whilst TAVI relieved many of the limiting symptoms, it was important for their recovery to make an independent effort to improve their physical abilities.
Limitations and applicability of evidence	No notable limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. The study was specifically on AS patients and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Lauck 2016[23]
Aim	To explore factors influencing patients' decision making to undergo TAVI eligibility assessment to inform practice, programme development, health policy and future research
Population	Adults recruited at the time of their referral for assessment of eligibility from the TAVI clinic. Inclusion criteria were age 75 years or older and ability to converse in English. Purposive sampling was used to ensure a heterogeneous sample. The variables driving heterogeneity included age, gender, clinical indications, comorbid burden, geographical location of residence and travel requirements, likelihood of eligibility for TAVI, socioeconomic status and education level. n=15; 9 male: 6 female; median age 86 years (range 75-92). Most (n=11) participants experienced New York Heart Association functional class III symptoms and had a median 5-metre gait speed of 6.3 seconds (range 4.8–8.3). The median Society of Thoracic Surgeons predicted risk of surgical mortality was 6.4% (range 2.6–16.3%); six participants had had previous cardiac surgery. The median mini-mental state examination score was 27/30, and all but one of the participants were able to complete all activities of daily living.
Setting	The study was conducted at a provincial cardiac TAVI centre that performs 200 procedures annually (Canada).
Study design	Qualitative interview study
Methods and analysis	Data was collected using exploratory semi-structured qualitative interviews. Questions were aimed at exploring participants' decision-making process, awareness and sources of information, and consideration of the potential risks, benefits, outcomes and alternative

Study	Lauck 2016[23]
	options. Interviews were conducted in person or by telephone at a time and location of convenience for the participants and were 15–60 minutes long. Interviews were digitally recorded and transcribed verbatim; the transcripts became the data to be analysed. Data collection concluded when informational redundancy was achieved. Data analysis was based on methods of coding and constant comparison, which led to the generation of the study's main themes. Interview transcripts were initially coded by the individual who had conducted the interview and one other researcher using a line-by-line analytical procedure involving the examination of every line of the transcribed interview to search for similarities and differences in incidents and phenomena. Similar incidents and phenomena described by the participants were labelled as codes. Coded data exemplars were constantly compared between and within transcripts, with particular care taken to ensure codes accurately captured a participant's meaning. Codes defined as coherent patterns –both within and across the data – were identified and developed through an iterative, collective process in which all research team members came together to discuss the coded transcripts and develop the main study themes. This process ultimately led to the formation of conceptual themes, as expressed in the factors influencing patients' decision making to undergo assessment for TAVI.
Findings	**Symptom burden** Consistent with the rapid progression of severe AS, patients' experience of progressive deterioration emerged as a common theme related to their decision to consider a definitive treatment to alleviate their symptom burden. The experience of severe fatigue and shortness of breath figured prominently, and was associated with limitations on activities of daily living, such as cooking and housekeeping, and reduced mobilisation:
	The 'experienced' patient Participants advanced age, complex health histories and previous cardiac procedures contributed to their self-perception as 'experienced' patients. They framed their decision to pursue a new minimally invasive treatment option within their previous experiences of cardiac care. Stories from trusted sources gave participants confidence or hope that TAVI would address at least to some extent, their symptom burden while avoiding longer recovery time with heart surgery
	Expectations Expectations from treatment related to duration and quality of life. Most participants believed that TAVI would extend their life and hoped it would improve their quality of life by allowing them to return to 'normal' activities. Some participants noted that successful TAVI would allow them to worry less about their symptoms and improve their mental wellbeing.
	Healthcare system and informal support Participants stressed the importance of the trusting relationship with their physicians and some relied solely on information provided by physicians who cared for them through previous health issues. Primary care physicians and specialists were perceived as essential sources of information, decision making guidance and facilitators of referral for TAVI. Participants also highlighted the influence of informal social support resources provided by family, friends and community members on their decision making.
	Logistical barriers and facilitators

Study	Lauck 2016[23]
	Logistical barriers and facilitators concerned the practicalities of pursuing specialised treatment at a TAVI centre located in a large urban area. Participants who lived away from the TAVI centre expressed concern about the expected personal costs and burden of travel.
	Obligations and responsibilities Participants considered their broader obligations and responsibilities in their life and relationships with others when making the decision to seek treatment. For example, they were concerned about the burden of their health-related needs on their caregivers, which was motivation to try to maintain health and pursue the assessment for TAVI. The sense of responsibility to maintain the best possible health was closely intertwined with participants' ability to fulfil other obligations including financial management, maintaining one's home and participating in day-to-day activities (e.g. chores, cleaning, grocery shopping). The shorter recovery time and/or potential benefits of TAVI were seen as very advantageous for participants who had obligations that they wanted to resume following the procedure.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, there is no indication of who conducted the interviews and how this may have influenced the collection and interpretation of the evidence. The Authors had conflicts of interest and were all consultants for companies that manufacture or sell cardiac devices although the study was not funded by these companies. The study was specifically on AS patients and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Lysell 2020[27]
Aim	To explore patients' experiences during everyday life before and after TAVI
Population	A total of 14 consecutive patients with severe aortic stenosis with a planned TAVI procedure between 2016 and 2017 consented to participate in an interview at 2-3 months following their TAVI procedure at a follow-up visit and were included in the study. Inclusion criteria were age ≥80 years, ability to speak and understand Swedish and no cognitive impairment. A further 3 patients that consented were excluded as their follow-up visits were unexpectedly changed to their residential communities in other parts of Sweden. One of the interviews included in the results was one of two pilot interviews performed to test the interview guide – the second was not included as the patient chose not to complete the interview. There does not appear to have been an attempt to obtain variation in the sample in relation to patient characteristics. Comorbidities: diabetes, 6/14; previous stroke, 2/14; previous myocardial infarction, 4/14; previous coronary artery bypass grafting, 1/13 and pacemaker, 5/14 n=14; 5 male:9 female; mean age 86 years; 8/14 living alone and 6/14 with home assistance; 9/14 with moderate symptoms and 5/14 with severe symptoms according to NYHA class

Study	**Lysell 2020**[27]
Setting	Conducted at a Swedish university hospital serving western part of Sweden
Study design	Qualitative research design
Methods and analysis	Qualitative method with inductive explorative design using interviews to capture thoughts and opinions of participants about subjects of interest. Two pilot interviews performed initially to refine interview document, which included questions on how participants felt about their illness and how symptoms affected everyday lives, what encouraged them to undergo the TAVI procedure, what did they hope to achieve from the procedure and how they would describe their lives following TAVI. Where necessary, supplementary questions, for were added to obtain further information, for example 'can you explain a little further' or 'tell me more about…'. Notes were taken during the semi-structured interviews and they were also recorded. The first pilot interview was considered of great value and was therefore included in the results. The time between TAVI and the interview being performed differed between patients and was between 2 and 6 months. Interviews lasted for 25-50 minutes, with a median duration of 30 minutes. Location of the interviews differed for different participants, including 11/14 at the hospital, 1/14 at a nursing home and the remaining 2/14 at the participants' homes, at the request of the interviewees. Interviews were transcribed and read multiple times. Data were analysed by qualitative content analysis, which implies an inductive, open-minded view when searching for patterns of the subject in question but keeping the pre-understanding of the subject in mind. Both manifest and latent content analysis were used. Text relating to the purpose of the study was condensed and made more manageable without losing the essential meaning or its context and grouped into categories and subcategories based on similarities and differences identified between interviews. All interviews and transcriptions were made by a specialist nurse with experience in cardiology and thoracic surgery care but who was not directly involved in the perioperative care of the included patients. Coding and categorisation were performed by the interviewer and discussed with a second researcher who is experienced in qualitative methods. This was also discussed with two clinical registered nurses with experience caring for patients undergoing TAVI. Interpretation of the data was reconsidered several times regarding relevance to the subject and to the participants' actual expressions.
Findings	**Life with aortic stenosis** 1. **Adapting to the deteriorating self and becoming vulnerable:** prior to TAVI, all participants experienced crippling fatigue and highlighted reduced energy and triggered dyspnoea were the main symptoms of their valve disease. Participants felt weak and were easily exhausted, both physically and mentally. They were also worried about the rapid development of their disease. Falling accidents or a growing fear of falling due to increased dizziness and weakness were reported by five participants. The period prior to diagnosis was reported to be a time of anxiety, with four people having feelings of uncertainty and burden as they felt responsible for their spouse's welfare even with their own health deteriorating. Participants felt uncomfortable with others due to mood swings and felt their lack of energy also impacted on life within their family. Six patients repeatedly required ambulance transport to the hospital and expressed doubts about the meaningfulness of such a life. Feelings of deterioration and a lack of satisfactory advice from doctors and hospitals created further uncertainty.

Study	Lysell 2020[27]
	2. **Coping with life:** to cope with everyday life, rationing of housework was inevitable. Most had help from family but also expressed that they did not want to burden relatives. Six participants had municipal home assistance to cover cleaning, shopping and medications. Having the ability to adapt and adjust was considered crucial, with some participants making adjustments to improve the safety of themselves and family, for example, one participant applied to be placed in a nursing home prior to the procedure to ensure the future life with her partner would be safer and six participants had technical devices installed at home to avoid accidents and make life safer. An optimistic outlook and ability to fight was highlighted as an asset when attempting to cope with the illness. Goals that contributed to the decision to undergo TAVI included reducing dyspnoea, being able to walk outdoors and being able to engage in hobbies. 3. **Feeling disconnected and not recognising oneself:** participants commented that life felt unpredictable and frightening, and there were times when they did not recognise themselves. Feeling alienated within a helping family and feeling a burden on relatives led to feelings of sadness. Participants saw being health and independent, and able to move around freely, as being signs of true well-being. Self-esteem was low among the participants and a lack of trust in themselves meant they often withdrew to avoid 'messing things up' for themselves or others. 4. **Involuntary loneliness:** ten participants described their health as 'tumbling downhill' as their deterioration and symptoms prevented them from doing physical activity and socialising with others. Fatigue and breathing difficulties were increased at social gatherings and some said they had given up on meeting with others as they thought the coughing and breathlessness was too much for other people. Participants felt their new reality was very different to their previous life. They were dependent on others and experienced loneliness. Some participants commented that although they had family, they felt lonely as many of their friends had passed away. All participants considered being confined to an indoor life as the worst consequence of their disease, longing for fresh air and daily walks.
	Life after TAVI 1. **Reconstruction of self and rebuilding capacity:** twelve participants felt their TAVI procedure was successful. The majority said improvement in symptoms became obvious within a couple of weeks, though three said symptom relief was rapid, occurring with a few days or less following TAVI. Participants experienced improve night sleep and had an increased feeling of energy, with their feelings of ability also increasing. They felt they had regained a more active life that was not confined to their home and had increased possibilities for social interaction. Progress after the procedure was slow but they began to take control of their lives again and resumed old hobbies. Participants commented on their strength returning and compared how their vigour had changed over time.

Study	Lysell 2020[27]
	Despite reduced cardiac symptoms, ongoing health issues remained. However, participants understood that TAVI could not cure everything and accepted this was the case for their comorbidities. Participants described the goals they had set before TAVI as a motivation for their continued rehabilitation and continued to preserve their hopes. 2. **Regaining self-confidence**: participants felt their mood became more stable as their self-esteem rose and being able to complete more goals and regaining capacities, as they felt they had 'regained their old life' and 'felt normal again'. Though some experienced minor complications related to the intervention, none talked about these complications as something they were fearful of or that had a major impact on their well-being. They were aware that these things could happen and participants commented on the trust and confidence they had in their healthcare professionals.
	Processing disappointment 1. **Feeling frustration:** two participants took longer to recover, experiencing no improvement and having breathlessness as before. They commented on a feeling of defeat and wondered if they may have had a better outcome had they been treated earlier. One of these participants expressed disappointment in the outcome of the procedure. Many participants shared some frustration about aftercare, particularly poor communication about being discharged from the hospital. 2. **Trying to accept:** none of the participants expressed any regret about their decision to have TAVI. This was even the two participants that took longer to recover and did not have the result they had hoped for, despite the complications reducing their energy and causing them to become disheartened.
Limitations and applicability of evidence	Moderate limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis; however, there was a small sample size with no apparent attempt to obtain a sample with variation in their characteristics as a consecutive sample was used. In addition, the timing and location of interviews differed for different participants and the interview guide followed may have differed for one of the participants as they were interviewed as part of the pilot stage before the interview guide was finalised. The fact that only one interview was performed following TAVI and not one prior to TAVI may have affected the data collected for experiences prior to TAVI. Though the background of the researcher collecting data was described, there was not a discussion about how this may have affected the results. The study was specifically on AS patients and not general HVD patients. In addition, the population was further limited to those ≥80 years. The evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Olsson 2019[41]
Aim	The aim of this study was to explore patients' experiences of being considered for transcatheter aortic valve implantation but judged ineligible.

Study	Olsson 2019[41]
Population	A purposeful sample of 8 patients with severe AS and functional New York Heart Association (NYHA) class III and IV. Inclusion criteria were being considered for TAVI but judged ineligible and to be Swedish speaking. Those with incurable cancer or cognitive impairment were excluded. n=8; 6 male: 2 female; mean age 82 years (range 74-93)
Setting	Interviews took place in the patient's home or in the county hospital
Study design	Qualitative interview study
Methods and analysis	Individual in-depth interviews were performed by the first author within one to four weeks after the eight participants had been informed of not being accepted for TAVI and lasted 20–70 min. The interviews were narrative and included questions such as 'What expectations did you have during the examination for TAVI? What was your reaction when you were told that it was not possible to do TAVI?'. The interviews were audio recorded digitally and transcribed verbatim by a secretary. Qualitative content analysis was used to identify differences and similarities in experiences. Initially the text was read through to find out what it was all about. Meaning units, corresponding to the aim were identified, condensed and labelled with codes relating to primarily manifest content. The codes were then, based on similarities and dissimilarities, sorted into subcategories and categories and abstracted to a main theme corresponding to all categories. The analysis was continually discussed in the research team and findings were adjusted when doubtful interpretations were discovered.
Findings	1. **Accepting the decision and continuing daily life:** Most participants tried to make the most of the situation, to manage life and stay as independent as possible based on their circumstances. a. **Trusting and accepting the doctors' judgment:** participants were all aware that they were high-risk patients, since they had comorbidities, and some were very old. They had great confidence that the decision made was carefully substantiated, since they had been thoroughly examined and provided with clear explanations. Several had good experiences from previous successful heart treatments, which strengthened trust. The decision was easier to accept and induced feelings of hope because they really believed that the doctors had their best interests in mind. They trusted that doctors, due to concern for their lives, did not want to expose them to treatment that was too risky. Some described being thankful when they were informed of the decision, since they were afraid of the operation. b. **Relieving symptoms in daily life increased hope:** The participants had severe symptoms, and the main reason for being under investigation was not primarily to survive, but rather to reduce or eliminate the symptoms. After receiving medical treatment (two had C-PAP and four had pacemakers) to lessen their symptoms, it was a big relief that inspired hope. Some participants expressed feelings of sadness, because of their own situation or because of severe life events or sorrow. When the doctor noticed their difficulties and took the time to listen and introduce medical treatment, it was a big relief. Some participants found it hard to understand that their breathing difficulty was a result of their AS and not related to the lungs. To receive any kind of relief from symptoms, whether or not it concerned their heart failure, increased their hope of coping with their current situation.
	2. **Missing a second chance in life:** This category illustrates how hope could be turned into despair. Being offered investigation for TAVI meant having a hope of being cured. Many had previously had other interventions such as heart surgery, angioplasty or pacemaker implantation that had made them feel better. They were hoping that TAVI would give them another chance but when this was not possible it led to feelings of despair including disappointment and depressive symptoms.

Study	Olsson 2019[41]
	a. **Being under surveillance yet missed:** Most participants reported being under surveillance for AS for several years, and some were very disappointed that the surgery had not been performed previously when they were in better condition. Not all had been aware of the reasons for surveillance and couldn't remember having information about or discussing surgery. They had the impression that doctors focused on the result of the echocardiography and symptoms of the heart, without weighing in other aspects that affected the possibility of valve replacement. Participants sometimes had problems understanding the connection between symptoms and the heart disease, which perhaps made them less motivated for surgery before it was too late. They suggested a sense of despair at not being involved until it was too late. b. **Feeling insecure and abandoned induced despair:** Thoughts about death were commonly expressed. The participants experienced despair and insecurity, since they did not know how much time they had to live. They asked themselves if death would come suddenly or cause extended suffering. Many had been repeatedly hospitalised for severe heart failure and reported frightening experiences of having severe symptoms. Although there were often many doctors involved, some participants reported that none of them had a holistic view. They were sometimes sent home from the hospital in a hurry, and there was no time for questions. A strong feeling of being abandoned and left alone with their symptoms and worries was expressed. c. **Becoming dependent and grieving lost life:** The participants expressed feelings of sadness and despair for the loss of functions and strength and the life they had lived before. Three of the participants were living together with a partner on whom they became more and more dependent, and thereby were grieving lost independence in daily life.
	3. **Coping with losses and struggling for control:** This category illustrates how participants tried to maintain and restore hope through various coping strategies such as trying to gain control over symptoms, to have a contact network for assistance and staying active and participating in social life. a. **Trying to take control and reduce anxiety.** Participants felt that the disease caused a sense of insecurity and despair. They sought methods to create a sense of control and to improve their condition through, for example, fluid restrictions, training programmes and diet. The participants asked many disease-related questions during and after the interviews, which was seen as an indication of having an urgent need for information and support to restore hope. b. **Getting necessary support from healthcare:** Some, but not all, had their own doctor or specialist nurse whom they relied on and knew how to get in touch with if needed, which provided an important sense of security and strengthened hope. c. **Preserving important social relationships:** All participants felt the necessity of being of use socially and taking part in the community, but this was hindered by the disease and advanced age and could result in loneliness. The importance of having supportive relatives and being an appreciated member of the family was a recurring subject in the interviews. Despite difficulties, most participants also attempted to somehow hold onto their previous activities to make life meaningful. Individuals who could accept taking a new, less strenuous role while still participating, expressed a feeling of hope and satisfaction.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, despite the data being collected and analysed by a nurse with long experience working with patients with heart disease, there was no discussion on reflexivity. The study was specifically on AS patients and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	**Olsson 2018**[43]
Aim	To explore how patients experienced the recovery process from TAVI
Population	Included 24 consecutive patients treated by TAVI at a single university clinic in Sweden within 1 year and who agreed to participate. All were Swedish-speaking. The present report concerns 6 months follow-up among those still alive (n=19). n=19; 11 male: 8 female; median (range) age was 80 (65-89) years for males and 82 (60-90) years for females. 12 participants lived alone and 2 had home assistance. 8 participants were in NYHA class III and 11 were in NYHA class IV. 5 had a history of syncope, 4 had diabetes, 10 had previous bypass surgery, 5 had a previous stroke, 7 had peripheral vascular disease and 7 had chronic obstructive pulmonary disease.
Setting	University clinic in Sweden. Interviews performed at outpatient clinic or in participants' homes.
Study design	Qualitative interview study
Methods and analysis	Grounded theory was used. The priority was to identify patterns and connections rather than seek causality and linear reasoning. Patients were individually interviewed in their home or at their county hospital with data collection performed in January 2012. Population said to represent a variety of people allowing the opportunity to identify multiple phenomena and sample size was sufficient for saturation. In-depth interviews were performed and audio-recorded by a nurse with long experience with cardiac care but who was not directly involved with the care of the patients. Interviews were approached narratively and started with the following broad open-ended question: 'can you please tell me about your experiences of undergoing TAVI and about your situation today?'. Participants often first described the situation before TAVI, followed by hospitalisation experiences and then their first time at home. Interviews ended with questions about their current situation and view of the future. Follow-up questions on emerging patterns were incorporated into interviews with subsequent participants to gain a deeper understanding. Interviews lasted between 15 and 60 minutes, with a median duration of 35 minutes. They were subsequently transcribed verbatim. Emerging patterns were documented using memos after interviews and throughout the analysis. Analysis was performed by the same nurse that conducted the interviews under supervision of another researcher with a experience in qualitative research. Preliminary and final results were discussed within the whole research group, which included various perspectives including two cardiologists, with one being a TAVI interventionist. Interviews were read multiple times thoroughly and coding used in order to obtain categories. When codes became saturated and no more dimensions emerged, they were compared and relationships identified to create a theory.
Findings	**Feeling threatened:** prior to TAVI, participants felt they were continuously getting weaker and this period was described as frightening. Increasing age combined with feeling in a bad condition, having to have examinations and a new treatment was life and death. 1. **Being exposed:** the period before TAVI was described as very distressing. Worries about being refused TAVI were present as well as the fear of undergoing it if they were accepted. Investigations prior to TAVI were also difficult to cope with, particularly transoesophageal echocardiography. Humiliation was described when risks were discussed when the patient was present but not necessarily included. Patients were aware that TAVI was a new procedure and some had a

Study	Olsson 2018[43]
	feeling of being a guinea pig. However, comments were also made about it being exciting to be one of the first at the hospital to receive the procedure and acknowledged that there would be no development without someone being the first to receive a particular procedure. 2. **Facing death:** various experiences prior to TAVI were reported when they thought they were dying and felt themselves becoming weaker. Men estimated a reduction in strength based on how far they could walk in meters or when they were last able to mow the lawn. Doctors had informed patients about the bad prognosis, and they asked questions such as whether they would live until Christmas without surgery. Some described preparing themselves for death and wondered whether it was best to die from the disease or on the operating table.
	Experiencing hope: despite a worsening condition, feelings of hope towards TAVI were expressed. Some had previously had surgery or been seriously ill and regained health, which implied confidence in healthcare and there was hope about also recovering from their current condition. 1. **Being respected and participating:** patients felt respected when they were involved in dialogue with doctors and kept informed and involved in treatment decisions. They felt mentally prepared after long discussions with doctors – they were aware that TAVI was a new procedure and informed of the risks. Participants shared concerns with doctors and did not feel forced to undergo TAVI. Having hope was described as essential and occurred in interaction with professionals. 2. **Having confidence:** confidence in doctors was very important. Doctors stating that they believed in TAVI and that this was the best treatment for them gave patients the courage to go on.
	Demanding rehabilitation: problems developed for some patients during rehabilitation, such as some having to stay in hospital for a long time post-TAVI due to complications or side effects of medication. This experience was described as demanding and depressing. 1. **Experiencing slow recovery:** a slow recovery and tiredness post-TAVI was described by some patients, which led to some time in a rehabilitation clinic for some and extended hospital stays due to complications, one of the most serious of which was a pulmonary complication which required respiratory therapy for several weeks. Periods of depression, nightmares and thoughts of suicide were reported during the recovery period. Those with comorbidities, such as s history of stroke, could require long periods of rehabilitation before being able to walk properly again. Urinary problems following catheter removal were commonly described by men and they could last a long time. Despite these problems, patients fought to improve their health and to cope with the situation. Past experiences of recovery from coronary bypass surgery were compared by some and were disappointed as they expected it to take around the same time rather than be slower, though the fact that they had grown older and were in a worse condition was appreciated. Maintaining hope when progress was slow was seen as important and the role professionals played in encouraging this was highlighted as having a major role. They also played a role in their own hope for example looking for signs of recovery in exercising and noticing their improvements over time.

Study	Olsson 2018[43]
	2. **Feeling weak and omitted:** immediately after TAVI patients felt weak and tired, with some experiencing it more than before the procedure. They required help but some were suspicious and avoided home care services. There was a strong desire to cope by themselves and they were unhappy if they became dependent, particularly if they hadn’t been before or if their relatives did not understand their needs. 3. **Being disappointed:** disappointment was described when their expectations of TAVI did not match their reality or when complications occurred. One participant suffered a stroke at 1-month post-TAVI and described her life as much worse than before and although the procedure was successful expressed that sometimes she regretted having the procedure. Avoiding finding out about risks of the TAVI procedure was a strategy sometimes used to control fear, with this participant relying on encouraging statements from friends and family. When unexpected problems such as atrial fibrillation occurred disappointment was expressed and commented that had they known it may have affected their decision to undergo TAVI.
	Surprisingly simple rehabilitation: some were not disappointed and some wo had been very worried before TAVI were surprised that they found it so easy and were grateful for the option of this procedure. 1. **Perceiving TAVI as easy to undergo:** participants compared TAVI with previous experiences of surgery or other serious illnesses and some felt TAVI was easy to undergo. They felt lucky to have the opportunity to have this procedure instead of surgery either due to reduced pain and recovery time or because they might not have survived surgery. 2. **Experiencing fast recovery:** several participants were surprised at the speed of their recovery and their ability to leave bed so quickly and walk around, compared to other patients who had open heart surgery or to their own previous experiences with surgery.
	Struggling with limitations: limitations still existed at 6 months post-TAVI for some patients, mainly due to other diseases or old age 1. **Being affected by other diseases:** at follow-up, the heart problems were almost forgotten. However, other ailments such as back pain, hip and knee problems or vision defects were reported that were constantly present in daily life, including one man who still had difficulty breathing due to chronic obstructive pulmonary disease but appreciated that it was much better compared to before the TAVI procedure. 2. **Being isolated and dependent:** participants were old and affected by others diseases that impaired their potential for a good social life and TAVI did not change these things. Patients reported being lonely and isolated and found it difficult becoming dependent on others.

Study	Olsson 2018[43]
	3. **Living only in the present:** some patients were tired and had no motivation to do anything extra. They commented that they were too old to think about the future or that the future was uncertain. However, most were happy with living in the present and took pleasure in small things.
	Returning to life: at follow-up, patients said they had got their lives back and had a new start in life. Fewer problems were reported in terms of breathing, they had put on weight and were in a better condition, which increased their ability to stay independent, continue social activities and plan for the future. 1. **Living in gratitude and joy:** happiness at having the opportunity to undergo TAVI was reported as well as their satisfaction with their decision to undergo it and take the risk. Gratitude towards doctors who recommended and treated them and the nursing team that supported them was expressed. TAVI affected their psychological wellbeing and attitude towards life, allowing them to experience being alive and simple joys such as listening to birds and spending time with family. 2. **Being independent:** the will to remain independent was described as important for life quality. Despite illness, participants were often socially active though in different ways. They could not go walking and shopping, visit church and see friends and family easier than before the procedure. Men described being able to drive as very important and impacting on quality of life. For some that were caring with a partner that was dependent on them (for example due to age, dementia or a mental disorder) it was described as a relief to be able to take care of their partner again. 3. **Having hope for the future and zest for life:** feeling that improvements had been made with fewer symptoms gave participants hope and energy. Some were looking forward to the spring and summer seasons and activities that they enjoyed during these seasons, such as mowing the lawn and building extensions to summer houses. Having projects was described as giving meaning to life and helped them to forget problems. Their hope for the future was demonstrated by various examples, including one buying a puppy knowing it would take several years to train and another reflecting on how she had thought the last time she got Christmas candles out it would be her last but now feeling like she would be doing so for a few more years yet.
Limitations and applicability of evidence	Minor limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis; however, the role of the researcher was not discussed in terms of how bias may have affected the results. Interviews were also performed in different places for different participants, with some at the hospital and some at home, which may have affected results. Additional questions based on emerging themes from the initial interviews were included for later interviews, meaning there may have been inconsistency between interviews in terms of the questions asked. The study was specifically on AS patients undergoing TAVI and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Olsson 2016[40]
Aim	To describe patients' experiences of coping with severe AS while waiting for TAVI
Population	Inclusion criteria were having severe AS and planned for TAVI. There were no exclusion criteria. 15 (62%) were living alone, 3 (12%) had home assistance. 11 (46%) were NYHA class III (moderate symptoms) and 13 (54%) were NYHA class IV (severe symptoms). Comorbidities included Diabetes, previous stroke and previous bypass graft surgery. n=24; 15 male: 9 female; mean age (SD) 80.7 years (7.4)
Setting	Participants were selected from the Heart Centre, University hospital of Umea, Sweden. Interviews were conducted the day before TAVI at the clinical ward.
Study design	Qualitative interview study
Methods and analysis	Short interview guide was used which included questions such as "please tell me about your experience living with the disease" and "what do you think about the future?" The interviews lasted 15-45 minutes and were recorded by the interviewer and transcribed verbatim by a secretary. Interviews were analysed using qualitative content analysis. The text was read and discussed by the research team to grasp a sense of the overall meaning. Relevant text corresponding to the aim of the study was then identified and inductively coded with labels. The codes were then compared and sorted based on similarities and dissimilarities into categories and subcategories. Finally, 1 theme that incorporated all the categories was identified. Trustworthiness was ensured by attending to: 1) credibility: selecting participants with a variety of experiences related to the phenomenon being studied and by using direct quotes from the original interviews. 2) dependability: use of open dialogue among the researchers about for example the categorisation of the data and labelling. All steps in the analysis were continuously reflected on within the research team and preliminary findings were adjusted when doubtful interpretations were discovered. 3) transferability: clear description of the context, participants' characteristics, data collection and process of analysis were published to ensure transferability to other settings by other researchers.
Findings	**1) Trying to cope with physical symptoms and anxiety** a. Managing symptoms and medication: participants described how they had to manage, adapt to, and plan their daily lives and activities around severe symptoms such as breathlessness, irregular heartbeat, fatigue and fainting. These symptoms often led to anxiety and difficulty sleeping. Comorbidities made symptom interpretation difficult (e.g. symptoms of asthma could be hard to distinguish from heart symptoms, fatigue was seen as related to age instead of heart disease). Medication was seen as necessary but affected social life and made planning more difficult. Dizziness and fainting led to the loss of feelings of control and security. The unpredictability of the disease was very troublesome and consequences of fainting and falling which could be serious were difficult to prevent. b. Adapting physical activities and social circumstances: participants described having to adapt previous activities such as household work and related activities to lighter forms. These had not only become much more difficult but also

Study	Olsson 2016[40]
	imbued with meaning. Participants had to rearrange their housing, use new technology and rely on support from relatives, friends and healthcare personnel to manage daily life despite symptoms, limitation and medications.
	2) Trying to preserve self and self-esteem despite life threatening illness a. Managing social limitations by shifting focus: Many participants described how the illness meant they had to handle dependency, social limitations and a new, less important role in the family especially men with severe symptoms and decreased capacity who grieved over their altered or lost roles. Family and friends helped in maintaining social life in which they could be the people they were before. Participants had to shift focus by reflecting on the activities they had previously considered to be important. b. Living with but confronting death: Participants tried to live as normally as possible despite knowing the risks of the disease. They tried to keep control and balance the living a normal life with suddenly being reminded of their vulnerability during incidence for which they sometimes blamed themselves. Some participants described how the situation normalises over time and thus made it easier to withstand. Stressful thoughts and life-threatening symptoms were described as eventually becoming part of life. Information from the physician was sometimes frightening, in terms of what was being said and how it was said, including the physician's body language and expressions.
	3) Trying to process the decision to undergo TAVI a. Negotiating and deciding whether to have treatment: Some of the participants were aware that of the risks and possible complications of TAVI and it was perceived as a new treatment. They knew that their decision was one of life and death and those who were alone found it difficult to make the decision on whether to accept the operation or not. They described how demanding for them to be alone with their concerns. Those who had support from partners and children in their decision making found it very valuable. b. Living with uncertainty about being accepted for TAVI: TAVI offered the possibility of recovery to participants after they were denied aortic valve replacement and had thought that nothing could be done. However, the day before the procedure, some participants were still uncertain whether the operation would still be performed. The waiting period was described as terrible especially when the symptoms worsened. c. Requiring trust and medical guidance: Participants said they needed more knowledge about the disease and treatment options but had different experiences of such support. The information given about TAVI was sometimes confusing. Some participants felt great trust as they had seen the same physician for many years. Others had not had the opportunity and had to struggle to get help. Overall there were differences in the information the participants had received from their family physician. Many of the participants expressed their confidence in the physicians at the specialist clinic and were thankful for the opportunity to be treated there. This trust helped them to relax at night which for some was the first time in many weeks.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, there was no discussion on the influence the researcher (a nurse with long experience working with patients with heart disease) may have had on the collection and interpretation of the data.

Study	Olsson 2016[40]
	Patients being interviewed in hospital the day before their procedure may have influenced their ability to describe their thoughts and situation. The study was specifically on AS patients and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population.

Study	Olsson 2016[42] - sister paper and part of the larger study Olsson 2016[40]
Aim	To describe the decision-making process about undergoing TAVI treatment in people with severe aortic stenosis
Population	Inclusion criteria were having severe AS and planned for TAVI. There were no exclusion criteria. 15 (62%) were living alone, 3 (12%) had home assistance. 11 (46%) were NYHA class III (moderate symptoms) and 13 (54%) were NYHA class IV (severe symptoms). Comorbidities included Diabetes, previous stroke and previous bypass graft surgery. n=24; 15 male: 9 female; mean age (SD) 80.7 years (7.4)
Setting	Participants were selected from the Heart Centre, University hospital of Umea, Sweden. Interviews were conducted the day before TAVI at the clinical ward.
Study design	Qualitative interview study
Methods and analysis	This study was part of a larger study with the purpose of evaluating patient-reported outcome measures and patient reported experience measures from TAVI treatment. Saturation was reached after 15 interviews but continued with all participants due to the connection with the larger study. Patients were interviewed by the author (a nurse with long experience working with patients with heart disease). Interviews lasted between 15-45 minutes and were performed at the clinic ward in a single room. Interviews were recorded and transcribed verbatim where nonverbal expressions such as sighs and laughs were also noted. There was an interview guide with topics concerning participants' experiences of living with AS and their decision to undergo TAVI treatment. All interviews started with: could you please tell me about the symptoms you experience and how they impact on your daily life? Examples of questions related to decision making about treatment were: could you please me about when the decision to undergo TAVI was made? What information have you received about TAVI and related risks? Interviews were analysed using qualitative content analysis. The text was read and discussed by the research team to grasp a sense of the overall meaning. Relevant text corresponding to the aim of the study was then identified and inductively coded with labels. The codes were then compared and sorted based on similarities and dissimilarities into themes and subthemes whereby 3 patterns of decision making were identified. The analysis and its different steps and interpretations were continuously reflected on within the research team. Interpretations were sometimes adjusted when doubtful interpretations were discovered to ensure trustworthiness.
	Ambivalent (8 participants) This pattern was characterised by being unsure, some participants were unsure about the diagnosis and some about the benefits and effects of undergoing TAVI. When participants were ambivalent, the risks of the procedure were taken more seriously into consideration. They were uncertain whether the TAVI was possible to perform and whether the physician was sufficiently skilled and

Study	Olsson 2016[42] - sister paper and part of the larger study Olsson 2016[40]
	prepared in case something went wrong. Researchers identified that in this pattern, the decision became easier when the responsibility for the decision could be shared with others such as husband or wife. Participants also stated that the decision to undergo TAVI took time. Those who expressed ambivalence described their symptoms as severe but possible to handle.
	Obedient (12 participants) This pattern was characterised by being doubtful about the value of one's own decisions. Participants who exhibited this pattern were used to relying on and listening to others especially those with expert knowledge. Thus, those who were sceptical about the value of the operations were still obedient to the recommendations of their doctors. Others relied on family members' opinions and often it was the wishes of the children that determined the decision. Many had a fatalistic view and risks and benefits were rarely negotiated. Participants classified as obedient generally had conditions that were described as not severe or very severe, with symptoms very limiting for daily life and activities.
	Reconciled (4 participants) In this pattern, participants felt that there was no longer any choice. They were aware of the extreme gravity of the situation and understood that their lives were threatened. They described a kind of turning point when they had to face the reality of their situation and the bad prognosis. Participants who were reconciled always felt confident and sure that the decision to undergo TAVI treatment was the right and only one. Although patients described their decision as an active one, it was actually defined as a subjection to the circumstances or the facts of the prognosis they had been confronted with. Participants classified as reconciled always experienced symptoms as very severe or having rapidly progressed and very limiting in daily life. They had also lost fortitude and could no longer cope with their life situation.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, there was no discussion on the influence the researcher (a nurse with long experience working with patients with heart disease) may have had on the collection and interpretation of the data. The study was specifically on AS patients and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population. Patients being interviewed in hospital the day before their procedure may have influenced their ability to describe their thoughts and situation.

Study	Skaar 2017[50]
Aim	To explore conditions for an autonomous choice experienced by older adults who recently underwent TAVI, with a special focus on relational and cognitive aspects.

Study	Skaar 2017[50]
Population	Adults 70 years and over who underwent TAVI. The only exclusion criterion was not speaking Norwegian. All underwent elective TAVI due to severe symptomatic aortic stenosis and high risk for complications to SAVR, but time to procedure varied from a few weeks after activity induced syncope to several months with less dramatic symptoms. Logistic EuroSCORE varied between 8 and 28. n=10 ; 4 male: 6 female; age: 3 patients aged 70-79 years and 7 aged 80-89 (no mean or median values reported)
Setting	Participants in the study were enrolled post-procedure from a large university hospital in Norway with 860 somatic beds. The hospital has advanced interventional and surgical expertise and has performed TAVI procedures since 2010.
Study design	Qualitative interview study
Methods and analysis	Semi-structured, individual interviews of TAVI patients. Interviews were conducted between February 2014 and April 2015 on a purposive sample aiming for diversity of age, gender and complication rate. Most interviews were conducted in the patients' own home. Inclusion of participants was stepwise according to analytical strategy. The interviews lasted from 30 to 60 min and were conducted 2 to 4 weeks after TAVI, except for three patients who were interviewed after 9, 41 and 52 days due to either practical reasons or the analytical process. Qualitative analysis was performed following systematic text condensation, proceeding through the following stages: (1) reading all the material to obtain an overall impression, bracketing previous preconceptions; (2) identifying units of meaning, representing different aspects of the patients' experiences and coding for these; (3) condensing and abstracting the meaning within each of the coded groups; and (4) summarizing the contents of each code group to generalized descriptions and concepts reflecting the most important elements of autonomy reported. The interview guide consisted of questions addressing how patients experienced the process preceding TAVI, focusing why they wanted the treatment, how they coped with risk information and the challenge of making a choice. An editing analysis style was used where categories were developed from the empirical data, not in a theory-driven template analysis style from predefined theoretical concepts. Analysis was done stepwise with new interviews supplementing the sample. A decision trail documented the choices during the analytical process.
Findings	**Deliberately taking the chance** Participants regarded declining the treatment to be worse than accepting the risk related to the procedure. Based on information about symptoms gradually increasing and no hope for recovery without the procedure, the patient perceived making a decision. None of them reported this as a difficult choice. They were aware that TAVI might not be an option later if they declined now. During the investigation period they realised that something had to be done, like a virtue of necessity. Thus, they barely experienced being in a situation where they should make a choice and reported little doubt or anguish.
	Autonomous trust in their doctors Participants chose to follow the physicians' treatment recommendation seeking symptom relief and trusting the physicians with whom they were interacting. The participants wished the physician to be honest and optimistic, still not concealing risk. Physicians spending time informing about the procedure and letting the patients take time to think it through, were cherished, as well as physicians recommending the procedure despite the risks. Patients expressed a general and strong confidence in GPs, private consultant

Study	Skaar 2017[50]
	cardiologists and hospital physicians. Even when the physicians described risks before surgery, it could not disturb the confidence and trust they also grounded in personal qualities of the physician. However, the patients did not have blind trust in their physicians, the physicians had to act trustworthy or else the patients seek a second opinion. Even if they considered the decision to be theirs, several highlighted that they felt an obligation to their relatives to accept a treatment that was recommended. One patient expressed how she did not want to let her children down if she died suddenly one day and they knew she could have had an intervention done to avoid it. Another patient took a more passive position during the decision-making process, possibly due to mild cognitive impairment and depressive symptoms. She explained that she accepted TAVI mostly because her daughter wanted her to, and that she didn't care too much herself:
	Fundamental self-determination based on personal identity The participants explicitly outlined how they made the decision on their own, and that this was important to them. This was expressed by a fundamental go-ahead spirit and strong lease of life when TAVI treatment was to be decided. They had a positive attitude towards themselves as robust and relatively strong, still acknowledging they were older and that their strength had declined. In general, TAVI candidates described themselves as feeling independent and coping well. They did not want to be a burden to their relatives. Most did not involve the family in the decision but informed them of their choice afterwards.
Limitations and applicability of evidence	No notable limitations. The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. The study was specifically on AS patients and not general HVD patients, the evidence is still applicable to the review question but relevance is limited to this sub-population.

Appendix E Qualitative evidence summary for subthemes

Study design and sample size			**Quality assessment**		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Impact of the illness					
Symptom burden/loss of control					
11 studies (from 12 papers)[1, 5, 10, 11, 19, 23, 27, 40-43, 50]	Semi-structured interviews	Symptoms such as fatigue and shortness of breath, as well as dizziness and fainting, often led to limitations in activities, prevented them from taking part in hobbies and led to anxiety and difficulty sleeping. Participants felt that the disease caused a sense of insecurity and despair for the loss of functions and strength they had before, with a short temper also being reported. Participants felt a loss of independence and did not want to be a burden on their relatives. Social limitations often occurred as a result of the physical restrictions caused by their illness. This led to feelings of loneliness, isolation and depression. Participants commonly expressed thoughts about death, which increased their anxiety, despair and insecurity and included a fear of dying alone as well as the effect their death would have on their spouse. It was difficult to live with bad prognoses since they did not know how much time they had to live. Some wondered whether death due to the disease or on the operating table was preferable. Stressful	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

Study design and sample size			Quality assessment		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		thoughts and life-threatening symptoms were described as eventually becoming part of life.			
Trying to take control and reducing anxiety					
10 studies (from 11 papers)[1, 5, 10, 11, 19, 23, 27, 40, 41, 43, 50]	Semi-structured interviews	Participants described having to adapt previous activities such as household work to lighter forms which had to be planned around severe symptoms such as breathlessness, fatigue and fainting. Participants had to rearrange their housing, learn to use new technology and rely on support from relatives, friends and healthcare professionals. The responsibility of having to fulfil obligations including financial management, maintaining one's home and participating in day-to-day activities increased the sense of responsibility to maintain the best possible health. Participants therefore sought methods to create a sense of control and to improve their condition. Relief of their symptoms, whether they were related to heart failure or not, inspired hope. Getting necessary support from healthcare and knowing who to get in touch with if needed provided an important sense of security and strengthened hope.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Preserving important social relationships					
5 studies (from 6	Semi-structured interviews	Participants felt the necessity of being of use socially and taking part in the community and attempted to hold on to their previous activities	Limitations	Minor concerns about methodological limitations[3]	MODERATE

Study design and sample size			Quality assessment		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
papers)[10, 11, 19, 40, 41, 43]		to make life meaningful. Those who were able to accept taking a new, less strenuous role while still participating, expressed a feeling of hope and satisfaction.	Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	Minor concerns about adequacy[4]	
Managing social limitation by shifting focus					
9 studies (from 10 papers)[1, 5, 10, 11, 19, 27, 40, 41, 43, 50]	Semi-structured interviews	The illness meant participants had to handle dependency, social limitations and a new, less important role in the family, especially men with severe symptoms and decreased capacity who grieved over their altered or lost roles. Family and friends helped in maintaining social life in which they could be the people they were before. Participants had to shift focus by reflecting on the activities they had previously considered to be important.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Formal and informal support					
Health care professionals					
12 studies (from 13 papers)[1-3, 10, 11, 13, 23, 27, 40-43, 50]	Semi-structured interviews	Healthcare professionals were perceived as essential sources of information and some patients were solely reliant on information provided by physicians. Patients appreciated honest but optimistic discussions, though some found the information frightening. Patients had great trust in their clinicians and relied on them for information and support before intervention, when deciding	Limitations	Minor concerns about methodological limitations[5]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

Study design and sample size			Quality assessment		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		whether to have the intervention and following intervention.			
Caregivers/families/informal					
10 studies (from 10 papers)[1-3, 13, 23, 27, 40-43]	Semi-structured interviews	Participants who had physical and emotional support from partners and children, or who knew people that had had a procedure, found their support very valuable and those who were alone had difficulty, especially with daily activities and decision making. Family caregivers were also described as having an important role during the recovery period following valve intervention, including TAVI and surgical valve replacement. Others reported that some relatives did not handle the changed situation well or made insensitive comments, particularly in the context of delirium following the procedure. The importance of informal caregivers having an understanding of the possible complications of the procedure was also emphasised.	Limitations	Minor concerns about methodological limitations[5]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Content/type of information sought					
8 studies (from 8 papers)[2, 3, 27, 40-43, 50]	Semi-structured interviews	Participants said they needed more knowledge about the disease and treatment options but had varying experiences of such support. Information given about TAVI was sometimes confusing.	Limitations	Minor concerns about methodological limitations[5]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	

Study design and sample size			**Quality assessment**		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		Patient education, particularly prior to a TAVI procedure, was highlighted as important in order to prepare patients for the experience in terms of complications and the process of being discharged. Caregiver knowledge about the possible complications of the procedure was also emphasised as important.	Adequacy	Minor concerns about adequacy[6]	
<u>Factors influencing decision to undergo TAVI or surgery</u>					
Symptom burden					
11 studies (from 12 papers)[1, 2, 5, 10, 11, 23, 27, 40-43, 50]	Semi-structured interviews (n=10 studies) or responses to a single question (n=1 study)	Increasing fatigue and breathlessness were the most commonly reported symptoms that influenced the decision to undergo TAVI. These were considered to be life-limiting and therefore the decision to undergo TAVI was no longer a choice but a necessity. They were aware of the extreme gravity of the situation and understood that their lives were threatened. They had also lost fortitude and could no longer cope with their life situation.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Expectations					
10 studies (from 11 papers)[1, 2, 5, 10, 11, 23, 27, 40, 41, 43, 50]	Semi-structured interviews (n=9 studies) or responses to a single question (n=1 study)	Expectations of intervention included the relief of symptoms and ability to participate in more activities, as well as an extended life and benefit to their mental health. Some saw the TAVI procedure as a bridge to be able to undergo other procedures that would improve their quality of life, such as hip replacements.	Limitations	Minor concerns about methodological limitations[5]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

Study design and sample size			Quality assessment		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
The 'experienced' patient					
8 studies (from 8 papers)[1, 2, 23, 27, 41-43, 50]	Semi-structured interviews	Some participants perceived themselves as being 'experienced' patients due to their advanced age, complex health histories and previous cardiac procedures. The decision to undergo TAVI was sometimes based on previous experiences of cardiac care. Participants understood that not having the procedure would be worse than accepting its risks and were aware that if they declined to have TAVI, it might not be an option later. They felt there was not much choice and that it was a necessity. They reported little doubt or anguish about having to make the decision. Participants were aware that due to them being at high surgical risk or surgery not being an option that their alternative options were limited and were grateful to have the option of TAVI.	Limitations	Minor concerns about methodological limitations[5]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Influence of healthcare system and informal support					
10 studies (from 10 papers)[1, 2, 5, 23, 27, 40-43, 50]	Semi-structured interviews (n=9 studies) or responses to a single question (n=1 study)	Participants relied heavily on health care professionals in their decision making and perceived them as essential. Informal social support resources provided by family, friends and community members were also reported as having a role in decision-making.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

Study design and sample size			Quality assessment		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Obligations and responsibilities					
10 studies (from 11 papers)[1, 2, 5, 10, 11, 23, 27, 40, 41, 43, 50]	Semi-structured interviews (n=9 studies) or responses to a single question (n=1 study)	Concerns about the burden of their health-related needs on their caregivers or the effect that their death might have on them contributed to the decision to have TAVI. Maintaining independence for other obligations, including financial management and chores were also mentioned.	Limitations	Minor concerns about methodological limitations[3]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Logistical barriers and facilitators					
2 studies (from 2 papers)[2, 23]	Semi-structured interviews	The practicalities of pursuing specialised treatment at a TAVI centre located far from their homes and the expected personal costs and burden of travel was a concern for some participants.	Limitations	Minor concerns about methodological limitations[5]	LOW
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	Moderate concerns about adequacy[7]	
Deciding against having TAVI					
1 study (from 1 paper)[5]	Responses to a single question	Of those that declined TAVI, avoiding invasive procedures and the possible complications of these procedures were the most cited reason for this decision.	Limitations	Moderate concerns about methodological limitations[8]	LOW
			Coherence	No concerns about coherence	

Study design and sample size			Quality assessment		
Number of contributing studies	Design	Finding	Criteria	Rating	Overall assessment of confidence
			Relevance	Minor concerns about relevance[2]	
			Adequacy	Moderate concerns about adequacy[9]	
Impact of TAVI or surgery on daily life					
Varying effects on bodily sensations and symptoms					
8 studies (from 9 papers)[1-3, 5, 10, 11, 19, 27, 43]	Semi-structured interviews (n=7 studies) or responses to a single question (n=1 study)	Although TAVI or surgery relieves symptoms and enhances physical abilities for many participants, the speed and extent of improvement differs for different participants. Body soreness and weakness after the procedure were common but dissipated over time, though some struggled with these and other complications for longer periods and did not experience the improvement in symptoms they had hoped.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	Minor concerns about coherence[10]	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
A changed bodily attention and complications					
7 studies (from 8 papers)[1-3, 10, 11, 19, 27, 43]	Semi-structured interviews	Increased bodily awareness following TAVI or surgery was described, including noticing the sounds of their heart more and an increased appreciate of the heart's function. For some, this led to anxiety about how to be active safely. Some were concerned about other illnesses they had and how their body would cope. They	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	Minor concerns about coherence[10]	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

Study design and sample size			**Quality assessment**		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		were unsure how to interpret bodily signs and symptoms. Some experienced complications following intervention that affected them physically and mentally. Thinking about the seriousness of their condition also affected them emotionally.			
Changes in physical possibilities and the ability to cope with life					
8 studies (from 9 papers)[1-3, 5, 10, 11, 19, 27, 43]	Semi-structured interviews (n=7 studies) or responses to a single question (n=1 study)	Despite the degree of improvement differing and it developing over time, many were able to do more than before intervention, which improved their mood. Many were aware of the need for self-intervention to improve their condition. Rehabilitation programmes were found to be useful for some but others preferred to do their own activity.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	Minor concerns about coherence[10]	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	
Meeting expectations and disappointment					
8 studies (from 9 papers)[1-3, 5, 10, 11, 19, 27, 43]	Semi-structured interviews (n=7 studies) or responses to a single question (n=1 study)	Although many participants were happy with the results of their intervention, reality did not match the expectations for many participants in terms of the extent and/or speed of their improvement. Expectations and disappointment were based on previous experiences of cardiac surgery, information provided to them by health care professionals and also influenced by family and carers.	Limitations	Minor concerns about methodological limitations[1]	MODERATE
			Coherence	Minor concerns about coherence[10]	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

Study design and sample size			Quality assessment		
Number of contributing studies	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		A lack of regret at having the procedure was reported even for most of those expressing disapoointment in the result.			
Impact of comorbidities					
4 studies (from 4 papers)[1, 2, 27, 43]	Semi-structured interviews	It was acknowledged that the presence of other conditions mediated the scale and speed of improvement as well as what activities they could do following TAVI. The existence of other conditions made it difficult for participants to assess symptom improvement due to TAVI, though most understood TAVI would not cure all of their health issues.	Limitations	Moderate concerns about methodological limitations[5]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[2]	
			Adequacy	No concerns about adequacy	

[1] Downgraded if there were concerns about methodological limitations. Most of the evidence comes from studies that did not address the role and influence of the researchers and their relationship with participants

[2] Downgraded due to concerns on the relevance and extent to which the body of evidence from the included studies is applicable to the context of the review as the majority of studies are limited to the AS population rather than heart valve disease in general.

[3] Downgraded if there were concerns about methodological limitations. Most of the evidence comes from studies that did not address the role and influence of the researcher and there were some concerns about data collection

[4] Fewer studies covered this area compared to other subthemes. Though further studies reported on negative consequences of the disease on social activity, only 5 explicitly touched on how attempts to preserve them did help.

[5] Downgraded if there were concerns about methodological limitations. Most of the evidence comes from studies that did not address the role and influence of the researcher. There were some concerns about data collection and about data richness based on limited information or sample size.

[6] Although 8 studies still report on some aspects of this subtheme, each tends to touch on slightly different elements rather than confirming statements seen in the other studies

[7] Only two studies touch on this area of potential logistical barriers

[8] Downgraded if there were concerns about methodological limitations. Study did not address the role and influence of the researcher, there were concerns about the retrospective nature of the study and data analysis was not well described

[9] Only 1 study reports on factors contributing to declining TAVI

[10] Downgraded as there were some concerns about coherence as one study suggested that all patients experienced improvements following TAVI whereas the others suggest a more balanced experience with some experiencing large improvements and others being disappointed following TAVI or surgery

Appendix F Excluded studies

F.1.1 Excluded clinical studies

Table 7: Studies excluded from the qualitative review

Reference	Reason for exclusion
Coylewright 2020[4]	Incorrect population (interview of clinicians not patients)
Danielsen 2020[6]	Insufficient qualitative reporting
Dharmarajan 2017[7]	Study design does not match protocol (quantitative)
Ehrlich 2000[8]	Study design does not match protocol (quantitative)
Guerbaii 2017[9]	Study design does not match protocol (quantitative)
Huygens 2019[12]	Study design does not match protocol (quantitative)
Instenes 2018[14]	Perspective does not match protocol (reports on experience of delirium rather than information and support requirements)
Johansson 2007[15]	Study design does not match protocol (quantitative) Incorrect population (coronary artery disease)
King-Shier 2012[17]	Incorrect population (coronary artery disease)
King-Shier 2013[16]	Incorrect population (acute coronary syndromes)
King-Shier 2017[18]	Incorrect population (coronary artery disease)
Kohlmann 2013[20]	Study design does not match protocol (quantitative)
Korteland 2015[21]	Study design does not match protocol (quantitative)
Korteland 2016[22]	Study design does not match protocol (quantitative)
Lie 2017[24]	Study design does not match protocol (protocol for qualitative study)
Lindman 2020[25]	Study design does not match protocol (narrative report)
Lloyd-Williams 2005[26]	Study design does not match protocol (quantitative)
Lytvyn 2016[28]	Study design does not match protocol (Systematic review)
MacInnes 2014[29]	Population does not match protocol (heart failure LVSD <35%)
Mahrer-Imhof 2007[30]	Population does not match protocol (acute coronary syndromes)
Malm 1980[31]	Unable to obtain paper (unavailable from British Library)
Marsh 2019[32]	Study design does not match protocol (quantitative)
Muirhead 1987[33]	Unable to obtain paper (unavailable from British Library)
Murray 2019[34]	Study design does not match protocol (quantitative)
Näsström 2015[35]	Population does not match protocol (heart failure no indication of % with HVD)
Noguchi-Watanabe 2017[37]	Study design does not match protocol (quantitative) Population does not match protocol (mixed population only 34% HVD)
O'Driscoll 2007[38]	Population does not match protocol (post MI patients)
Olsen 2017[39]	Study design does not match protocol (quantitative)
Olsson 2017[44]	Study design does not match protocol (quantitative)
Overgaard 2012[45]	Population does not match protocol (HF patients adjusting to life after ventricular assist devices)
Pryor 2014[46]	Population does not match protocol (MI patients)
Reed 2019[47]	Study design does not match protocol (quantitative)
Sanford 2011[48]	Population does not match protocol (mixed HF no indication of % HVD)
Schjoedt 2013[49]	Study design does not match protocol (protocol for qualitative study)

Reference	Reason for exclusion
Sumi 2014[51]	Study design does not match protocol (quantitative)
Taghadosi 2014[52]	Population does not match protocol (qualitative study specific to the setting in Iran)
Tolmie 2009[53]	Population does not match protocol (MI patients)
Van Beek-Peeters 2020[54]	Study design does not match protocol (Systematic review)
van Geldorp 2013[55]	Study design does not match protocol (quantitative)
Varrica 2020[56]	Study design does not match protocol (not qualitative)

Appendix G Research recommendations – full details

G.1 Information and advice

G.1.1 Research recommendation

What are the information and advice needs of all adult age groups with heart valve disease of all severities and stages?

G.1.2 Why this is important

Patient choice is essential for clinical decision making in heart valve disease; informed choice is desirable, so patient education regarding disease characteristics, assessment, monitoring and valve intervention options is very important. Furthermore, the central role of onset of symptoms in timing of intervention, makes it essential for patients, family and carers to develop awareness of symptoms and observe decline in exercise tolerance. Information regarding preparation for intervention and the subsequent recovery is also essential.

G.1.3 Rationale for research recommendation

Importance to 'patients' or the population	Having this information and advice will be beneficial for planning appropriately, reducing anxiety, and supporting shared decision making.
Relevance to NICE guidance	Additional evidence will support more specific recommendations on information and advice
Relevance to the NHS	Information and advice is essential to support shared decision making
National priorities	None identified
Current evidence base	Evidence was mainly from a limited subset of the overall heart valve disease population, older adults with aortic stenosis being considered for TAVI. There was no evidence for tricuspid valve disease, and only a small proportion of patients in one study had mitral valve disease. There was also no evidence about the information and support needs of those with mild/moderate valve disease.
Equality considerations	All people need access to high quality information and advice provided in a variety and formats to support shared decision making. The information and advice needs to be tailored to the needs of the individual

G.1.4 Modified PICO table

Population	Inclusion Adults aged 18 years and over with diagnosed heart valve disease and their family and carers. Information concerning people with different stages of heart valve disease will be stratified, as follows: • mild • moderate • severe A heterogeneous sample will be sought to ensure a broad spectrum within the following factors: • Age • Severity • Disease stage (intervention not needed, intervention planned, post-intervention) Exclusion • Children (aged <18 years) • Adults with congenital heart disease (excluding bicuspid aortic valves). • Tricuspid stenosis and pulmonary valve disease
Context	To gather qualitative data on patient and carer opinions and experiences relating to information, education or support.
Outcome	Areas will emerge for the qualitative data but may include: • Patient-reported outcomes • Decision making, including the use of decision aids • Preferred format of information provision • Content of information • Impact of treatment on lifestyle • Information sources other than healthcare professionals (e.g. support groups, online resources) • Psychological support • Delivery of support (e.g. nurse, peer groups)
Study design	Qualitative
Timeframe	Short-term
Additional information	None