

# Hope and Life-struggle

## Patients' Experiences with Transcatheter Aortic Valve Implantation

**Karin Olsson**



**Department of Public Health and Clinical Medicine  
and Department of Nursing**  
Umeå 2016

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ISBN: 978-91-7601-569-8  
ISSN: 0346-6612  
New Series Number 1850  
Omslag: Silkeshäger, Maspalomas. Foto: Stig Viklund  
Elektronisk version tillgänglig på <http://umu.diva-portal.org/>  
Tryck/Printed by: Print & Media  
Umeå, Sweden 2016

*“The best medicine and the best caregivers are powerless  
in the absence of hope” (RF Jevne, 1991)*

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# Abstract

Aortic stenosis is the most common valve disease in the Western countries and is increasing due to the aging population. The disease has bad prognosis without surgical replacement of the valve. Transcatheter aortic valve implantation (TAVI) is a less invasive method that has made it possible to treat patients previously denied surgery. The overall aim of this thesis was to explore experiences and self-reported outcomes of TAVI among people with severe aortic stenosis.

One quantitative and three qualitative studies are reported. In Papers I and II, all patients treated with TAVI for one year, n=24, were interviewed the day before TAVI about their experiences of the disease and of decision-making about TAVI. Qualitative content analysis was used for the analyses. In Paper III all patients that were alive at follow-up after six months, n=19, were interviewed about their well-being and their experiences from TAVI process. Grounded theory was used for the analysis. In Paper IV a quantitative study of patient-reported outcomes was completed. To mirror the result from the TAVI group, a comparison group of age-matched patients treated with surgical aortic valve replacement (SAVR) was added.

Study I described the vulnerable situation for patients with severe aortic stenosis before TAVI. They were facing death and at the same time struggling to cope with their symptoms and to be independent. TAVI offered hope but also uncertainty about the new method, and whether it was wise or not to accept TAVI.

Study II the patients' decision-making process was in focus. Three patterns in the decision-making process about TAVI treatment were identified; the ambivalent, the obedient and the reconciled. The ambivalent patient was unsure of the value of treatment and aware of the risks; the obedient patient was unsure of the value of one's own decision and wishes to leave the decision to others; and the reconciled patient had reached a point where there was no choice anymore and they were sure that the decision to undergo TAVI was right.

Study III offered a deeper understanding of the whole trajectory of TAVI and the necessity of having hope throughout the whole process. A journey of balancing between hope and life-struggle was the core concept that was highlighted through the analysis. Prior to TAVI patients felt threatened, but they also experienced hope. The rehabilitation phase was described as

demanding and depressing or, the opposite, surprisingly simple. At the six months follow-up many described how they had returned to life. TAVI had made it possible to be independent and participate in social life; however, many still struggled with limitations due to other diseases or disabilities.

Study IV focused on quantifying the symptom burden, function and health-related quality of life, HRQoL, before and after TAVI and SAVR. Among TAVI-patients self-rated function was low before treatment and increased at follow-up. One out of four patients reported syncope at baseline, none at follow-up. Breathlessness was reported by all patients but the TAVI patients reported more severe symptoms. At six months follow-up, symptoms were reduced, but breathlessness and fatigue were still common. HRQoL, which was very low in the TAVI group at baseline, increased in all dimensions except social function.

Aortic stenosis is a life-threatening disease that is treatable if the patient arrives in due time for investigation and treatment. Coping strategies may lead to delay in seeking medical advice and impair the preconditions for treatment. Patients with AS planned for TAVI have to cope with increasing symptoms and limitations in social life but still wish to be and be seen as the people they were before illness. The TAVI patients are often “experienced”, but in bad physical condition and with comorbidities. They need to be treated by skilled nurses and physicians who make them feel safe. Patients planned for TAVI should, if possible, be involved early, giving time to prepare themselves. Their specific needs, which are often due to comorbidities and other problems, must be taken into account.

The recovery from TAVI can be slow due to previous condition, comorbidities or complications and patients need support to cope with the situation and to be hopeful. Although six months after TAVI, most patients are satisfied with the treatment and report increased health related quality of life and decreased severe symptoms, they are still tired. Their major problems though, are mainly described as related to other diseases or disabilities.

Having hope is essential throughout the whole process. It is therefore of great importance that nurses and physicians support hopeful thinking. By involving patients we can help them have control over their own destiny, and also feel trust in being cared for and treated by health care professionals with expert knowledge.

## **Keywords**

Aortic stenosis, transcatheter aortic valve implantation, experiences, coping, decision-making, health-related quality of life, symptoms, function

# Abbreviations

AS	Aortic stenosis
EQ-5D	EuroQol 5 Dimensions
GT	Grounded Theory
HRQoL	Health-Related Quality of Life
KCCQ	Kansas City Cardiomyopathy Questionnaire
MLHFQ	Minnesota Living with Heart Failure Questionnaire
NYHA	New York Heart Association
QCA	Qualitative Content Analysis
QoL	Quality of Life
SAVR	Surgical Aortic Valve Replacement
SDM	Shared Decision Making
SF-36	Short Form (36) Health Survey
TAVI	Transcatheter Aortic Valve Implantation

## Papers I-IV

### Paper I:

Olsson K, Näslund U, Nilsson J, Hörnsten Å. (2016) Experiences of and coping with severe aortic stenosis among patients waiting for transcatheter aortic valve implantation. *Journal of Cardiovascular Nursing* 31 (3): 255-261.

### Paper II:

Olsson K, Näslund U, Nilsson J, Hörnsten Å. (2016 ) Patients' decision making about undergoing transcatheter aortic valve implantation for severe aortic stenosis. *Journal of Cardiovascular Nursing* 31(6):523-528.

### Paper III:

Olsson K, Näslund U, Nilsson, J, Hörnsten Å. The trajectory of undergoing transcatheter aortic valve implantation: a grounded theory study. Submitted.

### Paper IV:

Olsson K, Nilsson J, Hörnsten Å, Näslund U. Patients' self-reported function, symptoms, and health-related quality of life before and six months after transcatheter aortic valve implantation and surgical aortic valve replacement. *European Journal of Cardiovascular Nursing*. Epub ahead of print 11 May 2016. DOI: 10.1177/1474515116650342

## Summary in Swedish

Aortastenosis, förträngning av aortaklaffen oftast orsakad av förkalkning, är det vanligaste klaffelet i västvärlden och förekomsten ökar på grund av den åldrande befolkningen. Sjukdomen har dålig prognos om inte den sjuka klaffen byts ut. Kateterburen klaffimplantation, TAVI, är ett mindre ingrepp som har gjort det möjligt att behandla patienter som tidigare nekats kirurgi på grund av hög operationsrisk. Det övergripande syftet med den här avhandlingen var att utforska patienters erfarenheter och egenrapporterade resultat från TAVI-behandling.

Tre kvalitativa och en kvantitativ studie finns med i avhandlingen. För delarbete I och II intervjuades alla patienter som genomgick TAVI under ett år, n=24, dagen före ingreppet. De tillfrågades om sina symptom, hur dessa påverkade deras liv och om hur det var att ta beslut om att genomgå TAVI. Kvalitativ innehållsanalys användes för analyserna. I delarbete III intervjuades patienterna i samband med en uppföljning efter sex månader, n=19. De fick berätta om hur de mådde och om sina erfarenheter av att genomgå TAVI. Grundad teori användes för analysen. I delarbete IV presenteras statistik från de patientrapporterade mätningar som gjordes före och sex månader efter behandling. För att spegla resultatet från TAVI-patienterna inkluderades en grupp med åldersmatchade patienter opererade med vanlig klaffkirurgi, SAVR, n=24.

I delarbete I beskrivs den svåra situation som patienterna befann sig i före TAVI sammanfattat i huvudtemat "Lever på gränsen men försöker behålla kontrollen". Patienterna kände att slutet närmade sig samtidigt som de kämpade med att hantera sina symptom, bevara sin självkänsla och att förbli oberoende. Att erbjudas TAVI ingav hopp, men samtidigt en känsla av osäkerhet eftersom metoden var ny och innebar risker.

I delarbete II var patienternas beslutsprocess i fokus. Tre mönster i beslutsprocessen identifierades. Den ambivalenta patienten var osäker på värdet av behandlingen och medveten om riskerna. Den följsamma patienten var osäker på värdet av egna beslut och överlät gärna beslutet till andra och slutligen, den förlikade patienten hade accepterat situationen och nått en punkt där det inte fanns något alternativ längre. Dessa var övertygade om att beslutet att genomgå TAVI var det rätta.

I delarbete III eftersträvades att förstå hela TAVI-förloppet. Nödvändigheten av att känna och bevara hoppet under hela processen framstod som central. "En resa balanserande mellan livskamp och hopp" var det övergripande

temat, och relaterade till de bipolära kategorier som framkom i analysen. Innan TAVI upplevde patienterna ett hot, men var också hoppfulla. Rehabiliteringen beskrevs som påfrestande men ibland också som det motsatta, förvånande enkel. Efter sex månader beskrev de flesta att de hade ”återvänt till livet”. TAVI hade gjort det möjligt att förbli oberoende och att delta i socialt liv, men många kämpade fortfarande med begränsningar orsakade av andra sjukdomar, social situation eller handikapp.

I delarbete IV var syftet att analysera patientrapporterad funktion, symptombörda och hälsorelaterad livskvalitet (HRQoL) före och efter TAVI och SAVR. Fysisk funktion var mycket låg före behandling, framför allt i TAVI-gruppen. Den förbättrades i båda grupperna liksom även HRQoL. En fjärdedel av patienterna rapporterade svimning före TAVI/SAVR, ingen efter. Andfåddhet var det vanligaste symptomet i båda grupperna, men symptomen var svårare i TAVI-gruppen där fler rapporterade symptom i vila före behandling. Symptomen minskade efter behandling, men efter sex månader var det fortfarande vanligt med andfåddhet och trötthet, framför allt i TAVI-gruppen som också var sjukare före behandling.

Aortastenosen är en livshotande sjukdom som går att bota om patienten kommer i tid till utredning och behandling. Patientens sätt att hantera sin sjukdom, kopingstrategier, kan i sämsta fall leda till fördröjning att söka läkare och därmed försämra förutsättningarna för behandling. Patienter med aortastenosen som planeras för TAVI måste hantera tilltagande besvär och sociala begränsningar, men vill vara och bli sedda som de personer de var innan de blev sjuka. TAVI-patienterna är ofta ”erfarna” patienter men i dålig fysisk kondition och ofta med flera sjukdomar. De behöver träffa kunniga sjuksköterskor och läkare som gör att de känner sig trygga. Patienterna bör, när det är möjligt, tidigt involveras i planeringen för att få tid att förbereda sig. Deras speciella behov, som ofta hänger samman med andra sjukdomar eller handikapp, måste tas med i planeringen. Återhämtningen efter TAVI tar ibland lång tid beroende på andra sjukdomar eller komplikationer och patienten kan behöva stöd för att känna sig hoppfull och hantera situationen. Sex månader efter TAVI kände sig de flesta nöjda med behandlingen, hade bättre livskvalitet och mindre symptom men var fortfarande trötta. Problem som beskrevs var ofta relaterade till andra sjukdomar eller handikapp.

Att ha hopp var nödvändigt genom hela processen. Det är därför viktigt att sjuksköterskor och läkare stödjer hoppfullhet. Genom att tidigt involvera patienterna kan vi hjälpa dem att ha kontroll över sin egen situation men också känna tillit till att de vårdas och behandlas av personal med expertkunskap.

# Introduction

In 2009 a new method for treating patients with aortic valve stenosis was introduced at the clinic where I worked as a care quality manager. Transcatheter Aortic Valve Implantation, (TAVI), is a less invasive method that makes it possible to treat patients, previous denied valve surgery. Since there were only a few studies on TAVI published at that time, we decided to perform this study of patients' experience and self-reported outcome of the treatment.

## Aortic stenosis

Aortic stenosis (AS), narrowing of the aortic valve usually caused by calcification, is the most common valve disease in the western countries with a prevalence of 3 - 4% of severe AS in people older than 75 years (Nkomo et al., 2006; Osnabrugge et al., 2013). During a long latency period, people with aortic stenosis experience no symptoms. When symptoms appear the disease has a high death rate; approximately 50% die within 2 years without surgery. Common symptoms in the progression phase of AS are exertional dyspnoea, decreased exercise tolerance, syncope, fatigue, chest pain and congestive heart failure. The arrival of symptoms are indications for aortic valve replacement (Bonow et al., 2008). The severity of the stenosis is assessed by echocardiography in which the valve area and the pressure gradient over the narrow valve are measured. Since it is essential to identify the onset of symptoms for the decision of treatment and timing of operation, the patients' narratives are important as a basis for judgment of their medical history (Iung, 2008). A common way of evaluating the degree to which the patient's function is affected, is the use New York Heart Association (NYHA) classifications which indicates stages of heart failure (NYHA, 1994).

- Class I: No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnoea.
- Class II: Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea.
- Class III: Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnoea.
- Class IV: Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

Surgical replacement of the aortic valve (SAVR), in absence of serious coexisting conditions, is associated with low mortality, reduced symptoms and improved survival (Leon et al., 2010). Health-related quality of life (HRQoL) is also increased after surgery and elderly people have reported as

good or better results compared to younger people (Olsson et al., 1996). In a detailed overview of the current literature on SAVR, the overall mortality for isolated SAVR was 2.5 – 4% in the younger population but tended to be higher in octogenarians. In patients presented with extensive comorbidity the perioperative risk of death significantly increased, up to 25% (Deutsch et al., 2013). In Sweden, the 30-day mortality for SAVR was 1.8% (mean age 70 years) in 2015 according to Swedeheart, the Swedish heart registry. <http://www.ucr.uu.se/swedeheart/>

About 30% of patients with severe AS are denied surgery due to technical and/or clinical reasons (Jung et al., 2005). SAVR means, among other things, to open up the chest, clamp the aorta and use a cardio-pulmonary bypass. If patients have a history of previous heart surgery, porcelain-aorta, renal dysfunction, left ventricular dysfunction, myocardial infarction, stroke, advanced vascular disease, high age, frailty, diabetes, pulmonary disease, other severe comorbidity or a combination of some of these factors, there is a major risk for open surgery (Makkar et al., 2014; Jung et al., 2005).

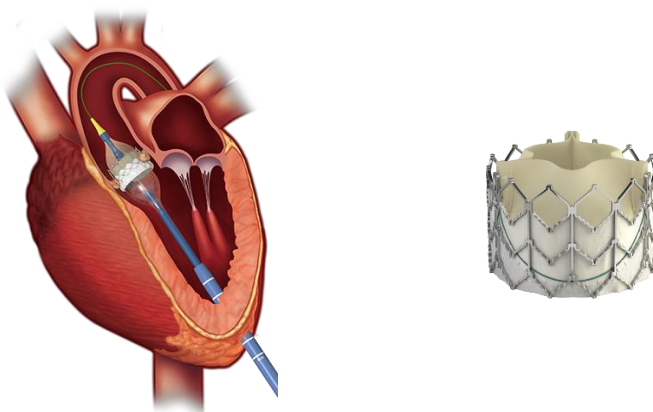
## **TAVI**

TAVI, transcatheter aortic valve implantation, where a biological aortic valve is implanted inside the patient's aortic valve, is a less invasive technique than surgical replacement. The first patient was treated with this new method 2002 in France by Dr Alain Cribier (Cribier et al., 2002). Since then the spread of TAVI treatment has been rapid, as well as has been the development of new types of valves. TAVI is now in use in more than 40 countries (Genereux et al., 2012). Despite the rapid adoption of TAVI across Europe, findings indicate that a sizeable treatment gap remains for surgical risk patients with severe aortic stenosis. TAVI is an expensive method and national economic indexes and reimbursement strategies may explain the unequal adoption of TAVI across nations (Mylotte et al., 2013).

Different techniques may be applied for TAVI. Patients in this thesis were treated with a transapical approach which means that it is performed by a mini-thoracotomy and implantation of the valve prosthesis through the left ventricular apex under general anaesthesia, Figure 1. With a transfemoral approach the catheter is inserted through the femoral artery and the procedure can be performed without general anaesthesia. The latter is preferred but not always possible to apply because of calcification of arteries.

Before patients are accepted for TAVI they undergo thorough examinations. Transthoracic and transoesophageal echocardiography are performed for evaluation of the valve area, gradient, ventricular function and angiography

for examination of the cardiac arteries and need for preoperative percutaneous coronary intervention (PCI). Functional and cognitive tests are usually performed and included in the basis for decision. The results are then discussed at a multi-disciplinary team-conference where risk-benefit are weighted and decisions about acceptance or not are made (cf. Kappetein et al., 2013).



**Figure 1.** Left picture illustrates transapical TAVI. Right picture illustrates the balloon-expandable bovine Edwards SAPIEN XT pericardial device used among participants in the thesis (Edwards Life Sciences, Irvine, California).

Many studies have been performed to evaluate TAVI treatment with regard to outcome and safety. Complications connected to TAVI are varied and related to the type of procedure, patient selection and device used. Stroke, vascular complications and paravalvular aortic regurgitation are the most common complications, but major bleeding, new need for pacemaker, new atrial fibrillation, kidney injury, pleural effusions and endocarditis have also been reported (Cao et al., 2013; McRae and Rodger, 2012).

The results from the prospective randomized trial Placement of Aortic Transcatheter Valves (PARTNER) have had a major impact on the treatment of patients with severe aortic stenosis. The trial was designed in two arms (Svensson et al., 2013). In PARTNER B on patients with severe aortic stenosis ineligible for conventional surgery, 358 individuals were randomized to either TAVI or standard therapy (medication). The 30-day mortality rate was 5.0% in the TAVI group compared to 2.8% in the standard treated. At 1-year follow-up the death rate was 30.7% in the TAVI group, as compared to 50.7% in the standard therapy group. The study showed not only decreased mortality, but also that TAVI reduced severe symptoms compared with medical treatment. However, TAVI increased the risk of stroke and vascular complications (Leon

et al., 2010). In PARTNER A, 699 high-risk surgical patients were randomized to SAVR or TAVI. Both methods were associated with similar survival rates at one year, but neurological complications were more common in the TAVI group (Smith et al., 2011). At two years follow-up, there was no difference in frequency of stroke between the groups, however, paravalvular regurgitation was more frequent after TAVI and was associated with increased late mortality (Kodali et al., 2012).

In a study of patients with severe aortic stenosis, the outcome of treatment with self-expanding TAVI bioprosthesis was compared with SAVR and showed an increased rate of survivals in the TAVI-group (Adams et al., 2014). Lately, a study, PARTNER 2, in intermediate-risk patients regarding the primary end point of death or disabling stroke has shown that TAVI was similar to surgical aortic-valve replacement (Leon et al., 2016).

TAVI is now the standard care for high-risk patients denied surgery and is a valid alternative to surgery for selected high-risk patients (Genereux et al., 2012). The question of long-time device durability remains yet to be answered before TAVI can be an alternative for younger patients who have a longer life expectancy (Arsalan and Walther, 2016).

## **Patient perspectives on TAVI**

When a new treatment is introduced a central concern is if the treatment prolongs life and if the treatment reduces symptoms and suffering with acceptable risk. Since patients considered for TAVI are elderly and have a limited life expectancy and comorbidities, their increased functional status and preserved independence are of great importance. Quality of life is therefore a common way of evaluating patient outcome in this population (Deutsch et al., 2013). Morbidity and mortality outcomes may fail to appreciate the full effects on emotional, physical, functional and mental wellbeing, particularly in an elderly population. Instead greater attention should be paid to QoL aspects so as not to underestimate the results (Gurvitch and Webb, 2010). Health-related quality of life (HRQoL) is therefore one of the recommended outcomes for evaluation of TAVI from the Valve Academic Research Consortium (VARC)-2 (Kappetein et al., 2013).

### ***Results from questionnaire studies***

HRQoL in relation to TAVI is measured with different questionnaires and at various times for follow-up. Bekereditjan and co-workers, using the generic 36-item questionnaire (SF-36), showed a general significant improvement 6 months after TAVI (Bekereditjan et al., 2010). Krane and co-workers, using the same questionnaire, showed improvement in physical health both at 3 months

follow-up (Krane et al., 2010) and after 12 months (Krane et al., 2012). Ussia and co-workers, using the Short Form-12 Health Survey (SF-12), showed improved physical and mental health both at 5 months (Ussia et al., 2009) and 12 months follow-up (Ussia et al., 2011).

Heart failure-specific measures of HRQoL, as the Minnesota Living with Heart Failure Questionnaire (MLHFQ), have been used and improvement from TAVI has been presented (Gotzmann et al., 2011). In the mentioned randomized PARTNER trial, the heart failure-specific Kansas City Cardiomyopathy Questionnaire (KCCQ) and the generic SF-12 were used to measure HRQoL at 1, 6 and 12 months follow-ups in two different cohorts. In PARTNER B including inoperable patients with severe aortic stenosis, patients treated with TAVI were compared with patients receiving medical treatment. The result was a significant improvement in the TAVI-population that was maintained at the 12 month follow-up (Reynolds et al., 2011). In PARTNER A, where surgical high-risk patients with severe AS were randomized to TAVI or SAVR, HRQoL improved substantially between baseline and one year after both TAVI and SAVR. Transfemoral TAVI but not transapical, was associated with benefit compared with surgery after one month (Reynolds et al., 2012). In conclusion, quantitative measures of QoL reports improvement from TAVI in both shorter and longer terms.

### ***Results from interview studies***

Interviews are of great value and a way of getting a deeper knowledge about patients' perspectives of e.g. experiences of coping, decision making and recovery. When reviewing the literature on TAVI, few qualitative studies have been found. Two studies made in connection to patients' decision making to undergo TAVI were identified. First, a study with the aim to identify patient-defined goals for treatment by asking patients with severe aortic stenosis planned for TAVI "What do you hope to accomplish by having your valve replaced?" The answers were categorized into four descriptive themes which were adapted from prior work in a similar elderly population. The themes were: *maintaining independence; staying alive; reducing/eliminating pain and symptoms* and; *to do specific activities*. They found that the ability to do specific activities (48%) and maintaining independence (30%) were the most common statements. Thus, it was a quite quantitative analysis of interview data. At follow-up after one month 87% had reached their goal (Coylewright et al., 2015). Second, a study of factors influencing the patients' decision of accepting TAVI by Lauck and co-workers (2015) revealed six, intersecting factors: *symptom burden, the experienced patient, expectations, healthcare system and informal support, logistical barriers and facilitators* and lastly *obligations and responsibilities* (Lauck et al., 2015). Berg and co-workers (2013) have reported patients' experiences of recovery after pulmonary or

aortic valve replacement including TAVI. The overall concept was *suffering weakness* and *struggling to resume normality* (Berg et al., 2013).

The experience of living and coping with aortic stenosis is still not well explored. However, in reviews living with heart failure, sometimes the result of aortic stenosis, is well described from different perspectives and gender differences (Yu et al., 2008; Jeon et al., 2010). These review studies describe how distressing symptoms and decreased physical function lead to social and role dysfunction and how various coping strategies among men and women are used to manage the effects of heart failure.

## **Theoretical framework**

### ***Coping***

Coping is a psychological term that describes a person's ability to handle stressful and emotionally demanding situations. A well-known model of coping is the Transactional Model of Stress and Coping by Lazarus and Folkman (Lazarus and Folkman, 1984). Stressors are demands made by the internal or external environment that upset balance, thus affecting physical and psychological well-being and requiring action to restore balance. *Coping* is defined as the person's constantly changing cognitive and behavioural efforts to manage stressors that are appraised as challenging or exceeding the person's resources (Folkman et al., 1986). There are three important elements in this definition. First, coping is *process oriented*, meaning that it focuses on what the person really thinks and does in a specific stressful situation, and how this changes as the situation unfolds. Second, coping is *contextual*, meaning that it is influenced by the person's appraisal of the actual demands in the encounter and the resources for managing them. Third, coping is defined as a person's *efforts* to manage demands. Coping has the two major functions: to regulate stressful emotions, *emotion-focused coping*; and to alter the troubled person-environment relation causing the distress, *problem-focused coping*. Common *coping strategies*, according to Folkman et al. (1986), are as follows:

- *Confrontative coping* is an aggressive effort to alter the situation; to act. It also suggests a degree of hostility and risk-taking.
- *Distancing* means efforts to detach oneself, to refuse to think about the stressor too much or try to look on the bright side of things.
- *Self-control* is efforts to regulate one's own feelings and actions; to keep feelings to oneself and not do anything hastily.
- *Seeking social support* is about efforts to seek informational support, tangible support and emotional support.

- *Accepting responsibility* acknowledges one's own role in the problem and trying to put things right.
- *Escape-avoidance* describes wishful thinking and behavioural efforts to escape or avoid.

### ***Coping in decision making***

Not only are different coping strategies used to handle stressful demands in daily living and of symptoms when having a disease, but also how to handle choices and conflicts in decision making about treatment (Balneaves and Long, 1999). Patients' decision making about undergoing treatment when they are confronted with a life-threatening disease, sometimes in the acute phase, is stressful and demanding (Kelly-Powell, 1997). When patients perceive risk in both accepting a new treatment and maintaining the current situation, i.e. being in a state of uncertainty about a course of action, they experience a decisional conflict (Janis and Mann, 1977). A decisional conflict is more likely when the choice concerns risk, loss or challenge to personal life values (Kremer et al., 2007).

*The Conflict Theory Model (CTM)* of Janis and Mann proposes ways of coping with decisional dilemma such as vigilance, defensive avoidance and hypervigilance (Janis and Mann, 1977). *Vigilance* is mainly associated with informed decision making, where the relevant information about alternatives and consequences is carefully searched for and evaluated before deciding. *Defensive avoidance* is a way of avoiding stress through procrastination (delaying decision making), buck-passing (shifting responsibility to others), and bolstering (to use rationalization and selective attention). Defensive avoidance is considered to be associated with a pessimistic view of finding a solution of the decisional conflict. *Hypervigilance* is a state of panic where decision is made in an impulsive way with a sense of being confronted with a big threat, and running out of time (Umeh and Omari-Asor, 2011).

Hope is a way of coping and has in nursing theory been highlighted by, for example, Joyce Travelbee (1971) in her nursing theory: Human-to-Human Relationship Model, also presented in a literature review of the concept of hope in healthcare context (Travelbee, 1971; Tutton et al., 2009). Travelbee regards hope as a central component of nursing and hope is seen as future orientated and strongly associated to dependence on other people. It is related to choice, wishes, courage and trust. Choice regards the feeling that the person has control over one's own destiny. Wishing concerns a desire that something unlikely would happen. Courage relates to the individual's ability to overcome limitations of fears and move towards the goal. Trust relates to knowing that someone will be there for you when needed (Travelbee, 1971).

## **Rationale**

Aortic stenosis is a common disease with severe symptoms and is increasing due to the aging population. The disease is life-threatening and about half of the patients die within two years after onset of symptoms if there is no replacement of the valve. Despite huge emotional and existential issues related to the disease and treatment, qualitative studies of patients' experiences are very scarce.

Transcatheter aortic valve implantation has made it possible to treat patients who previously were denied surgery. TAVI is though an expensive method, mostly offered to elderly people with comorbidities and relatively short life expectancy. Many studies have presented an outcome on survival and QoL from TAVI but only a few addressed qualitative design. Patients' involvement in treatment decision making is an interesting task with growing interest and the role of the patient is also recently strengthened in the Swedish Patient Law (2015) with respect to e.g. information and empowerment, individual planning and choice of treatment. No published study has described the TAVI trajectory from a patient perspective although it concerns very frail patients in need for special attention. Increased knowledge deriving from the experiences of patients could give rise to suggestions for improved care.

## **Aim**

The overall aim of this thesis was to explore experiences and self-reported outcomes of TAVI among people with severe aortic stenosis

### ***The specific aims of the included papers were:***

Paper I: To describe patients' experiences of coping with severe AS and awaiting TAVI.

Paper II: To describe the decision-making process about undergoing TAVI treatment among people with severe aortic stenosis.

Paper III: To explore the patients' view of the trajectory and recovery process from TAVI.

Paper IV: To describe patients' self-reported outcomes in terms of physical function, symptoms, dependence, HRQoL, and cognitive function after TAVI and SAVR.

# **Materials and methods**

## **Methodological assumptions**

In this thesis, with the purpose of exploring the patients' experiences from TAVI, we decided to use both qualitative and quantitative methods. In searching for individual experiences qualitative methods were used. They belong to the naturalistic paradigm in which reality is seen as multiple, subjective and constructed by individuals (Polit and Beck, 2014). By asking patients about their experiences, memories and expectations, we as researchers get information that help us to understand "what is this all about". In order to evaluate the effect from TAVI on symptom burden and health-related quality of life, we used quantitative methods that included specific questionnaires that made it possible to quantify experiences and make statistical analyses. By performing a blood test, NT-proBNP we intended to measure the effect on heart failure and, through a six minute walk test, the effect on physical function.

## **Constructivism**

Constructivism places priority on the phenomena of study and sees both data collection and analysis as created from shared experiences and relationships with participants. Both qualitative data and analyses are social constructions and analysis is contextually situated in time, place, culture and situation. Facts and values are linked, and what we see and what we don't see depends on values. Therefore, researchers must become aware of their presuppositions and handle how they affect the research (Charmaz, 2006; Morse et al., 2002).

## **Prospective study design**

The prospective design made it possible to explore the patient's situation and decision making, without being affected by the outcome of TAVI (I, II). The quantitative study in the thesis (IV) is a descriptive study of self-reported outcome. All patients admitted to hospital for TAVI were included and, apart from those who died, participated in the follow-up. This reduced the risk of sampling bias compared to a retrospective study design (Polit and Beck, 2014).

## **Setting**

The studies were performed at a University clinic in Sweden. The hospital serves a region consisting of four county councils that represent a large area with a population of 885 000 in 2016.

## **Participants and sampling**

All patients treated with TAVI for severe aortic stenosis during a period from May 2010 to June 2011, were consecutively sampled. The participants (9 women, 15 men), all Swedish speaking, were informed about the study orally and in writing. They all accepted participation and signed an informed consent. The baseline data of the patients are presented in Table 1. A flow-chart of the sampling and participation is presented in Figure 2.

The patients were offered participation in the study the day before TAVI and interviews and the quantitative data were collected the same day. At baseline the interviews were performed in a single room at the hospital ward. The follow-up was usually completed in connection with the planned visit to the cardiologist at the outpatient clinic at the University hospital. If not possible, follow-up was performed in the patient's home or at an outpatient clinic at a county hospital.

To mirror the results from the TAVI-patients, age-matched patients with severe aortic stenosis treated with SAVR at the same clinic were included in study IV. Patients in need for combined surgery were excluded.

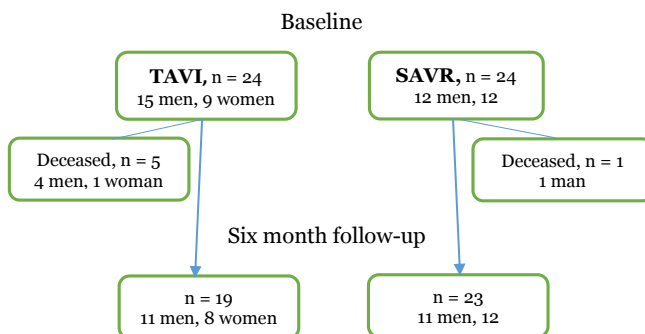
The number of participants was chosen according to a power analysis for Paper IV and based on the first results of SF-36. In the qualitative studies (I-III), all patients were included even if it was a quite large sample for qualitative studies.

**Table 1.** Baseline data of the TAVI and SAVR patients

	<b>TAVI</b> n = 24	<b>SAVR</b> n = 24	<b>p</b>
<b>Sociodemographics</b>			
Participants, n	24	24	1.000
Men/women, n	15/9	12/12	0.383
Age in years, md (min-max)	81 (60–90)	80 (61–88)	0.386
Living alone, n	15	11	0.247
Home care service, n	3	3	1.000
<b>Function and symptoms</b>			
NYHA classes III and IV, n	24	13	0.006
NT - proBNP, md (min-max)	2042 (102–22740)	690 (79–6 119)	0.010
Cognitive function, MMSE, md (min-max)	28 (20–30)	29 (25–30)	0.017
Dependent P-ADL, n	5	0	0.050
Dependent I-ADL, n	15	10	0.149
Syncope, n	7	5	0.509
6 minutes' walk test, meters, md (min-max)*	240 (98–496)	374 (228–570)	0.006
<b>Comorbidities</b>			
Diabetes, n	5	3	0.701
Chronic obstructive lung disease, n	7	2	0.137
Prior stroke, n	8	3	0.168
Peripheral vascular disease, n	7	1	0.048
Myocardial infarction <3 months before TAVI, n	4	0	0.109
Prior bypass graft surgery, n	13	0	0.000
EuroScore, md (min-max)	17.740 (5.010–56.190)	8.345 (2.230–36.780)	0.009
Creatinine, md (min-max)	92 (69–140)	77 (59–116)	0.014

\*TAVI, n = 21, SAVR, n = 14

Five of the TAVI-patients died before follow-up, four in the first two weeks after TAVI, none during implantation. Two of those who died shortly after TAVI had the highest measured values of NT-proBNP as a sign of very severe heart failure. Another of the deceased had reported the highest values on the scale related to depression, worry and anxiety, feelings that also emerged in the interview. One patient died in relation to treatment for pulmonary complication, and the last deceased person, died from sepsis about 3 months after TAVI. In the SAVR group one patient died of postoperative complications. All patients that were alive after six months participated in the follow-up.



**Figure 2.** Flow-chart of sampling and participation

## Data collection and procedure

The various designs, data collections, analyses and participants in Paper I-IV are presented in Table 2.

**Table 2.** Overview of design, data collection, analyses and participants

Paper	Design	Data collection	Analysis	Participants (n)
I	Qualitative	Semi structured interviews	<b>QCA</b> Before TAVI	24
II	Qualitative	Semi structured interviews	<b>QCA</b> Before TAVI	24
III	Qualitative	Narrative interviews	<b>GT</b> After TAVI	19
IV	Quantitative	Questionnaires	<b>Statistics</b> Before and after TAVI/SAVR	24 and 19/ 24 and 23

The data collection procedure for all participants began with the interview that was followed by the cognitive test, after which the questionnaires were completed.

### *Interviews*

Interviewing is a common method in qualitative research. A research interview is a conversation with a given structure and purpose. By carefully asking questions, encouraging attitude, active listening and probing questions, it is a means of obtaining deepened knowledge. A research interview is not a chat between equal partners, since the researcher is responsible and in control of the situation (Kvale and Brinkmann, 2009).

The baseline interviews were semi structured. The participants were asked: Could you please describe your symptoms and how they affect your life? They were also asked to describe their perceptions about undergoing TAVI and what expectations they had for the future. The interviews were recorded and lasted for 15-45 minutes (commonly 25 minutes). Even in shorter interviews, many participants expressed emotions and personal stories that gave rich data.

The interviews at six months follow-up were held in a less stressful situation. It was thereby possible to be more open and the interviews were longer, 15-60 minutes, (commonly 35 minutes) and more narrative in nature. It made it possible for experiences that were meaningful to the participants to be highlighted in a higher degree. These interviews started with the broad open-ended question: Could you please tell me about the recovery from TAVI and how you feel today? Intermediate questions concerned support, satisfaction with treatment and result. Specific follow-up questions on emerging patterns were incorporated into interviews with subsequent participants to fill knowledge gaps. The interviews ended with the question: Is there anything else you want to tell me about your experiences? (cf. Charmaz, 2006)

## ***Questionnaires and function***

### **Cognitive assessment**

A cognitive test is usually part of the clinical assessment before TAVI. In this study the cognitive test was performed before and at the six months follow-up, and we used Mini Mental State Examination (MMSE). The instrument consists of 20 questions covering areas of cognitive functions related to orientation in time and place, memory, attention, language and spatial functions (relating to visual and spatial interpretation skills). Results of 24 points or less (out of 30) indicate impairment. The result of the test can be influenced by age, education and language habits (Folstein et al., 1975).

### **Health-related quality of life**

Two questionnaires for HRQoL were used. SF-36 was chosen since we had long experience of using it at the clinic and it is well accepted and validated. EQ-5D was chosen since it is simple and commonly used in quality registers in Sweden.

*SF-36.* This questionnaire includes 36 items grouped into 8 multi-item domains: physical functioning, role limitation due to physical health problems, bodily pain, general health, vitality as a measure of energy and fatigue, social functioning, role limitations due to emotional problems, and lastly mental health related to psychological distress and psychological well-

being. The domains are rated 0 – 100, the higher score the better HRQoL. The usefulness, validity, and reliability are well documented and the questionnaire has proved to be responsive to changes in health status throughout time (Sullivan et al., 1995). It is a generic measure and the SF-36 has proven useful in surveys of general and specific populations, comparing the relative burden of diseases (Turner-Bowker et al., 2002; Sullivan et al., 1995).

*EQ-5D.* The questionnaire includes the five dimensions of HRQoL, mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, each of which could be scored at three levels of severity. The answers are transformed to a population-based index with a range from 0 to 1, where 1 represents ideal health and 0 worst health state. Since a Swedish population based index is lacking, the UK index was used. The test was completed with a visual analogue scale (VAS), 0-100, the higher the better, measuring current health status, with endpoints labelled “the worst health you can imagine” and “the best health you can imagine”. The questionnaire is generally accepted and has demonstrated high validity and reliability (The EuroQol Group, 1990).

### **Independence**

*The Katz Index of Independence in Activities of Daily Living*, commonly referred to as the Katz ADL, is an instrument for assessing functional status as a measurement of the ability to perform activities of daily living independently. The index ranks adequacy of performance in the functions of personal activities (P-ADL) like bathing, dressing, toileting, transferring, continence, and feeding (Katz et al., 1963). Instrumental ADL (I-ADL) like cleaning, food-shopping, transport and cooking have been added (Borsson and Asberg, 1984). In this study I-ADL and P-ADL were dichotomized to dependent or independent variables, for confirmation of any of the questions. The questionnaire was also completed with questions about having home-care service, alarm and transportation service.

### **Self-rated symptoms and function**

A survey about presence of heart-related symptoms was completed. The questionnaire included questions about physical function similar to the NYHA classification; one question on what heart-related symptom that affected patients the most; nine questions on symptoms of heart failure answered by yes/no; and with the addition of one question about fainting. This questionnaire was previously used in a study of patients with hypertrophic cardiomyopathy. It contains questions from “The study of men born in 1913”, that started in 1963 about men living in Gothenburg by Professor Gösta Tibblin and co-workers.

<https://snd.gu.se/sv/catalogue/study/SND0010>

### **Physical capacity**

The patients physical capacity was measured with a 6 minute walk test (6MWT), a common way of testing patients with heart failure (Guyatt et al., 1985). The 6MWT was performed indoors, along a long, flat, straight, enclosed corridor with a hard surface that was seldom travelled. The walking course was 30 meters in length and marked with a starting line and a turnaround point. The object of this test is to walk as far as possible for 6 minutes. The participants were informed to walk back and forth for six minutes. They were permitted to slow down, to stop, and to rest if necessary. They were also told to pivot briskly around the turning point and continue back the other way without hesitation. In this study the first test was performed the day before TAVI by a physiotherapist in a corridor at the University hospital. The follow-up test was performed by a physiotherapist, either at the University hospital or at a county hospital following guidelines for 6MWT.

### ***Medical data***

#### **Laboratory test**

A blood test NT-proBNP (B-type natriuretic protein, normal value <100ng/l), was completed before TAVI and at follow-up. It is a useful clinical marker for heart failure and high value is a negative prognostic indicator (Ruskoaho, 2003).

#### **Register data and medical record data**

Baseline data of comorbidities was collected from the medical record and NYHA-classification and EuroScore from Carath, a local register for thoracic surgery (Friberg et al., 2011).

### **Data analyses**

The interviews were interpreted to get a deeper understanding of the patients' perspectives. The interpretation was influenced by my preunderstanding; long practice as a nurse in cardiac care. Therefore I tried to be open-minded, both when I interviewed and analysed the patients' stories. Despite my long experience, patients' ways of reasoning often was surprising. This gave greater insights throughout the study and helped me to improve probing questions in order to get a deeper understanding (Charmaz, 2006).

Two methods for the qualitative studies were used. In Paper I and II, the experience of living with aortic stenosis, being offered TAVI and making the decision of accepting or not, was in focus. Qualitative content analysis seemed appropriate since it offers a flexible method for developing extending knowledge of variations in human experiences of illness (Hsieh and Shannon,

2005). In Paper III the process of undergoing TAVI from patient's perspective was in focus, and grounded theory was therefore used (Charmaz, 2006).

### ***Qualitative content analysis***

The baseline interviews were analysed using qualitative content analysis, a method for systematically describing the meaning of qualitative material (Schreier, 2012). It was suitable since we wanted to explore the variations of experiences of living and coping with severe aortic stenosis (Paper I); the manifest content as well as an interpretation of the latent message (Graneheim and Lundman, 2004). The analysis was performed in steps in accordance to Graneheim and Lundman (2004). The interviews were transcribed verbatim and the text was initially read several times to grasp a sense of the whole. Text corresponding to the aim was then identified and marked and inductively coded with labels. These codes were then compared and sorted based on similarities and dissimilarities in categories and subcategories. During the analysis we moved back and forth, from original text to categories, to make our interpretations. A theme, a thread of an underlying meaning going through the categories, was finally identified. To ensure trustworthiness of the analysis, all steps in the analysis and the preliminary findings were continuously reflected on within the research team and sometimes adjusted when doubtful interpretations were discovered.

In the analysis, we identified another area of interest that was not covered by the analysis of Paper I; the patient's decision making process. Therefore we used the same interviews and made a secondary analysis in the same way as in Paper I. We identified codes corresponding to the aim, sorted them into categories and interpreted the categories into three themes, as reported in Paper II.

### ***Grounded Theory***

Grounded theory (GT) was used to analyse the follow-up interviews for Paper III. GT emerged from the sociologists Barney G. Glaser and Anselm L. Strauss in their studies of dying in hospitals in the USA. The aim of the GT analysis is to construct a theory. It is a suitable method when the process is in focus (Glaser and Strauss, 1968). The method is characterized by data collection and analysis made simultaneously; codes and categories constructed from data, not from deductive hypothesis; the analysis characterized by constant comparing in all stages; theory development proceeding during data collection and analysis; memo writing used throughout the procedure to identify gaps, elaborate categories, specify their properties and define relationships; sampling aimed toward theory construction and lastly literature review conducted after developing an independent analysis (Charmaz, 2006).

We performed the analysis according to the method described by Charmaz (2006) with the exception of the theoretical sampling, as this study was one part of the larger study. In connection to performing the interviews, memos were written of emerging ideas and patterns. The recorded interviews were transcribed verbatim and read line by line. The next step in the analysis was the initial coding, i.e. labelling the text with codes, which used words close to data. In the focused coding, the initial codes that were most significant and made the most analytical sense, were identified, compared with memos and recoded to a more abstract level. Those codes were then organised according to categories and subcategories. In the theoretical coding, concepts were constructed to identify the connection between the categories and to describe a theoretical direction. Finally, a core concept of the model was identified. Notes were made throughout the whole analytical process. In this constant comparison analysis we moved back and forth, using our memos, going back to the interviews, reading the text and discussing results in the research team to ensure credibility (Charmaz, 2006). A further analysis of all results in Papers I-IV generated a broad understanding of the whole thesis reported in the result section. In order to reach this comprehensive understanding we started with highlighting all results, both qualitative and quantitative, and thereafter comparing and arranging them as a process, illustrating the general aim. The interpretation was discussed and revised after discussion with supervisors and illustrated with a figure (Figure 3).

### ***Statistics***

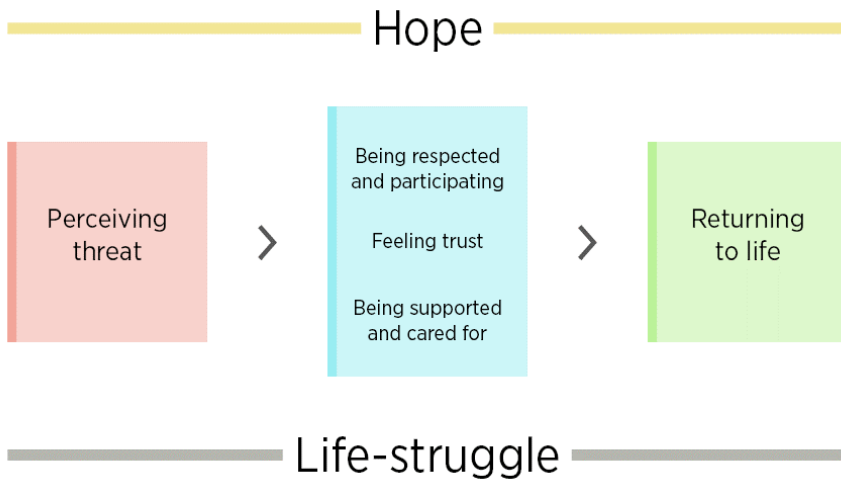
Nonparametric tests were used in this study, due to a small study population. Chi-square test, or Fisher's exact test when appropriate, was used for categorical variables for comparisons between groups, and McNemar's test for comparisons within groups. Mann-Whitney U-test was used for continuous variables in comparisons between groups, and Wilcoxon signed rank test within groups. Statistical significance was defined as  $p$  value  $<0.05$ . SPSS statistics for Windows, version 22 (SPSS, Inc.) was used for statistical analyses.

### **Ethical considerations**

The study was approved by the Regional Ethics Board in Umeå Dno 2011-340-31M. The baseline data collection, consisting of an interview, questionnaires and other examinations were conducted the day before TAVI which was not optimal since some of the patients were in quiet bad condition. Despite that, they all accepted to participate in the study. For their convenience, we did not use many questionnaires. Mostly, the participants were positive about talking about their problems and expressed their feelings concerning their situation and no one expressed a need for support afterwards.

# Results

The result is presented as a model made up of five categories ranging from “Perceiving threat” to “Returning to life”, that are arranged as a process with the core concept “Hope” being a goal to obtain, and the core concept “Life-struggle” always present as a serious dimension to consider (Figure 3). The model is based on a synthesis of the results from the four papers included in the thesis.



**Figure 3.** Model of the synthesized results in the thesis

## Life-struggle

The patients in the studies were almost all physically frail with comorbidities or disabilities. Before TAVI they had to cope with physical symptoms and limitations in their daily life. They tried hard to stay independent and handle activities in flexible ways (I). Many lived alone or with a partner who was old and sometimes ill, and they struggled to manage daily life together. The wish to facilitate for one’s partner could be a motive for accepting TAVI. “The shopping, we do it together me and my husband. He carries all the heavy stuff, but he is also old and in poor health. Yes it works so far, but I thought that if I could become a little better, it would be easier for him because he is much older. One must pull together.” (I, II). The illness often led to changed roles. “I contribute minimally, it is my wife that does all the heavy work”. The increasing tiredness was sometimes seen as a natural cause of advanced age or other diseases which many had gradually adapted to. The patients had different needs due to other diseases and psychosocial circumstances and

therefore individual preparation of care and follow-up was essential. When this was not the case, they felt threatened and their anxiety increased (I).

In the recovery phase after TAVI, various kinds of problems were described. One man had problems with lungs and thought that he would never recover, which made him depressed. Another patient had a stroke a few weeks after TAVI and became wheelchair bound, dependent on home care service and had difficulties speaking. There was also a patient who had got atrial fibrillation and did not experience any improvement. Urinary problems were common among men and, in some cases, the problems lasted for long. Most patients felt weak when they came home and relatives were not always understanding. Some males made training programs on their own to get strong and recover (III).

At follow-up, the participants were mostly occupied with current problems and the struggle to manage daily life. For some, new health problems had appeared, either for themselves or for their partners. Having a partner who was ill, depressed or suffering with dementia led to new worries and, in combination with own frailty, made it even harder to manage everyday life. Their increased physical capacity though made it easier to cope with the situation. “Despite all difficulties, I have never regret the surgery. I’m used to struggle” (III, IV).

### **Perceiving threat**

To have severe aortic stenosis means living with a life-threatening disease, something that most of the participants were aware of. Some had very severe symptoms that constantly reminded them of this and, when the symptoms had worsened rapidly, they felt that their time was running out. “It does not work anymore, I have no strength. I can only take 4 to 5 steps and then stop.” Some of the participants had experienced syncope which they described as very frightening and they struggled to cope with their increasing physical symptoms and the anxiety caused by the disease. They were “living on the edge”, but they tried to stay in control (I). When the disease progressed their independence and social roles was threatened. They tried to preserve self and self-esteem by shifting focus and living as normal as possible (I).

However, the threat was not only caused by the disease. The patients had previously been denied surgery and were now living with the uncertainty about being accepted for TAVI and, if they were accepted, they had to process the decision of undergoing this new treatment (I-II). They were confronted with thoughts of death and wondered what way was the best to die; from surgery or from heart stop working (I).

## **Being respected and participating**

To be participating and mentally prepared for TAVI was described as of great value (II, III). Some had good knowledge about their disease and had undertaken controls by their family doctor or cardiologist for several years (I). “These previous two years were very good. I had time to mentally prepare myself in these changes and to wait for this new method and also read about it on the Internet and follow it and ... no, it was the perfect arrangement” (III). When risks were discussed over their heads, they felt disregarded and unprofessionally treated so that their confidence was reduced (III).

Many of the participants ensured that they were involved in the decision to do TAVI. They were not forced to accept and they felt respected. Some expressed ambivalence and had discussed pros and cons with their doctors. One of the participants stressed her own influence like this: “I have talked to my doctor about the concerns I have had, we had a very good dialogue he and I. We agreed to wait as long as possible so that they can start using the new method, so that they can do a number of test operations on less high risk patients” (II). Those who had a brief medical history, didn’t have the time for preparation and didn’t always understand the meaning of the valve disease and the treatment. Others did not want to participate in the decision and avoided to be involved. They were often obedient and followed the advice from experts or from their children (II). “I do TAVI because my doctor told me to do so.” One of those who did not want to be involved in the decision making process expressed disappointment afterwards. “Yes, I have said to those who asks that, if I had known it was so tough, I probably would not have agreed to do TAVI” (III).

## **Feeling trust**

The importance of getting medical guidance was described as crucial for feeling trust (I, III). Many of the participants were experienced patients and had a history of bypass surgery from which they had successfully recovered from (IV). This, they said, increased their trust in TAVI. Some of the participants lacked regular contacts with family doctors and others perceived that TAVI treatment was not well known outside the specialist clinics. Some patients had also waited long and were in a bad condition (I, II, IV). Being at the specialist clinic was described as a relief and one of the participants said that now he had slept the whole night for the first time in weeks (I). Feeling that the doctors really believed in the method and the patients’ possibility to survive, made them feel trust. “I need to have confidence in the doctors to whom I will leave myself. After all, I put my life in their hands, it's those things that makes you actually agreeing to this thing [TAVI] that is actually vital, and

there is no guarantee...” (III). When the symptoms of the disease suddenly became alarming, the patients felt that they had no choice if they wanted to survive. They were reconciled to their situation, trusted the doctors, and felt confident that the decision to undergo TAVI was right (II).

### **Being supported and cared for**

The level of use of home-care service and support from health care differed among the participants (IV). Many preferred to have their children helping them in daily life. Some, mostly women, also received help from friends and neighbours (I). The medical support varied and the importance of having continuity in contact with a physician emerged in the interviews (I). Being really cared for in hospital was important, as described by a woman: “When I was here the first time for investigation, when they had discovered that my symptoms were caused by the diseased heart valve, a young nurse sat beside me on the bed and asked if I felt more worried now when I had been informed about that. It made me feel good to talk to him, I became calm. It felt so nice, it really means a lot if you can talk a little” (III).

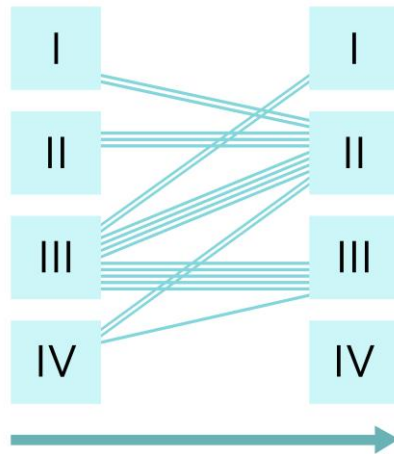
When it was time for TAVI, many patients expressed worries and were thankful for being supported and cared for. Some had discussed their situation with a supportive family. Others didn’t have anyone to talk to or preferred to keep family away (II). One of the women expressed her gratitude to the supporting doctors before TAVI like this: “Those doctors really supported me, they thought that this would be possible. They felt like my backbones” (III).

Sometimes, during rehabilitation when patients felt discouraged over slow recovery, they expressed need of support from others to remain hopeful and they got valuable contributions from e.g. doctors and physiotherapists who helped them regain hopeful thoughts. A previous stroke made the recovery time longer and assistance with training would have been desirable. Those who were living alone had to manage by themselves or to accept home-care service for a period (III).

### **Returning to life**

To be recovered was described as “returning to life” and of great relief for the patients; just being alive, although still struggling with other diseases or health problems. Values changed and many described how they lived in gratitude and joy. “Yes, it feels like I’ve got my life back a little, I have been given another chance, and I try to really take advantage of it and to remember that I actually have got another chance.” Decreased symptoms, better physical function and condition made them feel like they had a new start in life. The treatment made

it possible to stay independent, although one who previously refused home-care service, had now accepted (III-IV). The participants reported increased possibilities to take part in social activities, see their children and grandchildren more often, take care of their partner, and to make plans for the future. Male patients often mentioned that they could continue driving their car, which pleased them very much and preserved their self-esteem and social role (III). The change in symptoms, physical function and health-related quality of life was improved, which is illustrated in Figure 4 and Table 3-6 (IV). Self-reported function (similar to NYHA-classification), among the TAVI-patients, differed from the ratings of the physicians who assessed them as having a lower function than they did themselves. The self-reported function was improved or unchanged for 17 participants out of 19, six months after TAVI as illustrated in figure 4. One of those who didn't improve had got atrial fibrillation that she was affected from. The other patient still perceived himself as the strong man he once had been, at the test before TAVI. At follow-up, he had become aware of his illness and reduced function (III).



**Figure 4.** Change in self-rated NYHA-class from baseline to follow-up among TAVI-patients,  $p=0,022$

Self-rated HRQoL was low before TAVI and was significantly improved at the follow-up in all dimensions except for social role function. Physical function, although improved, was still low after TAVI and did not reach the baseline level for the SAVR patients. However, the physical role function was considerably improved among TAVI-patients (Table 3).

**Table 3.** Health-related quality of life before and six months after TAVI and SAVR

	TAVI			SAVR		
	Baseline n = 24	Follow-up n = 19	<i>p</i>	Baseline n = 24	Follow-up n = 23	<i>p</i>
<b>SF-36 md</b>						
Physical function	37.5	55	0.003	62.5	80	0.007
Role physical	0	75	0.001	50	100	0.008
Bodily pain	62	100	0.009	78	84	0.115
General health	50	72	0.002	65	87	0.014
Vitality	47.5	60	0.016	55	75	0.001
Social function	87	100	0.415	100	100	0.059
Role emotional	100	100	0.038	100	100	0.039
Mental health	84	88	0.002	84	88	0.006
<b>EQ-5D md</b>						
Index	0.64	0.80	0.002	0.73	0.90	0.001
VAS score	50	70	0.005	60	75	0.006

The most limiting heart-related symptom was shortness of breath, followed by fatigue in both groups, both at baseline and at follow-up (Table 4).

**Table 4.** The most limiting heart-related symptom

	TAVI		SAVR	
	Baseline n = 24	Follow up n = 19	Baseline n = 24	Follow-up n = 23
<b>Shortness of breath, n (%)</b>	12 (50.0)	7 (36.8)	14 (58.3)	6 (26)
<b>Abnormal fatigue, n (%)</b>	6 (25.0)	6 (31.6)	4 (16.7)	5 (21.7)
<b>Chest pain, n (%)</b>	4 (16.7)	1 (5.3)	1 (4.2)	0 (0)
<b>Palpitations, n (%)</b>	0 (0)	2 (10.5)	1 (4.2)	1 (4.3)
<b>Vertigo, n (%)</b>	1 (4.2)	0 (0)	2 (8.3)	2 (8.7)
<b>No symptoms, n (%)</b>	1 (4.2)	3 (15.8)	2 (8.3)	9 (39.1)

Before TAVI, many patients had severe symptoms like shortness of breath at rest and at night and seven patients reported syncope. The symptoms were reduced after TAVI, and no patients reported severe symptoms like syncope or symptoms at rest or at night at follow-up. Many of the results though, are not significant, probably due to the small study population (Table 5).

**Table 5.** Symptoms of heart failure before and at follow-up in the TAVI group

	<b>Baseline n = 24</b>	<b>Follow-up n = 19</b>	<b>p</b>
<b>You become short of breath if you walk briskly on flat ground, n (%)</b>	21 (91.3)	12 (70.6)	<i>ns</i>
<b>You become short of breath if you walk with peers on flat ground, n (%)</b>	15 (65.2)	8 (47.1)	<i>ns</i>
<b>You have to stop and catch your breath if you walk on flat ground at your own pace, n (%)</b>	15 (65.2)	2 (11.8)	<i>0.004</i>
<b>You become short of breath when you dress or wash, n (%)</b>	9 (39.1)	2 (11.1)	<i>ns</i>
<b>You get short of breath at rest, when you sit down, or at rest, n (%)</b>	7 (29.2)	0 (0)	<i>ns</i>
<b>You have to sit down and rest when you get home after a walk, n (%)</b>	18 (78.3)	7 (41.2)	<i>0.031</i>
<b>You wake up at night because of shortness of breath, n (%)</b>	6 (25.0)	0 (0)	<i>ns</i>
<b>You have swelling of your legs during the day, n (%)</b>	7 (33.3)	6 (33.3)	<i>ns</i>
<b>You are troubled by shortness of breath when you sleep with your head low, n (%)</b>	8 (34.8)	1 (5.6)	<i>ns</i>

The variation among TAVI patients at baseline was considerable when it came to cognitive function as measured by the MMSE, physical capacity as measured by 6MWT and the degree of heart failure, as measured by the NT-proBNP test. Cognitive function did not change significantly to follow-up. The result of the NT-proBNP test was improved as well as the 6MWT, although it did not include all patients. These results are not previously presented in the articles of the thesis (Table 6).

**Table 6.** Cognitive function, NT-proBNP and physical capacity before and after TAVI

	<b>Baseline, n = 24</b>	<b>Follow-up, n = 19</b>	<b>p</b>
<b>MMSE, md (min-max)</b>	28 (20-30)	27 (18-30)	<i>0,234</i>
<b>NT-proBNP, md (min-max) <sup>a</sup></b>	2343 (102-22740)	1730 (190-3927)	<i>0,039</i>
<b>6MWT, meters, md (min-max) <sup>b</sup></b>	240 (98-496)	356 (100-530)	<i>0,039</i>

<sup>a</sup> baseline, n = 24, follow-up, n = 16

<sup>b</sup> baseline, n = 21, follow-up, n = 14

## Hope

The TAVI trajectory is interpreted as a journey of balancing between life-struggle and hope, where hope is the state patients wanted to achieve and remain in. The necessity of having hope was a constantly recurrent topic in the interviews and a core concept in the above model in Figure 3. Some were very happy and relieved when they were offered TAVI. This was their last chance to be treated and hopefully cured (II). It was important that the doctors really believed in the method and that it was a suitable therapy. When the doctors could convey feelings of trust and security, it made the patients feel like having a future to look forward to. “I am so happy to be here at the hospital. I thought that it was over, but my doctor lit a flame of hope” (I-II).

The patients didn't have unrealistic hopes for the future; just being able to take a walk or visit a neighbour was enough (I). During the recovery process, which sometimes was a struggle that was long and hard to withstand, it was of great necessity to remain hopeful to recover. Some of the participants put up short-term targets for recovery and when they reached their goals they were very happy and saw it as a sign that they indeed were on the mend (III).

After six months some were in good shape and made bigger plans for future. TAVI had made them look forward to more years of independence and years together with loved ones and family (III).

## Discussion

The studies in this thesis demonstrate the difficult and stressful situation patients with severe aortic stenosis undergoing TAVI experience, but also the changes the treatment causes in physical function as well as in the view of life and the hope for future. Other diseases are still present and, for some, had worsened and the struggle to manage life was still present. However, the improvements in physical function, reduction of symptoms and increased HRQoL makes a difference. It has become easier to stay independent, take part in social activities and to have hope for future.

### ***Coping to manage life-struggle and threats***

Aortic stenosis has a bad prognosis and different coping strategies were used among the participants to handle threats caused by the disease. Many had chosen to live a quiet life and did not force themselves to do anything physically demanding that could initiate symptoms or had normalized their problems as a way of coping with the feeling of progressive disease (cf.

Folkman et al., 1986). Similar to findings of Bosworth and co-workers in their focus-group study of men with heart failure, I found that fears often lead to avoidance and denial of symptoms (cf. Bosworth et al., 2004). These coping strategies could lead to delayed medical consultation and obstructing patients from being in time for investigation and crucial treatment (Bach et al., 2009; Freed et al., 2010). The importance of time is shown in a study aimed to investigate the change in functional status while waiting for TAVI. If the waiting time was more than six weeks, frailty increased and gait speed decreased. Patients living alone had a larger increase in frailty scores compared to those who lived with another adult (Forman et al., 2015).

Others instead felt very keen to get treated quickly, especially those who had got severe symptoms. Risks and uncertainty of outcome was overshadowed by the desperate call for action. Their coping strategy was interpreted as confrontative (cf. Folkman et al., 1986) and the decision-making process hypervigilant (cf. Janis and Mann, 1977). Schaufel and co-workers studied patient-doctor dialogues preceding high risk surgery or interventions. They found that when handling uncertainty, doctors communicated complex information about risks and recommendations, while patients required and trusted doctors' advice (Schaufel et al., 2009). The importance of trust in medicine is expressed by the former president of the American Heart Association. She states that trust is built on three pillars. First, technical competence meaning how skilled doctors are at diagnosing and treating patients; second, interpersonal competence which refers to skills of communication and relation building; and third, agency, meaning that doctors do what they think is the best for the patients i.e. putting patients' well-fare before cost or other considerations. "Patients don't care how much you know before they know how much you care" (Jacobs, 2005, p. 3497).

Many of our patients expressed that they felt safe when they were in the specialist clinic and that they could at last relax and sleep well at night. A study aimed to explore the critical attributes of the concept "feeling safe" in hospitalization, identified four key attributes: *trust*, *cared for*, *presence* and *knowledge*. Feelings of control, hope and relaxation/calm were reported to be the consequences of these attributes (Mollon, 2014). This is congruent with Travelbee's relational model where trust is related to knowing that someone will be there for you when needed and this strengthens hope (Travelbee, 1971). Making patients feel safe therefore seems to be a goal and an important task for caregivers.

The struggle to cope with increasing symptoms and problems in managing daily activities were recurrent topics in the interviews and congruent with findings of others that described patients with heart failure (Pihl et al., 2011;

Bosworth et al., 2004; Nahlen and Saboonchi, 2010). Couples struggled together and a reason to accept TAVI could be the concerns for their partner and a wish to hopefully become better equipped to cope with daily life. This is in line with findings of Carroll and co-workers who stated that social influences and responsibilities to provide for relatives, influenced participants to accept an implantable defibrillator (Carroll et al., 2013).

In studies of older women with heart failure, women are reported being more likely to accept the losses caused by the disease (Rhodes and Bowles, 2002; Mårtensson et al., 1998). Similar to these findings, our female patients seemed to accept their situation more easily than did men, and sought social support as a coping strategy (cf. Folkman et al., 1986). In a study to determine the possible gender difference in how men and women perceived the seriousness of their disease, 490 patients were examined after acute coronary syndrome. The result of a logistic regression analysis showed that female gender was associated with lower perceived severity (Nau et al., 2005). Men in our study often expressed the feeling of being a burden or feeling worthless. The loss of a masculine role is previously highlighted in a study of men with heart failure (Bosworth et al., 2004).

Patients planned for TAVI can be seen as “experts” due to advanced age and long experience from illness and previous surgery and are therefore commonly mentally prepared. In a study by Lauck and co-workers investigating factors influencing the decision of older adults to undergo TAVI, they stated that this experience made them feel well prepared for accepting TAVI. The experienced patients in their study had hope and confidence that this minor surgery would succeed (Lauck et al., 2015). Other diseases or disabilities sometimes caused need for special preparation before TAVI among our patients. When this was not planned for in advance patients felt anxious and insecure. This could be avoided by having a nurse coordinator who ensures the continuity and that special needs are planned for (cf. Lauck et al., 2013). Patients who had recently been diagnosed did not have the time to prepare themselves but mostly trusted health care and their doctors.

Our patients generally stated that they felt involved in the decision making for TAVI, often with support from partners and children (cf. Folkman et al., 1986). When evaluating patients suitable for treatment with TAVI from a biomedical perspective, patients’ values have not been taken into account much (Lauck et al., 2014; Arnold et al., 2014). In a study of Kelly-Powell, 18 people with cancer, renal failure and heart disease were interviewed after they had made decisions to accept treatment for their disease. The core variable, *personalizing choices*, meaning that choices were congruous with their view of themselves within the context of their lives, past events, relationship with

others and their view of the future, was identified as important for them (Kelly-Powell, 1997). Shared decision making (SDM) is a way of implementing person-centred care and incorporating the values and preferences of the patient in the decision making (Kremer et al., 2007). SDM has been defined as: “an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them” (Elwyn et al., 2010). The goal with SDM is to respect patient autonomy without making the patient feel abandoned. Elwyn and co-workers have constructed a model for SDM in clinical practice where three steps are described. In *choice talk* you make sure that the patients know which treatments are available. *Option talk* is detailed information about the options and *decision talk* is the support of considering the preferences and deciding what is the best (Elwyn et al., 2012). SDM is described to be associated with reduced decisional conflict (Davison et al., 1999; Kremer et al., 2007). SDM is also in line with the Code of Ethics for Nurses (ICN, 2012) which states that the nurses’ responsibility, as the basis for consent to care and treatment, is to give accurate, adequate and appropriate information in a culturally appropriate way, respecting human rights, values, customs and beliefs. The right to be involved in care and decision making is also regulated in legislation, The Swedish Patient Law (2015).

Most of our participants considered themselves as competent and many had made their decision about undergoing TAVI in a vigilant way cf. (Janis and Mann, 1977). Information about AS and TAVI was almost always received from their doctors, but a few individuals had also used the Internet for information. The use of the Internet among TAVI candidates is likely to increase in the future, even in the older population. Since the results of TAVI is improving compared with SAVR (Leon et al., 2016), there will be more options to decide upon for future patients with AS. In a review of studies made between 1988 and 2007 on patients’ preferences of shared decision making, the authors identified a time trend. In later studies, after 2000, 71% of the respondents preferred shared roles compared to 50% before 2000 (Chewning et al., 2012).

However, some of our participants didn’t want to be involved in the decision making. A review by Benbasset and co-workers (1998) about patients’ preference of being involved in decision making concluded that most patients wanted to participate in planning treatment, but that some patients would rather be completely passive and avoid any information. Severe conditions, being older, less well educated, and male gender were predictors of a

preference for the passive role. The authors suggest that the only way a physician can gain insight into an individual patient's desire to participate in decision making is by asking (Benbassat et al., 1998). Kaufman and co-workers interviewed older patients who had undergone different cardiac interventions and surgeries. Most of the patients said that their doctors had told them what treatment was needed and, as they trusted their doctors, they did not refuse procedures. They had faith in technology, and medical action gave hope (Kaufman et al., 2006).

Being old and having diseases or impairment is often related to struggles. However, it is part of life and some of our patients identified themselves as being people that did not give up and they forced themselves forward. This finding is coherent with those of Schaufel and co-workers (2011) describing how patients facing cardiac death could create a go-ahead spirit instead of resignation. In a study of the oldest old, Nygren and co-workers (2007) interviewed old people to illuminate the meaning of having inner strength. The participants were chosen on the basis of high score in specific instruments, related to inner strength. They identified five themes that illuminated personal meanings of inner strength: *Feeling competent in oneself yet having faith in others*; *Looking on the bright side of life without hiding from the dark*; *Feeling eased and also being active*; *Being oneself yet growing into new garment*; and lastly, *Living in a connected present and also in the past and future* (Nygren et al., 2007). All these themes could be viewed as ways of coping with struggles (cf. Folkman et al., 1986). Inner strength helps persons to overcome negative experiences such as physical limitations and losses. The findings of Nygren and co-workers in a study in northern Sweden, showed that the oldest old had higher or the same level of inner strength as younger people (Nygren et al., 2005).

### ***The journey towards recovery***

Our patients were still feeling weak several months after TAVI. In line with findings of Berg and co-workers they struggled to reach normality (Berg et al., 2013). Ekman and co-workers identified two themes in a study of older persons' experiences of living with severe heart failure; *Feeling imprisoned in illness* and *Feeling free despite illness* (Ekman et al., 2000). Some men in our study described how they made training programs to regain strength, which was necessary for managing their hobbies and activities and not becoming "imprisoned in illness". They also expressed happiness over being able to continue driving their car which made them feel "free despite illness". In a review of older people with chronic heart failure the authors suggest that exercise therapy is especially important for men, as male patients are more likely to interpret the disease as devitalizing (Yu et al., 2008).

Russo and co-workers made a study in order to evaluate the effect of an exercise-based cardiac rehabilitation program for TAVI and SAVR patients (mean age=82). The training program started the second week after discharge from hospital and consisted of three sets of training; respiratory workout, aerobic sessions on an exercise bicycle (or on an arm ergometer) and callisthenic exercises, for six days per week for two weeks. The result showed that training was safe and gave a significant change in 6MWT in both the TAVI and SAVR groups (Russo et al., 2014). This good result and the expressed desire from our patients indicate that exercise programs beneficially could be offered TAVI patients. A Danish study evaluating cardiac rehabilitation programs for patients undergoing heart valve surgery, reported that patients undergoing TAVI were less likely to be referred to the program and also more likely to decline participation (Hansen et al., 2015). Some of our patients had complications after TAVI that made them almost lose hope. Asher (2004) claims that all surgical patients should be out of bed as soon as possible to prevent complications, and this is especially important in this fragile population (Asher, 2004).

Good recovery from TAVI was obvious on a group level. At follow-up of the patients, HRQoL had increased in all dimensions except social function which was not significantly improved. In interviews however, most patients also described how their social lives had changed positively. After TAVI, they could meet their relatives more often, join social activities and take care of their partner, which indicates that they experienced a better social function. The ability to facilitate for their partners seemed to be an important goal to obtain, and has also been described previously (Lauck et al., 2015).

### ***Achieving and maintaining hope***

The importance of having hope was a main finding in this thesis. In interviews before TAVI, it was strongly expressed by those who were most affected by the disease. “My doctor lit a flame of hope” was a metaphor from one of the participants, in line with the one “hope as a light on the horizon” from a review of hope in nursing research (Hammer et al., 2009).

The meaning of hope, as a universal human phenomenon, has been studied from various perspectives and in different cultures for long time. Hope has been discussed in literature related to philosophy, theology and psychology as well as in nursing research (Cutcliffe and Herth, 2002). Many researchers have tried to define hope by exploring the definitions and contextual usage of the word hope in the literature. Hope has, for example, been described as an expectation, an emotion or a need (Kylma and Vehvilainen-Julkunen, 1997; Benzein and Saveman, 1998). Stephenson has proposed a definition of the concept as “a process of anticipation that involves the interaction of thinking,

acting, feeling and relating, and is directed towards a future fulfilment that is personally meaningful” (Stephenson, 1991, page 1459).

Schaufel and co-workers (2011) made an interview study of patients with cardiac disease or cancer, to explore how patients with life-threatening diseases experienced hope when coping with mortality and other existential challenges. They found that hope could enhance and diminish existential distress and was described in the four themes: *Perceiving the realities of death—between overwhelming horror and peaceful acceptance*; *Adapting to a new phase in life—between reconciliation and uncertainty*; *Identity as seriously ill—between go-ahead spirit and resignation*; and lastly, *The impact of relationship—between support and concern*. Their study shows how patients cope with existential challenges by applying hope, and how the work of hope can be supported or disrupted (Schaufel et al., 2011). Similar to their findings, our participants expressed different reactions to the threat of the disease and the uncertainty before being accepted for TAVI. When the patients were reconciled in their situation and had accepted TAVI they felt hopeful. Some described how they scrutinised the meaning of the physician’s words in order to find out if they were going to survive or not. If the physician seemed unsure of the treatment and of the expected outcome, the patients perceived a sense of impending threat. On the opposite, when the physician could convey a sense that everything would be fine, they experienced a go-ahead spirit. In feelings of resignation patients expressed needs to be supported and cared for by skilled personnel, something that seemed to encourage hope during the whole TAVI trajectory (cf. Travelbee, 1971; Schaufel et al., 2011).

In critical stages in life, hope is considered to be an important coping strategy. The importance of hope has been examined in relation to different diseases, especially life-threatening ones like cancer or HIV (Miller, 1989; Herth, 1990; Briton, 2000). DuFault and Martocchio collected data from elderly patients with cancer. Their definition of hope was: “A multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, that to the hopeful person, is realistically possible and personally significant” (Dufault and Martocchio, 1985). They claimed that strengthening patients’ hope was an important task for nurses, especially in the last phase of a person’s life.

The theory of hope, as presented by the psychologist C R Snyder is a cognitive coping theory that consists of four categories; goals, pathway thoughts, agency thoughts, and barriers. *Goals* that are valuable and uncertain are described as the foundation of the hope theory, as they provide direction and an endpoint for hopeful thinking. *Pathway thoughts* are the routes to achieve the desired goals and include the individual’s perceived ability to produce these routes.

*Agency thoughts* refer to the motivation to undertake the routes towards the goals. *Barriers* can block the realization of desired goals and, if that happens, you can either give up or use pathway thoughts to create new routes. Snyder indicates that high hope individuals view barriers as challenges to overcome and use their pathway thoughts to plan an alternative route to their goals (Snyder, 2000). During rehabilitation our patients tried to be hopeful despite struggles and, as described by Snyder in the theory of hope, many made up realistic goals and pathways to reach their goals. When barriers occurred, like complications or long time recovery, they made up new goals to be hopeful. For some of our patients however, the struggle was in focus and their diseases were seen as the barrier to reach a good life. To help these patients to regain hope, making it possible to generate new goals, such as accepting assistance from others, is an important but difficult challenge for health care professionals (Gum and Snyder, 2002).

Mårtensson and co-workers interviewed men with heart failure about their conception of their situation and identified six categories: *Feeling a belief in the future*; *Gaining awareness*; *Feeling support of the environment*; *Feeling limitation*; *Feeling a lack of energy*; and, *Feeling resignation*. Feeling a belief in the future means that is possible to influence the future, that life situation can be improved and, primarily, that it is possible to increase impaired physical capacity (Mårtensson et al., 1997). Our patients experienced a change; the joy of feeling better, where recovery went in the right direction and where it was a possible to improve the situation, including hope for future. However, it was not easy to be hopeful throughout the rehabilitation and they were grateful for the help they had received to achieve hopeful thinking. Nursing interventions could here be of help according to Mårtensson (1997).

Rustoen and co-workers (2005) have examined patients with heart failure in relation to having hope. A group of hospitalized patients diagnosed with heart failure were compared with a group of healthy people of the same age. Hope was measured using the Herth Hope Index, a scale based on the previous definition of hope by Dufault and Martocchio (1985). The result showed that patients with heart failure had a higher global hope score compared with a general population. The authors suggested that the difference was due to a change in personal internal values or standards and recommended that interventions focusing on what is meaningful and brings hope to a person, could be beneficial (Rustoen et al., 2005).

Most of our patients felt hopeful at follow-up and some of the participants made big plans for the future which increased their wellbeing. The connection between wellbeing and having hope, as interpreted among our patients, has also been shown by others. Davis has examined *wellbeing* using the Index of

Well-Being in relation to the variables of *hope* measured with the Herth Hope Scale. The result showed a positive correlation between hope and wellbeing and a negative correlation between anxiety and wellbeing (Davis, 2005).

The above studies support that hope is an effective coping strategy and an important task for nurses to encourage, but is it possible to enhance? To answer that question an intervention study of patients with cancer was performed to test the efficacy of a specific program designed to enhance hope. Patients (n=115) were randomized to three groups; one treatment group (hope), one attentional control group (informational) and one control group (usual treatment). The intervention lasted for four months and consisted of seven sessions supporting different processes of hope; experimental, relational, transcendent and rational thought processes. Hope was measured with Herth Hope Index and QoL was measured with the cancer specific instrument CARES-SF on five occasions during nine months. The study reported increased hope and quality of life in the treatment group, indicating that hope is possible to enhance (Herth, 2000).

Tutton and co-workers stated that nurses need skills in the area, if they take the role of helping others to be hopeful (Tutton et al., 2009). Moore puts it this way: "It is my belief, however, that in order for nurses to help others have or find hope, they must have hope themselves. This implies that nurses need to understand what hope is in their own lives and to intentionally use strategies to nourish and sustain their own hope" (Moore, 2005, p 103).

### ***Methodological considerations***

This thesis consists of studies of one population from a single centre and discloses experiences in this context. The result nevertheless gives enhanced knowledge of this growing population of patients with aortic stenosis in relation to TAVI.

Criteria for grounded theory studies, according to Charmaz (2005), could be defined as credibility, originality, resonance and usefulness. To ensure credibility, I interviewed many patients with various backgrounds. By systematically comparing between interviews and categories, I tried to ensure that there was a logical link in the analysis and that it covered the data, and the emerging results were discussed in the research group. Since TAVI is a new area and few studies on patients' experiences of TAVI are published, the study offers new insights which strengthens originality. I used quotations from the participants in presentation of the result to demonstrate the resonance, the links between the larger collective and the individual. The

result from the study could be useful in the care of the increasing number of patients treated with TAVI (cf. Charmaz 2005).

All patients in this thesis were treated with a transapical approach that was most common during the study period and the outcome compared with those treated with transfemoral TAVI may differ. Comparisons between these groups in literature should therefore be made with caution.

Having too few participants makes it difficult to generalize the results from the quantitative study (IV). Numerically, patients' severe symptoms reduces or disappear but the changes are not statistically significant. The sample size was calculated on a power analysis based on the first results from the SF-36, and was too small to find significant difference in the nonparametric McNemar's test for categorical variables from the symptom questionnaire. A larger study population would have been desirable for that study (cf. Polit and Beck, 2014).

The recovery from TAVI is in this thesis reported both in statistics and in qualitative reports, something that has made it possible to understand aspects behind the figures. In a narrative review by Horrocks and co-workers on QoL after TAVI and SAVR, they stated that valve replacement generally improves QoL but when it does not, we don't know why (Horrocks et al., 2014). In our study all but two participants reported improved or unchanged function/NYHA-class after TAVI. One of those who did not improve described himself as being a very strong and capable man in the interview before TAVI and scored himself as being in NYHA class I, while the doctor estimated NYHA class IV. At follow-up he had adapted to a more realistic view and accepted that he was affected by disease and he scored NYHA class II, even if he described himself as having improved health. This is in line with findings of Charmaz who has explored identity dilemmas of men with chronic illness. She has described *preserving self* as maintaining essential qualities, identities or attributes of the past that fundamentally shape the self-concept (Charmaz, 1994).

There were some difficulties regarding the six minutes' walk test. Some of the participants had walking problems and needed a wheelchair or walker. The follow-up was also in some cases made in another hospital which was a risk for decreased interrater reliability (Polit and Beck, 2014). When follow-up was performed in the patients' homes, it was difficult to implement and, therefore, some data are missing.

The questions used in the thesis for measuring self-rated function and symptoms were not previously used or recommended for this population. This

has caused some problems when reporting the results. Disease specific instruments like KCCQ and MLHFQ are now recommended together with generic HRQoL questionnaires like SF-36 (Kappetein et al., 2013). However, our questions were easy to answer with “yes” or “no”, and gave valuable information about self-rated function and specific symptoms. Since the patients in this thesis were of advanced age and seriously ill, it was necessary to have few questions and these questions had to be easily understood (cf. Mallinson, 2002).

The EQ-5D questionnaire includes a couple of questions that are ambiguous, for example the question “Do you feel any pain or discomfort.” Patients who do not have any pain often answered no, even if they were suffering from huge discomfort from breathing problems, as they just took notice of the first part of the question. I therefore find those questions doubtful. I have also experienced difficulties in the use of SF-36. Many of the questions are long and contains of many options to choose from and the patients needed to reflect before they answered. It could not be rushed (cf. Mallinson, 2002). The patients often had vision problems or were tired and since I had used HRQoL instruments previously, I had recognized that there were some problems with filling in the forms. In order to overcome these problems, I took the time needed and the questions were read aloud to all patients. They answered verbally or by pointing at the reply (cf. Isaksson et al., 2007).

The patients were informed about the study when they arrived at hospital and they did not have much time to reflect on participation or not. It would have been more appropriate to contact them earlier to inform them about the study. However, many participants spontaneously expressed gratitude for the opportunity to share their experiences.

## **Conclusions**

Aortic stenosis is a life-threatening disease that is treatable if the patient arrives in due time for investigation and treatment, even for patients with advanced age and comorbidities. All patients with aortic stenosis do not perceive the threat of the disease. It may be because they have adapted their lifestyle and do not take notice of their symptoms or use emotional coping strategies to deal with the feeling of an emerging threat. This may delay patients from seeking medical advice and impair their preconditions for treatment. Doctors and health care workers who meet these patients need to be aware of this.

Patients with AS planned for TAVI have to cope with increasing symptoms and limitations in social life but they still wish to be and be seen as the people they were before. The TAVI patient is often an experienced patient, though with bad physical condition and with comorbidities, and aware of the deadly threat of the disease. Therefore these patients need to meet skilled nurses and physicians who make them feel safe. They may need support and guidance to process their experiences and feelings, to attach personal meaning to clinical information about their condition and its treatment, and to use all this in their decision about whether to undergo TAVI or not. Based on findings in this thesis, patients planned for TAVI should, if possible, be involved early and given time to prepare themselves, both mentally and practically. Their specific needs, which are often due to comorbidities and other problems, must also be taken into account.

The recovery from TAVI can be slow due to previous condition, comorbidities or complications and patients need support to cope with the situation and to be hopeful. Six months after TAVI, most patients seem to be satisfied with the treatment, report increased health-related quality of life and decreased severe symptoms but, mostly, they still report shortness of breath and they are still tired. Though, in this phase of recovery six months after TAVI, their major problems are mainly described as related to other diseases or disabilities.

Having hope is essential through the whole process, from being diagnosed to recovery. It is therefore of great importance that nurses and physicians support hopeful thinking. There should be a balance between giving information about the risks and supporting hope. By involving patients we can not only help them have control over their own destiny, but also feel trust in being cared for and treated by health care professionals with expert knowledge. It is also important to help patients maintain hope during the recovery process by to creating compensatory goals when needed, such as accepting assistance from others.

## **Clinical implications**

A specialist nurse with knowledge and insight into the problems that may arise both before, during and after the hospitalization, should preferably be available to support patients in this process. People with aortic stenosis who are offered TAVI often need to discuss risks and benefits in decisions about whether or not to agree to treatment. Specialist nurses may be of particular help for this task since patients may need extra time, and a nurse could easily be a professional sounding board to reflect and share thoughts with.

Patients with different patterns in decision making would benefit if health care professionals are informed and observant about individual patterns because they may require different responses. The ambivalent patient may need more general knowledge to process the decision to undergo TAVI; the obedient patient may need to discuss risks and benefits to get realistic expectations on treatment, and lastly, the reconciled patient should be strengthened in that their decision is right and get support in maintaining hope. A decision aid could be useful for patients in all patterns, as well as for practitioners. Development of decision aids in relation to treatment of aortic stenosis could be appropriate assignments for specialist nurses.

Several men complained on urinary problems a period after TAVI. Early mobilisation is important and one way to reduce that and other complications.

Moreover, many patients also strived to regain strength and normality after TAVI. Adapted training programs developed by a team of different professions should therefore be available for TAVI patients during the rehabilitation process.

## **Further research**

Despite a rapid development in the treatment, there are still patients undergoing investigation for AS who are not accepted for either SAVR or TAVI due to high risks. It would be interesting to focus on this group, making qualitative research on their experienced needs and how hope could be retained among them. Another interesting area for further research is to closely examine gender aspects in relation to TAVI. Lastly, it would be of great interest to perform intervention studies with RCT-design, including developing and using decision aids to gain insight about patient' needs and wishes for decision making about TAVI.

## **Acknowledgements – Tack**

Först och främst vill jag tacka alla patienter som delat med sig av sina erfarenheter av att ha aortastenos och av att genomgå TAVI. Tack för att jag fick ta er tid i anspråk.

Ett stort tack till mina fantastiska handledare Åsa Hörnsten och Ulf Näslund, som på olika sätt har varit stödjande. Åsa, min huvudhandledare, som med värme och humor delat med sig av sin kunskap i framför allt kvalitativ innehållsanalys och skrivandets konst. Du har varit ett ovärderligt stöd och har hjälpt mig att ha hopp under den här resan. Ulf, min bihandledare och tidigare chef på Hjärtcentrum, som initierade studien och bad mig göra patientintervjuer. Tack för att du trodde på min förmåga att klara av det. Tack till Johan Nilsson, medförfattare i artiklarna, för att du delat med dig av din stora faktakunskap om TAVI och för att du har hjälpt mig att söka forskningsmedel vilket har gjort detta arbete möjligt. Tack till Christine Brulin, min examinerare, som med fasthet uppmuntrat mig till att anta nya utmaningar.

Tack till Hjärtcentrums sjukgymnaster för att ni gjorde gångtester trots att tiden ibland inte fanns. Tack till personal vid sjukhusen runt om i regionen, som hjälpt till med provtagningar, gångtester och med att ordna samtalsrum.

Tack till Patricia Niemelä, Agnetha Göthe och Hilda Vigren-Näslund för att ni på ett förtjänstfullt sätt transkriberade intervjuerna.

Tack till Marie Lindkvist för råd i statistiska frågor. Tack till doktorander och lärare på institutionen för omvårdnad för att ni deltagit i seminarier och kommit med konstruktiv kritik. Tack till Johan Hörnsten för hjälp med design av figur. Tack till Karin Hellström Ångerud och Camilla Sandberg för värdefulla råd och uppmuntrande pep talk.

Tack till mina chefer Kerstin Franzén och Magnus Hedström för allt stöd och för att ni har varit förstående när jag har tagit ledigt för forskningsresor och kurser. Tack till alla arbetskamrater på Hjärtcentrum för att ni på olika sätt hjälpt till med praktiska saker och svarat på frågor. Ett särskilt tack till mina arbetskamrater i Hjärtcentrums stab för goda råd och uppmuntran.

Tack till min familj och mina vänner. Ert stöd har varit ovärderligt!

Till sist, tack till Medicinska fakulteten, Västerbottens läns landsting och Norrländska Hjärtfonden för ekonomiskt stöd.

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# **Appendices**

## **Paper I-IV**