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Symptom distress after heart transplantation

Prevalence, predictors and intervention

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DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY

Symptom distress after heart transplantation- prevalence, predictors and intervention

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Prevalence, predictors and intervention

Marita Dalvindt

DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) at the Faculty of Medicine at Lund University to be publicly defended on 3 of October 2024 at 09.00 in Belfrage Hall, Department of Health Sciences

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Title and subtitle: Symptom distress after heart transplantation – prevalence, predictors and intervention

Abstract:

Background
Heart transplantation is the most effective treatment for persons with terminal heart failure. Being a heart recipient with a life-long medication regimen is a chronic condition that requires the ability to manage symptoms, treatment, physical and psychosocial consequences as well as life-style changes. Symptoms are a challenge in the long-term perspective. Symptom occurrence and distress after heart transplantation has not been studied sufficiently and symptom management support does not exist in a systematic way, possibly leading to sub-optimal treatment and support from transplant professionals.

Aim
The overall aim was to explore and explain chronic pain and symptom distress after heart transplantation from a patient perspective and evaluate whether person-centred symptom management support is feasible and might promote health.

Methods
A mixed-method design was used to explore and explain symptom distress from a patient perspective, and to evaluate whether person-centred symptom-management support is feasible. Two cross-sectional studies explored chronic pain and other symptoms in relation to relevant variables using a deductive approach and self-report questionnaires. One longitudinal study prospectively explored chronic pain and symptom distress and possible explanatory factors in relation to relevant variables from pre-transplant to five years after transplantation. The final study was an inductive, theory-based, pilot feasibility intervention study to assess the feasibility and acceptability of systematic, person-centred symptom management support. Data were analysed using non-parametric statistics and the interviews were analysed using a phenomenological hermeneutic approach.

Results
Chronic pain is a prominent symptom after heart transplantation that peaks after three years. Heart recipients with the highest pain intensity score are strongly fatigued and report poor psychological well-being. In addition to pain, common symptoms are decreased libido, sleep problems, fatigue and tremor. Heart recipients most burdened by symptoms are most likely to be found among those not working, strongly fatigued, living alone or younger than 50 years. Transplant specific well-being improved for those with good psychological well-being during the five-year follow-up. Those with poor psychological well-being never improved in terms of transplant specific well-being except for the first year after transplantation and were more burdened by symptom distress. Symptom distress predicts psychological well-being regardless of the prevalence of pain. All participants in the intervention found it feasible and acceptable.

Conclusions
Symptom distress explains more than 80 % of the variation in psychological well-being regardless of the prevalence of chronic pain and is thus a key area of assessment and interventions. Sleep problems are common (86%) and fatigue is a strong predictor of transplant specific well-being that explains over 60% of the variance. Heart recipients reporting poor psychological well-being fail to improve their transplant-specific well-being during the first five years after transplantation. Poor psychological well-being in combination with symptom distress, in particular chronic pain, might be a major barrier for life satisfaction and quality of life in the first five years after heart transplantation.

Key words:

Heart transplantation, symptoms, symptom distress, self-management, pain, mixed method

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Jag tillägnar denna avhandling till alla hjärtmottagare

I dedicate this thesis to all heart recipients

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Abstract

Background

Heart transplantation is the most effective treatment for persons with terminal heart failure. Being a heart recipient with a life-long medication regimen is a chronic condition that requires the ability to manage symptoms, treatment, physical and psychosocial consequences as well as life-style changes. Symptoms are a challenge in the long-term perspective. Symptom occurrence and distress after heart transplantation has not been studied sufficiently and symptom management support does not exist in a systematic way, possibly leading to sub-optimal treatment and support from transplant professionals.

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The overall aim was to explore and explain chronic pain and symptom distress after heart transplantation from a patient perspective and evaluate whether person-centred symptom management support is feasible and might promote health.

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Symptom distress explains more than 80 % of the variation in psychological well-being regardless of the prevalence of chronic pain and is thus a key area of assessment and interventions. Sleep problems are common (86%) and fatigue is a strong predictor of transplant specific well-being that explains over 60% of the variance. Heart recipients reporting poor psychological well-being fail to improve their transplant-specific well-being during the first five years after transplantation. Poor psychological well-being in combination with symptom distress, in particular chronic pain, might be a major barrier for life satisfaction and quality of life in the first five years after heart transplantation.

Key words: Heart transplantation, symptoms, symptom distress, self-management, pain, mixed method

Original papers

This thesis is based on the following papers referred to in the text by their Roman numerals. The papers are reprinted with permission of the publishers.

I Dalvindt, M., Kisch, A., Nozohoor, S., Lennerling, A. & Forsberg, A. (2020). Chronic pain 1-5 years after heart transplantation-A nationwide cross-sectional cohort study. Nursing open, 7(4), 1146–1156. doi:10.1002/nop2.489

II Dalvindt, M., Nozohoor, S., Kisch, A., Lennerling, A. & Forsberg, A. (2020). Symptom Occurrence and Distress after Heart Transplantation-A Nationwide Cross-Sectional Cohort Study. International journal of environmental research and public health, 17(21), 8052. doi: 10.3390/ijerph17218052

III Dalvindt, M., Veungen, H. L., Kisch, A., Nozohoor, S., Lennerling, A. & Forsberg, A. (2024). Symptom Distress Before and After Heart Transplantation - A Longitudinal 5-Year Follow-Up. Clinical transplantation, 38(7), e15385. doi: 10.1111/ctr.15385

IV Dalvindt, M., Veungen, H. L., Kisch, A., Nozohoor, S. & Forsberg, A. (2024). A mixed method pilot feasibility study of a symptom management support intervention for heart transplant recipients with chronic pain and extensive symptom distress. Submitted to the Scandinavian Journal of Caring Sciences 240712.

Abbreviations

ACR	Acute cardiac rejection
AMR	Antibody mediated rejection
BMI	Body mass index
BTSQ-P	Being Taken Seriously Questionnaire-patient version
CAD	Coronary artery disease
CAV	Cardiac allograft vasculopathy
CIM	Chronic illness management
CIPS	Calcineurin inhibitor pain syndrome
CMV	Cytomegalovirus
CNI	Calcineurin inhibitor
CT	Computed tomography
EBV	Epstein-Barr virus
ECG	Electrocardiogram
HCP	Healthcare professional
HF	Heart failure
HLA	Human leukocyte antigen
HPV	Human papillomavirus
HRQoL	Health related quality of life
ISHLT	International society for heart and lung transplantation
LV	Left ventricle
LVAD	Left ventricular assist device
MFI	Multidimensional Fatigue Inventory
MRI	Magnetic resonance imaging
NMSC	Non melanoma skin cancer

NRS	Numeric rating scale
NYHA	New York heart association
OTSWI	Organ transplant symptom and well-being instrument
PGWB	Psychological General Well-being
PIS	Pain intensity score
POM	Pain-o-meter
PRP	Postoperative Recovery Profile
QoL	Quality of Life
RBBB	Right bundle branch block
SES6G	Self-Efficacy for Managing Chronic Disease 6-item scale
SMATT	Self-management after thoracic transplantation
TSM	Theory of symptom management
VAS	Visual analogue scale
WHO	World Health Organisation

Introduction - A life gained…

Heart transplantation is a surgical transplant procedure that aims to remove a person's failing heart and replace it with a deceased person's healthy heart. Being a heart transplant recipient means having a chronic condition and starting a transitional journey immediately after transplantation. It also means a situation of great uncertainty with many physical, mental and social challenges as well as the need to change one's habits. The aim of heart transplantation is not merely survival but quality of life (QoL) (Ponikowski et al., 2016). A life gained should also be lived. *"You have gained a healthy and strong heart"* is often said with the best of intentions to a heart recipient. However, it is also a comment that might upset that person. The history of being ill before the transplantation is not erased with the removal of the old heart and all the subsequent challenges do not become any easier due to that new and strong heart. Thus, this thesis is about the challenges involved when adapting to heart transplantation while coping with symptom distress and how the transplant follow-up care can be adjusted to focus on the person with an organ not only the organ in the person.

To fully understand the impact that symptoms after a heart transplantation can have on a heart recipient, one needs to understand what heart failure and heart transplantation entail. The first part of this thesis provides insights into the medical aspects of heart transplantation, while the second presents an overview of the nursing part of heart transplantation. Hopefully this thesis will bring both areas together to form a whole, which can be compared to the wholeness of a human being. We begin with how the life can be gained by performing a heart transplantation to ensure survival.

Background

Globally approximately 6,000 persons including children receive a transplanted heart every year (Kusch et al., 2021). In Sweden around 65-70 persons undergo heart transplantation annually (Scandiatransplant, 2024) of whom 3 - 10 are children (Hjärtebarnsfonden, 2024). This is comparable to international statistics where 10% of all heart transplantations are paediatric (Rossano et al., 2019). The distribution between men and women receiving a heart is 74.4% versus 25.6% (Khush et al., 2021).

Indications for heart transplantation

The main indication for heart transplantation is end-stage heart failure (HF) due to various aetiologies such as cardiomyopathies, ischemic heart disease, congenital heart disease or terminal valve disease. For those with end-stage HF, heart transplantation is the only way to prolong life and gain QoL (Ponikowski et al., 2016).

Improved QoL is a key goal of heart transplantation (Ponikowski et al., 2016). Thus, much research is about how QoL can be improved after heart transplantation.

According to the World Health Organisation (WHO, 1996) QoL is defined as:

> Individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (The World Health Organisation Quality of Health Assessment, 1996, retrieved 240615).

This definition reflects the subjective interpretation of what is considered QoL. It is very dependent on the context in which someone lives and acts, meaning that QoL differs from person to person and between social and cultural contexts.

Health Related Quality of Life (HRQoL) is defined as:

> A multidomain concept that represents the patient´s general perception of the impact of an illness and its treatment (U.S. Department of Health and Human Services FDA, 2006, p.18).

Consequently, HRQoL tries to capture individuals’ QoL regarding physical, psychological, and social aspects of life, as well as their health and illness.

Heart failure

The definition of HF has changed over time. In this thesis the proposed definition of HF by Bozkurt et al. (2021) is used:

> “a clinical syndrome with symptoms and/or signs caused by a structural and/or functional cardiac abnormality and corroborated by elevated natriuretic peptide levels and/or objective evidence of pulmonary or systemic congestion” (Bozkurt et al., 2021. p. 354).

Heart failure is a common disease. Around 200,000 persons in Sweden and 64 million worldwide suffer from HF (Shahim et al., 2023). Age is a major risk factor and around one percent of those younger than 55 years and more than 10% of those over the age of 70 suffer from HF.

Typical symptoms of HF are breathlessness, fatigue, tiredness, ankle swelling, orthopnoea, reduced exercise tolerance, inability to exercise, paroxysmal nocturnal dyspnoea, bendopnoea and swelling of parts of the body other than the ankles (Bozkurt et al., 2021). Specific signs of HF are elevated jugular venous pressure, third heart sound, summation gallop with third and fourth heart sound, cardiomegaly, laterally displaced apical impulse, hepatojugular reflux and Cheyne-stokes respiration in advanced HF. Less specific signs are, e.g., unintentional weight gain of more than 2 kg/week, cold extremities, peripheral oedema, pulmonary rales and cardiac murmur (Bozkurt et al., 2021).

Based on the definition by Bozkurt et al. (2021) four stages of HF and it´s development and progression, stages A, B, C and D, are suggested (Figure 1).

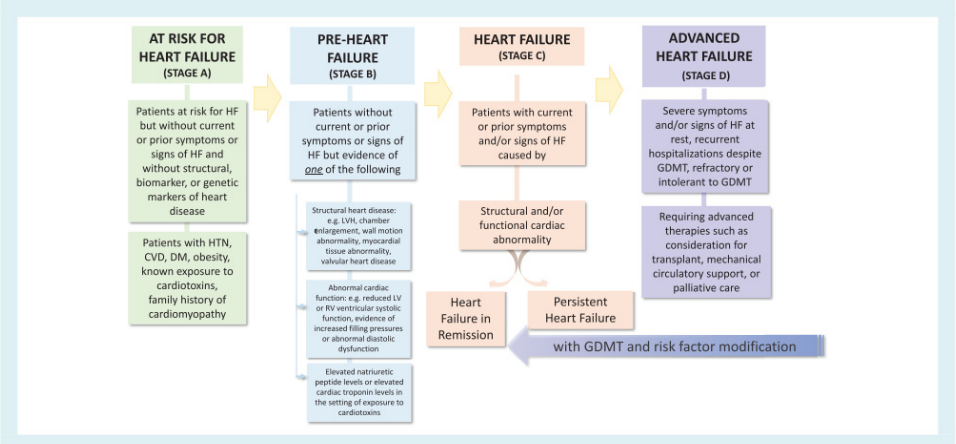
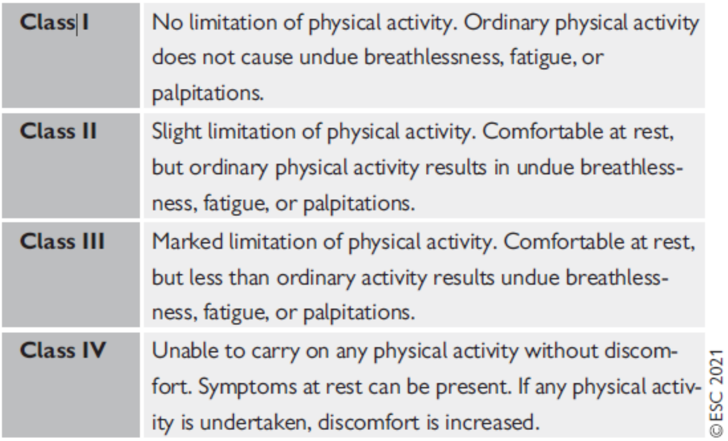


Figure 1. The four stages of heart failure from A: being at risk of heart failure to D: advanced heart failure and possibly in need of a heart transplantation. HF: heart failure, HTN: hypertension, CVD: cardiovascular disease, DM: diabetes mellitus, LVH: left ventricular hypertrophy, LV: left ventricular, RV: right ventricular, GDMT: guideline-directed medical therapy (Bozkurt et al., 2021. p. 367).

Risk factors for HF in developed and Western-type countries are generally coronary artery disease (CAD), hypertension, valve diseases and arrhythmias (McDonagh et al., 2021). The risk of developing HF is the same for men and women (Arata et al., 2023), but they tend to have different risk factors in addition to the general ones. Risk factors for men are hypertension, dyslipidaemia, smoking and excess alcohol use whereas for women they are diabetes mellitus, obesity, hypertensive disorders of pregnancy, menopause and emotional stress. (Arata et al., 2023).

There are various classifications of heart failure that also address different areas of importance. A frequently used one for the terminology and classification of HF is New York Heart Association (NYHA) class I-IV (Figure 2). This classification is used to describe the severity of heart failure in relation to physical activity (McDonagh et al., 2021).



Class I	No limitation of physical activity. Ordinary physical activity does not cause undue breathlessness, fatigue, or palpitations.
Class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in undue breathlessness, fatigue, or palpitations.
Class III	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity results undue breathlessness, fatigue, or palpitations.
Class IV	Unable to carry on any physical activity without discomfort. Symptoms at rest can be present. If any physical activity is undertaken, discomfort is increased.

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Figure 2. NYHA-classification, based on severity of symptoms and physical activity (McDonagh et al., 2021. P. 3614.)

To qualify as a heart transplantation candidate the patient must have HF NYHA class IIIb-IV with severe symptom burden, long-time survival of an approximate maximum of two years, every surgical option tested or confirmed hopeless, every medical aspect considered and proven to be hopeless or inappropriate and therefore in stage D (Kalogeropoulos et al., 2017).

Around 5% of those with HF develop advanced disease and are considered for heart transplantation (Kalogeropoulos et al., 2017). Men and women tend to develop advanced disease in similar numbers (Morris et al., 2021).

The mean age of a heart recipient in Europe is 54 years (Khush et al., 2021). According to data from 2010 – 2018, 74.4% of heart recipients are men, with women only constituting 25.6%. It is not clear whether these figures reflect the prevalence of women meeting the criteria for a heart transplantation or if women are underrepresented for heart transplantation (Khush et al., 2021).

When the patient is considered for heart transplantation, she/he undergoes a rigorous and comprehensive evaluation covering physical and mental health.

Evaluation of the heart transplant candidate

There is great imbalance between the need for and availability of donor hearts, with far fewer hearts available than people who need a heart transplantation (Stehlik et al., 2018). For that reason and as transplantation and life-long medications are both physically and psychologically demanding, the heart transplant candidate undergoes a rigorous examination and evaluation before being put on the waiting list. The waiting list is not dealt with in chronological order, but the patient most in need and with the best match receives the available heart.

As the studies in this thesis were performed in Sweden, when it comes to medical, surgical and psychosocial evaluation the focus is on the Swedish evaluation protocol (Nilsson et al., 2024), which follows the International Society for Heart and Lung Transplantation (ISHLT) guidelines (Velleca et al., 2023). Basically, the evaluation is based on a positive response to the following two questions: 1. Is the heart sick enough to be replaced? and 2. Is the rest of the body healthy enough to manage the surgery and medical treatment thereafter? (Mehra et al., 2016).

In Sweden two centres perform heart transplantation, Sahlgrenska University Hospital in Gothenburg and Skåne University Hospital in Lund. Patients at other units and hospitals are evaluated and referred to either of these two centres by their cardiologist. During the evaluation the need for a Left Ventricular Assist Device (LVAD) as a bridge to transplantation or decision is considered.

An LVAD is a device intended to assist the circulatory system and improve perfusion. It is implanted in the left ventricle (LV) of the heart and maintains circulation by a continuous flow from the LV to the ascending aorta driven by a battery motor connected to a percutaneous lead to both the inserted pump and external system controller. The LVAD is dependent on a battery that is worn in an external battery pack (Moriguchi, 2017). Among other instructions the person with a LVAD is instructed to always carry an extra battery and to connect the device to an electrical outlet while asleep.

Numerous invasive and non-invasive examinations of the heart are performed, such as blood-sampling, radiologic imaging, coronary angiography, echocardiography, computed tomography (CT) and magnetic resonance imaging (MRI), in addition to computed tomography of thorax and abdomen, lung x-ray, spirometry, electrocardiogram (ECG) and bone density measurement (Nilsson et al., 2024). In combination with these examinations a rigorous psychosocial evaluation takes place.

The registered nurse is present at the multidisciplinary team meeting when a patient is a potential heart recipient. The nurse also informs the patient and her/his significant other about the waiting list, examinations, routines while awaiting a heart and the time after transplantation (Nilsson et al., 2024).

An assessment and screening for depression, anxiety, stress, coping strategies, alcohol- and drug abuse as well as cognitive status are carried out by a psychologist, while a social worker assesses the patient’s life situation such as family, occupation, social network, education, coping strategies and goals.

The physiotherapist maps the candidate´s physical activities, exercising, respiratory function and musculoskeletal problems, objectively tests the candidate for physical functioning and inform about the importance of daily physical exercise. During interviews an occupational therapist maps and assesses the candidate's context, focusing on activities at home and the role in the family, financial situation, social contacts, balance between leisure and work, ability to relax and daily occupation.

In combination with bio-chemical blood-samples a dietitian assesses whether there are any problems with weight, diet, gastrointestinal function, appetite, altered taste experience and any difficulties with chewing and swallowing (Nilsson et al., 2024).

A dermatologist assesses the candidate's skin for skin cancer, which might hamper a transplantation. The skin is also evaluated for the risk of skin cancer after the transplantation as immunosuppressive medication increases the risk of different forms of malignancies including skin cancer. There is also a risk of developing or exacerbating osteoporosis after the transplantation due to corticosteroids. For that reason, a bone density measurement is performed to determine osteoporosis. Treatment may start prior to the transplantation if necessary (Nilsson et al., 2024).

The candidate's need for vaccination is also assessed. Due to the immunosuppressive medication the candidate should be vaccinated against influenza, pneumococcus, measles, different forms of hepatitis, diphtheria, tetanus, whooping cough, polio, human papillomavirus and tick-borne encephalitis. After transplantation vaccines are compromised because of the immunosuppression but yearly vaccinations against influenza and COVID-19 are administered. Live attenuated vaccines are contraindicated after heart transplantation (Nilsson et al., 2024).

The risk of being immunized with human leukocyte antigen-antibodies (HLA-antibodies) is a major concern within transplantation. As a result, the candidate needs to be HLA-typed and controlled every three months or when receiving a blood transfusion or becomes pregnant, which is done by means of blood-sampling.

During the evaluation contraindications for heart transplantation might be revealed such as a high frailty score, diseases that limit survival or QoL, or increase the risk of rejection or side-effects of immune suppression. These include malignancies, irreversible renal or liver dysfunction, severe lung disease, diabetes with serious complications, severe pulmonary vascular resistance, recent pulmonary embolism or infarction, infections that are not cured, severe ulcer disease, obesity or underweight, severe cachexia, serious psychiatric illness, severe neurological or neuromuscular disease, smoking and/or alcohol and drug abuse (McDonagh et al., 2021; Nilsson et al., 2024).

After the investigations all results are carefully evaluated at multidisciplinary level and a joint decision is taken about whether or not the patient is suitable as a heart transplant recipient. The patient and her/his significant other are informed about the decision. Close contact with the transplantation clinic is maintained and regular blood-sampling conducted. Now the wait for a suitable heart begins.

Heart transplantation

The first human heart transplantation was conducted in Cape Town by Dr Christian Barnard and his team in 1967. The patient survived for 18 days and eventually died of pneumonia (Barnard, 2017). In the following years several hundred heart transplants were conducted around the world (Barnard & Cooper, 1981) and the first Swedish heart transplantation was performed in 1984 (Söderlund & Rådegran, 2018).

Heart transplantation would be impossible without great knowledge of cardiothoracic surgery, cardiology immunology, biochemistry and other specialities (Barnard, 2017). There have been great milestones in the development of heart transplantation. The detection of allograft rejection using the percutaneous transvenous endomyocardial biopsy technique, and the development of the immunosuppression Cyclosporin A are of great importance (DiBardino 1999). Immunosuppression aims to lower the risk of rejection. Since the development of Cyclosporin in the early 1980s heart transplantation has become the gold standard treatment for some of those suffering from adverse HF (DiBardino, 1999).

The surgery

The surgical techniques have been developed over decades (DiBardino, 1999). The most common technique today is orthotopic heart transplantation where the recipient´s failing heart is removed and replaced by a healthy heart from a donor (Stehlik et al., 2018). To minimize the risk of myocardial damage during the transportation between the donor and the recipient, a solution is administered to the donor heart to arrest and cool it to lower the use of oxygen. There is a time limit of approximately four hours between arresting the heart and starting it in the recipient. Studies that aim to preserve the heart so that a longer time outside the body is possible are ongoing (Nilsson et al., 2020; Qin et al., 2022). If the time outside the body could be extended, more hearts could be used.

After the surgery the patient is taken to the cardiac intensive care unit. A potential and serious complication occurring within 24 hours after transplantation is primary graft dysfunction (PGD). It is a common reason for early mortality and the intensive care after surgery is intended to monitor for this complication along with sepsis, bleeding and elevated pulmonary artery systolic pressure (Awad et al., 2022). When the patient no longer requires intensive care, she/he is transferred to the ward for 2-4 weeks depending on where the follow-up care will take place. During her/his stay at the ward the patient undergoes rehabilitation and is offered education about how to manage life as a heart recipient. It is a period of recovery from major surgery and switching from being critically ill to a new life with better health but still demanding and challenging.

Transplantation immunobiology and rejection mechanism

Our body is constantly under attack from pathogens such as viruses, bacteria, fungi and protozoans (Kobashigawa & Luu, 2017). Our immune system has developed to prevent us from becoming ill or even dying from these pathogens. It is divided into the innate and the adaptive immune system. These systems act both alone and together to contain and destroy pathogens. Throughout our bodies we have cells that can detect foreign molecules called antigens and quickly activate chain reactions in our immune system (Kobashigawa & Luu, 2017). It is a very complex system, but the basic function is to distinguish between what is foreign and what is part of the own body, resulting in attacks against everything that is foreign, e.g., a transplanted heart (Ohler & Bray, 2017).

Important parts of the immune systems are major proteins such as antibodies (immunoglobulins), chemokines, cytokines and complement proteins. Lymphocytes such as neutrophils, monocytes, T-cell, B-cells and natural killers (NK) are found in the white blood cells (Kobashigawa & Luu, 2017).

Heart transplantation is, with some experimental exceptions, allogeneic transplantation, which means transplantation within the same species, but with different DNA such as human to human. Even in siblings who partly share the same DNA the probability of a perfect match is one to four, while in other cases it is one to 50,000 (Ohler & Bray, 2017). Without immunosuppression allogeneic solid organ transplantation, i.e., transplantation of a solid organ from one human to another, always results in rejection because the graft is identified as a foreign threat and an immune response is immediately activated to kill it (Kobashigawa & Luu, 2017).

Almost every human has Human Leukocyte Antigen (HLA). These are proteins that act as a genetic identification label to detect what is foreign. The HLA system is responsible for presenting foreign proteins to the immune system that reacts by starting a cascade of reactions to destroy the foreign threat. If a heart recipient has specific antibodies against the donor´s HLA antigens (allosensitization) the risk of severe rejection is considered high and the recipient will face a longer time on the waiting list (Ohler & Bray, 2017). All heart transplant candidates are screened for anti-HLA (Stehlik et al., 2018). Those patients who are sensitized have a higher risk of post-transplant mortality (Kobashigawa & Luu, 2017).

Immunosuppression

Heart transplantation means taking life-long immunosuppression. Suppression of the immune system aims to lower the risk of rejection of the heart and starts during the transplantation, after which it has to be maintained for life (Stehlik et al., 2018). It often consists of a three-drug regimen; calcineurin inhibitor, antimetabolite, and corticosteroids (Stehlik et al., 2018). Antimetabolites may be changed to mTOR-inhibitors (m-TORi). Immunosuppressives affect important areas in the immune system in different ways.

Calcineurin inhibitors (CNIs) affect the T-cells' response to alloantigens. The revolutionary discovery of the calcineurin inhibitor Cyclosporin made it possible for heart transplantation to become a viable treatment. Before the introduction of Cyclosporin the rejection rate was too high to consider heart transplantation as a viable treatment (Stehlik et al., 2018). Unfortunately, calcineurin inhibitors also have severe side-effects. A known side-effect is renal failure due to CNI (Chrysacis et al., 2024) and increased risk of nonmelanoma skin cancer (NMSC) (Eckembrecher et al., 2023). Calcineurin inhibitor pain syndrome (CIPS) is described by Grotz et al. (2001), who were the first to use the term. It affects 1-17% of solid organ transplant recipients and is described as having a negative impact on the bones in the feet, ankles and knees, possibly due to vasoconstriction in the bone marrow vasculature (Prommer, 2012).

Antimetabolites reduce the robustness of the immune system by inhibiting cell division and cell growth (Ritter et al., 2020). Common side-effects of this cytotoxic agent are depression of bone marrow, liver toxicity, nausea, vomiting and skin eruptions (Ritter et al., 2020).

Corticosteroids have a broad effect including an anti-inflammatory one and inhibit the immune system response. (Ritter et al., 2020). As they affect several parts of the immune system, they also have a broad side-effect profile (Chrysakis et al., 2024). Known side-effects are a higher risk of different forms of skin cancer (Eckembrecher et al., 2023), impaired wound healing, fungal infections, osteoporosis, hyperglycaemia, muscle wasting and effects on the central nervous system such as psychosis, depression and euphoria (Ritter et al., 2020) Some patients at low risk of rejection can cease taking corticosteroids, but no earlier than one-year post-transplant (Stehlik et al., 2018).

Proliferation signal inhibitors: Rapamycin and mammalian target of rapamycin (mTOR) inhibit several interleukins and reduce replication of T lymphocyte (Chrysakis et al., 2024; Ritter et al., 2020). There are data suggesting that switching from a calcineurin inhibitor to m-TORi is beneficial due to decreased rates of malignancy (Ritter et al., 2020), lower rates of nephrotoxicity when combined with low doses of CNI and no increase in rejection rates (Saber-Moghaddam et al., 2019). On the other hand, m-TORs seem to increase triglyceride levels (Chrysakis et al., 2024), bone marrow suppression, diarrhoea, vomiting and nausea (Kobashigawa & Luu, 2017).

Immunosuppression is lifesaving and an absolute necessity after heart transplantation but has significant side-effects that affect the heart recipient in various ways, e.g., symptom distress. One way to lower the risk of side-effects is to reduce the dosage of immunosuppression, leading to an increased risk of rejection. Thus, a tricky balance on a fine line.

Balancing between infection and graft rejection

Finding the right dosage of immunosuppression is a constant balancing act between the risk of infection and rejection, sometimes on a fine line.

Infection

The risk of infections is due to two main factors, namely exposure to pathogens and the net state of immunosuppression (Fishman, 2017). The net state of immunosuppression is a measure of all factors that contribute to the risk of infection, e.g., the immunosuppression therapy, metabolic conditions, viral infections, any underlying immune defects, neutropenia, prior chemotherapy or antimicrobials, any mucocutaneous barrier integrity (lines, drains, catheters) and complications such as graft injury, wounds and fluid collections (Fishman, 2017). Preventing and managing infections is vital for an improved outcome after heart transplantation. It is difficult because immunosuppressed individuals often do not exhibit typical signs of infection such as fever and tend to become infected with even infrequent pathogens. Healthcare professionals´ clinical skill is vital, as there is a lack of effective methods to diagnose an infection among a patient group that manifests few signs of infection (Fishman, 2017). Significant infections are Cytomegalovirus (CMV), Epstein-Barr virus (EBV), Human papillomavirus (HPV) and Human immunodeficiency virus (HIV). Fungal infections, mainly caused by Candida and Aspergillus, Pneumocystis jiroveci that causes pneumonia (Fishman, 2017) and parasites such as Toxoplasma Gondii found in cat faeces and raw meat are also common (Nilsson et al., 2024; Payá, et al., 2012). To prevent infections the heart recipient receives vaccinations (as described above), prophylaxis and instructions about how to prevent infections and detect signs of infection in everyday life (Nilsson et al., 2024). Important strategies in everyday life are good hand hygiene, storing food properly, knowing how to prepare food and what to avoid, e.g., washing hands before and after preparing and eating food, separating clean and dirty kitchen utensils, avoiding unpasteurized cheese, raw meat and berries that have not been cleaned properly. It is also necessary to be cautious petting animals and avoid public gatherings during infection times (Payá et al., 2012). The patient takes antiviral and antimicrobial medicine to prevent and/or treat infections (Fishman, 2017; Nilsson et al., 2024).

Graft rejection

Even though transplantation is possible due to immunosuppression, the risk of graft rejection remains. In a worst case scenario, a rejection due to an immune response leads to graft destruction and graft loss (Stehlik et al., 2018). The early detection of rejection is vital to treat it successfully. Since the development of percutaneous transvenous endomyocardial biopsy it has been possible to detect and treat early rejections. The procedure is performed by accessing the right ventricle via, most commonly, the right internal jugular vein and collecting biopsies by means of a bioptome. For some heart recipients this procedure is associated with fear and discomfort (Chang & Kobashigawa, 2017) as well as a 6 % rate of severe complications such as tricuspid valve injury, ventricular arrhythmia, right bundle branch block (RBBB) and bleeding leading to tamponade (Vallée et al., 2024).

Allograft rejection is divided into either antibody mediated rejection (AMR) or cellular rejection and acute or chronic rejection. Most rejections are acute cellular ones and more common in the first year after transplantation.

Acute cardiac rejection (ACR) affects 12% of heart recipients in the first year post transplant and almost 10% of all fatalities in that period are explained by ACR (Vallée et al., 2024). The risk of acute rejection is highest in the first half-year post-transplant. Many centres perform biopsies for 1-3 years post-transplant (Stehlik, 2018). In Sweden, heart recipients undergo 13 biopsies in the first year. In subsequent years, biopsies are performed if rejection is suspected (Nilsson et al., 2024). Methods to develop less invasive procedures, such as biomarkers (Castellani et al., 2020; Constanso-Conde et al., 2020) and echocardiography are being examined (Vallée et al., 2024).

Other complications after heart transplantation

Besides infection and graft rejection, which are the two dominant limiting factors for long term survival and a worry amongst many heart recipients (Forsberg et al., 2023), there are other complications after heart transplantation. The most common are cardiac allograft vasculopathy (CAV), malignancies and renal failure. I have chosen to mention diabetes mellitus as well because it is common and has a major impact on the heart and kidneys.

Cardiac allograft vasculopathy

Cardiac allograft vasculopathy is a form of coronary artery disease associated with sudden cardiac death after heart transplantation. Although the incidence has decreased over the last 20 years, CAV remain a major reason for long term mortality after heart transplantation (Potena et al., 2018). Inflammatory processes injure the endothelium, which causes smooth cell proliferation leading to thickened and narrowed vessels (Awad et al., 2022). It is an immune-mediated remodelling of the vessels, often referred to as chronic rejection (Pober et al., 2021). The heart recipient might not experience chest pains because of the heart being denervated and instead the first clinical sign might be other severe symptoms such as sudden death and ventricular arrhythmias. To detect CAV at an early stage most centres perform coronary angiography (Potena et al., 2018). Risk factors for CAV are e.g., dyslipidaemia, ischemic cardiomyopathy aetiology, re-transplantation, acute rejection and alloantibody (Awad et al., 2022). Younger heart recipients are at higher risk of developing CAV, and one likely factor is that their immune response is more robust (Kusch et al., 2021). To lower the risk of CAV the heart recipient takes medication for hypertension and dyslipidaemia along with acetylsalicylic acid (Awad et al., 2022). CAV increases over time with 7.7% of heart recipients experiencing it at one year, almost 30% at five years and 47% at ten years after heart transplantation (Kusch et al., 2019).

Malignancies

Malignancies are common due to immunosuppression (Awad et al., 2022). Other risk factors are male gender, re-transplantation and malignancies prior to transplantation. Around 5 % develop cancer after one year, 16% after five years and 27.7% after ten years. The most common malignancy is skin cancer (Awad et al., 2022). For that reason, the heart recipient is advised to protect her/himself from solar radiation, attend regular check-ups with a dermatologist and participate in the national screening-programme for breast and prostate cancer (Nilsson et al., 2024).

Renal failure

Renal failure is common after heart transplantation for several reasons, a major one being the nephrotoxic calcineurin inhibitors (CNI). One year post-transplant 6.7% of heart recipients suffer renal failure and more than one in five heart recipients have renal failure ten years after transplantation. Among those heart recipients who develop renal failure, 1.5% need chronic dialysis one year after transplantation, 2.9% after five years and 6 % after 10 years. The numbers needing a renal transplantation due to renal failure after heart transplantation are 0.1%, 0.6% and 2%. Reduction in CNI therapy or changing the regimen might be possible ways of lowering the risk (Awad et al., 2022).

Diabetes mellitus

The prevalence of diabetes mellitus is >30% one year after transplantation (Khush et al., 2019) whilst Vest et al., (2022) report that 21% develop diabetes mellitus in the first five years after heart transplantation. Risk factors for developing diabetes mellitus after heart transplantation are female sex, high body mass index (BMI) of more than 25 kg/m2, tacrolimus use (instead of Cyclosporine), steroid use and ischemic cardiomyopathy (Vest et al., 2022). Immunosuppression more specifically; calcineurin inhibitors, corticosteroids and mTOR inhibitors are associated with post-transplant diabetes mellitus (Lund et al., 2016; Newman et al., 2022). Post-transplant diabetes mellitus is also associated with renal dysfunction, re-transplantation and death (Vest et al., 2022).

Post-transplant survival

Post-transplant survival has improved over time (Kush et al., 2019). Reasons are the synergy of refinements in surgical techniques, organ preservation, increased clinical experience and improvements in immunosuppression, to name a few. The median survival after adult heart transplants performed between 2002 and 2009 is 12.5 years globally. For those who have survived their first year the median survival has increased to 14.8 years (Kusch et al., 2019). One-year survival in Sweden is 94% (National board of Health and Welfare, 2024) and five-year survival and ten-year survival are 85% and 74% (Söderlund et al., 2014). In 2009 the median survival was 13.2 years (Dellgren et al., 2013), which increased to 14.1% in the centre in Gothenburg a few years later (Dellgren et al., 2017). One reason for increased survival in Sweden might be the centralisation of heart transplantation (Gjesdal et al., 2024).

Re-transplantation is a factor that improves long-term survival and for that reason it might be valuable to mention graft survival as well as post-transplant survival. By ten years post-transplant 1.5% of heart recipients have undergone a re-transplant (Singh et al., 2023). Even though heart transplant recipients have a 20-year shorter life expectancy compared to the general population (Gjesdal et al., 2022) the trend is that survival rates are increasing, even more so during the last decade (Kush et al., 2019).

Follow-up care

The cardiothoracic centres in Lund and Gothenburg are assigned the national centralization of heart and lung transplantation including paediatric cases in Sweden. The follow-up care in Sweden during the first year after transplantation is located at three main centres in Lund, Gothenburg and Stockholm as well as designated out-patient units. After one year the heart recipient is followed-up by the nearest hospital with competent cardiology units, which communicates with the transplant-centres when needed. The team-based follow-up care comprises interprofessional collaboration and aims to prevent all the above-mentioned complications or deal with them in the best possible way. This work is very challenging without the cooperation of the most important team members, namely the heart recipient and his or her/his significant other. The healthcare professionals only meet the heart recipient for a few hours per week, month and later, years. But the heart recipient is constantly feeling and dealing with different aspects of being transplanted. It is in many ways a challenging endeavour with a dynamic nature. Every day is a new day with new challenges and lessons. The life gained should now be lived.

…Should also be lived! - Perspectives and viewpoints

Even in Descartes's era (1596-1650) the world of knowledge was divided into two, the subject and the object, with a distinction between, on the one hand, the body that represents an outer reality containing the mechanical material world and on the other, the soul that embodies an inner reality containing consciousness and thinking. These two parts were eventually divided into naturalism and humanism (Uggla, 2020).

This division is still valid and consists of positivism and humanism, where medicine is characterized by positivism and nursing by humanism. Medicine has had an incredible development during the last century but has also led to an objectification of the human body within healthcare, as well as a focus on the biological material or the anatomical construction rather than the person as a whole of body, soul and spirit. One consequence of this is that what can be objectively measured is perceived as valid and what the person perceives is less so. But there is a need to combine positivism and humanism to do justice to the whole person and not merely the biological material (Uggla, 2014).

Epistemology

Epistemology can be referred to as the theory of knowledge, for example how knowledge is developed and how the things in world are understood (Uggla, 2020). In this thesis both quantitative and qualitative research methods were used, with knowledge developed through inductive and deductive approaches. When using a deductive approach, questionnaires were operationalized into variables that measured pain, symptoms, psychological well-being, transplant specific well-being, recovery, self-efficacy and being taken seriously. This enabled testing of hypothesis, where the aim of a hypothetical deductive approach is to test or statistically demonstrate whether a certain assumption is correct. When the inductive approach was used the hermeneutic research tradition constituted the starting point, which allowed interpretation and understanding of what systematic, person-centred symptom management support after heart transplantation means to heart recipients.

Ontological assumptions

In this thesis subject experiences have been operationalized into questionnaires that aimed at measuring, among other things, the heart recipient's symptom distress. The results are treated with the utmost respect as they constitute the experience of the one best suited to interpret her/his own experiences.

Even when experiences have been operationalized into measurable variables the ontological perspective never changes. In this thesis the heart recipient is viewed as a capable person, hence the focus is on the heart recipient as a subject and her/his interpretation is given precedence. Thus, the focus in this thesis is the person with an organ not the organ in the person. This assumption is based on the person-centred approach, emanating from Paul Ricœur's philosophy, which is an action ethic that recognizes the person as a capable being who can speak, act, narrate and take responsibility (Ricœur, 2011).

Person-centred approach and the heart recipient

Person-centred care originates from the French philosopher Paul Ricœur and his ethic that implies to "strive for the good life, with and for others in just institutions" (Ricœur, 1992, p. 172). The good life is individual and accomplished with and for personnel, patients and significant others in just institutions, without determining what is the good life for the other (Ricœur, 2011). It is an action ethics that requires that every action is preceded by an ethical reflection.

A central concept in person-centred care is "The capable human" who is both acting and suffering. The capable person can speak, act, narrate and take responsibility. Being an active and competent individual also means being vulnerable and experiencing suffering. Ricœur (2011) defines suffering as being limited in one's capacity. However, vulnerability should not be seen negatively, it is also a part of a person that makes her/him receptive and open to others. Furthermore, suffering does not solely refer to physical or even psychological suffering, but to the undermining of the person's capabilities, experienced as an attack on her/his self-esteem (Ricœur, 1992). Historically, patients have not been actively involved but instead relegated to passive roles. The word "patient" itself refers to a passive and suffering person (Oxford English Dictionaries, 2024). It is important to understand that being a patient is a role adopted by a person in a certain setting and that a patient has a threefold disadvantage. When being a patient you are 1: placed at the bottom of the hierarchy, which implies institutional disadvantage, 2: at an existential disadvantage due to the vulnerability associated with deteriorating health and 3: at a cognitive disadvantage due to lack of knowledge in certain situations (Uggla, 2014). Healthcare professional should attempt to balance these inequalities in every meeting.

Main concepts

The main concepts in this thesis are symptom distress and symptom management. Although several other important concepts are mentioned, symptom distress and symptom management are the concepts on which the thesis is based.

There is an important need to structure follow-up care in accordance with chronic illness management (CIM), which will therefore be briefly presented along with self-management and transplant nurse´s role.

Health is a concept often mentioned and discussed but not explicitly measured or explored. The concept will be presented and the three often synonymously used terms; illness, disease and sickness, will be clarified.

The concept of symptom distress

In this thesis the following definition of a symptom is used:

> …a subjective experience reflecting changes in the biopsychosocial functioning, sensations, or cognition of an individual" (Dodd et al., 2001, p. 669).

A symptom is a manifestation of illness. It is therefore subjective and can only become known through the narrative of the person who experiences and reports it. The person experiencing a symptom forms an opinion about its frequency, duration and severity (Rhodes & Watson, 1987). Millions of patients seek medical attention due to their symptoms, which affect their social functioning and might cause distress (Dodd et al., 2001).

Symptoms and signs might be proof of illness or a health-related condition and are often used synonymously, but they differ in whether they are experienced subjectively or observed objectively. The objective sign of heart failure, for example, might be elevated jugular venous pressure, whilst the subjectively experienced symptom might be breathlessness. Illness is affected by the context, which means that social structures and cultural settings have an impact on how the person experiences symptoms and how she/he reacts to and acts on the symptom experience (Hedelin et al., 2014).

Symptom distress is a component of symptoms and means the degree of discomfort from the specific symptom, as reported by the patient (McCorkle & Young, 1978) and might also be described as the emotional response applied within the person to produce or withhold action (Rhodes & Watson, 1987). Thus, it refers to how physically or mentally upset or how anguished, or suffering the person might be from one or several symptoms (Rhodes & Watson, 1978). Symptoms are important for the interpretation and understanding the patient as they reflect either the disease or the patients´ perception of it (Ekman et al., 2005). Important knowledge is that the most frequent symptom is not necessarily the most distressing one, and that a particular symptom might act as a stressor to the individual. If an intervention succeeds in easing a symptom or lowering the discomfort, the occurrence of a symptom might be experienced as less difficult (Rhodes & Watson, 1987). It is also possible to experience symptoms that never distress the person and the opposite, a seemingly innocent symptom that causes a lot of distress.

Symptoms and symptom distress are in this thesis measured and explored via self-reported instruments, which is further described in the method section.

The concept of symptom management

The goal of symptom management is to avert or delay negative consequences of what the symptoms represent (Dodd et al., 2001). The outcome of symptom management is dependent on how the symptom was experienced, what reactions it created and which strategies were used.

Symptom management is well developed within other healthcare areas such as cancer, but scarcely used within transplantation care. Heart recipients experience several symptoms such as pain, fatigue, constipation, decreased libido and tremor, and there is a need for strategies to manage one or often several symptoms in everyday life.

Managing symptoms is a dynamic process that varies over time because symptoms exacerbate or are dealt with, and a person's capacities vary from day to day. It is important that symptom management is applicable to persons at risk of developing symptoms because of a context variable and not only when a symptom already exists (Dodd et al., 2001), such as being a heart recipient. Symptom management can be used in contexts including not merely the patient but the family, work environment or groups (Dodd et al., 2001).

In this thesis symptom management is tested in Paper IV to assess the feasibility and acceptability of systematic, person-centred symptom management support. More details can be found in the method section.

Chronic illness management and self-management

The definition of a chronic condition has not yet been agreed upon; even though most literature states that key components are the need for ongoing medical care and a duration of more than a year (Bernell & Howard, 2016; Goodman et al., 2013). Being a heart transplant recipient includes those components and often comorbidities and impairments due to, e.g., side effects of the immune suppression. The WHO formulated a document in 2002 on how to organise the care within chronic conditions, which reveals a need for further improvements within organisations globally. According to the WHO, focus needs to shift from an acute model of care to encompass care for chronic conditions. Bengoa & Yach (2002) describe a framework originating from the earlier Chronic Care Model, showing what functions poorly and what needs to be changed on a micro, meso and macro level. They describe the need to integrate patients and relatives into the care along with a new way of thinking about how to organize healthcare systems, how to connect patients, communities and health care organizations, how to empower patients and educate personnel (Bengoa & Yach, 2002).

According to Bengoa & Yach (2002), a major part of chronic illness management and an important aspect when structuring the care of chronic conditions is self-management. Symptoms and symptom-management are a part of self-management. Thus, self-management is a common concept within chronic illness, often mentioned in this thesis and defined as:

> …the individual´s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one´s condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus a dynamic and continuous process of self-regulation is established (Barlow et al., 2002, s. 178).

To maintain effective self-management self-efficacy is necessary. Self-efficacy is the confidence to carry out a specific behaviour to achieve a certain goal (Bandura, 2004). Self-management capabilities decrease in line with increasing numbers of chronic conditions (Bayliss et al., 2003). Due to the way in which the care surrounding heart recipients in Sweden today is organised, the patients sometimes lack sufficient support to handle their life situation (Ivarsson et al., 2012) including symptoms and symptom management.

Transplant nurse’s role

Nurses play a pivotal role in health promotion by, for example, developing personal skills and creating supportive environments (Iriarte-Roteta et al., 2020).

The American Nurses´ Association and International Transplant Nurses´ Society have published statements within The ISHLT concerning nursing practice and scope within transplant nursing. They used the following definition for transplant nursing practice:

> Specialized nursing care focused on the protection, promotion, and optimization of the health and abilities of both the transplant recipient and the living donor across the life span. The depth and breadth in which individual registered nurses engage in the total scope of nursing practice is dependent upon education, experience, role, and the population served (Coleman et al., 2015, p. 140).

Coleman, Blumenthal et al. (2015) state that European transplantation nurses are burdened by, among other things, increasing workloads and decisions that go against their mission and scope. In their consensus they recommend delineation of roles and guidelines on education, staffing, licensing and certification to support nurses.

Health

Health is a central concept within nursing, the core focus of which is health promotion, representing the humanistic approach in science. Health is more than absence of disease, illness or sickness, meaning that a person can have a disease and health at the same time (Hedelin et al., 2014). Health is thus a balance between a desirable goal and the person's ability in a certain setting and situation. Health is also associated with being able to gain better health (Hedelin et al., 2014).

The WHO has made several efforts to define health, which can be summarized in the following principles:

> Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition. The health of all peoples is fundamental to the attainment of peace and security and is dependent on the fullest co-operation of individuals and States…(WHO, 2024).

The perspective on health in this thesis is in line with the WHO definition; unique, individual and achieved in co-operation with others.

Illness, disease and sickness

Illness is a subjective experience of something being wrong in the body and is used to describe how the heart recipients´ daily life is affected. Disease is an objective perspective and used to describe the diagnoses and find a treatment or cure for what is disrupting normal life or graft function. Sickness adopts a social and cultural perspective and describes how society, or the social context, views the disease or the person with a disease.

As the different concepts suggest, it is possible to have a disease, a diagnosis, but experience health as well as the opposite, feeling ill but without a diagnosis. The problem starts when one concept is viewed as more valid than the others. For a heart recipient, the societal view might be that the person was ill but became healthy again after receiving a new heart, while the heart recipient experiences illness. The care surrounding the heart recipient is largely governed by the medical perspective, i.e., diagnosis and objective assessments.

In this thesis, the illness-perspective is adopted. Illness is a subjective experience and cannot be questioned objectively even when signs of disease are absent. Adopting the illness-perspective means taking the person seriously when it comes to symptoms.

Theoretical framework

The theory of symptom management constitutes the theoretical framework in this thesis. It originates from different nursing models that were considered insufficient for addressing the patient´s role in terms of experience, management, self-care and outcomes. A symptom management model was developed, which was revised by Dodd et al. (2001) and later became the Theory of Symptom Management (TSM) (Weiss et al., 2024), which is illustrated in Figure 3.

The theory is generic and tested for different patient groups but not heart recipients. It has met the criteria of significance, internal consistency, parsimony testability, empirical adequacy and pragmatic adequacy. Nevertheless, it is a theory that requires insights and deep knowledge when several simultaneous symptoms complicate its use. Important knowledge is that heart recipients often experience more than one symptom at a time, so called cluster symptoms, similar to patients with different forms of cancer, on whom the theory has mainly been tested (Mathew et al., 2021).

It consists of three domains within which nurses and nursing science operate: person, environment and health & Illness. Within these domains three concepts are visualized: symptom experience, components of symptom management strategies and outcomes (Dodd et al., 2001).

Symptom experience is a complex process and concerns how a person perceives, reacts to, acts on and evaluates a symptom. Symptom management is about, e.g., who will act and how much, to whom, why and when and what these decisions are based on, such as previous experiences and knowledge. The process also involves Self-management strategies (Dodd et al., 2001).

The theory describes the complex, multidimensional and dynamic process involved in experiencing and managing symptoms. It also emphasizes the need for a person-centred approach and a will to shift the responsibility of symptom management to the person with the help of a healthcare professional and shared treatment decisions (Weiss et al., 2024).

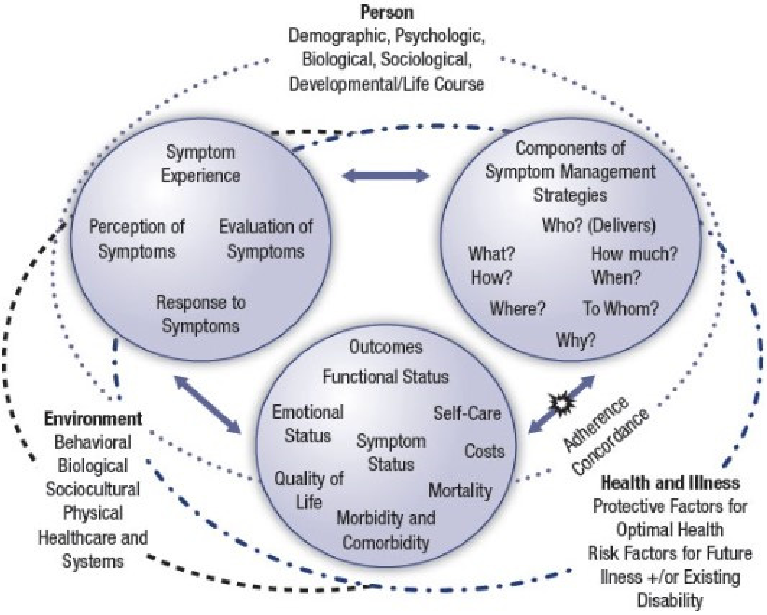


Figure 3. Illustration of the symtom management model developed by Dodd et al.(2001, p. 670) and revised by Weiss et al. (2024, p. 151).

The complexity of symptom management lies partly in the human being due to her/his thoughts and emotions affecting reactions and actions. How one perceives, evaluates and responds to a symptom is dependent on, e.g., cognitive function, physical reactions, previous knowledge, cultural meaning and a combination of these (Dodd et al., 2001). Weiss et al. (2024) emphasize the need for support from healthcare professionals in this complex practice.

The SMATT project and previous research on symptom distress

This thesis is part of the Self-Management After Thoracic Transplantation (SMATT) project, a Swedish multi-centre study conducted from 2014 to 2024. The overall aim of the SMATT project was to comprehensively map factors of importance for recovery, self-management and HRQoL after heart and lung transplantation. The project has produced four finalized cohorts and the group has published 22 original papers, two doctoral theses, one licentiate thesis, six master theses and one bachelor thesis. All studies published within the SMATT project are presented in Appendix A.

Symptom distress after heart transplantation

Previous research on pain after solid organ transplantation among kidney, liver, abdominal and lung recipients is described in Paper I. To avoid duplication, in the following section the focus is primarily on what is known about heart recipients and complementary research that has not been mentioned earlier.

Early research on symptoms after solid organ transplantation focused on side effects that affected morbidity and mortality, such as malignancies, hypertension and nephrotoxicity. However, that research did not capture the patients′ experiences (Dandel et al., 2010; Kugler et al., 2009). Symptoms and symptom distress after heart transplantation were not sufficiently investigated, particularly regarding long-term follow-up. Most studies of symptoms and symptom distress have been conducted of solid organ recipients, where heart recipients were part of the group. However, few studies have been conducted in which heart recipients constituted the main study population.

Lough et al. (1987) conducted a cross sectional study measuring the impact of symptom frequency and symptom distress on self-reported QoL in a population consisting of 100 heart recipients divided into two groups based on whether the participants were on Azathioprine or Cyclosporin immunosuppression. A main result was that the most frequently occurring symptom was not necessarily the most distressing. Although due to the introduction of Cyclosporin much focus was on symptoms related to the heart recipient’s immunosuppression, the study nevertheless examined all the heart recipients’ experiences. The ten most experienced symptoms in the Azathioprine group were bruises, fragile skin, changed bodily appearance, changed facial appearance, poor vision, pain, lack of sleep, impotence, fatigue and decreased interest in sex. The ten most reported symptoms in the Cyclosporin group were excessive hair growth, changed bodily appearance, changed facial appearance, menstrual problems, overeating, fragile skin, bruises, acne, depression and pain. Distressing symptoms were impotence and decreased interest in sex (Lough et al., 1987).

Heart recipients experience numerous symptoms due to the surgery and medications (Stiefel et al., 2013) and face emotional issues such as disruption of their own identity and bodily integrity. The most prevalent symptoms were tiredness (89%), lack of energy (80%) and feeling nervous (75%). The most distressing symptoms were erectile dysfunction (23%), decreased libido (16%) and muscle weakness (16%). Women reported more symptom distress than men (Stiefel et al., 2013). Pain, depression, sexual dysfunction, poor oral health and gastrointestinal problems affect heart recipients’ QoL in a negative way (Tackman & Dettmer, 2020). Depression also increases the risk of morbidity and mortality (Dew et al., 2015). Experiencing symptoms might hamper self-efficacy and make the heart recipients feel less recovered (Almgren et al., 2017). In summary, Almgren (2020) stated in her thesis that uncertainty is an important aspect in the process after transplantation. Symptoms, complications and setbacks hamper the heart recipient's ability to recover and increase uncertainty, which eventually affects self-management. Almgren (2020) stressed the need for deeper knowledge of which symptoms are common after heart transplantation and how heart recipients experience them in order to provide efficient self-management support.

Chronic pain after solid organ transplantation

Pain is a leading cause of suffering and disability and one of the most common reasons for seeking medical care (Treede et al., 2019). Chronic pain is pain that lasts at least three months. It can originate from a primary or secondary diagnosis. The impact of pain on the individual is multidimensional and therefore an assessment of pain intensity, pain-related distress and pain-related interference has been recommended (Treede et al., 2019). Around 20% of the adult European population reports experiencing chronic pain (Breivik et al., 2006), which lowers QoL compared with other long-term conditions and the general population (Hadi et al., 2019). It has been shown to be associated with an adverse impact on daily life, general health and employment status. All these domains affect social adaptation after solid organ transplantation, where returning to work is most important to the organ recipients and an indicator of successful social integration and adaptation (Cavallini et al., 2015).

Studies of pain after solid organ transplantation started in the 1970s among those receiving abdominal organs (Pierides et al., 1975). Liver recipients' experiences of pain were reported in the 1990s (Hellgren et al., 1998; Nicholas et al., 1994). Pain is a symptom that continued to be reported in studies regarding solid organ transplantation including heart recipients (Dobbels et al., 2008; Forsberg et al., 2018; Kugler et al., 2009; Stiefel et al., 2012) and shown to have a negative impact on QoL (Holtzman et al., 2010; Rosenblum et al., 1993).

In a review by Kugler et al. (2009) pain was reported in five different studies and classified as specific or unspecific. Most pain was unspecific and of unclear origin, but one study reported pain from the incision site and another described low-back pain. Pain might also be due to Calcineurin Inhibitor Pain Syndrome (CIPS), which is described in the immunosuppression paragraph. Prommer (2012) reported that up to 17% of solid organ recipients suffer from it. In more recent research it is stated that CIPS is an unusual but severe condition that affects 0.82% - 6% of kidney recipients, with one study showing that almost 21% of kidney recipients were affected and that it was seen in the groups using Cyclosporin and Tacrolimus immunosuppression (Hassan et al., 2021).

Sahay et al. (2013) reported on CIPS following lung transplantation and Forsberg et al. (2018) showed that 51% - 75% of lung recipients reported having pain after lung transplantation. Women reported more pain and those with pain also reported lower well-being than those with no pain. Wildgaard et al. (2010) also explored pain after lung transplantation, focusing on post-surgical pain. Moderate to severe pain was reported among 5-10% of the patients following lung transplantation via thoracotomy. This is less than the patients reporting post-surgical pain after nontransplant thoracotomy. Interestingly, 71% of those experiencing postsurgical pain also reported pain from other parts of the body (Wildgaard et al., 2010). This is relevant because heart transplantation is also performed via thoracotomy.

Fatigue after solid organ transplantation

Fatigue is a well-known symptom after heart transplantation (Almgren et al., 2021a; Grady et al., 2009; Kugler et al., 2009; Reyes et al., 2004; Tung et al., 2011). Heart recipients' QoL in relation to fatigue has been studied (Chou et al., 2017), showing that fatigue is one of the most common and distressing symptoms after heart transplantation, leading to decreased QoL. It was also a symptom focused on by Almgren et al. (2021), who reported low to moderate levels of fatigue among heart recipients except for those younger than fifty years, with pre-transplant mechanical circulatory support, who were not working and not recovered were especially distressed by fatigue. The prevalence of fatigue in the general adult global population is 20.4% (Yoon et al., 2023). Fatigue is also a common and distressing symptom among persons with heart failure (Pavlovic et al., 2022).

Another problem with experiencing symptoms after transplantation is that it might cause unwillingness to take prescribed medications. Those reporting adverse symptoms had more drug holidays, i.e., a period of not taking medications, than those reporting less severe effects of medication (Kugler et al., 2007). More recent research showed that those not taking their medications as prescribed also perceived that the medication caused more symptoms and experienced more symptom distress compared to those who took their medications as prescribed (Kung et al., 2012).

Besides experiencing symptoms, heart recipients also struggle with mental challenges such as thinking about the donor and how a transplanted heart impacts their identity (Mauthner et al., 2015). In addition, they must adapt from being critically ill to a life with, hopefully, better health. In their grounded theory, Forsberg et al. (2016) explain the transition from pre-transplant, where the solid organ transplant recipient had to e.g., put her/his life on hold, maybe isolating themselves, needing help from others and accepting the severe illness, to the first six months post-transplant, which is characterised by, e.g., adhering to restrictions, mourning losses and enjoying vitality. The final step, the reconstruction, in the social adaptation after transplantation starts about one-year post-transplant and is characterised by, among other things, working, meeting friends, enjoying travelling and being sexually intimate (Forsberg et al., 2016). Almgren et al. (2017) described the meaning of being a heart recipient one year after transplantation as doubting survival, doubting the recovery process, doubting one´s performance, struggling with close relationships, feeling abandoned and doubting the future. It was later compared with the meaning of being a heart recipient three years after transplantation (Lindberg et al., 2020), who found that time enables the acceptance of limitations through adaptation. Main themes three years after transplantation were accepting life as it is, adapting to post transplant limitations, adapting to a changed body, social adaptation, showing gratitude and trusting oneself and others. Being a heart recipient is being an uncertain human being facing many challenges along the way.

In summary, previous research about symptom management after heart transplantation indicates that there is a multitude of symptoms, among which pain is a prominent one. When preparing this thesis, pain was a symptom that recurred in research on symptoms after solid organ transplantation, highlighting the need for detailed exploration of this area of the post-transplant period. As symptom management is one skill requested by the heart recipients as part of their self-management endeavour, it is valuable to understand the magnitude of the challenges they face and how symptom management support can be provided by transplant professionals.

Rationale

Heart transplantation is an advanced and expensive treatment with the purpose of prolonging life and substantially improving QoL in persons with end-stage HF. Heart recipients have often faced many “cardiac events” during their disease trajectory leading to end-stage HF, where heart transplantation might be viewed as the cardiac event of all cardiac events due to its life changing and existential components. Being transplanted with a heart is a chronic condition that requires extensive self-management, which is defined as the heart recipient’s ability to manage the symptoms, treatment, physical and psychosocial consequences, as well as the lifestyle changes inherent in being a heart recipient. Efficacious self-management encompasses the ability to monitor one´s condition, i.e., vital signs and signs of graft rejection, and to affect the cognitive, behavioural and emotional responses necessary to achieve and maintain a satisfactory QoL. Heart recipients face many challenges after transplantation including recovering from the surgery, various complications and side-effects from the immunosuppressive medications as well as lifestyle challenges and recommended restrictions regarding hygiene, food, sun exposure, exercise, how to avoid infections and adjusting to everyday life. Previous research from the last two decades suggests that chronic pain and symptom distress are a challenge in the long-term perspective, constituting barriers to health and QoL. Health is part of well-being, thus by providing symptom management support as an essential part of health promotion, overall well-being will presumably increase.

Today, transplant professionals have great expectations that heart recipients will be partners and co-actors in their adaptation process to achieve and maintain long-term health. However, there is a considerable lack of scientific knowledge regarding heart recipients’ symptom distress, which hampers targeted and evidence-based symptom management support. Therefore, the rationale behind this study was to comprehensibly explore symptom distress before and after heart transplantation and how it affects the recipients´ everyday life. A basic assumption in this thesis is that chronic pain prevents proper symptom management. As chronic pain is a well-known and common problem after solid organ transplantation, in addition to the fact that those with chronic pain are also distressed by several other symptoms, it is important to gain a comprehensive understanding of this issue. Thus, in **Paper I** a deductive approach was adopted by means of a cross-sectional study involving 79 heart recipients one to five years after transplantation self-reporting their chronic pain distress. As it was shown that heart recipients experiencing pain are most likely to be found among those not working, not recovered, more burdened by other symptoms and who have worse psychological well-being, in **Paper II**, specific cross-sectional analyses of symptom occurrence and distress were performed regarding psychological well-being and sociodemographic variables. However, there were no pre-transplant baseline data available in the first two quantitative studies. Subsequently, a third rationale (**Paper III**) was to prospectively explore the chronic pain and symptom distress trajectory from pre-transplant to five years after transplantation and possible explanatory factors. A comprehensive picture of the symptom distress and its impact on transplant specific well-being was revealed, highlighting the need for an intervention to support symptom management and if possible, promote health. Thus, **Paper IV** was designed as a theory based inductive pilot feasibility study using a mixed methods approach to explore the acceptability and feasibility of a symptom management support intervention by means of three consecutive one-hour person-centred supportive conversations on the heart recipient's experienced ability to manage her/his symptoms, self-efficacy and transplant specific wellbeing.

A key concern in transplant nursing is how to affect and promote health behaviours to engage heart recipients in the extensive task of symptom-management with limited support from healthcare. The basic assumption in this thesis is that how the heart transplant recipient experiences her/his symptom distress and access to person-centred care is fundamental for developing symptom-management support. The self-reported level of distress and the understanding of the patient perspective regarding their symptoms are essential aspects for promoting health and well-being after heart transplantation. The goal of this thesis is to narrow the knowledge-gap regarding how chronic pain and symptom distress affect health and well-being after heart transplantation and propose evidence-based clinical strategies concerning how symptom management support should be tailored.

Aim

The overall aim was to explore and explain chronic pain and symptom distress after heart transplantation from a patient perspective and evaluate whether person-centred symptom management support is feasible and might promote health.

Specific aims were:

Paper 1: To provide a multidimensional assessment of self-reported chronic pain 1–5 years after heart transplantation and its relationship with self-reported well-being, fatigue, recovery, self-efficacy and socio-economic factors and to explore differences between heart recipients and a cohort of lung recipients.

Paper 2: To explore self-reported symptom occurrence and distress after heart transplantation and their relationship with self-reported psychological well-being and sociodemographic factors.

Paper 3: To explore self-reported symptom distress from time on the waiting list to five years after heart transplantation and its association with self-reported psychological well-being, chronic pain and fatigue in order to identify possible predictors of psychological or transplant specific well-being.

Paper 4: To assess the feasibility and acceptability of systematic, person-centred symptom management support for heart recipients with chronic pain to reduce symptom distress.

Methods

Overview of the design of the studies

In this thesis three quantitative studies and one mixed-method study were used to explore and explain symptom distress from a patient perspective and evaluate whether person-centred symptom-management support is feasible. All four studies are part of the SMATT project described previously. Initially, two cross-sectional studies were performed to measure and assess chronic pain, symptom occurrence and distress from one year to five years post-transplant. The third study followed each participant from pre-transplant to five years post-transplant to explore symptom distress. The final study was a mixed-method study with an inductive approach to grasp the patients´ perspective of a person-centred symptom-management support intervention and its acceptability and feasibility. A brief graphic overview of the four studies is presented in Table 1.

Table 1. Overview of the research design of the included papers.

Paper	Design	Participants (n)	Data collection	Data analysis
I	Quantitative, cross-sectional, explorative	79	Self-assessment questionnaires	Non-parametric analysis
II	Quantitative, cross-sectional, explorative	79	Self-assessment questionnaires	Non-parametric analysis
III	Quantitative, longitudinal, explorative	48	Self-assessment questionnaires	Non-parametric analysis
IV	Mixed-method, inductive, pretest-posttest	13	Interviews, Self-assessment guestionnaires	Phenomenological-hermeneutic, Non-parametric analysis

Selection, participants and data collection Papers I and II

Selection and participants

Papers I and II were based on the same data set and context. Participants were selected from the two transplant centres performing heart transplantation in Sweden, namely Lund and Gothenburg. They were invited to participate in the study at one of the three follow-up outpatient clinics in Lund, Gothenburg and Stockholm, which are responsible of most of the annual follow-ups throughout Sweden. The presumptive participants were consecutively invited at their annual follow up either 1, 2-, 3-, 4-, or 5-years post-transplantation during the years 2014-2017. Inclusion criteria were Swedish speaking adult heart recipients who were mentally lucid, without on-going rejection nor hospitalized. Exclusion criteria were being transplanted with more than one solid organ, poor health status and language barrier.

Data collection

At the start of the study in 2014, there were 303 eligible heart recipients, of whom 153 were invited to participate. A total of 90 heart recipients accepted and were included. The reason for each drop-out cannot be reconstructed, but ten heart recipients did not return their questionnaires and did not receive a reminder. Other reasons were being included more than once, feeling too ill to participate or lacking strength to complete many questionnaires. Logistic difficulties in the outpatient clinics also resulted in some random missing data. In total, the study group comprised 79 heart recipients, 25 women and 54 men with a mean age of 52.68 years (SD 14.63) ranging from 19 to 72 years. An overview of the sample selection is shown in Figure 4.

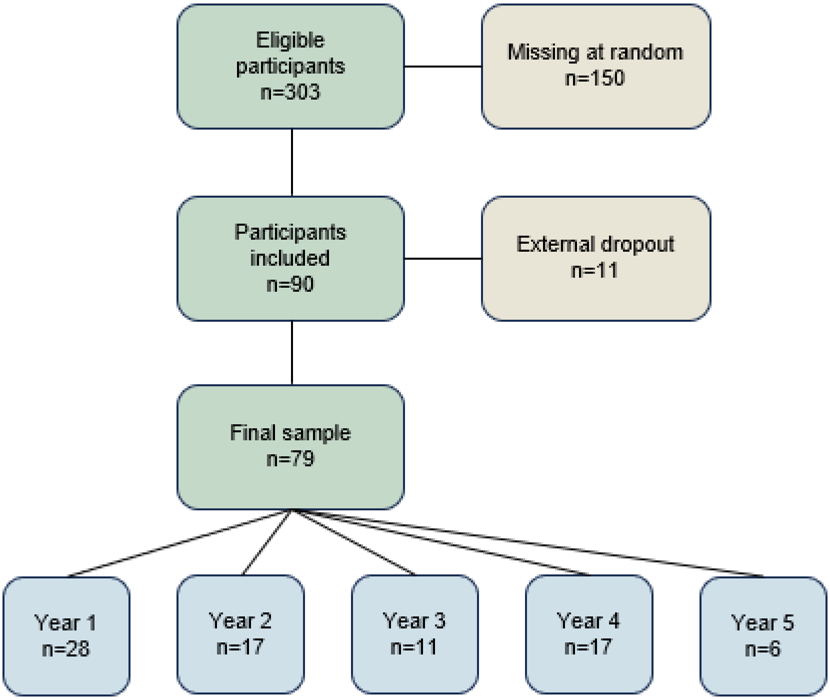


Figure 4. Overview of the sample selection in Papers I and II.

After written informed consent was obtained data were collected through self-report questionnaires at the out-patient clinics distributed by registered nurses and an occupational therapist. The participants filled out the questionnaires either at the outpatient clinic or at home. The completed questionnaires were handed to the personnel or returned by post in coded envelopes. Perioperative data such as time on ventilator and length of intensive care were obtained from patient records after permission had been granted.

The following instruments were used in Papers I and II:

- The Pain-O-Meter (POM) to multidimensionally measure chronic pain in Paper I.
- The Psychological General Well-Being (PGWB) index to measure psychological well-being in Papers I and II.
- The Organ Transplant Symptom and Well-being Instrument (OTSWI) to measure symptom occurrence, symptom distress and transplant-specific well-being in Papers I and II.

- The Multidimensional Fatigue Inventory (MFI) to measure different dimensions of fatigue in Paper I.
- The Postoperative Recovery Profile (PRP) to measure recovery in Paper I.
- The Self-Efficacy for Managing Chronic Disease 6-item scale (SES6G) instrument to measure self-efficacy in Paper I.

The Pain-O-Meter (POM)

The POM is an instrument that enables a multidimensional assessment of self-reported acute and chronic pain (Gaston-Johansson, 1996). It was developed to measure the intensity of pain as well as sensory and affective pain in a clinical setting that requires an easy, fast and comprehensive tool. The POM combines the best of the visual analogue scale (VAS) and McGill's pain questionnaire (Gaston-Johansson, 1996; Melzack, 1975). In its original form it is a hard plastic tool for clinical use on which the VAS is printed (POM-VAS) together with words that describe the pain from a sensory and affective perspective (POM-WDS) and a body template.

The POM-VAS is a 10-cm scale that measures the intensity of pain, where 0 indicates no pain and 10 worst possible pain (Gaston- Johansson, 1996). The POM-VAS does not have a maximum value as it is dependent on the number of reported pain locations. There are 11 words describing affective pain and 15 words describing sensory pain. Each word has a value from 1-5 that can be added together to form a pain intensity score (PIS). The minimum score is 0 and the maximum is dependent on the number of affective and sensory words for each location. The patient is free to use as many affective and sensory words as she/he needs. Stabbing has the highest intensity value and sharp the lowest. The 11 affective words are: Nagging, agonizing, annoying, troublesome, killing, tiring, unbearable, terrifying, miserable, torturing and suffocating. Torturing is an example of a word with the highest intensity value (5) and irritating with the lowest intensity value (1).

In order to use the POM in research, a questionnaire was developed by Professor Forsberg in her thesis entitled Health related quality of life and coping after liver transplantation (2001). It consists of a body template, the VAS, as well as the sensory and the affective words. All 11 words describing affective pain were used together with five of the sensory words. The five sensory words were: numb, burning, stabbing, sharp and dull, which were selected based on a pragmatic choice grounded in a pain guide and body template received from the pain department at Sahlgrenska University Hospital. The questionnaire also contains questions on how daily life is affected; When did the pain start?, How did the pain start?, Do you take any pain killers?, How does the pain affect your daily life? and What are your own thoughts about the reason behind the pain?

The timeframe varies and is dependent on the pain to be measured. Hence, in the studies in this thesis the timeframe was set to the previous seven days.

The POM has been psychometrically tested for test-retest reliability using Pearson´s correlation test. It showed high correlations between initial and repeat pain intensity ratings POM-VAS ($r = .88$, $p < .001$) and POM-WDS ($r= .84$, $p < .001$) for different kinds of pain (labour pain, postoperative pain and rheumatoid arthritis). The concurrent validity for POM-WDS was supported by correlations between POM-WDS and the McGill Questionnaire ($r = .69$, $p < .001$) and between the POM-WDS and POM-VAS ($r =.85$, $p < .001$). Construct validity for the POM was also supported (Gaston-Johansson, 1996). In solid organ transplantation the POM has been used among liver-, kidney-, and heart recipients (Forsberg et al., 1999) and lung recipients (Forsberg et al., 2018).

The Psychological General Well-Being index (PGWB)

The PGWB index was developed by Dupuy (1984) to measure "self-representations of intrapersonal affective or emotional states reflecting a sense of subjective well-being or distress". Wiklund & Karlberg's (1991) translation of the PGWB into Swedish was used in this thesis. *Anxiety, depressed mood, positive well-being, self-control, general health* and *vitality* constitute the six sub-scales, each of which contains three to five items, giving a total of 22 items that are rated on a six-point scale. The ratings are then added together, from which an overall PGWB index score is derived, which varies between 22 and 132, where 22 indicates the poorest well-being and 132 the highest. A normal score is between 100-105 (Dupuy, 1984) and women tend to score lower than men (Dimenäs et al., 1996).

The original PGWB index showed very high internal consistency with Cronbach´s alpha coefficient .94 (Dupuy, 1984.) and good internal consistency in the Swedish version, with Cronbach´s alpha coefficient ranging from .61 – .89 (Wiklund & Karlberg, 1991). The PGWB index has good test-retest reliability and is sensitive to the changes in an individual´s psychological well-being (Dupuy, 1984).

The Organ Transplant Symptom and Well-being Instrument (OTSWI)

The OTSWI is a transplant specific instrument measuring symptom prevalence, symptom distress and transplant specific well-being after solid organ transplantation by means of the presence or absence of symptom distress (Appendix B). The basic assumption is that well-being is present in the absence of various symptoms and impairments. It was developed in a Swedish context among solid organ recipients, including heart recipients (Forsberg et al., 2012) and used in previous Scandinavian studies (Dengsø et al., 2024; Forsberg et al., 2018; Lundmark et al., 2019a).

The instrument consists of eight factors measuring well-being: *fatigue, joint and muscle pain, cognitive functioning, basic activities in daily life, sleep problems, mood, foot pain* and *financial situation.* These factors comprise 2-3 items each with a total of 20 items. Each response is assessed on a five-point scale from; “not at all”, (0 points), “a little” (1 point), “somewhat” (2 points), “quite a bit” (3 points) to “very much”, which is 4 points. The rating of each item is related to the discomfort involved. The ratings are summarized to an OTSWI-SUM score value, where the lowest score is 0 and the highest is 80. A lower score indicates higher well-being. The OTSWI also measures the symptom occurrence and distress by means of 20 transplant specific symptoms. Each response is rated on a five-point scale ranging from “not at all” (0) to “very much” (4) (Forsberg et al., 2012).

Item-scale correlations for the eight factors varied between .66 and .98 and Cronbach´s alpha ranged from .81 to .92. The eight factors accounted for 86% of the variance and the internal convergent validity was satisfactory, indicating that the OTSWI correlates with the items in the Short Form-36 (SF-36) that was used to test the OTSWI. The item-scale discriminatory validity was good, meaning that the individual items correlated well with the SF-36 (Forsberg et al., 2012).

The timeframe was set to the previous seven days.

The Multidimensional Fatigue Inventory (MFI)

The MFI is a comprehensive self-report instrument measuring fatigue. It was developed among cancer patients, well known to be burdened with fatigue (Smets et al., 1995), with special focus on fatigue following treatment (Hagelin et al., 2007). It aims to measure five dimensions of fatigue. *General fatigue* refers to the person’s concerns about her/his function, *physical fatigue* relates to the person’s feeling of tiredness, *mental fatigue* concerns the person’s ability to concentrate, *reduced motivation* refers to the willingness to start an activity and *reduced activity* refers to refraining from activities (Smets et al., 1995). Every dimension comprises four items, thus a total of 20 items, each of which is worded in a positive or negative direction. The five dimensions of fatigue are measured by rating fatigue in the last seven days on a 7-point scale ranging from “Yes, that is true” to “No, that is not true”. Both Smets et al. (1995) and Hagelin et al. (2007) stated that the instrument has difficulty distinguishing between *General fatigue* and *Physical fatigue* among persons with illness compared to healthy persons. One explanation might be that the ill person may find it hard to separate general and physical aspects of fatigue. She/he may experience different dimensions of fatigue than a healthy person. Nevertheless, the MFI has good internal consistency with an average Cronbach´s alpha coefficient of .84 and construct validity showing good discrimination between groups, within groups and between conditions. The convergent validity varied, with the highest for *General fatigue* (0.8) and the lowest for *Mental fatigue* (0.23). The MFI was psychometrically tested in 2015 and showed good to strong correlations when test-retest reliability was analysed (α = .66 - .91). Analysis of convergent construct validity was significantly correlated, internal consistency was .92 and it was considered understandable and easy to answer (Hedlund et al., 2015).

The instrument was revised and translated into a Swedish version, MFI-19, by Hagelin et al. (2007), who also used it to measure fatigue among heart patients. It has one item less than the original version namely "My thoughts easily wander" belonging to the *Mental fatigue* dimension, which was considered problematic due to cultural and language differences. The Swedish version supports earlier findings showing that the MFI-19 is a valid and reliable instrument (Hagelin et al., 2007). It consists of a 5-point scale ranging from "Yes, that is true" to "No, that is not true". All items in the different dimensions are given a score from 1 to 5 and summarized to a scale ranging from 4-20 points. A high score indicates a greater degree of fatigue (Hagelin et al., 2007). There is no accepted cut off for the whole MFI (Hinz et al., 2020). However, based on previous studies (Jakobsson et al., 2010) scores in the general fatigue dimension were grouped accordingly: low fatigue = 4-11 points and high fatigue = 12-20 points. Reliability was tested using three tests. Inter-item correlation, meaning the extent to which scores on one item are related to scores on the other items on a scale ranging from .21 to .9. Corrected item-to-total correlation, which is the correlation between a scored item and the total test score, was considered good. Cronbach´s alpha ranged between .67 - .94. The convergent validity was deemed satisfactory. The timeframe was set to "the last few days" (Hagelin et al., 2007). The instrument was previously used in the SMATT project among lung recipients and for Swedish stem cell recipients (Forsberg et al., 2018; Forsberg et al., 2019; Kisch et al., 2020).

The Postoperative Recovery Profile (PRP)

The PRP was developed from a content analysis that provided a definition for recovery:

> Postoperative recovery is an energy-requiring process of returning to normality and wholeness as defined by comparative standards, achieved by regaining control over physical, psychological, social and habitual functions, which results in returning to preoperative levels of independence/dependence in activities of daily living and an optimum level of psychological well-being (Allvin et al., 2007. p. 557).

The PRP that measures recovery and symptom distress consists of the following five dimensions: *physical symptoms, physical functions, psychological, social* and *activity.* The dimensions are constituted by 19 items that are formulated as statements, e.g., "Right now I experience…nausea". The statements can be answered by means of following four alternatives: "none" "mild", "moderate" and "severe". The answers are calculated and converted to a level of recovery scale. The level of recovery is based on the number of "none-responses" and graded as "Fully recovered", "Almost fully recovered", "Partly recovered", "Slightly recovered" to "Not at all recovered". Fully recovered means 19 "none" responses, while "not at all recovered" implies 0-6 "none" responses (Allvin et al., 2009).

The PRP has high content validity and most items had a high level of test-retest reliability ranging from 80% to 100%. Construct validity was assessed as good and the instrument discriminates recovery profiles between different groups (Allvin et al., 2009). It has been used previously in the SMATT project for lung recipients (Lundmark et al., 2019a).

The timeframe is set to how the participants felt when filling out the instrument.

The Self-Efficacy for Managing Chronic disease 6-item (SES6G)

The SES6G measures self-efficacy and consists of six items graded on a 10-point scale ranging from “not at all confident” (1 point) to “totally confident” (10 points). It was developed from several Self-Efficacy scales and covers different domains common in chronic conditions, i.e., symptom control, role function, emotional functioning and communicating with physicians. It is considered a less burdensome instrument for patients and useful in clinical practise and research. The instrument was translated into German by Freund et al. (2013) following accepted standards, after which it was translated into Swedish by the SMATT research group and used in several studies (Almgren et al., 2020; Almgren et al., 2021). No psychometrical testing of the Swedish version was conducted due to similarities with the German context. A mean score is calculated based on at least four of the six items, meaning that two can be missing. The mean score is then interpreted and ranges from 1 to 10, with higher values indicating a greater level of self-efficacy.

The SES6G was externally validated using the German General Self-efficacy scale and Spearman´s rho correlation test and showed good convergent construct validity (.578, $p < .001$). Correlations between .44 and .6 are considered good. The internal consistency was high with Cronbach´s alpha .930. A value of more than .8 is considered desirable (Polit & Beck, 2021). The SES6G had low floor and moderate ceiling effects (Freund et al., 2013).

The timeframe was set to the previous seven days.

Selection, participants and data collection Paper III

Selection and participants

Participants were selected from two transplant centres performing heart transplantation in Sweden, namely Lund and Gothenburg. They were invited to participate in the study at one of the three follow-up outpatient clinics in Lund, Gothenburg and Stockholm, which manage most of the annual follow-ups throughout Sweden. Those not invited to the study were followed-up at hospitals other than Lund. Gothenburg and Stockholm. The inclusion criteria were Swedish speaking, adults on the waiting list for a heart transplantation. Exclusion criteria were poor health due to conditions other than HF or illness that was considered normal in the pre-transplant phase and being hospitalized.

The presumptive participants were consecutively invited during their transplantation evaluation. Known reasons for dropout were being removed from the waiting list (n=1), death while on waiting list (n=2), death after heart transplantation (n=5), re-transplantation (n=1), only filled in baseline questionnaires pre-tx (n=17) and changed follow-up clinic and thereby lost to the study (n=3). Apart from the known reasons, an important reason for internal dropout was probably the COVID-19 pandemic, which placed a great burden on transplant care professionals in the outpatient clinics and discouraged patients from attending their annual check-ups. The final study group comprised 48 participants, 12 women and 36 men, with a mean age of 54.25 years (SD 10.61) ranging from 29 to 68 years who were followed from baseline (pre-transplantation) to five years post-transplantation as illustrated in Figure 5.

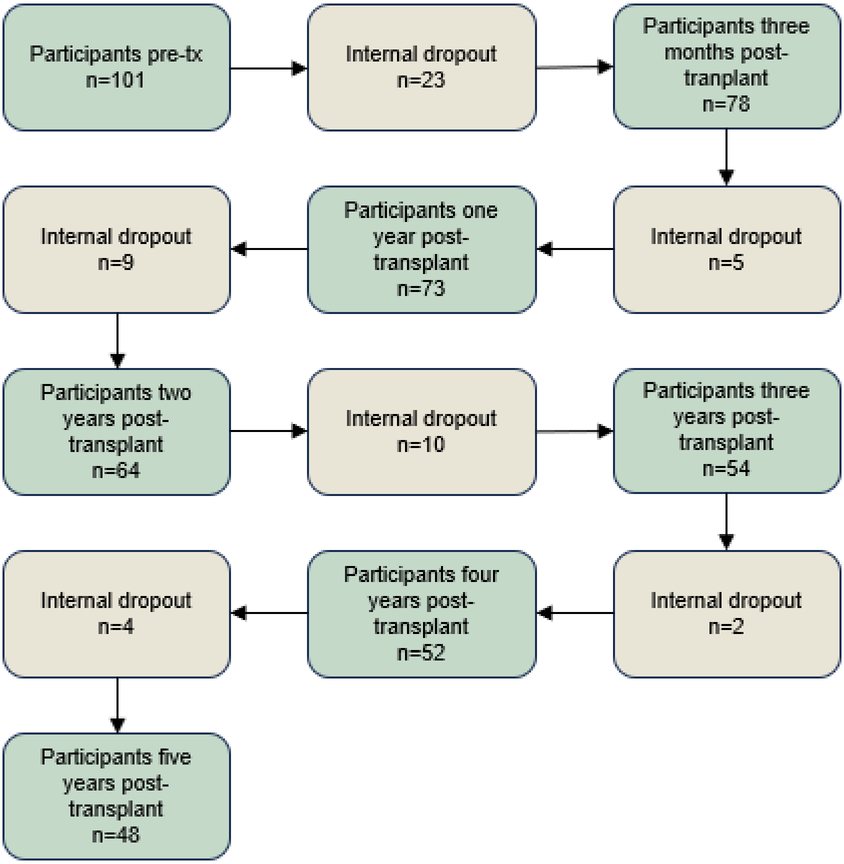


Figure 5. Overview of the sample selection in Paper III.

Data collection

Recruitment took place between 2014 and 2018 and data were collected until spring 2024 at the three outpatient clinics as described above. A total of ten questionnaires were handed out by registered nurses after written informed consent was obtained, of which four were analysed in Paper III. Having completed the questionnaires, the participants placed them in the coded envelope provided and either handed them back to the registered nurse who had distributed them or returned them by post. The first measure was conducted pre-transplantation and constituted the baseline. Measurements were then conducted three months, six months, one year, two years, three years, four years and five years after transplantation.

The following four instruments were used in Paper III and have been described above.

- The Pain-O-Meter (POM) to multidimensionally measure chronic pain.
- The Psychological General Well-Being (PGWB) index to measure psychological well-being and illness.
- The Organ Transplant Symptom and Well-being Instrument (OTSWI) to measure transplant-specific well-being and symptom distress.
- The Multidimensional Fatigue Inventory (MFI) to measure different dimensions of fatigue.

Selection, participants, intervention and data collection Paper IV

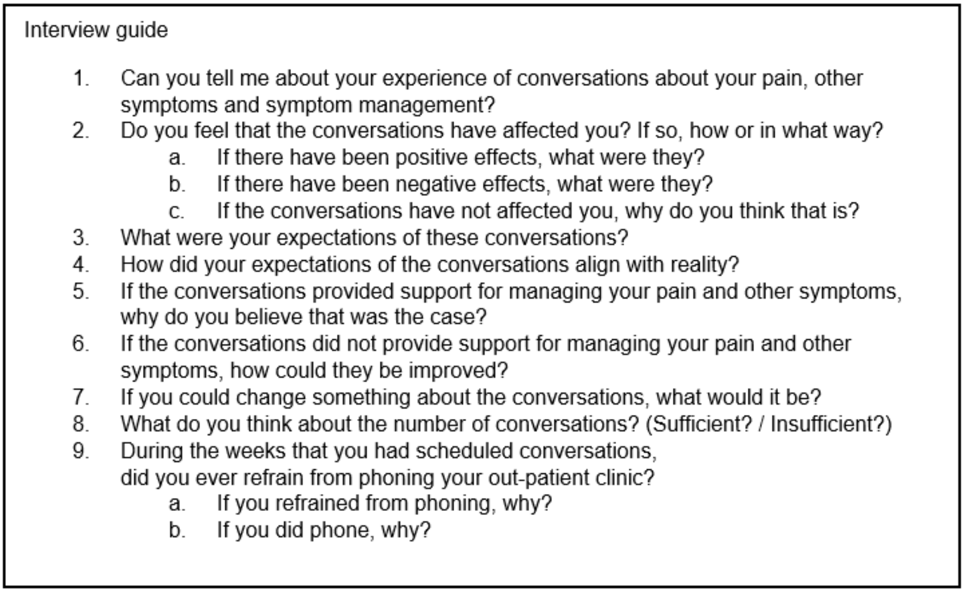
Selection and participants

Participants were invited consecutively 12-48 months after their heart transplantation at one of the three follow-up outpatient clinics in Lund, Gothenburg and Stockholm. Those not invited to the study were followed up at hospitals other than in Lund, Gothenburg and Stockholm. The inclusion criteria were Swedish speaking, adult, 12-48 months post-transplant, able to handle spoken and written Swedish, providing written informed consent and experiencing pain ≥ 4 on the Numeric Rating Scale (NRS). Exclusion criteria were being treated for acute graft rejection and/or admitted to in-hospital care. A total of 17 heart recipients were invited to participate in the study. Three participants declined participation before signing the written consent. All three stated extensive symptom distress as a reason for being unable to participate. A consecutive sample of 14 heart recipients (seven men and seven women) accepted participation. One man withdrew from the study after the first conversation due to extensive symptom distress, as well as mental and psychological challenges. Thus, a total of 13 participants completed the intervention, seven women and six men with a mean age of 54.38 years (SD 13.74 years) ranging from 26 to 67 years.

Data collection

In this mixed-method study conducted between May 2023 and March 2024 data collection took the form of self-report questionnaires and interviews. The questionnaires were answered using a one group pre-test/post-test design followed by individual semi-structured interviews to evaluate the feasibility and acceptability of a person-centred symptom management support intervention. The main study method was qualitative. The intervention consisted of three consecutive person-centred supportive conversations on the heart recipient's experienced ability to manage her/his symptoms, self-efficacy and transplant specific well-being. Each conversation lasted approximately one hour. The total time for the intervention ranged from three to six weeks depending on the participant's possibility to schedule conversations. Some participants were able to schedule conversations for three consecutive weeks, while others needed longer intervals.

The interviews explored the lived experience of receiving person-centred symptom management support and assessed the feasibility and acceptability of the intervention. Interviews took place by phone and on one occasion digitally a few days after the intervention ended. They lasted from 30 to 60 minutes and were recorded and transcribed verbatim. After transcription the recorded sound file was deleted. The participants were encouraged to narrate freely. The interview guide is presented in Figure 6. Every interview ended with the question "Is there anything you would like to add that we have not discussed or talked insufficiently about?" The interviews were performed by one of the co-authors who had no information about the participants apart from their surname and telephone number.



Interview guide

1. Can you tell me about your experience of conversations about your pain, other symptoms and symptom management?
2. Do you feel that the conversations have affected you? If so, how or in what way?
    a. If there have been positive effects, what were they?
    b. If there have been negative effects, what were they?
    c. If the conversations have not affected you, why do you think that is?
3. What were your expectations of these conversations?
4. How did your expectations of the conversations align with reality?
5. If the conversations provided support for managing your pain and other symptoms, why do you believe that was the case?
6. If the conversations did not provide support for managing your pain and other symptoms, how could they be improved?
7. If you could change something about the conversations, what would it be?
8. What do you think about the number of conversations? (Sufficient? / Insufficient?)
9. During the weeks that you had scheduled conversations, did you ever refrain from phoning your out-patient clinic?
    a. If you refrained from phoning, why?
    b. If you did phone, why?

Figure 6. The interview guide used as a support during the conversations with the participants.

The following four instruments were used in Paper IV, of which the OTSWI and the SES6G have been described above.

- The Numeric Rating Scale (NRS) to measure pain.

- The Being Taken Seriously Questionnaire-patient version (BTSQ-P) to measure experiences of person-centred care.
- The Self-Efficacy for Managing Chronic Disease 6-item scale (SES6G) to measure self-efficacy.
- The Organ Transplant Symptom and Well-being Instrument (OTSWI) to measure transplant-specific well-being and symptom distress.

The NRS was used to screen patients for inclusion. The participants self-assessed their pain verbally by giving a number on a ten-point scale, where 0 indicates no pain and 10 worst possible pain. No other data were collected by means of the NRS.

The BTSQ-P, SES6G and the OTSWI were answered twice to examine the impact of a person-centred symptom management support intervention. The first occasion was at their regular follow-up in their outpatient clinic at baseline and the second directly after the intervention but before the interview.

The intervention trajectory is illustrated in Figure 7 and the total time from inclusion to closure ranged from four to eight weeks.

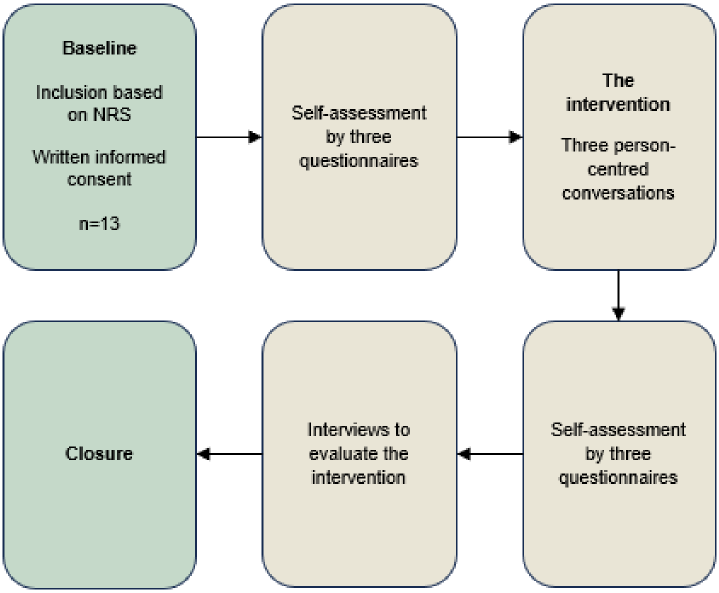


Figure 7. The study trajectory from inclusion to closure.

The Being Taken Seriously Questionnaire – patient version (BTSQ-P)

The BTSQ-P developed by Forsberg & Rantala (2020) in Swedish high-tech care environments, e.g., transplantation care, was used to measure person-centredness. It is a generic instrument that is supposed to be discriminative and evaluative. It was developed for adults undergoing healthcare and consists of eight items, forming one single construct. The items were chosen from in-depth interviews, reviews and discussions among healthcare professionals (Forsberg & Rantala, 2020) The items are: *The staff listened to me, I received help to understand what has happened, I received help to understand what is about to happen, My concerns have been taken seriously, My symptoms have been taken seriously, I have been taken seriously as a person, The staff made me feel good in the present moment* and *The staff made me feel safe.* The items can be graded on a six-point scale ranging from “No, I do not agree at all” to “Yes, I agree completely” where six is the lowest value and 48 the highest (Forsberg & Rantala, 2020).

The BTSQ-P has been psychometrically evaluated using factor analysis with interim correlations ranging from .759 to .908. The one-factor solution accounted for 80.4% of the variance. The internal consistency measured with Cronbach´s alpha was .87 and the ordinal alpha was .93. Even though the BTSQ-P has good psychometric properties it is a new instrument and is undergoing continued testing and evaluation.

Data analysis

Preunderstanding

As a clinical specialist nurse in cardiac care at a thoracic ward I have many years of experience of working with thoracic transplant recipients. Working in the context of both heart and lung recipients, my preunderstanding has been that heart recipients are less burdened with symptoms and complications in comparison with lung recipients. In early discussions with health professionals irrespective of their profession, the overall picture was that heart recipients generally do well and recover. That might be because several studies of lung recipient were presented during my early years at the thoracic ward. Later, a thesis about lung recipients from the SMATT project presented new knowledge about their demanding adaptation process (Lundmark, 2019b) and a couple of years after that the thesis about heart recipients by Almgren (2020) was published, showing their profound sense of uncertainty. The image of heart recipients being and feeling a little better than lung recipients remained but began to be questioned by our research group.

Non-parametric statistical analysis in Papers I & II

As mentioned before, Papers I and II have a cross-sectional design and originate from the same cohort. Non-parametric analysis was performed due to not normally distributed data collected from instruments generating nominal and ordinal variables on a small group. Statistical analyses were performed on the whole group as well as at each follow-up year and two independent sub-groups were compared. The SPSS Statistics 23 (IBM Corporation, 2017) was used for analysing data. Single scale ordered data were summarized with medians and percentiles. When applicable, values of $p<0.05$ (two-tailed) were considered significant.

The statistical analysis was performed as follows:

1. Exploring proportions with the Chi square test and describing the prevalence of variables, i.e., pain including location, sensory and affective components, symptom occurrence and symptom distress.
2. Exploring differences between two independent groups by means of the Mann Whitney U test.
3. Exploring correlations between different variables by means of Spearman´s rho test.
4. In Paper II multiple linear regression was employed to assess how much the different factors in the OTSWI explained the variance in the OTSWI-sum, thus assessing possible predictors of symptom distress.
5. In Paper II logistic regression was used to assess the impact of several independent variables on the likelihood that heart recipients would report poor psychological well-being.

When using the Chi square for exploring proportions between different groups age was dichotomised, younger than 50 years (i.e., 18-49 years) or 50 years and older. Time on ventilator was also dichotomised, less than 48 hours or 48 hours and more, based on a clinically established cut-off. Finally, the PGWB sum score was dichotomised into two groups based on the established cut-off above or below a score of 100, where a score below 100 indicates poor psychological well-being (Dupuy, 1984).

The Mann Whitney U test was utilized for non-parametric statistics for testing significant differences between two independent groups' medians. The test compares medians by converting the scores on the continuous variable to ranks across the two groups and then evaluating if the ranks for the two groups differ significantly (Polit & Beck, 2021).

To explore the strength of relationships Spearman´s rho was used for correlational analyses (Polit & Beck, 2021). Possible correlations between pain, well-being and self-efficacy in Paper I were explored. In Paper II possible correlations between the factors in the OTSWI and the OTSWI-sum as well as between the OTSWI-sum and the PGWB-sum were analysed. The rho-value ranges from -1.00 and + 1.00 (Polit & Beck, 2021). The strength of the correlation was established based on the guidelines by Cohen (1988, pp. 79-81), where weak relationships were .10-.29, medium .30-.49 and strong .50-1.00.

Multiple regression was used as a regression model with at least two variables (predictors) to improve predictions of the OTSWI-sum (Polit & Beck, 2021). In the model in Paper II, we used “sleep problems”, “fatigue”, “vitality” and “PGWB-sum” as predictors (x) for the OTSWI-sum (Y) based on the correlations found in Spearman´s rho test.

Logistic regression was used to predict categorical dependent variables, analyse the relationship between multiple independent variables and a dependent variable and finally yield a predictive equation (Polit & Beck, 2021). In Paper II, the dependent variable was the PGWB-sum and the independent variables were gender, age and fatigue.

Non-parametric statistical analysis in Paper III

Paper III has a longitudinal design. Non-parametric analysis was performed because the data were not normally distributed and statistical calculations were made on nominal and ordinal data collected from a small sample. SPSS Statistics 28 (IBM Corporation, 2022) was used for analysing data. Nominal data were summarized with medians and percentiles. When applicable, values of $p<0.05$ (two-tailed) were considered significant. Data were analysed for both independent and dependent groups.

The statistical analysis was performed as follows:

1. Exploring proportions by means of the Chi square test and describing the prevalence of variables, i.e., pain, PIS, OTSWI, OTSWI-sum and fatigue in independent groups.
2. Exploring differences between two dependent groups by means of the Wilcoxon signed ranks test in terms of transplant specific well-being, psychological general well-being, fatigue and chronic pain.
3. Exploring differences between two independent groups by means of the Mann Whitney U test.
4. Exploring age differences between men and women by means of the paired t-test.
5. Exploring correlations between different variables by means of Spearman´s rho test.
6. Multiple linear regression to assess possible predictors of transplant-specific or psychological well-being.

When using the Chi square test for exploring proportions between different groups age was dichotomised as younger than 50 years (i.e., 18-49 years) or 50 years and older. Finally, the PGWB sum score was dichotomised into two groups with points either up to 99 or 100 and above.

The Mann Whitney U test is utilized for non-parametric statistics for testing significant differences between the medians of two independent groups. The test compares medians by converting the scores on the continuous variable to ranks across the two groups and then evaluating whether the ranks for the two groups differ significantly (Polit & Beck, 2021). In Paper III analyses were performed to explore differences between men and women, between younger and older heart recipients and between those with high versus low psychological well-being.

The t-test was utilized for non-parametric statistics for testing significant differences between the means of two dependent groups.

To explore the strength of relationships Spearman´s rho was used for correlational analyses (Polit & Beck, 2021). Possible correlations between the PGWB, chronic pain and OTSWI were explored. The rho-value ranges from -1.00 and + 1.00 (Polit & Beck, 2021). The strength of the correlation was established based on the guidelines by Cohen (1988, pp. 79-81) where weak relationships were .10-.29, medium .30-.49 and strong .50-1.00.

Multiple regression analyses were performed to assess possible predictors of psychological well-being (PGWB-sum) and transplant-specific psychological well-being (OTSWI-sum).

Due to the strong relationships between the PGWB-sum and PIS and OTSWI sum and PGWB after 2-4 years post-transplant, a linear multiple regression was conducted to explore how PGWB is predicted by the OTSWI-sum and PIS 2-4 years after transplantation. Thus, multiple regression was used as a regression model with at least two variables (predictors) to improve predictions of the OTSWI-sum (Polit & Beck, 2021). In the model in Paper III, we used “PIS and OTSWI-sum” as predictors (x) for PGWB (Y) based on the correlations found in Spearman´s rho test.

Linear regression was also used to explore how PIS predicts the variation in the OTSWI-sum.

Phenomenological hermeneutics and non-parametric statistical analysis in Paper IV

Paper IV is a mixed-method study. The data originate primarily from interviews. However, self-report instruments as in Papers I-III were also used, although the sample was considerably smaller because the qualitative interview method requires fewer informants.

Phenomenological hermeneutics

Paper IV focused on the patient´s lived experience of the meaning of being subjected to a supportive, person-centred symptom management intervention to explore its feasibility and acceptability. Lived experience is a depiction of a person´s impressions and actions, as well as the knowledge gained from them as opposed to the knowledge gained from a second-hand source (Given, 2008).

The phenomenological hermeneutic method developed by Lindseth & Norberg, (2004) originates from the Theory of interpretation by Paul Ricœur. The method is based on text interpretation and phenomenology with focus on the understandable meaning of experiences. Thus, phenomenological hermeneutics strives to grasp the essence of meaning by interpreting texts (Lindseth & Norberg, 2004). The starting point is the lived experience and a phenomenologist must strive for the essential meaning of that experience. To grasp the meaning of a phenomenon it must be explained and written down in order to interpret the meaning structure of the narrative. Only then we can reveal the essential meaning of the phenomenon, in this study the lived experience of a person-centred symptom-management intervention.

Data were analysed in three steps:

- *Naïve reading*, which involves reading the text several times and being open to it so that it can speak to the reader, who becomes moved and touched by it. The reader becomes familiar with the text and its content and gains understanding of the narrative reflected in the text.
- *Structural analyses,* to identify and formulate themes. A theme is a *thread of meaning* (Lindseth & Norberg, 2004) that goes through the text, which stands out and illustrates the essential meaning of the lived experience. In this study it meant that the researchers tested the first understanding separately. Meaning units were identified, read, reflected upon and condensed. Reflection continued regarding the condensed meaning units, which were abstracted to sub-themes and grouped together as themes. The researchers reflected on every theme in relation to the naïve understanding. It is important to be aware of one's pre-understanding and to strive for a phenomenological attitude. An example of the process from meaning units to theme is presented in Table 2.
- *Comprehensive understanding,* where the sub-themes and themes were read, reflected upon and summarized, while keeping the research question, context, validated themes and naïve understanding in mind (Lindseth & Norberg, 2004). Although the researchers cannot free themselves from their pre-understanding the awareness of its existence together with critical reflection enabled them to deepen and broaden their recognition of it (Lindseth & Norberg, 2004). During the final interpretation the researchers referred to the Theory of Symptom Management (TSM) framework as well

as the person-centred care approach. Thus, the comprehensive understanding emerged by means of TSM and a person-centred approach.

Table 2. An example of the process from meaning units to theme.

Meaning units	Condensed meaning units	Sub themes	Theme
"I talked… and nobody interrupted me… she allowed me to talk, about everything I needed, everything that I had been through. I went on… Then after a while she also talked… *Yes, these conversations were great. She treated me like a human, a fellow human being".*	*Feeling allowed to talk.* *Treated like a human being.*	Feeling listened to	*Feeling that one's dignity has been restored*
"Nobody has backed me up… But during these conversations, when I told her about what I've been through… She confirmed me several times, my strength, my resilience… *It was so rewarding, and I bring this with me now".*	*Feeling confirmed after being through a lot.*	Feeling confirmed in one's suffering	

Non-parametric statistical analysis

Non-parametric analysis was performed because the data were not normally distributed and statistical calculations were made on nominal and ordinal data collected from a small sample (Polit & Beck, 2021). SPSS Statistics 28 (IBM Corporation, 2022) was used for analysing data. Nominal data were summarized with medians and percentiles. When applicable for independent groups, values of $p<0.05$ (two-tailed) were considered significant. The Wilcoxon signed rank test was used to analyse possible differences over time in dependent groups, i.e., pain, person-centredness, transplant specific well-being and self-efficacy.

The statistical analysis was performed as follows:

1. Exploring proportions with the Chi square test and describing the prevalence of variables.
2. Exploring differences between two dependent groups by means of the Wilcoxon signed ranks test.
3. Exploring the strength of relationships between the OTSWI and Self-efficacy by means of Spearman´s rho.

Ethical considerations

The first three studies in this thesis have been approved by the Regional Ethics Board of Lund (Dnr. 2014/124) with supplementary approval from the Swedish Ethical Review authority (Dnr 2019/02769) because of the addition of one more centre for recruiting patients. The fourth paper was approved by the Swedish Ethical Review Authority (Dnr. 2023-00132-01). All studies conform to the ethical principles for medical research involving human subjects as defined in the Declaration of Helsinki (World Medical Association, 2013) and Swedish research ethics legislation (*Lag om etikprövning om forskning som avser människor* SFS 2003:460). If severe symptom distress was identified when analysing the completed questionnaires during the longitudinal study, i.e., extensive pain or very low psychological well-being, each outpatient clinic was contacted as it was deemed unethical not to intervene and reduce the participants' suffering. However, this happened less than ten times.

There are some risks involved in conducting studies when the participants fill in self-report questionnaires and act as informants in interviews. One risk is the time-consuming effort that might burden the participants in their everyday life (Polit & Beck, 2021). Another risk is that the questions might trigger and stir up emotions that burden the participant. For that reason, a researcher must carefully consider the benefit of the study and the instruments used (Polit & Beck, 2021). A further risk is that personal information might be leaked to unauthorized persons. It is the researcher's duty to follow legislation and do her/his utmost to prevent that from happening (World Medical Association, 2013). Participation is always voluntary and a participant can withdraw from the study at any time without any consequences for their future care or contacts with healthcare. Before a presumptive participant gives informed written consent, she/he must be adequately informed of aims, methods, sources of funding, conflict of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail, post-study provisions and any other relevant aspects of the study (World Medical Association, 2013).

Participants in the studies in this thesis were informed about the above stated obligations, including information about confidentiality, protection of their identity and other sensitive personal data. To avoid making the patients feel obliged to participate, the nurse in the out-patient clinic and in some cases their occupational therapist asked them if they would be interested in participating and handed them the questionnaires, thus the researcher was not involved in recruitment. The participants in Paper IV were free to decide how they wanted to meet for the conversations, with all deciding to talk over the phone or digitally. The location or media of the conversation is important for creating a sense of security (Polit & Beck, 2021). There was a plan for dealing with participants who felt unwell during the studies. A social worker was available at the University hospital in Lund and continuous contact was maintained with the outpatient clinic nurses so that participants who seemed upset received follow-up. During data collection and data management it became clear that some participants had great symptom distress and for that reason the out-patient clinic was contacted. During the intervention in Paper IV two participants were asked for permission to contact the outpatient clinic due to severe pain and symptom distress.

The results of all studies are presented at group level and the quotations in Paper IV are anonymous, which minimizes the risk of identities being revealed. All questionnaires, personal identification, code-keys, transcribed interviews and informed consent were stored in accordance with Swedish research legislation, e.g., in a locked fireproof cabinet, to which only the supervisor had access. Data processing took place offline adjacent to the cabinet. Raw data and analyses of data were stored on an external hard drive.

Results

The findings, which are reported below as a whole based on the four papers, provide a comprehensive picture of chronic pain and symptom distress after heart transplantation from a patient perspective, suggesting that a person-centred symptom management support intervention might be feasible and promote health.

The magnitude of the problem

In the first study, the magnitude of the problem became evident. Chronic pain is common, reported by 58% in the first five years after heart transplantation. The proportion of women with pain was 68 % (n=17) versus 54 % of men (n= 29). In Paper III where 40-60% reported pain, a reversed pattern was evident regarding sex differences as the men reported higher pain intensity than the women after one year and four years. The peak pain intensity occurred three years post-transplant as illustrated by Figure 8 below.

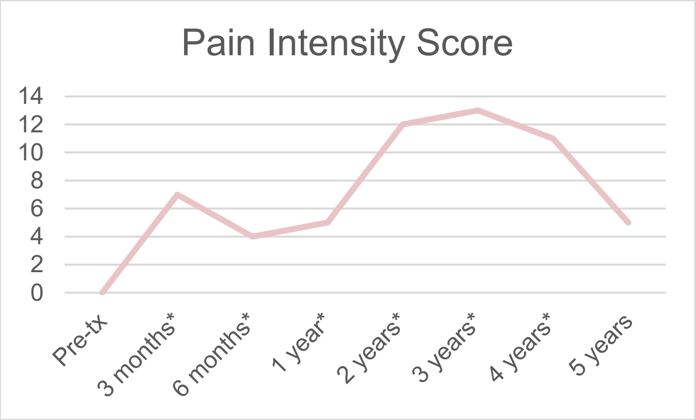


Figure 8. Median profile showing the Pain Intensity Score among 48 heart recipients from pre-heart transplantation to five years post-transplant. *= significant increase compared to pre-transplant as follows: 3 months (p=.017), 6 months (p=.004), 1 year (p=.009), 2 years (p=.004), 3 years (p=.004), 4 years (p=.019). After 5 years a non-significant increase was shown (p=.136). The number of missing responders varied over the five years as follows: Pre-heart transplantation (n=3), 3 months (n=5), 6 months (n=5), 1 year (n=3), 2 years (n=8), 3 years (n=14), 4 years (n=9) and 5 years (n=2).

The most common pain locations were feet, calves and back. The pain was primarily reported as dull, stabbing and numb and the three most common affective responses were annoying, tiring and troublesome.

Table 3: Self-reported pain locations 1-5 years after heart transplantation among 46 heart recipients. The heart recipients were permitted to report several locations. The three most common locations are marked in light brown.

Pain locations	1 year n=16	2 years n=13	3 years n=8	4 years n=6	5 years n=3	Total n=46
Feet	3	7	8	4	2	24
Back	7	3	3	2	2	17
Calves	3	3	3	3	1	13
Hands	2	4		2	3	11
Chest	4	3	1	1	1	10
Knees	2	3	1	1		7
Shoulders	2	1	1	2	1	7
Head	3		2	1		6
Thighs	2	1	2		1	6
Arms	2	1	1		2	6
Neck	3		1	1		5
Abdomen			1	2		3
Heart	1				1	2
Groin			2			2
Ribs	1					1
Hips				1		1

Those strongly fatigued as well as those with poor psychological well-being reported a significantly higher pain intensity score (PIS). Heart recipients reporting pain suffer from more symptom distress and worse transplant specific well-being than those without pain, in particular sleep problems, joint and muscle pain, foot pain, mood problems, headache and numbness in the hands. Those with pain report overall lower psychological general well-being (PGWB). The heart recipients with pain are found among those slightly recovered or not recovered at all. Low transplant specific well-being was related to high pain intensity, which in turn was related to low PGWB. Heart recipients report a clinically higher pain intensity than lung recipients in the first three post-transplant years. However, the difference is not significant.

Most of the heart recipients reported sleep problems (86%), fatigue (73%), joint and muscle pain (65%) and impaired cognitive function (63%). Symptom occurrence after heart transplantation varied depending on type of symptom and follow-up year. Trembling hands and decreased libido were prominent regardless of follow-up time, while other symptoms were more common in the first year after transplantation, i.e., feeling breathless or bloated. The most frequently occurring symptoms in the cross-sectional study, trembling hands and decreased libido, were also the most distressing, but this does not hold true for the other most common symptoms as shown in Table 4 below.

Table 4: The ten most occurring and distressing symptoms among 79 heart recipients one to five years after heart transplantation. The top three symptoms are marked in light brown.

Rank order	Most prevalent symptom	Most distressing symptom
1	My hands are trembling	My hands are trembling
2	My libido is decreased	My libido is decreased
3	I am breathless	I feel sad
4	I have increased appetite for food	I have headache
5	I have headache	I am breathless
6	I feel dizzy	I need to rest because I am breathless
7	I feel sad	I have increased appetite for food
8	I need to rest because I am breathless	I feel dizzy
9	I am bloated	I am bloated
10	I have diarrhoea	I have diarrhoea

The characteristics of those suffering from chronic pain and high symptom distress

The heart recipients most burdened by symptoms are most likely to be found among those younger than 50 years, who are not working, have poor psychological well-being, are strongly fatigued or live alone. However, during the first two years older heart recipients report more symptom distress than their younger counterparts. Heart recipients with extensive symptom distress experienced that nobody listened to them nor confirmed, restored or empowered them to manage their symptom distress. During their follow-up focus had been on the organ in the person, not the person with an organ. All participants in the intervention study described their heart transplant trajectory and post-transplant follow-up as a complete feeling of being objectified and evaluated solely on their physical performance like an anatomical construction or a graft. Habitual recovery, emotional transition and meaning making as well as their daily occupation were not addressed or emphasized by healthcare professionals (HCPs).

> "It has been a very clinical approach [from the out-patient clinic]. All interaction focused on checking the graft function, how my medication is working and has been adjusted. There have been highly clinical tests and check-ups and hardly any conversations… Nobody has ever asked me how I am doing after the transplantation. They have no interest in anything except my physical condition. I have great vital signs, my heart is working, I perform incredibly well physically. And eh... everything

> is so great, and they send me home. No one has ever asked me about my feelings. Or if there are any consequences in my everyday life that I find challenging. – Do you worry about something? Have you ever felt sad or depressed? I have never had these questions (Male, 63 years).

All participants in Paper IV described feelings of impotency and being subjected to the will and wishes of the HCPs in the various outpatient transplant clinics. Their heart had been well monitored, but the rest of them, i.e., the whole person, felt neglected. Transplant specific well-being improved in a stepwise manner for the first five years compared to pre-transplant for those with good psychological well-being. Heart recipients with poor psychological well-being were significantly more burdened by symptom distress, in particular sleep problems and fatigue for up to five years after heart transplantation and their transplant-specific well-being never improved compared to baseline except after the first year where a minor improvement occurred compared to pre-transplantation. Overall, fatigue decreased over time after heart transplantation with a few variations in certain fatigue dimensions (Figure 9).

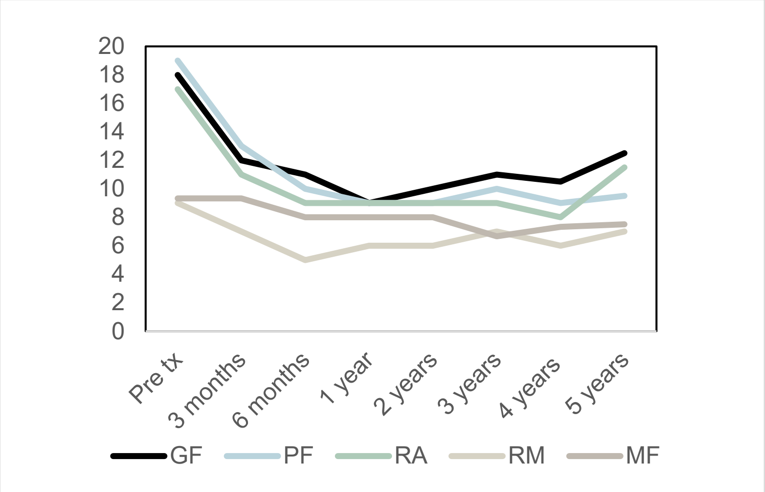


Figure 9. Changes in fatigue among 48 heart transplant recipients from pre-transplant to five years after heart transplantation expressed as a median score. GF= General fatigue, PF= Physical fatigue, RM= Reduced motivation, RA= Reduced activity and MF= Mental fatigue. A score of GF≥12 represents high fatigue. The number of missing responders varied over the five years as follows: Pre-heart transplantation (n=3), 3 months (n=5), 6 months (n=3), 1 year (n=3), 2 years (n=8), 3 years (n=8), 4 years (n=7) and 5 years (n=2).

In summary, those with good PGWB improved significantly at every measurement point compared to baseline in the OTSWI sum score, while the trajectory of those with poor PGWB revealed a higher OTSWI sum score at every measurement point except after one year, where a minor improvement occurred compared to pre-transplantation. In addition, heart recipients with poor PGWB reported higher symptom distress (i.e., a higher OTSWI sum score) than those with good well-being in most domains over the five years as illustrated in the median profile below (Figure 10).

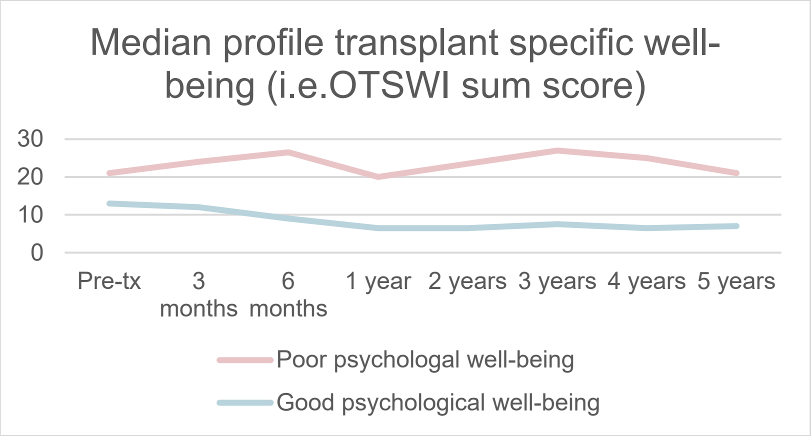


Figure 10. Differences between those with good and poor psychological well-being in median sum scores for the Organ Transplant Symptom and Well-being Instrument (OTSWI) from pre-transplant to five years. The number of missing responders varied over the five years as follows: Pre tx (n=7), 3 months (n=18), 6 months (n=19), 1 year (n=19), 2 years (n=8), 3 years (n=13), 4 years (n=9) and 5 years (n=1).

Possible explanations and predictors

All fatigue dimensions improved after heart transplantation and general fatigue reached its lowest level one year after heart transplantation. In the cross-sectional studies fatigue explained more than 60% of the variation in transplant specific well-being (OTSWI-sum) followed by sleep problems. The strongest predictor of reporting poor PGWB after heart transplantation was fatigue, with an odds ratio of 1.43. The prevalence of pain varied from 40-60 % and explained a significant proportion of the variance in transplant-specific well-being, while PGWB was mainly predicted by the overall symptom distress, i.e., the OTSWI-sum. Among those reporting pain, the OTSWI sum predicted 52-70 % of the variation in PGWB while pain only explained 9-10 % of the variation. Among those not reporting pain the OTSWI sum explained more than 70- 80% of the PGWB. When the transplant specific well-being improves, i.e., a lower OTSWI sum score, the PGWB score increases, indicating better PGWB. After two to four years the symptom distress, i.e., the OTSWI-sum, largely predicts PGWB regardless of the prevalence of pain. Less pain would improve transplant-specific well-being three and four years after heart transplantation. In summary, pain intensity predicts transplant specific well-being but not PGWB. Transplant specific well-being (i.e., symptom distress) predicts PGWB.

Is it possible to intervene?

The intervention led to a profound sense of being taken seriously for the first time during the heart transplant trajectory. The participants, who all suffered from extensive physical and/or emotional pain, felt confirmed in their suffering and restored as persons. Being able to share one's narrative with an attentive, competent and present listener narrowed the perceived distance between the heart recipients and HCPs. The perceived experience of being taken seriously involved four themes: dignity, restoration, empowerment and comprehensibility (Table 5).

Table 5. The structural analysis of the meaning of being taken seriously expressed by 13 heart recipients with extensive symptom distress.

Sub themes	Main themes
Feeling listened to Feeling confirmed in one's suffering	Feeling that one´s dignity has been restored
Feeling recognized and validated Being in a temporary communion Feeling viewed as a whole person not simply a body	Experiencing being recognised as a whole person
Feeling disburdened through sharing Feeling capable	Feeling empowered as a person
Making sense in togetherness Finding coherence	Achieving a sense of comprehensibility

The core was that the heart recipients experienced both sameness and otherness through reduced asymmetry in the caring encounter. Thus, their dignity as persons capable of interpreting their own health was restored. Transplant specific well-being improved clinically after the intervention and significantly in basic activities of daily life (p=.014). Self-efficacy remained the same as before the intervention. The self-rated experience of being taken seriously improved.

The comprehensive understanding is that the core of being taken seriously in the intervention was that the heart recipients experienced both sameness and otherness through reduced asymmetry and the restoration of their dignity as persons capable of interpreting their own health. The strong relationship after the intervention, rho-.84 (p=.001), suggests that better well-being leads to stronger self-efficacy. The findings as a whole revealed that if you suffer from chronic pain, you are also burdened by several other distressing symptoms causing poor PGWB. As heart transplant follow-up is organized to monitor graft function and not to support self-management, a sense of impotency occurs among the heart recipients including a lack of empowerment. By focusing on resources and health aspects as well as taking the heart recipient seriously, it is possible to restore the heart recipient’s dignity and balance the disease burden.

Discussion

Methodological considerations

A strength in this thesis is that both quantitative and qualitative methods were used to address the aim in a comprehensive way. The different designs enabled exploration, explanation and intervention using unique data collected within the comprehensive SMATT project. Papers I and II included the same participants, while Papers III and IV comprised new and different participants. Thus, the results are derived from different groups, which is considered a strength as the studies confirm each other. When Papers I and II were concluded Paper III was decided upon to explore symptom distress and other relevant variables over a period of time. Paper IV was decided upon when data from Paper III were calculated and analysed. Thus, the results from prior studies led to the development of the subsequent studies.

Quantitative method, Papers I, II & III

The inclusion of two cross-sectional and one longitudinal study is considered a strength because it allowed the mapping of a presumptive problem, which could then be followed over time. Cross-sectional studies are easy to perform, require few resources and can be conducted relatively quickly to explore a phenomenon of interest. They also provide information about the prevalence of a certain outcome, such as symptom distress (Polit & Beck, 2021; Ranganathan & Aggarwal, 2018; Wang & Cheng, 2020). The disadvantages of cross-sectional studies are that they only give a snapshot of the outcome and that the outcome and exposure are measured at the same time, which makes it very difficult to establish causal relationships. For this reason, it is considered a strength that Paper III is a longitudinal study that follows participants over time, making it possible to discern trends. A disadvantage in the longitudinal design that has to be considered was the incomplete and interrupted follow-up. In addition, the unexpected COVID-19 pandemic really tested the ability to conduct real life clinical studies in rough times. HCPs were moved around, heart recipients were afraid to visit the hospital and failed to attend their appointments. Nevertheless, a five year follow-up of symptom occurrence and distress is now available, which provides a platform to obtain further knowledge about this group of people.

Selection and participants

Recruitment took place at the three large transplant outpatient clinics in Sweden, making it a multicentre study reaching most heart recipients in Sweden with just a few exceptions. The goal was to invite all heart recipients who met the inclusion criteria, but unfortunately, some practical obstacles made it difficult to collect data as planned. Reasons were lack of a tradition of facilitating nursing research and staff turnover, which led to recipients not being invited and made it difficult to assess the actual number of eligible heart recipients. The number of eligible heart recipients is based on data from a registry of heart transplantations performed during the study period and therefore included both those who attended their follow-up and deceased heart recipients. It would have been preferable to have more participants, as it increases the representativeness of the population and reduces sampling error (Polit & Beck, 2021). The reasons for exclusion and declining to participate were only partly recorded, making them impossible to analyse, thus they were considered missing at random. In retrospect, a hired research nurse would have enabled a more structured follow-up of dropouts and missing responses. However, the initial funding of the SMATT project did not allow that.

The heart recipients were invited consecutively by their regular nurse at the outpatient clinic, or in some cases by an occupational therapist. It was considered ethical and a strength that the researchers did not exert pressure on the heart recipients. Consecutive sampling over time reduces the risk of bias (Polit & Beck, 2021). Papers I & II were cross-sectional studies and the participants were invited at one of their follow-ups in years 1, 2, 3, 4 and 5. Paper III was a longitudinal study and the participants were invited while on the waiting list. For the three papers it was only possible to be invited once in either the cross-sectional or the longitudinal study. On some occasions participants were invited by mistake more than once in the cross-sectional study. When that was discovered, the last inclusion was removed. The nurses and the occupational therapist at the outpatient clinics received instructions about how to include participants and were in regular contact with the researchers involved. Nevertheless, whether participants were invited because the nurses and occupational therapist had a good relationship with them and hence deemed them suitable for the study was beyond the researchers´ control.

The recruitment plan is considered to yield a representative sample as it lasted for several years and targeted a broad group of heart recipients with just a few excluded. It was considered unethical to approach severely ill patients receiving in hospital care and the risk of them being outliers in the data was a further reason for excluding them. Excluding persons who do not speak Swedish leads to a systematic exclusion of a growing group of immigrants in Sweden. This exclusion was due to the fact that there were no questionnaires that had been translated into languages other than English. Making the group homogeneous decreases the size and generalizability of the sample (Polit & Beck, 2021). The proportions of men and women and the mean age in this thesis reflect recipients in Europe (Khush et al., 2021). Women are fewer than men but also have heart failure that does not advance to the same extent as that of men and present with heart failure at an older age (Khush et al., 2021). Overall, the selection in Papers I-III is likely to be representative of the population.

Instruments

All instruments and their validity and reliability are described in the Method section. An overall strength of this thesis is that the instruments have been tested for their validity and reliability to various extents, meaning that they measure what they are intended to measure in a consistent way. Validity is defined as "the degree to which an instrument is measuring the construct it purports to measure" (Polit & Beck, 2017. p. 322). There are no equations to apply, instead evidence must be built to conclude the validity (Polit & Beck, 2021). On the other hand, reliability is easier to measure with different reliability coefficients ranging from a low to a high value, indicating low versus high reliability (Polit & Beck, 2021). It is important to note that high reliability does not guarantee high validity, although high validity presupposes high reliability (Polit & Beck, 2021). The OTSWI is a transplant specific instrument, which is desirable (Shahabeddin Parizi et al., 2018). It was developed in a Swedish context for solid organ recipients and has good psychometric properties covering 86% of the variance (Forsberg et al., 2012). It was translated and tested for reliability and validity for Chinese solid organ recipients in 2022 (Shi et al., 2022). The Chinese tests showed that the OTSWI is also a reliable and valid instrument in that context. Item analysis was good, no items were deleted and internal consistency using Cronbachs´α was .934 ranging from .726 - .861. The test-retest showed high reliability (r=.713, p=< .001) and the factor analysis was satisfactory.

The use of instruments that to some degree measure the same variables confirms and strengthens the results. Some examples are the MFI and the OTSWI that both measure fatigue, the POM and the OTSWI that both measure pain and the OTSWI and PGWB that both measure well-being. The MFI covers five dimensions of fatigue and is considered a strength due to fatigue being a complex phenomenon. The SESG6 has not been tested for reliability nor validated in the solid organ recipient population, which is considered a limitation. However, it was developed for chronic conditions and blending generic and specific instruments also facilitates the comparison of results with various other populations (Shahabeddin Parizi et al., 2018). The PRP has recently been psychometrically evaluated again and Jakobsson (2023) argues that the instrument needs further development to be considered robust. Using an instrument that has not been shown to be valid and reliable is a limitation. The PRP is used in Paper I to explore recovery in relation to pain. The result showed that those not recovered reported more pain. Thus, this result should be viewed with caution.

Non-responses

Unfortunately, there are no data on or analyses of the non-responses in Papers I-III. Knowing the reasons for non-responses and the characteristics of the non-responders might be important information (Polit & Beck, 2021). Reasonable causes of non-responses are deaths and participants feeling frightened during the COVID-19 pandemic, which led to avoidance of attending appointments. The total number of questionnaires to be completed was 10, which was a major reason why some participants lacked the energy or will to fill them all in, especially in Paper III where the participants were asked to fill in the questionnaires eight times during the study period. One could argue that it was too burdensome but the SMATT project, which is a comprehensive study with six cohorts of lung and heart recipients, comprises a solid foundation of data regarding several variables after thoracic transplantation. It has produced numerous papers and theses. In light of that achievement, the effort of voluntarily filling in questionnaires on a maximum of eight occasions during a period of more than five years is considered an extraordinary contribution to research by the transplant recipients.

Data analysis

Statistical analyses were conducted on the whole samples as well as subgroups, e.g., follow-up year, sex and age. Descriptive as well as inferential statistics were performed. As suggested by Polit & Beck (2021), non-parametric statistics were used in both independent (Papers I, II & III) and dependent groups (Paper III) as the sample sizes were small and the measurement levels nominal and ordinal. Data were analysed per year in all the three papers, which enabled explorations of deviations in each post-transplant year. Some data were dichotomized into two different groups to determine possible differences such as age, sex, time on ventilator and high or low PGWB. Age was dichotomized based on the mean in the sample being close to 50. Time on the ventilator was dichotomized based on the clinical cut off. Longer than 48 hours on the ventilator is clinically regarded as a more complicated course of events. The dichotomization of PGWB into two groups was deemed useful based on clinical relevance and to obtain a clearer description of the proportions between those with poor versus good psychological well-being. Regarding sex, there was no other option than dividing the participants into groups of men and women. Future studies should include the option of non-binary. Comparisons of heart recipients transplanted at either of the two centres in Lund and Gothenburg was considered irrelevant because the centres collaborate and the follow-up care is organized in a similar way. Comparisons were made between heart and lung recipients in Paper I. The rationale for doing so was that both groups had undergone thoracic surgery, were medicated with immunosuppression, had self-reported their pain with the POM and comparisons between the groups had not been previously performed. Some follow-up years consisted of very few participants e.g., five years post-transplant, which made them unsuitable for some analytic methods. Descriptive statistics were utilized even on small groups.

In Papers I and II correlation analyses were conducted to examine relationship. Due to the fact that the studies were cross-sectional, causal relationships cannot be determined. A multiple linear regression analysis was used in Paper II to assess the extent to which sleep problems, fatigue and vitality explained the variance in transplant specific well-being (OTSWI-sum). Analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity as described in the SPSS manual (IBM Corporation, 2017; IBM Corporation, 2022). Direct logistic regression was performed to assess the impact of several factors on the likelihood that heart recipients would report poor psychological well-being.

In Paper III median profiles were considered suitable to visualise the OTSWI-sum, PIS and fatigue due to the ordinal and skewed data. Using medians is preferable when the material is skewed (Polit & Beck, 2021). Correlation analyses were performed to analyse the strength of relationships between PGWB, chronic pain and the OTSWI. Linear multiple regression was used to assess possible predictors following the same procedure as in Paper II to ensure that there was no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. The longitudinal design confirms much of what had been found in Papers I and II, which is considered a strength.

Exploring differences in a data set concerns whether a null hypothesis is rejected or accepted. A null hypothesis is always based on negative inference. For example, in Paper I a null hypothesis was "there are no differences in self-reported pain between men and women". The statistical tests performed either reject or accept that hypothesis. Two different errors called Type I and Type II error can occur when analysing quantitative data and testing hypothesis, Type I error occurs when the researcher rejects a true null hypothesis, thus a false positive conclusion is drawn, leading to the belief that there is a difference when in fact there is none. Type II error occurs when the researcher accepts the null hypothesis even when it is false, a false negative conclusion, leading to the belief that there are no differences when in reality there are. To lower the risk of drawing wrong conclusions about the analyses the researcher selects the level of significance, which means that the results not likely to have been caused by chance are at a certain level (Polit & Beck, 2021). The level in the Papers is alpha 0.05, meaning that 5 null hypotheses out of 100 would be rejected even if it they are true, in other words, a 5% probability of Type I error. Performing several tests in a study increases the risk of Type I error. It is important to note that lowering the risk of Type I error increases the risk of Type II error. Accepting alpha 0.05 instead of a lower value reduces the risk of Type II error (Polit & Beck, 2021).

The risk of Type II error is reduced by power analysis. The power analysis estimates how big the sample needs to be to avoid Type II error. No power analysis has been conducted in the papers and a value of Type II error is missing. The reason for not conducting a power analysis is based on the following: The main study is an observational study. Power is required for experimental studies (Polit & Beck, 2021). In this case the study design involves testing hypothesis that could potentially lead to an experimental study with an intervention at a later stage. At that point a power calculation will have to be performed, after completing the feasibility study (Paper IV). In this thesis there are various types of group constellations where differences are investigated, making it difficult to determine the groups for which to calculate power. There are also statistically significant differences in the findings. For these statistically significant comparisons, sufficient power already exists.

Generalizability

When discussing generalizability, the main question is whether the study participants reflect the population (Polit & Beck, 2021). The decision to exclude non-Swedish speaking and hospitalized heart recipients could constitute a limitation. On the other hand, the inclusion was consecutive over time, lowering the risk of selection bias, e.g., choosing those with presumed pain and symptom distress. With the sole exception of the PRP, the instruments used were all tested and considered valid and reliable for the purpose. The demographics of the included participants reflect international statistics regarding age, sex and indication for transplantation. Swedish transplant centres and transplant units follow international guidelines (Velleca et al., 2022). Thus, Swedish heart recipients undergo the same procedures, are prescribed the same medications and are followed up in the same way as heart recipients globally. The results of the studies are considered to be generalizable to the larger population of heart recipients, with the exception of multi-ethnic populations due to the lack of immigrants among the study participants.

Mixed method Paper IV

The fourth paper has a mixed method design. Triangulation of qualitative and quantitative data in considered enriching (Östlund et al., 2011). The two methods complement each other and compensate for the limitations of each method. In addition, it is valuable to use the tool best suited to the research question. (Polit & Beck, 2021). When using a mixed method design, it is common that one method is given priority and the aim, rationale and the weighting of each method determine if and how the findings will be integrated (Östlund et al., 2011). In Paper IV the qualitative method was given priority. The advantage of this was that a qualitative inquiry adds an in-depth understanding and lived experience of the intervention, thus was best suited to fulfil the study aim. The disadvantage of giving the qualitative method priority is the difficulty reaching definitive conclusions based on the findings, which might not be representative or generalizable (Polit & Beck, 2021).

Selection and participants

The participants were invited by their regular nurses at three outpatient clinics in Sweden as described earlier, making it a multi-centre study. There was an equal number of men and women with a mean and median age reflective of international statistics (Khush et al., 2021) The group was small, but an interesting aspect is that women constitute a larger part than in previous studies within this thesis. Those who declined participation and those who withdrew from the study due to extensive symptoms were all men. No further analysis of the non-responders was made. The goal was to include at least 20 participants, but due to the time limit of the study and lack of eligible individuals, the final number of participants was 13. While the limited number of participants reduced the possibility of sufficient statistical calculations and analyses, on the other hand 13 informants is considered adequate for analysing interviews (Polit & Beck, 2021). Probably more would have been included had there been more time. However, this was a pilot study and the intention is to scale up later. If the intervention had been shown to be not feasible the low number of participants would have been an advantage as less individuals would have been exposed to negative impacts.

The participants were invited based on their experienced pain. When conducting the study there were discussions about whether participants should be included regardless of whether or not they had pain. While that would have increased the number of participants it was considered desirable to test the intervention on those who were likely to benefit most from it, i.e., heart recipients with chronic pain and possibly symptom distress. The fact that such heart recipients were selected raises the question of sampling bias, but following discussions it was concluded that heart recipients with chronic pain and symptom distress were the most relevant for evaluating the intervention. Patients with mild or no symptom distress would not be prioritised in a clinical setting and it would probably be hard to interpret the results from heart recipients who do not need symptom management support in the first place. Either decision affects generalizability but including those with chronic pain was considered the best option.

There is no such thing as a perfect study. This was a pilot study and the most important aspect when conducting a larger study based on the present one would be to allocate sufficient time to ensure a larger number of participants. Also, to enrol a comparison group. Another thing would be to use the questionnaires to evaluate the intervention. Östlund et al. (2011) state that it is common to separate the methods instead of integrating them to a greater extent. All research involves decisions and being aware of what is discarded in favour of other priorities (Polit & Beck, 2021). One option would be to use a case-control study, which was briefly discussed but considered too time consuming.

Instruments

A numeric rating scale was used to identify those with pain. Repeated measures of pain were not conducted as the aim of the pain measurement was to find participants to include. Three instruments were handed out by the nurses at the outpatient clinic and were answered on two occasions, baseline and after the intervention. The OTSWI and the SES6G were discussed earlier. The BTSQ-P, which has excellent psychometric properties, is nevertheless a newly developed instrument and needs further testing and evaluation regarding validity and reliability. The quantitative measurements performed at baseline and after the intervention did not measure the intervention itself but were considered to support the qualitative findings.

Data analysis

All issues regarding a limited amount of data material that have been previously discussed are valid for Paper IV.

The qualitative method chosen aimed to describe the lived experience of the intervention, what it really meant to the participants. The chosen method, phenomenological hermeneutics, both describes and interprets, which enables a deeper understanding of certain phenomena, i.e., symptom management support as in this study (Lindseth & Norberg, 2004).

The qualitative method will be discussed based on four criteria for ensuring trustworthiness developed by Lincoln & Guba (1985); *credibility, dependability, conformability* and *transferability,* which are equivalents of the positivists′ terms *internal validity, external validity, reliability* and *objectivity* (Lincoln & Guba, 1985; Polit & Beck, 2021).

Credibility is viewed as especially important and refers to the confidence in the truth and interpretation of data (Lincoln & Guba, 1985). It is maintained through different steps, e.g., reflexivity, prolonged engagement and persistent observation (Polit & Beck, 2021). Reflexivity was strengthened by constant critical reflection regarding self-awareness and the researchers' biases and assumptions throughout the data collection, analysis and interpretation. These steps were deliberately performed by different persons in the research group to avoid bias. The qualitative findings were continuously discussed in the research group regarding rigor and reflexivity. Prolonged engagement and persistent observation mean that sufficient time is invested to understand the participants. Prolonged engagement is essential for building trust (Lincoln & Guba, 1985), which was obtained in Paper IV.

The researcher who conducted the intervention was not involved in the evaluative interviews to ensure that the participants felt safe to narrate freely about the conversations. This means that they and not the researcher evaluated the intervention. To avoid presumptions, no conversations about the intervention took place between the researcher who performed the intervention and the researcher who conducted the evaluative interviews. It was deemed a risk that the relationship established during the conversations might make the participants too positive about the intervention. Thus, the focus in the interview was on the meaning of the intervention not primarily the person who performed it, despite the fact that these two parts are closely related. To enable an inductive approach towards data, the analysis was made by two senior researchers with no involvement in either the conversations or the interviews, only in the design of the study. In phenomenological hermeneutics it is considered a strength if the interviewer also performs the analysis (Lindseth & Norberg, 2004). For obvious reasons, this was not the case in the present study because the researcher conducting the intervention, i.e., the interventionist, would then become the subject of the evaluation.

The knowledge about the participants gained by the interventionist during the conversations was later used in the research group when scrutinizing the analysis made by the senior researcher. The fact that the interventionist recognized all text and knew which informant had said what based on the quotations indicates credibility. What was said during the conversations was repeated during the interviews and emerged during the analysis. One could argue that the participants would answer differently if the person carrying out the intervention also performed the interviews but the interview questions would still be the same and the fact that the interviews and analyses were familiar to the interventionist to such an extent tends to disprove this assertion. Quotations were provided to ensure that the reader can make judgements on credibility. The study was theory driven, which also increases the credibility (Lincoln & Guba, 1985; Polit & Beck, 2021). Data triangulation was carried out through the mixed-method design, member checking, by asking the participants if their statements were interpreted correctly and the fact that the interpretation was carried out by several researchers working together (Polit & Beck, 2021).

Dependability refers to the stability of conditions and data over time. If there is no dependability, there will be no credibility. Including participants from the three largest outpatient clinics minimizes the risk of context bias, which strengthens the dependability (Lincoln & Guba, 1985). All the interviews were performed by the same person using an interview guide and the results and possible outcomes were discussed as suggested in Polit & Beck (2021). When arguing for dependability the question is whether the findings would be the same (or similar) if the participants were asked to participate once again under the same conditions. It is believed that they would be.

Confirmability refers to objectivity, meaning that the findings must reflect the participants′ voices and not the researchers′ biases or perspectives (Lincoln & Guba, 1985). To achieve this, the researchers thoroughly discussed their pre-understanding and perspectives throughout the whole study as well as during the analysis, categorisation and interpretation of the results. It was an absolute goal to present the voice of the participants and not invent the findings based on assumptions among the researchers.

Transferability refers to the extent to which the findings can be transferred to other populations and settings (Lincoln & Guba, 1985; Polit & Beck, 2021). One must always be careful when claiming transferability. Given the above description of how the data collection, analysis and interpretation were handled in combination with the fact that the group was heterogeneous regarding sex, age, pre-transplantation diagnosis and socioeconomic aspects, it is believed to be transferable to other heart recipients in Sweden and the Scandinavian countries.

Authenticity is a criterion that was added by Lincoln and Guba in 1994 (Polit & Beck, 2021). It refers to the extent to which the researchers show a range of realities. By describing and making visible the lives of the heart recipients the text becomes authentic. To achieve authenticity in Paper IV, the researcher included several quotations to illustrate and strengthen the description of the lived experience. During the first round of reviewer comments from the targeted scientific journal, it was suggested that the result should be described to a larger extent instead of devoting too much space to the quotations. This resulted in a revision of Paper IV where we expanded the description of the findings in the manuscript and the quotations were added in a box to support the text, while adhering to the 5,000-word limit. Thus, the intention was to strengthen the authenticity by letting the participants´ voices be heard in the text but, as always in research, there are several perspectives to consider.

General discussion of the results

This thesis provides a comprehensive picture of chronic pain and symptom distress after heart transplantation It also describes the lived experience of person-centred symptom management support for heart recipients with chronic pain. The main findings will be discussed under the same headings as in the Results section; *The magnitude of the problem, The characteristics of those suffering from chronic pain and high symptom distress, Possible explanations and predictors* and *Is it possible to intervene?*

The main findings in this thesis were:

- Chronic pain is common after heart transplantation as well as decreased libido, sleep problems and tremor.
- Heart recipients with pain suffer more symptom distress, are more fatigued, have lower transplant specific well-being and lower psychological well-being than those not reporting pain.
- Trembling hands and decreased libido were prominent symptoms regardless of follow-up year.

- The transplant specific well-being of those with poor psychological well-being does not improve up to five years after heart transplantation.
- Those with symptom distress are more likely to have poor psychological well-being.
- Person-centred symptom management support made heart recipients feel that they were taken seriously by being listened to, confirmed, restored and empowered. There was a strong relationship between transplant specific well-being and self-efficacy.
- Heart recipients with extensive symptom distress experienced that nobody listened to them nor confirmed or empowered them to manage their symptom distress.
- All participants in the intervention study described their heart transplant trajectory and post-transplant follow-up as a feeling of being objectified and evaluated solely based on their physical performance.

The magnitude of the problem

Experiencing symptoms after heart transplantation is common and chronic pain is a prominent symptom. The findings in Paper I were confirmed in Papers II, III and IV, which all showed that pain is common and peaks three years after transplantation. Over half of the heart recipients experienced pain, with three quarters reporting pain three years after transplantation. That can be compared with lung recipients, where 58% - 65.5% experience chronic pain after transplantation (Forsberg et al., 2017; Klinger et al., 2020) or 20% of the general population in Europe experiencing chronic pain, which is considered a major problem (Breivik et al., 2006; European pain federation, 2023; Pain alliance Europe, 2024). Postsurgical pain is considered a huge issue amongst solid organ transplant recipients and 20% are estimated to suffer from it but it varies depending on type of transplanted organ (Saliba, 2023). A prospective study explored pain after lung transplantation by assessing three different components: physical, mental and quality of life (Laurent et al., 2022). Six months after the transplantation 68% reported pain, where back pain, pain around the surgical scar and thoracic pain were the top three locations, in comparison with Paper I, where feet, calves and back were the top three pain locations. The patients with pain were more frequently depressed and anxious (Laurent et al., 2022). Pain is linked to mental health and they often influence each other (European Pain Federation, 2023). In Papers I, III and IV the findings confirm that pain is more prominent among those with low psychological well-being, to which it is strongly related.

As mentioned in Paper I, for the last 20 years research has suggested that chronic pain is common and underestimated after solid organ transplantation. The findings in this thesis emphasize and confirm this statement. Adequate pain treatment is considered a human right (Brennan et al., 2007). Based on the findings in this thesis it is fair to say that heart recipients might be undertreated when it comes to chronic pain. In addition, as evidenced by the participants in Paper IV who reported severe pain, expectations of post-transplant life are not met. Symptoms, setbacks and complications cause uncertainty that leads to disappointments, grief, low self-efficacy and psychological distress as discussed in Almgren´s thesis (2020). Identifying, assessing and treating chronic pain after heart transplantation should be a priority in the long-term follow-up, specifically in year two to four. A specialist in chronic pain management might be a relevant addition to the transplant team.

Even in 1987 pain was a symptom reported by more than half of all heart recipients (Lough et al., 1987). At that time, the focus was on symptoms due to the side-effects of different immunosuppression groups since the introduction of Cyclosporin. In this thesis the focus is the patient perspective on symptoms, irrespective of the reason for experiencing them. This explains why no group comparisons on immune suppression in relation to symptom experience have been made. Lough et al. (1987) stated that the most frequently occurring symptom is not necessarily the most distressing symptom. Even so, in Paper II trembling hands and decreased libido were the two most frequently occurring and distressing symptoms regardless of follow-up year. Impotence and decreased libido were the two most distressing symptoms reported by Lough et al. (1987).

Apart from pain, many of the symptoms reported in previous research occurred in the papers on which this thesis is based, such as sleep problems, fatigue, tremor and decreased libido. The latter is rarely investigated but probably generic regardless of the transplanted organ. In a large Danish cohort study of long-term survivors after liver transplantation, the key findings were that the most common symptoms reported by the recipients were decreased libido, followed by diarrhoea and headache and they were all strongly related to poor psychological well-being (Dengsø et al., 2024). The focus in research is often sexual dysfunction and almost exclusively involves men (Fuczylo et al., 2020). There are also findings suggesting that sexual function is less problematic. In a cross-sectional study comprising 17 heart recipients, 88.2% reported minor or no problems regarding sexual activity (Hasin et al., 2014). This is interesting when looking at the findings in the present thesis, where decreased libido is both common and distressing to a vast extent. Basile et al. (2001) also studied a small group of 25 male heart recipients with focus on the relationship between partners. The findings showed that sexual impairment prior to the transplantation remained afterwards. The authors argued that it is mandatory to follow heart recipients for a long time regarding sexual behaviour and focus on the relationship between partners. In addition, they suggested that heart recipients would probably benefit from support in recovering from a long period of distressing fears connected to the initial illness (Basile et al., 2001). Stiefel et al. (2012) reported that more than 45% of heart recipients experienced moderate to extreme decreased interest in sex. In a review it was revealed that sexual dysfunction is higher in heart recipients than in the general population and when the dysfunction appears before the transplantation it becomes worse afterwards. The cause is unclear but has been associated with type of immunosuppression (Fuczylo et al., 2020). Decreased libido, reduced interest in sex and various types of dysfunctions affect a large group of heart recipients and it is worrying that these issues do not receive more clinical attention, particularly when being intimate is part of the adaptation process described by Forsberg et al. (2016) and affects QoL (Phan et al., 2010). In the long term the experience of decreased libido is a major issue that negatively affects the recipients´ QoL (Ho et al., 2006) and might also be related to depression (Baranyi et al., 2012). It seems important that clinicians focus systematically on this concern during follow-up and invite a sexologist to the transplant team for consultation. We need to include this area of transplant recipients' lives as a target for health promotion interventions.

Sleep problems are a distressing symptom reported by 86% in Paper II. A review showed that 38.9% - 52% of renal, liver and lung recipients report poor quality sleep, which was associated with anxiety, depression, poorer QoL, restless legs syndrome and higher comorbidity (Cordoza et al., 2021). In Europe, the prevalence of insomnia, which means difficulties initiating or maintaining sleep, is 10% (Ellis et al., 2023). Common side effects of insomnia are headache, somnolence, dizziness, nausea and fatigue, all of which are symptoms reported by heart recipients. Persons with insomnia are also at risk of developing cardiovascular disease, diabetes, arterial hypertension, depression, anxiety and cognitive functioning impairment (Ellis et al., 2023). Sleep problems have not been investigated further among heart recipients (Cordoza et al., 2021), which raises questions about what it means to have sleep problems as a heart recipient and how it affects symptom distress. Even though sleep problems have been reported among solid organ recipient (Liaveri et al., 2017; Yo et al., 2019; Zhu et al., 2020;) the extent of sleep problems in Paper III was surprising. In Paper III sleep problems were reported at every measurement point except at one year post transplant and heart recipients with poor psychological well-being were especially distressed by them, which further underlines the need for continued research in this group. Together with chronic pain, sleep problems are underestimated after heart transplantation and require far more clinical attention to limit the negative health implications.

Fatigue is a commonly reported symptom after heart transplantation in Papers I, II (73%) & III and the findings confirm and are strengthened by earlier research. As a comparison, fatigue is the fifth most common health complaint in the general global population (Yoon et al., 2023) and among lung recipients 56 % report fatigue (Forsberg et al., 2019). Women are known to be more affected than men (Almgren et al., 2021) but this was not found in the present thesis. As with sleep problems, heart recipients with poor psychological well-being are affected the most, which highlights the need for robust interventions. Fatigue might be a symptom of sleep problems (Ellis et al., 2023) and often appears as a cluster together with pain and depression in cancer patients (Kalantar-Zadeh et al., 2022). Even before transplantation fatigue is the most common symptom among persons with HF (Falk et al., 2009).

As the heart recipients with poor psychological well-being experienced fatigue, sleep problems and pain and as pain and fatigue are a predictor of transplant specific well-being, it is reasonable to assume that they might be depressed and have cluster symptoms. Diagnostic criteria for depression include fatigue and sleep problems (American Psychiatric Association, DSM-5 Task Force, 2013). Indeed, depression is common after heart transplantation, affecting 26.3% of recipients (de la Rosa et al., 2021), as are fatigue and pain, which especially affect those with low psychological well-being. It is still unclear whether those with fatigue, pain and low psychological well-being are depressed. It is also possible to experience these symptoms in the absence of depression. However, it is dreadful to think that those experiencing fatigue and pain may also be depressed. A recent study by Aksut et al. (2024) reported that the two most common symptoms among heart recipients were fatigue (91.4%) and pain in the back, neck and joints (86.4%). They also stated that more than 50% suffered from insomnia and almost half of the heart recipients had nightmares and that the sleep problems could be a reason for them being fatigued (Aksut et al., 2024). What is the chicken and what is the egg remains for future research to explore.

Tremor is a known symptom often seen in the clinical setting and thus not surprising that it was rated as the most commonly occurring and distressing symptom in Paper II. Previous research on heart recipients (Aksut et al., 2024; Kugler et al., 2009 Stiefel et al., 2012) has also reported tremor as a frequently occurring and distressing symptom and in a study of lung recipients it was the most commonly occurring symptom (Lundmark et al., 2019a) Tremor can make daily tasks such as writing, eating and dressing difficult (NIH, 2024). Mild or severe tremor impairs life activities and severe tremor decreased HRQoL among solid organ recipients (Riemersma et al., 2023). Tremor is a disabling symptom depending on its severity and further research to explore the impact of tremor is warranted. Interventions to improve everyday functioning should also be offered and tailored. An occupational therapist in the transplant team enables the prescription of aids and advice on how to adjust various parts of the daily occupation.

The characteristics of those suffering from chronic pain and high symptom distress?

When discussing the findings, it is important to understand that many heart recipients are doing well. Those with good psychological well-being improved in terms of transplant specific well-being at every measurement point. Being a heart recipient is a chronic condition associated with low to moderate symptom distress. The clinical challenge lies in identifying those who experience symptom distress. Those with good psychological well-being are less likely to experience symptom distress that exceeds their ability to cope. As argued by Dodd et al. (2001), the ability to manage symptoms varies between and within individuals. In addition, the number and intensity of symptoms play a role. Less symptoms or symptoms that the heart recipient can manage strengthen self-efficacy.

The participants´ symptoms were not analysed in relation to their comorbidities in any of the papers, which would have been interesting. In Paper IV it became evident during the intervention that all the participants had a severe symptom burden and other comorbidities both pre- and post-transplantation, yet again these were not statistically calculated nor analysed. This gives rise to the question of why the outpatient clinics maintain their narrow perspective on follow-up when some of the heart recipients´ suffering is obvious and impossible to miss. The management of these patients does not align with their needs. Previous research about the adaptation process one to three years after heart transplantation reveals that there is a general difficulty in accepting their new circumstances (Almgren et al., 2017; Lindberg et al., 2020). Many expressed that they lacked support and education from HCPs, also shown in Paper IV, which resulted in a sense of being abandoned. There was a clear need for psychological support to help with adjustment. Patients also felt there was limited support for relatives.

Even though this thesis does not focus on medication induced side-effects, it is important to note that such side-effects might be the cause of certain symptoms. In Paper IV during the intervention many of the participants did not know that the symptoms they experienced could be caused by their medication. This becomes a problem because not knowing is stressful and lowers the ability to manage the symptom (Dodd et al., 2001; Rhodes & Watson, 1978). It also causes uncertainty, which has been shown to be a source of distress after heart transplantation (Almgren et al., 2017). Uncertainty should be recognized as a natural state that occurs when a person suffers from a condition that changes their worldview, i.e., heart transplantation. Ensuring transplant patients are well conditioned to adapt to their new circumstances is in many ways just as important as the transplant itself.

It is not surprising that those with much pain, strongly fatigued, with poor psychological well-being, or not working experience symptom distress to a greater extent as shown in Papers I, II & III. It was satisfying that fatigue improved in all dimensions in Paper III. Nevertheless, it was surprising as almost three quarters reported being fatigued in Paper II. As in Almgren (2021), fatigue is not a widespread problem, although this does not mean that it is unproblematic. Those suffering from it and likely from other symptoms and low psychological well-being need symptom management support. When it comes to fatigue an occupational therapist is important as she/he can enable adjustment of the current energy resources in an appropriate way.

The transplant specific well-being of those with poor psychological well-being did not improve during the five-year follow-up. They spent year after year without experiencing any improvement in their well-being and symptom distress. These heart recipients need symptom management support and continuous follow-up regarding their process of adaptation. In order to identify those who suffer from fatigue, symptom distress and poor psychological well-being HCPs must ask and screen heart recipients. The care needs to be organized in a way that promotes shared decisions and participation in the care by enabling the heart recipient to be a valid partner in the healthcare team (Karazivan et al., 2015). Patients and their families are the most undervalued resources in healthcare systems and need to be prepared, informed and motivated to manage chronic conditions (Bengoa & Yach, 2002). This is where the system probably fails. To what extent does a heart recipient feel prepared, informed and motivated when, as in Paper IV, they are not feeling listened to or taken seriously?

Concerning work, resumption of which is a goal for the heart recipient as well as society and an important indicator of social function, there are some obstacles (Cavallini et al., 2015). Somewhere between 12%-83% of solid organ recipients resume work worldwide, but no studies showed that solid organ recipients work to the same extent as the general population (Cavallini et al., 2015). The chance of resuming work increases if the recipient was employed prior to transplantation, had a less heavy job, was motivated, of a younger age and in financial need (Cavallini et al., 2015). Resuming work is also included in the adaptation process after solid organ transplantation (Forsberg et al., 2016). One major reason for not working was related to physical aspects. Based on the findings in this thesis, heart recipients not working might be experiencing symptom distress and most likely require tailored interventions to return to work.

There were some contradictory differences in age and sex. Younger heart recipients reported higher symptom distress in Papers I and II, but older heart recipients were more burdened in Paper III. Women reported worse pain intensity than men in Paper I but the contrary in Paper III. There were also no differences in self-efficacy among those with pain as was found in a study of lung recipients (Almgren et al., 2017). Results from different studies are affected by various factors, such as which instrument was used, number of participants, time since transplantation, immunosuppression, age, gender etc. This explains some of the differences observed in various studies and in the four papers in this thesis. Nevertheless, women generally report more pain and the reasons are multifactorial, but one is due to fundamental differences in the sexes´ pain processing systems, which increases the risk of women experiencing pain (Fillingim, 2017) along with psychosocial processes (Bartley & Fillingim, 2013).

In Paper IV it was revealed that heart recipients experienced not being listened to. When discussing this it is important to note that the initiative must come from the HCP. The follow-up appointments are structured so that heart recipients have little room to talk about their concerns. Unless the heart recipient is invited by the HCP asking how she/he is doing and what are her/his main concerns, it is unlikely that these matters will be discussed, leading to management not aligned with the patient´s needs as discussed above. The lack of support from HCPs is confirmed in Paper IV by not feeling listened to, confirmed, restored or empowered. The participants were scattered across the country, followed-up at three different out-patient clinics and were consistent in the experiences regarding person-centred care. This raises the question if the lack of person-centred care as shown in Paper IV is a Swedish phenomenon or culturally inherent in most post-transplant follow-up? A report from the National Health Competence Council in Sweden (2024) presents results from the annual International Health Policy Survey and compared the Swedish results with nine other OECD countries (Organisation for economic Co-operation and Development). The other countries were Australia, France, Canada, The Netherlands, New Zeeland, Switzerland, Great Britain, Germany and the USA. In summary, Swedish citizens had more negative experiences of healthcare than citizens from the other countries. Two questions addressed being taken seriously and being treated unfairly, on which Sweden got the worst result of all 10 countries. In Paper IV it was clear that heart recipients with extensive symptom distress experienced not being taken seriously, contrary to the decisions made at a national level regarding person-centred care in Sweden (National Board of Health and Welfare, 2024).

Person-centred care on an institutional level is referred to as justice within an institution and involves creating space to care for various groups and variations within these groups. Only then can an institution be considered truly just (Ricœur, 2011). What is fair for one person might not be fair for another and a just institution should cater to everyone. In practical terms, this would involve establishing a structure where each heart recipient´s personal history and narrative becomes integral to their care. By doing so, existing resources could be directed toward those who need them. A just institution would adapt to the reality it faces, creating frameworks that allow holistic care of the whole person, not just the organ. This approach would enable a pursuit of a good life for the heart recipients, aligning with their individual aspirations. It would also establish a permissive environment and a structure to provide necessary support to those who require it.

The injustice lies in not recognizing the patient’s subjective experiences as part of rehabilitation and follow-up care. Failing to inquire about pain or other symptoms beyond obvious cases deprives patients of their capacity to co-create their own care. For instance, a patient might say “they don´t talk about pain so maybe it doesn´t matter or perhaps I’m complaining to much, I did receive a heart after all”. Allowing heart recipients’ narratives to emerge provides opportunities for them to be true capable persons in Ricœur’s sense – individuals who can speak, act, tell their stories and take responsibility.

Possible explanations and predictors

Papers I and II are derived from the same sample and their results are confirmed in Paper III regarding those with poor psychological well-being experiencing symptom distress to a larger extent. It has been described in this thesis that heart recipients deal with mental challenges and other symptoms while adapting to a new normality. A question that arises is whether it is reasonable to expect heart recipients to manage their symptom distress along with poor psychological well-being. The perspective in this thesis is the capable human being and heart recipients are capable but lack support in a new part of their lives, as described in Paper IV.

Heart recipients deal with many symptoms. Initially in this thesis and throughout the studies pain played a pivotal role as it continued to be reported and was correlated to psychological well-being as well as the OTSWI-sum, where it predicts the variation. Fatigue was another prominent symptom that explained over 60% of the variation in the OTSWI-sum and predicts the likelihood of reporting poor psychological well-being. Sleep problems were also prevalent, distressing and correlated with OTSWI-sum. However, there was no answer to what is the chicken and what is the egg. In Paper III it emerged that it is the sum of the symptom distress that predicts poor psychological well-being.

How can we understand this? The findings in Paper III comprehensively explain how symptom distress leads to poor psychological well-being. This picture is unique as there are no longitudinal studies demonstrating how poor psychological well-being can be explained by symptom distress. In other words, if a heart recipient experiences symptom distress, she/he is more likely to have poor psychological well-being and the greater the symptom distress the poorer the psychological well-being. These findings are confirmed in Almgren et al. (2017), who stated that symptoms, setbacks and complications cause uncertainty that leads to disappointments, grief, low self-efficacy and psychological distress. The heart recipients with poor psychological well-being are probably in great uncertainty. This indeed underlines the need for serious systematic self-management support from the outpatient clinics. As argued by Dodd et al. (2001), everyone at risk of developing symptoms is a candidate for the Theory of Symptom Management (TSM). For those with symptom distress interventions are crucial. The adaptation process takes about three years and during this time the heart recipients are accepting life as it is, adapting to post-transplant limitations, adapting to a changed body, going through social adaptation, showing gratitude and trust (Lindberg et al., 2020). In Lundmark et al. (2019b) lung recipients strived for a new normality by comparing, adjusting and accepting. In Lindberg et al. (2020) the adaptation was considered a lonely process, lacking the support of HCPs who had medical expectations of outcomes but did not understand the patient perspective.

As stated above, being an active and competent individual also means being vulnerable and suffering (Ricœur, 2011).

Heart recipients might have unmet expectations. Their physical limitations along with unrealistic hopes for life after the transplantation contribute to their suffering (Almgren et al., 2016). What happens within a person when the body does not cooperate? When the heart functions well but other parts of the body fail, it leads to disappointment. HCPs must assist in adjusting expectations while offering rehabilitation and care that aligns with individual needs. While the primary goal from a healthcare perspective has long been a well-functioning heart, there is a need for an additional dimension, as seen in Paper IV and in line with national decisions (National Board of Health and Wellfare, 2024) and the structure for Chronic illness management suggested by Bengoa & Yach (2002).

Symptoms often appear more than one at a time. A symptom cluster includes two or more symptoms that are stable and independent of other clusters and may have shared outcomes (Weiss et al., 2024). Symptom clusters studied within cancer patients show that they are stable across time and occurrence, severity and distress. To deal with symptom clusters it might be beneficial to identify symptoms that act as sentinels in a cluster, in order to target interventions against them. Given the findings in Paper III, pain is a possible symptom for an intervention, as it explained 58.2% in the OTSWI. Further research should address identifying symptom clusters after heart transplantation for effective interventions. As a parallel process systematic symptom management support provided by HCPs at the outpatient clinics is essential. Providing symptom management is not about HPCs or the healthcare organisation assuming the full responsibility. The goal of symptom management in line with chronic illness management (Bengoa & Yach, 2002) is that the heart recipients become their own primary caregiver and manage their own symptoms with support from HCPs (Weiss et al., 2024). To make it possible HCPs need to provide education and training to the patient who will perform the intervention. Time for repeated explanations and practice until the patient is competent enough to perform the intervention must be ensured. The reason behind the intervention must be fully understood. The intervention itself is dependent on what symptoms need to be addressed. The patient's environment and available resources must be assessed in order to perform the intervention, e.g., instrumental and emotional social support.

Is it possible to intervene?

The findings in Paper IV showed that it is possible to intervene to relieve symptom distress using the theory of symptom management and the ethical approach of person-centred care. Considering the costs and resources inherent in heart transplantation, an intervention as in Paper IV is justified. The intervention was simple as it required few resources yet the outcome was powerful. A reason for improvement in the OTSWI dimensions might be that the participants felt empowered, acknowledged and thereby aware of their capabilities, which might have led to decreased uncertainty. Practicing the theory of symptom management involves believing in the person's capabilities (Dodd et al., 2001; Weiss et al., 2024), which is the very core of person-centred care (Ricœur, 2011). This also aligns with chronic illness management (Bengoa & Yach, 2002). The possible reason for symptom distress decreasing and basic ADL increasing was the combination of being taken seriously and thereby assigned exercise interventions and feeling empowered by managing it. The strong relationship between transplant specific well-being and self-efficacy is another argument for empowering heart recipients as it leads to improved self-efficacy, a key concept in self-management (Bandura, 2004) and thus symptom management.

Reducing the inherent asymmetry was important during the intervention and presumably the reason for a good relationship as a foundation for the conversations. This was done by the understanding of sameness and otherness as described by Marja Schuster (2013). The researcher was genuinely interested in and curious about the heart recipients as human beings or persons, i.e., the sameness. The heart recipients were first and foremost treated as persons with unique experiences and competencies. The respect for the heart recipients' experiences and competencies enabled a close and genuine conversation that led to mutual learning where the otherness became visible. The researcher´s honesty about the lack of an inside perspective on being a heart recipient presumably gave the heart recipients the courage to share their knowledge. Schuster (2013) argues that recognition of the other can only be achieved by the HCP seeing what unites and what separates. It is obvious that listening to the heart recipients is fundamental. It enables them to learn about themselves by narrating their story and created a reflective situation that leads to experience-based learning.

Gaining insights into how individuals experience their situation as heart recipients can benefit the development of transplant care. The medical objectivity within heart transplantation must be complemented by the subjective experiences of patients. In creating a just institution, patients are seen for who they are; unique individuals, co-creators of their care, capable of speaking, sharing their stories, acting and assuming responsibility. However, a just institution also requires practical wisdom, grounded in ethical reflection, for each unique case (Ricœur, 2011).

> For the "acting and suffering" human, the journey is long until they recognize and acknowledge themselves as they truly are – capable of various achievements. At each step, they require assistance from others… (Ricœur, 2011, p. 229).

Conclusion

Based on the aims and the findings of this thesis the following conclusions can be drawn:

- Heart transplantation should be viewed as a chronic condition involving persistent low to moderate symptom distress.
- Chronic pain, sleep problems, fatigue, tremor and decreased libido are common problems after heart transplantation.
- The most common symptoms are also the most distressing.
- Heart recipients experiencing pain are most likely to be found among those not working, not recovered, more burdened by other symptoms and who have poor psychological well-being.
- Chronic pain explains a significant proportion of transplant-specific well-being and should be the key target area for person-centred interventions together with sleep problems and fatigue during the first five years of follow-up after heart transplantation.
- Two to four years after heart transplantation symptom distress largely predicts psychological general well-being regardless of the prevalence of pain and explains over 70 % of the variation in psychological general well-being.
- Sleep problems are common (86%) and fatigue is a strong predictor of transplant specific well-being that explains over 60% of the variance.
- Heart recipients reporting poor psychological well-being do not improve their transplant-specific well-being during the first five years after transplantation.
- Three consecutively performed one-hour conversations including person-centred symptom management support are feasible and acceptable as an intervention for heart recipients with chronic pain and extensive symptom distress.

In summary, there seems to be a cluster of symptoms after heart transplantation causing distress, where chronic pain probably causes poor psychological well-being together with an overall symptom burden. In addition, sleep problems and fatigue are prominent issues, probably negatively affecting the heart recipient's resilience towards symptom distress. Poor psychological well-being in combination with symptom distress, in particular chronic pain, might be a major barrier to life satisfaction and quality of life in the first five years after heart transplantation. Thus, symptom distress should be a key area of assessment and interventions during the long-term follow-up after heart transplantation.

Clinical implications

Based on the findings in this thesis the long-term follow up after heart transplantation must be re-organized in line with the chronic illness management framework and with a distinct focus on assessing and dealing with symptom distress. This thesis provides a road map for transplant professionals on what to expect during each follow-up year. Symptom management is an essential part of self-management, thus the provision of targeted self-management support should be a priority. The groups to prioritize are those with poor psychological general well-being, where the PGWB instrument can be used as a clinical screening tool, as well as those with chronic pain.

As argued in Paper IV, the dominant objectified and biological view of the transplant recipient must be transformed to one of the person as unique, capable and worthy being taken seriously. A daily clinical practice that includes person-centred care is essential. Transplant care practice should be team based and guided by person-centred ethics and protection of the vulnerable person. Consequently, awareness of human vulnerability after heart transplantation including uncertainty, unmet expectations, frequent disappointments, symptom distress and possible grief should be made more evident and an essential attribute of transplant care. All these aspects should be assessed on a regular basis. To enable a clinical framework with a focus on the person with an organ, not the organ in the person, a specialist nurse-led multidisciplinary team model might be feasible, starting with a primary contact nurse who establishes a continuous person-centred caring relationship to enable personalized follow-up.

Person-centred transplant care can be implemented by the following three steps:

- Initiate the partnership by starting with the organ recipient’s narrative. The patient narrative is the transplanted person’s personal account of her/his illness, symptoms and their impact on her/his life. It captures her/his everyday challenges and concerns.
- Building the partnership by shared decision making, i.e., telling and listening is a way of creating a common understanding.
- Safeguarding the partnership by documenting the health plan.

The health plan might include three different parts as follows:

- This is how I want to feel. This is the performance level I wish to achieve.
- These are the efforts I can make on my own. These are my useful coping strategies.
- These are the areas in my everyday life where I need assistance from the transplant unit or other HCPs.

The theory of symptom management together with a person-centred approach is useful and can be accompanied by a clinical tool to assess challenging areas in everyday life. It is developed within the ongoing My life-My health project launched by European Society for Organ Transplantation (ESOT) in 2023. The tool is called the Life Balance Puzzle and is shown in Appendix C.

Future research

Based on the findings from studying heart and lung recipients within the SMATT project (Appendix A), future research should primarily focus on:

- Interventions targeting common symptoms after heart transplantation, i.e., chronic pain, sleep problems, decreased libido, fatigue and tremor, preferably in interprofessional collaboration.
- Identifying symptom clusters after heart transplantation.
- International research collaborations to map, analyse and intervene on symptoms after heart transplantation.
- Evaluating the integration of new specialist members in the transplant teams to address symptoms with sufficient competencies, e.g., sexologists.
- Further exploring the development of a person-centred approach and including significant others to a greater extent.
- Testing the hypothesis that heart recipients' grief due to serious disease and illness.

Summary in Swedish

Svensk sammanfattning

Hjärttransplantation är den mest effektiva behandlingsmetoden för personer med terminal hjärtsvikt. En hjärttransplantation blir aktuell när alla andra behandlingsalternativ är prövade och inte längre räcker till. För att bli aktuell som hjärtmottagare genomgår personen en utvärdering innehållande flertalet undersökningar och tester för att bedömas vara tillräckligt hjärtsviktande för att ta emot ett hjärta men samtidigt tillräckligt frisk, både fysiskt och psykiskt, för att kunna ta emot ett hjärta eftersom kirurgin och den efterföljande kroniska behandlingen ställer höga krav på personen och på kroppen. För att inte drabbas av avstötning behöver personen ta immunhämmande läkemedel resten av livet. De immunhämmande läkemedlen innebär i sig en risk för andra sjukdomar och tillstånd såsom infektioner, njursvikt, cancer och diabetes mellitus. Hjärtmottagare deltar i omfattande uppföljningsprogram för att tidigt upptäcka tecken på avstötning, infektioner eller andra problem. Det finns en begäran från sjukvården att hjärtmottagaren i sin tur följer rekommendationer avseende kost, motion, hygien och försiktighetsåtgärder såsom att undvika sol för att inte utveckla hudcancer.

En hjärtmottagare går från att ha varit dödligt sjuk till en möjlighet till ett friskare liv, med kronisk behandling, i och med det nya hjärtat. Behandlingen är krävande både fysiskt och psykiskt och återhämtningen är lång. Det tar flera år att anpassa sig till den nya situationen som är kantad av fysiska och psykiska utmaningar. Sjukvården är organiserad att monitorera de fysiska aspekterna kopplade till hjärttransplantationen men hjärtmottagare saknar systematiskt stöd i sin egenvård (ung. self-management) och förutsätts hantera det på egen hand.

Self-management handlar om att hantera allt i dagligt liv kopplat till hjärttransplantationen såsom medicinering, emotionella samt sociala aspekter. Inom self-management ryms symtomhantering. Teorin om symtomhantering består av tre domäner inom vilka sjuksköterskor och omvårdnadsforskning rör sig nämligen person, miljö och hälsa & sjukdom. Inom dessa domäner hanteras symtomupplevelse, symtomhanteringsstrategier och utfall av strategierna.

För att kunna hantera symtom behövs kunskap om vad symtomen står för, varför de uppkommer, hur de kan hanteras, hur mycket de ska hanteras, vem som ska hantera dem och förmåga att utvärdera om insatsen mot symtomen varit tillräcklig. Ofta är symtom kopplade till olika känslomässiga reaktioner såsom rädsla, frustration eller oro. För att hantera sina symtom är hjärtmottagare hjälpta av att få stöd av hälso- och sjukvårdspersonal i symtomhantering där ett lärande kring, förståelse för och normalisering av symtomen kan utvecklas. Kunskaper i teorin möjliggör för sjuksköterskor att ge stöd i symtomhantering till hjärtmottagare som ofta upplever symtom och används med fördel i kombination med ett personcentrerat förhållningssätt. Idag saknas systematiskt stöd från hälso- och sjukvården för hjärtmottagare att hantera sin livssituation som transplanterad inkluderat symtomhantering.

I Sverige är det nationellt beslutat att hälso- och sjukvård ska organiseras så att personal kan arbeta personcentrerat. Filosofin bakom personcentrerad vård eller personcentrerat förhållningssätt härstammar från den franske filosofen Paul Ricœur. Det är en handlingsetik som förutsätter att varje handling föregås av en etisk reflektion i syfte att sträva efter det goda livet med och för den andre i rättvisa institutioner. Vad det goda livet innebär är individuellt för alla personer. Ett centralt begrepp inom personcentrerad vård är den kapabla människan, som kan tala, agera, berätta och ta ansvar.

Att vara patient innebär att inneha en roll inom en institution och patienten betraktas ofta som en passiv mottagare av vård med ett trefaldigt underskott genom att hierarkiskt placeras i botten, i ett existentiellt utsatt läge med oftast minst kännedom och kunskap om det som händer. Inom den personcentrerade filosofin ska all hälso- och sjukvårdspersonal sträva efter att utjämna den maktobalans som uppstår på grund av det trefaldiga underskottet.

Att var hjärtmottagare är således ett kroniskt tillstånd med flertalet utmaningar där symtom och symtomhantering är några. Mottagare av solida organ, däribland hjärta, upplever symtom som en yttring av sjukdom. Den subjektiva upplevelsen av ett symtom kan visa sig som ett tecken som objektivt kan ses, men ett symtom kan också vara dolt för andra att se och blir då endast känt för omgivningen via personens berättelse.

Symtombesvär (symptom distress) är en del av det upplevda symtomet och den grad av obehag som symtomet ger upphov till. Det återspeglar med andra ord hur personen reagerar känslomässigt på symtomet. Symtom är viktiga att ta hänsyn till eftersom de speglar antingen sjukdomen eller personens uppfattning om sjukdomen eller båda delar.

Ett vanligt symtom efter transplantation av solida organ är smärta och de med smärta upplever ofta fler symtom såsom fatigue (hjärntrötthet). Symtom och symtombesvär har inte studerats i någon särskild omfattning men utgör ett hinder för adaption, self-efficacy och self-management bland hjärtmottagare. Av den anledningen behövde smärta, andra symtom samt symtombesvär efter hjärttransplantation studeras närmre. Ett antagande var att smärta hindrar adekvat symtomhantering och med vetskapen att det är ett vanligt förekommande symtom efter solid organtransplantation kartlades smärta efter hjärttransplantation i Artikel I.

Artikel I var en tvärsnittsstudie med ett deduktivt tillvägagångssätt som innefattade 79 hjärtmottagare som självrapporterade sin långvariga smärta. Syftet var att ge en flerdimensionell bedömning av självskattad långvarig smärta 1–5 år efter hjärttransplantation och dess relation med självskattat välbefinnande, self-efficacy (tron på den egna förmågan att hantera sin situation) och socioekonomiska faktorer och att utforska skillnader mellan hjärtmottagare och lungmottagare. Smärta studerades utifrån flera dimensioner såsom intensitet, affektiv och sensorisk smärta. Smärta analyserades i relation till socio-ekonomiska faktorer, psykologiskt välbefinnande, symtombesvär, fatigue, grad av återhämtning och self-efficacy. Hjärtmottagarna fyllde i självskattningsformulär antingen 1, 2, 3, 4 eller 5 år efter deras hjärttransplantation under åren 2014–2017. Resultaten visade att smärta är vanligt förekommande samt att de hjärtmottagare som rapporterade smärta var fler bland de som inte arbetade, inte var återhämtade, hade fler övriga symtom och lågt psykologiskt välbefinnande.

Artikel II hade syftet att utforska självskattad symtomförekomst och symtombesvär efter hjärttransplantation och deras relation med självrapporterad psykologiskt välbefinnande och sociodemografiska faktorer. Den baserades på samma datamaterial som Artikel I och var även den en tvärsnittsstudie med deduktivt tillvägagångssätt. Två självskattningsformulär delades ut och data analyserades för att ta reda på vanliga symtom, symtombesvär och psykologiskt välbefinnande. Det gjordes specifika analyser på långvarig smärta avseende psykologiskt välbefinnande och socioekonomiska variabler. Resultaten visade att de som hade mest symtombesvär var under 50 år, levde själv och hade lågt psykologiskt välbefinnande. Det visade sig också att fatigue är en stark prediktor för lågt psykologiskt välbefinnande.

Artikel III var en longitudinell studie där 48 hjärtmottagare följdes från tiden innan transplantation till och med 5 år efter transplantationen. Syftet var att utforska självskattad symtombesvär från tiden på väntelista till fem år efter hjärttransplantation och dess association med självskattad psykologiskt välbefinnande, långvarig smärta och fatigue för att identifiera möjliga prediktorer för psykologiskt eller transplantationsspecifikt välbefinnande. Symtombesvär utforskades med hjälp av fyra instrument som mätte smärta, psykologiskt välbefinnande, transplantationsspecifikt välbefinnande, smärta och fatigue. Resultaten visade att transplantationsspecifikt välbefinnande förbättrades under de första fem åren jämfört med innan transplantationen för gruppen i stort. Hjärtmottagare med lågt psykologiskt välbefinnande var signifikant mer belastade med symtombesvär i synnerhet av sömnproblem och fatigue upp till fem år efter hjärttransplantationen och deras transplantationsspecifika välbefinnande förbättrades inte jämfört med innan transplantationen. Förekomst av smärta varierade och förklarade en signifikant andel av variationen av transplantationsspecifikt välbefinnande, medan psykologiskt välmående huvudsakligen predikterades av symtombesvär oavsett om de upplevde smärta eller ej.

I Artikel IV som innehåller både kvantitativ och kvalitativ metod var syftet att bedöma genomförbarheten och acceptansen för en systematisk, personcentrerad support i symtomhantering för hjärtmottagare med långvarig smärta för att reducera symtombesvär. Tretton hjärtmottagare rekryterades till studien som genomfördes mellan maj 2023 och mars 2024. De självskattade sin smärta, self-efficacy, personcentrering och transplantationsspecifikt välbefinnande före och efter en intervention. Interventionen var baserad på teorin om symtomhanering och innebar att få tre stödsamtal som var personcentrerade och ca en timme långa per gång. Interventionen utvärderades genom intervjuer för att få reda på hur hjärtmottagare upplever att få den typen av stödsamtal. Intervjuerna analyserades med fenomenologisk hermeneutik och visade att alla hjärtmottagarna accepterade interventionen. Det framkom också att de hade upplevt sig tagna på allvar alltså att samtalen var personcentrerade i den utformning de genomfördes. Utöver det upplevde hjärtmottagarna att asymmetrin mellan dem och genomföraren av samtalen reducerades och fick dem att uppleva sig kompetenta. Hjärtmottagarnas transplantationsspecifika välmående förbättrades och aktiviteter I dagligt liv förbättrades. Det fanns också en relation mellan transplantationsspecifikt välbefinnande och self-efficacy. Det skulle kunna innebära att reducerade symtombesvär ökar self-efficacy men också att ökad self-efficacy leder till bättre förmåga att hantera eller förstå sina symtom vilket sänker besvären de orsakar.

Sammantaget visar denna avhandling att många hjärtmottagare upplever symptom och att en del upplever svåra besvär av sina symtom. Hjärtmottagare verkar uppleva kluster av symptom där långvarig smärta sannolikt orsakar lågt psykologiskt välbefinnande tillsammans med en generell symtombörda. Utöver smärta är sömnproblem och fatigue framträdande symptom som sannolikt påverkar hjärtmottagarnas motståndskraft att hantera symtombesvär negativt. Lågt psykologiskt välbefinnande i kombination med symtombesvär, i synnerhet långvarig smärta, skulle kunna utgöra ett hinder för tillfredsställelse och livskvalitet de första fem åren efter hjärttransplantationen. Därför bör symtombesvär bedömas och interveneras kring under långtidsuppföljningen efter hjärttransplantation.

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Appendix A

SMATT-publications

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The Organ Transplant Symptom and Wellbeing Instrument (OTSWI)

Below there is a list of statements that other persons with the same health condition, as you have considered important. Please state how well you consider that each of the statements reflect your situation during **the last seven days.** Please mark a figure at each row.

		Not at all 0	**A little 1**	**Somewhat 2**	**Quiet a bit 3**	**Very much 4**
1	I have difficulties falling asleep	0	1	2	3	4
2	I sleep poorly	0	1	2	3	4
3	I wake up during the night	0	1	2	3	4
4	My muscles are aching	0	1	2	3	4
5	My joints are aching	0	1	2	3	4
6	My legs are aching	0	1	2	3	4
7	There is a burning ache in my feet	0	1	2	3	4
8	There is a numb and stabbing feeling in my feet	0	1	2	3	4
9	I am physically tired	0	1	2	3	4
10	I have no energy	0	1	2	3	4
11	I feel lazy and listless	0	1	2	3	4
12	I have difficulties to remember	0	1	2	3	4
13	I find it hard to concentrate	0	1	2	3	4

The Organ Transplant Symptom and Wellbeing Instrument (OTSWI)

Below there is a list of statements that other persons with the same health condition, as you have consider important. Please state how well you consider that each of the statements reflect your situation during **the last seven days.** Please mark a figure at each row.

		Not at all 0	**A little 1**	**Somewhat 2**	**Quiet a bit 3**	**Very much 4**
14	Due to my physical condition, I can't take a bath or shower	0	1	2	3	4
15	Due to my physical condition, I can't get dressed by myself	0	1	2	3	4
16	Due to my physical condition, I can't by food by myself	0	1	2	3	4
17	I am irritated	0	1	2	3	4
18	I feel angry	0	1	2	3	4
19	I worry about not being able to keep my job due to my health condition	0	1	2	3	4
20	I worry about my economy due to my health condition	0	1	2	3	4

The Organ Transplant Symptom and Wellbeing Instrument (OTSWI)

Below there is a list of statements that other persons with the same health condition, as you have consider important. Please state how well you consider that each of the statements reflect your situation during **the last seven days.** Please mark a figure at each row.

		Not at all 0	**A little 1**	**Somewhat 2**	**Quiet a bit 3**	**Very much 4**
1	I am breathless	0	1	2	3	4
2	I need to rest because I am breathless	0	1	2	3	4
3	I am swollen	0	1	2	3	4
4	I feel nauseous	0	1	2	3	4
5	I have oral fungus	0	1	2	3	4
6	I have oral herpes	0	1	2	3	4
7	I have increased appetite of food	0	1	2	3	4
8	I have decreased appetite of food	0	1	2	3	4
9	I have dyspepsia	0	1	2	3	4
10	I am constipated	0	1	2	3	4
11	I have diarrhea	0	1	2	3	4
12	My skin is itching	0	1	2	3	4
13	I have headache	0	1	2	3	4
14	There is a burning pain in my hands	0	1	2	3	4
15	There is a numb and stabbing pain in my hands	0	1	2	3	4
16	My hands are trembling	0	1	2	3	4
17	I am dizzy	0	1	2	3	4
18	I feel sad	0	1	2	3	4
19	I am embarrassed by my looks	0	1	2	3	4
20	My libido is decreased	0	1	2	3	4

Appendix C.

Illustration of the Life-balance puzzle

THE LIFE-BALANCE PUZZLE

What challenges do you need assistance with?

Different aspects of life are affected at different times for those living with a long-term illness.
Use the puzzle to identify which areas you need to prioritize right now. Go through the pieces together and select up to three areas that require support and change. Also, choose three areas where you need to collectively think.

☺ I am confident that I can handle this in my everyday life and I know how to reach out for support. life. I need assistance.

😕 I can manage this if I am given advice and some support on how to start.

☹ I do not know how to manage this part of my everyday life. I need assistance.

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