Managing uncertainty and expectations after heart transplantation. Enabling adaptation, self-efficacy and self-management

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Managing uncertainty and expectations after heart transplantation

Enabling adaptation, self-efficacy and self-management

Matilda Almgren

LUND
UNIVERSITY

DOCTORAL DISSERTATION

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Title and subtitle:
Managing uncertainty and expectations after heart transplantation. Enabling adaptation, self-efficacy and self-management

Abstract:

Background

Self-management is the main concept constituting the foundation of follow-up care after heart transplantation. Self-efficacy is the key concept in self-management. Little is known about heart recipients' experiences in relation of self-efficacy and self-management after their heart transplantation and how these are associated with other factors such as symptoms and complications.

Aim

The overall aim was to understand, explore and explain self-efficacy in relation to heart transplantation.

Methods

A mixed method approach was used in order to understand, explore and to some extent explain self-efficacy in the context of heart transplantation. The qualitative design was both inductive and deductive and it was based on interviews and analysed using phenomenological hermeneutic (Paper I) and deductive content analysis (Paper II). The quantitative studies had a cross-sectional design based on self-report questionnaires. Due to the properties of the data, they were analysed using non-parametric statistics.

Results

The meaning of uncertainty after heart transplantation involved: doubting survival, doubting the recovery process, doubting one's performance, struggling with close relationships, feeling abandoned and doubting the future. Performance accomplishment was the most prominent factor affecting self-efficacy after heart transplantation, evident in physical, social and mental aspects. Lack of performance accomplishment led to disappointment and therefore our hypothesis was that self-efficacy after heart transplantation concerns balancing expectations with present abilities. The reported level of self-efficacy for the whole group was high. Pre-transplant Mechanical Circulatory Support was associated with a lower level of self-efficacy and higher levels of fatigue. The majority of the heart recipients were reasonably recovered. Not being recovered was associated with a lower level of
self-efficacy.

Conclusions

Uncertainty is prominent phenomenon during the first year post heart transplantation and occurs when the experience of symptoms, set-backs and complications is not congruent with what was expected. Performance accomplishment is a key factor for developing self-efficacy, but can may hindered by symptoms and complications. Self-efficacy from the heart recipients' perspective require balancing expectations in accordance with existing present abilities. A person-centred approach addressing heart recipients' understanding of their experience and their expectations might be helpful for enabling them to adapt to their new self and life with a transplanted heart.

Key words: Heart Transplantation, Self-Managemetn, Self-Efficacy, Uncertainty, Fatigue		
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How bad will I really get?, or just, Can I join this and that?, or Is this food something I can't eat?, or How can I get a job when I only manage halftime?, or maybe the thought What will my partner think if I say this routine is to protect my health? Will he/she understand, or will he/she think that I am a neurotic psychopath? How much work out is good and how much are too much? Am I going to tell the hostess at the party that I can't eat this and that or should I just skip this get-together? Can I go to work today when there is flu-season? Can I by any means discuss vaccination for the flu season with parents of kids I'm around a lot? What will my family or friends say, or my transplant-community, if I for ones do take this tasty pastry that I shouldn't eat because it's in the open air?
Can I really pick this specific career choice? What if I pick this choice and I end up dead? What if people don't understand why I am acting the way I am concerning my health? My medication might not be available forever, especially when 2019 autumn they started making it troublesome to get specific medication in Sweden. There is all and everything. All the time and completely different ranges. Totally limiting. And the fact that there are no specific guidelines. In the transplant community I hang out, there is a multitude of different specific advices that different people got. Some people can eat sushi or have kids, and some got doctors saying absolute no to those things? The only thing that seem certain for everyone is, Do not eat grapefruit!!!

Organ recipient
From the ESOT-ETPO survey, 2020

Contents

Abstract

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Original papers

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

I Almgren M., Lennerling A., Lundmark M., Forsberg A. (2017). The meaning of being in uncertainty after heart transplantation - an unrevealed source to distress. European Journal of Cardiovascular Nursing Feb;16(2):167-174. Epub 2016 Jul 7.

II Almgren M., Lennerling A., Lundmark M., Forsberg A. (2017). Self-efficacy in the context of heart transplantation- a new perspective. Journal of Clinical Nursing Oct;26(19-20): 3007-3017. Epub 2017 Feb 9.

III Almgren M., Lundqvist P., Lennerling A., Forsberg A. (2020). Self-efficacy, recovery and psychological well-being one to five years after heart transplantation: A Swedish cross-sectional study. *European Journal of Cardiovascular Nursing,* 2020 Jun 9;1474515120927121

IV Almgren M., Lundqvist P., Lennerling A., Forsberg A. (2020). Fatigue after heart transplantation- a possible barrier to self-efficacy. *(resubmitted after review)*

Abbreviations

HTx	Heart transplantation
ESHF	End stage heart failure
EMB	Endo Myocardial biopsy
CAV	Cardiac allograft vasculopathy
HRQoL	Health related quality of life
WHO	World Health organisation
CIM	Chronic Illness Management
NYHA	New York Heart Association
MCS	Mechanical Circulatory Support
VAD	Ventricular Assist Device
LVAD	Left Ventricular Assist Device
ISHLT	The International Society of Heart and Lung Transplantation
ICCC	The Innovative Care for Chronic Conditions
PTSD	Post Traumatic Stress Disorder
SMATT	Self-Management After Thoracic Transplantation
PROM	Patient Related Outcome Measures
SES6G	Self-Efficacy for Managing Chronic Disease 6-Item Scale
PRP	The Postoperative Recovery Profile
PGWB	Psychological General Well-Being

MFI	Multidimensional Fatigue Inventory
MF	Mental Fatigue
RM	Reduced Motivation
GF	General Fatigue
RA	Reduced Activity
PF	Physical Fatigue
SF-36	Short-Form Health Survey-36

Introduction

End-stage organ failure is estimated to affect more than six million people worldwide (Levin et al., 2017). In 2018, 150,000 patients around the world benefitted from the transplant of a kidney, heart, lung, liver, or other solid organ. However, this figure is far below the actual requirement**.** According to data from the World Health Organisation (WHO), at present more than 1,500,000 people worldwide live with a transplanted organ (Loupy et al., 2020).

Heart transplantation (HTx) is the most effective choice of life-saving treatment for patients with end-stage heart failure (ESHF)) when all other therapies have been unsuccessful (Cupples et al., 2006; Lund et al., 2013. In Europe, over 1,800 HTx are performed every year (Khush et al., 2019), while the equivalent figure for Sweden in 2019 was 60 HTx (Scandiatransplant, 2020). The number of transplantations is primarily limited by the number of donor organs available (Davis & Hunt, 2014)

After transplantation, the treatment consists of medication to subdue the immune system defences in order to prevent graft rejection and from a clinical viewpoint, graft rejection and infections pose the greatest threat to a heart recipient. HTx is considered a chronic condition due to the life-long medical regime with immunosuppressive treatment needed to prevent rejection and Cardiac Allograft Vasculopathy (CAV) (Berben et al., 2015; Redman, 2009). The heart recipient has to submit to an extensive follow-up programme for the purpose of early identification of graft rejection, infection or other complications. This includes engaging in health promoting behaviours such as physical activity, no intake of harmful substances and protection from the sun in order to reduce the risk of complications and the side effects of medications. The healthcare system is mainly organized with focus on medical procedures aimed at identifying graft rejection and providing treatment rather than promoting health by means of preventive measures and effective self-management (Berben et al., 2015).

Self-management is a part of chronic illness management (CIM) and refers to activities carried out by people to create order, structure and control in their lives (Lorig & Gonzalez, 1992; Lorig & Holman, 1993). Self-management

involves medical, role and emotional management (Lorig & Holman, 2003). The person with chronic illness i.e. the heart recipient, must develop skills in order to manage the various goals involved in managing the transplantation, including problem solving, decision making, resource utilization, establishing a patient-provider partnership and taking action (Lorig & Gonzalez, 1992). In the context of HTx this means taking medications, adhering to diet restrictions and avoiding infections. The emotional and social aspects include mastering the emotions involved in being seriously ill, being a transplant recipient and trying to continue with life, social adaptation and returning to work (Forsberg, Cavallini, Fridh & Lennerling, 2015).

Although HTx extends life and offers the possibility of improved functional ability and Health Related Quality of Life (HRQoL) (Grady et al., 2007), recovery is characterised by burdensome medical, physical and psychosocial challenges (Dew et al., 2005; Taylor et al., 2008), including adaptive tasks (Mauthner et al., 2015) that require self-management skills and support. Thus it is of great importance to explore the experience of being a heart recipient during the first year after transplantation in order to develop efficient self-management support.

Due to advances in immunosuppressive therapy and surgical techniques, the survival rate has increased (Lodhi, Lamb & Meier-Kriesche, 2011). However, the improvement is mainly seen during the first post-transplant year (Lodhi et al., 2011; Lund et al., 2013), indicating that other factors need to be examined in order to understand the whole context affecting the recipients both in the short- and the long-term.

Research shows that healthcare systems focusing on self-management and CIM report improved long-term survival in a range of chronic conditions (Nuno, Coleman, Bengoa & Sauto, 2012), suggesting that research within the area of self-management in the context of HTx is required in order to improve long-term outcomes.

Healthcare providers and health education programmes have tended to focus on behavioural and medical management, thus failing to pay sufficient attention to the importance of addressing emotional and role management (Lorig & Holman, 2003). Furthermore, research has shown that patients and healthcare professionals have different conceptions of self-management (Kralik, Koch, Price & Howard, 2004).

Knowledge about patients' reactions to and understanding of the HTx is a necessary foundation for high quality person-centred care. Nursing interventions should be tailored in order to increase patients' ability to constructively handle various stressors and thereby allowing them to

experience a good HRQoL. There is a lack of scientific knowledge about self-management among heart recipients and its relationship with their experienced well-being. The basic idea behind this thesis is to adopt a person-centred approach in order to understand, explore and explain in-depth the drivers behind self-management and how it affects well-being after HTx. This approach might provide the necessary foundation for organizing healthcare in an efficient and person-centred way.

Perspectives and viewpoints

Ontological assumptions

The ontological assumption in this thesis is that uncertainty is inherent in the human experience. As humans we can never predict with certainty how anything in life will turn out, something we must learn to accept. Uncertainty will arise when facing an illness, as it constitutes a concrete threat to life, life-roles and health. This needs to be emphasized in order to promote acceptance and health. Furthermore, in this thesis the heart recipient will be viewed as a capable person. This emanates from the philosopher Ricœur's anthropological philosophy, which is captured in the concept Homo Capax – The capable human being (Ricœur2004/2011). Ricœur defines the person as someone who can speak, act, narrate and take responsibility. Moreover, being an acting person means being vulnerable and being suffering (Ricœur 2004/2011). Ricœur also formulated an ethic, defined as striving for the good life with and for others in just institutions (Ricœur 1990/2011). With this approach the ethic in the outermost perspective is about what makes life worth living, which is why appreciation of self comes before moral demands. Using this ethic as a point of departure, Ricœur states that moral dilemmas cannot be solved by principles, but rather through people changing perspectives with each other and that with the help of practical wisdom, they will act in an accountable way based on a well-informed conviction (Kristensson Uggla, 2011) This thesis is an effort to promote just institutions. Understanding the perspective of the heart recipients enables transplant professionals to act in an accountable way based on scientific knowledge. Person-centred care is a key component in illness management (Ekman et al., 2011) and also a way to organize and structure transplant care, inspired by Ricœur's philosophy and its basic assumption about the capable human being. The persons' narratives are the central part of person-centred care (Ekman et al., 2011), as they provide an opportunity for the transplant care providers to become familiar with the person's account of her/his illness, symptoms and their impact on daily life. Medical narratives focus on the process of diagnosis and treatment of the disease and are the most common approach because of the prevailing medical paradigm. However, the person-centred approach provides an opportunity to

capture the person's suffering in an everyday context, including the medical aspects. Inviting and listening to the person's narrative and acknowledging her/his feelings, experiences, beliefs and preferences. (Ekman et al., 2011) are of importance when structuring the long-term transplant follow-up. In organizations that fulfil the principle of justice the persons´ narratives are taken into consideration and used in the provision of healthcare based on the capable human being and her/his strive for the good life.

Epistemology

This thesis was developed by a mixed method approach including both qualitative and quantitative research methods, in order to understand, explore and to some extent explain self-efficacy after HTx. The epistemological point of departure was the hermeneutic research tradition, which allows interpretation (Polit&Beck, 2010) and understanding of what self-efficacy means to persons receiving a transplanted heart. The inductive approach based on the inside perspective of being a person (Toombs, 1987) enabled the formulation of several hypothesis. Without losing the hermeneutic viewpoint the heart recipient's perspective was reduced to measurable, self-reported variables by operationalization of concepts, which enabled comparisons, generalisations and possible explanations. Hypotheses could be tested, confirmed or rejected by means of this deductive approach.

Background

The medical aspects of heart transplantation

The historical background of heart transplantation

In 1967 the first HTx was performed by Christiaan Barnard in South Africa (Barnard, 1968). However, without effective immunosuppression the outcomes in the early days were characterized by high mortality due to infections and rejections. In the late 1970s the discovery of cyclosporine made it possible to suppress the immune system more effectively (Kahan, 2011). Together with the development of the endomyocardial biopsy (EMB) procedure (Nguyen, Lee, Luo & Siegel, 2011) these two most important factors revolutionized the field of HTx. Improved surgical techniques, patient selections, donor heart preservation methods, immunosuppression and rejection surveillance have contributed to continuous improvements in survival, especially during recent decades (Davis & Hunt, 2014). Nevertheless, long-term survival is still inhibited by cardiac allograft vasculopathy (CAV), an immune-mediated process (Chang, Kobashigawa & Luu, 2017), gradually destroying the transplanted heart.

However, long-term survival has reached a level where it cannot solely consist of objective measurement and today recipients' expectations are not only focused on survival but also on good health and improved quality of life.

Indications for heart transplantation

The indications for HTx are ESHF and advanced congestive heart failure with the New York Heart Association (NYHA) functional classification III-IV (severest stage), where no other medical or surgical options are available to improve survival or quality of life (Mehra et al., 2006). The goal of HTx is prolonged survival and enhanced quality of life. The main diagnoses prior to HTx are: myopathy (55%), coronary artery disease (36%), valvular (3%), congenital (3%), re-transplantation (3%) and other (1%) (Lund et al., 2013).

While medication, cardiac resynchronization and implantable cardiac defibrillators have improved survival as well as HRQoL in patients with heart failure, overall morbidity and mortality is still high and ultimately these patients require a transplantation, which is the gold standard treatment for ESHF (Moriguchi, 2017). Patients with ESHF undergo a comprehensive, interdisciplinary pre-transplant evaluation to identify the severity of functional impairment, prognosis and physiological or psychological comorbidities (Mehra et al., 2006). The likelihood of the patient being able to resume an active and relatively normal lifestyle following transplantation is also evaluated. The potential to adhere to the post-transplant regimen and the level of psychosocial support are important aspects for long-term success (Mehra et al., 2006).

Mechanical Circulatory Support as a bridge to heart transplantation

The use of mechanical circulatory support (MCS) has increased due to the lack of donor organs as well as the prevalence of comorbidities in patients, which constitute a contraindication for transplantation (Moriguchi, 2017). As a bridge to transplantation, MCS therapy has been shown to improve HRQoL, survival-to-transplantation rates and post-transplant survival.

Ventricular assist devices (VAD) are mechanical circulatory pumps for the purpose of assisting systemic circulation and improving organ perfusion where Left Ventricular assist devices (LVAD) is the most common type for long-term support. Pre-transplant treatment with VADs is intended to stabilize the patient on the waiting list for transplantation until a donor heart becomes available (bridge-to-transplantation) (Moriguchi, 2017).

Experiences of living with Mechanical Circulatory Support

In an interview study by Kostick et al. (2019) the time after receiving the LVAD implant was described as having got your life back and becoming normal. It included improved mobility and HRQoL, described as an adaptation on a journey (Kostick, Trejo & Blumenthal-Barby, 2019). However, the informants in an interview study by Standing et al., (2017) stated that living with a VAD implant led to a liminal existence due to the impact on their self-identity, the loss of basic aspects of daily life and a disruption of their experience of time while waiting for a new and improved state (Standing, Rapley, MacGowan & Exley, 2017). It appeared that their hope of undergoing HTx decreased the longer they lived with the pump. VAD became a new and different normality, but associated with worries about developing an infection or that the pump would fail. One informant

acknowledged that the transplantation would be a continuation of the uncertainty (Standing et al., 2017).

In the study by Kostick et al. (2019), LVAD recipients also described the time before the LVAD as physical suffering, "daily hell", severe fatigue as well as emotional suffering due to their inability to continue engaging in social activities (Kostick et al., 2019). The illness experience of their failing heart was profound and the symptoms included tiredness, difficulty breathing when walking or engaging in other activities, difficulties sleeping, an experience of weakness in the whole body (Grady, Jalowiec, Grusk, White-Williams & Robinson, 1992; Kostick et al., 2019), dizziness and swelling of the limbs and body due to water retention. Additionally the frequent hospitalization was a huge burden (Kostick et al., 2019), thus implying impairment in their daily life. Anxiety about the worsening of the disease, uncertainty about treatment options and outcomes and changed life-roles are sources of disappointment and depression. The physical limitations inherent in living with ESHF also affected mental health and well-being (Kostick et al., 2019). Life is on hold while waiting for a donor heart and for the future to come (Sadala & Stolf, 2008).

Survival after heart transplantation

Recent data presented by the International Society of Heart and Lung Transplantation (ISHLT) reveal survival rates of 84.5% after 1 year and 72% after 5 years (Lund et al., 2013), with even better rates in Sweden with 1, 5 and 10 year survival of 86%, 77% and 63% (Dellgren et al., 2017). The median survival after HTx is 10.7 years. If the survival rates are based on those who lived through the first year the median survival is 14 years (Lund et al., 2013). The improvements are mostly due to the gain in the 1-year survival rate. HTx requires lifelong immunosuppressive medication, which often involves several side effects and co-morbidities. In the long term cardiac allograft vasculopathy (CAV), rejection, infection, malignancies (Davis & Hunt, 2014) and graft failure (Chang et al., 2017) limits survival.

Complications and immunosuppression

Cardiac allograft rejection

Cardiac allograft rejection occurs when the recipient´s immune system recognizes the new heart as a foreign object, triggering a cascade of immune responses (Kittleson, 2012). During the first year there are routine controls for Cardiac allograft rejection in order to increase the possibility of early

treatment, as it can develop gradually together with latent symptoms (Cupples, McCalmont & Ohler, 2017). Rejection is most common during the first 6 months and is often asymptomatic, but if symptomatic, the common symptoms are dyspnoea, oedema, syncope, tachyarrhythmias, dizziness or fever (Chang & Kobashigawa, 2017). Rejection is divided into 4 grades, i.e. No rejection (0R); mild (1R); moderate (2R); and severe (3R). However, the histological examinations vary due to the subjectivity of interpretation (Chang & Kobashigawa, 2017). EMB are the gold standard for surveillance, diagnosis and grading of rejection, where the histological examination provides information about rejection status. The EMB procedure is stressful and uncomfortable for patients and involves risks (Chang & Kobashigawa, 2017). If not treated, acute rejection episodes lead to CAV, which is a major cause of long-term morbidity and mortality after HTx (Kostick et al. 2019; Chang et al., 2017). CAV involves a diffuse immune-mediated process causing a thickening of the wall of the coronary arteries. Because of the innervated donor heart, CAV often remains asymptomatic. Diagnosis of CAV is made by means of coronary angiogram (Chang et al., 2017).

After the first post-transplantation year biopsies are generally only performed when the patient shows symptoms of rejection, but the risk of rejection persists throughout the patient´s life (Cupples et al., 2017). Unlike renal and liver recipients, there are no laboratory markers for rejection heart recipients. However, new methods of non-invasive detection of rejection have begun to emerge, which will hopefully be further developed and eventually replace EMB (Chang & Kobashigawa, 2017).

Immunosuppression and side-effects

The development of immunosuppressive agents and regimens has been crucial for the improvement in survival rates after HTx. However, there is still no accepted universal protocol for immunosuppression. Due to the risk of both short- and long-term side-effects, it is important that the immuno-suppression is individualized to take account of the patient's risk profile and medical history. The immunosuppression therapy has three different possible scenarios, which in some cases overlap, i.e. achievement of optimal immunosuppressive effects; adverse effects of immunodeficiency (infection and malignancy) and non-immune toxicities (diabetes, hypertension and renal insufficiency). Among these complications, malignancy causes 24% of deaths after 5 years post-transplant, thus is a serious risk and complication caused by the immunosuppressive therapy. Carcinogens such as nicotine, UV-light exposure and oncogenic viruses, i.e. Epstein-Barr virus and the human papilloma virus, have synergistic effects with the impaired immune regulation. In addition, the incidence of skin cancer is higher in transplant

recipients compared to the general population (Kobashigawa & Luu, 2017). The immunosuppression can also imply a risk of a pre-existing malignancy recurring, which must be taken into account in the pre-transplant evaluation process (Chang et al., 2017). The triple-therapy medicine regimen is the most common long-term regimen consisting of corticosteroid, calcineurin inhibitor and antiproliferative. But there is still no consensus about which agents are most effective and in which combination they should be administered. Clinical trials of immunosuppressive regimens after HTx typically include one or a combination of end points, i.e. survival, rejection, CAV and adverse events (Kobashigawa & Luu, 2017).

Theoretical framework and main concepts

Two theoretical frameworks constituted the foundation of the studies; the middle-range theory of uncertainty in illness (Mishel, 1988) and Self-efficacy: toward a unifying theory of behavioural change (Bandura, 1977). The two theoretical frameworks address similar aspects such as information, education and support, i.e. self-management skills. However, the ontological assumptions and how human beings are viewed differ between the two concepts. The ontological assumption of self-efficacy is that a person's behaviour can be changed through specific external actions (Bandura, 1977), which is the reason self-efficacy constitutes the foundation of self-management (Lorig & Holman, 1993). Uncertainty is defined as the inability to find meaning in illness related events and emerges when the person is unable to form a cognitive schema for illness events (Mishel, 1988). The goal is to construct meaning as method of reducing uncertainty and to achieve adaptation through coping strategies in order to experience health (Mishel, 1988). As in any other chronic disease there is an on-going threat to life after HTx, where survival is estimated to evaluate the prognosis of the disease, which will continue. However, the initial experience can be of great importance for enabling the heart recipient to cognitively create meaning of the situation, initiate coping strategies and thereby adapt to the chronicity of the disease. As the ontological assumption is that uncertainty is inherent in being a person, uncertainty will be the main concept of this thesis and therefore self-efficacy will be illuminated from this perspective.

Uncertainty in illness

Uncertainty related to illness is defined as a person's "*inability to determine the meaning of an illness-related event that occurs in situations where the decision-maker is unable to assign definite value to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking"* (Mishel, 1988, p.225). Uncertainty develops when situation are interpreted by the person as ambiguous, complex, unpredictable or probabilistic, which is connected with unavailable or inconsistent information and insecurity in terms of knowledge (Brashers, 2001). Uncertainty connected to the disease/illness has shown to be the greatest single psychological stressor for the patient living with a life-threatening illness (Mishel, 1997).

Uncertainty in relation to illness, as distinct from functional uncertainty, was studied for the first time in the 1960s (Mishel, 1997). Uncertainty as a concept in relation to acute illness was subsequently developed into a theoretical framework by Mishel (Mishel, 1988). The framework was later reconceptualised to explain the phenomenon in chronic disease (Mishel, 1990). The evidence supporting the theory is strongest regarding persons experiencing the acute phase of the disease or having an illness with a downward trajectory (Mishel, 1997).

Uncertainty in acute illness

In illness, uncertainty emerges when the person is unable to interpret illness-related events and attribute meaning to them (Mishel, 1988), e.g. the heart recipient facing an acute rejection or unexpected infection. The person tries to form a cognitive schema of the illness events and when she/he fails, uncertainty emerges. She/he also attempts to find a pattern in the appearance of the symptoms in order to create meaning in relation to the illness, in addition to assessing whether the events are familiar, i.e. similar to previous experiences within the health care environment and in line with the pre-understanding and cognitive map she/he has constructed. In order to interpret these factors the person uses resources defined as one's cognitive capacity (i.e., the ability to process information), social support, education and credible authority (i.e., the degree of trust in the healthcare professionals). Various levels of uncertainty emerge depending on how the person manages to cognitively process the illness-related event. Uncertainty will then be appraised either as a danger or as an opportunity. By using different coping strategies, adaptation to the situation will occur (Figure 1) (Mishel, 1988).

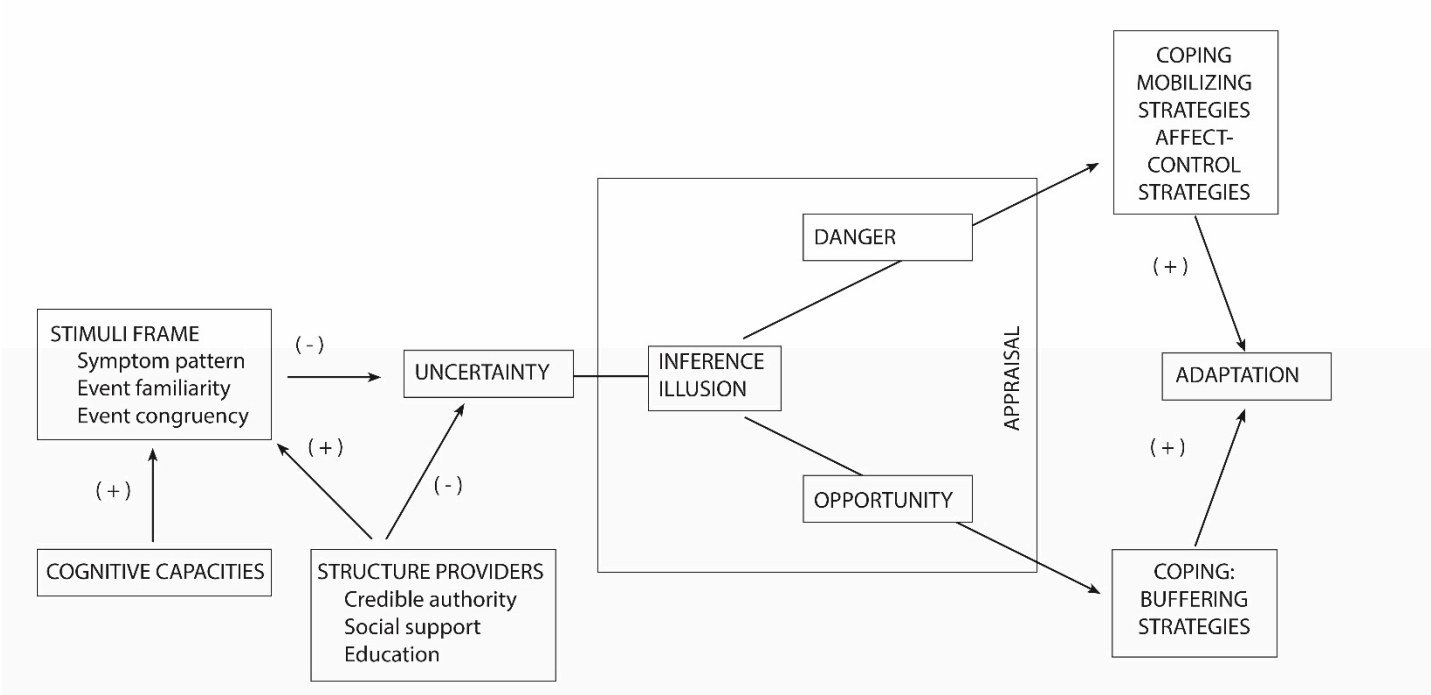

Figure 1. Uncertainty in Illness framework (Mishel, 1988, p. 226)

Uncertainty in chronic illness

The reconceptualization theory is an expansion of the original theory with focus on chronic illness, i.e. it does not replace the original theory, only expands it (Mishel, 1990).

Living with a chronic disease, e.g. being a heart recipient, means living in constant uncertainty in contrast to an acute disease where uncertainty is more likely to be short-term. HTx can be considered a chronic condition due to lifelong immunosuppressive medication, risk of graft rejection and expectations of extensive self-management. In acute illness uncertainty is connected to issues of diagnosis, treatment and recovery, in contrast to chronic illness where it involves more areas of life and influences daily routines and activities (Mishel, 1999). When the person is unable to handle the situation, the uncertainty connected with chronic illness spreads into many different life areas, which according to Mishel, will affect the person's view of self and life. Over time this disorganization caused by uncertainty will decrease, thus uncertainty can be a state in which a transition towards a new view of life can emerge .To enable this transition, the heart recipient needs to embrace a probabilistic view of life, which means focusing on possibilities and accepting that life is fragile and unpredictable. It also means letting go of the prevailing mechanistic paradigm advocating cause-and-effect (Mishel, 1990). This is a complex transition, which needs support from significant others and especially from transplant care professionals.

Previous research regarding uncertainty

Heart transplant recipients have reported that uncertainty is a salient aspect of the transplantation experience, including uncertainty related to their illness, identity and relationships (Martin, Stone, Scott & Brashers, 2010; Scott, Martin, Stone & Brashers, 2011). This also involves the pre-transplant period when waiting for an organ (Brown, Sorrell, McClaren & Creswell, 2006).

Research reveals a relationship between uncertainty and emotional distress, anxiety and depression across various populations (Mishel, 1997). Uncertainty is related to poor psychosocial adjustment, less life satisfaction, as well as negative attitudes towards health care, family relationships, recreation and employment, which were found to continue over time. It is also related to the severity of the illness and negative effects on quality of life (Mishel, 1997). Furthermore, uncertainty has been associated with increased stress, psychological mood disturbances, poor quality of life, decreased coping ability and reduced perceived health status (Kang, 2009).

Uncertainty is a part of the transplantation process, but the sources of uncertainty change over time (Martin et al., 2010). In the last decade there has been more focus on communication and its effects on uncertainty with a pronounced shift in how uncertainty is addressed from a focus on "uncertainty reduction" to "uncertainty management" (Kuang, 2017). The handful of intervention studies aimed at reducing uncertainty in illness, have demonstrated positive outcomes due to beneficial use of emotion regulation, self-management skill training and psychological management (Johnson Wright, Afari & Zautra, 2009).

As human beings we all experience uncertainty and one goal for both heart recipients and transplant care providers would be to reduce and/or manage uncertainty, especially regarding something as important as illness (Johnson Wright et al., 2009). When uncertainty due to illness is appraised as a threat, it can lead to difficulty adjusting and adapting. If left untreated or unaddressed, it may cause increased psychosocial problems. Furthermore, there is evidence suggesting that uncertainty is a nonlinear process and may fluctuate as a function of changing levels of symptoms and stress. (Johnson Wright et al., 2009)

Self-efficacy

Self-efficacy is a concept developed by Bandura (1977) that refers to a person´s belief in her/his ability to manage a given task. It is defined as confidence to carry out a behaviour to reach a desired goal (Bandura, 1977). In the context of HTx this means accepting uncertainty and managing the skills involved in being a heart recipient in order to achieve health and a good quality of life. The fundamental hypothesis of the self-efficacy theory is that the personal expectations of succeeding in a task will predict how much effort the person will put into the task and how long this will be sustained despite obstacles or other threatening experiences. The person´s expectation of efficacy in a specific task derives from four different sources: verbal persuasion, performance accomplishment, vicarious experience and physiological state (Bandura, 1977).

Self-efficacy is belief and behaviour specific, meaning that it is possible to influence through education. The theory proposes four different ways in which self-efficacy can be enhanced, namely skills mastery, modelling, reinterpretation of psychological symptoms and persuasion (Bandura, 1977). The main concepts from the theory are presented in Box 1 (p.52).

Self-efficacy has been shown to be associated with changes in health behaviour and health status as well as in future health status, indicating that

self-efficacy is part of one of the mechanisms responsible for change in health behaviours. For this reason self-efficacy enhancement components are important when designing and developing self-management programmes (Lorig & Holman, 2003), e.g. after HTx.

Self-management

The term "self-management" refers to the activities people undertake to create order, discipline and control in their lives (Kralik et al., 2004), including medical management, role management and emotional management (Lorig & Holman, 2003). Self-management was defined by Barlow et al. (2002) as:

> "The individual´s ability to manage 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 effect the cognitive, behavioural responses necessary to maintain a satisfactory quality of life" (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002 p. 178)

Self-management involves five core skills that need to be developed by persons suffering from a chronic condition, i.e. problem solving, decision making, resource utilization, forming a partnership with healthcare providers and acting. The heart recipient must therefore be educated in basic problem solving in relation to transplantation. Knowledge and appropriate information concerning the transplantation are necessary to handle changes in the recovery trajectory and facilitate decision making on an everyday basis. Skills in utilizing resources involve how to search for information in an effective way. Establishing a partnership with transplant care providers is important in transplant follow-up care as it enables support for informed decision making. Finally, taking action is about being able to plan for and change one's behaviour in order to meet the demands of managing the condition post-transplant (Lorig & Holman, 2003). All of these skills are necessary for engaging in self-management and behavioural change, thus almost all patient education programmes and health promotion programmes focus on behavioural perspectives of medical or behavioural management. However, as self-management contains three different tasks, i.e. medical-, role- and emotional management, these programmes fail to address emotional and role management (Lorig & Holman, 2003), thus missing essential parts of the whole challenge.

Depression, problems or difficulties exercising, fatigue, poor support from family and friends, pain and lack of a partnership with healthcare providers have been identified as barriers to self-management (Richard & Shea, 2011). Within the context of chronic illness the self-management process has been described as comprising three stages, i.e. focusing on illness needs, activating resources and living with a chronic disease. This means that the person initially gains knowledge about the disease, her/his health needs and which health activities she/he needs to learn. Thereafter, identifies the resources that must be activated in order to handle the disease. Finally she/he manages to integrate the illness into her/his life including processing emotions, adjusting and integrating illness into daily life and finding a meaning in life (Schulman-Green et al., 2012).

Self-management programmes

The theory of behavioural change promoting self-efficacy became the foundation in the early development of self-management programmes for chronic disease (Lorig & Gonzalez, 1992). It has been widely accepted and now constitutes the foundation of CIM initiated by the WHO (Yach, 2002). A basic assumption in self-management programmes is that if people have knowledge about the reasons why and how they should make effective self-management decisions, they will be motivated to do so (Anderson, Blue & Lau, 1991). Many factors influencing the way people self-manage chronic illness have been identified and what meaning they ascribe this process (Paterson, Russell & Thorne, 2001). Kralik et al. (2004) conclude that patient education may provide a structure for people to absorb passively, whereas the process of self-management involves learning about their responses to illness through daily life experiences and as a result of trial and error (Kralik et al., 2004). Many existing self-management interventions have a compliance based approach intended to make the patient do what she/he is told to do, with plans and goals set by the healthcare provider. However, the plans and goals mainly focus on medical management and disregard the other aspects (Knight & Shea, 2014)

Self-management in health care systems

The Innovative Care for Chronic Conditions (ICCC) framework presented by the WHO (Yach, 2002) proposes that forming partnerships between informed, motivated and prepared patients and families, a motivated healthcare team and informed community partners constitutes the basis for better outcomes in those who are chronically ill (Yach, 2002). Healthcare should promote continuity and coordination, enhance quality through leadership and incentives, organize and equip healthcare teams, make use of

information systems and support self-management and prevention (Yach, 2002). Healthcare systems organized with a focus on self-care management and chronic illness management report better long-term outcomes in chronically ill populations (Nuno et al., 2012; Richard & Shea, 2011).

Specially trained nurses (e.g. nurse practitioners, clinical nurse specialists) are key players in managing and coordinating the care of chronically ill patients and improving health outcomes (Berben et al., 2015), which is also recommended in the heart and lung transplant care guidelines developed by ISHLT (Coleman et al., 2015).

Self-management and Self-efficacy

Self-management programmes demonstrate that self-efficacy has an important impact on self-care behaviour and HRQoL. Self-efficacy was chosen to constitute the foundational aspect of self-management programmes because it can be improved (Lorig & Holman, 1993). However, research shows a link between low self-efficacy, greater symptom burden and worse quality of life as well as worse overall health (Sarkar, Ali & Whooley, 2007) and the presence of symptoms correlated with anxiety, even when symptom distress was reported as low (McCormick, Naimark & Tate, 2006). Self-efficacy was also seen as an important determinant of depressive symptoms among kidney transplant recipients and self-care behaviour had a negative correlation with depressive symptoms (Weng, Dai, Wang, Huang & Chiang, 2008). A significant relationship between illness perception and self-efficacy has also been shown, indicating that the greater the patients perceived the consequences of their heart disease, the lower self-efficacy to cope with the condition (Lau-Walker, 2004). This implies that factors affecting self-efficacy, and thereby self-management, might be more complex. Hence, the hypothesis in this thesis is that uncertainty due to the heart recipients' inability to create meaning, in terms of the transplant-related events might be an important factor affecting self-efficacy, which needs to be explored.

Health promotion

This thesis stems from the assumption that health promotion in the context of transplantation needs to focus on acceptance and adaptation as a process towards health, based on Mishel´s theory of uncertainty in illness (Mishel, 1988). It is also assumed that transplantation means transition, which is facilitated when uncertainty is relieved and self-efficacy strengthened. Health has been described in different ways, such as adaptation, a process of life, a normal state, as well as a process of development and growth, depending on the perspective (Wärnå-Furu, 2015).

The concept of health has been discussed for centuries from different perspectives, i.e. philosophical, positivistic and of course in the caring context, where health is a central concept. From the medical perspective health has been defined as the absence of illness. However, in the context of caring sciences the definition of health is more complex, due to the holistic approach where it is seen as a multidimensional concept (Wärnå-Furu, 2015).

According to Mishel (1988), uncertainty will be appraised as a danger or an opportunity. Depending on the effectiveness of a person's coping strategies for handling the danger or opportunity, this will lead to adaptation (Figure 1) (Mishel, 1988). Adaptation is defined as *"a biopsychosocial behaviour occurring within the persons´ individually defined range of usual behaviour"* (Mishel, 1988, p231). Thus adaptation is the goal for achieving health. In previous studies adaptation has been operationalized as health, recovery, psychosocial adjustment and life quality, while uncertainty about the outcome of a negative event is associated with poorer health (Mishel, 1988).

Being a heart recipient - Previous relevant outcome research

Previous relevant outcome research regarding illness and health after HTx will be presented in four main areas:

- Quality of life
- Symptom occurrence and symptom distress
- Psychiatric disorders and distress
- Experiences of being a heart recipient

Quality of life

Studies demonstrate that heart recipients experience good quality of life, which is stable at least ten years after transplantation (Delgado et al., 2015; Grady et al., 2007; Politi et al., 2004). This also includes satisfaction with their health and functioning. Predictors of good quality of life were less depression, more positive emotions, less uncertainty, less family related stress, use of more positive coping styles, less sleep disturbance, more social interaction, less dermatological symptom distress. Further, more helpful self-care management interventions, not working, being married and not having complications, i.e. rejection, vasculopathy and genitourinary co-existing

illnesses also contributed to quality of life (Grady et al., 2007). Sexual dysfunction is also identified as a factor that impairs quality of life after HTx (Phan et al., 2010). Another study demonstrated that perceived control was associated with improved HRQoL. Low perceived control was associated with symptoms of depression and anxiety (Doering et al., 2018). In a study comparing quantitative and qualitative methods and their likelihood of capturing experiences, the quantitative self-report data showed that only 22% of the heart recipients reported poor QoL. However, when using qualitative interviews pervasive distress was identified in 52% and significant transient distress in 88% of the same individuals (Abbey et al., 2011). According to the authors, this might indicate an overestimated HRQoL (Abbey et al., 2011). A growing number of heart recipients are surviving for more than 15 years. A study by Dew et al. shows that mental and social HRQoL is high, despite physical functional HRQoL impairments. Other HRQoL benefits such as personal growth, life engagement and satisfaction were also satisfactory (Dew et al., 2020).

Functional status among heart recipients is affected and many report problems, including work (90%), eating due to dietary restrictions (87%), social interaction (70%), recreation (63%), home management (62%) and ambulation (54%) (Jalowiec, Grady & White-Williams, 2007). Predictors of worse functional status one year after transplantation were symptom distress, more stressors, neurological problems, depression, female sex, older age and worse cardiac function (Jalowiec et al., 2007).

Social functioning regarding interpersonal relationships, social role participation and leisure activities improves post-transplant and continuous to improve over time (Cupples et al., 2006). Returning to work is an important factor among the social aspects of quality of life (Cavallini,Forsberg & Lennerling, 2015). However, working rates after HTx are low both in the short and long term (White-Williams, Jalowiec & Grady, 2005; White-Williams, Wang, Rybarczyk & Grady, 2011). One year after transplantation only 24-26% of recipients had returned to work (Jalowiec et al., 2007; White-Williams et al., 2005). One year after transplantation non-workers had more rejection, infections, medical complications and hospital days (White-Williams et al., 2005). After five years heart recipients who were working had less overall physical and psychological functional disability, while after ten years those who were working had significantly less depression. Predictors of working at five to ten years also included demographic, psychosocial and clinical values (White-Williams et al., 2011).

Being able to go return to work is identified as an important factor for organ recipients (Cavallini et al., 2015). One study shows that 90% of heart recipients had work related problems, either not working at all or reporting health related problems at work one year after transplantation (Jalowiec et al., 2007). Only 26% where working one year post transplant (Jalowiec et al., 2007). Employment has been shown to be associated with less depression (Milaniak et al., 2018; White-Williams et al., 2011), also in long term follow-ups (White-Williams et al., 2011). Return to work after HTx has been found to be associated with fewer physical and psychosocial disabilities (White-Williams et al., 2011) and an increased quality of life (Shih et al., 2000).

Functional performance has been shown to improve during the first six months post transplantation, which was sustained for at least three years (Butler et al., 2003). Furthermore, a strong association has been identified between physical capacity after and long-term survival (Yardley, Gullestad & Nytroen, 2018).

Symptom occurrence and symptom distress

Stiefel et al. (2013) reported that the most prevalent symptoms after HTx were tiredness (88.8%), lack of energy (79.5%) and nervousness (74.5%). However, it was not the most frequently occurring symptoms that had greatest impact on symptom distress (Stiefel et al., 2013). The majority of the symptoms reported were experienced as "not" or "mildly" distressing. Women and younger patients reported significantly higher levels of distress, which increased with time after HTx (Stiefel et al., 2013). Women also reported worse symptom distress and more functional disability in the study by Jalowiec et al. (2011). In another study the most distressing symptoms after HTx were identified as poor vision, sleeplessness, back pain, fatigue and depression (Tung, Chen, Wei & Tsay, 2011). Symptom distress was a predictor of the physical aspect of quality of life (Tung et al., 2011). Grady et al. (2009) revealed that predictors of low symptom distress were higher education and no psychological problems (Grady et al., 2009). They also demonstrated that significant predictors for lower symptom frequency were not having CAV and having no psychological problems at five years. The most distressing symptoms five to ten years after HTx were memory problems, fatigue, easy bruising, cramps in the extremities and sexual dysfunction. Over time symptom distress and symptom frequency steadily declined, with symptom frequency stabilizing after seven years (Grady et al., 2009).

Fatigue

Fatigue is a common symptom after HTx (Grady et al., 2009; Reyes et al., 2004; Tung et al., 2011) and in one study was significantly associated with depression, functional status and mental health (Reyes et al., 2004). Fatigue is reported to be one of the most common and distressing symptoms after HTx (Chou, Lai, Wang & Shun, 2017; Reyes et al., 2004; Tung et al., 2011), which is prevalent over time (Grady et al., 2009) and leads to decreased quality of life (Chou et al., 2017). Fatigue is also prevalent among other organ transplant recipients (Forsberg, Lennerling, Kisch & Jakobsson, 2019; Kang et al., 2018; Procópio et al., 2014; van Ginneken et al., 2010). Furthermore, fatigue has been found to be the most frequent symptom affecting the ability to work among liver transplant recipients (Kang et al., 2018) and was poorly reported in the medical records of kidney recipients, despite the fact that it affected their ability to perform daily activities (Procópio et al., 2014). Fatigue was shown to be a predictor of daily functioning and all domains of HRQoL and associated with sleep problems, anxiety and depression in liver recipients (van Ginneken et al., 2010).

Fatigue is also a common symptom in the general population, where the incidence has been reported between 5-20% (Sharpe & Wilks, 2002). Although it is a common symptom in various conditions, the underlying physiological and psychological mechanisms are poorly understood (Sharpe & Wilks, 2002). Studies of fatigue among a range of diagnoses reveal that it is a non-specific phenomenon especially connected to chronic conditions and their treatment (Tiesinga, Dassen & Halfens, 1996). Fatigue is a disabling symptom, which highlights the importance of alleviating it. However, doctors generally have little interest in focusing on fatigue because it is poorly defined and thereby a non-specific diagnosis (Sharpe & Wilks, 2002). This discrepancy is a potent source of potential difficulty in the doctor-patient relationship. Fatigue is more common in women (Sharpe & Wilks, 2002; van den Berg-Emons et al., 2006) and among liver recipients, those belonging to the older age group reported more fatigue than their younger counterparts (van den Berg-Emons et al., 2006). Irrespective of the cause, fatigue has a major impact on day to day functioning and quality of life (Sharpe & Wilks, 2002). Physiological, psychological and social stressors are factors that predispose an individual to fatigue. Therefore, physical inactivity, disturbed sleep, emotional disorders and ongoing psychological and social stressors are factors that potentially perpetuate fatigue (Sharpe & Wilks, 2002).

Psychiatric disorders and distress

Depressive and anxiety disorders are the most investigated and frequent psychiatric diagnoses in heart recipients. The prevalence of major depression has been estimated to be 17% to 41% up to five years after HTx but most common during the first year (Dew et al., 2001; Dew et al., 1996; Dobbels et al., 2004). The reported prevalence of transplant related posttraumatic stress disorder is 12-17% (Dew et al., 2001; Favaro et al., 2011) and is seen almost exclusively during the first year post transplant. In a longitudinal study, major depressive disorder was shown to be the most prevalent disorder post-transplant with a rate of 17% during the first year (Dew et al., 1996). Pre transplant factors identified as increasing the risk of having any psychiatric disorder post-transplant included a pre transplant psychiatric history, poor social support, use of avoidance coping strategies for managing health problems and low self-esteem early post-transplant (Dew et al., 1996).

Depression is shown to be the strongest predictor of low quality of life in heart recipients (Tung et al., 2011) and has also been identified a risk factor for non-adherence (DiMatteo, Lepper & Croghan, 2000). In addition, clinically significant depression has been identified as a significant predictor of mortality in long-term (median 5 years) follow-up (Bürker et al., 2019)

Mood and anxiety disorders are the most commonly observed conditions after HTx with the highest risk during the first year post transplant (Dew & DiMartini, 2005). Heart recipients are also reported to be at higher risk of developing these disorders than other community-based populations or those suffering from many other chronic diseases (Dew & DiMartini, 2005). An interview study by Ross et al. (2010) showed that 88% of the heart recipients exhibited distress. Distress among heart recipients has also been shown to persist over time, evident for up to 18 years after HTx (Fusar-Poli et al., 2005), indicating that it is an underestimated problem. In a study by Grady et al. (2016) women did not report higher levels of distress, but more difficulty managing and adhering to the transplant regimen, even though they were shown to be more adherent than men.

Growing evidence indicates a correlation between psychosocial factors as predictors of clinical outcomes in heart recipients (Rosenberger, Fox, DiMartini & Dew, 2012). Diagnosed depression or symptoms of depression may increase the mortality risk among candidates on the waiting list and recipients early post-transplant (Dew et al., 2015; Rosenberger, Dew, Crone & DiMartini, 2012). A link has also been seen between psychological status during the first year post-transplant and physical health outcomes. Persistent elevated depressive symptoms and anger-hostility were shown to predict

chronic graft rejection, which in turn predicted mortality (Dew & DiMartini, 2005). Heart recipients who experienced post-traumatic stress disorder (PTSD) were also at increased risk of mortality (Dew & DiMartini, 2005).

In a study by Milaniak et al. (2018), 40.5% of the patients reported symptoms of depression, while 30% of the patients were observed to suffer from severe stress. Both depression and distress were associated with a number of comorbidities (De Vito Dabbs et al., 2003; Milaniak et al., 2018).

Experiences of being a heart recipient

Being a transplant candidate means being accepted for HTx, but no guarantees can be given about actually receiving a new heart. The wait for a suitable organ can be days, weeks or years. During this period the transplant candidate needs to deal with the progress of her/his disease and symptoms as well as undergo further medical treatment. The situation is stressful and filled with anxiety, described as "Awful and unbearable" (Dressler, 1991).

Receiving the new organ (the heart) means shifting perspectives from concern about dying to concern about surviving (Mackenzie, 2001). HTx means new opportunities, a future, a new life, described as being born again (Sadala & Stolf, 2008). Living with someone else's heart is a unique and unusual experience that requires time to accept. It is a period characterized by uncertainty about the heart, its sustainability and whether it will stop beating. It is also a time of joy of being alive. However, a common feeling among heart recipients is guilt about being alive because someone else had died (Sadala & Stolf, 2008). In order to cope with this, heart recipients express the importance of keeping a positive attitude and maintaining hope (Mauthner et al., 2012).

Social support from family, friends, caregivers and other transplant recipients is considered important throughout the transplant process (Conway et al., 2013; Kaba, Thompson, & Burnard, 2000; Mauthner et al., 2012; Sadala & Stolf, 2008) by helping the recipient to understand what is happening (Sadala & Stolf, 2008).

When waiting for the HTx the expectation was that the transplantation would be the cure, but afterwards a sense of lost autonomy emerged when facing limitations and difficulties managing their care. A phenomenological study by Mauthner et al. (2015) describes that heart recipients experience an identity disruption due to having a heart from another person, leading to the question "Who am I now?". They also felt interconnectedness with the donor, which might contribute to them struggling with their identity.

In summary, being a heart recipient is an extensive undertaking for the person involved. The demanding process post-transplant that requires managing one's identity, social contacts and emotional processes should not be underestimated. With prolonged survival it is possible that the heart recipient will face various and sometimes unpredictable symptoms, setbacks and complications along with psychological distress and profound fatigue. Simultaneously heart recipients are expected to adapt to the transitional process of moving from end-stage heart failure, to a life with better health but with life-long immunosuppressive medication and the risk of several side-effects. Furthermore, changes in role and emotions occur, when mastering recommended restrictions from the transplant professionals regarding lifestyle and behavioural changes. Despite this well-known fact, the transplantation is commonly viewed by the transplant professionals as a transition point from illness to health with an opportunity for the recipient to return to a normal life (O'Connor et al., 2009), which is a perspective that might need to change in light of previous research as well as the findings in this thesis.

Rationale

The main goal of HTx is survival and improved HRQoL. However, transplantation of a new heart is not an insurance of change from illness to health. The post-transplant medical regimen involves life-long treatment with immunosuppressive medications in order to avoid rejection of the new heart. However this leads to side-effects and an increased risk of malignancies in the long term as well as the need to avoid infections and adhere to dietary restrictions. Becoming a heart recipient is a life changing event that potentially affects one's self-identity (Mauthner et al., 2015). In addition, HTx implies a great contrast of emotions when managing the journey from *towards death* to *towards life,* where at various stages of this journey the recipients find themselves at *the frontier between life and death* (Palmar-Santos et al., 2019 p.50). The goal of healthcare professionals and presumably also of the heart recipient, is to manage the medical regimen; master psychological and physiological changes inherent in being a heart recipient and in the process of regaining health. Although there have been great advances regarding survival and medical treatment, e.g. the prevention of graft rejection as well as improvement in HRQoL, heart recipients still struggle with psychological challenges after HTx. Thus more research is needed to gain a deeper understanding of the heart recipient's perspective in order to address these issues. Moreover, self-efficacy is poorly understood in the context of HTx despite the fact that it is an important driver in self-management, which is considered a prerequisite in the long-term care after transplantation. This means a risk that, fundamental aspects affecting self-efficacy and thereby the ability to achieve the behavioural change necessary for efficient self-management, will be missed. Therefore the rationale behind this thesis was to understand and explore the experience of being a heart recipient when reflecting on the first post-operative year (Paper I). Furthermore, we aimed to explore and deepen our understanding of self-efficacy in the context of HTx due to its importance in relation to self-management. Therefore we deductively analysed the interviews using the theoretical framework of self-efficacy developed by Bandura (Bandura, 1977) (Paper II). The understanding from those studies was that being in uncertainty after HTx might be a source of distress during the first year post transplantation and that self-efficacy seemed to be the ability to balance

expectations in order to avoid disappointments, i.e. adjusting expectations to one's performance ability. Thus we hypothesized that disappointments such as set-backs, side-effects and complications during recovery after HTx, might hinder self-efficacy when expectations are not fulfilled. The rationale of Paper III and IV was therefore to explore self-reported symptoms, recovery and well-being in relation to self-efficacy in order to provide heart recipients and transplant professionals with more knowledge about what to expect from the HTx recovery process in order to avoid disappointments due to unfulfilled expectations. In order to gain information about the occurrence of symptoms and their potential association with self-efficacy and thus self-management, we explored self-reported recovery and psychological well-being in relation to self-efficacy in Paper III. Fatigue was identified as a distressing symptom in the interviews and therefore the aim of Paper IV was to explore fatigue after HTx and possibly explain how it is related to self-efficacy.

Unfulfilled expectations, disappointments, unachieved life goals, lost life roles, symptoms, fatigue and inability to work were identified as sources of uncertainty, potentially affecting the ability to manage life with a new heart. The heart recipient must manage and process these experiences, with or without help from healthcare professionals. Uncertainty might therefore constitute an obstacle to self-efficacy. Thus, it is essential to explore the concepts of uncertainty and self-efficacy together with symptoms, recovery and well-being in order to gain a deeper understanding and knowledge of heart recipients' experience that enables the provision of efficient self-management support. By contributing with more knowledge about potential barriers to recovery and well-being, i.e. health, we will enable healthcare professionals to guide heart recipients through their recovery and help them to manage their medical, emotional and social challenges. Furthermore, this knowledge can also help heart recipients to set realistic expectations, thus enabling the follow-up after HTx to more effectively address self-management aspects that are less focused on in existing education programmes. More focus on emotional and role management has the potential to optimize the adaptation process and address psychological barriers to self-management, and thereby possibly reducing long-term complications.

Aim

The overall aim of this thesis was to understand, explore and explain self-efficacy in relation to heart transplantation.

Specific aims

I. An in-depth exploration of the meaning of uncertainty during the first year after a heart transplantation.

II. An in-depth exploration of self-efficacy among heart transplant recipients by means of Bandura's self-efficacy theory.

III. To explore self-efficacy in relation to the self-reported level of recovery and psychological well-being among adult heart recipients one to 5 years after transplantation.

IV. To explore the prevalence of fatigue and its relationship to self-efficacy among heart recipients one to five years after transplantation.

Methods

Overview of the design of the studies

For this thesis a mixed method approach was utilized in order to understand, explore and explain important aspects of self-efficacy in the context of HTx. Two qualitative methods were used to understand the experience of being a person with a new heart during the first year after transplantation. Initially an inductive approach was adopted in order to grasp the inside perspective, followed by a deductive approach to explore self-efficacy in the context of HTx. The quantitative methods, both with cross sectional design, were used to explore self-efficacy among a larger group of heart recipients as well as aspects potentially affecting self-efficacy. The mixed method approach enabled hypothesis generated by the qualitative design to be tested. Overview of the designs are presented in Table 1.

The Self-Management After Thoracic Transplantation (SMATT)-project is based on the use of patient-related outcome measures (PROM). The use of PROM enables systematic collection of patient-reported experiences of e.g. symptom burden, level of activity and health. The use of non-diagnostically specific instruments enables unknown health issues to be observed and thereby possible to address (Nilsson & Kristenson, 2017). Thus, by using these non-specific instruments the data collection was also somewhat inductive.

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

Study	Design	Participants (n)	Data collection	Data analysis
I	Qualitative, inductive	14	Interviews	Phenomenological hermeneutic
II	Qualitative, deductive	14	Interviews	Deductive content analysis
III	Quantitative cross-sectional	79	Self-report questionnaires	Non-parametric analysis
IV	Quantitative, cross-sectional	79	Self-report questionnaires	Non-parametric analysis

Sample selection, participants and data collection - Paper I and II

Sample selection and participants

The two papers were derived from the same data set and thus the same context (Figure 2). The inclusion criteria were Swedish speaking adult heart recipients who were due to attend their 12 month follow-up after the transplantation, not hospitalized and who were able and willing to participate in an interview. Recruitment took place at the two centres in Sweden performing heart transplantation, Lund and Gothenburg. A total of 16 patients were invited to participate in this study, of whom one declined and one was excluded. The reason for exclusion was that it was not possible to carry out an interview face to face. After consultation with the nurse at the follow-up clinic we excluded this patient for ethical reasons. The 14 heart recipients, four women and ten men with a mean age of 51 years (range 28-67 years), were interviewed. Data collection ended after 14 interviews.

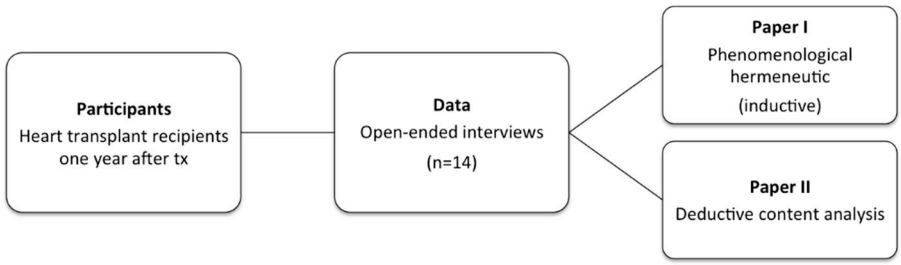

Figure 2. Research design overview, qualitative Paper I and II

Data collection Paper I and II

Data were collected between September 2014 and February 2015. The interviews were conducted individually and took place at the hospital where the one-year follow-up was performed i.e. at either Skåne University Hospital in Lund or Sahlgrenska University Hospital in Gothenburg. The nurse at the follow-up clinic contacted the potential informants and their written informed consent was obtained. They were informed that they could withdraw from the study at any time until publication of the findings. The interviews had a mean duration of 76 minutes (range 40-107 mins), they were digitally recorded and transcribed verbatim. An open ended in-depth method was employed during the interviews. The informants were encouraged to narrate freely about their experience of the first year after HTx. The interview started with the question "Could you tell me how it all began?", after which the interviewer deepened the understanding and reflection by asking probing questions such as "Could you please describe…?", "What happened next?" and "How did that make you feel?" The focus during the interviews was to explore the experience of being a person receiving a new heart, illuminated by the concept of self-efficacy. The interviews were performed by one of the authors (MA), who had no knowledge about informants' condition. The interviewer only had experience of post-transplant intensive care of heart recipients and therefore a limited pre-understanding of long-term follow-up.

Sample selection, participants and data collection - Paper III & IV

Sample selection and participants

Inclusion criteria were adult (>18 years) heart recipients due for their annual follow-up one to five years after HTx, who were able to read and understand the Swedish language, mentally lucid, not hospitalized and not undergoing treatment for acute rejection. The participants were consecutively included from the two transplant centres in Sweden performing HTx and the largest follow-up centre, i.e. Karolinska University Hospital, where the yearly follow-up of patients from their catchment area transplanted at Skåne University Hospital takes place. Data collection lasted from 2014-2017. According to the registry, 303 heart recipients were eligible for inclusion during this period (Svensk Transplantationsförening, 2020), but as some heart recipients have their follow-up at their local hospital it was not possible to include them. Of the 153 who were invited to participate in the study a total of 90 were finally included. Reasons for exclusion were being included twice, declining to participate, language barrier, being transplanted with several solid organs and being seriously ill. The exact figure for each reason for drop-out cannot be reconstructed. Questionnaires from ten participants were not returned, thus the final sample comprised 79 heart recipients.

Data collection Paper III & IV

Data collection for paper III & IV took the form of self-report questionnaires. The questionnaires in paper form were handed out by the nurse at the out-patient clinic. The questionnaires could either be filled in at the clinic or at home. If filled in at the clinic the questionnaire could be returned directly to the nurse, or by post if filled in at home.

To measure self-efficacy, recovery, psychological well-being and fatigue, four different instruments were used:

- Self-efficacy for managing chronic disease 6-item Scale (SES6G) (Paper III + IV)
- The Postoperative Recovery Profile (PRP) (Paper III+IV)
- The Swedish version of the Psychological General Well-being (PGWB) instrument (Paper III)
- The Swedish version of the Multidimensional Fatigue Inventory- 19 (MFI-19) (Paper IV)

The psychometric properties of Self-efficacy for managing chronic disease 6-item Scale

The German version of the SES6G was translated into Swedish by the research group and used to measure the self-efficacy score. SES6G consists of 6 items with a 10 grade Likert scale from 1 *"not at all confident"* to 10 *"totally confident"* (Freund, Gensichen, Goetz, Szecsenyi & Mahler, 2013). A mean score of at least four of the six items is calculated (allowing two missing item responses). The mean score ranges from 1 to 10, with higher values indicating greater self-efficacy. Convergent construct validity was 0.578 ($p < .001$), assessed by Spearman's rho correlation test between SES6G and the German General self-efficacy scale, where correlations between .44 and .6 are regarded as good. Internal consistency was high (Cronbach's alpha 0.930), where values above 0.7 are considered high (Freund et al., 2013). The German version was translated from English to German according to published standards and a cultural adaptation was made. No testing of the Swedish version took place as the cultural aspects were deemed to be similar.

The psychometric properties of the Psychological General Well-being-Index

Originally the PGWB-Index was developed with the intention of "providing an index that could be used to measure self-representations of intrapersonal affective or emotional states reflecting a sense of well-being or distress" (Dupuy, 1984). The Swedish version was used, consisting of six sub-scales *anxiety, depressed mood, positive well-being, self-control, general health* and *vitality* covered by 22 questions, where each question is rated on a six-point scale. The sub-scales are combined to a sum score, where a higher value indicates better well-being (Wiklund & Karlberg, 1991). A normal sum score is defined as being in the range of 100-105, where women tend to report lower

well-being than men (Dimenäs, Carlsson, Glise, Israelsson & Wiklund, 1996). The instrument was translated into Swedish according to standard principles (Wiklund & Karlberg, 1991). Cronbach's alpha for the Swedish version ranges from .61 to .89.

The psychometric evaluation of the original PGWB-index showed a very high internal consistency reliability (.94), making it possible to use as an overall index score (Dupuy, 1984).

The psychometric properties of the Postoperative Recovery Profile

This questionnaire was designed to evaluate patient-reported postoperative recovery as well as follow-up with the opportunity of evaluating interventions during recovery. The development of the questionnaire emanates from a concept analysis with descriptions of postoperative recovery from the perspectives of patients, nurses and surgeons (Allvin, Berg, Idvall & Nilsson, 2007). Operationalization of the concept of postoperative recovery resulted in 19 items divided into five dimensions, i.e. *physical symptoms, physical functions, psychological aspects, social aspects* and *activity*. The content validity of the items was determined by letting nurses, surgeons and patients systematically judge the relevance and usefulness of each item, where 85% (range 71-97%) chose the alternatives agree/strongly agree when judging the items. (Allvin, Ehnfors, Rawal, Svensson & Idvall, 2009). Thus the content validity can be considered high. Reliability was tested by test-retest assessment among 25 patients. The percentage agreement between the measures ranged from 72-100%, where the Rank Variance (individual variability) was negligible, suggesting a high level of test-retest reliability (Allvin et al., 2009).

Each item constitutes a statement in the questionnaire (Allvin et al., 2009) and is answered by a four point scale graded *none, mild, moderate* and *severe.* The level of recovery is defined by number of items answered with the response *none*, hence the more none responses the higher the level of recovery (Allvin et al., 2011). The extent of recovery is defined in five levels based on number of "none" responses, i.e. *Fully recovered* (19 "none" responses), *Almost fully recovered* (15-18 "none" responses), *Partly recovered* (8-14 "none" responses), *Slightly recovered* (7 "none" responses) and *Not recovered at all* (<7 "none" responses) (Allvin et al., 2011). The statements request the patient to rate how she/he is feeling at the present moment.

The psychometric properties of the Multidimensional Fatigue Inventory

The MFI has been widely used for measuring fatigue among cancer patients. The original MFI-20 questionnaire contains five dimensions (*General fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation* and *Mental Fatigue)* (Smets, Garssen, Bonke & De Haes, 1995), based on how fatigue is manifested. An attempt was made to ensure an equal number of items in each dimension, resulting in 20 items. The MFI-20 scale showed good (>.80) internal consistency in the majority of cases. Construct validity was studied by "between group comparisons". The instrument was demonstrated to detect differences in fatigue between groups, within groups and between conditions (Smets et al., 1995). The psychometric tests of the MFI-20 have shown that it is difficult to distinguish between General fatigue and Physical fatigue (Hagelin, Wengström, Runesdotter & Fürst, 2007; Smets et al., 1995). However, as removing one dimension was equal to keeping it, no changes were made and the five-dimension solution was retained (Smets et al., 1995). The General Fatigue sub-scale was shown to be sensitive to changes in fatigue levels and could be used as a short form instrument if required (Smets et al., 1995).

The Swedish version of the MFI (MFI-19) was used to measure fatigue among the heart recipients (Hagelin et al.,2007). The reliability of the Swedish version of the instrument was tested using inter-item correlation, corrected item-to-total correlation and Cronbach's alpha. Cronbach's alpha ranged from .67 to .94 and inter-item correlations ranged between .21 and .90 (Hagelin et al., 2007). In the Swedish version Item 19 was removed due to cultural and language differences (Hagelin et al., 2007). The 19 items related to each sub-dimension of fatigue are graded on a five point Likert scale from "yes that is accurate" to "no, that is not true". Sub-scale scores range from 4 to 20, where a higher score indicates greater fatigue. The timeframe specified in the instrument is the last few days (Hagelin et al., 2007)

Data analysis

Phenomenological hermeneutics (Paper I)

The focus of the study was the patients' lived experience as well as interpretation and understanding of the meaning of being in uncertainty during the first year after transplantation. A phenomenological-hermeneutic approach based on Ricœur's philosophy and developed by Lindseth & Norberg (2004) was chosen.

Data were analysed in three steps:

- *Naïve reading*, in which all researchers read the interviews several times to become familiar with the content and gain an initial understanding, i.e. a naïve understanding of the narrative.
- *Structural analysis*, in which the initial understanding was tested separately by each researcher. In this phase, meaning units were identified, brought together and grouped into themes and sub-themes; i.e. thematic structural analysis. Every theme in the structural analysis was reflected on in relation to the naïve understanding and each researcher's pre-understanding in order to be as open as possible to the phenomenon under investigation and to ensure that the themes validate the naïve understanding.
- *Comprehensive understanding* in which the interview text was read again and the researchers reflected together on the themes pertaining to the meaning of being in uncertainty one year after HTx. The interpretation was guided by the researchers' pre-understanding, based on their experience of caring for heart recipients during the early phase as well as in the long-term. The pre-understanding was constantly reflected on and reconsidered during the data analysis and interpretation process. A critical stance and integrity were maintained by means of continuous self-reflection and self-scrutiny to ensure that the interpretations were valid and grounded in the data. (Whittemore, Chase & Mandle, 2001).

  The comprehensive understanding was also scrutinized during the final interpretation and developed by illuminating the findings by means of Michel's theory of uncertainty in illness. Thus, the theory was used to understand the phenomenon of uncertainty, described in a comprehensive way in the structural analysis.

Content analysis (Paper II)

For the second paper, directed content analysis as described by Hsieh & Shannon (2015) was conducted retrospectively in order to gain a deeper understanding of the phenomenon of self-efficacy and to validate or extend its meaning in the context of heart transplantation. Bandura's theoretical self-efficacy framework was chosen when analysing the text. Bandura developed the concept of self-efficacy and his theory comprehensively describes it Bandura, 1977).

The analysis was performed step-wise as follows:

- Bandura's theory was scrutinised in detail in order to identify the main concepts.
- The main concepts and contextual factors of self-efficacy were chosen from the theory (Box 1). Those were applied to the data when searching for meaning units that corresponded with the content of each main concept in Bandura's theory.
- The authors read the text and highlighted all parts that seemed to be connected to the main concepts, which were then converted into meaning units.
- After identifying the meaning units that corresponded with the main concepts in the theory, relevant data that did not fit the concepts were analysed, which led to the division of performance accomplishment into several parts.
- Two of the authors (MA and AF) collaborated in comparing and condensing the meaning units as well as the additional data, which were specific to the context of HTx.
- All the authors discussed the condensation and core meaning of self-efficacy in the given context.

Box 1. Self-efficacy sources and contextual factors according to Bandura (Bandura, 1977).

Efficacy expectation: Belief that one can successfully carry out the necessary behaviour to achieve a desired goal.

Outcome expectation: A person's belief that a specific behaviour will lead to a certain outcome.

Performance accomplishment: Experiences of mastery and success in different tasks raise efficacy expectations. This is the most influential source of efficacy expectations.

Vicarious experience: Efficacy expectations derived from seeing others succeed without setbacks in various tasks that appear threatening.

Verbal persuasion: Others trying to persuade a person to believe that she/he will manage to carry out tasks that seem threatening or difficult. This source of efficacy expectations is weaker than that arising from succeeding in performance oneself.

Emotional arousal: Stressful and strenuous situations generate emotional arousal, which affects how the person will perceive her/his ability to succeed in a task or activity. Therefore emotional arousal affects a person's self-efficacy related to ability to perform in threatening situations.

Contextual factors: These comprise the social, situational and temporal circumstances under which the event occurs and affect how the efficacy information is processed, thus influencing the expectations of personal efficacy.

Non-parametric statistical analysis (Paper III+IV)

Paper III and IV have a cross-sectional design. The data originate from instruments generating ordinal data in a relatively small sample, not normally distributed. Therefore non-parametric analysis was performed. Due to the small sample size at each follow-up year, the statistical analyses were made for the whole group. The SPSS Statistics 24 (SPSS Inc. IBM Corporation, Armonk, N.Y., USA) was used for analysing the data.

The statistical analyses were performed stepwise as follows:

- Exploration of proportions and levels of the studied factors (self-efficacy, psychological well-being, recovery and fatigue)
- Exploration of the concept in relation to demographic characteristics as well as the other self-reported factors.
- Exploration of possible differences between two unpaired groups.
- Exploration of associations between the different factor studied
- Hierarchical multiple regression was conducted in order to investigate how much of the variance in self-efficacy could be explained by fatigue (Paper IV).

Mann-Whitney U test was used to assess whether there were differences between two unpaired groups. This test is applicable to ordinal data and when comparing medians. The Mann Whitney U test ranks the medians in order to make comparisons between groups (Björk, 2010). Values of $p<.05$ were considered significant.

Recovery was dichotomized into two groups, i.e. reasonably recovered, which included the PRP instrument levels *fully recovered*, *reasonably recovered* and *partly recovered* and not recovered at all, including the levels *slightly recovered* and *not recovered at all* in the PRP instrument. We divided the two groups based on what was considered to be clinically relevant. Age was dichotomized as younger or older than 50 years, based on the median age of the participants, which was close to 50 years.

Spearman's Rho, which is the non-parametric alternative to Pearson's correlation coefficient (Pearson's r), was applied in order to explore relations between the different factors (Björk, 2010). Spearman's Rho is calculated between the ranks of the ordinal data (Björk, 2010).

Multiple hierarchical regression analysis was conducted, in order to assess the ability of mental fatigue (MF) and reduced motivation (RM) to explain the variance in self-efficacy. Multiple regression is based on correlations and used to explore how well a variable can predict a particular outcome. By adding more than one variable it is possible to see the relative contribution of each variable (Pallant, 2013).

The regression analysis was performed in three steps:

- Preliminary analysis in order to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity.
- A linear regression was performed, where MF and RM (dependent variables) were entered into the model together with self-efficacy (independent variable)
- A multiple regression analysis was computed where age and gender were entered into the model in order to control for their possible effect of the relationship between fatigue and self-efficacy.

Ethical considerations

This thesis conforms to the ethical principles outlined in the Declaration of Helsinki (WMA, 2013) and Swedish research ethics legalisation (SFS 2003:460). The project was approved by the Regional Ethics Board of Lund (Dnr. 2014/670-14/10). Supplementary ethical approval was obtained due to the addition of one more centre for the recruitment of patients. Approval was obtained from the Swedish Ethical Review Authority (Dnr. 219-02769).

It was emphasized that participation was voluntary. In order to minimize the risk of the study participants feeling obliged to participate, the nurses at the follow-up clinic asked them if they wanted to participate in the interviews and in filling out questionnaires for the quantitative study. The participants were informed about the aim and importance of the study together with information about confidentiality, protection of their identity and their right to withdraw at any time without giving a reason. The information was provided both verbally and in writing on several occasions together with contact information for the researchers in case of questions or which of withdrawal from the study. Although the participants were allowed to choose a location that was convenient for them, none used this opportunity, thus the interviews were performed at the outpatient clinic.

The potential risks and burden to the participants connected to the interviews were judged to be limited. However, there is always a risk that the interview could evoke memories causing strong emotional reactions, which is why a social worker was available at each outpatient clinic at the time of the interview. Two of the interviews provided information that was judged by the researcher as important for the transplant team. In order to protect and help the participants and not ignore important information that might affect the follow-up care and potentially their medical condition, the two participants were asked for permission to contact the transplant team.

The questionnaires were somewhat time-consuming as they involved a total of nine instruments, thus might be considered burdensome. Rating both physical and psychological symptoms might awake feelings about the whole situation. The risk-benefit analysis revealed that the advantage of participating exceeded the risks and provided an opportunity to contribute to

the development of transplant follow-up care. Furthermore, information obtained from the questionnaires that was considered important for the transplant team, e.g. high levels of pain and low adherence, was reported to the outpatient clinic staff for intervention.

All documentation from the studies including the questionnaires, code-keys, personal identification transcribed interviews and informed consent was stored according to Swedish regulations on research data storage.

Results

The results will be presented in two different sections below in order to illuminate the deeper understanding gained from the mixed-method approach. Firstly Paper I and IV are presented, describing uncertainty and fatigue. Thereafter Paper II and III are presented, describing self-efficacy in the context of heart transplantation.

Uncertainty and fatigue (Paper I+IV)

The main phenomenon derived from the interviews by means of structural analysis (Paper I) was uncertainty, evident in the interviews as; *doubting survival, doubting the recovery process, doubting one´s performance, struggling with close relationships, feeling abandoned* and *doubting the future.* Fatigue was a prominent symptom in the interviews. Thus, we hypothesised that fatigue might be a factor affecting self-efficacy. We also hypothesised fatigue to affect the recovery process in lowering the capacity to perform tasks as well as its contribution to uncertainty due to its ambiguous character. The association between self-efficacy and fatigue was explored in Paper IV as well as if the level of fatigue was associated with level of recovery.

Almost all informants contemplated survival. They found it difficult to accept that their new heart was not as sustainable as their own heart would have been, and the survival of the graft became a threat that led them to *doubting survival*. The recovery process after HTx was another factor (Paper I). Medical test results that agreed with the recipients' experience of health gave them a sense of security. In contrast, when test results were good but the recipient still experienced illness it evoked doubts. Sometimes when test results were good and confirmed the feeling of health the heart recipients lacked the confidence to rely on the fact that everything seemed to be all right (Paper I).

> "…and they have done all the test and exams available I think… so it feels anyway… and everything looks fine… however fatigue has been a problem, and it still is. I´m exhausted!"
>
> Male 42 years

In Paper IV the levels of fatigue for the whole group of heart recipients were analysed, showing that the reported levels of fatigue were moderate in all dimensions of the MFI-19 scale, with highest levels in the dimension General Fatigue (GF) (paper IV). Women reported significantly higher levels of GF than men (p=.041) and those < 50 years reported significantly higher level of GF (p=.029) and MF (p=.018) than those > 50 years (Paper IV).

The recovery process differed widely between the informants, which affected their experience. Having had a MCS before transplantation was a mediator for expectations on the recovery, thus the informants compared recovery after the MCS surgery with recovery after the transplantation. Recipients treated with MCS pre-transplant reported significantly higher levels of Reduced Activity (RA) (p=.05), RM (p=.045) and MF (p=.006), with a tendency (p=.06) towards higher Physical Fatigue (PF) than among those without MCS treatment pre-HTx (Paper IV). The frequency of complications, symptoms and set-backs affected the recovery process and led to the informants *doubting the recovery process*. Heart recipients who reported not being recovered had significantly higher levels of fatigue in all sub-dimensions; GF (p=.008), PF (p=.017), RA (p=.003), RM (p=.007) and MF (p=.003), than those who reported being reasonable recovered (Paper IV). Even for those with few symptoms, set-backs and complications contributed to fear of future complications due to medication, e.g. cancer, diabetes or kidney failure. They also worried about getting infections because of the impact that might have on the recovery process (paper I). In order to optimize their recovery and survival the informants struggled to follow the recommendations made by the healthcare professionals to the best of their ability. This involved medication, food restrictions, avoiding infections and carrying out their exercise programme. However, despite their efforts they worried that they were not doing enough, thus *doubting their performance*, which made it even more difficult for them to master their new situation (Paper I).

The informants experienced expectations and disappointment from family and friends that made them doubt the sustainability of the relationships, which required *struggling with close relationships*. Their expectations concerned faster recovery and that everything would return to normal again. A fear of appearing ungrateful emerged and they were ashamed of their fatigue and infirmity.

> ”It´s very difficult when you feel that…. well now I´m feeling just about the same as before I received a new heart… damn it… that makes you really depressed… It has been pretty difficult because I have been the same as I was before (the HTx). This summer I was really tired and did not manage much at all… It was like it was before and that really made both me and my spouse devastated…”
>
> “Male 42 years”

The lack of support for as well as acceptance and understanding of their situation made some attempt to play a role and live up to the expectations of others in order to avoid disappointments. Lack of support from family and friends was a great source of disappointment and induced a fear of being left alone. Heart recipients living alone reported significantly higher levels of fatigue in the sub-dimensions GF (p=.035), PF (p=.015) and RA (p=.013) (Paper IV), compared to those cohabiting. The whole experience of having a HTx was overwhelming and the informants had a difficult time trying to interpret and understand their new situation. Many expressed that they lacked support and education from healthcare professionals to master their situation. They also expressed concerns about not involving their relatives in the health care process. Some of the informants felt that they were not taken seriously by healthcare professionals, which in turn resulted in a sense of *feeling abandoned.* The future was hard to visualize due to all the concerns revealed in the analysis. Concerns about being able to live a normal life, being able to work and seeing one´s children grow up were common when *doubting the future* (Paper I). Heart recipients who were not working reported significantly higher levels of fatigue in all sub-dimensions; GF (p=. 024), PF (p=.013), RA (p=.042), RM (p=.028) and MF (p=.006), compared to those working part or full time (Paper IV). The differences between the groups, by means of median and inter quartile range, are presented in Table 2.

Heart recipients reporting high levels of fatigue (12-20) in the sub-dimension GF had significantly lower level of self-efficacy (p=≤.001) than those reporting low levels of fatigue (4-11).The relationship between self-efficacy and fatigue was strongest in the sub-dimension RM (ρ= -.617) and MF (ρ= -.649). The hierarchical regression analysis showed that RM and MF explained 40.1% of the variance in self-efficacy when controlled for age and gender.

Table 2. Differences in fatigue between two unpaired groups as displayed by median (p_{25}; p_{75}). Significance level were set to $p<.05$ where p-values in bold are significant. A General fatigue score ≥ 12 means severe fatigue.

Variable dichotomized in two groups	Median (p_{25}; p_{75})	Median (p_{25}; p_{75})	p-value
Gender	**Men**	**Women**	
General fatigue	9.00 (6.00; 12.00)	11.00 (9.00; 14.00)	**.041**
Physical fatigue	9.00 (6.00; 13.00)	12.00 (6.25; 14.75)	.118
Reduced activity	9.00 (6.00; 12.50)	11.50 (7.25; 14.50)	.115
Reduced motivation	6.00 (4.00; 9.50)	6.50 (5.00; 9.75)	.824
Mental fatigue	8.00 (4.00; 12.00)	8.65 (4.33; 12.00)	.794
Age groups	**>50 Years**	**< 50 years**	
General fatigue	9.00 (6.00; 12.00)	11.50 (8.00; 14.00)	**.029**
Physical fatigue	8.00 (6.00; 13.00)	11.00 (8.50; 13.25)	.068
Reduced activity	9.00 (6.00; 13.00)	11.00 (7.00; 13.25)	.348
Reduced motivation	6.00 (4.00; 9.00)	8.00 (5.00; 11.25)	.056
Mental fatigue	6.70 (4.00; 10.70)	9.67 (7.68; 13.65)	**.018**
Mechanical Circulatory Support (MCS)	**MCS**	**No MCS**	
General fatigue	11.00 (8.00; 14.00)	10.00 (6.00; 12.00)	.189
Physical fatigue	11.50 (8.00; 14.25)	9.00 (6.00; 13.00)	.06
Reduced activity	12.00 (7.00; 14.25)	9.00 (6.00; 12.00)	**.05**
Reduced motivation	8.00 (6.00; 10.50)	6.00 (4.00; 9.00)	**.045**
Mental fatigue	10.70 (8.75; 13.30)	6.70 (4.00; 10.70)	**.006**
Recovery	**Reasonably recovered**	**Not recovered**	
General fatigue	10.00 (6.00; 12.00)	12.00 (11.00; 16.00)	**.008**
Physical fatigue	9.00 (6.00; 13.00)	12.00 (11.00; 14.00)	**.017**
Reduced activity	9.00 (5.00; 13.00)	13.00 (12.00; 15.00)	**.003**
Reduced motivation	6.00 (4.00; 8.00)	9.00 (7.00; 13.00)	**.007**
Mental fatigue	4.00 (4.00; 10.70)	12.00 (10.70; 14.70)	**.003**
Living conditions	**Single**	**Co-habiting**	
General fatigue	11.50 (8.75; 15.50)	10.00 (6; 12.25)	**.035**
Physical fatigue	13.00 (9.75; 14.25)	9.00 (6.00; 13.00)	**.015**
Reduced activity	12.00 (10.25; 14.25)	9.00 (5.75; 12.25)	**.013**
Reduced motivation	7.50 (5.75; 9.25)	6.00 (4.00; 10.25)	.470
Mental fatigue	9.65 (6.69; 13.65)	8.00 (4.00; 11.00)	.061
Education	**University/College**	**Basic level**	
General fatigue	10.00 (7.00; 12.50)	11.50 (7.00; 13.75)	.357
Physical fatigue	9.00 (6.00; 13.00)	10.00 (6.25; 14.75)	.386
Reduced activity	9.00 (6.50; 13.00)	12.00 (5.25; 13.00)	.555
Reduced motivation	6.00 (5.00; 9.00)	7.50 (4.00; 11.00)	.828
Mental fatigue	8.00 (4.65; 10.70)	9.65 (4.00; 13.30)	.516

Table 2, continuing

Graft rejection	**Previous rejection**	**No rejection**	
General fatigue	11.00 (7.00; 14.00)	10.00 (6.00; 12.50)	.269
Physical fatigue	10.00 (6.00; 14.00)	9.00 (6.00; 13.00)	.793
Reduced activity	10.00 (8.00; 13.00)	10.50 (6.00; 13.00)	.627
Reduced motivation	7.00 (5.00; 11.00)	6.00 (4.00; 9.00)	.507
Mental fatigue	8.00 (4.00; 13.30)	8.50 (4.00; 11.00)	.641
Working ability	**Working**	**Not able to work**	
General fatigue	9.50 (6.75; 12.00)	12.50 (7.00; 16.25)	**.024**
Physical fatigue	9.00 (6.00; 13.00)	13.00 (8.25; 16.25)	**.013**
Reduced activity	9.00 (6.00; 12.00)	12.00 (7.00; 15.25)	**.042**
Reduced motivation	6.00 (4.00; 9.00)	8.00 (6.00; 13.00)	**.028**
Mental fatigue	8.00 (4.00; 10.70)	12.00 (6.70; 13.65)	**.006**

Self-efficacy in the context of heart transplantation (Paper II+III)

In Paper II we used Bandura's theoretical framework (Bandura, 1977) was used in order to analyse the interviews and thereby gain a deeper understanding of the concept of self-efficacy, while in Paper III the concept in different sub-groups was explored. The differences between the groups, by means of median and inter quartile range, are presented in Table 3.

The result is categorised according to the contextual factors of self-efficacy and further described by statistical measures derived from the cross-sectional study that included 79 heart recipients.

Performance accomplishment

Efficacy by means of performance accomplishment was evident in *physical, mental* and *social* aspects, which was merged into subthemes that are presented in the following.

Physical accomplishment

Each *physical accomplishment* served as a step towards recovery. It initially meant being able to get out of bed, sit on a chair, take a few steps and take a shower without assistance. The physiotherapist played an important role in helping the informants to achieve physical accomplishment. Being able to do whatever they wanted without assistance was a clear performance marker and

accomplishment increased their trust in their own ability. Physical accomplishments after discharge ranged from reconstructing daily occupations to increased physical exercise, where achieving an excellent physical condition was the ultimate confirmation of accomplishment and improved health. Discharge to the rehabilitation clinic provided increased opportunities for confirmation of physical accomplishments. In conclusion, physical recovery and achievements act as concrete recovery markers and necessary evidence of physical performance accomplishments (Paper II).

Mental accomplishments

Uncertainty regarding the possible level of physical accomplishment caused doubts about the recovery, recovery process and ultimately survival, thus affecting future plans and social aspects. However, being positive served as a mediator for *mental accomplishments*, helping the recipients to feel stronger and better over time. Positive emotions included feeling optimistic, perceiving a sense of control over the situation, feeling free and being able to manage the demands of everyday life without becoming stressed. Thus, *metal accomplishment* involves accepting uncertainty and adopting a new view of life (Paper II).

Psychological well-being could be a measure of mental accomplishment as described in paper II. Psychological well-being among the group of heart recipients was explored in paper III, showing that the median total PGWB score was 108, min 54, max 129 (p_{25} 24, p_{75} 117). Thus, suggesting an overall good level of psychological well-being in the whole group of heart recipients (Paper III). The median self-efficacy was 6.80 among those with a low PGWB score, which is lower than that for the whole group (Paper III). No significant differences in self-efficacy were seen among those who reported low psychological well-being and those who reported good psychological well-being. However, there was a correlation between those who reported low self-efficacy and had a lower PGWB score (ρ= .446) in the *General Health* sub-dimension of the PGWB scale (Paper III).

Social accomplishments

Being socially active was considered important. Contacting friends and participating in social activities and being part of society again were strategies to achieve *social accomplishment* (paper II). However, no significant relationship was found between the groups living alone versus cohabiting (Paper III). Being able to return to work was one of the major *social accomplishments.* Having no limitations and being able to do whatever they wanted was a great achievement. Those who had returned to work had a

significantly higher level of self-efficacy (p=.003) than those not working (Paper III).

Symptoms, setbacks and treatment side-effects

Several physical complications and setbacks negatively affected their performance accomplishments and thereby self-efficacy. For some of the recipients recovery was a major challenge due to depression, lack of energy, fatigue and graft rejection. Sleep disturbances together with numerous medical complications and side-effects, including wound infections, nausea, vomiting and increased sensitivity to light, noise and smell affected their performance. Feeling just as ill and drained as before the transplantation was a huge disappointment and stress factor. During their recovery they found it difficult to concentrate and learn new things, as they felt mentally exhausted. They had expected to recover more rapidly and requested increased support from the transplant professionals (Paper II).

The self-reported level of recovery was explored in Paper III, showing that in the whole group of heart recipients 4 were *fully recovered*, 18 *almost fully recovered* and 30 *partly recovered*, 2 *slightly recovered* and 10 *not recovered at all.* Thus, 52 (81%) were reasonably recovered and 12 (18.8%) were not recovered. Median self-efficacy among those who were not recovered was 7.5, which was significantly lower than among those who were reasonably recovered (p=.047). Of the heart recipients who were not recovered, seven (58%) reported low psychological well-being (Paper III).

Vicarious experience

Vicarious experience means being inspired by others, which can lead to increased hope of recovery and encourage the recipients to intensify and persist in their efforts. Attending physiotherapy and observing other patients exercising in the gym gave an impression of what it could be like. It seemed that successful heart recipients acted as role models. However, hearing about others' experiences could also lead to stress and constitute a negative reminder of all the possible complications that could occur, resulting in disappointment and increased emotional arousal (Paper II).

A third form of vicarious experience was comparing themselves with others and concluding that they were better off in many ways, which strengthened their self-belief and sense of accomplishment (Paper II).

Verbal persuasion

Verbal persuasion from transplant professionals included positive remarks about the quality of the graft, which was encouraging for those experiencing a straightforward recovery. However, for those experiencing complications and side-effects as well as setbacks in the recovery process, such encouraging remarks gave rise to uncertainty due to not corresponding with their experience (Paper II).

Verbal persuasion expressed as expectations from transplant professionals caused increased doubts. Anxiety and disappointment became greater when the recipients were unable to meet the expectations, which led to a profound sense of uncertainty (Paper II).

Outcome expectations and emotional arousal

The core of self-efficacy seemed to be the ability to balance expectations to the current situation and performance level, in order to avoid disappointments leading to emotional arousal and stress. The self-reported level of self-efficacy for the whole group was relatively high with a median of 8.3 (p_{25} 6.28, p_{75} 9.23), with no difference between men and women. There was a tendency that those older than 50 years reported higher self-efficacy than those younger than 50 years (p=.05) (Paper III).

The outcome expectations varied, but a common theme was surprise and disappointment that recovery took so long. Having undergone MCS treatment was also a mediator for outcome expectations, as the initial post-transplant period was more difficult for some informants compared with their recovery after MCS surgery. Heart recipients who underwent MCS before HTx had significantly lower self-efficacy that those who did not (p=.033) (Paper III).

A strong sense of disappointment leading to emotional arousal occurred when physical achievements were lacking and accomplishments were poor. This often resulted in weakened willpower and they considered that their efforts were in vain, which gave rise to depressive thoughts. Fatigue, difficulties concentrating and fear of cardiac arrest also caused negative emotions. Not knowing which bodily signs required attention created uncertainty, in addition to a great deal of pondering, strong emotional arousal and intrusive thoughts. Returning to the transplant unit for the one-year follow-up evoked a cascade of emotions (Paper II).

Performance adjustment

Lack of performance accomplishment or the occurrence of setbacks and complications meant that the heart recipients had to adjust to their current health status. Social factors also affected their ability to adjust and therefore their perceived self-efficacy. A long hospital stay and reduced memory function were other factors that required adjustment. Resuming daily activities became an onerous task due to lack of concentration, energy and confidence, which also affected their ability to perform at work (Paper II).

The informants adopted a variety of adjustment strategies including striving for autonomy, as they believed it was necessary to recover thanks to one's own efforts. Keeping the pre-transplant illness period in mind helped some to appreciate their new, improved health status. Feeling content with what they had achieved in terms of health, appreciating that the wound had healed and being grateful for the heart and to the donor led to a sense of satisfaction. Physical adjustment to the new health situation was considered easier than mental adjustment. Adjustment strategies also involved meeting the performance accomplishment expectations of spouses, friends and healthcare professionals. Some recipients experienced a constant sense of guilt due to their lack of energy and failure to meet the expectations of their spouse. Others felt that people in their environment constantly questioned their strength and recovery making them reluctant to talk about the transplantation (Paper II).

Several strategies were adapted to constantly focus on positive thoughts. Keeping up one's spirits, not giving in, using willpower and accepting the role of being a patient, often created positive emotions. Other useful approaches included not dwelling on the situation, avoiding reading negative information on the internet and adopting an optimistic attitude. A common strategy for coping with outcome expectations was to expect the worst and thereby be surprised when everything turned out better. In the long term, the ability to adjust their expectations to avoid frequent disappointments was the key to better self-efficacy (Paper II).

Table 3. Differences in self-efficacy between two unpaired groups as displayed by median (p_{25}; p_{75}). Significance level were set to $p<.05$ where p-values in bold are significant

Variable dichotomized in two groups	**Median (p_{25}; p_{75})**	**Median (p_{25}; p_{75})**	**p-value**
Gender	Men 8.25 (5.77; 9.27)	Women 8.41 (6.80; 9.24)	.421
Age groups	> 50 Years 8.50 (6.80; 9.50)	< 50 years 7.60 (5.40; 9.00)	**.050**
Mechanical Circulatory Support (MCS)	MCS 7.20 (5.30; 8.71)	No MCS 8.80 (6.80; 9.37)	**.033**
Psychological General Well-being (PGWB)	Good PGWB 8.81 (7.22; 9.37)	Poor PGWB 7.60 (5.65; 9.00)	.074
Recovery	Reasonably recovered 8.83 (6.20; 9.50)	Not recovered 7.50 (5.50; 8.00)	**.047**
Living conditions	Single 7.25 (5.25; 8.83)	Co-habiting 8.50 (6.65; 9.45)	.068
Education	University/College 8.73 (6.80; 9.27)	Basic level 7.51 (4.87; 9.12)	.065
Graft rejection	Previous rejection 8.20 (6.00; 9.00)	No rejection 8.30 (6.35; 9.35)	.376
Working ability	Working 8.80 (7.20; 9.30)	Not able to work 6.20 (4.41; 8.35)	**.003**
Low vs High General fatigue (GF)	Low GF 9.00 (7.30; 9.50)	High GF 6.80 (5.10; 8.00)	**≤.001**

Discussion

Methodological considerations

A strength in this thesis is that it include both qualitative and quantitative studies in order to address the aim of the thesis in a comprehensive way. Combining an inductive and deductive approach enables both the generation of hypotheses (Paper I-II) and the testing of them (Paper III-IV). The qualitative papers stem from two different approaches: an inductive approach using phenomenological hermeneutics (Lindseth & Norberg, 2004) (Paper I) and a deductive approach employing directed content analysis (Hsieh & Shannon, 2005) (Paper II). These methods were utilized in order to gain as much understanding as possible of the experience of being a heart recipient, illuminating the person's perspective as a solid scientific foundation for person-centred care. The methodological considerations will be discussed with focus on sample selection and participants, the chosen method as well as validity and trustworthiness.

Qualitative method (Paper I &II)

The two qualitative papers (Paper I and Paper II) both stem from the same interview material and will therefore be discussed together based on the framework developed by Lincoln and Guba (1985), which presents four criteria for ensuring the trustworthiness of qualitative research: *credibility, dependability, conformability* and *transferability.*

Sample selection and participants

A total of 14 interviews were performed with consecutive sampling. The sampling ended when no new information emerged regarding uncertainty and self-efficacy. Consecutive sampling was efficient for reaching the relatively small number of eligible heart recipients. The interviews were extensive and the rich data provided indicated the ability of the participants to verbally express their experiences. It was therefore not considered necessary to select other participants to enrich the material further. Moreover, only two centres in Sweden perform HTx. Participants were included consecutively from both

centres to avoid the risk of reflecting local medical or caring traditions. A large number of geographical areas of Sweden are covered, which is a strength. Nevertheless, it is important to acknowledge that the Swedish context had an impact on the result as only Swedish speaking informants were recruited, which limits transferability.

Data analysis and pre-understanding

Initially we aimed for a Grounded Theory approach. Our intention was to explore the process of change by means of self-efficacy after HTx. However, self-efficacy is a complex concept. When performing the analysis and data collection simultaneously it became obvious that it was impossible to capture the process of change by means of this theoretical concept. We therefore decided to focus on the meaning of being a heart recipient and instead analysed the interviews using a phenomenological hermeneutic method. Thus we abandoned the constant comparative method inherent in Grounded Theory and instead approached the transcribed interview text with an open mind-set during the naive reading (Paper I) (Lindseth & Norberg, 2004). The change of methodological approach might constitute a threat to credibility and dependability (Lincon & Guba, 1985). However, both grounded theory and phenomenological hermeneutics has an inductive approach with open-ended questions, suggesting that the interview techniques were comparable. The participants narrated freely about their experiences during the past year and clarifying questions were posed when necessary in order to deepen the understanding of the narrative. The phenomenon of uncertainty emerged from the interviews through the structural analysis and was later found either implicitly or explicitly in several studies, thus there is reason to believe that the results (Paper I) are transferable to other settings (Lincon & Guba, 1985).

The interviews were evaluated to be extensive and a great deal of the information they contained was not used in the first analysis. They were subsequently reanalysed in order to utilize and make the most out of all the data, which is important from an ethical perspective.

All the interviews were conducted and transcribed verbatim by the author of this thesis. The pre-understanding of the author is based on several years of clinical experience working within the field of transplantation, especially in intensive care. Such previous experience means that one probably develops perceptions of the patients under investigation that need to be identified, questioned and dealt with during the analysis. As the author's clinical experience was limited to the stay at the intensive care unit (ICU) and not to the long-term follow-up, made it easier to bracket the pre-understanding. The supervisor had experience of follow-up care after solid organ transplantation, mainly in the area of abdominal organs, and mostly "this experience" was

considered an advantage. A strength of the study is that the same person performed the interviews and participated in the analysis of the transcribed text. This enabled closeness to the text and selection of presentative quotations from the participants (Lindseth & Norberg, 2004), thus enhancing credibility as well as confirmability (Polit & Beck, 2010). To avoid the risk of bias caused by becoming too familiar with the text, the analysis was performed in collaboration with one of the supervisors, after which it was discussed with the rest of the research group in order to improve creditability.

Although only two centres in Sweden perform heart transplantation, our approach minimizes the effects of context bias, thus strengthening dependability and possibly also transferability (Lincon & Guba, 1985). The informants varied in age, gender and diagnosis prior to heart transplantation (Table 1). This might also strengthen dependability (Lincon & Guba, 1985). Transferability could be hampered by the fact that all informants except one stem from a Swedish socio-cultural context (Lincon & Guba, 1985).

One methodological assumption in this thesis is that it is only possible to be truly inductive on one occasion. Thus, in the second analysis (Paper II) directed content analysis was chosen in order to further comprehend self-efficacy. The starting point was to gain an in-depth grasp of the theoretical framework of self-efficacy (Bandura, 1977). The choice of directed content analysis meant that the researchers were doubly biased. Firstly, using the theory increases the likelihood of finding evidence to support it (Hsieh & Shannon, 2005) and secondly, the researchers were very familiar with the interview text from the earlier analysis. As the original interview approach was inductive, the researchers tried to be as objective as possible, letting the participants talk freely and minimising the risk of providing cues or leading the interviews. Thus, not influencing the participants by means of the theoretical framework (Hsieh & Shannon, 2005). None of the researchers were familiar with the self-efficacy framework at the time of conducting the interviews, which enhances conformability.

Re-analysing interviews demands careful consideration regarding the inherent bias due to being familiar with the text. However, this familiarity can also be an advantage as it enables a deepened understanding of the heart recipients. The human being is complex in nature, meaning that there is never only one explanation. Applying two theoretical perspectives provides an opportunity to grasp the complexity of undergoing heart transplantation. In addition, the argumentation in this thesis is that uncertainty from an ontological perspective is a basic part of being human. Uncertainty connected to illness is a well explored phenomenon as is self-efficacy, which suggests that the results from this thesis might be transferable to a wider population.

Quantitative method

The hypothesis generated in the qualitative papers were tested by means of data from the cross-sectional studies, giving us opportunity to describe the reported magnitude of those factors as well as test associations and relations between the various concepts and factors. The design also enables exploration and description of characteristics of interest (Polit & Beck, 2010). A limitation of the cross-sectional design is that it does not allow causal relationships to be determined, which must be considered when presenting the results. However, as the data are collected at only one point they become easier to manage and less resources are required (Polit & Beck, 2010). Furthermore, attrition is avoided due to only one measure, as well as the potential effect of maturation and the impact of external events on the participants. The sample and method used in Paper III and IV are the same and will therefore be discussed together.

Sample selection and participants

The intention of the cross-sectional study was to consecutively include all heart recipients fulfilling the inclusion criteria and willing to participate, who were due to attend their 1, 2, 3, 4 or 5 year follow-up at both centres in Sweden where HTx is performed. However, due to the clinical reality this was not possible and unfortunately difficulties at out-patient clinics, e.g. staff turnover and lack of a tradition of facilitating nursing research, made it impossible to assess the actual eligible number of heart recipients visiting the transplant centre for follow-up. The total number of eligible heart recipients is based on data from a registry of HTx performed during the period in question and therefore includes both deceased heart recipients as well as those who attended their home clinic for follow-up. In addition, the reasons for exclusion and declining participation were not noted in a consistent way, thus no further analysis was possible and they are considered missing at random. While not ideal it is nevertheless pragmatic and illustrates some of the challenges inherent in clinical research. However, in view of the relatively small number of HTx performed at each year the sample size for all 5 years is considered acceptable. The characteristics of the participants included in our sample were comparable to international population data (ISHLT, 2020) regarding median age, gender distribution and reason for transplantation (Lund et al., 2013). Selection bias in our study was the exclusion of non-Swedish speaking participants as well as those who were seriously ill and hospitalized. Exclusion of non-Swedish speaking participants was due to practical reasons and limited resources, as it would have been complicated to administer the self-report instruments in several languages. Furthermore, those hospitalized due to serious illness might not have contributed anything

to the aim of the study in terms of increased understanding of self-management related to chronic disease. The issue of self-management mainly involves those not too burdened by illness or disease.

Data analysis

Because of the small sample size at each follow-up year statistical analysis was not performed for each year. Instead, we performed the analysis on the whole sample. However, some descriptive statistics for each year were found to be relevant. Because of the character of the data and the size of the sample, not normally distributed, non-parametric statistics were utilized. The data were dichotomized into different groups, i.e. age, gender, recovered or not, pre-transplant MCS or not, in order to determine if there were any differences. The groups of interest were selected based on our understanding from the interviews, which generated the hypothesis about potential important differences. The use of several instruments in order to compare the different groups was discussed, carefully considered and appraised in relation to our assumptions from the interviews. In Paper IV, multiple regression was utilized in order to determine whether fatigue could explain the variation in self-efficacy.

A preliminary analysis was conducted to ensure that there was no violation of the assumptions of normality, linearity, multicollinearity and homo-scedasticity. By ensuring that the sample size was sufficient to permit the multiple regression and the validity of the findings was strengthened. As the two transplant units performing HTx collaborate, the follow-up is organized in a fairly similar way with the exception of minor local differences and consequently comparison between the two units was considered irrelevant.

Self-report instruments

The self-report instruments included in Paper III and IV were chosen due to the aims of the study and based on the hypothesis derived from the interviews. Self-report instruments make it possible to grasp the patient's experience, i.e. of symptoms, by enabling her/his subjective experience to be obtained instead of being objectively considered by physicians. However, the development of such instruments must be by means of well-established methods as well as extensive psychometric testing in order to ensure that they measure what they are intended to measure (validity) in a consistent way (reliability). As previously described in the Method section of the thesis, the instruments were psychometrically tested and developed according to established methods, which is a strength together with the fact that several were tested for in a Swedish context.

The Swedish version of the Self-efficacy for managing chronic disease 6-item Scale, utilized in our studies lacks test-re test and validity testing for the Swedish translation. Instead, we chose to rely on the German version of the scale, which has been psychometrically evaluated. The German context was valued to be similar and transferable to the Swedish context. Nevertheless, it would have been desirable for the Swedish version to have been tested in a consistent way, which constitutes a target for further research and instrument development.

General discussion of the results

This thesis provides a comprehensive picture and in-depth understanding of how uncertainty and self-efficacy interact and affect adaptation and recovery after HTx based on the following key findings:

- Performance accomplishment is an important aspect of self-efficacy, especially physical accomplishment (Paper II)
- Uncertainty is a prominent part of being a heart recipient during the first year and involves all aspects of the heart recipient's life (Paper I).
- Symptoms, setbacks and complications causes uncertainty, hinders performance accomplishment and thereby self-efficacy (Paper I and II).
- The level of self-efficacy for the whole group was relatively high with no gender differences (Paper III)
- The majority of heart recipients were reasonably recovered (Paper III)
- Fatigue was moderate for the whole group, but intrusive for those troubled by it and as such a possible source of uncertainty and a barrier to performance accomplishment (Paper I, II and IV)
- Those with pre-transplant MCS treatment reported lower self-efficacy and were more fatigued than those without pre-transplant MCS (Paper III and IV).

Performance accomplishment, expectations and uncertainty

Performance accomplishment was identified as the key factor of self-efficacy among heart recipients (Paper II), which is in line with Bandura's theory (Bandura, 1977), suggesting that successful performance strengthens the conviction that one can carry out a required task. Performance in this context was about proceeding in the recovery process, by means of decreased symptom burden, resuming daily activities and overall improved well-being and health (Paper II). The heart recipients' evaluation of whether or not performance accomplishment was achieved depends on their expectations, i.e. their goals and their repertoire for reaching the goals. According to Bandura´s theory, efficacy expectation, i.e. self-efficacy, is the conviction that one can carry out the required behaviour to reach one´s goal (Bandura, 1977). If the person has serious doubts about her/his performance, or if the required performance is valued to exceed her/his abilities, it will affect the performance of the task, how much effort she/he will put invest and for how long it will be sustained (Bandura, 1977). This is why it is of great importance to evaluate and explore barriers to performance, as well as assessing the heart recipient's expectations and goals related to the transplantation.

Experience of uncertainty is a more or less prominent part of being a heart recipient during the first-year post transplant, evidenced by *doubting survival, doubting the recovery process, doubting one´s performance, struggling with close relationships, feeling abandoned* and *doubting the future* (Paper I). Symptoms, set-backs and complications are sources of uncertainty if the heart recipient is unable to ascribe meaning to them and understand them in relation to the HTx (Mishel, 1988). The inability to appraise symptoms will lead to cognitive difficulties interpreting the impact of the disease. Symptom frequency, intensity, duration and consistency with previous illness experiences will be evaluated and interpreted with help from transplant professionals as well as from the cultural and social environment. Furthermore, event congruence refers to whether or not an event is in line with what was expected, i.e. whether or not one expected to be fatigued for a long time period. Unexpected and unfamiliar events that are hard to appraise, are sources of uncertainty. Apart from being a source of uncertainty, inability to manage and understand symptoms and complications also hinders performance accomplishment.

In conclusion, performance accomplishment is the most influential self-efficacy enhancing factor (Paper II) and enables expectations to be fulfilled. Absence of performance accomplishment is a source of disappointment that potentially generates uncertainty, emotional arousal and distress. High expectations are also sources of disappointment and uncertainty when

accomplishment fails and expectations remain unfulfilled (Figure 3). A possibly useful strategy is to adopt balanced expectations as a way of preventing too much disappointment. Although the level of reported self-efficacy for the whole group was relatively high (Paper III), dichotomization into different groups revealed differences in the reported level of self-efficacy as discussed below.

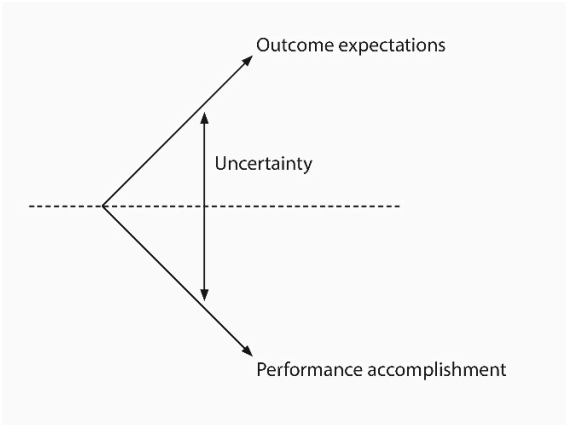

Figure 3. High expections diminish the possibility of performance accomplishment i.e. reached expectations. The gap between expectations and actual performance can be understood as uncertainty..

Physical accomplishment

Physical capacity and physical performance were identified as important aspects of performance accomplishment (Paper II) and must therefore be understood in the context of HTx. Physical capacity has also been shown to have a strong association with long-term survival (Yardley, Gullestad & Nytroen, 2018), while low physical activity is associated with poor transplant clinical outcomes (Smith et al., 2019). Physical capacity has been identified as a modifiable risk factor following transplantation (Langer, 2015). Capacity to exercise is related to depression and HRQoL, e.g. the SF-36 dimensions of bodily pain, general health perception and vitality, indicating that exercise ability originates from different aspects and involves complex interactions, i.e. cardiac, psychological and muscular (Ulubay, Ulasli, Sezgin & Haberal, 2007). A low level of physical activity has been associated with not working, low expectations and self-confidence regarding recovery, poor health status and limited physical outcomes among solid organ recipients (van Adrichem et al., 2018). Furthermore, it has been shown that despite substantial

improvement in functional capacity, heart recipients continue to exhibit limited exercise performance in terms of heart rate and oxygen consumption response (Carter, Al-Rawas, Stevenson, Mcdonagh & Stevenson, 2006).

The importance of exercise during recovery should not be underestimated. Physical performance was described by means of expectations of resuming daily activities and regaining excellent physical condition (Paper II). Unfulfilled expectations are a sources of uncertainty described in the interviews as *doubting performance* and *doubting the recovery process* (Paper I). Illustrating a lack of performance accomplishment one year after transplantation, leading to uncertainty when incongruent with expectations. Schmidt & DeShon (2010), identified ambiguity, which is one form of uncertainty, as a boundary condition between performance and self-efficacy. Furthermore, self-efficacy was found to be negatively related to performance when ambiguity was high and positively related to performance when ambiguity was low (Bandura, 1977; Schmidt & DeShon, 2010). The findings of Paper III showed that those not being recovered i.e. unreached accomplishment, reported lower level of self-efficacy. Thus, indicating that performance accomplishment is important to consider as it has the potential to strengthen self-efficacy when accomplished but being a source to uncertainty when not possible to reach. But also the possibility of the other way around, meaning uncertainty hampers the ability to perform and thereby diminishes performance accomplishment.

Returning to work - an important indicator of accomplishment

Returning to work was an important factor of accomplishment and heart recipients who were working had significantly higher self-efficacy (Paper II and III). Returning to work is an important aspect of social functioning (Cavallini et al., 2015). A study by Jalowiec et al. (2007) shows that 90% of heart recipients had work related problems, either not working at all or health related problems at work one year after transplantation (Jalowiec et al., 2007), Employment after transplantation is reported in different studies to be between 12-70% and seems to increase over time (Cupples et al., 2006). Employment status pre-transplantation is an important predictor of returning to work (Samaranayake, Ruygrok, Wasywich & Coverdale, 2013), where 60% of those in employment pre-transplant were working one-year post transplant (Marsh et al., 2020). These figures constitute reason for discussing both heart recipients' and professionals' expectations of returning to work.

A study by White-Williams et al. showed that at the five year follow-up, heart recipients who were working had fewer co-existing illnesses and CAV. Moreover, they had less overall functional disability and less physical and psychosocial disability than non-working patients. Heart recipients

who were working reported better overall satisfaction with life (White-Williams et al., 2011) and increased quality of life (Shih et al., 2000). As going returning to work was identified as an important part of performance accomplishment (Paper II) and as a source of uncertainty when not achieved (Paper I), expectations about when it is reasonable to return to work must be discussed both before and after transplantation. It must be individually evaluated in relation to existing performance barriers and the time-consuming adaptation process (Lindberg, Almgren, Lennerling & Forsberg, 2020).

Symptoms, set-backs and complications as barriers to performance and sources of uncertainty

Expectations and disappointments were frequently described regarding unachieved recovery and the duration of recovery. The heart recipients had expected to recover faster than they did, leaving them pondering if they would ever recover fully (Paper I and II). The findings in Paper III show that the majority of the heart recipients are reasonably recovered. However, the hypothesis that poor recovery is associated with lower levels of self-efficacy was confirmed. This is in line with previous findings revealing that the level of self-efficacy was associated with the extent to which the illness interfered with daily activities (Gentry, Belza & Simpson, 2009). A recent publication reported that three years after HTx the adaption process was successful and that the heart recipients had achieved a level of acceptance and sufficient life satisfaction (Lindberg et al., 2020). Thus, adaptation after HTx seems to require time.

Fatigue as a barrier to performance accomplishment

Fatigue was a prominent symptom mentioned in the interviews (Paper I and II) and was further explored in Paper IV. Those heart recipients experiencing fatigue, described it as a symptom difficult to understand in general and especially in relation to the transplantation. Uncertainty will arise if the person is unable to appraise the symptoms (Mishel, 1988), complications and side-effects, resulting in cognitive difficulties in interpreting their impact on the disease. Fatigue might be hard to interpret and foresee because of its ambiguous character, suggesting that it is a source of uncertainty.

Fatigue was also a barrier to the recovery process (Paper I) and the heart recipients' ability to perform and achieve progress in various activities. Furthermore, fatigue was challenging within close relationships because of its great impact on daily activities. The heart recipients worried that their relationships would break, due to expectations from family and friends about regaining energy with the new heart. All of the above aspects are sources of

uncertainty, defined as doubting the recovery process and doubting close relationships (Paper I), as well as having an impact on performance accomplishment and thus self-efficacy (Paper II). Fatigue needs to be highlighted and addressed by transplant professionals, heart recipients and their significant others, both before and after the transplantation, as fatigue is also present pre-transplant and is a common symptom among patients with heart failure (Fredriksson-Larsson, Alsen & Brink, 2013). The recurrence of fatigue might also contribute to stress.

The heart recipients experienced that the transplant professionals neglected the complexity of the symptom and did not take their fatigue seriously. Confirming that the outcomes of laboratory tests and other assessments were good and declaring that nothing was wrong led to uncertainty, as it was not congruent with the heart recipients' experience. This approach made the heart recipients feel abandoned (Paper I), while Paper IV revealed that for those suffering from severe fatigue it is a troublesome symptom affecting the recovery process and their ability to return to work, as well as possibly acting as a barrier to self-management. Sharpe & Wilks confirm this observation that patients commonly regard fatigue as important because it is disabling and thus has a great impact on daily activities and quality of life, whereas physicians do not, as it isn't diagnostically specific(Sharpe & Wilks, 2002). It is also reported that the person´s understanding of her/his illness is an important aspect of the assessment, as confirmation that fatigue is a common symptom and thereby not necessarily a sign of other diseases, can often be a relief to the patient (Sharpe & Wilks, 2002).

In a review by Drachler et al. (2009) the prerequisites for managing illness among patients with chronic fatigue syndrome were identified as the need to make sense of symptoms and obtain a diagnosis, gain information about the symptoms, develop strategies for how to become active, manage barriers and maintain social participation, as well as sufficient support from caregivers and family. Recommended therapies for managing fatigue are cognitive behavioural therapy and graded exercise therapy (Sharpe & Wilks, 2002; White et al., 2011). Thus, management of fatigue also stresses the importance of supporting heart recipients by means of exercise. Fatigue and weakness were symptoms reported by liver recipients that affected their health and ruled out the possibility of returning to work post-transplant (Kang et al., 2018). Among female heart recipients functional status and depression were related to fatigue (Reyes et al., 2004). Compared to those suffering from other chronic diseases patients diagnosed with chronic fatigue syndrome appeared strikingly disabled in terms of HRQoL, especially in the role functioning, social functioning and vitality domains (Hardt et al., 2001). In patients who have had a cardiac event, fatigue interfered with all levels of physical activity

and quality of life, which led to failure in engage in the amount, intensity and frequency of recommended physical activity (Newland, Lunsford & Flach, 2017). Persons who have had a myocardial infarction described fatigue as incomprehensible, i.e. unpredictable, unrelated to effort and as occurring for unknown reasons (Newland et al., 2017). Heart recipients have reported that general activities, enjoyment of life and mood were the aspects most affected by fatigue (Chou et al., 2017).

Consequently, fatigue must be acknowledged by transplant professionals as important to address and manage in order to minimize its effect on the ability to handle daily activities, proceed with recovery and accomplish expected performance, i.e. self-management. Fatigue is also a problem pre-transplant and when it returns post-transplant it might contribute to more stress. Paper IV shows the relationship between fatigue and self-efficacy. As fatigue explained 40% of the variance in self-efficacy, it suggests that fatigue affects self-efficacy and thereby self-management.

Low psychological well-being - a barrier to self-efficacy

Overall, self-reported psychological well-being was good for the whole group but with a wide inter-quartile range, indicating a wide variety within the measures. The median self-efficacy among those who reported low psychological well-being was poor (median 6.8 (p_{25} 5.65, p_{75} 9.0)), but there were no significant differences in self-efficacy between those who reported high or low psychological well-being. However, when comparing the median self-efficacy for the whole group, which was 8.3, one can see that low psychological well-being is associated with poor self-efficacy (Paper III). Despite the fact that there are no measures of uncertainty in this study, low psychological well-being could reflect emotional arousal or distress, potentially originating from uncertainty.

The PGWB-Index was also developed to measure subjective well-being and distress (Dupuy, 1984). Emotional arousal (Paper II) might be a consequence of uncertainty, constituting a reaction to stressful and strenuous situations that to a high degree has a negative effect on performance (Bandura, 1977). The most negative effects can be seen when emotional arousal appears early in the process, affecting perceived self-efficacy (Bandura, 1977), which suggests that uncertainty per se inhibits performance and self-efficacy.

Pre-transplant treatment with Mechanical Circulatory Support affected post-transplant expectations

The heart recipients with pre-transplant MCS compared their recovery after MCS-surgery with the recovery after transplantation (Paper II), leading to incongruence between experience and expectation. Those findings revealed that pre-transplant treatment with MCS was associated with significantly lower levels of self-efficacy (Paper III). This knowledge is somewhat surprising, as one might have thought that the previous accomplishment of recovering from MSC-surgery would have strengthened self-efficacy. This again indicates that unfulfilled expectations affect the post-transplant recovery and adaptation process. The experience of living with an MCS and expectations on the transplantation are probably of great importance for how the transplantation is experienced, thus needs to be part of the evaluation of the patients' expectations.

An interview study by Wilhelms et al. (2017) revealed that worry about the risks involved having to undergo a new surgery, risks and limitations associated with the immunosuppressive medical regimen and concerns pertaining to rejection. Another aspect was satisfaction with life with the LVAD (Wilhelms, Blumenthal-Barby, Kostick, Estep & Bruce, 2017), which from the patient perspective reduced both the incentive and requirement to undergo a transplantation. However, these experiences can change over time (Standing et al., 2017; Wilhelms et al., 2017) along with the patient's adaptation process of living with an MCS and must be frequently evaluated. In another interview study, the patients experienced ambivalence towards MCS treatment comprising gratitude and frustration, while as they tried to prepare themselves for transplantation they experienced ambivalence in the form of hope and fear (Overgaard, Grufstedt Kjeldgaard & Egerod, 2012).

Although a lifesaving event, the whole process of implanting a MCS device, disrupts self-identity and leads to an experience of time where basic aspects of life will be questioned, thus patients are in a liminal time, waiting for a new time and an improved state (Standing et al., 2017). It was also described that living with a MCS became a new normality, but an unstable one, with continuous risk of infection or pump failure. However, the unstable existence will continue even after transplantation. MCS recipients as well as heart recipients will still be followed by the question "How long will it last?" (Standing et al., 2017), thus uncertainty about survival is a continuum as highlighted in this thesis.

Self-management support with a person-centred approach

Partnership is advocated in both chronic illness management (Yach, 2002) and person-centred care (Ekman, 2014). However, the concept of self-efficacy requires behavioural change in order to manage physical and psychological challenges.

A meta-synthesis by Shulman-Green et al. (2012) defined three categories of self-management processes, i.e. focusing on illness needs, activating resources and living with chronic illness. The category *focusing on illness needs* included all the practical and medical tasks and skills necessary to handle the chronic illness (Schulman-Green et al., 2012). This is the category focused on by health professionals and also defined as medical management by Lorig & Holman, 2003. This indicates that health care providers in general and transplant professionals in particular fail to address essential aspects. Thus, the meta-synthesis also described *living with chronic illness* as consisting of four tasks; processing emotions, adjusting, integrating illness into daily life and meaning-making (Schulman-Green et al., 2012). Those tasks could be transferred into the by Lorig & Holman, (2003) defined categories emotional and role management. Thus, those are important processes within the self-management concept. Seen from the perspective of an uncertain human being and with the understanding provided by this thesis, self-management support with a person-centred approach, based on the framework developed by Mishel will help transplant professionals to address role and emotional management and thereby providing support comprising the essential aspects. The results of Paper I are consistent with the findings in another meta-synthesis from Schulman-Green et al. (2016) that summarizes factors affecting self-management. These included knowledge, beliefs, psychological distress, motivation, comorbidities, illness severity, symptoms/side effects, cognitive functioning, psychosocial aspects and aspects connected to the healthcare system (Schulman-Green, Jaser, Park & Whittemore, 2016).

Person-centred care has been shown to enhance self-efficacy and reduce uncertainty (Dudas et al., 2013; Fors, Taft, Ulin & Ekman, 2016), while self-efficacy and uncertainty have been found to predict self-care behaviour. With adequate support and a credible relationship (Dudas et al., 2013), i.e. partnership, between healthcare professionals and the heart recipient, an understanding of the situation will be created, enabling the recipient to handle the situation, i.e. self-management.

In order to provide adequate self-management support, it is essential to clarify the purpose of the support. A study by Morgan et al. (2017) stated that support can be narrow, focused on helping the person to manage in terms of

biomedical and disease-control. This approach is often associated with experiences of frustration and failure potentially leading to uncertainty and low self-efficacy. Self-management can also have a broader focus, aimed at helping people manage well (or live well) *with* their conditions (Morgan et al., 2017). The latter approach makes it easier for the person to manage disease control in a wider perspective, because attention is on what is important to her/him and how the healthcare professional can support her/him in order to shape her/his own life (Morgan et al., 2017). This strengthens the argumentation in the present thesis that there is a need to change perspective and focus on the person's definition of her/his needs, discuss expectations and supply sufficient individual support.

The overall understanding of the results

Being a heart recipient means being in uncertainty as evidenced by doubting survival, doubting the recovery process, doubting one´s performance, struggling with close relationships, feeling abandoned and doubting the future (Paper I). Uncertainty is inherent in being a person, thus considered a natural state that is not necessary to manage or reflect on every day. However, uncertainty will arise when illness or other life-threatening events occur and potentially impinge on essential parts of daily life. The transition from critical illness to better health involves managing a chronic condition due to life-long medication and a permanent risk of graft-rejection and infections. This inevitably triggers pondering about survival, i.e. "How long will it last?"

Symptoms, complication and set-backs are sources of uncertainty. The level and impact of uncertainty depend on how the sources of distress are interpreted and understood by the heart recipient in relation to the transplantation as well as her/his expectations. Expectations are also important in relation to self-efficacy, as self-efficacy address the expectations and the heart recipient's belief in her/his ability to fulfil those expectations. The core of self-efficacy in the context of heart transplantation seemed to be the ability to balance expectations in order to avoid frequent disappointments, i.e. adjusting expectations to the present performance ability. When interpreted with reference to Mishel's framework, this means reducing uncertainty in order to enhance self-efficacy.

Self-efficacy depends on the person´s expectations. Expectations can vary between individuals, which is why it is important to gain information about each heart recipient's expectations in relation to having a new heart. Expectations that exceed the accomplishments are a source of disappointment, e.g. when fatigue is a significant problem (Paper IV). Furthermore, if the heart recipient is unable to attribute meaning to, or identify an explanation for being unable to fulfil expectations, i.e. interpret symptoms such as fatigue and complications and understand how they affect her/his abilities, it will be a source of uncertainty. Thus, unmet expectations lead to disappointment and uncertainty which, if not addressed and managed,

are sources of distress. It is important to acknowledge that the expectations of the transplant professionals affect the heart recipient's own expectations as the transplant professionals are a credible provider of information and knowledge. It is therefore vital that transplant professionals have the knowledge and understanding about how heart recipients experience the process, and what affects them during it, in order to provide sufficient support. Transplant professionals must help the heart recipients to interpret their symptoms, complications and the side-effects of medications, as well as provide support in order to adjust expectations in relation to the present abilities, thus facilitating the process of adaptation in order to achieve health.

By using Michel's theoretical framework of uncertainty in illness (Mishel, 1990) the understanding from this thesis is that being in uncertainty is a source of distress. In chronic illness uncertainty arises when the patient, in this case the heart recipient, loses the sense of coherence, shattering her/his view of life. In order to manage uncertainty, heart recipients need to embrace uncertainty and treat it as a natural part of life, which becomes part of a transition toward a new view of life. Healthcare professionals are mostly engaged with the positivistic and mechanistic paradigm, i.e. test results and prognosis, valuing control and certainty, allowing no place for uncertainty and probabilistic thinking. This approach hinders the heart recipient's ability to adopt a probabilistic worldview and thereby blocks or constrains the transition towards a new meaning and view of life. When this transition is hindered or blocked the situation appears more cryptic and becomes more difficult to cognitively interpret, thus creating distress within the heart recipient. If the transition remains blocked the distress might accelerate and lead to a condition that resembles that seen in post-traumatic stress disorder, which can arise from exposure to uncertainty and unpredictability.

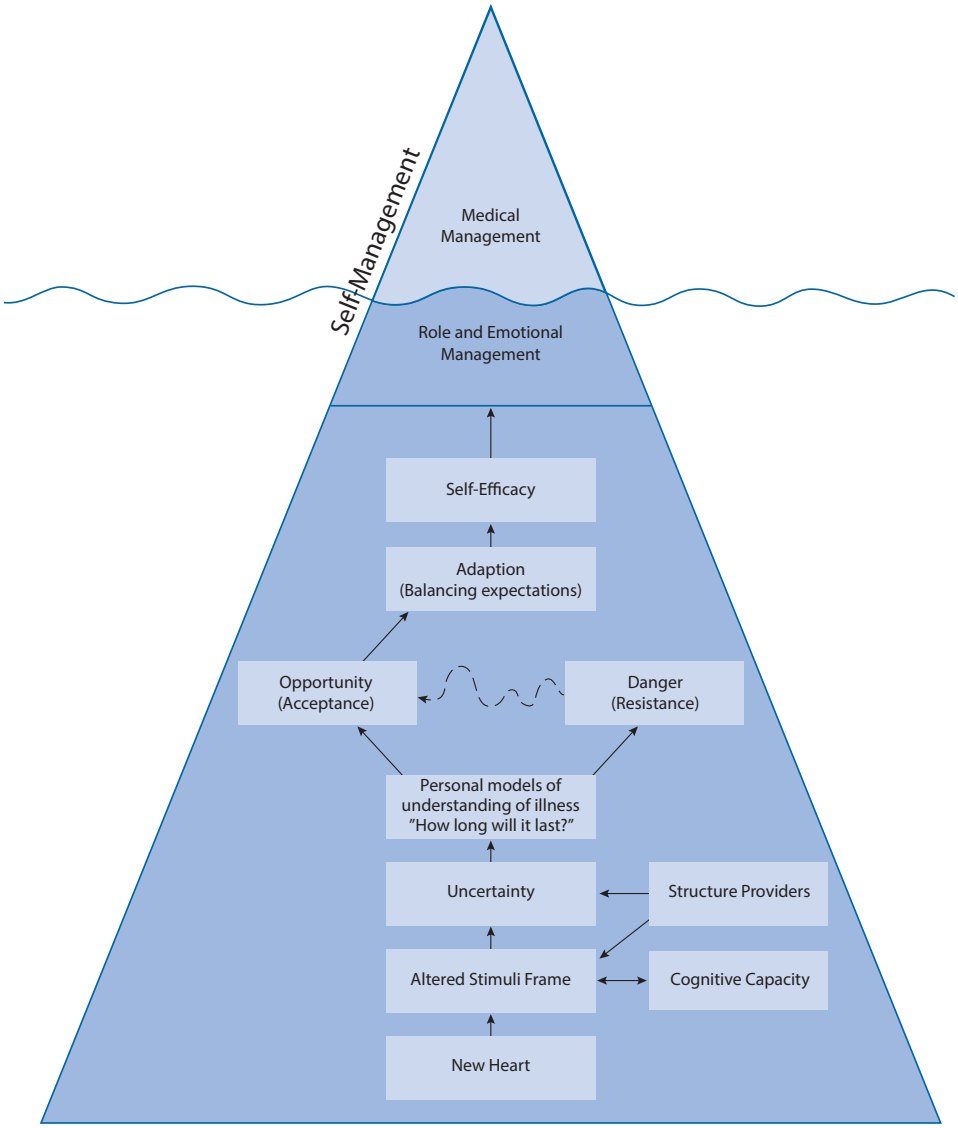
Self-Management
Medical Management
Role and Emotional Management
Self-Efficacy
Adaption (Balancing expectations)
Opportunity (Acceptance)
Danger (Resistance)
Personal models of understanding of illness "How long will it last?"
Uncertainty
Structure Providers
Altered Stimuli Frame
Cognitive Capacity
New Heart

Figure 4. Michel's theoretical framework (see Figure 1, p.26) adjusted to the context of heart transplantation.

Having a new heart leads to an altered stimuli frame, including new symptoms and an unfamiliar situation not always congruent with what was expected. The altered stimuli frame might include symptoms which in turn reduces cognitive capacity. Reduced cognitive capacity, on the other hand, hampers the ability to interpret the altered stimuli leading to uncertainty. Structure providers needs to help the heart recipient process and interpret the new situation included in the stimuli frame. Having a new heart implicitly means being in uncertainty. The new situation "life with a new heart" will be appraised by the heart recipient depending on her/his personal understanding of the illness, outermost ending up in the question "How long will it last?". The new situation will be appraised as either a danger or an opportunity. If the situation is appraised as a danger this means the situation is valued by the heart recipient as a threat including a negative outlook of the future. This is a stressful state generating negative emotions and stress. Being in resistance of accepting the uncertain situation ultimately blocks the process of adaptation. In order to achieve adaptation the person needs to accept the uncertainty, and value the uncertainty as an opportunity. When the new situation is valued as an opportunity, adaptation to the new situation is possible. Adaptation involves balancing expectations and managing uncertainty. Once adaptation is reached, self-efficacy can be strengthened, which in turn is a mediator for self-management i.e. Role, Emotional and Medical management. Thus, those complex processes, of handling the new situation, being a person with a new heart, needs so be acknowledge by transplant professional. It is important to understand that those processes might be hidden under the surface, not always evident to transplant professionals. However, this is the foundation for helping the heart recipient managing their life living with a new heart.

Conclusions

This thesis contributes to an understanding of self-efficacy in the context of heart transplantation as well as uncertainty as a prominent factor affecting both the recovery process post-transplant and the adaptation to a new view of life. Thus, understanding these processes might be helpful for transplant professionals when guiding and supporting heart recipients during their post-transplant period.

The main conclusions of this thesis are

- Uncertainty is a prominent phenomenon during the first-year post transplantation.
- The heart recipient's interpretation of complications, setbacks and symptoms together with expectations are sources of uncertainty.
- Heart recipients are unlikely to be recovered and to have adapted to their new situation one-year post transplant, which emphasises the importance of reconsidering the timeline for follow-up.
- Performance accomplishment is a key marker of self-efficacy.
- Self-efficacy from the heart recipients' perspective is about finding the optimum level of expectations, depending on her/his ability.
- Balancing expectations might minimise disappointments and consequently distress.
- Symptoms, complications and setbacks have a major impact, causing disappointments and affecting perceived self-efficacy.
- Pre-transplant MCS treatment is a source of transplant outcome expectations affecting the recovery process and adaptation. Thus, the pre-transplant MCS group might need special attention during post-transplant follow-up.
- It is possible to achieve a high level of self-efficacy after HTx.

- High levels of self-efficacy might be a marker for returning to work and being reasonably recovered.
- Low psychological well-being might be associated with low self-efficacy.
- Physical aspects of accomplishment might have a greater impact on self-efficacy than mental aspects.
- The reported levels of fatigue were moderate. However, the interviews imply that for those heart recipients suffering from fatigue it is disabling and affects the recovery process and performance accomplishment ability.
- Systematic evaluation and screening of symptoms, complications and well-being should be mandatory in order to identify potential barriers in the recovery process for which support is needed.
- HTx affects the heart recipient's whole existence as she/he has known it and it therefore it needs to be reconsidered and reconstructed. Thus, identity transformation as well as role and emotional management, must receive more attention.

Clinical implications

This thesis contributes with the heart recipient's perspective of receiving a heart. The findings can be used to develop follow-up care in order to address the needs identified. Clinical implications based on the findings will be presented as follows:

- Self-management support with a person-centred approach to address uncertainty
- Acknowledging performance accomplishment as a key aspect of developing self-efficacy
- Systematic use of self-report questionnaires
- Adopting a new perspective to improve follow-up.

Self-management support with a person-centred approach to addressing uncertainty

The first year after HTx is influenced by uncertainty, regardless of the objective outcome of the transplantation and recovery process. Educational conversations starting with the question "How do you understand your situation?" are essential in order to grasp the recipient's interpretation of the situation. This approach is also a foundation for establishing a credible relationship between the recipient and the healthcare professional. The interviews in Paper I, revealed that the heart recipients felt that they lacked adequate support from transplant professionals to be able to master their situation. The recipients' interpretation of complications, setbacks and symptoms in combination with their expectations about recovery and life as a heart recipient were sources for uncertainty. Some recipients expressed that their experience was not taken seriously and thereby they felt abandoned. The heart recipients also expressed a lack of emotional support in order to manage and understand their new situation. Establishing a credible partnership with the recipient will help transplant professionals to explore and understand the

barriers experienced in the recovery process as well as in the adaptation to a new situation. Consequently, this will enable transplant professionals to provide heart recipients with sufficient information about causes and consequences of symptoms based on the heart recipient's perspective, thus reducing uncertainty and helping the heart recipient in the adaptation process towards acceptance of the new life situation. However, it is of crucial importance to understand that uncertainty is primarily a self-perception about one´s own cognitions or ability to derive meaning. Thus, a person who perceives herself/himself as uncertain, is per se uncertain irrespectively of how much knowledge she/he possesses. Based on the findings on Paper I and II, heart recipients are unlikely to be recovered or have adapted to their new situation one year post-transplant, emphasising the importance of reconsidering the timeline for follow-up and self-management support.

Acknowledging performance accomplishment as a key aspect of developing self-efficacy

Acknowledgement and awareness of the importance of performance accomplishment as a vital aspect of the recovery process and a key marker of the development of self-efficacy are necessary. Performance accomplishment enables expectations to be achieved. Thus, the consequences and impact of unfulfilled expectations, i.e. failed accomplishment, must be acknowledged as it is a source of disappointment and uncertainty. A clinical psychologist is probably the key professional in the team for introducing tools to balance expectations, which might minimise disappointments and consequently distress. Symptoms, complications and setbacks have a major impact, causing disappointments and affecting perceived self-efficacy. Thus, discussing the patient's goals and expectations about the heart transplantation as well as her/his expectations of the recovery process, is of great importance in order to balance expectations in relation to individual abilities. Due to the fact that important aspects of performance involve physical achievements, physiotherapists have a vital role in helping heart recipients to set goals and challenging them to dare to advance and balance expectations and goals. Self-efficacy from the heart recipient's perspective is about finding the optimum level of expectations, depending on individual abilities. Recovery after HTx might need to embrace a rehabilitation focus. That would probably be very helpful in addressing self-management barriers. This would potentially facilitate the recovery process by developing a structured rehabilitation plan and thereby possibly easing the struggle of adaptation and promoting acceptance of the new situation.

Systematic use of self-report questionnaires

Based on the findings it was revealed that symptoms, setbacks and complications as well as how they are interpreted and experienced by the heart recipients have a major impact on the recovery process. In addition, these factors have a major impact on the possibility of achieving performance accomplishments, thus, affecting both self-efficacy and uncertainty.

In order to identify symptoms and provide adequate support, the use of self-report instrument is needed to map out symptoms and complications in a structured way. Furthermore, systematic screening enables evaluation of advances in the recovery process after HTx. Self-report instruments can be seen as a guide when talking to patients, as they help healthcare professionals to identify existing symptoms as well as expectations, beliefs, how daily life is affected and what kind of support is required to manage the symptoms. Our use of diagnostically non-specific instruments also contributed to revealing symptoms that seem to have a major impact on recovery. Despite the fact that fatigue was moderate, the interviews revealed that those suffering from fatigue were burdened. This demonstrates the importance of combining information from self-report questionnaires with person-centred dialogue.

Adopting a new perspective to improve follow-up

The point of departure in self-efficacy means we can change the patients' behaviour in order to achieve effective self-management. The point of departure in uncertainty implies the need to embrace the patient's experiences and establish a partnership. This will enable healthcare professionals to grasp the underlying sources of uncertainty and stress, and thereby helping the patient to reduce and/or manage uncertainty and embrace a probabilistic worldview. In turn, this might lead to enhanced self-efficacy and effective self-management, but implies embracing a probabilistic view. Persuading the heart recipient to perform new accomplishments, when not achievable due to physical barriers, might create incongruence between what is expected and what is possible to achieve. Using verbal persuasion as a self-efficacy enhancing strategy is dependent on the perceived credibility of the persuaders, i.e. transplant professionals, their prestige, trustworthiness, expertise and assuredness. Verbal persuasion is commonly used by healthcare professionals because it is easy, hoping that patients will do as they are told. However, this approach fails to identify fundamental aspects affecting the patient's behaviour and choices in life. Instead by embracing the patient's

perspective of the situation, letting that be the starting point for the dialogue, the heart recipients' actual needs can be addressed and a sufficient self-management support can be provided. Thus giving heart recipients the prerequisites to achieve sufficient self-management.

HTx has been described as a disruption of the patient's identity and bodily integrity, thus adaptation after heart transplantation includes regaining a new view of self or self-identity (Mauthner et al., 2015). The journey from pre-transplant to post-transplant is described by three themes *towards death, the frontier between life and death* and *towards life* (Palmar-Santos et al., 2019, p. 50). Together with the findings of this thesis, this stresses the importance of transplant professionals starting to focus on other aspects than only managing medical skills. It is necessary to acknowledge that HTx affects the person's whole existence and therefore needs to be reconsidered and reconstructed. Thus, self-management support must address uncertainty, including emotional and role-management, in order to achieve adequate medical management.

Further research

- Prospective studies are of great importance for establishing how different factors affect each other. An ongoing prospective study within the SMATT-project is following heart transplant recipients from pre-transplant for up to five years port-transplant. This approach can hopefully help us to better understand how different symptoms and factors affect self-efficacy.
- As uncertainty as a concept was revealed during the inductive process, no instrument for measuring uncertainty was included. Based on the findings of this thesis, exploring the trajectories of self-efficacy and uncertainty from the pre-transplant period, could be helpful for gaining increased understanding.
- Person-centred interventions with focus on symptom management and uncertainty might contribute to more evidence on how to structure follow-up care.
- Based on the findings of this thesis, further research should also address symptoms and symptom distress in order to explore and gain more understanding of their complexity. This is important in order to develop adequate self-management support.

Summary in Swedish

Svensk sammanfattning

Hjärttransplantation är den mest effektiva behandlingen för personer med terminal hjärtsvikt, och kan bli aktuell när alla andra behandlingsalternativ har uttömts och inte längre har effekt. Hjärttransplantation bör ses som ett kroniskt tillstånd med tanke på den livslånga medicinska behandlingen med immundämpande läkemedel som krävs för att undvika avstötning av det nya hjärtat. Från ett kliniskt perspektiv utgör avstötning av hjärtat samt infektioner de största riskerna för hjärtmottagaren. Hjärtmottagaren behöver delta i ett omfattande uppföljningsprogram med syfte att identifiera tidiga tecken på avstötning, infektioner eller andra komplikationer. Detta innefattar att man deltar i hälsofrämjande aktiviteter, så som medicinering, fysisk aktivitet, undvika sol, samt följa kostrestriktioner, för att undvika komplikationer till följd av den medicinska behandlingen.

Hjärttransplantation är en behandling som förlänger liv och möjliggör bättre hälsa och livskvalitet. Det är en krävande behandling och återhämtningen är kantad av medicinska, fysiska och psykosociala utmaningar som kräver nya anpassningar. För att klara detta krävs stöd från sjukvården som är inriktat på att hjälpa hjärtmottagaren att hantera dessa utmaningar.

Sjukvårdssystemet är primärt organiserat med fokus på medicinska undersökningar med syfte att identifiera avstötning och andra komplikationer efter hjärttransplantationen. Mindre fokus läggs på hälsoförebyggande åtgärder och stöd för effektivare self-management (ung. egenvård).

Self-management syftar på aktiviteter som människor utför för att skapa ordning, struktur och kontroll i sina liv. Self-management innefattar hantering av medicinska, emotionella aspekter samt hantering av ändrade livsroller. Hjärtmottagaren, måste utveckla förmågor för att kunna hantera de olika utmaningarna som innefattas i att hantera transplantationen. I kontexten hjärttransplantation innebär det att ta sina mediciner, följa matrestriktioner samt undvika infektioner. De emotionella och sociala aspekterna innefattar att hantera känslor kopplade till att leva med en kronisk sjukdom, att vara en

hjärtmottagare och försöka fortsätta leva, återgå till arbete och andra sociala aktiviteter.

Self-efficacy är ett begrepp som syftar på personens tro på sin egen förmåga att hantera en given uppgift. Det är definierat som tillit till att kunna ändra beteende för att nå ett uppsatt mål. Self-efficacy är associerat med ändringar i hälsofrämjande beteende som påverkar både hälsa och framtida hälsa.

Sjukvårdspersonal och utbildningsprogram med hälsofrämjande syfte tenderar att fokusera på faktorer kopplade till beteende och medicinsk behandling, och missar därmed att uppmärksamma behovet av emotionellt stöd samt stöd att hantera livsroller.

Ovisshet i relation till sjukdom är definierat som en persons oförmåga att förstå händelser kopplad till sjukdomen. Ovisshet uppstår när situationen relaterad till sjukdomen upplevs som otydlig, komplex eller oförutsägbar. Ovisshet har i tidigare forskning visats vara en framträdande upplevelse i sjukdomssammanhang. Det har visat sig vara kopplat till känslomässig stress, oro, ångest och depression.

Artikel I hade syftet att undersöka hur upplevelsen var av att ha fått ett nytt hjärta. Därför genomfördes fjorton djupintervjuer med personer som genomgått en hjärttransplantation och som var inbokade för ettårsuppföljning efter transplantationen. Utgångspunkten var att hjärtmottagarna skulle berätta fritt om sin upplevelse av att ha fått ett nytt hjärta baserat på det första året som nu passerat. Analysen av intervjuerna gjordes med fenomenologisk hermeneutisk metod. En metod som används för att kunna beskriva en persons upplevelse i relation till en händelse. Analysen av intervjuerna visade att ovisshet var en framträdande upplevelse under första året. Hjärtmottagarna hade mycket tankar om överlevnaden och hur länge det nya hjärtat skulle hålla. De som hade en mer utmanande återhämtning efter transplantationen tvivlade på att de skulle bli återhämtade alls. Det fanns också en osäkerhet hos hjärtmottagaren om man gjorde tillräckligt för att må bra och återhämta sig och optimera sina chanser till ett bra liv. De beskrev vidare att relationer upplevdes utmanande och en vanlig känsla var att man efter transplantationen förväntades må bra och ”vara frisk” igen vilket kändes jobbigt om så inte var fallet. Vissa hjärtmottagare försökte i vissa fall verka piggare än de egentligen var för att möta dessa förväntningar och inte tära på relationerna i onödan. Andra kände sig övergivna och saknade stöd för sig själv och sina anhöriga för att hantera situationen. Slutligen fanns också en ovisshet om framtiden och om möjligheten till arbete, våga köpa hus eller se sina barn växa upp.

Artikel II utgick från samma intervjumaterial som artikel I, men analyserades istället med en annan metod kallad deduktiv innehållsanalys. I den analysen

användes teorin bakom begreppet self-efficacy (tilltro till sin egen förmåga att hantera behandling). Viktiga aspekter ur teorin valdes ut och användes för att analysera texten. Analysen visade att uppnådd prestation (performance accomplishment) och att därmed att uppnå uppsatta mål var den mest framträdande och betydande faktorn för Self-efficacy efter hjärt-transplantation. Prestationen kunde delas upp i fysisk, social och mental prestation. Utebliven prestation ledde till besvikelse om förväntningarna var högre än den möjliga prestationen. Därför var en av slutsatserna, att man måste hjälpa hjärtmottagaren att balansera sina förväntningar så att de motsvarar den möjliga prestationen. Komplikationer, bakslag och biverkningar från läkemedel hade stark påverkan på återhämtningen och därmed möjligheten att prestera och uppnå sina förväntningar. När den förväntade prestationen uteblev var det en källa till stress men också till ovisshet om man inte hade en tydlig bild av varför prestationen inte kunde uppnås.

Artikel III var en kvantitativ tvärsnittsstudie baserad på data insamlad med hjälp av självskattnings instrument. 79 hjärtmottagare som hade sin årsuppföljning 1, 2, 3, 4 eller 5 år efter transplantationen inkluderades. Självskattningsinstrumenten var utvalda för att mäta self-efficacy, grad av återhämtning och psykologiskt välbefinnande hos hjärtmottagarna. Resultaten visade att self-efficacy var generellt hög för hela gruppen utan skillnad mellan män och kvinnor. Högre self-efficacy sågs hos de som återgått till arbete och de som inte haft en hjärtpump inopererad som stöd för hjärtat innan transplantationen. De flesta var rimligt återhämtade (81%), men 19% rapporterade sig inte vara återhämtade. Self-efficacy hos de som inte var återhämtade var lägre jämfört med de som var rimligt återhämtade det vill säga de som inte var återhämtade hade lägre tilltro till sin förmåga att hantera sin situation. Psykologiskt välbefinnande för gruppen generellt var bra men med väldig stor spridning i de rapporterade värdena vilket visar att välbefinnandet varierar stort inom gruppen.

Artikel IV var också en del av den kvantitativ tvärsnittsstudie som inkluderade 79 hjärtmottagare som hade sin årsuppföljning 1, 2, 3, 4 eller 5 år efter transplantationen. Data samlades även här in med hjälp av självskattningsinstrument, gällande självskattad fatigue (hjärntrötthet), grad av återhämtning och self-efficacy. De självrapporterade nivåerna av fatigue för gruppen hjärttransplanterade var måttlig. De hjärtmottagare som hade hög fatigue skattade lägre nivå av self-efficacy jämfört med de som hade låg nivå av fatigue. De hjärtmottagare som inte var återhämtade och de som hade haft hjärtpump som stöd för hjärtat innan transplantationen rapporterade högre nivå av fatigue än de som var återhämtade eller som inte haft hjärtpump innan transplantationen.

Sammantaget visar denna avhandling att ovisshet är en viktig aspekt att ta hänsyn till i transplantationsprocessen. Ovissheten är en starkt bidragande orsak till stress och oro och påverkar hela hjärtmottagarens situation. Vidare är det viktigt att hjärtmottagarens förväntningar diskuteras för att kunna stödja hjärtmottagaren i att sätta upp balanserade och rimliga mål, möjliga att nå utifrån givna förutsättningar. Ouppfyllda förväntningar kan vara en källa till ovisshet och stress vilket i sin tur påverkar patientens förmåga att hantera sin situation. Symtom, bakslag och komplikationer påverkar möjligheten att prestera och uppnå förväntningar kring återhämtning och hälsa och välbefinnande. Ökad kunskap kring vanliga symtom och hur de upplevs av hjärtmottagaren är grundläggande för att kunna ge adekvat stöd i hantering av symtomen. En ökad kunskap kring symtom och symtomupplevelse ger också transplantationsteamet ett bättre underlag för att hjälpa hjärtmottagarna att ha rimliga förväntningar kring återhämtningen. Att genomgå en hjärttransplantation påverkar hela personen vad gäller livet i stort, roller och identitet. Transplantationsteamet behöver stödja de processer som hjärtmottagaren behöver hantera för att hitta en balans i livet, nå acceptans och därmed möjliggöra adaption till det nya livet med ett nytt hjärta.

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The meaning of being in uncertainty after heart transplantation – an unrevealed source to distress

Matilda Almgren[1,2], Annette Lennerling[3,4], Martina Lundmark[1,2] and Anna Forsberg[2,5]

Abstract

Background: As many as 88% of heart transplant recipients (HTRs) suffer from psychological distress. Both psychosocial factors and physical health are associated with increased psychological distress. However, the causes and impacts of psychological distress are unclear. HTRs strive for a sense of control over their health and daily lives in order to improve their psychological well-being. Perceived control was found to be related to the patients' construction of normality, their emotional state, as well as their thoughts and feelings of uncertainty about the future.

Aim: An in-depth exploration of the meaning of uncertainty during the first year after a heart transplantation (HTX).

Method: A phenomenological–hermeneutic method was employed. Interviews were conducted with 14 patients, four women and ten men, with a mean age of 51 years (range: 28–67 years).

Results: Being in uncertainty after HTX means losing a sense of coherence, which shatters the HTR's whole worldview. The HTRs search for meaning and strive for coherence, which is no longer achievable. By using a nursing theory, we understand that uncertainty should be seen as a natural state among HTRs. It constitutes the starting point from which the HTRs can reorganise their self-structure and find a new view of life. When striving for normality, certainty and predictability (i.e., the healthcare professional's perspective), we block or prolong this process, thus causing distress among HTRs because they are unable to create a new orientation in life.

Conclusion: This study presents a hypothesis of the primary cause of psychological distress after HTX and provides a useful framework for how to approach this condition.

Keywords

Heart transplantation, distress, uncertainty, cardiac event, qualitative study, phenomenological–hermeneutic

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Introduction

Heart transplantation (HTX) is the most effective therapy for prolonging survival among patients with end-stage heart failure.[1] Recent data indicate that the median life expectancy after HTX is now 11 years and that the conditional median survival among transplant recipients who survive the first year is 13 years.[1] The majority of survival gains have been in the first post-transplant year. Cardiac allograft vasculopathy (CAV), rejection, infection and malignancy continue to be the greatest threats to long-term survival after HTX.[1] The need for lifelong immunosuppression continues to generate numerous challenges for

[1]Skåne University Hospital, Thoracic Intensive Care Unit, Lund, Sweden
[2]Department of Health Sciences at Lund University, Lund, Sweden
[3]The Transplant Centre Sahlgrenska University Hospital, Gothenburg, Sweden
[4]The Institute of Health and Caring Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden
[5]Skåne University Hospital, Department of Transplantation and Cardiology, Lund, Sweden

Corresponding author:
Matilda Almgren, Skåne University Hospital, Thoracic Intensive Care Unit, SE-221 85 Lund, Sweden.
Email: matilda.almgren@med.lu.se

transplant recipients.[2] Non-invasive monitoring methods for rejection and CAV may further improve quality of life, thus, minimising complications associated with invasive procedures.[2]

The rationale behind this study is that extended survival often generates new demands in the heart transplant recipient's (HTR's) everyday life due to healthcare professionals' strong focus on self-management in their encounter with the patient.[3] When exploring symptom frequency and distress from 5 to 10 years after HTX, not having psychological problems was a strong predictor of low symptom distress.[4] Unfortunately, psychological disorders and a high level of psychological distress are common after HTX.[5] A total of 32% of HTRs suffer from distress, which seems to persist over time and is present for up to 18 years after transplantation.[6] However, self-report distress questionnaires do not provide the whole picture. Recent qualitative research has shown that as many as 88% of HTRs suffer from distress.[7] The causes of this distress and its impact on the HTR's everyday life are unclear. Both psychosocial factors and physical health were found to be associated with increased psychological distress.[5] Social support[8] and the social situation, as well as support from healthcare professionals, have a great impact on perceived distress among HTRs.[9–11] HTRs strive for a sense of control over their health and daily life in order to improve their psychological well-being.[8] Hallas, Banner and Wray (2009)[12] described perceived control as being related to a patient's construction of normality, their emotional state, as well as thoughts and feelings of uncertainty about the future. Control was important in order to make sense of their prognosis, mental well-being and social world, over which they subjectively perceived that they had minimal control.[12] Feelings of uncertainty about health and quality of life in the future were also reported by Lin et al. (2010).[11] They also described worries about becoming a burden to ones families, unfamiliarity with the healthcare environment or the treatment received and stress caused by invasive examinations and an unstable health condition.[11] Furthermore, uncertainty is a more or less explicit theme in several studies, suggesting that it might be an important aspect of the perceived distress.[7,9–11,13]

In order to explain and to comprehensively understand the phenomenon of uncertainty, we used the reconceptualisation of the middle-range theory of uncertainty developed by Mishel (1990).[14] This theory suggested that it is the uncertainty that evolves early in the illness that contributes to the sense of disturbance[14] seen among many patients with chronic illnesses. During illness, uncertainty may be a state in which a person can experience a transition to a new perspective in life with a higher order and a more complex orientation. This constitutes the starting point from which the patients can reorganise their self-structure and find a new view of life.[14] Striving for control and predictability is a way for a person to achieve and maintain order and coherence, as minted by the western society's point of view.[14] In medicine, there is an implicit expectation that the cause of an illness can be determined with certainty and that the illness can be controlled.[14] However, there is a need for the development of probabilistic and conditional thinking in order to create a new orientation towards life, including abandoning the expectation of continual certainty and predictability.[14] According to Mishel (1990),[14] by adopting such probabilistic thinking, patients with a chronic condition might accept that there are many options and opportunities in life that one can choose to focus on. This creates a need for redefining what is important in life. They can also learn to appreciate and accept the fragility and impermanence of life, which in time leads to a more balanced and stable existence.[14]

Being a HTR is a condition in which *per se* one is frequently exposed to uncertainty and unpredictability, especially during the first post-transplant year, when HTRs are at high risk of infections, graft rejection and might be frequently hospitalised due to various complications. Thus, the aim of this study is an in-depth exploration of the meaning of uncertainty during the first year after a HTX.

Method

We chose a phenomenological–hermeneutic approach based on Ricoeur's philosophy[15,16] by using the phenomenological–hermeneutic method developed by Lindseth and Norberg,[17] as the focus was the patients' lived experiences, as well as interpretation and understanding of the meaning of being in uncertainty during the first year after a transplantation.

Setting

This multicentre study was carried out at the two hospitals in Sweden where HTXs are performed. A total of 1007 HTXs have been performed in Sweden until the end of 2014, of which 67 took place in 2014.[18]

Participants

A total of 16 patients were invited to participate in this study, of whom one declined and one was excluded due to ethical considerations. The inclusion criteria were HTRs who were due for their 12-month follow-up and who were willing to participate in an interview. We excluded patients who were medically unstable, had limited knowledge of the Swedish language or were under the age of 18 years. The informants were included consecutively. The 14 patients who were interviewed comprised four women and ten men with a mean age of 51 years (range: 28–67 years). They received both written and oral information on several occasions before providing their written informed consent. The demographics of the informants are presented in Table 1.

Data collection

The interviews took place at the hospital where the 1-year follow-up was performed. They were digitally recorded and transcribed verbatim after each interview. The informants were asked to describe their experiences of the first year after transplantation. Reflective and open-ended questions were posed,[19] and they began with the following questions: "Could you tell me how it all started?" and "What have been your main concerns during this year?" Follow-up questions such as "Can you please describe…?" or "Can you please explain about…?" were posed for clarification and to avoid misunderstanding. The interviews lasted for a median time of 76 minutes (range: 40–107 minutes).

Ethical considerations

The study was approved by the Regional Ethics Board of Lund (Dnr. 2014/670-14/10) and conforms with the principles outlined in the Declaration of Helsinki.[20]

Data analysis

Data were analysed in three steps according to Lindseth and Norberg (2004)[17]: 1) naïve reading, in which all researchers read the interviews several times to become familiar with the content and reach an initial understanding. 2) Structural analysis, in which the initial understanding was tested separately by each researcher (Table 2). In this phase, meaning units were identified, brought together and grouped into themes and subthemes (Table 3). 3) Comprehensive understanding, in which the interview text was read again and the researchers reflected together on the themes pertaining to the meaning of being in uncertainty at 1 year after a HTX. The interpretation was guided by the researchers' pre-understanding and based on their experience of caring for HTRs during the early phase of treatment as well as in the long term. The pre-understanding was constantly reflected on and reconsidered during the data analysis and interpretation process, while a critical stance and integrity were maintained by means of continuous self-reflection and self-scrutiny in order to ensure that the interpretations were valid and grounded in the data.[21] Every theme in the structural analysis was questioned in relation to the pre-understanding of each researcher in an attempt to be as open as possible regarding the phenomenon under investigation.

The comprehensive understanding was also scrutinized during the final interpretation and was developed by illuminating the findings through the mirror of Michel's theory of uncertainty in illness described previously. Thus, the theory was used to understand the phenomenon of uncertainty, as described in the structural analyses, in a comprehensive way.

Table 1. Demographics of the 14 heart transplant recipients.

Characteristics	Number of participants
Male	10
Female	4
Left ventricular assist device	7
Dilated cardiomyopathy	9
Ischemic heart disease	1
Uni-ventricular heart	1
Cardiomyopathy	1
ARVD/C (cardiomyopathy)	1
Ischemic cardiomyopathy	1

Results

The naïve understanding revealed that the HTRs had strong feelings of uncertainty regarding survival, recovery and the possibility of living a normal life in the future.

Therefore, the thematic structural analyses cover six main themes illustrating the meaning of uncertainty (i.e., doubting survival, doubting the recovery process, doubting one's performance, struggling with close relationships, feeling abandoned and doubting the future), as presented in Table 3.

Doubting survival

The informants brooded a great deal about the survival of the graft and many found it really difficult to accept that the graft might not be as sustainable as their own heart would have been. They spent a lot of time wondering about how long they would survive.

Table 2. An example of the analysing process.

Meaning unit	Condensed meaning unit	Subtheme	Theme
"Now afterwards, well, it is that you could have a cardiac arrest, or if you notice that… if you have just a slight feeling that something is wrong you react very strongly because you are not familiar with what it is supposed to be like when you are transplanted…"	"You could have a cardiac arrest…"	Not knowing how long one will live	Doubting survival
"It's very hard to let go of the fact that the heart is not as durable as a real heart."	"Will the new heart sustain…?"	Brooding about the survival of the graft	Doubting survival

Table 3. Structural analysis of the meaning of uncertainty among the 14 heart transplant recipients.

Subtheme	Main theme
Brooding about the survival of the graft	Doubting survival
Not knowing how long one will live	
Preparing for the worst	
Questioning one's current health condition	Doubting the recovery process
Fearing illness or disease	
Coping with setbacks and test results	
Struggling and moving on	Doubting one's performance
Coping with restrictions or prescriptions	
Avoiding looking back	
Playing a role	Struggling with close relationships
Being disappointed in family and friends	
Experiencing partner's disappointment	
Not taken seriously	Feeling abandoned
Lacking knowledge and experience	
Lacking support from healthcare professionals	
Worrying about one's financial situation	Doubting the future
Worrying about returning to work	

"Now afterwards, well, it is that you could have a cardiac arrest, or if you notice that… if you have just a slight feeling that something is wrong you react very strongly because you are not familiar with what it is supposed to be like when you are transplanted…" (Describing thoughts after transplantation; male, 34 years)

Doubting the recovery process

Few informants felt that they had fully recovered at 1 year after their HTX. Instead, the majority perceived themselves as being far from healthy and worried a great deal about whether they would ever recover fully. Some informants who had a left ventricular assist device (LVAD) pre-transplant compared their post-transplant health status with their previous status and wondered why they felt much better with the LVAD than with their new heart.

The informants feared complications due to the medication (e.g., cancer, diabetes or kidney failure). They also worried about getting infections because of the impact that these might have on the recovery process. Many of the informants experienced one or several setbacks during the first year that they had to overcome in order to continue their recovery. Some put their trust in the test results and feedback from healthcare professionals. A sense of security occurred when the information about the test results was congruent with the informants' experienced health. However, insecurity emerged when they were told that the test results were good while they experienced illness, leading to doubt about whose judgement to trust. Sometimes the test results were good and they felt healthy, but still lacked the confidence to rely on the fact that everything seemed to be alright.

"…and I still don't really know, yes, it's been 15 months since I… I don't really know how it… if I will be, that is, more fit from the heart itself, I kind of don't know, but…" (Male, 34 years)

Doubting one's performance

The informants pondered a great deal about whether they were doing enough to promote the recovery process. They wished to do as much as they could to optimise their recovery. They tried to follow all of the recommendations made by the healthcare professionals to the best of their ability. This involved medication, food restrictions, avoiding infections and carrying out their exercise programme. However, despite their efforts, they worried that they were not doing enough, which made it more difficult for them to master their new situation. They struggled to move on after setbacks and restrictions. One strategy was to focus on the future and to avoid looking back. Comparing the current situation with their lives pre-transplant was distressing and hindered their progress.

"…I guess it's the urge to never give up… Yes, I guess it is. You try to think positively and do something about it instead of becoming resigned and giving up."

(Male, 61 years)

Struggling with close relationships

Some of the informants had the impression that their spouse was disappointed with the outcome of the HTX. They described how their spouse more or less explicitly expressed expecting the HTR to feel better and to manage more than she/he could or did. The informants were also aware of family and friends' expectations that they were now cured, healthy and that everything would return to normal. They lacked support, as well as acceptance and understanding of their situation. To master this frustration, they felt forced to play a role and to attempt to live up to the expectations of others in order to avoid disappointing them. They were afraid to appear ungrateful and felt ashamed of their fatigue and infirmity. At the same time, they expressed disappointment about the lack of support from family and friends, which made them doubt the sustainability of their relationships and led to worry that they would be left alone.

"…it is a bit like it was before and that devastated both me and my partner then, who also thought that it was really hard. Yeah, so now we are there again, I mean, we were supposed to…" (Male, 41 years)

Feeling abandoned

The experience of having a HTX was overwhelming and the informants had a really difficult time trying to interpret and understand their new situation. Many expressed that they lacked support and education from healthcare professionals in order to master their situation.

> "You seldom get to see a doctor… he is the one who prescribes medicines. He is the one with the answers if I have any questions…" (Male, 61 years)

Because of this knowledge gap, there was a constant worry about not doing enough, and many of the informants expressed their need for support. The knowledge gap concerned food restrictions, physical activity and medications. In addition, there was also a strong need for emotional support from a psychologist in order to understand their new situation and cope with their worries. They considered that their relatives were left behind, as they were not a part of the process from the healthcare professionals' point of view.

> "…there is a lot of focus on me as a patient, but the rest of the family so to speak…" (Female, 59 years)

Many commented on the failure to provide support for their relatives. Some of the informants felt that they themselves were not taken seriously by healthcare professionals, which in turn resulted in a sense of being abandoned.

Doubting the future

The informants pondered a great deal about the future and what it would be like. They wondered if they would be able to live a "normal" life, be able to work and thereby manage their financial situation. The social services and their approach affected their feelings and stress about returning to work. Many of the informants wished to travel again and wondered if that would be possible. Those who had children wondered if they would live long enough to see them grow up.

> "But now I don't know what will happen in October if it is decided that I am able to work 50% every day, that won't be possible." (Male, 47 years)

Comprehensive understanding

Being in uncertainty after a HTX means losing a sense of coherence, which shatters the HTR's whole worldview. The HTR searches for meaning and strive for coherence, which is no longer achievable. As long as healthcare professionals and the HTR's social network continue to strive for control and predictability, which defines a mechanistic worldview, the HTR's ability to adopt a probabilistic worldview and thereby create a new meaning and view of life is hindered and the transition prolonged. This creates distress among HTRs that becomes even worse the more complicated and cryptic the situation seems, leading to a condition that resembles that which is seen in post-traumatic stress disorder, which is a condition that can arise from exposure to uncertainty and unpredictability.[14]

Discussion

Distress is common among HTRs and studies have indicated that as many as 88%[7] of HTRs may be affected by distress. Previous research[7,9–11,13] has suggested that HTRs experience a great deal of stress due to their condition, treatment and medication, but this research has not elaborated on the root cause of the problem. By linking Mishel's (1990)[14] reconceptualisation of the uncertainty in illness theory to our findings, we believe that we have, for the first time, provided a reasonable hypothesis regarding the primary cause of distress after a HTX. By adopting this new paradigm, the post-transplant follow-up might help HTRs to reduce their distress and construct a new order in life. We argue that the current self-management paradigm might be problematic due to its emphasis on self-management support. By strongly focusing on the behavioural aspects of chronic illness management, the root cause behind the behaviour might be neglected (e.g., uncertainty) and interventions will not reach their full potential. We have to understand uncertainty as a natural state that occurs when a person suffers from a condition that shatters her/his entire worldview. According to Antonovsky (1987), events must be structured, ordered and predictable for life to appear coherent.[22] When the stimuli associated with illness, treatment and recovery are vague, ill-defined, probabilistic, ambiguous and unpredictable (i.e., uncertain), a sense of coherence is lost. "The uncertainty in the illness situation is the source of a flux that shifts the person from an original position through a point of bifurcation towards a new state" (p. 260).[14] According to Mishel, HTRs should attempt to adjust to the experienced chronic uncertainty and make it a part of themselves. This is a cognitive process by which the experience of uncertainty as being aversive should instead be assessed as opportunistic.[14] This process is driven by the natural human need to cognitively structure life events, which continues unless hindered.[14] By adopting Mishel's framework, it is possible to truly support the HTRs' transition to a new orientation towards life by accepting that uncertainty is an important part of their new journey. In order to support this transition, it is essential to understand that uncertainty *per se* is not a negative emotion.[14] Instead, it must be seen as a medium that enables reorganisation and makes life understandable.[14] The new view of life also develops from the individual's interactions and exchanges with the external environment.[14] Other factors that influence the ill person's formation of a new

orientation towards life are prior life experiences, physiological status, social resources and the attitudes of healthcare professionals.[14] As described in the introduction to this manuscript, social support, social situation and support from healthcare professionals are of great importance and have a significant impact on perceived distress,[9–11] which further confirms their importance in the process of a new life orientation. Putting these results into our context demonstrates the importance of this support for helping HTRs to adopt a probabilistic perspective and reduce their distress. When creating a new perspective on life, a dynamic process occurs in the interactions with the social network and with healthcare professionals,[14] meaning that the latter must be perceptive in terms of the patient and the progress of the process. It must be understood that this is a demanding and fragile process that can easily be disrupted by a lack of support. If healthcare professionals do not adopt the probabilistic paradigm, they will block the natural transition[14] by which HTRs can gain a new orientation towards life, leading to a great risk of consolidating distress among HTRs. However, when healthcare professionals promote a probabilistic worldview, this helps the HTRs to develop a new sense of order.[14] Healthcare professionals should encourage HTRs to consider alternative choices, and through this teach them to change their thinking from mechanistic to probabilistic.[14] It is crucial to support this natural process in order to reduce distress among HTRs, as this will prevent them from struggling for something that is not attainable (i.e., certainty, predictability and control).

These findings contribute to an increased understanding of HTRs' needs in the follow-up after a HTX. Our opinion is that follow-up today is structured around medical aspects, especially biopsies and scanning for rejection. We know from previous studies that the biopsy procedure is a very stressful event that serves as a concrete reminder of the threat to health and life.[23] This means that healthcare professionals struggle to obtain medical certainty at the expense of increasing the HTR's uncertainty. This new paradigm within post-transplant follow-up requires reflecting on the organisation in which the follow-up takes place. Our results show that the majority of HTRs do not feel fully recovered by 1 year after a HTX, showing that the follow-up might have to change its perspective and put more focus on the need for psychosocial support. A multi-professional team including a nurse, a transplant psychologist, a physiotherapist and an occupational therapist is required in order to help the patient reorganise her/his life and daily occupation[24] and to provide psychosocial support.

Recovery after a HTX is described as being different from before and involves learning to live with watchful insecurity,[25] indicating a relationship between uncertainty and recovery. We have reason to believe that the concept of recovery prolongs uncertainty and the creation of a new perspective on life. Perhaps there is a need to redefine the meaning of recovery after a HTX, because recovery generally implies a return to 'normal'.[26]

We know from previous research[27,28] that being a relative of a HTR is very stressful. Even though it was not the aim of this study, the informants described their concern for their relatives in terms of a lack of information and a need for support. This in turn has a negative effect on HTRs in their process of accepting uncertainty and creating a new perspective on life, of which social support is an important component.[14,29] Several studies reporting the experiences of being the spouse of a patient who has suffered a cardiac event (CE) support the findings that a CE affects the life situation and creates emotional, cognitive, social, economic and physical challenges.[30] Furthermore, a CE is stressful, generating a need for support and information among spouses.[31] If this remains undetected, there is a risk that the stress will make the spouse 'a hidden patient'.[32] According to our findings, this is most likely to be transferrable to our context as well, indicating the need for separate support functions for the spouses of HTRs.

Several studies report the experiences of a CE (e.g., myocardial infarction). When reviewing such studies, we found that our interpretation of the meaning of uncertainty was more or less explicitly evident in the results, despite the fact that the link to the theory was missing and thereby the primary cause of the problem was not identified.[25,33–35] It is also well known that distress and depression are common among patients with a CE and are difficult to treat.[36] This indicates that uncertainty might be the undefined source of distress, even in this larger CE context.

Methodological considerations

In qualitative research, there is always a risk that the researchers' pre-understanding will influence the results. In order to ensure trustworthiness, which requires transparency in the research process as well as the final interpretation, the Lincon and Guba framework[37] was used. The present results were unexpected, which indicates that our pre-understanding did not affect the results and that we remained sufficiently open to the observed phenomena.

We argue that our findings empirically confirm Mishel's theoretical framework in a way that profoundly enriches our clinical understanding of how to approach HTRs after transplantation. It would have been impossible to understand the richness of the findings without adopting Mishel's framework, which highlights the importance of using theories in nursing research in order to support everyday practice.

Limitations

We have selected informants from the two transplant units in Sweden where HTXs are performed in order to cover various parts of the country. We interviewed more men

than women, thus reflecting the clinical reality. Most of the informants were born in Sweden, which limits the findings to a solely western perspective. However, some similar findings have been reported from Taiwan, suggesting that uncertainty might be a universal phenomenon.

Conclusion

In conclusion, this study presents a reasonable understanding and hypothesis regarding the primary cause of psychological distress after a HTX and provides a useful framework from Mishel (1990) for how to approach this health condition that leads to extensive illness among HTRs.

Implications for practice

- A focus on mastering uncertainty in illness should be mandatory.
- A multi-professional team including a psychologist would be valuable.
- We have to reconsider concepts such as 'recovery' and 'returning to normal'.

Acknowledgement

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Conflict of interest

The authors declare that there are no conflicts of interest.

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Paper II

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ORIGINAL ARTICLE

Self-efficacy in the context of heart transplantation – a new perspective

Matilda Almgren, Annette Lennerling, Martina Lundmark and Anna Forsberg

Aims and objectives. An in-depth exploration of self-efficacy among heart transplant recipients by means of Bandura's self-efficacy theory.

Background. An essential component of chronic illness management is self-management, which refers to activities carried out by people to create order, structure and control in their lives. Self-efficacy is an important aspect of self-management, which seems to have become the main paradigm for long-term management after solid organ transplantation.

Design. A directed content analysis using Bandura's self-efficacy theory.

Methods. Open-ended, in-depth interviews were conducted with 14 heart transplant recipients at their 12-month follow-up after heart transplantation.

Results. This study generated the hypothesis that from the patients' perspective, self-efficacy after heart transplantation concerns balancing expectations to find the optimum level of self-efficacy. Performance accomplishment was found to have the greatest impact on self-efficacy, while its absence was the main source of disappointments. It was also revealed that the gap between performance accomplishment and efficacy expectations can be understood as uncertainty.

Conclusions. It is essential to assess both expectations and disappointments from the patient perspective in order to promote an optimum level of self-efficacy among heart transplant recipients. This includes supporting the heart recipient to adopt mental and physical adjustment strategies to balance her/his expectations as a means of minimising disappointments. The understanding that uncertainty can undermine self-efficacy is crucial.

Relevance to clinical practice. The merging of the uncertainty in illness and self-efficacy theories provides an excellent framework for the provision of self-management support. In addition, focusing on a partnership between the transplant professionals and the recipient is essential because it minimises the use of a behavioural approach.

What does this paper contribute to the wider global clinical community?

- An understanding of the importance of the concept uncertainty in the context of transplant nursing.
- An understanding of how to reduce the use of a behavioural approach towards organ transplant recipient when providing self-management support.
- A framework for providing self-management support based on the theory of self-efficacy.

Key words: chronic illness management, content analysis, heart transplantation, patient perspective, qualitative, self-efficacy, self-management, uncertainty

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Authors: *Matilda Almgren*, MSc, RN, PhD Student, Thoracic Intensive Care Unit, Skåne University Hospital, Lund and Department of Health Sciences, Lund University, Lund; *Annette Lennerling*, PhD, RN, Assistant Professor, The Transplant Center, Sahlgrenska University Hospital, Gothenburg and The Institute of Health and Caring Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg; *Martina Lundmark*, MSc, RN, PhD Student, Thoracic Intensive Care Unit, Skåne University Hospital, Lund and Department of Health Sciences, Lund University, Lund; *Anna Forsberg*, PhD, RN, Professor, Department of Health Sciences, Lund University, Lund and Department of Transplantation and Cardiology, Skåne University Hospital, Lund, Sweden

Correspondence: Matilda Almgren, PhD Student, Thoracic Intensive Care Unit, Skåne University Hospital, Lund SE-221 85, Sweden. Telephone: +46709-922360.

E-mail: matilda.almgren@med.lu.se

Introduction

The rationale behind this study is that we know very little about the in-depth meaning of self-efficacy after heart transplantation (HTX) from the patient perspective. Self-efficacy is an important aspect of self-management (Lorig & Gonzalez 1992). Healthcare systems that focus on self-management and chronic illness management (CIM) report improved long-term survival in a range of chronic conditions (Nuno *et al.* 2012). Self-management is an important part of CIM and seems to have become the main long-term management paradigm after solid organ transplantation (Berben *et al.* 2015).

Background

Heart transplantation is the most effective choice of treatment for patients with end-stage heart failure (Lund *et al.* 2013), and around 1500 heart transplantations are performed every year in Europe (ishlt.org., 2015). Due to advances in immunosuppressive therapy and surgical techniques, the survival rate has increased (Lodhi *et al.* 2011). However, the improvement is mainly seen during the first year post-transplant. Long-term survival is still reduced by cardiac allograft vasculopathy (CAV), rejection, infections and malignancy (Lodhi *et al.* 2011, Lund *et al.* 2013).

In chronic conditions, care should be based on a partnership between patients, their social network and healthcare teams. An important part of CIM is enabling the patient to become her/his own caregiver and manage her/his illness with focus on medication, diet and exercise, that is self-management. CIM also involves supporting the patient in decision-making, in addition to making use of clinical information systems and redesigning the delivery of care to make it more effective and relevant for patients (Lorig & Gonzalez 1992, Bodenheimer *et al.* 2002, Yach 2002, Epping-Jordan *et al.* 2004). Self-management refers to activities carried out by people to create order, structure and control in their lives (Lorig & Holman 1993). It is applicable in a variety of chronic conditions (Kralik *et al.* 2004) where the aim is to increase self-efficacy among patients (Barlow *et al.* 2000), for example the self-management programme presented by Lorig and Holman (1993). Self-efficacy, which is outlined in Box 1, is a complex phenomenon (Bandura 1977).

Psychological disorders and high levels of psychological distress are common after HTX (Dew & DiMartini 2005), with 32% of heart transplant recipients exhibiting stress symptoms after transplantation (Fusar-Poli *et al.* 2005). Distress is recognised as the strongest predictor of quality of life (Tung *et al.* 2011). There is both a positive (Barlow *et al.* 2000) and a negative relationship between self-efficacy and depressive symptoms (McCathie *et al.* 2002, Weng *et al.* 2008). Self-efficacy is also linked to uncertainty, where the latter seems to cause high levels of stress after renal transplantation (Chen *et al.* 2010). Uncertainty about graft function, recovery and future health has been identified as a major stressor after solid organ transplantation (White *et al.* 1990, Kong & Molassiotis 1999, Weng *et al.* 2008, Almgren *et al.* 2016). As self-efficacy is the key aspect of self-management, it is vital to understand the inside perspective of self-efficacy among heart transplant recipients in order to develop appropriate self-management support strategies. Therefore, the aim of this study was an in-depth exploration of self-efficacy among heart transplant recipients by means of Bandura's self-efficacy theory.

Methods

Design

A directed content analysis (Hsieh & Shannon 2005) using Bandura's self-efficacy theory (Bandura 1977) was conducted retrospectively to deductively explore self-efficacy in the context of HTX. We chose this theory as Bandura is the one who developed the concept of self-efficacy, and it is the only available theory that comprehensively describes the concept.

Sample

The inclusion criteria were Swedish speaking adult heart transplant recipients who were due to attend their 12-month follow-up after the transplantation and who were able to participate in an interview. The nurse at the follow-up clinic contacted the potential informants, and their written consent was obtained. They were informed that they could withdraw from the study at any time. The informants, who were only heart recipients, were included consecutively, and a total of 14 heart transplant recipients, four women and ten men, with a mean age of 51 years (28–67 years) were interviewed. Data saturation was achieved after the 14 interviews. Demographic characteristics are presented in Table 1.

Data collection

Data collection was conducted between September 2014 and February 2015 in the form of interviews at the two hospitals in Sweden that perform thoracic transplantation.

Box 1. Self-efficacy sources and contextual factors

Efficacy expectation: Belief that one can successfully carry out the necessary behaviour to achieve a desired goal.
Outcome expectation: A person's belief that a specific behaviour will lead to a certain outcome.
Performance accomplishment: Experiences of mastery and success in different tasks raise efficacy expectations. This is the most influential source of efficacy expectations.
Vicarious experience: Efficacy expectations derived from seeing others succeed without setbacks in various tasks that appear threatening.
Verbal persuasion: Others trying to persuade a person to believe that she/he will manage to carry out tasks that seem threatening or difficult. This source of efficacy expectations is weaker than that arising from succeeding in performance oneself.
Emotional arousal: Stressful and strenuous situations generate emotional arousal, which affects how the person will perceive her/his ability to succeed in a task or activity. Therefore, emotional arousal affects a person's self-efficacy related to ability to perform in threatening situations.
Contextual factors: These comprise the social, situational and temporal circumstances under which the event occurs and affect how the efficacy information is processed, thus influencing the expectations of personal efficacy.

The interviews had a mean duration of 76 minutes (40–107 minutes), resulting in approximately 300 pages of transcribed text. An open ended and in-depth method was employed during the interviews, parts of which were analysed in accordance with interpretive phenomenology. The latter results are reported elsewhere (Almgren *et al.* 2016).

Ethical considerations

Approval was obtained from the regional ethics board of the university (Dnr. 2014/670-14/10). One informant was excluded due to being unable to attend a face-to-face interview, as we considered that we might fail to provide emotional support, if necessary, when not present with the informant. The researcher who conducted the interviews had no relationship with the informants. A social worker at the follow-up clinic was on hand to provide emotional support to informants in the event that the interview would prove emotionally demanding for them. However, this need did not arise.

Data analysis

The analysis was performed in accordance with the following steps:

1 Bandura's theory was scrutinised in detail to identify the main concepts (Box 1).

Table 1 Demographic characteristics of the 14 heart transplant recipients

Characteristics	Number of participants
Male	10
Female	4
Left ventricular assistant device	7
Dilated cardiomyopathy	9
Ischaemic heart disease	1
Univentricular heart	1
Cardiomyopathy	1
ARVD/C (cardiomyopathy)	1
Ischaemic cardiomyopathy	1

2 In the second step, we chose the main concepts of self-efficacy and the contextual factors from the theory described in Box 1 and applied them to the data, that is we searched for meaning units (MUs) that corresponded with the content of each main concept in Bandura's theory.
3 Two of the authors independently identified these MUs, resulting in 60 pages of meaning units.
4 After identifying the MUs that corresponded with the main concepts in the theory, relevant data not fitting the concepts were analysed which led to the dividing of performance accomplishment in several parts.
5 Two of the authors collaborated in comparing and condensing the meaning units as well as the additional data, which were specific for the context of heart transplantation.
6 All the authors discussed the condensation and decided which quotations should be presented.
7 All the authors discussed the core meaning of self-efficacy in the context of HTX.

Rigour

A directed content analysis was challenging for the authors because they approached the data with an informed but strong bias (Hsieh & Shannon 2005). The concept of self-efficacy is fairly complex, and in our opinion, the use of the framework is necessary to capture its essence. To increase the trustworthiness of the analysis, the authors took a broad perspective aimed at capturing all possible occurrences of self-efficacy (Hsieh & Shannon 2005) and decided to interview recipients from both HTX centres in Sweden. Our choice of informants reflected the gender and age of recipients in general. To avoid bias, we reflected both jointly and individually when categorising and scrutinising the result, as well as attempting to remain as open as possible about our preunderstanding and experience. We believe that our results are transferrable to all solid organ

recipients, as well as to other chronic conditions. The concept of self-management as a part of CIM is applicable in various chronic illness populations (Nuno *et al.* 2012). Transferability is supported by the fact that uncertainty is a generic experience common to all human beings. To further strengthen the trustworthiness, we reflected on the concepts of credibility, dependability, conformability and transformability as described by Polit & Beck (Polit & Beck 2010).

Results

The findings are presented according to the main sources of self-efficacy, as well as the contextual factors emphasised in Bandura's theory (Box 1) and illustrated by quotations.

Performance accomplishment

Efficacy by means of performance accomplishment was evident in physical, mental and social aspects, which we merged into subthemes that are presented in the following. The informants acknowledged that physical, mental and social accomplishments would be impossible without medical interventions.

Physical accomplishment

Persons with a left ventricular assistant device (LVAD) pretransplant regarded the period with the LVAD as a reason for being physically prepared for transplantation. Physical improvement was obvious almost immediately after the withdrawal of sedation in the thoracic intensive care unit (ThICU), and recuperation was experienced at an early stage in the trajectory. Despite anxiety during mobilisation, being able to get out of bed unaided boosted their self-confidence. Each physical accomplishment served as a step-wise recovery marker, from being bedridden to sitting in a chair in the ThICU, followed by taking a shower without assistance for the first time. Working out with the physiotherapist and later at home on their own resulted in several physical accomplishments that increased their trust in their own ability. Being able to do whatever they wanted without assistance was a clear performance marker.

The informants were amazed that they made it through the demanding physical recovery phase, implying an unexpected inner strength of which they were not aware. Although they recognised this strength, they nevertheless experienced a greater sense of illness compared with pretransplant:

'... the worst thing afterwards was that I felt a thousand times worse than before' (Female, 52 years)

Physical accomplishments after discharge went from reconstructing daily occupations to increased physical exercise, for example jogging or cycling, where achieving an excellent physical condition was the ultimate confirmation of accomplishment and improved health. Every sign of progress was an achievement that seemed to boost their self-confidence, proving that their recovery strategy was effective:

Simply the fact that you can ride a bike. I haven't been able to ride a bike for many years. However this summer I could and it simply makes me very happy. I just want to cry because it is so amazing that I can ride a bike again. (Female, 58 years)

Discharge to the rehabilitation clinic provided increased opportunities for confirmation of physical accomplishments. In conclusion, the physical recovery and achievements act as concrete recovery markers and necessary evidence of physical performance accomplishments.

Mental accomplishments

Adjusting expectations was necessary to achieve mental accomplishments. The will to survive and being as independent as possible throughout the recovery process served as a catalyst for inner strength and a fighting spirit:

Well it was me, I was the one fighting to survive. I want to survive, I want to live a little longer. (Male, 68 years)

However, uncertainty regarding the possible level of accomplishment could also cause doubts about one's ability to recover. Being positive served as a mediator for mental accomplishments, helping the recipients to feel stronger and better over time. Positive emotions included feeling optimistic, perceiving a sense of control over the situation, feeling free and being able to manage the demands of everyday life without becoming stressed:

'I believe it's easier to be positive, but I'm not sure that it is important from a medical point of view ...' (Male, 65 years)

Resilience was created by being stubborn and viewing the heart transplantation as a once in a lifetime experience. Even if they did not feel they had recovered, the mere belief of having the potential to recover increased their self-esteem. Pretransplant they had had doubts about surviving until a heart became available. Waking up after the surgery was therefore considered an accomplishment in itself:

You see, I was one hundred percent certain that I would never receive a heart in time. And afterwards I woke up and thought now I will live for at least another 25 years. (Male, 35 years)

Social accomplishments

Being socially active was considered important. Social accomplishments were assessed by the ability to work. Working on a half time basis after one year was considered a major accomplishment:

I've been working 25% for two months now and I will try to work half time next year. (Male, 30 years)

Travelling and resuming leisure activities, for example dancing, were also positive. Having no limitations and being able to do whatever they wanted was a great achievement that boosted self-esteem.

Complications, setbacks, treatment and side effects

Several physical complications and setbacks negatively affected their performance accomplishments and thereby self-efficacy, as such events caused disappointment leading to emotional arousal (Table 2). Some recipients lacked strength and energy, were unable to run and found bending and climbing stairs difficult. They had expected to recover more rapidly and requested increased support from the transplant professionals. The first five months after transplantation were viewed as climbing a steep hill due to depression, lack of energy as a result of the medication, graft rejection and acute kidney failure or dysfunction, evoking fear that kidney transplantation would be needed in the near future.

Table 2 Disappointments reported by the 14 heart transplant recipients during the first year post-transplant

Domain	Disappointments
Physical	Muscle weakness
	Joint and bodily pain
	Wound healing
	Kidney failure
	Fatigue
	Sleep problems
	Dyspnoea
	Heart sensations
	Diabetes
	Stomach problems
Mental	Catastrophic thoughts
	Depression
	Loss of meaning
Social	Disappointment in the family
	Negative feedback from friends and relatives
	Losing friends
	Being isolated
	Lack of interest from employer
	Having to quit work

The informants reported chest pain and stomach problems due to the medication. One informant also experienced anxiety due to an ileac stoma:

And the stoma, it was just … I wouldn't have managed … I would have killed myself … if they hadn't removed it. (Male, 30 years)

The medical complications and side effects were numerous, including wound infections, nausea, vomiting and increased sensitivity to light, noise and smell. Together with sleep disturbances and the biopsy procedure, developing insulin dependent diabetes was considered worse than anything else:

I got diabetes after the heart transplantation. It was bloody frightening, I can tell you. It was worse than anything else. (Male, 30 years)

During the recovery, they found it difficult to concentrate and learn new things as they felt mentally exhausted. One coping strategy was to try to relax and avoid mental stress. However, feeling just as ill and drained as before the transplantation was a huge disappointment:

Now I feel almost as bad as before the heart transplantation, it's all crap and it makes me very depressed. It feels bad when you already had an incurable disease so to speak. (Male, 42 years)

Vicarious experience

Vicarious experience means being inspired by others, which can lead to increased hope of recovery, less disappointment and reduced emotional arousal. Attending physiotherapy and observing other patients exercising in the gym gave an impression of what it could be like. Overall, it seemed that successful heart recipients acted as role models:

I guess it's all about being stubborn. When you see others recovering you believe in your own ability to succeed. (Male, 34 years)

However, hearing about others' experiences could also lead to stress and constitute a negative reminder of all the possible complications that could occur, resulting in disappointment and increased emotional arousal:

On Facebook my wife follows different people who have had a lot of trouble. Finally she had to stop telling me all these stories

because I simply didn't want to hear about it. There is enough going on in my own life. I don't need to hear about everything that can go wrong. (Male, 42 years)

A third form of vicarious experience was comparing themselves with others and concluding that they were better off in many ways.

Verbal persuasion

Verbal persuasion from transplant professionals included encouraging remarks about the quality of the graft. When the transplant surgeon stresses the importance of adopting the right approach, the heart recipient listens and is inspired to adhere to the advice:

I do exactly as I am told without exception. I won't miss my exercise or going for a walk or things like that. (Male, 68 years)

However, verbal persuasion expressed as expectations from transplant professionals also caused increased doubts. Anxiety and disappointment became greater when the recipients were unable to meet the expectations, which led to a profound sense of uncertainty.

Outcome expectations and emotional arousal

The core of self-efficacy seemed to be the ability to balance expectations in order to avoid frequent disappointments. The outcome expectations varied as presented in Table 3. A common theme in these expectations was surprise and disappointment that recovery took so long:

I expected that when my sternum healed after around three months, I would be 90% fit and back in business, but that was really not the case … (Male, 35 years)

Table 3 Outcome expectations among the 14 heart transplant recipients during the first year post-transplant

Domain	Type of expectations or strategies
Physical	Being able to run
	Climbing stairs
	Not having to sit upright while sleeping
	Improved fitness
	Having the same physical capacity as with the LVAD
	Being fully active
	Riding a motorbike again
	Climbing a mountain
	Reducing weight and being fitter
Mental	Hoping for and noticing progress
Overall well-being	Expecting better health than with the LVAD
	Increased time at work

LVAD, left ventricular assistant device.

Having had an LVAD was also a mediator for outcome expectations, as the initial post-transplant period was more difficult for some informants compared with their recovery after LVAD.

One temporal aspect was that a long time on the waiting list gave rise to a great deal of brooding and reflection, leading to fear about the transplantation. After discharge, the ICU-diary was kept in a drawer for the moment when it would feel appropriate to read it. One year post-transplant was still considered too early. There was a strong sense of disappointment when physical achievements were lacking and accomplishments were poor, resulting in weakened willpower. They considered that their efforts were in vain, which gave rise to depressive thoughts. Fatigue, difficulties concentrating and fear of a cardiac arrest also caused negative emotions. Not knowing which bodily signs required attention created uncertainty, as well as a great deal of pondering and strong emotional arousal brought about by intrusive thoughts:

Well afterwards, it's about whether the heart will stop beating and if you notice that something might be wrong you react very strongly. You're not used to what it's like or how it's supposed to be when you're transplanted. I guess you have a lot of anxiety. I was very anxious after the transplantation and that anxiety is still there. (Male, 34 years)

Emotional coping involved crying every day when thinking about the donor. At the same time, there was gratitude and concern for the donor's relatives and family. Returning to the transplant unit for the one-year follow-up evoked a cascade of emotions. As a consequence, one informant preferred to sleep at the patients' hotel and not in the hospital ward, as she/he did not want to be reminded about the past year and constantly tried to suppress memories of the recovery period.

Some informants complained of feeling aggressive, having mood swings and of nagging thoughts in the evening and at night about whether they would live to see their children growing up, how long the new heart would function and the fact that the heart was previously part of another person's body. These thoughts served as a constant reminder of the illness trajectory and the fact that they had been so close to death. As people in their environment constantly questioned their strength and recovery, they became reluctant to talk about the transplantation. One strategy was to avoid discussing the HTX, while another was joking about it with friends.

Performance adjustment

Lack of performance accomplishments or the occurrence of setbacks and complications meant that the heart recipients

had to adjust to their current health condition. Social factors as presented in Table 4 also affected their ability to adjust and therefore their perceived self-efficacy. A long hospital stay and reduced memory function were other factors that demanded adaptation. Reconstructing daily occupations became a great task due to lack of concentration, energy and confidence regarding the ability to perform at work.

The informants adopted a variety of adjustment strategies (Table 4). A common one was striving for autonomy, as they believed it was necessary to recover thanks to one's own efforts. Being fatalistic and crossing one's fingers to keep rejection at bay was another approach. Keeping the pretransplant illness period in mind helped some to appreciate their new, improved health status. Feeling content with what they had achieved in terms of health, appreciating that the wound had healed and being grateful for the heart and to the donor contributed to a sense of satisfaction. Physical adjustment to the new health situation was considered easier than mental adjustment. Contacting friends and participating in social activities were strategies for resisting mental fatigue and being part of society again. Finally, adaptation strategies also involved meeting the performance accomplishment expectations of spouses, friends and healthcare professionals. Some recipients experienced a constant sense of guilt due to their lack of energy and failure to meet the expectations of their spouse.

Mental adjustment

Several conscious strategies were adopted to constantly focus on positive thoughts (Table 4). Keeping up one's spirits, not giving in, using will power and accepting the temporary role of being a patient often created positive emotions. Other useful approaches included not dwelling on the situation, avoiding reading negative information on the Internet and adopting an optimistic attitude. A common strategy for coping with outcome expectations was to expect the worst and thereby be surprised when everything turned out better. In the long term, the ability to adjust their expectations to avoid frequent disappointments was the key to better self-efficacy:

> If you don't expect too much and simply wait and see what happens, you can't be disappointed if things don't turn out the way you wanted. (Female, 58 years)

Table 4 Adjustment strategies that seemed to balance expectations among the 14 heart transplant recipients during the first year post-transplant

Domain	Strategies
Physical	Adjusting expectations to present performance
	Expecting better health than with the left ventricular assistant device
	Not taking health for granted
Mental	Being positive
	Believing in one's ability
	Focusing on survival
	Having low or reasonable expectations
	Hoping for improvements
	Preparing for the possibility of death
	Being satisfied with the present situation
Social	Being with the family
	Accepting around the clock support from friends
	Adjusting work performance expectations

Discussion

By analysing the interviews in the light of Bandura′s theory of self-efficacy, our core understanding and main hypothesis is that self-efficacy after heart transplantation concerns balancing expectations about being a person living with a new heart to minimise disappointments and thereby find the optimum level of self-efficacy. When expectations are too high, there is a risk of disappointment, leading to negative emotional arousal and stress. In contrast, low or no expectations lead to a risk of becoming inefficient and simply relying on external factors beyond one's own control, for example social support and the healthcare system. In our interviews, we identified three typical cases that illuminate our main hypothesis, which are presented in Box 2. However, this hypothesis needs further testing.

A second hypothesis generated in line with Bandura is that after HTX, performance accomplishment has the greatest impact on efficacy expectations. Low performance accomplishment seems to generate disappointment if the efficacy expectations are higher than what is achieved (Case 1, Box 2). Adjustment is therefore necessary to maintain a successful balance in terms of both performance and outcome expectations (Case 2, Box 2). A study by Kralik *et al.* (2004) revealed that healthcare professionals and patients had different perceptions about self-management. The healthcare professionals described it as structured education, while the patients perceived it more as a process initiated to bring order into their lives. This process included being aware of boundaries, the need to recuperate, manage a shift in self-identity and finally learn to balance, plan and prioritise in life (Kralik *et al.* 2004), which is also supported by Lundmark *et al.* (2016). During follow-up, it is important to be aware that performance accomplishments are strongly linked to the recovery process, where every positive recovery marker serves as a concrete sign of performance accomplishment.

Box 2. Three typical cases illuminating our main hypothesis

CASE 1: A person with high expectations of living with a new heart

This recipient had high expectations about recovery and performance, in addition to many expectations from his social network, which he was unable to fulfil. This generated uncertainty and doubts about recovery, leading to disappointment that might prevent self-efficacy:

... you had persuaded yourself and the doctors did as well, that just as long as you receive a new heart everything would be fine. A new heart and you can run ten kilometres ... And then I came home from the hospital ... and I felt that X [wife] thought that now we could do everything but I had no strength although I tried as hard as I could. As soon as there was something going on I was there, but when she left the house I simply crashed on the sofa. I pretended to be stronger than I was. (Male, 35 years)

CASE 2: A person with balanced expectations about living with a new heart

This recipient seemed to have the optimum level of self-efficacy. She was successful in terms of performance accomplishment, which seemed to accord with or even surpass her expectations. She also appeared to accept and adjust to the current situation, thus did not experience many disappointments:

If you don't expect too much and simply wait and see what happens, you can't be disappointed if things don't turn out the way you wanted. (Female, 58 years)

CASE 3: A person with low expectations about living with a new heart

This recipient seemed to rely on faith and hoped for the best, which involved depending on others, for example healthcare professionals and social support. He doubted his performance accomplishment, leading to uncertainty about recovery:

... I mean it takes time, I can see that. I believed it would take a few weeks, but it didn't ... I have stairs that I go up and down every day and after a few months I could feel that it was getting better and better. So I can feel it is improving, but it is slow, very much so, but I guess I'll just have to keep going ... (Male, 65 years)

Repeated failure lowers the expectations of success, especially if it happens early in the process (Bandura 1977). Therefore, many complications and setbacks early in the recovery process can be devastating as they create disappointment and undermine self-efficacy.

Being socially active was viewed as important, but it was the ability to work that seemed to be the ultimate affirmation of success (Cavallini *et al.* 2015). We defined social accomplishment as a subcategory of performance accomplishment because it constituted an essential and major part. Social adaptation is described as the main concern after solid organ transplantation (Forsberg *et al.* 2015). Social support affects depression and anxiety levels (McCathie *et al.* 2002), indicating that successful social adaptation and social support enhance performance accomplishment and perceived self-efficacy, which is also in line with (Holahan & Holahan 1987a,b).

Vicarious experience, for example comparing oneself with other transplant recipients or taking part in discussions on the Internet, builds up expectations and leads to either increased or decreased self-esteem, depending on the nature of the vicarious experience and one's own performance level. Our hypothesis is that vicarious experiences might increase expectations and possibly even self-efficacy to an unrealistically high level that the heart recipient cannot live up to, thus generating disappointment and stress.

In this particular context, we argue that it is not sufficient to distinguish between outcome expectations and efficacy expectations as suggested by Bandura. The reason is because the transplant recipients try to cope with uncertainty due to ambiguous situational and task factors, for example pain or fatigue, without distinguishing between their belief in their ability to perform and the actual expected outcome of a particular performance. Bandura states that people judge their capabilities in relation to their somatic and emotional states. Stress, fatigue and pain, which are common symptoms after solid organ transplantation, are considered signs of inefficacy and physical debility. Mood also impacts on one's perceived efficacy, that is being positive enhances perceived self-efficacy while the opposite diminishes it. Bandura suggested three explicit strategies to modify self-beliefs pertaining to efficacy. When applied to the present context they are (1) helping heart recipients to reduce their stress reaction, (2) helping them to alter their negative emotional tendencies and (3) helping them to interpret their physical state (Bandura 1998). The key understanding for transplant professionals is that when performance accomplishment is absent and constant disappointments occur, that is setbacks and complications, the transplant recipient becomes uncertain about her/his ability to perform. Consequently, it is impossible to enhance efficacy expectations, resulting in poor self-efficacy.

The findings reveal numerous situations and events linked to the transplant recipient, her/his significant others or the transplant professionals that caused disappointments during the first year post-transplant. Every side effect of the

immunosuppression, every complication, infection or sign of graft rejection can be viewed as a huge disappointment, which also generates stress as suggested by Chen *et al.* (2010). In line with Bandura, our results indicate that disappointments are characterised by emotional arousal, which affects perceived efficacy. The gap between efficacy expectations and performance is influenced by ambiguous conditions and cues in the environment (Bandura 1977) that cause uncertainty. Previous studies have revealed a relationship between uncertainty and self-efficacy (Chen *et al.* 2010, Zhang *et al.* 2015). It is of vital importance to help the patient express uncertainty, as it is a factor with the potential to undermine self-efficacy. Transplant professionals should not view uncertainty as an obstacle or a problem but as a natural part of the illness and of life.

Furthermore, it is evident that even when the patient adheres to the advice provided by healthcare professionals in the form of verbal persuasion, there is no guarantee that it will lead to well-being. Instead, it can create further uncertainty, disappointments and emotional arousal. Our healthcare system and the current perspective on self-management support have a strong focus on behaviour and performance (Berben *et al.* 2015). By strategies such as verbal persuasion, we try to make patients adhere to the medical regimen, dietary restrictions or protection from the sun. This involves an implicit risk of patients experiencing disappointment when they behave in accordance with the advice provided (verbal persuasion), but still feel unwell. In our opinion, verbal persuasion should be replaced by establishing a partnership with the goal of mutual understanding, where we guide heart recipients by means of educational conversations and enable them to keep their expectations at a realistic level, thus preventing disappointments. The key intervention involves supporting their emotional transition in terms of accepting uncertainty (Almgren *et al.* 2016).

Finally, Berben *et al.* (2015) argue that nurses play a key role in outpatient transplant care and in promoting patients' self-management behaviour. However, our findings together with the data presented by Almgren *et al.* (2016) suggest that behavioural aspects are not the key issue. Instead, healthcare professionals' ability to understand the importance of uncertainty in illness is a driver for both self-efficacy and self-management. We believe it is impossible to re-design the transplant follow-up without this fundamental understanding of being a person living with a new heart. In conclusion, our study contributes by positioning self-efficacy in relation to uncertainty and by merging Bandura's theory of self-efficacy with Mishel's theory of uncertainty in illness, which we hope will deepen the knowledge of self-management.

Conclusions

In conclusion, this study generated the following hypothesis:

- Self-efficacy from the patient perspective is about finding the optimum level of expectations.
- Balancing expectations might minimise disappointments and consequently distress.
- It is not sufficient to distinguish between outcome expectations and efficacy expectations as suggested in Bandura's theory
- Setbacks and complications have a major impact, causing disappointments and affecting perceived self-efficacy.
- The gap between performance accomplishment and efficacy expectations can be understood as uncertainty in illness. This understanding can provide transplant professionals with a tool to comprehend recipients and support them in accepting uncertainty as a natural part of the transition, thereby reducing the stress that can undermine self-efficacy.

In summary, our study has adjusted Bandura's theory but still suggests that it is useful in its main parts in the context of heart transplantation with some exceptions. First, it is not useful to distinguish between outcome expectations and efficacy expectations. Also in the context of heart transplantation, vicarious experiences might be problematic and add additional stress to the heart recipient. Finally, we defined social accomplishment and mental accomplishment as a subcategory of performance accomplishment.

Relevance to clinical practice

- The inside perspective on self-efficacy demands a new ontological point of departure when discussing self-management.
- Self-efficacy after heart transplantation concerns balancing expectations, that is finding the optimum level of self-efficacy.
- The gap between efficacy expectations and performance is understood as uncertainty in illness.
- Uncertainty in illness undermines self-efficacy and generates distress.

Study limitations

Most of the informants were born in Sweden, which limits the finding to a solely western perspective. The retrospective design increases the risk of recall bias. The fact that we reanalysed interviews might also constitute a bias, although on the other hand, it could also have contributed to a deeper comprehension of the findings. The interviews were

extensive and the reanalysis mainly involved parts of the interviews that were not included in the original analysis. The findings are based on our interpretation of Bandura's theory. Other researchers might understand his theory differently.

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Contributions

Study design: MA, AF; Data collection and analysis: MA, AF; Manuscript preparation: MA, AF, ML.

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Conflicts of interests

No conflict of interest has been declared by the authors.

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Paper III

Original Article

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ESC European Society of Cardiology

Self-efficacy, recovery and psychological wellbeing one to five years after heart transplantation: a Swedish cross-sectional study

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Matilda Almgren[1], Pia Lundqvist[1], Annette Lennerling[2,3] and Anna Forsberg[1,4]

Abstract

Background: Self-efficacy refers to a person's confidence in carrying out treatment-related activities and constitutes the foundation of self-management as well as long-term follow-up after heart transplantation. Exploring the heart recipients' experiences by means of self-report instruments provides healthcare professionals with valuable information on how to supply self-management support after heart transplantation.

Aims: The aim was to explore self-efficacy in relation to the self-reported level of recovery and psychological wellbeing, among adult heart recipients, one to 5 years after transplantation.

Methods: This cross-sectional study includes 79 heart recipients, due for follow-up one to 5 years after transplantation. Three different self-assessment instruments were employed: the self-efficacy for managing chronic disease 6-item scale; the postoperative recovery profile; and the psychological general wellbeing instrument.

Results: The reported level of self-efficacy was high (median 8.3, maximum score 10). Significantly higher self-efficacy was seen among those who had returned to work ($P = 0.003$) and those without pre-transplant mechanical circulatory support ($P = 0.033$). In total, 65.5% ($n = 52$) reported being reasonably recovered, while 18.8% ($n = 12$) were not recovered. The median total psychological general wellbeing score was 108 ($P_{25} = 24$, $P_{75} = 117$), suggesting overall good psychological wellbeing in the whole group of heart recipients.

Conclusion: The heart transplant recipients in our study had an overall high level of self-efficacy. Low self-efficacy was found among those with a low self-reported level of recovery, pre-transplant treatment with mechanical circulatory support or who had not returned to work. This is important information for transplant professionals when helping heart recipients to balance their expectations about recovery.

Keywords

Heart transplantation, self-efficacy, self-management, wellbeing, recovery

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Introduction

Heart transplantation (HTx) is an established life-saving treatment for people with end-stage heart failure.[1] As a result of medical advances, survival after HTx has improved.[2] With a one year survival rate of 83% and 71% surviving for 5 years,[3] perceived health and quality of life become highly important outcome measures after HTx. Despite the replacement of

[1]Institute of Health Sciences, Lund University, Sweden
[2]The Transplant Centre, Sahlgrenska University Hospital, Sweden
[3]Institute of Health and Care Sciences, University of Gothenburg, Sweden
[4]Department of Thoracic Surgery, Skåne University Hospital, Sweden

Corresponding author:
Matilda Almgren, Institute of Health Sciences at Lund University, S-222 40 Lund, Sweden.
Email: matilda.almgren@med.lu.se

the heart, HTx should be viewed as a chronic condition due to the life-long immunosuppressive medication and numerous recommended restrictions involving healthy eating, physical exercise, sun protection and mastering the risk of infections.[4] It also involves psychosocial challenges during the transition from a life-threatening condition to a chronic but more stable state including coping with the threat of graft rejection[5] or other medical problems, thus constituting an uncertain and unpredictable future. The success of transplantation partly rests on the self-management ability of the heart transplant recipient (HTR), in conjunction with family and transplant professionals to manage symptoms, treatments, lifestyle changes and psychosocial, cultural and spiritual consequences. After HTx self-management is mainly constituted by the ability and process that the HTR uses in conscious attempts to gain control of his or her everyday life with a new heart rather than being controlled by it.[6]

One important aspect of chronic illness management is self-efficacy,[7] which is also a part of mastering the uncertainty of being a HTR.[8] Self-efficacy is defined as a person's confidence in carrying out a specific task.[9] In the context of chronic illness this includes managing self-care despite the presence of symptoms or side effects from the disease or medications. Self-efficacy is acting as a moderator in self-management,[6] which is why self-efficacy constitutes the foundation of self-management and self-management programmes,[10] thus it is highly relevant for transplant nurses involved in long-term management. Self-management focuses on the activities people carry out in order to create structure, discipline and control in their lives.[11] Self-management programmes enhance self-efficacy and thereby previous research has reported high levels of self-efficacy among HTRs, suggesting a great confidence about their post-transplant management.[13] This has also been shown in other transplant populations,[14] in which a high self-efficacy score was related to the extent of illness interference in activities of daily life.[14] Self-efficacy has been shown to be related to stress among HTRs[13] and also seems to correlate with depression.[13] Good perceived health among HTRs[15,16] has been demonstrated up to 10 years after transplantation,[16] with a general increase in perceived health from pre-transplant levels.[17] Predictors of good perceived health after HTx are fewer psychological symptoms, social interaction, not having any transplant-related complications and low symptom distress.[15] Symptoms, setbacks and complications negatively affect performance accomplishment which potentially decreases self-efficacy.[7]

However, despite the overall findings of improved health and wellbeing, some HTRs still struggle with psychological problems post-transplant. The prevalence of depression has been estimated at 17–41% up to 5 years after HTx.[13,18] A high level of comorbidities and a high New York Heart Association (NYHA) score have been shown to correlate with symptoms of depression and severe distress.[19] Finally, interviews with HTRs have indicated that perceived distress after HTx is underestimated.[20] Also, health-related quality of life seems to be overestimated when using self-report instruments compared to qualitative methods in outcome research after HTx,[21] thus indicating distress to be an underestimated problem after HTx.

To the best of our knowledge, this cross-sectional, nationwide study is the first to explore HTRs' self-reported degree of recovery in relation to self-efficacy. In order to help HTRs to balance their expectations we need to understand how the recovery process is experienced from their perspective. This exploration can provide HTRs and caregivers with a road map of what to expect regarding recovery and psychological wellbeing, thus illustrating the factors potentially affecting self-management.

The rationale behind this study is that in a previous qualitative investigation we hypothesised that disappointments related to expectations, such as setbacks and complications during recovery after HTx, might hinder self-efficacy when performance accomplishment fails.[7] The absence of physical improvements during the recovery process caused by muscle weakness, sleep problems and fatigue have been identified as factors affecting performance among HTRs.[7] Our previous study suggested that assessing the HTRs' expectations and providing support and strategies for how to balance them might generate an optimum level of self-efficacy and enable HTRs to master uncertainty.[7] Thus in order to promote adaptation to accepting uncertainty as a natural state as well as to accepting one's present physical abilities, the aim of this study was to explore self-efficacy in relation to the self-reported level of recovery and psychological wellbeing, among adult HTRs, one to 5 years after transplantation.

Methods

Study design and participants

This cross-sectional study is a part of the Swedish national Self-Management After Thoracic Transplantation (SMATT) study, which involves six different cohorts of heart or lung recipients, who completed nine different self-report instruments. The instruments in this paper have also been used within the main project for lung recipients.

The study was carried out at the two thoracic transplant units in Sweden where HTx is performed, in

addition to the largest HTx follow-up clinic. Data collection took place from 2014 to 2017. Adult HTRs who were due for their annual follow-up one to 5 years after HTx were consecutively included. Due to small groups in each year we considered all included HTRs as a single group, irrespective of which follow-up year they attended. Inclusion criteria were transplant recipients receiving only a heart, over 18 years of age, Swedish speaking, mentally lucid, no ongoing treatment for acute rejection and not hospitalised. A reason for exclusion was previous transplantation with either an organ or tissue. The patients were approached by the nurse at the outpatient clinic and received both verbal and written information about the study and provided their written informed consent. They were asked to fill in a total of nine self-report instruments, three of which are included in this study. Each participant could choose either to fill in the instruments at the clinic or at home and send them back in a pre-paid envelope.

During the data collection period a total of 303 HTRs due for their annual follow-up one to 5 years after transplantation were eligible for inclusion.[22] However, practical difficulties occurred such as staff turnover at the outpatient clinic and the fact that follow-up visits also took place at local hospitals where we were unable to contact the patients. Thus, from the 303 eligible HTRs, 153 were invited to participate and 90 (58%) were consecutively included in the study. The reason for external drop-out was being included twice instead of once, declining to participate, being transplanted with several solid organs or being severely ill. The exact figure for each reason for drop-out cannot be reconstructed. Ten HTRs forgot to send back their questionnaires and were not reminded due to the high nursing turnover at each outpatient clinic. Thus the final sample consisted of 79 HTRs who were due for follow-up at one year ($n = 28$), 2 years ($n = 17$), 3 years ($n = 11$), 4 years ($n = 17$) and 5 years ($n = 6$). Transplantation indications and medications are presented in Table 1.

Table 1. Demographics of the included heart recipients ($n = 79$).

	Frequency *n* and proportions (%)
Demographics	
Median age	56 years ($P_{25} = 43$, $P_{75} = 64$)
≤50 years	43 (54)
≥49 years	27 (34)
Gender	
Women	25 (32)
Men	54 (68)
Living arrangements	
Living alone	20 (25)
Single with children	3 (4)
Cohabiting without children	20 (38)
Cohabiting with children	13 (17)
Other	10 (13)
Missing	3 (3)
Education	
Compulsory	7 (9)
High school	46 (58)
University	26 (33)
Employment status	
Employed (full time/part time)	32 (40)
Not employed	33 (42)
Own company, working	9 (11)
Own company, not working	3 (4)
Missing data	2 (3)
Work ability	
Able to work full time/part time	54 (68)
Unable to work or study	20 (25)
Missing data	5 (7)
Sick leave or retired	
Temporary sick leave full time/part time	18 (23)
Permanent sick leave full time/part time	14 (18)
Retired	14 (18)
Indications for transplantation	
Dilated cardiomyopathy (different forms)	63 (87)
Other (e.g. hereditary conditions)	7 (9)
Congenital heart disease	4 (5)
Ischaemic heart disease	4 (5)
Eisenmenger	1 (1)
Mechanical assist device and time on ventilator	
Mechanical circulatory support (MCS)	24 (30)
>48 hours on ventilator after HTx	16 (20)
<48 hours on ventilator after HTx	2 (3)
Immunosuppressive medications and rejections	
Cyclosporin	18 (23)
Tacrolimus	59 (75)
Mycofenolate mofetil (MMF)	72 (91)
Azatioprine	3 (4)
Steroids	20 (25)
Other (e.g. certican)	23 (29)
Persons with one or more rejections	23 (29)

HTx: heart transplantation.

Instruments

The German version of the self-efficacy for managing chronic disease 6-item scale (SES6G)[23] was translated into Swedish by the research group and used to measure the self-efficacy score. The scale consists of six items graded in 10 steps on a Likert scale from 1 'not at all confident' to 10 'totally confident'. A mean score is calculated with a minimum of four of the six items (allowing for two missing item responses). Thus the mean score can vary between 1 and 10, in which higher values indicate stronger self-efficacy. The German version of the scale showed good convergent

construct validity with the self-efficacy for managing chronic disease 6-item scale (SES6G) (Spearman rank correlation 0.578) as well as high internal consistency (Cronbachś alpha coefficient 0.93).[23] No validation in the Swedish context was made.

The postoperative recovery profile (PRP) was used to measure the degree of self-reported recovery.[24] The 19 questions in the instrument evaluate both mental and physical symptoms, in addition to the possible effects of daily occupation and social life. The scale has four grades, that is, none, mild, moderate and severe and the level of self-reported recovery is based on the number of 'none' answers. Nineteen 'none' answers equal fully recovered with a descending gradient down to over seven 'none' answers, which means not recovered at all. The content validity of the instrument was high, and a vast majority of the items showed a high level of intra-patient validity.[24]

The Swedish version of the psychological general wellbeing (PGWB) instrument was used to measure psychological wellbeing (Table 2).[25] It contains 20 questions constituting six dimensions: anxiety, depressed mood, positive wellbeing, self-control, general health and vitality. A high score indicates better health status and psychological wellbeing. The timeframe is specified in the instrument as the last 7 days. The maximum PGWB index is 132 (best subjective wellbeing), descending to 22 (poor subjective wellbeing).[25] A normal sum score is defined as being in the range of 100–105, in which women tend to report lower wellbeing than men.[26] Inter-item correlation values range from 0.53 to 0.79 and Cronbach's alpha ranges from 0.61 to 0.89.[25]

Statistical analysis

Due to the small sample size at each follow-up, the correlations between self-efficacy, demographics, subjective recovery and psychological wellbeing included the whole group, regardless of time since HTx (1–5 years).

Table 2. Score for each sub-dimension of PGWB for the whole group of HTRs (n=79).

Sub-dimensions PGWB	Score; median	Score; min, max	Score; IQR
Anxiety	26	Min 13, max 30	24–28.75
Depression	17	Min 12, max 18	15–18
Positive wellbeing	18	Min 9, max 23	15.25–19
Self-control	16	Min 5, max 18	15–17
General health	14.5	Min 7, max 18	12–25
Vitality	17	Min 9, max 23	14–20

PGWB: psychological general wellbeing; HTRs: heart transplant recipients; IQR: interquartile range.

SPSS Statistics 24 (SPSS Inc., IBM Corporation, Armonk, NY, USA) was used for analysing data, which were mainly ordinal. Descriptive statistics (patient demographics, sociodemographics, medical indication and medical treatment) are presented with frequencies. In order to test for differences between two unpaired groups we used the Mann–Whitney U test and when testing relationships between the different aspects reported we employed Spearman's rho.

The statistical analysis was performed stepwise as follows:

1. Exploration of the level of self-efficacy for the whole group at each yearly follow-up.
2. Exploration of self-efficacy depending on demographic characteristics, self-reported level of recovery and psychological wellbeing.
3. Exploration of possible differences in the self-reported level of self-efficacy between two unpaired groups (e.g. men and women, working or not working...).
4. Exploration of associations between the level of self-efficacy and psychological wellbeing and self-reported degree of recovery.

Ethical considerations

The study was approved by the regional ethics board of Lund (no. 2014/670-14/10) with supplementary approval from the Swedish ethical review authority (no. 2019-02769). The study conforms to the principles outlined in the Declaration of Helsinki.[27] The data were kept confidentially and stored in accordance with Swedish regulations for protection and storage of data.

Results

Patient characteristics

Demographics, indication for transplantation and immunosuppressive medication are presented in Table 1. The whole group of HTRs ($n = 79$) comprised 54 men (68%) and 25 women (32%). Their median age was 56 years ($P_{25} = 43$, $P_{75} = 64$) and 24 (33%) had mechanical circulatory support (MCS) pre-transplant. The response rate varied between the instruments: self-efficacy 89% ($n = 70$), PGWB 85% ($n = 67$) and PRP 81% ($n = 64$).

Self-efficacy

The overall self-efficacy score was high, with a median of 8.3 ($P_{25} = 6.27$, $P_{75} = 9.23$) and no differences between men and women. There was a tendency that HTRs aged over 50 years reported higher self-efficacy ($P = 0.05$) than those aged under 50 years. Significantly

higher self-efficacy was found among those who had started work again ($P = 0.003$) and those without pre-transplant MCS ($P = 0.033$). No significant relationship was found between the groups living alone versus those cohabiting, or between those who reported having had a rejection and those who did not or between those with a higher educational level (university) and those with only an elementary education.

Self-efficacy and recovery

The self-reported recovery data showed that in the whole group, four HTRs were fully recovered, 18 almost fully recovered and 30 partly recovered. Thus 52 (81%) were reasonably recovered, while 12 (18.8%) were slightly ($n = 2$) or not recovered at all ($n = 10$). Those not recovered were seven men and five women, with a median age of 47.5 years. Seven were due for their one-year follow-up, one the 2-year follow-up, two the 3-year follow-up and two the 5-year follow-up. Half of those not recovered were working and seven had a high school or university education. Among the 12 not recovered, seven (58%) also reported low psychological wellbeing. The median self-efficacy among those not recovered was 7.5, which was significantly lower than that of those who were reasonably recovered ($P = 0.047$).

Self-efficacy and psychological wellbeing

The median total PGWB score was 108, minimum 54 and maximum 129, ($P_{25} = 24$, $P_{75} = 117$) suggesting overall good psychological wellbeing in the whole group of HTRs. In Table 2 scores for each sub-dimension is provided.

There were 23 HTRs, 11 men and 12 women, with a median age of 48 years, with poor psychological wellbeing defined by a PGWB sum score of less than 105. The majority ($n = 9$) were due for their one-year follow-up, followed by the 2-year follow-up ($n = 5$), 3 year ($n = 5$), 4 year ($n = 3$) and finally the 5-year follow-up ($n = 1$). Among those, 16 had a high school or university education, while the rest ($n = 7$) had compulsory education, 14 were working half or full time and nine could not work. The median self-efficacy among those with poor psychological wellbeing was 6.80. No significant differences in self-efficacy were seen between those reporting low psychological wellbeing and those who reported good psychological wellbeing. However, there was a correlation between those who reported low self-efficacy and had a lower score ($r = 0.446$) in the general health sub-dimension of the PGWB scale.

Discussion

The key findings in this study were that HTRs reported a relatively high level of self-efficacy with no gender differences. Higher levels of self-efficacy were found among those who had returned to work and among those who reported being reasonably recovered. HTRs treated with MCS pre-transplant reported lower self-efficacy than those who had not received MCS. The overall psychological wellbeing could be regarded as good, with no significant differences in self-efficacy among those reporting low psychological wellbeing and those reporting good psychological wellbeing.

Our results show that HTRs who were due for their yearly follow up one to 5 years after HTx report a high level of self-efficacy (median 8.3), which is in line with previous research.[13,14] Self-efficacy was lower among those who reported poor recovery, which supports previous findings, showing that self-efficacy is related to the amount of illness interference in daily life.[14] In this study we have not focused on expectations. However, our assumption is that self-efficacy is about balancing expectations, in this context about being a person living with a new heart, and thereby minimising disappointments related to the current status. Our hypothesis is that HTRs by doing this will find an optimum level of self-efficacy.[7] High expectations about recovery and wellbeing after HTx might therefore increase the risk of disappointment, leading to uncertainty about recovery and regaining health, which in turn might undermine self-efficacy, thus raising the importance of discussing what the optimum level of self-efficacy is and how it is valued.

Compared to the results in our interview study with HTRs at their one-year follow up,[7] the high level of self-efficacy in the present study was surprising. Those interviews indicated experiences of disappointment and uncertainty about the future, recovery and health, which could potentially have affected self-efficacy. Another study reported work, eating, social interaction, recreation, home management and ambulation as major problems one year after transplantation that affected functional status among HTRs,[28] which is in line with the results of our interview study.[7] This prompts the question about how to interpret the self-efficacy level. The self-efficacy score might need other complementary measurements in order to understand whether the rated level is optimal, or alternatively could be used as a measure over time to follow possible improvement. However, neither the studies by Jalowiec et al.[28] or our present study investigated self-management ability, which might have added information, because self-efficacy is a mediator for self-management. Disparities between the results of different methods might indicate a gap between data from self-report instruments or narratives, thus highlighting the importance of providing a more comprehensive

picture by using complementary measurements and methods.

No differences in self-efficacy between genders were observed, which was also the hypothesis from our previous research. However, gender differences became apparent regarding symptoms and disability, in which women reported worse symptom distress and more functional disability.[29]

Our results showed that those who had MCS before transplantation reported lower self-efficacy than those who did not. This is interesting, because they were probably in better condition at the time of the transplantation and had already undergone surgery, an accomplishment that could potentially have strengthened their self-efficacy. However, expectations based on previous experiences are a potential source of disappointment, especially if recovery after transplantation is more complicated and time consuming than it was after the MCS surgery. Recovery after MCS and HTx can differ, which is important information when guiding HTRs and balancing their expectations.

HTRs who had returned to work reported a higher level of self-efficacy than those who did not work. Performance accomplishment is acknowledged as an important aspect of self-efficacy,[8] which in this study was identified as returning to work and being recovered. Those who reported a low level of recovery also reported lower self-efficacy. This strengthens the results of our previous study about sources of performance accomplishment.[7] Previous studies have identified greater symptom distress and lower left ventricular ejection fraction as predictors of low functional status.[28] Those who do not return to work after HTx have been shown to experience more rejections, infections and medical complications[30] and more depression up to 10 years after HTx.[31]

We hypothesised that lower psychological wellbeing would generate a lower level of self-efficacy, but surprisingly this was not the case. This result suggests that the physical aspects of accomplishment have a greater impact on self-efficacy than the mental aspects.

Methodological considerations and limitations

About 65 HTxs are performed each year in Sweden,[22] which is a relatively small number. However, this explorative design is still of great importance for optimising recovery and the prerequisite for returning to wellbeing and health after HTx. Due to the small sample size it is not relevant to present analysis of the data for each year.

According to the registry, 303 HTRs in Sweden were eligible for the study during our data collection period. However, not all HTRs have their annual follow-up at any of the transplant centres where the study took place. Due to limited resources it was only possible to include those visiting the transplant centres for their yearly follow-up in the study. The final sample illustrates the challenges involved in performing clinical studies.

The SES6G cale was translated by the research group, and due to limited resources, was not psychometrically tested in the Swedish context. However, the German and Swedish context was considered to be similar in terms of language, culture and healthcare.

Conclusion

In conclusion, it is possible to experience high self-efficacy after HTx. High self-efficacy might be a marker for return to work and being fairly recovered. However, because of the potential effects of a low level of self-efficacy on self-management ability it is important to focus on these aspects in order to provide efficient self-management support.

Implications for practice

- Exploring the patients' self-reported experiences provides healthcare professionals with a road map, which is of great importance in order to supply heart transplant recipients with enough support.
- Gaining more knowledge regarding what heart transplant recipients struggle with after transplantation gives healthcare professionals an opportunity to adjust efforts to match the actual needs of the heart transplant recipients.
- Exploring recovery and wellbeing as well as their relation to self-efficacy is essential for helping heart transplant recipients to balance their expectations about recovery and life with a new heart, thereby boosting performance accomplishment.

Declaration of conflicting interests

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