Uncertainty after heart transplantation. A new perspective on self-efficacy and self-management.

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Uncertainty after heart transplantation

- A new perspective on self-efficacy and self-management

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Till pappa

För att du aldrig slutade hoppas
Ovissheten blev ditt hopp
Du ville aldrig veta
Älskar dig! Saknar dig!

Contents

Abstract

Background

Self-management is the main concept constituting the foundation of follow-up care after heart transplantation. Self-efficacy is a foundation of self-management. Little is known about heart recipients' experiences in relation to self-efficacy and self-management after heart transplantation.

Aim

The overall aim of this thesis was to explore uncertainty and self-efficacy as important aspects of the lived experience of heart recipients one year after heart transplantation.

Methods

Both an inductive and a deductive approach have been used in combination with qualitative research methods.

The study group consisted of 14 patients (I and II) who were due for their one year follow-up after heart transplantation. Interviews were performed and analysed by phenomenological hermeneutics (inductive) developed by Lindseth & Norberg and directed content analysis (deductive) developed by Hsieh & Shannon.

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*. Uncertainty emerges when the heart recipients are unable to ascribe meaning to illness-related events and might therefore be a source of distress. Performance accomplishment, which comprises physical, social and mental aspects, was seen as the main factor affecting self-efficacy after heart transplantation. Lack of performance accomplishment led to disappointment and therefore our hypothesis was that self-efficacy after heart transplantation concerns balancing expectations in accordance with realistic accomplishments.

Conclusions

Complications, setbacks and symptoms together with expectations are sources of uncertainty. Performance accomplishment enables expectations to be met and might therefore constitute a source of uncertainty when accomplishments are not achieved. Uncertainty can undermine performance and might thereby hamper self-efficacy and self-management.

Original papers

This thesis is based on the following papers referred to in the text by their Roman numerals:

1 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.

Abbreviations

CAV	Cardiac allograft vasculopathy
CIM	Chronic Illness Management
EMB	Endo Myocardial biopsy
HRQoL	Health related quality of life
HTx	Heart transplantation
ICCC	The Innovative Care for Chronic Conditions
ISHLT	The International Society for Heart and Lung Transplantation
MCS	Mechanical Circulatory Support
QoL	Quality of Life
WHO	World Health Organization

Introduction

Heart transplantation (HTx) is the most effective choice of life-saving treatment for patients with end-stage heart disease (ESHD) (Lund et al., 2013) when all other therapies have been attempted without success. In Europe, about 1,700 HTx are performed every year (The International Society for Heart and Lung Transplantation (ISHLT), 2017), while in Sweden, 64 HTx were performed in 2016 (Scandiatransplant, 2017).

Indications for HTx are end-stage heart failure 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 to prolong survival and enhance the person's quality of life. Mechanical circulator support (MCS) can be an option as a bridge to transplantation (Lund et al., 2017). The main diagnoses prior to HTx are: myopathy (55%), coronary artery disease (36%), valvular heart disease (3%), congenital heart disease (3%), re-transplantation (3 %) and other (1%) (Lund et al., 2013)

Patients with ESHD undergo a comprehensive, interdisciplinary pre-transplant evaluation to identify the severity of functional impairment, their prognosis as well as 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. Potential for adherence to the post-transplant regimen and the available level of psychosocial support are important aspects for long-term success (Mehra et al., 2006)

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

Self-efficacy, which refers to activities carried out by people to create order, structure and control in their lives, is an important aspect of self-management (Lorig & Gonzalez, 1992; Lorig & Holman, 1993). However, research has shown that patients and healthcare professionals have different conceptions of self-management (Kralik, Koch, Price & Howard, 2004). Therefore, it is important to understand the inside perspective of self-efficacy among persons who underwent a HTx in order to develop supportive self-management strategies. Uncertainty might constitute an obstacle to self-management as it leads to distress, thereby possibly reducing the recipient's ability to create cognitive patterns and meaning in the illness events. Understanding the concepts of uncertainty and self-efficacy as well as their possible impact on self-management might be of importance for the focus, structure and organisation of follow-up care after HTx and are therefore explored in this thesis.

Background

The development of heart transplantation

The first HTx was performed in 1967 by Christiaan Barnard in South Africa (Barnard, 1968). However, due to the absence of effective immunosuppression the outcomes were characterised by high mortality caused by infections and rejections. In the 1970s the discovery of cyclosporine made it possible to suppress the immune system more effectively (Kahan, 2011), which together with the development of the endomyocardial biopsy (EMB) procedure (Nguyen, Lee, Luo, & Siegel, 2011) revolutionized the field of HTx. Improved surgical techniques, patient selection, donor heart preservation methods and immunosuppression have contributed to continuous improvements in survival, especially during recent decades (Davis & Hunt, 2014). However, long-term survival has now reached a level where survival per se can no longer be the only form of measurement. Today, recipients' expectations concern not only survival but also good health and improved quality of life.

Survival after heart transplantation

Recent data presented by the ISHLT reveal survival rates of 84.5% after one year and 72% after five years (Lund et al., 2013). 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 mainly due to the increase in one-year survival. HTx requires lifelong immunosuppressive medication, which often has side effects and co-morbidities. In the long term cardiac allograft vasculopathy (CAV), rejection, infection and malignity still limit survival (Davis & Hunt, 2014).

Complications and risk factors

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 after HTx there are routine controls for CAV to increase the possibility for early treatment, as CAV can develop gradually with latent symptoms (Cupples, Larret, Mccalmont & Ohler, 2017). Unlike renal and liver recipients, heart recipients have no laboratory markers for CAV, which is why EMB remains the key diagnostic test for evaluating rejection after HTx. After the first year biopsies are generally only performed when the patient shows symptoms of rejection, although the risk of rejection persists throughout the patient´s life (Cupples et al., 2017).

HTx is considered a chronic condition due to the life-long medical regime with immunosuppressive treatment necessary to prevent CAV (Berben et al., 2015). Recipients need to engage in health promoting behaviours such as physical activity, no intake of harmful substances and protection from the sun in order to diminish the risk of complications and side effects from medications. The healthcare system is mostly organized with a focus on medical procedures aimed at identifying graft rejection and providing treatment rather than promoting health by preventive measures and supporting effective self-management (Berben et al., 2015). Although HTx extends life and offers the possibility of improved functional ability and HRQoL (Grady et al., 2007), recovery involves burdensome

medical and psychosocial challenges (Dew et al., 2005; Taylor et al., 2008), including several adaptive tasks (Rauch & Kneen, 1989) demanding self-management skills and the need for support. It is thus of great importance to explore the experience of being a heart recipient during the first year after transplantation.

In the context of HTx there is often an initial acute development of the illness, which gradually develops into a chronic disease ending up with the need for transplantation. The duration of the process can vary between several years or a few months, leaving the recipient with a threat to health and life as well as an uncertain future. The process involves many different forms of uncertainty, for example uncertainty about receiving a new heart in time, fear of rejection and uncertainty about survival, all of which require adaptation (Rauch & Kneen, 1989). Uncertainty in the illness context has been shown to be the greatest single psychological stressor for patients living with a life-threatening illness (Kang, 2009; Mishel, 1997).

Previous research

Heart transplantation and outcomes

Previous relevant research on illness and health after HTx can be divided into three main areas:

- Quality of life
- Symptom and symptom distress
- Psychiatric disorders and distress

Quality of life

Studies demonstrate that heart recipients experience good QoL, which is stable for at least ten years after the transplantation (Grady et al., 2007; Politi et al., 2004). This includes satisfaction with their health and functioning. Predictors of good QoL 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, more helpful self-care management interventions, not working, being married and not having HTx -related complications (i.e., rejection, vasculopathy and genitourinary illnesses) (Grady et al., 2007).

In a study comparing quantitative and qualitative methods and their ability to capture 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 overestimation of QoL (Abbey et al., 2011).

Symptom 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 reported symptoms were experienced as "not" or "mildly" distressing. Women and younger patients reported significantly higher levels of distress, which increased with time after transplant (Stiefel et al., 2013). 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 predicted the physical aspect of QoL (Tung et al., 2011). Grady et al. (2009) demonstrated that predictors of low symptom distress were higher education and no psychological problems. They also found that significant predictors of lower symptom frequency were not having CAV and having no psychological problems at five years. The most distressing symptoms at five to ten years after HTx were memory

problems, fatigue, easy bruising, cramps in the extremities and sexual problems. Over time symptom distress and frequency steadily declined, with symptom frequency stabilizing after seven years (Grady et al., 2009). Fatigue is a common symptom after HTx (Grady et al., 2009; Reyes et al., 2004; Tung et al., 2011) and in one study was found to be significantly associated with depression, functional status and mental health (Reyes et al., 2004).

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 at 17% to 41% up to five years after HTx but is 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 developing 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 in the post-transplant period (Dew et al., 1996).

Depression is shown to be the strongest predictor of QoL in heart recipients (Tung et al., 2011) and has also been identified as a risk factor for non-adherence (DiMatteo, Lepper & Croghan, 2000).

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 found to be at higher risk of developing these disorders than other community-based populations or those with many other chronic diseases (Dew & DiMartini, 2005).

An interview study by Ross et al. (2010) revealed that 88% of the heart recipients exhibited distress. Distress among heart recipients has also been shown to be persistent over time, evident up to 18 years after HTx (Fusar-Poli et al., 2005), indicating that it is an underestimated problem.

Growing evidence indicates a correlation between psychosocial factors as predictors of clinical outcomes in heart recipients (Rosenberger, Fox, DiMartini & Dew, 2012). A linkage between psychological status during the first year post-transplant and physical health outcomes has been seen. Persistently elevated depressive symptoms or anger-hostility were shown to predict chronic graft rejection, which in turn predicted mortality (Dew & DiMartini, 2005). The heart recipients who experienced PTSD-T also had an increased mortality risk (Dew & DiMartini, 2005). 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)

Viewpoints and perspectives

The ontological assumption in this thesis is that uncertainty is inherent in the human experience. As humans we can never prophesy with certainty how anything in life will turn out. This is something we must learn to accept. Uncertainty will emerge when facing an illness, as illness constitutes a concrete threat to life, life-roles and health.

The two theoretical frameworks in this thesis address similar aspects such as information, education and support, i.e., self-management skills. However, the ontological assumptions and how persons are viewed differ between the two concepts. The ontological assumption of self-efficacy is that a person's behaviour is changeable 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 attribute meaning to illness-related events and emerges when the person is unable to form a cognitive schema for such events (Mishel, 1988). The goal is to construct meaning, thus reducing uncertainty and achieving adaptation by means of coping strategies, leading to the experience of health (Mishel, 1988).

In the context of HTx, the goal of healthcare professionals and presumably also the heart recipient is managing the medical regimen; coping with the psychological and physiological changes inherent in the transplantation process and regaining health. Self-efficacy addresses how healthcare professionals can change a person's health behaviour to enable her/him to become an adherent heart recipient who follows the medical regimen and recommendations in order to optimize self-management. Uncertainty is seen as a part of being a human, thereby potentially affecting healthcare behaviour and self-management. Unmet expectations, disappointments, unachieved life goals, lost life roles, symptoms, fatigue and inability to work are sources of uncertainty that will potentially affect a person´s ability to manage life with a new heart.

This thesis stems from the hermeneutic research tradition, which uses experiences as a tool for better understanding the context in which the experiences occur by focusing on meaning and interpretation (Polit & Beck, 2010). An inductive approach was employed in order to understand the inside perspective of being a person (Toombs, 1987) receiving a new heart in relation to healthcare and her/his own experiences. Interpretation of the transcripts of interviews with the heart recipients constitutes the knowledge. This method is necessary for grasping experiences and describing the phenomenon, leading us to a deeper knowledge of what it is like to be a person living with a new heart.

In this thesis uncertainty in HTx will be viewed both from an acute and a chronic perspective. The focus of this thesis is the first year after transplantation, which means that it is limited to exploring the experience of the chronic phase of HTx. There is an on-going threat to life as in any other chronic disease, where survival is estimated to evaluate the prognosis. 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 have the opportunity to adjust to living with a chronic disease. Thus it is vital to explore the experience of being a heart recipient during the first year after transplantation.

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.

Theoretical framework

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 theory of Uncertainty in illness will be the main framework and point of departure in this thesis. The discussion of the results and the framework of self-efficacy will be illuminated through the framework of uncertainty.

Uncertainty in illness

Uncertainty related to illness is defined as a person's *"inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorized an event because of the lack of sufficient cues. Uncertainty occurs in a situation in which the decision-maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately"* (Mishel, 1988, p.225). Uncertainty develops when situations are interpreted by the person as ambiguous, complex, unpredictable or probabilistic, which is connected with unavailable or inconsistent information and insecurity about the state of knowledge (Brashers, 2001). Uncertainty connected to the disease/illness has been shown to be the greatest single psychological stressor for the patient living with a life-threatening illness (Mishel, 1997).

Uncertainty in relation to illness, differentiated from functional uncertainty, was studied for the first time in the 1960s (Mishel, 1997). Uncertainty as a concept in relation to acute illness was later developed into a theoretical framework by Mishel (Mishel, 1988). The framework was then reconceptualised to explain the phenomenon in chronic disease (Mishel, 1990).

The evidence supporting the theory is strongest in relation to 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). The person tries to form a cognitive schema of the illness events and when this fails, uncertainty emerges. She/he attempts to find a pattern in the way the symptoms appear in order to create meaning in relation to the illness. The person will also assess whether the events are similar to earlier experiences and her/his familiarity with healthcare providers and procedures. In order to interpret these factors the person uses resources defined as cognitive capacity (i.e., the ability to process information), social support, education and credible authority (i.e., the degree of trust in healthcare professionals). Uncertainty can emerge at various levels depending on how the person manages to cognitively process the illness-related event. Uncertainty will then be appraised either as a danger or an opportunity. By using different coping strategies adaptation to the situation will occur (Mishel, 1988) (also see Figure 1 p. 22).

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 but merely expands it (Mishel, 1990).

Living with a chronic disease 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 rejection and the need for self-care actions. In acute illness uncertainty is connected to issues of diagnosis, treatment and recovery, while uncertainty in chronic illness involves more areas of life and influences daily routines and activities (Mishel, 1999). When the person is unable to handle it the uncertainty connected to chronic illness can spread into many different areas of life. According to Mishel, this will, affect the person's view of self and view of life, thus turning her/his whole world upside down. In time this disorganization will settle and uncertainty might be a state in which a transition towards a new view of life can be found and considered. To enable this transition, the heart recipient needs to embrace a probabilistic view of life, meaning focusing on possibilities and accepting that life is fragile and unpredictable. It also implies letting go of the prevailing mechanistic paradigm advocating cause-and-effect. This is a complex transition, which needs support from close relatives and more importantly from healthcare professionals (Mishel, 1990). Across all illnesses studied to date, uncertainty decreases over time but returns due to recurrence or exacerbation of the illness (Mishel, 1997).

Previous research on uncertainty

Most heart recipients reported that uncertainty related to their illness, identity and relationships is a salient aspect of their transplantation experience (Martin, Stone, Scott & Brashers, 2010; Scott, Martin, Stone & Brashers, 2011), which includes the pre-transplant period when waiting for an organ (Brown, Sorrell, McClaren & Creswell, 2006). Research reveals a positive relationship between uncertainty and emotional distress, anxiety and depression across various populations (Mishel, 1997). However, it has also been demonstrated that uncertainty is related to poor psychosocial adjustment in the areas of life satisfaction, negative attitudes towards health care, family relationships, recreation and employment, which continues over time (Mishel, 1997). Furthermore, uncertainty has been associated with increased stress, psychological mood disturbances, poor QoL, less coping effectiveness and reduction in perceived health status (Kang, 2009). Research also reveals a relationship between uncertainty and severity of the illness as well as negative effects on QoL (Mishel, 1997). Uncertainty has been shown to be associated with the transplantation process, but the sources of uncertainty change over time (Martin et al., 2010). Unpredictability and ambiguity, which are forms of uncertainty, were found in a study to distinguish adherent from non-adherent persons (DiIorio, Faherty & Manteuffel, 1991). As adherence is one of the main goals of self-management, this suggests that uncertainty might be an important aspect. In the last decade there has been more focus on communication and its effects on uncertainty, leading to a pronounced shift in how uncertainty is viewed from "uncertainty reduction" to "uncertainty management" (Kuang, 2017). The handful of intervention studies aimed at reducing or managing uncertainty in illness have demonstrated positive outcomes due to beneficial use of emotion regulation, self-management skills training and psychoeducation (a therapeutic intervention for coping with illness) (Johnson Wright, Afari & Zautra, 2009).

As humans we all experience uncertainty and a goal for both patients and healthcare providers would be to reduce uncertainty, especially about something as important as illness (Johnson Wright et al., 2009). When illness uncertainty is appraised as a threat, it can lead to difficulty adjusting. If left untreated or unaddressed uncertainty may cause increased psychosocial problems. Furthermore, there is evidence suggesting that uncertainty is a nonlinear process that may fluctuate as a function of changing symptom and stress levels (Johnson Wright et al., 2009).

Additional important concepts

Self-efficacy

Self-efficacy is a concept developed by Bandura (1977), referring to a person´s belief in her/his ability to manage a given task. The fundamental hypothesis of the 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 the effort 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. Self-efficacy is belief and behaviour specific, meaning that it is possible to influence it through education. The theory encompasses four different ways in which self-efficacy could be enhanced, namely skills mastery, modelling, reinterpretation of psychological symptoms and persuasion (Bandura, 1977). The main concepts from the theory are shown in Box 1 (p.25).

Self-management

The theory of behavioural change from which the concept of self-efficacy is derived became the foundation for the early development of self-management programmes (Lorig & Gonzalez, 1992), which have been widely accepted and now constitute the foundation of the Chronic illness management (CIM) project initiated by the World Health Organization (WHO) (Yach, 2002).

The term "self-management" refers to the activities people undertake to create order, discipline and control in their lives (Kralik et al., 2004). A basic assumption is that if people have knowledge about the reasons for why and how they should make effective self-management decisions it will motivate them to do so (Anderson, Blue & Lau, 1991)

Many factors that influence the way people self-manage chronic illness and what meaning they ascribe to the process have been identified (Paterson, Russell & Thorne, 2001).

Kralik et al. (2004) conclude that patient education may provide a structure that people absorb passively, whereas the self-management process involves learning about their responses to illness through daily life experiences and as a result of trial and error (Kralik et al., 2004).

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 chronically ill individuals (Yach, 2002). The healthcare system should promote continuity and coordination, encourage quality through leadership and incentives, organize and equip healthcare teams and make use of information systems to support self-management and prevention (Yach, 2002). Healthcare systems that focus on self-care management and chronic illness management report better long-term outcomes in chronically ill populations (Nuno et al., 2012). Specially trained nurses (e.g., nurse practitioners, clinical nurse specialists) are key players in the management and coordination of the care of chronically ill patients and for improving health outcomes (Berben et al., 2015), which is also stated in the transplant care recommendations and guidelines developed by the ISHLT (Coleman et al., 2015).

The self-management programme demonstrates that self-efficacy has an important effect on self-care behaviour and HRQoL. Self-efficacy was chosen to constitute the foundation of self-management programmes due to the fact that it can be influenced (Lorig & Holman, 1993). However, research demonstrates a relationship between a high level of symptoms and low self-efficacy and QoL (Sarkar, Ali & Whooley, 2007), where the presence of symptoms correlates with anxiety, even when symptom distress is reported as low (McCormick, Naimark & Tate,

2006). Self-efficacy is also seen as an important determinant of depressive symptoms among kidney transplant recipients, while self-care behaviour has 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' perception of the consequences of their heart disease, the lower their 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 than originally envisioned. Hence, the hypothesis in this thesis is that uncertainty caused by heart recipients' inability to attribute meaning to illness-related events might have a major impact on self-efficacy, something that needs to be explored.

Rationale

Self-management refers to activities carried out by people to create order, structure and control in their lives (Lorig & Holman, 1993). Self-efficacy is an important aspect of self-management (Lorig & Gonzalez, 1992). It is therefore essential to understand the inside perspective on self-efficacy among heart recipients in order to develop appropriate self-management support strategies. Uncertainty is shown to be a salient aspect of the transplant experience (Martin et al., 2010) and has been found to be associated with emotional distress, anxiety and depression (Mishel, 1997). Thus uncertainty might constitute an obstacle to self-management by possibly reducing a person's cognitive ability to create patterns and meaning in the illness-related events. For this reason it is vital to explore the concepts of uncertainty and self-efficacy as well as their possible impact on self-management. This knowledge will enable the re-design of follow-up care after HTx in order to more effectively address the psychological barriers to self-management, thereby possibly reducing long-term complications and providing better HRQoL.

Aim

The overall aim of this thesis was to explore whether uncertainty and self-efficacy are important aspects of the experience of heart recipients one year after heart transplantation.

Specific aims

- An in-depth exploration of the meaning of uncertainty during the first year after heart transplantation
- An in-depth exploration of self-efficacy among heart recipients by means of Bandura's self-efficacy theory.

Methods

Design

Two qualitative methods were used in order to illuminate the overall aim, which was to understand the lived experience of being a person with a new heart during the first year after HTx. Initially an inductive approach was utilised in order to grasp the inside perspective, followed by deductive approach to explore the concept of self-efficacy in the context of HTx. The methods used are described in Figure 1.

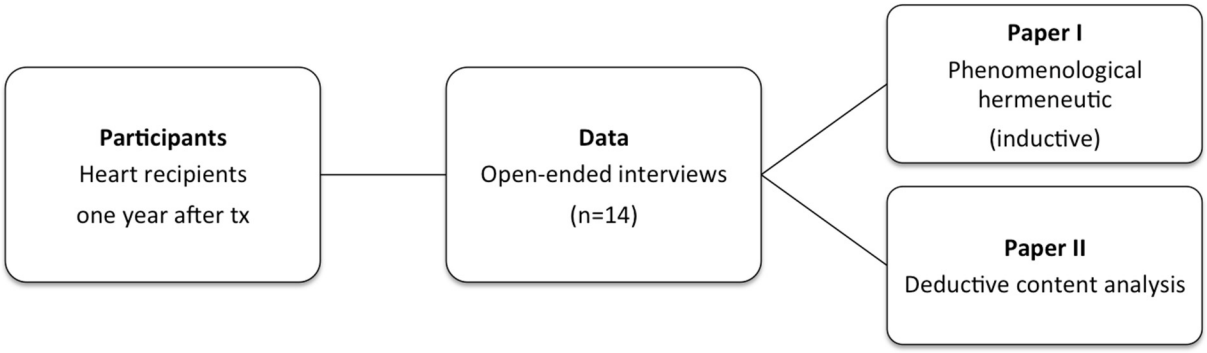

Figure 1. Overview of the research design

Sample selection and context of the study

The two papers were derived from the same data set and therefore the same context. The inclusion criteria were Swedish speaking adult heart recipients who were due to attend their 12 month follow-up after the transplantation and who were able and willing to participate in an interview. The participants were recruited at Lund and Gothenburg, the two centres in Sweden where HTx is performed. The nurse at the follow-up clinic contacted the potential participants and their written consent was obtained. They were informed that they could withdraw from the study at any time. A total of 16 patients were invited to participate, of whom one declined and one was excluded. The reason for exclusion was that it was not possible to carry out a face to face interview. After consultation with the nurse at the follow-up clinic we decided not to proceed with this interview for ethical reasons. The 14 heart recipients, 4 women and 10 men with a mean age of 51 years (28-67 years), were interviewed. Demographic characteristics are presented in Table 1.

Table 1. Demographics of the 14 heart recipients

Characteristics	Number of participants
Gender	
Male	10
Female	4
Indication for transplantation	
MCS (Mechanical Circulatory Support)	7
Dilated cardiomyopathy	9
Ischemic heart disease	1
Uni ventricular heart	1
Cardiomyopathy	1
ARVD/C (cardiomyopathy)	1
Ischemic cardiomyopathy	1

Data collection

Data were collected between September 2014 and February 2015. The interviews were performed individually and took place at the hospital where the one-year follow-up was conducted (Lund University hospital or Sahlgrenska University hospital, Gothenburg). They were digitally recorded and transcribed verbatim. The interviews had a mean duration of 76 minutes (40-107 minutes). An open ended and in-depth method was employed during the interviews. The participants were encouraged to narrate freely about their experience of the first year after their HTx. The interview started with the question "Could you tell me how it all began?" and the interviewer deepened the understanding and reflection by probing questions such as "Could you please describe…?" "What happened next?" and "How did that make you feel?" The purpose of the interviews was to explore the experience of being a person who received a new heart with focus on the concept of self-efficacy.

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 Ricoeur's philosophy (Ricoeur, 1976, 1981) as developed by (Lindseth & Norberg, 2004) was chosen.

Data were analysed in three steps (Lindseth & Norberg, 2004).

Naïve reading, in which all researchers read the interviews several times to become familiar with the content and achieve an initial understanding, i.e., a naïve understanding, of the narrative.

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 sub-themes; i.e., thematic structural analysis. Every theme in the structural analysis was reflected on in relation to each researcher's pre-

understanding and the naïve understanding in order to be as open as possible to the phenomenon under investigation and to ensure that the themes validated the naïve understanding.

Comprehensive understanding. 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 was 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 the structural analysis in a comprehensive way.

Content analysis (Paper II)

For the second paper directed content analysis as described by Hsieh & Shannon (2005) 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 HTx. When analysing the text we chose to employ Bandura's theoretical framework, as Bandura developed the concept of self-efficacy and his theory comprehensively describes it.

Firstly Bandura's theory was scrutinised in detail in order to identify the main concepts. In the second step the main concepts and the contextual factors of self-efficacy were chosen from the theory (Box 1) and applied to the data, i.e., identifying meaning units that corresponded with the content of each main concept in Bandura's theory. The authors read and highlighted all text 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 dividing performance accomplishment into several parts. Two of the authors 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 the core meaning of self-efficacy in this 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.

Ethical considerations

This thesis conforms to the ethical principles outlined in the Declaration of Helsinki (World Medical Association, 2013) and the Swedish research ethics legalisation (SFS 2003:460). The project was approved by Regional Ethics Board of Lund (Dnr. 2014/670-14/10).

The nurses working at the follow-up clinic asked the participants if they wished to take part in the interview in order to minimize the risk of them feeling obliged to participate.

The participants were informed about the aim and value of the study together with information about confidentiality, protection of their identity and their right to withdraw their consent to participate at any time without giving a reason. The information was provided both verbally and in writing on several occasions together with contact information for researchers in case of questions or withdrawal from the study.

The potential risks and burdens to the participants connected with the interviews were judged to be small. 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 clinic.

Two of the participants provided information that the researcher considered to be of importance to the transplant team. In order to protect and help the participants and not ignore the important information that might affect their follow-up care and potentially their health status, the two participants were asked for permission to contact the transplant team.

Results

The main results and hypothesis from the two studies regarding uncertainty and self-efficacy are:

- Heart recipients have strong feelings of uncertainty about survival, recovery and the possibility of living a normal life in the future.
- The meaning of uncertainty after HTx comprises: *doubting survival, doubting the recovery process, doubting one's performance, struggling with close relationships, feeling abandoned* and *doubting the future*.
- Symptoms, complications and set-backs might be sources to uncertainty when the heart recipients are unable to interpret, understand and thereby ascribe meaning to them.
- Performance accomplishment, which comprises physical, social and mental aspects, is the main contextual factor of self-efficacy. It is also the key factor when measuring self-efficacy.
- Lack of performance accomplishment is a source of disappointment
- Self-efficacy after HTx was hypothesised to concern balancing expectations in accordance with realistic accomplishments.

Uncertainty

The phenomenon derived from the structural analysis of the interviews (Paper I) was uncertainty, which comprised the following themes; *doubting survival, doubting the recovery process, doubting one's performance, struggling with close relationships, feeling abandoned* and *doubting the future* (Table 2).

Table 2. Structural analysis of the meaning of uncertainty among the 14 heart recipients

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

Almost all participants brooded about survival. They found it difficult to accept that their new heart was not as sustainable as their own heart would have been. The survival of the graft became a threat that led to them doubting survival. The recovery process after the HTx was another factor that contributed to uncertainty. The recovery process differed widely between the participants, which affected their experience and thereby caused uncertainty. Having had a MCS before the HTx was a mediator for expectations of the recovery and they compared the recovery after MCS surgery with the recovery after HTx. The frequency of complications, symptoms and set-backs affected the recovery process and led to the participants *doubting the recovery process*. 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 it could have on the recovery process. In order to optimize their recovery and in the long term their survival, the participants 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 one's performance*. This made it more difficult for them to master their new situation.

The participants experienced expectations and disappointment from family and friends, which made them doubt the sustainability of the relationship and involved *struggling with close relationships*. Their family members and friends had expected a faster recovery and that everything would return to normal again. The lack of support as well as acceptance and understanding of their situation made some play a role and attempt to live up to the expectations of others in order to avoid disappointment. Lack of support from family and friends was a great source of distress and induced a fear of being left alone. The whole experience of having a HTx was overwhelming and the participants had a hard time trying to interpret and understand their new situation. Many stated that they lacked support and education from healthcare professionals to master their situation. They also expressed concerns about not involving their relatives in the healthcare process. Some felt that they were not taken seriously by healthcare professionals, which resulted in feeling abandoned. All the concerns revealed in the analysis underlined the fact that it was difficult to visualize the future. 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*.

By using Mishel's theoretical framework of Uncertainty in illness (Mishel, 1990) we comprehended the meaning of being in uncertainty and that it is a source of distress. Mishel describes that uncertainty arises in chronic illness when the person loses the sense of coherence, demolishing her/his view of life (Mishel, 1990). Heart recipients search for meaning and strive for coherence but this is no longer achievable in the way they experienced previously. In order to manage uncertainty heart recipients need to embrace and integrate it as a natural feature of life, where it becomes part of a transition towards a new view of life. Healthcare professionals are mostly engaged with the positivistic and mechanistic paradigm, valuing control and certainty, leaving no room for uncertainty and probabilistic thinking. This approach hinders the heart recipient's ability to adopt a probabilistic worldview, thereby blocking or constraining the transition towards a new meaning and view of life. When this transition is hindered or blocked the situation appears more cryptic and becomes harder to interpret cognitively, thus creating distress in the heart recipient. If the transition remains blocked the distress might accelerate and lead to a condition that resembles post-traumatic stress disorder, which can arise from exposure to uncertainty and unpredictability.

Self-efficacy in the context of heart transplantation

Performance accomplishment

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

Physical accomplishment

Each *physical accomplishment* served as a step towards recovery. It initially means being able to get out of bed, sit in a chair, take a few steps and take a shower without assistance. The physiotherapist played an important role in helping the participants to achieve physical accomplishment. Being able to do whatever they wanted without assistance was a clear performance marker and increased their trust in their own ability. Physical accomplishments after discharge went 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 are necessary evidence of physical performance accomplishments.

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, *mental accomplishment* involves accepting uncertainty and adopting a new view of life.

Social accomplishments

Being socially active was considered important. Contacting friends, participating in social activities and being part of society again were strategies for achieving *social accomplishment*. Being able to work was a major social accomplishment. Having no limitations and being able to do whatever they wanted was a great achievement.

Complications, setbacks, treatment and side effects

Several physical complications and setbacks negatively affected performance accomplishments and thereby self-efficacy. For some of the recipients the recovery was a major challenge due to depression, lack of energy 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 HTx was a huge disappointment and a major stress factor. During 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.

Vicarious experience

Vicarious experience means being inspired by others, which can lead to increased hope of recovery and motivation 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.

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.

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, side effects and setbacks in the recovery process, such encouraging remarks gave rise to uncertainty due to incongruence with their personal experience.

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.

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 outcome expectations varied but a common theme was surprise and disappointment that recovery took so long. Having undergone MCS was also a mediator of outcome expectations, as the initial post-transplant period was more difficult for some compared with their recovery after MCS surgery. A strong sense of disappointment leading to emotional arousal and weakened willpower arose when physical achievements were lacking and accomplishments were poor. 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. Returning to the transplant unit for the one-year follow-up evoked a cascade of emotions.

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 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 difficulties that required adjustment. Resuming daily activities became a major task due to lack of concentration, energy and confidence, which also affected their ability to perform at work.

The participants adopted a variety of adjustment strategies, but a common strategy was 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 contributed 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 people in their environment constantly questioned their strength and recovery, making them reluctant to talk about the HTx.

Several conscious strategies were adopted to constantly focus on positive thoughts. 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.

Discussion

Methodological considerations

The papers in this thesis stem from two different qualitative designs with contrasting 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). The methodological considerations will be discussed with reference to Lincoln & Guba´s framework (1985) and the recommended four criteria of *trustworthiness* in qualitative research: *credibility, dependability, conformability* and *transferability*. (Lincoln & Guba, 1985).

Papers I and II stem from the same interview material. All the interviews were performed and transcribed verbatim by the author of this thesis. This can be considered an advantage when analysing the text as it makes it easier to be close to the text and choose representative quotations from the participants, thus enhancing credibility. To avoid the risk of bias caused by being too familiar with the text, the analysis was performed in collaboration with one of the supervisors. It was then discussed with the rest of the research group in order to improve credibility.

When the 14 interviews had been performed the data set was considered complete as no new aspects of self-efficacy emerged. The interviews were extensive and rich, indicating that the participants were given the opportunity to verbally express their experiences. Therefore it was not considered necessary to recruit more participants in order to further enrich the material. However, 13 out of the 14 participants were born in Sweden, all of them live in a Swedish sociocultural context and are cared for by the Swedish healthcare system, which of course is a limitation when it comes to transferability (Lincoln & Guba, 1985).

The multicentre approach enabled us to include participants from the whole country. Although there are only two centres in Sweden that perform HTx, our approach minimizes the effects of context bias by strengthening dependability and possibly also transferability (Lincoln & Guba, 1985). The participants varied in age, gender and diagnosis prior to HTx (Table 1). The gender distribution of 72% male is similar to the general HTx population, as statistics from the ISHLT show that 75% of heart recipients are male (Lund et al., 2017). This might also strengthen dependability (Lincoln & Guba, 1985).

We initially 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. Therefore we decided to focus on the meaning of being a heart recipient and to analyse the interviews by employing a phenomenological hermeneutic method instead. We abandoned the constant comparative method inherent in Grounded Theory and instead approached the naive reading of the transcribed interview text with an open mind (Lindseth & Norberg, 2004). The change of methodological approach might constitute a threat to credibility and dependability (Lincoln & Guba, 1985). However, both Grounded Theory and Phenomenological Hermeneutics are based on an inductive approach with open-ended questions, suggesting that the interview techniques are similar. The structural analysis revealed the phenomenon of uncertainty that emerged from the interviews and later in the process we found the same phenomenon either implicitly or explicitly in several studies, which gives us reason to believe that the results (Paper I) are transferable to other settings (Lincoln & Guba, 1985).

The interviews were judged to be extensive and a great deal of material was not used in the first analysis. In order to utilize all the data and make the most of it, which is important from a research ethics perspective, the interviews were subsequently re-analysed.

In the second analysis directed content analysis was chosen (Paper II) in order to comprehend self-efficacy in the context of HTx. The starting point was to gain an in-depth grasp of the theoretical framework of Self-efficacy (Bandura, 1977). By choosing directed content analysis of the interviews the researchers faced a situation of double bias. Firstly, the theory generates the risk of a greater likelihood of finding evidence that supports the theory (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 by letting the participants talk freely, thus reducing the risk of providing cues or leading the interviews and influencing the participants (Hsieh & Shannon, 2005). When conducting the interviews none of the researchers were familiar with the Self-efficacy framework, which might enhance conformability.

The pre-understanding within the research group differed. When the interviews were performed the interviewer was familiar with caring for heart recipients during their time at the Intensive Care Unit (ICU). However, the researcher had no experience of long-term follow-up care, which might strengthen objectivity and thereby confirmability (Lincoln & Guba, 1985). The supervisor had experience of follow-up care and was familiar with the research area of solid organ transplantation, but mostly with solid organs other than the heart.

Re-analysing interviews requires careful consideration of inherent bias due to familiarity with the text. However, it can also be beneficial as it deepens the understanding. The human being is complex by nature, meaning that there is never just one explanation. Applying two theoretical perspectives enables us to grasp the complexity of being a person undergoing HTx. In addition, the argumentation in this thesis is that uncertainty from an ontological perspective is a foundation of being human. The phenomenon of uncertainty connected to illness has been well explored in various diseases, as has self-efficacy as a concept, which could indicate that the results of this thesis might be transferable to a wider population.

General discussion of the results

In the discussion, the results from both Paper I and Paper II will be illuminated through Mishel's framework (Mishel, 1988) in terms of the acute and chronic aspects of uncertainty in illness in the context of HTx. Mishel's framework (Mishel, 1988), which elaborates on the uncertainty associated with acute illness, contains three different dimensions defined as Stimuli frame, Structure providers and Cognitive capacities (Figure 2). These dimensions will constitute the structure of the discussion as the first year after HTx has many similarities to acute disease.

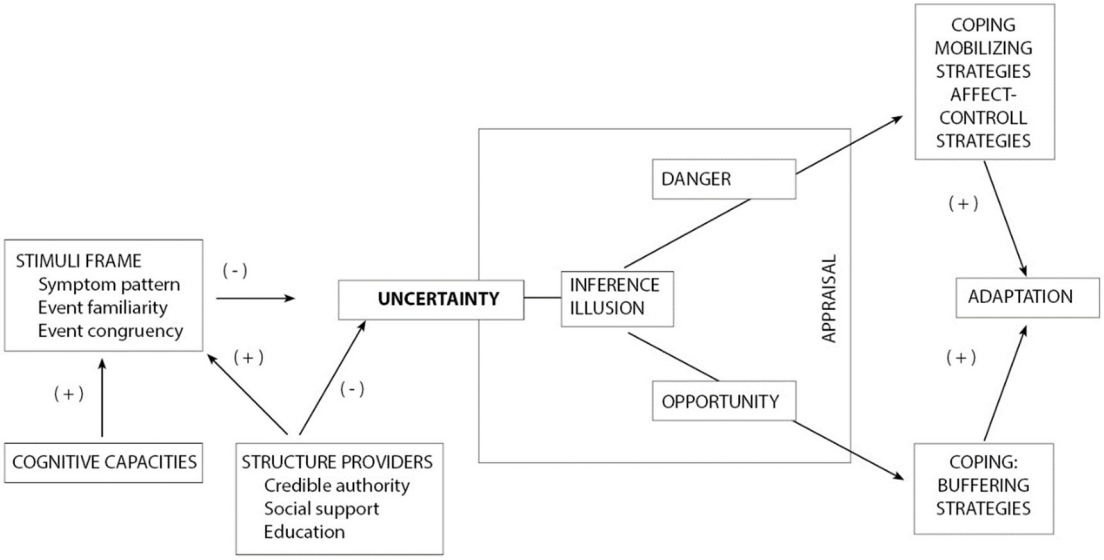

Figure 2. Uncertainty in illness framework (Mishel, 1988, p. 226)

Stimuli frame

Symptom pattern

The theme *doubting recovery* in the structural analysis stems from being unable to interpret symptoms, complications and side effects that in some cases made the heart recipient feel worse after the HTx than before. Having a new heart means having to relearn the signals from one's body and from the heart. The heart recipients stated that their new heart did not feel or react in the way they were used to (Paper I). Post-transplant complications, setbacks and side effects caused uncertainty, thereby negatively affecting the recipients' performance accomplishment and self-efficacy (Paper II).

Uncertainty will occur if the person is unable to appraise the symptoms (Mishel, 1988), complications and side effects, resulting in 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 the cultural and social environment as well as healthcare professionals (Mishel, 1988).

Mishel's theoretical framework is confirmed by the findings in this thesis and previous research, demonstrating a relationship between symptom distress and uncertainty in patients awaiting coronary artery bypass surgery (McCormick et al., 2006). McCormick et al. (2006) also showed correlations between physical limitations and symptom distress, uncertainty and anxiety. This emphasises the importance of identifying those heart recipients suffering from various symptoms that hinder the recovery process, as they are at risk of increased uncertainty and thereby anxiety, either as a result of unachieved accomplishments and high expectations or due to setbacks and complications (Paper II).

Research shows a relationship between uncertainty and severity of the illness, where recurrence indicates the severity of the disease and implies an inability to control it (Mishel, 1997). When it comes to transplantation one threat is rejection. Among solid organ transplant recipients fear of graft rejection has been described as a struggle to control the uncontrollable (Nilsson, Persson & Forsberg, 2008), including five domains: an abstract threat to life, the concrete threat to health, trust in the body, striving to control the threat and one´s identity (Nilsson et al., 2008). This is an important aspect in long term follow-up, as the threat is constant over time if one fails to adhere to medication and prescriptions. Fear of graft rejection seems to continue over time (Nilsson, Forsberg, Backman,

Lennerling & Persson, 2011), implying uncertainty about graft sustainability, and might be one of the main concerns that healthcare professionals should address at an early stage because it can persist as a source of uncertainty if the heart recipient is unable to adopt the probabilistic view (Paper I).

The interviews with the recipients were performed one year after the transplantation and comprise experiences from the first year, which is when biopsies of the heart are performed continuously together with laboratory tests and other medical examinations, where a higher level of uncertainty has been shown during treatment and medical assessments (Mishel, 1997). Furthermore, the highest level of uncertainty is prominent during the acute phase of an illness, fading away over time and recurring if the patient's condition deteriorates (Mishel, 1997). This understanding might be important when meeting patients who are experiencing rejection, as they have many negative thoughts and anxiety, giving rise to uncertainty.

Event congruence

Expectations and disappointments regarding the duration of recovery were frequently expressed. The heart recipients had expected that they would recover faster than they actually did, leaving them pondering if they would ever recover fully (Papers I and II). Having undergone MCS was seen as a mediator of outcome expectations, as the initial post-transplant period was more difficult for some compared with their recovery after MCS (Paper II), leading to incongruence between experience and expectation. The theme *doubting performance* indicates that heart recipients receive poorly defined performance expectations from healthcare professionals, which hinder the accomplishments to be achieved, leaving them in uncertainty (Paper I).

Vicarious experience (Paper II) is another potential source of incongruent expectations. Successful heart recipients might generate impossible expectations for those experiencing side effects of medication, complications from surgery, rejection or other setbacks. However, comparisons with others who are less fortunate seen in previous research (Kaba, Thompson & Burnard, 2000) and defined as a self-efficacy enhancing factor in Paper II could assist in redefining what is important in life, thereby enabling management of uncertainty over time.

When incongruence between what is expected and what is experienced in an illness-related event occurs, the predictability and stability of the event is questioned, leading to uncertainty (Mishel, 1988). The core of self-efficacy in the context of HTx seemed to be the ability to balance expectations in order to avoid frequent disappointments, i.e., adjusting expectations to the actual performance ability. Illuminated by Mishel's framework, this means reducing uncertainty in order to enhance self-efficacy. Research has shown that when one´s own experience is comparable to that of others, it helps one to reappraise uncertainty, thereby enabling a person to reassess her/his circumstances and accept uncertainty as part of life (Scott et al., 2011).

It seems that heart recipients have high expectations on the outcome of the transplantation (Paper II) and that those expectations are promoted by healthcare professionals. A study by O´Connor et al. (2009) revealed that heart recipients identified the transplantation as a transition between illness and normality, although they recognized the need for further care. This indicates an approach that might give rise to high expectations. The good survival rates (Lund et al., 2013) are another source of expectations, together with the approach taken by healthcare professionals. It seems that healthcare professionals have high expectations on heart recipients, who they encourage to continue their efforts in order to achieve accomplishment together with positive remarks about the quality of the graft.

The media and organizations such as MOD (More Organ Donation), which works to enhance the donation rate in Sweden, might also be sources of high expectations as it is usually the "happy stories" that get attention. From a clinical perspective it seems that the expectation of healthcare professionals is that HTx will restore the patient to an almost normal state and that the process is much easier in comparison to lung transplantation. This indicates that healthcare professionals might also contribute to unrealistic expectations of recovery among heart recipients.

Event familiarity

Event familiarity arises when heart recipients recognize symptoms and bodily reactions, enabling them to form symptom patterns and cognitive comprehension. The familiarity of the situation decreases uncertainty. Heart recipients without a demanding recovery process experienced familiarity with the situation within the first year and might therefore experience less uncertainty. When the recipients have become familiar with new symptoms or sensations in their body, event familiarity strengthens and supports them in managing uncertainty. The ability to manage uncertainty might help the recipients in creating a new sense of self, enabling the transition towards a probabilistic view of life and thereby reducing distress (Paper I).

Structure providers

Education

The theme *doubting performance* describes the uncertainty experienced by the recipient if her/his efforts are insufficient to optimize recovery and health, which might indicate that education has failed to provide the patient with sufficient knowledge. Although patient education forms a prominent part of follow-up care, it is important to understand how to provide education in the most efficient way.

According to Mishel, education contributes to enlarging the patient's knowledge base, thus providing meaning and context leading to reduced uncertainty (Mishel, 1988). The importance of education was confirmed in a study by Germino et al. (2013), where an uncertainty management intervention was performed in breast cancer survivors. The results showed reductions in uncertainty and significant improvements in behavioural and cognitive coping strategies to manage uncertainty and self-efficacy, which remained over time. The study also revealed a negative relationship between self-efficacy and uncertainty (r=-0.58) (Germino et al., 2013). This emphasises the importance of addressing uncertainty by specifically focusing on education, behaviour and cognitive coping strategies at an early stage post-transplantation in order to achieve positive long-term effects.

The overall goal of education post-transplantation is to improve self-management, as poor self-management might affect clinical outcomes negatively, including rejection, infection, graft failure or death. For this reason it is of great importance to understand the barriers to education (Cupples et al., 2017). Three information strategies have been identified in the literature: information seeking, avoidance and cognitive reappraisal of the situation, which all affect uncertainty in different ways (Kuang, 2017). Uncertainty can also arise as a result of too much information that the person cannot comprehend. In such cases information seeking might lead to greater uncertainty and avoidance coping (Kuang, 2017).

Social support

Social support was of major importance for helping the recipients to interpret symptoms and seek information, enabling them to form a cognitive comprehension of the situation, which reduces uncertainty (Mishel, 1988). However, the heart recipients experienced expectations from family, friends and healthcare professionals. When expectations were difficult to live up to, i.e., when performance accomplishment was not achieved, it made them doubt the sustainability of the relationship and affected the actual support (Papers I and II).

Family members and close friends might also be affected by uncertainty, which in turn hinders their ability to act in a supportive way. Previous research has described behavioural change among family members from pre-transplant to the post-transplant period involving a demanding process of adjustment to the HTx (Mishel &

Murdaugh, 1987). This knowledge is of major importance as social support constitutes a significant component of the pre-transplant evaluation of suitability for HTx. Failure to provide families and friends with adequate information and realistic expectations could affect their support function. Close relatives and family members were not investigated in our studies, but the heart recipients expressed disappointment about the lack of support for family members and friends from healthcare professionals. Although social support has the potential to lessen uncertainty, studies show that it can also create uncertainty for transplant patients, which is in accordance with our findings (Scott et al., 2011).

The heart recipients also expressed disappointment about the lack of support from family and friends. Sudden dependence on others caused uncertainty about the sense of self and life roles, while accepting support made the recipients question themselves. Support was sometimes seen as an unwanted reminder of the HTx and made them aware of their own lack of control. Relational uncertainty included questions about relationships with others, disappointment about the lack of support from close friends and uncertainty about how draining it is for others to provide social support, which is also reported in previous studies (Forsberg, Cavallini & Lennerling, 2015; Scott et al., 2011). Social support is perceived by heart recipients as a prominent and essential factor (Conway et al., 2013; Sadala & Stolf, 2008) and seems to be one of the most important correlates of psychological health after HTx (Conway et al., 2013; Favaro et al., 2011). Adequate support helps the transplant recipients to adjust to their new situation by encouraging them to change their habits, but also in the longer perspective by motivating them to redesign life goals and balance expectations (Forsberg et al., 2015). Our results (Paper II) showed that expectations (physical, social and mental) were a great source of uncertainty when not balanced against the actual situation and that social accomplishment was seen as a sub-dimension of performance accomplishment (Paper II). Thus social support is an important aspect in managing uncertainty in terms of interpreting the symptoms, adjusting to the situation and balancing expectations. Given the physical and psychological challenges associated with HTx, social support is central to the experience (Ullrich, Jansch, Schmidt, Struber & Niedermeyer, 2004).

Credible authority

Uncertainty about adequacy of performance in the theme *doubting performance* might stem from ill-defined expectations on the heart recipients, indicating insufficient support and guidance from healthcare professionals. The theme feeling abandoned (Paper I) indicates that fundamental trust is not established, implying the absence of credible authority. Some recipients described not being taken seriously and thereby feeling abandoned. Verbal persuasion (Paper II) might also affect healthcare professionals' credibility. Persuading the heart recipient to perform tasks that are impossible to accomplish due to physical barriers could create incongruence between what is expected and what is possible to achieve, thus weakening the healthcare professionals' credibility. Credible authority refers to patients' degree of trust and confidence in healthcare providers (Mishel, 1988). Providing the patient with sufficient information about the causes and consequences of symptoms will strengthen the stimuli frame, thus reducing uncertainty (Mishel, 1988). Verbal persuasion as a self-efficacy enhancing strategy is dependent on the perceived credibility of the persuaders, i.e., healthcare professionals, their prestige, trust-worthiness, expertise and assuredness (Bandura, 1977).

Person-centred care has been shown to enhance self-efficacy and reduce uncertainty (Dudas et al., 2013; Fors, Taft, Ulin & Ekman, 2016). Therefore person centredness with focus on a partnership between the patient and caregiver might be an excellent approach to helping the patient manage uncertainty. With adequate support and a credible relationship, i.e., partnership, between healthcare professionals and the heart recipient an understanding of the situation will be established, enabling the recipient to handle it, i.e., self-management (Dudas et al., 2013).

The first year after HTx is influenced by uncertainty to a greater or lesser degree, irrespective of the objective outcome and recovery process. As the situation is always interpreted subjectively by the recipients (Brashers, 2001), it is vital that individual assessments are performed in order to establish a credible relationship between recipients

and healthcare professionals. Providing the recipients with sufficient information, education, continuity of care and a credible relationship with healthcare professionals enables guidance throughout the post-transplant process. However, it is crucial to understand that uncertainty is primarily a self-perception about one´s own cognition or ability to derive meaning, thus a person who perceives her/himself as uncertain is per se uncertain, irrespective of how much knowledge she/he possesses (Brashers, 2001)

The theory of uncertainty highlights the importance of a credible authority, constituting the foundation for establishing a partnership between the heart recipient and healthcare professionals. This enables a discussion of an agreement on expectations and goal setting, which might reduce uncertainty and strengthen self-efficacy. The transition towards a new view of life and a new worldview also depends on a credible authority advocating probabilistic thinking, which in the long term might influence the distress levels experienced by the heart recipient (Paper I).

Cognitive Capacity

The theme *doubting performance* might also be an indication of reduced cognitive capacity, which in turn could be a manifestation of stress. The more uncertainty a person experiences the greater the stress, which could reduce cognitive capacity leading to a negative spiral. If the person is unable to assimilate information and education it will affect her/his ability to develop a cognitive comprehension of the situation and lead to uncertainty. A disrupted transition in accepting uncertainty as a part of the HTx experience is also a source of distress that continues over time.

Appraisal of uncertainty

The heart recipient will appraise uncertainty as either a danger or a possibility, which will influence the choice of coping strategies to achieve adaptation and thereby health. High levels of uncertainty experienced by heart recipients will presumably lead to an appraisal of danger (Mishel, 1988).

The themes *doubting survival* and *doubting the future* (Paper I) indicate that heart recipients might appraise uncertainty as a danger during the first year after HTx. There is limited quantitative research about the "unknown future", which is more often explored in qualitative research where it is identified as a source of uncertainty (Mishel, 1999).

Uncertainty appraised as a danger is associated with psychological distress (Kang, 2009), but when it is appraised as an opportunity it is associated with less distress, as the patient has emphasized the positive aspects of her/his situation, which is in accordance with probabilistic thinking (Mishel, 1990). The focus on communication as an important aspect of uncertainty management has led to a discussion where a distinction was made between the constructs of actual uncertainty and desired uncertainty. Discrepancy between actual uncertainty and desired uncertainty was found to generate anxiety, which in turn could trigger avoidance and reappraisal of uncertainty (Kuang, 2017). This indicates the importance of establishing a credible relationship with the patient in order to evaluate her/his perceptions of the situation.

A study by Kaba et al. (2000) identified the following coping strategies among heart recipients: acceptance/-optimism, denial/avoidance, setting targets, comparing oneself with others, seeking social support, having faith and changing priorities/perceptions (Kaba et al., 2000). This supports the results of our studies and shows that the coping strategies initiated by heart recipients focus on managing uncertainty by accepting the situation, seeking social support, having faith and changing priorities (Paper I). Self-efficacy is strengthened by setting targets and comparing oneself with others (Paper II). It is important to identify the coping strategy of denial/avoidance as it can hinder the transition to probabilistic thinking and acceptance of uncertainty.

Emotional arousal (Paper II) might be a consequence of uncertainty and a reaction to stressful and strenuous situations. A high level of emotional arousal has a negative effect on performance (Bandura, 1977), especially at an early stage of the process when it affects perceived self-efficacy (Bandura, 1977), suggesting that uncertainty per se inhibits self-efficacy.

Adaptation over time is not always evident in chronic conditions and some patients still exhibit high levels of uncertainty in the long term (Johnson Wright et al., 2009). Adaptation to illness in the face of uncertainty depends on one's appraisal of the uncertainty, which may be viewed as an opportunity when the alternative is certainty of a more undesirable outcome (Johnson Wright et al., 2009).

Comprehensive understanding

Performance accomplishment is the most influential self-efficacy enhancing factor (Paper II), and also the factor that enables expectations to be achieved. The absence of performance accomplishment is a source of disappointment with the potential to generate uncertainty, emotional arousal and stress. High expectations might be sources of uncertainty when accomplishment fails and expectations remain unfulfilled (Figure 2).

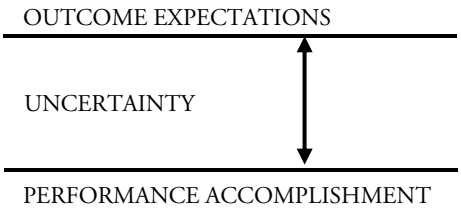

Figure 2. The gap between expectations and actual performance can be understood as uncertainty. High expectations might be sources of uncertainty when accomplishment fails and expectations remain unfulfilled

This argumentation is supported by a study by Schmidt & DeShon (2010), who identified ambiguity, which is one form of uncertainty, as a boundary condition between performance and self-efficacy. Self-efficacy was found to be negatively related to performance in situations where ambiguity was high and positively related to performance when ambiguity was low (Bandura, 1977; Schmidt & DeShon, 2010). Thus high levels of ambiguity, i.e., uncertainty, might influence the heart recipients' perceived self-efficacy and thereby self-management. Therefore, when it comes to achieving adequate self-management after HTx, one of the main obstacles might be the level of uncertainty experienced. A high level of uncertainty might hinder performance accomplishment, which is one of the main components of self-efficacy. This in turn could have a negative impact on self-management ability (Figure 3).

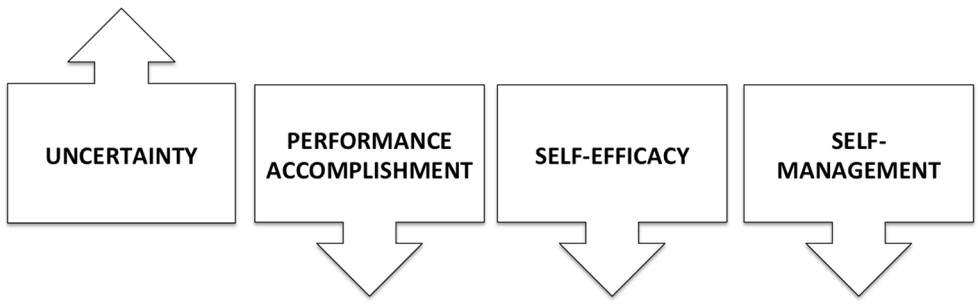

Figure 3. The possible relationship between the concepts of uncertainty, performance accomplishment, self-efficacy and self-management.

Addressing uncertainty means embracing the patient's experience and understanding of the situation, symptoms, setbacks and complications. In addition, it implies adopting a probabilistic worldview and supporting the heart recipients in their transition towards accepting uncertainty as a part of their life. Discussing outcome expectations as well as expectations on life and life goals is of great importance for understanding the patient's situation. Family members need to be involved by means of information and education in order to enable social support and probabilistic thinking.

Sufficient education and information must be provided to allow the heart recipient to cognitively interpret the situation, which requires the establishment of a partnership based on a credible relationship between the heart recipient and healthcare professionals. Partnership is advocated by both chronic illness management (Yach, 2002) and person-centred care (Ekman, 2014).

The concept of self-efficacy involves behavioural change in order to manage physical and psychological challenges. The fundamental notion in the concept of Self-efficacy is that we can change the patient's behaviour in order to achieve effective self-management. When addressing uncertainty the fundamental view is that we need to embrace the patient's experiences and establish a partnership. This allows healthcare professionals to comprehend the underlying sources of uncertainty and stress, thereby enabling them to help the person reduce and/or manage uncertainty and embrace a probabilistic worldview, thus enhancing self-efficacy and self-management.

Conclusions

The main conclusions of this thesis are:

- The recipient's interpretation of complications, setbacks and symptoms together with expectations are sources of uncertainty.
- Performance accomplishment enables expectations to be achieved and might therefore constitute a source of uncertainty when accomplishments are lacking.
- Uncertainty emerges when expectations are not in accordance with experiences, which might result in decreased self-efficacy due to lack of accomplishments.
- Uncertainty undermines performance and can thereby hamper self-efficacy and self-management.

Clinical implications

Uncertainty is inherent in being human, especially when it comes to illness experiences. However, uncertainty is draining when there is a lack of adequate support, or when healthcare professionals do not help the person to cognitively create meaning in the situation, thereby enabling her/him to reduce and manage uncertainty. Psychological distress, anxiety and depression are common after HTx and uncertainty might be a contributory factor. This thesis highlights the fundamental need to address uncertainty by altering the perspective from a focus on changing behaviour to trying to grasp fundamental human experiences that influence the person's actions, choices and experiences. Promoting probabilistic thinking and building the caring relation in a partnership based on the heart recipient's views, expectations and experiences might enable the transition to accepting uncertainty as part of being a heart recipient.

Follow-up care after HTx in Sweden is focused on medical assessments, procedures and survival. A fundamental change in the perspective on follow-up care is necessary in order to promote health and provide psychosocial support to the recipients, which is in accordance with the ICCC framework (Yach, 2002). When designing follow-up care that addresses self-management, Mishel's framework can be used as a tool to reduce and manage uncertainty and possibly enhance self-efficacy. According to the consensus document from the ISHLT regarding qualifications and recommendations for the education of transplant nurses (Coleman et al., 2015), follow-up care after HTx should preferably be led by advanced nurse practitioners. It is also stated that specialized nursing care should focus on the protection, promotion and optimization of the health and abilities of transplant recipients (Coleman et al., 2015).

The main clinical implications of this thesis are:

- The basic assumption in follow-up care should be that heart recipients experience uncertainty.
- In order to help heart recipients manage uncertainty, the care should be built on a partnership between the recipient and healthcare professionals.
- The focus of follow-up care should be broadened from the medical perspective to include health and psychosocial aspects

- Mishel's framework can serve as a guide to help healthcare professionals address uncertainty.
- Promoting probabilistic thinking is an important part of managing uncertainty.
- When assessing the patient a discussion about her/his expectations is necessary for identifying her/his beliefs about recovery and life goals, thereby making it possible to establish sources of uncertainty.
- Patient participation in goal setting and follow-up could be important for strengthening self-efficacy and self-management.
- Balancing the recipient's expectations might be essential for reducing and managing uncertainty, thereby possibly enhancing self-efficacy.
- The perspective of follow-up care must be revised in order to provide care that corresponds to the heart recipient's needs

One of the key missions of transplant nurses is health promotion by helping heart recipients to reduce and manage uncertainty. This might enable effective self-management, strengthen self-efficacy and possibly diminish psychological distress. Outcome expectations are possible sources of uncertainty and this understanding, together with knowledge about which other factors contribute to uncertainty, is of vital importance for transplant nurses in order to support self-management.

Summary in Swedish

Hjärttransplantation är en behandling för patienter med terminal hjärtsvikt. Transplantation blir aktuellt när ingen annan behandling längre har effekt och överlevnaden förväntas vara mindre än ett år utan transplantationen, samt att överlevnaden och livskvaliteten förväntas bli bättre. Utvecklingen av kirurgiska tekniker, förbättrade kriterier för patienturval, bättre bevaringsmetoder av det donerade hjärtat samt mer effektiv immundämpande behandling har sammantaget bidragit till förbättrad överlevnad efter en hjärttransplantation. Överlevnaden är nu så bra att den i sig inte bör vara det enda målet för transplantationen. Den förbättrade överlevnaden leder till förväntningar om en förbättrad livskvalitet och hälsa hos hjärtmottagaren. Framstegen har dock framförallt berott på förbättringar av ettårs överlevnaden. Långtidsöverlevnaden är fortfarande begränsad av avstötning och biverkningar från den immundämpande behandlingen.

Hjärttransplantation ses som ett kroniskt tillstånd med tanke på den livslånga behandlingen med immundämpande läkemedel för att undvika avstötning. Sjukvårdsystemet är huvudsakligen organiserat kring medicinska procedurer som har till syfte att identifiera avstötning och hantera den immundämpande behandlingen snarare än att fokusera på förebyggande arbete med fokus på hälsa. Även om en hjärttransplantation förlänger överlevnaden, ger ökade möjligheter fysiskt och möjliggör förbättrad livskvalitet, så innebär återhämtningen efter en transplantation betungande och besvärliga medicinska och psykosociala utmaningar som kräver anpassning och bra self-management kunskaper.

Self-management (ung. egenvård) syftar till aktiviteter som utförs av människor för att skapa struktur och kontroll i sina liv. Self-efficacy, är ett begrepp som handlar om en persons tilltro till sin förmåga att klara en uppgift. Self-efficacy är det huvudbegrepp som lagt grunden för self-managementprogrammen. Därför är det viktigt att förstå den hjärttransplanterade personens perspektiv på self-management och self-efficacy för att vi ska kunna utveckla och organisera en effektiv sjukvård som stödjer self-management.

I kontextet hjärttransplantation har det antingen varit en akut utveckling av sjukdomen alternativt ett långsamt förlopp som blir till ett kroniskt tillstånd med tiden. Processen fram till hjärttransplantationen kan fortgå under flera år eller utvecklas under endast ett par veckor eller månader. Denna period innebär för patienten ett pågående hot mot hälsan och livet samt en oviss framtid. Processen är mer eller mindre kantad av ovisshet utifrån många olika dimensioner. Alltifrån ovissheten om att hinna få ett hjärta i tid, att klara operationen, återhämtningen och rädsla för avstötning. Ovisshet i relation till sjukdom har visats vara den enskilt största psykologiska stressen för patienten som lever med livshotande sjukdom.

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. Ovisshet skulle därför kunna utgöra ett hinder för effektiv self-management genom att patientens kognitiva förmåga reduceras till följd av stress och oro. Det kan därför vara viktigt att undersöka begreppen ovisshet och self-efficacy samt deras potentiella påverkan på self-managment. Detta skulle kunna bidra till en ökad förståelse och vara en hjälp för att möjliggöra en omorganisering av uppföljningsvården med fokus att möta hjärtmottagarens behov baserat på deras upplevelser av sin hjärttransplantation.

Det övergripande syftet med den här avhandlingen var att studera om ovisshet och self-efficacy är viktiga aspekter av hjärtmottagarens upplevelser ett år efter en hjärttransplantation.

Två delstudier genomfördes med olika syften. Studie I hade som syfte att subjektivt undersöka innebörden av ovisshet ett år efter en hjärtoperation. Studie II hade som syfte att djupgående utforska betydelsen av begreppet self-efficacy hos hjärtmottagare med hjälp av Banduras teori om self-efficacy.

I Studie I visade strukturanalysen att ovisshet var ett framträdande fenomen under det första året efter hjärttransplantationen. De hjärttransplanterade hade mycket tankar om överlevnaden och hur länge det nya hjärtat skulle hålla. De som hade en mer utmanande återhämtningsprocess 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. Nära relationer upplevdes utmanande och en vanlig känsla var att man efter transplantationen förväntades må bra ”vara frisk” igen och det var vissa som gick in i en roll för att möta förväntningarna. Vissa kände sig övergivna av vården 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.

Studie II visade att klara av att prestera (performance accomplishment) var den mest framträdande faktorn för Self-efficacy efter hjärttransplantation, och 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 hypoteserna 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. Vår hypotes var vidare att när förväntad prestation inte kan nås kan det vara en källa till ovisshet.

Sammantaget visar denna avhandling att ovisshet är viktig aspekt att ta hänsyn till i transplantationsprocessen. Ovissheten är en starkt bidragande orsak till stress och oro och påverkar hela hjärtmottagarens situation och därmed också möjlighet till att hantera situationen. Vidare är det viktigt att hjärtmottagarens förväntningar diskuteras för att kunna stödja hjärtmottagaren i att sätta upp balanserade och rimliga mål. Ouppfyllda förväntningar kan vara en källa till ovisshet och stress vilket i sin tur påverkar patientens förmåga att hantera sin situation. Detta kräver en omorganisering av uppföljningsvården med ett breddat fokus från att till största del fokusera på medicinska aspekter och undersökningar till mer fokus på hälsa och psykosociala aspekter.

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