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Recovery After Lung Transplantation

Adaptation to a New Normality

MARTINA LUNDMARK

FACULTY OF MEDICINE | LUND UNIVERSITY



Recovery After Lung Transplantation

Adaptation to a New Normality

Martina Lundmark



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DOCTORAL DISSERTATION

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Title and subtitle: Recovery After Lung Transplantation – Adaptation to a New Normality	
<p>Abstract</p> <p>Background: Lung transplantation (LuTx) is an established and effective treatment for patients with end-stage pulmonary disease. Recovery after LuTx is demanding and as part of post-transplant care, lung recipients (LuRs) must adhere to a complex self-management regime. By exploring the patient perspective on recovery, health and well-being, efforts can be made to tailor self-management support, thereby promoting health after LuTx.</p> <p>Aim: The overall aim was to understand, explore and explain the recovery process, symptoms and well-being after LuTx from an inside perspective.</p> <p>Methods: A mixed method approach was used in order to both understand and explain important aspects of recovery, symptoms and well-being after LuTx. The design of the studies was both qualitative based on interviews (Papers I, II & IV) and quantitative (Paper III) by means of a cross-sectional explorative design based on self-report questionnaires. The data analysis was performed using the Grounded Theory Method (GTM), deductive content analysis and non-parametric statistical analysis.</p> <p>Results: The data from the interviews analysed by means of the GTM generated two grounded theories. During the first year, the LuRs focus on Reconstructing Daily Occupation and a detailed description is provided of how the LuRs adjust habitually as part of the overall process, namely Adaptation to a New Normality. Adaptation to a new normality begins immediately post-transplant and involves all areas of the recipients' lives. This continuous process is individual, where successful adaptation generates health and well-being, whereas too heavy a symptom burden hinders adaptation and causes illness. The findings demonstrate the possibility of experiencing health despite the prevalence of symptoms and complications. Few LuRs perceived themselves as fully recovered although a majority had made a reasonable recovery. There was a strong relationship between recovery and well-being, with those not recovered experiencing a higher symptom burden as well as decreased well-being. The result provides a deeper understanding of how recovery after LuTx should be defined. The complexity of the concept of recovery is also explored and a previous concept analysis is further developed to fit the transplantation context.</p> <p>Conclusion: Important health and illness trajectories are revealed, which demonstrates the LuRs' highly developed ability to adapt to a new normality. Recovery after LuTx differs from recovery after general surgery due to the implicit chronic condition and immunosuppressive treatment. Few LuRs recover fully and a low degree of recovery and high symptom distress might be markers of impaired well-being and health. Transplant nursing should focus on health management by facilitating the adaptation process as well as identifying those LuRs in need of increased support. Transplant follow-up should comprise measurement of symptoms and well-being as well as the inclusion of an occupational therapist in the transplant team in order to support or change occupational patterns.</p>	
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Recovery After Lung Transplantation

Adaptation to a New Normality

Martina Lundmark



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Abstract

Background: Lung transplantation (LuTx) is an established and effective treatment for patients with end-stage pulmonary disease. Recovery after LuTx is demanding and as part of post-transplant care, lung recipients (LuRs) must adhere to a complex self-management regime. By exploring the patient perspective on recovery, health and well-being, efforts can be made to tailor self-management support, thereby promoting health after LuTx.

Aim: The overall aim was to understand, explore and explain the recovery process, symptoms and well-being after LuTx from an inside perspective.

Method: A mixed method approach was used in order to both understand and explain important aspects of recovery, symptoms and well-being after LuTx. The design of the studies was both qualitative based on interviews (Papers I, II & IV) and quantitative (Paper III) by means of a cross-sectional explorative design based on self-report questionnaires. The data analysis was performed using the Grounded Theory Method (GTM), deductive content analysis and non-parametric statistical analysis.

Result: The data from the interviews analysed by means of the GTM generated two grounded theories. During the first year, the LuRs focus on Reconstructing Daily Occupation and a detailed description is provided of how the LuRs adjust habitually as part of the overall process, namely Adaptation to a New Normality. Adaptation to a new normality begins immediately post-transplant and involves all areas of the recipients' lives. This continuous process is individual, where successful adaptation generates health and well-being, whereas too heavy a symptom burden hinders adaptation and causes illness. The findings demonstrate the possibility of experiencing health despite the prevalence of symptoms and complications. Few LuRs perceived themselves as fully recovered although a majority had made a reasonable recovery. There was a strong relationship between recovery and well-being, with those not recovered experiencing a higher symptom burden as well as decreased well-being. The result provides a deeper understanding of how recovery after LuTx should be defined. The complexity of the concept of recovery is also explored and a previous concept analysis is further developed to fit the transplantation context.

Conclusions: Important health and illness trajectories are revealed, which demonstrates the LuRs' highly developed ability to adapt to a new normality. Recovery after LuTx differs from recovery after general surgery due to the implicit chronic condition and

immunosuppressive treatment. Few LuRs recover fully and a low degree of recovery and high symptom distress might be markers of impaired well-being and health. Transplant nursing should focus on health management by facilitating the adaptation process as well as identifying those LuRs in need of increased support. Transplant follow-up should comprise measurement of symptoms and well-being as well as the inclusion of an occupational therapist in the transplant team in order to support or change occupational patterns.

Original papers

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

- I **Lundmark M**, Erlandsson L-K, Lennerling A, Almgren M, Forsberg A (2016). Health Transition after Lung Transplantation – A grounded theory study. *Journal of Clinical Nursing*, 25, 2285-2294, doi: 10.1111/jocn.13269. Epub 2016 May 27.
- II **Lundmark M**, Lennerling A, Almgren M, Forsberg A (2016). Recovery after Lung Transplantation from a Patient Perspective – Proposing a New Framework. *Journal of Advanced Nursing*. 2016 Dec; 72(12): 3113-3124. doi: 10.1111/jan.13058. Epub 2016 Jul 19.
- III **Lundmark M**, Lennerling A, Almgren M, Forsberg A (2018) Recovery, Symptoms and Well-being One to Five Years after Lung Transplantation – A Multi-centre Study. *Scandinavian Journal of Caring Sciences*. 2018 Oct 15. doi: 10.1111/scs.12618. [Epub ahead of print].
- IV **Lundmark M**, Lennerling A, Forsberg A (2019) Developing a Grounded Theory on Adaptation after Lung Transplantation from Intermediate-Term Patient Experiences. *Progress in Transplantation*. doi: 10.1177/1526924819835823. In Press.

Abbreviations

BOS	Bronchiolitis Obliterans Syndrome
ECMO	Extracorporeal Membrane Oxygenation
GT	Grounded Theory
GTM	Grounded Theory Method
HRQoL	Health Related Quality of Life
ISHLT	International Society of Heart and Lung Transplantation
LuR	Lung Recipient
LuRs	Lung Recipients
LuTx	Lung Transplantation
LuTxS	Lung Transplantations
PRO	Patient Related Outcomes
PRP	Post-operative Recovery Profile
PSR	Post-discharge Surgical Recovery Scale
PGWB	Psychological General Well-Being
PTG	Post-Traumatic Growth
QoL	Quality of Life
QoR-40	Quality of Recovery-40
SMATT	Self-Management After Thoracic Transplantation
OTSWI	The Organ Transplant and Well-being Instrument
TICU	Thoracic Intensive Care Unit
Tx	Transplantation

Preface

Since 2009 I have worked as an intensive care nurse at the Thoracic Intensive Care Unit in Lund, which provides post-operative care for patients undergoing heart and lung surgery, transplantation or ECMO-treatment. I was accepted as a PhD student at Lund University in 2014 and my interest in research is based on my clinical experience.

When I first started working as an intensive care nurse I had no experience of caring for transplant recipients and had never even met a person with a transplanted organ. One day, a woman who had just woken up from surgery after receiving new lungs asked me in a worried voice, “What is my life going to be like now?” and I remember thinking I actually don’t really know. I had extensive knowledge of how to provide high quality intensive care but the woman’s question left me with a feeling of personal inadequacy and a desire to find the answer to her question.

The research presented in my thesis address this question in the most profound way by using an inductive approach and exploring the main concerns after LuTx, e.g., providing a possible answer to what kind of life the woman who received new lungs can expect afterwards. The hope behind this thesis is that it will provide valuable knowledge about post-transplant life to be used by transplant professionals like myself, but with the overall purpose of improving the health and well-being of LuRs.

Introduction

During the past three decades lung transplantation (LuTx) has become an established and effective treatment for patients with end-stage pulmonary disease (Cupples, Lerret, McCalmont & Ohler, 2017; Yusen et al., 2013). More than 50,000 single and double lung transplantations (LuTx) have been performed worldwide (ISHLT, 2018) and up to 2015, 2,317 LuTx were reported to Scandiatransplant, which is the organ exchange organization with centres in Sweden, Norway, Finland, Denmark, Iceland and Estonia (Scandiatransplant, 2015). During 2018, 151 LuTx were performed in these countries (Scandiatransplant, 2019).

Patients eligible for LuTx are those with chronic end-stage lung disease who are at high risk of death (> 50%) within two years if LuTx is not performed and who meet the criteria listed in The International Society for Heart and Lung Transplantation (ISHLT) consensus guidelines (Weill et al., 2015). The most common indications for LuTx worldwide are;

- Chronic Obstructive Pulmonary Disease (COPD), (~33%)
- Interstitial Lung Disease (ILD, including idiopathic pulmonary fibrosis), (~24%)
- Cystic Fibrosis (CF), (~16%) (Weill et al., 2015; Yusen et al., 2014)

Other examples of diagnoses accepted as indications for transplantation are lack of alpha 1-antitrypsin, idiopathic pulmonary arterial hypertension and bronchiectasis (Yusen et al., 2014).

Adults who underwent primary LuTx in the period from January 1990 to June 2012 had a median survival of 5.7 years with unadjusted survival rates of 80% at 1 year, 65% at 3 years, 53% at 5 years and 32% at 10 years (Yusen et al., 2014). Worldwide, and from a historical perspective, improvement in survival rates has been registered, with more recent periods showing better survival than previous ones (1990-1997, 1998-2004, 2005-2012). Three month survival improved between the earliest and the most recent period from 83 to 91% and 1 year survival improved from 72 to 83% (Yusen et al., 2014).

Sweden, with a population of 10 million (Statistics Sweden, 2019), has two LuTx centres. The centre at Skåne University Hospital has performed LuTx since January 1990 with a total of 371 double- and single LuTx up to 2018 (OFO, 2019). In the

other LuTx centre in Gothenburg, 745 LuTxes were performed between 1991-2018 (OFO, 2019). In a 25-year LuTx follow-up study at one of the transplant centres in Sweden, overall (both double and single LuTx) 1-, 5-, 10- and 20-year survival rates were 88, 65, 49 and 19% respectively (Fakhro et al., 2016). Double LuTxes had superior survival rates compared to single LuTxes, especially at 10 years post-transplant and superior long-term survival rates were also seen in recipients diagnosed with cystic fibrosis, alpha 1-antitrypsin deficiency and pulmonary hypertension (Fakhro et al., 2016).

Survival is limited by the prevalence of Bronchiolitis Obliterans Syndrome (BOS), i.e., chronic allograft rejection, graft failure, non-CMV infections and by the shortage of donor organs (Yusen et al., 2014). However, despite improvements in short- and intermediate-term survival, long-term survival after LuTx has remained largely unchanged (ISHLT, 2018) with the annual attrition rate (annualized graft loss rates) 5-10 years post LuTx changing from 10.9 to 10.1 (Lodhi, Lamb & Meier-Kriesche, 2011). Thus, long-term attrition rates have not changed significantly over the past 20 years, with increased survival being due to improvements in short-term attrition rates. This indicates an urgent need to identify and improve factors associated with long-term survival.

Recovery after LuTx is demanding and as part of the post-transplant care, LuRs must adhere to a complex self-management regime (Hu, Lingler, Sereika et al., 2017) due to their high rates of infection and acute or chronic rejection (ISHLT, 2018) (Studer, Levy, McNeil & Orens, 2004). Although LuTx is a life-saving treatment, it involves the replacement of an end-stage disease with a chronic condition requiring life-long medication that causes side-effects and comorbidities, albeit for the purpose of better health and well-being. Today, health systems and health care are often organized around an acute care model that does not meet the needs of patients with chronic conditions and multiple comorbidities (Holman & Lorig, 2000) such as LuRs. Due to the management of gradual deterioration and complex treatment strategies, patients with chronic conditions often have substantial knowledge and experience of their own health, which can complement that of healthcare professionals. This complementary knowledge is an important factor that is often disregarded (Holman & Lorig, 2000). Therefore, follow-up care after LuTx should be reorganized and based on research of patients' own experience of their chronic condition during the recovery process.

There is a lack of knowledge today about living with a chronic condition such as after a LuTx, especially when it comes to how well-being is affected by physical and psychosocial factors during the recovery process and what kind of self-management support LuRs require. Healthcare professionals can provide self-management support by focusing on helping the LuRs to deal with the day-to-day problems of living with a chronic illness (Coleman & Newton, 2005) but the first step is gaining an understanding of the LuRs' main concerns after a LuTx. A deeper understanding of the

recovery process from a patient perspective is important in order to provide self-management support that might affect the long-term outcome in terms of well-being and health.

By understanding the patient perspective on the post-transplant follow-up regime and their main concerns during recovery, their adherence to long-term treatment might improve. Developing self-management skills is fundamental for preventing complications and acute exacerbations, thereby improving long-term outcomes. However, no evidence-based practice guidelines are available to support LuRs during recovery and there is a lack of knowledge regarding the recovery process from a patient perspective as well as the possible impact of symptoms on well-being and health.

One of the most important goals of transplant nursing is health promotion (Coleman, Blumenthal et al., 2015), which consists of both support provided by the transplant nurses at the hospital clinics and self-management support, which is a major part of self-care after discharge. Research has revealed that self-management support is a key component of effective chronic illness management and improves patient outcomes (Coleman & Newton, 2005). Understanding the recovery process is a prerequisite for the development of guidelines to enable healthcare professionals to conduct health promotion and enhance well-being. An understanding of the patient perspective on the recovery process enables target oriented long-term treatment and person-centred care. By exploring the inside patient perspective on recovery, health and well-being as well as factors of concern to LuRs, efforts can be made to tailor self-management support and thereby promote health after LuTx, which is the focus of this thesis.

Perspective and viewpoints

A LuTx is viewed as an intervention that leaves the LuR with a chronic condition and specific requirements, such as how healthcare professionals organise the post-transplant follow-up but also in terms of the demanding self-management skills required by the LuRs themselves.

The four separate papers stem from an inside perspective as opposed to an outside perspective. The latter represents the symptoms of the disease based on pathophysiology, while the former involves the patient's view of the disease and its consequences for everyday life (Thorne & Paterson, 2000). The outside and inside perspective can be termed the professional and personal understanding of the chronic condition (Toombs, 1992), where both perspectives are important. While the patient views the disease in terms of consequences for her/his daily life and creates meaning in various ways, the transplant professionals expect LuRs to adhere to restrictions, medical treatment and recommended lifestyle changes.

In addition to exploring the inside perspective, the recovery process will be illuminated and interpreted from a nursing perspective in terms of how to promote health and well-being, which is a key feature of nursing.

Ontological assumptions

In this thesis the ontological assumption is that a “patient” or “recipient” who receives new lungs is seen as a subjective human being within the healthcare setting and also as a partner in the transplant team who can contribute knowledge. The recipient faces extensive self-care demands and the post-transplant chronic condition will provide her/him with substantial knowledge and experience complementary to that of healthcare professionals, a factor that must be taken into consideration when designing follow-up care. The meaning a person ascribes to the self-management process will influence the way she/he adheres to the recommendations prescribed by healthcare professionals.

How a person who receives new lungs understands her/his situation is important for how she/he engages in self-management activities related to healthcare. Therefore, the

studies that constitute this thesis stem from an inside perspective and describe patients' experiences of their disease and self-reported symptoms, e.g., sense of well-being and illness.

Epistemological assumptions

Knowledge can be obtained both by understanding and explaining a phenomenon of interest, which is the reason why both qualitative and quantitative methods were used. In order to understand what it means to be a person who receives new lungs in relation to healthcare, qualitative methods were employed to analyse patients' narratives both inductively and deductively. As a means of explaining possible differences among unrelated groups, quantitative sampling based on self-reported questionnaires was performed and statistical analysis used. A nursing theory framework was applied in the discussion in order to deepen the understanding of the result and provide a possible explanation of how it can be interpreted.

The health perspective in relation to lung transplantation

Historically, LuTx has been performed within a strong biomedical perspective where health is defined as the absence of disease (Boorse, 1977) with the consequence of making health an impossible goal to achieve for patients with terminal or chronic conditions, i.e., LuTx.

In this thesis, health is viewed from a holistic perspective and as a continuous subjective process in constant change involving several different dimensions (Berman & Snyder, 2012). Health after LuTx will be understood in the light of nursing theorist Callista Roy and The Roy Adaptation Model, which will be introduced below and elaborated in the Discussion.

Callista Roy's adaptation model states that health is an inevitable dimension of a person's life represented by a health-illness continuum (Roy, 2009). Health is also described as a state and process of being and becoming integrated and whole. Applying Roy's model, a LuTx is a bio-psycho social being in constant interaction with a changing environment (Roy, 2009). In the context of LuTx, the changing environment is constituted by all factors inherent in living with a chronic condition, life-long medications as well as the setbacks and complications that might occur.

In accordance with Roy's theory, health is viewed as a process where LuRs strive to achieve their maximum potential. This process can be expressed as both the LuRs' effort to adhere to self-management regimes such as exercising regularly, smoking cessation and dietary habits as well as in the terminal stages of rejection when they strive to seek control over symptoms or for integration within themselves and in relation to significant others.

Main concepts

The main concepts in this thesis are *recovery*, *well-being* and *health*. As presented in Figure 1, these concepts are important aspects underlying the umbrella terms of Chronic Illness Management (CIM) and Self-management. Although self-management is frequently referred to and discussed it will not be explicitly measured or explored in the thesis, which is the reason why a brief introduction of the concept will be presented. An overview and summary of the main concepts will be provided initially, followed by a comprehensive description of each concept as well as how they can be measured.

Recovery will be explored in terms of a process that occurs post-transplant with well-being and health as possible outcomes. Recovery after LuTx is a highly complex and demanding process that possibly affects well-being and health. The concept of recovery includes symptoms and several other dimensions described below.

Well-being consists of several dimensions where the point of departure in this thesis is the belief that the concept is a subjective multidimensional construct concerning the quality of a person's life, where health is one aspect of well-being. The instruments in the included studies measure *transplant specific well-being* and *psychological well-being*, with one dimension measuring *general health*. Health can be viewed as a factor that contributes to well-being and is a component explored in the context of recovery and well-being. Self-management can be considered a means for LuRs to achieve health and well-being.

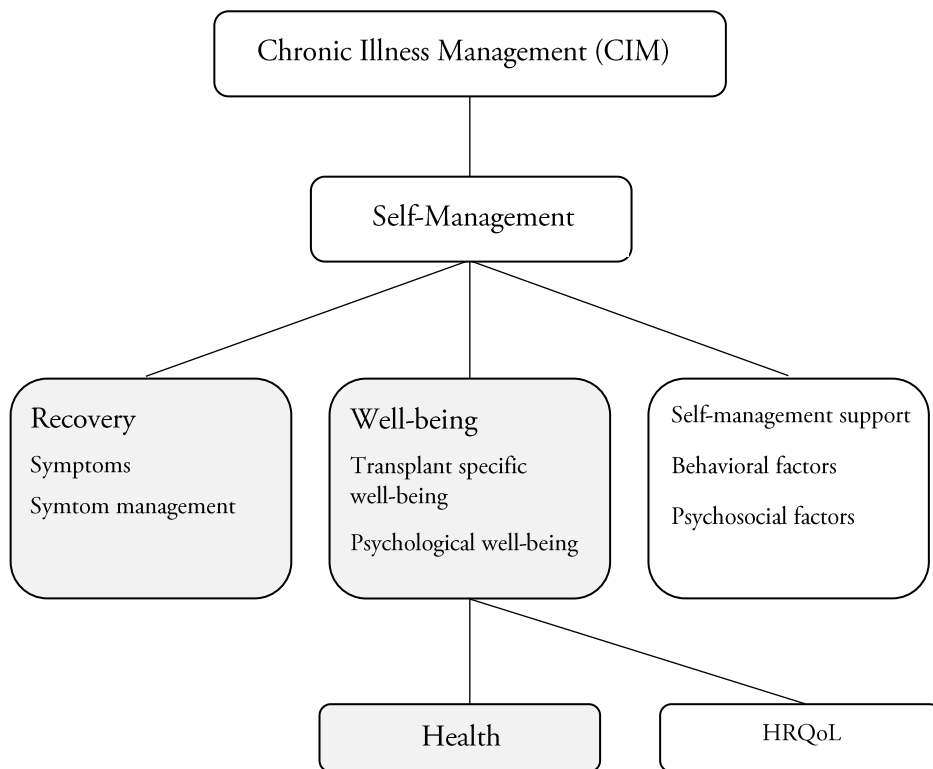


Figure 1. Overview of important concepts related to chronic illness management. The concepts in the grey coloured boxes are the main concepts in this thesis and described below.

Self-management

Self-management is a key concept in the care of chronic conditions such as LuTx. It refers to a complex process where people undertake activities to create order, discipline and control in their lives from the disorder imposed by illness (Kralik, Koch, Price & Howard, 2004). Self-management is defined as;

“the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life” (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002 p. 178).

Self-management programmes have proven to offer substantial benefits in terms of enhanced sense of control, reduction in pain and increased use of cognitive and behavioural techniques (Barlow, Williams & Wright, 1999). Self-management approaches are also effective in increasing patients' knowledge, symptom management and other aspects of health such as depression (Barlow et al., 2002). However, relying on professionally driven programmes assumes that individuals who are provided with adequate education will self-manage illness (Kralik et al., 2004), although there are many other factors that influence the way people self-manage long-term illness, especially the meaning they ascribe to the self-management process (Thorne & Paterson, 2001).

Self-management support consists of far more than knowledge-based education and includes processes that develop patient problem-solving skills and support in real-life situations of importance to patients (Coleman & Newton, 2005). The importance of engaging individuals with chronic conditions in identifying self-management strategies that have meaning in their lives is essential (Kralik et al., 2004). Patient education may provide a structure but self-management involves learning about responses to illnesses through daily life experiences and as a result of trial and error. A prerequisite for developing self-management strategies is an understanding of what is important for individuals living with chronic conditions, thus leading to a holistic approach (Kralik et al., 2004). An understanding of the inside perspective of LuRs is therefore crucial.

The terms self-management and self-care are often used interchangeably or simultaneously but there has been no agreement about their definition and operationalization in the literature (Peeters, Wiegers & Friele, 2013). The concepts of self-management and self-care include tasks, skills and competences for the purpose of coping with illness, but there is a need to further operationalize their meaning (Peeters et al., 2013). In this thesis the term self-management will be used based on the definition described above, except when referring to studies that specifically contain the term self-care.

Self-management and healthcare systems in chronic conditions

The World Health Organization (WHO) created a document; *Innovative Care for Chronic Conditions: Building Blocks for Action*, to alert healthcare professionals to the increase in chronic conditions throughout the world and the need for new healthcare solutions for managing the growing problem (Bengoa & Yach, 2002). Evidence indicates better outcomes for chronically ill patients, e.g. LuRs, if they receive effective treatment, self-management support and regular follow-up in organized care systems. In addition, improving healthcare after LuTx also involves focusing on adherence to long-term therapies such as immunosuppressive medication. A chronic condition such

as LuTx requires changes in lifestyle and daily behaviour, thus emphasising the patients' central role. Healthcare must be re-oriented towards the patient and her/his family (Bengoa & Yach, 2002).

Models have been developed to enable healthcare systems to provide better care for chronic conditions, such as The Innovative Care for Chronic Conditions (ICCC) framework (Bengoa & Yach, 2002). The latter consists of fundamental components within the patient (micro-), healthcare organization and community (meso-) and policy (macro-) levels, which can be used to re-design a healthcare system with the aim of more effectively managing chronic conditions. The ICCC framework is centred on a partnership between patients and families, healthcare teams and community support. Optimal outcomes occur when each member is an active participant who is informed, motivated and prepared to manage chronic conditions. Innovative programmes improve functioning, productivity and quality of life (QoL) as well as facilitating changes in patients' lifestyles and self-management abilities (Bengoa & Yach, 2002). Studies in other chronically ill patient populations reveal that the healthcare system, level of chronic illness management and patient self-management lead to improved outcomes (Nuno, Coleman, Bengoa & Sauto, 2012).

The role of transplant nurses in health promotion

The American Nurses' Association and International Transplant Nurses' Society have published statements regarding the scope of nursing practice within the field of transplantation (Coleman, Blumenthal et al., 2015). Transplant nursing practice should be focused on the protection, promotion and optimization of the transplant recipient's health and abilities. The ISHLT consensus document consists of guidelines and recommendations concerning the education, certification, licensing and staffing levels required by transplant nurses to manage complex pre-and post-transplant issues (Coleman, Blumenthal et al., 2015). Chronically ill patients often need to adjust their activities of daily living, social relationships and perception of self and also adapt to increasing physical limitations and discomfort (Berman & Snyder, 2012). Living with a chronic condition is a constant process that includes being aware of bodily responses, planning daily activities and learning new strategies (Kralik et al., 2004). Nurses involved in caring for chronically ill patients, i.e., LuRs, need to focus on promoting the highest possible level of independence, sense of control and well-being.

The concept of recovery

Post-operative recovery is a commonly used concept within healthcare but it is conceptually complex due to its multidimensional nature and the fact that there are few standard definitions of the various dimensions (Wu & Richman, 2004). Different disciplines might attribute an alternative meaning to the term recovery depending on the context, leading to a risk of the term being confused with other concepts such as rehabilitation or convalescence.

A concept analysis of the phenomenon of post-operative recovery after general surgery has been developed, where the process of recovery was divided into four dimensions; physiological, psychological, social and habitual (Allvin, Berg, Idvall & Nilsson, 2007). The definition of post-operative recovery based on the concept analysis is:

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

In an interview study focusing on patient and staff experiences of post-operative recovery after abdominal or gynaecological surgery, recovery was described as a *“Dynamic process in an endeavour to continue with everyday life”*, where everyday life was defined as the initial condition before surgery (Allvin, Ehnfors, Rawal & Idvall, 2008). Returning to everyday life afterwards did not always lead to a life comparable to that before surgery. Another interview study exploring recovery after cholecystectomy also described recovery as a *“process of returning to normal”* (Baker, 1989).

The definition stated above where recovery is described as *“returning to normality”* and *“returning to preoperative levels”* as well as the ability to *“continue with everyday life as before surgery”* might be challenging after a LuTx. As the subsequent chronic condition demands adherence and adjustment to a complex self-management regime and post-transplant follow-up, the ability to return to life as it was before might be hampered.

Studies of recovery after surgery often focus on clinically oriented endpoints such as length of hospital stay, morbidity and mortality. However, of equal importance for the overall recovery process is the measurement of subjective patient-reported outcomes.

Today, knowledge about the post-operative recovery process after LuTx is scarce. However, research has been conducted on recovery within areas other than LuTx. In a study of post-operative pain and quality of recovery it was suggested that the most important determinants of quality of recovery were cognitive functioning, energy/fatigue/sleep, mental health, pain, physical, psychological and psychosocial functioning, side-effects of analgesics and symptoms (Wu & Richman, 2004).

According to Allvin et al. (2008), the recovery process extends over a long period of time, during which patients are at home and responsible for their own recovery. This is consistent with another qualitative study concerning recovery after heart valve surgery, which revealed physical, existential and mental challenges for up to nine months after surgery (Hansen et al., 2016). Research also shows that a poor quality of recovery on the days after cardiac surgery can predict a poor quality of life after three months (Myles et al., 2001). If recovery is measured at an early stage after surgery and on a regular basis, more effective and supportive strategies can be employed if necessary.

Measurement of recovery

The assessment of post-operative recovery requires a psychometrically developed instrument and the process of accurately capturing the complexity of the concept is challenging (Herrera, Wong & Chung, 2007). In recovery assessment two kinds of instrument can be distinguished; general post-operative recovery instruments and disease-specific instruments (Kluivers, Riphagen, Vierhout, Broilmann & de Vet, 2008). A systematic review exploring recovery specific quality of life instruments found no fully validated instrument, although the Post-discharge Surgical Recovery Scale (PSR) and the Quality of Recovery-40 (QoR-40) were recommended for use in short-term post-operative recovery (Kluivers et al., 2008). The instruments reviewed were developed to measure the early and intermediate phases of recovery after day surgery (Kluivers et al., 2008). The psychometric properties of the Swedish version of the PSR have been evaluated and found to be acceptable in terms of data quality, internal consistency, dimensionality and responsiveness (Berg, Idvall, Nilsson, Arestedt & Unosson, 2010). The 40-item QoR-40 questionnaire has previously been tested in a population of Swedish day-surgery patients (Idvall, Berg, Unosson, Brudin & Nilsson, 2009). It was further developed into a web-based instrument, the Swedish Web version of the Quality of Recovery (SwQoR) questionnaire and adapted for use in the Recovery Assessment by Phone Points (RAPP) mobile app (Dahlberg, Jaensson, Eriksson & Nilsson, 2016; Jaensson, Dahlberg, Eriksson, Gronlund & Nilsson, 2015). However, these measure the short-term perspective, i.e., the first 14 days after day surgery. Another multi-dimensional questionnaire, The Postoperative Recovery Profile (PRP), measures patient-reported post-operative recovery from both a short- and a long-term perspective (Allvin, Ehnfors, Rawal, Svensson & Idvall, 2009). The PRP instrument was used in this thesis and is described in the Method section.

The experience of symptoms during recovery is a critical post-transplant outcome, possibly affecting well-being and self-management, which includes symptom management by the patient her/himself. Symptoms are defined as a subjective change in usual functioning, sensations or feelings, perceived and experienced by an individual and believed to be indicative of an illness (Heggyvary, 1993).

The concept of recovery after LuTx needs to be further explored. Moreover, no framework exists to support transplant nurses in promoting recovery after solid organ transplantation in general or after LuTx in particular.

The concept of well-being

Well-being is a prioritized concept and there is an increasing interest in using indicators of subjective well-being and ill-being when assessing the need for certain policies but also for measuring and evaluating policies within the healthcare and public health domain (Diener, 2005; Linton, Dieppe & Medina-Lara, 2016).

There are several definitions of the term well-being, which can be seen as an umbrella term that refers to different evaluations people make regarding their lives (Diener, 2005). An extensive review of 99 self-report measures for assessing generic well-being explored the dimensions of well-being and the developments over time (Linton et al., 2016). Definitions of well-being differed by discipline and were frequently confused with other terms such as health-related quality of life (HRQoL), happiness and wellness. Incomplete and unclear definitions of well-being were provided in the above mentioned literature review and the term was broadly defined as a multidimensional construct. The subjective component of well-being was divided into an *affective* component concerning emotions and a *cognitive* component regarding how people evaluate their lives. Synonyms were often used, subjective well-being as a synonym for happiness, while mental well-being, psychological well-being and mental health were used interchangeably. Sometimes the difference between well-being and health was also unclear as the measures of well-being in many instruments resemble multidimensional measures of health. While the difference between measuring well-being and health may be subtle, one distinction is that subjective well-being targets how individuals think and feel about the quality of their own lives, thus being healthy does not guarantee a sense of well-being. A dimension such as general health can be understood as a possible precursor of and central to the concept of well-being (Linton et al., 2016).

The term *well-being* is often used instead of *subjective well-being* to avoid suggestions concerning anything arbitrary or unknowable about the concept involved (Diener, 2005). Well-being is subjective and occurs within a person's experience, which includes reflective cognitive evaluations concerning life and work satisfaction as well as affective reactions to life events. Although well-being is subjective it can still be observed objectively in, for example, verbal and non-verbal behaviour and actions. Well-being is a desirable goal, first and foremost for the person her/himself but also because a high level of well-being has beneficial societal outcomes, whereas ill-being such as depression tends to produce negative societal outcomes (Diener, 2005).

Measurement of well-being

The fundamental challenge of measuring well-being lies in the extent of the disagreement about its definition and theoretical basis (Linton et al., 2016). An extensive review of instruments measuring well-being demonstrated variability in the dimensions used, leading to further ambiguity. The majority of the instruments were multidimensional and well-being should be seen as a multidimensional construct. The dimensions clustered around six key themes; *mental well-being*, *social well-being*, *physical well-being*, *spiritual well-being*, *personal circumstances* and *activities and functioning*. The review concluded that the evidence suggested little agreement on how well-being should be measured, how instruments should be designed or which dimensions should be included (Linton et al., 2016).

The concept of health

The concept of health is highly complex and has for centuries been the focus for scientists, philosophers and nurses in their efforts to develop models and paradigms in order to explain health and its relationship to illness. The concept of health has many different meanings and interpretations based on various theoretical and philosophical perspectives (Friberg & Öhlén, 2014). The definition and perspective of health used within nursing has consequences for patients and the care provided by healthcare professionals (Berman & Snyder, 2012). Furthermore, by understanding patient perceptions of health and illness, healthcare professionals can provide care that is more meaningful to patients, which might help them to maintain, regain or attain a state of health (Berman & Snyder, 2012). The interaction and communication between transplant care professionals and LuRs are vital for promoting self-management, thereby improving health and well-being as well as long-term outcomes.

Health is a core concept in transplant nursing as in all nursing practice. In relation to LuTx, two different approaches, the scientific biomedical perspective and the humanist holistic perspective can be used to understand the concept of health. The biomedical perspective defines health as the absence of disease and is characterised by the work of medicine to relieve and cure diseases, thereby restoring health (Edberg & Wijk, 2014). In the context of transplantation it means an effort to cure an end-stage disease by replacing the diseased organ. Health is evaluated by statistical normality, which implies the impossibility of having a disease and still experiencing health (Boorse, 1977). This means that a chronically ill patient can never experience health. A second consequence of this perspective is that all healthcare is focused on treating diseases, as the only opposite to health is disease that deviates from normality. Furthermore, if the patient

feels ill but no disease is diagnosed, she/he will not receive treatment due to being considered healthy (Boorse, 1977).

The humanistic perspective on health comprises several diverse explanation models, the common denominator being a holistic approach to human beings (Edberg & Wijk, 2014). Health is viewed as a process and influenced by experiences, well-being and sense of coherence, thus health is more than the absence of disease (Edberg & Wijk, 2014). The consequence of a holistic characterization of health after LuTx is a focus on health instead of disease, indicating the prioritisation of health promotion and recovery.

The two perspectives do not exclude each other, as both are necessary for promoting health after LuTx and because serious diseases constitute the greatest threat to human health. However, the biomedical perspective should not exhaust the scope of healthcare and more importantly does not constitute the definition of healthcare (Nordenfelt, 1993).

The opposite of health is illness, which is common both before and after LuTx depending on the recovery process and overall course of the event. Illness is a subjective and personal state of mind in which the person's physical, emotional, social and intellectual developmental or spiritual functioning is experienced as decreased (Berman & Snyder, 2012). A chronic illness lasts for an extended period of time and is often life-long with both remissions when symptoms disappear and exacerbations when symptoms reappear (Berman & Snyder, 2012). Illness may or may not be related to disease, i.e., it is not synonymous with disease and can be described as both acute and chronic.

Measurement of health

As previously described, the concepts of health and well-being are complex and often intertwined, not only as concepts but also when measuring patient related outcomes (PRO). Besides measuring well-being and general health, HRQoL is a major concept in the international literature that is recognized as a key patient-centred outcome and extensively measured (Singer et al., 2013). Health utility-based instruments quantitatively measure patients' health statuses or outcomes and capture the degree of impairment and distress (McDowell, 2006). Health utility-based instruments are conceptually related to HRQoL and offer an alternative for measuring the health benefit although they are not entirely interchangeable as the item content in utility-based instruments rarely reflects the multidimensional nature of HRQoL (McDowell, 2006).

Background

The background consists of two sections where the first provides an overview of LuTx as a treatment, followed by an overview of previous nursing research concerning the main concepts in relation to LuTx.

Overview of lung transplantation as a treatment

This section will provide an overview of LuTx as a treatment and briefly describes;

- The historical background of lung transplantation
- Referral and evaluation of potential lung recipients
- Contraindications for lung transplantation
- Surgical procedure and immunosuppressive medication
- Complications, side-effects and the threat of graft rejection
- Post-transplant follow-up

The historical background of lung transplantation

The first human LuTx was performed at the University of Mississippi in 1963 (Hardy, Webb, Dalton & Walker, 1963) although poor outcomes during the following decades resulted in slow progress within the field. The University of Wisconsin team reported the first successful lung transplant in 1993 (Carney, Hobson & McCalmont, 2017). The knowledge obtained during the evolvement led to several clinical advances such as improved selection criteria, refined surgical techniques and advances in immunosuppression treatment. Further understanding of transplant immunology, microbiology, pathology and surgical improvements continue to drive the progress in transplantation (Carney et al., 2017).

Referral and evaluation of potential lung recipients

Patients are usually referred to the LuTx programme by their primary care physician or local pulmonologist and medical information is sent to the transplant centre for a thorough evaluation (Carney et al., 2017). The evaluation includes a medical and physical history, consultations with specialists and interdisciplinary team members as well as lab-tests, scans and ultrasound (Carney et al., 2017). The ISHLT consensus guidelines state that patients to be considered for LuTx should meet the following criteria;

- at high risk (> 50%) of death within two years if LuTx is not performed
- at high (> 80%) likelihood of surviving at least 90 days after LuTx and
- at high (> 80%) likelihood of 5-year post-transplant survival provided graft function is adequate (Weill et al., 2015).

In 2014-2015 the mortality rate on the waiting list in the United States was 16.5 deaths per 100, which is why the timing of the referral is an important aspect of LuTx (Valapour et al., 2017). Referrals at a late stage in the disease process might result in the patient being too ill for transplantation, while older age might also preclude the patient from being listed. Measures of QoL with and without a transplant must also be taken into consideration (Kreider, Hadjiliadis & Kotloff, 2011). The health status of the LuTx candidate is monitored regularly during her/his time on the waiting list.

Contraindications for lung transplantation

There are several absolute contraindications for LuTx as well as medical conditions that have an impact on eligibility (Weill et al., 2015). Examples of absolute contraindications are;

- recent history of malignancy
- irreversible end-stage disease in another organ
- acute medical instability
- atherosclerotic disease with end-organ ischemia that cannot be re-vascularized and chronic infection

There are also relative contraindications listed for LuTx as well as controversial criteria such as upper age limits, patients colonized or infected by antibiotic-resistant organisms, patients with a history of non-adherence and lack of reliable social support (Carney et al., 2017). Both younger and female recipients have a better survival rate

than older and male recipients and survival also varies in accordance with the indication for LuTx (Yusen et al., 2014).

Surgical procedure and immunosuppressive medication

Several types of lung procedure are utilized as well as different surgical techniques such as single-lung or bilateral LuTx, heart-lung transplantation or living donor lobar transplant (Davis & Hartwig, 2014). LuTx procedures have changed over time where the frequency of single LuTx has decreased since 2006/2007 and that of double LuTx has increased (Scandiatransplant, 2015). A majority of recipients underwent bilateral procedures in recent years (Yusen et al., 2014). LuRs who received bilateral LuTx had better survival rates compared to single LuTx (median 7.0 years versus 4.5 years) (Yusen et al., 2014). The surgical incisions applied are the clamshell approach, median sternotomy, standard thoracotomy or minimally invasive thoracotomy (Davis & Hartwig, 2014).

Immunosuppressive medication is a major part of the post-transplant treatment. It usually begins on the day of surgery in the intensive care unit (ICU) with the goal of preventing rejection of the allograft (Moten & Doligalski, 2013). Optimal management of immunosuppressive treatment involves:

- maintaining drug levels within the therapeutic range
- balancing immunosuppression while minimizing the risk of infection, rejection, or cancer
- minimizing or preventing side-effects of immunosuppressive medications
- minimizing or preventing complications associated with immunosuppressive medications (Carney et al., 2017)

Standard care at most transplant centres comprises induction therapy followed by three immunosuppressive drugs post-transplant (Moten & Doligalski, 2013). The most frequently used triple immunosuppressive regime consists of a combination of tacrolimus, mycophenolate mofetil (MMF) and a corticosteroid (Ensor & McCalmont, 2017). In recent decades there has been a move towards reducing the use of steroids where possible (Moten & Doligalski, 2013). Risks associated with immunosuppressive medications involve rejection, infection and cancer (Ensor & McCalmont, 2017).

Complications, side-effects and the threat of graft rejection

During the recovery process and throughout the lives of the LuRs, a major part of self-management involves managing side-effects and comorbidities due to immuno-

suppressive medications. Medical complications are common in transplant recipients due to the complexities of post-transplant care (Ensor & McCalmont, 2017).

They involve;

- medication toxicities
- drug interactions between immunosuppressive medications
- adjuvant medications prescribed to manage medical complications, opportunistic infections, metabolic, gastro intestinal (GI) and cardiovascular complications due to immunosuppressive medications (Ensor & McCalmont, 2017).

One of the major complications of immunosuppression therapy after LuTx is infection, where the lung is the most common site and the risk highest during the first months post-transplant, after which it decreases (Floreth & Bhorage, 2010). Another complication and common toxicity due to immunosuppressive medications is nephrotoxicity of calcineurin inhibitors, which also cause several other toxicities including diabetogenicity, dyslipidemia, hypertension and tremor in addition to other cardiovascular and chronic kidney diseases (Bloom & Reese, 2007). Side-effects of corticosteroids are related to the dose and duration of exposure and include glucose intolerance, weight gain, psychotic disturbances, osteoporosis, hypertension and hyperlipidemia (Ensor & McCalmont, 2017). Apart from rejection, other complications post-transplant include surgical complications such as inadequate bronchial anastomosis or tracheal stenosis as well as pleural complications, e.g., pneumothorax or pulmonary oedema (Carney et al., 2017).

Rejection after LuTx is a reality most recipients have to face during the recovery process or at a later stage. There are three types of graft rejection after LuTx; hyperacute, acute and chronic (Carney et al., 2017). Chronic rejection can occur with or without the presence of BOS. Most recipients will experience at least one acute rejection episode during the first year post-transplant, with the highest risk in the early months, after which it decreases over time (Carney et al., 2017). Recurrent acute rejections have been associated with the development of BOS, as approximately 48% of LuRs develop BOS by 5 years and 76% after 10 years (Yusen et al., 2014). Chronic lung allograft dysfunction (CLAD) refers to all types of graft dysfunction, and is a progressive form of chronic rejection that may be irreversible (Carney et al., 2017).

The improvement in the rate of acute rejection over the last 20 years has been seen as a result of more potent immunosuppression. However, a consequence of this is more infectious and malignancy-related complications as well as other direct toxicities (Lodhi et al., 2011).

Post-transplant follow-up

Post-transplant follow-up is extensive in order to optimize medical therapy. It involves bronchoscopies, biopsies, lab tests, chest radiographs and clinical examinations (Cupples et al., 2017) but also active patient engagement in a variety of health behaviours (Berben et al., 2015), i.e., self-management. This includes intake of medication, regular physical activity, reduced use of alcohol, smoking cessation, sun-protection, keeping medical appointments (Berben et al., 2015) as well as self-monitoring of lung function, vital signs and symptoms (Hu, DeVito Dabbs, Dew, Sereika & Lingler, 2017; Kugler, Gottlieb et al., 2010).

Overview of previous nursing research after lung transplantation

This section will provide an overview of previous nursing research concerning the main concepts included in this thesis in relation to LuTx. The following will be described;

- The knowledge gap in the research field of lung transplantation
- Recovery and symptoms after lung transplantation
- Symptoms, immunosuppressive treatment and adherence
- Well-being and health after lung transplantation

The knowledge gap in the research field of lung transplantation

A substantial part of previous research concerning LuTx from a nursing perspective focuses on QoL, but little is known about the LuRs' recovery process and the possible effect on health and well-being. Although research has been conducted on different aspects after LuTx such as symptom frequency, symptom distress (Kugler et al., 2009; Lanuza et al., 2012), HRQoL (Baranyi, Krauseneck & Rothenhausler, 2013; Kugler et al., 2013; Kugler, Tegtbur et al., 2010; Studer et al., 2004) and psychological factors (Dew et al., 2015; Rosenberger et al., 2016; Smith et al., 2016), measurement of the degree of recovery and which factors affect the recovery process are missing. Several studies have focused on how to practically optimize physical rehabilitation after LuTx such as increasing general mobility, functional capacity, muscle strength and early mobilization (Wickerson et al., 2016). A review study found evidence to support the assumption that structured exercise training after LuTx could improve maximal and functional exercise capacity (Wickerson, Mathur & Brooks, 2010).

In the following section, previous research on recovery after LuTx will include symptoms due to the fact that the recovery process is strongly influenced by various symptoms caused by the side-effects of immunosuppressive medications as well as medical and surgical complications. Another important aspect of the recovery process is adherence to medications and health behaviours, which might be influenced by the experience of symptoms and will therefore be briefly illuminated. Furthermore, previous research on well-being will be outlined, which includes the effects of psychological distress, anxiety and depression.

Recovery and symptoms after lung transplantation

Today, knowledge about the post-transplant recovery process after LuTx is scarce. However, other areas addressed in the research field indirectly describe post-transplant recovery such as experienced symptoms. LuRs suffer from many different symptoms during the recovery process (Kugler et al., 2007; Kugler et al., 2009; Lanuza et al., 2012; Lanuza, McCabe, Norton-Rosko, Corliss & Garrity, 1999). In a study by Kugler et al. (2007) including 287 LuRs, the most common symptoms reported after transplantation were tremor (70%) and hirsutism (68%), while the most distressing were Cushingoid appearance (39%) and muscle weakness (32%). In a study by Forsberg et al. (2012) including 185 solid organ recipients, 79% reported sleep problems, of whom 27% were severely distressed. Other frequently reported symptoms were muscle and joint pain (68%), fatigue (67%), decreased libido (58%), increased appetite (56%), trembling hands (53%) and dyspnoea (51%) (Forsberg, Persson, Nilsson & Lennerling, 2012). Symptoms can increase in frequency and severity until they cause severe psychological and/or physical distress (Lanuza et al., 2012). Many studies show that the most frequently experienced symptoms do not necessarily have the greatest impact on perceived stress (Kugler et al., 2007; Kugler et al., 2009; Lanuza et al., 1999). Another symptom thoroughly investigated after LuTx is chronic pain, where two papers published within the Swedish SMATT project (Self-Management After Thoracic Transplantation) including 117 LuRs showed that the prevalence of pain was 51% after 1 year, 68% after 2 years, 69.5% after 3 years, 75% after 4 years and 54.5% after 5 years (Forsberg, Claesson, Dahlman & Lennerling, 2017). LuRs with pain reported lower well-being and higher symptom distress (Forsberg, Claesson, Dahlman & Lennerling, 2017).

Symptoms, immunosuppressive treatment and adherence

Many post-transplant symptoms experienced by recipients during the recovery process originate from immunosuppressive medications (Kugler et al., 2007). There is an association between the side-effects of immunosuppressive medications, symptom

experience and non-adherence as patients try to decrease their symptom burden by reducing dosage or taking drug holidays (Kugler et al., 2007). The challenge of immunosuppressive medications lies in the balance between sufficient immune-suppression to prevent acute rejection and prolonged graft survival contra toxicities causing side-effects and symptoms (Lodhi et al., 2011). The immunosuppressive regimes are developed for populations rather than individuals, resulting in inappropriately high doses for some individuals and doses that are too low for others with regard to the risk of rejection. There is a need for individual assessment of immunosuppressive treatment in order to identify the optimal dosage to lower the risk of acute rejection but at the same time reduce the risk of toxicity and symptoms (Lodhi et al., 2011).

Adherence to health behaviours such as regular self-monitoring of lung function at home has been shown to be effective in detecting and preventing early post-transplant complications and rejection as well as improving health outcomes (Hu, DeVito Dabbs et al., 2017; Kugler, Gottlieb et al., 2010). However, research reveals that despite the widely agreed importance of these self-care health behaviours, the actual performance of and adherence to them are far below the recommended levels (Dew et al., 2008; Hu, DeVito Dabbs et al., 2017; Hu, Lingler, Sereika et al., 2017). A systematic review of non-adherence after LuTx included 30 articles and demonstrated a medication non-adherence ranging from 2.3% to 72.2%, a non-adherence to self-monitoring of lung function ranging from 16% to 65.9%, while non-adherence to other aspects of the post-transplant medical regime such as tobacco use ranged from 12-45% (Hu, Lingler, Sereika et al., 2017). The rates varied greatly across studies and could not be consistently attributed to any specific factors, which may be due to the complex nature of non-adherence or the methodological heterogeneity across studies. A study within the SMATT project revealed that 30% of the LuRs were non-adherent (Lennerling, Kisch & Forsberg, 2019). The non-adherence to taking medication was 43% and the most frequent non-adherence behaviour was timing (punctuality). Of those working full or part time 43% were non-adherent. LuRs able to work full or part time were significantly ($p=.032$) less adherent than those unable to work (Lennerling et al., 2019).

Well-being and health after lung transplantation

As previously described, health, well-being and HRQoL are often intertwined when measuring PRO, although the predominant focus has been on HRQoL where extensive research has been conducted that demonstrates improvements (Kugler et al., 2013; Kugler, Tegtbur et al., 2010; Studer et al., 2004). In a systematic literature review including 73 studies it was concluded that LuTx significantly and substantially improves HRQoL, predominantly in domains related to physical health and

functioning (Singer et al., 2013). The review demonstrated the largest improvements during the first six months post-transplant, which continued up to one year, after which the HRQoL trajectories were less stable and negatively affected by BOS and comorbidities (Singer et al., 2013).

Depressive and anxiety-related disorders are common after LuTx (Dew et al., 2012; Rosenberger et al., 2016) and might affect health and well-being. Psychological distress includes symptoms of anxiety and depression, which can negatively affect a person's motivation, self-concept, coping and problem-solving ability (Coleman & Newton, 2005). One risk factor for developing such disorders is early post-transplant health problems as well as a pre-transplant psychiatric history, longer wait for transplant, female gender and psychosocial characteristics (Dew et al., 2012). A study of 178 LuRs revealed a high rate of panic disorder (18%) as well as major depression (30%) post-transplant (Dew et al., 2012). In a study including 123 solid organ transplant recipients, almost 32% suffered from overall mental distress such as anxiety and depression (Baranyi et al., 2013). Depression early post-transplant increases the risk of long-term transplant-related mortality (Dew et al., 2015) and morbidity (Rosenberger et al., 2016) with an elevated risk of BOS, patient death and graft loss (Rosenberger et al., 2016). A meta-analysis reviewing patient adherence revealed that the odds are three times greater that depressed patients will be non-adherent to medical treatment recommendations compared with non-depressed patients (DiMatteo, Lepper & Croghan, 2000). Another study demonstrated a correlation between psychological distress and the level of self-care agency, where higher levels of baseline anxiety were associated with lower levels of self-care agency (Hu, Lingler, DeVito Dabbs, Dew & Sereika, 2017). Self-care agency was defined as one's ability and willingness to engage in self-care behaviours. This study highlights the importance of screening, monitoring and reducing psychological distress among LuRs, not only to improve well-being but also to enable self-management behaviours.

In the light of the negative effect of depression and decreased well-being on transplant outcomes demonstrated by previous research, the importance of elucidating possible relationships between recovery, symptoms and well-being is evident. The relationship between these important post-transplant aspects suggests that self-management might be affected, leading to the need for targeted self-management support from healthcare professionals. However, the knowledge gap concerning these areas is substantial.

Rationale

LuTx is an advanced and expensive treatment with the purpose of prolonging life and substantially improving well-being in persons with end-stage lung disease. LuRs face many challenges including recovering from the surgery, a range of complications and side-effects caused by the immunosuppressive medications as well as lifestyle changes and recommended restrictions pertaining to hygiene, food and sun exposure. Outcome results reveal that survival after a LuTx is limited, thus the need to identify factors that can improve recovery, well-being and thereby long-term survival is crucial. Health is considered to be a part of well-being and by pursuing health promotion overall well-being will presumably also increase. One important aspect of health promotion is self-management support as the major part of recovery takes place at home and requires advanced self-care skills.

Today there are great expectations on the part of transplant professionals that LuRs should be partners and co-actors in their recovery process in order to achieve long-term health. However, there is a considerable lack of scientific knowledge regarding LuRs' experiences of symptoms, recovery and well-being. Therefore, the rationale behind this thesis was to describe in-depth what the main concerns among LuRs are and how they deal with them. Thus, in **Paper I** an inductive approach by means of the Grounded Theory Method (GTM) was adopted. Interviews with 15 LuRs generated a hypothesis concerning the recovery process that was developed into a grounded theory concerning the LuRs' main concern after LuTx as well as how they experienced their recovery process. Because there was no meaningful definition or framework of post-transplant recovery, a second rationale emerged, namely to explore whether a concept analysis of recovery after general surgery was applicable or needed adjustment to fit the LuTx context. Hence, in **Paper II**, the interviews from Paper I were re-analysed using a deductive content analysis approach (Figure 2). A transplant specific definition of recovery was developed and a new framework emerged.

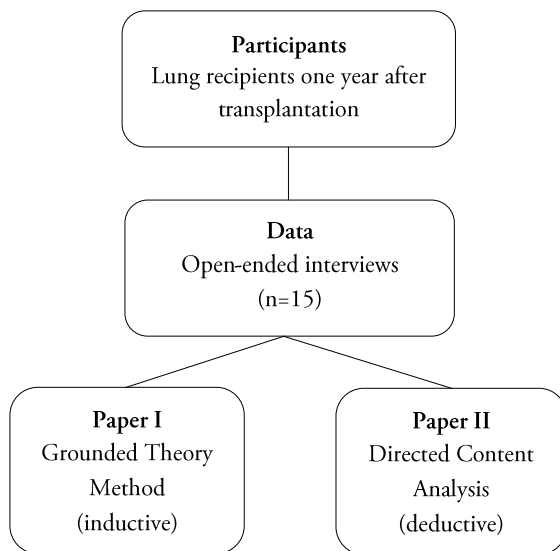


Figure 2. Overview of the analysis used in Papers I & II based on interviews performed one year after lung transplantation.

As the two qualitative studies generated several hypotheses concerning recovery, health and well-being, a third rationale in **Paper III** was to test these by means of a multicentre, cross-sectional cohort study including 117 recipients 1-5 years after LuTx. A comprehensive picture of recovery, symptoms and well-being was revealed and the hypothesis that it is possible to experience health without being recovered was confirmed.

The GTM used in Paper I provided the possibility of approaching the same participants again with follow-up questions aimed at further developing the theory. As the hypothesis based on the interviews performed one year after LuTx was that the health transition continued, it was decided to deepen the understanding and further develop the original grounded theory by interviewing the same informants three years after their transplantation. Thus, in **Paper IV** the rationale was to further understand how it is possible to experience health despite lack of recovery by means of an in-depth follow-up study three years after LuTx. This enabled a longitudinal understanding of the process of health transition by expanding the grounded theory developed in Paper I.

A key concern of transplant nursing is how to promote and support health behaviours in order to involve LuRs in the extensive task of self-management and adherence to healthcare recommendations. The basic assumption in this thesis is that the way in which LuRs perceive the recovery process and what they experience as their main concern are fundamental for developing self-management support. Understanding the patient perspective and knowledge of the recovery trajectory are essential aspects in

promoting health and well-being after a LuTx. Symptoms during the recovery process, psychological distress and decreased well-being are all potential threats to adherence to prescribed recommendations but foremost to health and well-being. Therefore, an increased understanding of these concepts is vital for promoting long-term outcomes after LuTx. The goal of this thesis is to narrow the knowledge gap regarding how well-being is affected by the recovery process and to develop research-based guidelines for how health promotion should be tailored to increase well-being and health after LuTx.

Aim

The overall aim was to understand, explore and explain the recovery process, symptoms and well-being after lung transplantation from an inside perspective.

Specific aims

- to investigate lung recipients' process of transition from before transplantation to one year afterwards, as well as what their main concerns are and how they deal with these concerns (Paper I)
- to develop the concept analysis by Allvin et al. (2007) from lung recipients' perspective on their post-transplant recovery process (Paper II)
- to identify the recovery trajectories including critical junctions in the post-transplant recovery process after lung transplantation (Paper II)
- to explore symptom prevalence and distress, as well as the degree of self-reported recovery and well-being one to five years after adult lung transplantation (Paper III)
- to further develop a grounded theory of health transition by exploring the process of change one to three years after lung transplantation (Paper IV)

Methods

Overview of the design of the studies

The studies and results included in the thesis derive from a multicentre research project entitled Self-Management After Thoracic Transplantation (SMATT), which includes the two thoracic transplant centres in Sweden; The Skåne University Hospital (Lund) and The Sahlgrenska University Hospital (Gothenburg). The mixed method approach in this thesis was motivated by the intention to both understand and explain important aspects of recovery, health and well-being after LuTx, as presented in Table 1.

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

Study	Design	Participants (n)	Data collection	Data analysis
I	Qualitative, inductive	15	Interviews	Grounded Theory Method
II	Qualitative, deductive	15	Interviews	Deductive content analysis
III	Quantitative cross-sectional, explorative	117	Self-assessment questionnaires	Non-parametric analysis
IV	Qualitative, prospective, theory development	14	Interviews	Grounded Theory Method

Sample selection, participants and data collection Papers I & II

Sample selection and participants

Participants were selected from the only two transplant units in Sweden where LuTx is performed, i.e. Lund and Gothenburg. The inclusion criteria were adult LuRs due for their one year follow-up, medically stable and who considered themselves fit for the

interview. Patients admitted to hospital or who had difficulty understanding and speaking Swedish were not included. Ten adult males and five adult females (n=15) with a mean age of 55 years (range 26–70 years) were consecutively included. The inclusion ended when saturation was achieved in accordance with the GTM used in Paper I and a sufficient understanding was obtained. All participants except one had undergone bilateral LuTx, the one exception having received bilateral lungs and a heart at the same time. The data derived from the interviews constituted the foundation of the analysis in both Paper I and Paper II, although by means of two different methods. However, the inclusion participants and the data collection were performed in accordance with the GTM, which is therefore described in detail below.

Although the participant selection was consecutive, it was also performed in accordance with the GTM and consisted of *convenience*, *purposeful* and *theoretical* sampling (Morse, 2011). *Convenience sampling* comprised available adult LuRs who had experienced the phenomenon of interest. *Purposeful sampling* was performed by exploring the phenomenon of interest during the interviews. The principle of *theoretical sampling* is that the emerging categories and understanding of the developing theory guide the subsequent sampling by ensuring that the researchers deliberately seek to identify participants who have the specific experience of interest (Morse, 2011). During the theoretical sampling the data were coded according to the identified trajectory and emerging categories, where the increased understanding guided the final sampling. The inclusion of participants continued consecutively but targeted questions concerning the meaning of each concept were posed to enable grounded definitions as well as clarification of the linkages between the categories. Four validation interviews were conducted by phone with participants who had already been interviewed, which deductively explored the analysis and theoretical model constructed. These participants were recruited by the researcher who performed the interviews (ML) due to their high reflective skills and ability to speak articulately about their experiences.

Data collection by means of interviews

The data collection was performed during 2014–2015. The potential participants were contacted by the nurse at the out-patient clinic who briefly explained the study and asked if they were interested in participating. The time of the interview was decided either between the nurse and the participant or the researcher conducting the interview and the participant but the location was chosen by the participants. All of the participants chose to be interviewed in a secluded room at the transplant centre in connection with their one year follow-up. Information about the study was provided including the possibility of terminating their participation at any time until publication of the findings. Written consent was obtained and stored in a locked, fire proof cabinet.

The individual face-to-face interviews began with an open-ended question where the participants were asked to describe their recovery experience after LuTx. They were then requested to narrate their experiences and thoughts from the onset of their illness until LuTx and the first year thereafter. Follow-up questions were posed to avoid misunderstanding and confirm what the participants had expressed. The interviews, which lasted for an average of 49 minutes (range 35–83 minutes), were digitally recorded and transcribed verbatim immediately after each interview. Written memoranda, so called memos, were made during the interviews and throughout the whole analysis process. The interviews were performed by one of the authors (ML) who had no knowledge of the participants' condition prior to the interview and was not involved in their present care.

When collecting data in GT, the scope of the phenomenon of interest must be captured (Morse, 2011). The participants in the study were invited to participate consecutively, where all but one accepted. The one exception declined due to her poor medical condition. Sampling ceased when saturation was achieved, i.e. when a sufficient understanding emerged, which is a stepwise decision that the categories or findings are complete (Polit & Beck, 2010). By the end of the analysis process in Paper I, the data retrieved from new interviews merely confirmed the analysis rather than adding new data to the categories, hence the sampling and data collection ceased.

The collection of data during the interviews was performed with the intention of performing a GT study and the questions asked were broad in order to capture the LuRs' main concern during the recovery process. The decision to deductively explore the process of recovery by employing a concept analysis of post-operative recovery in Paper II was made after the completion of the interviews as the data were considered to contain enough information to answer the research questions posed.

Sample selection, participants and data collection Paper III

Sample selection and participants

The inclusion criteria were Swedish speaking adult LuRs due for their annual follow-up 1-5 years after LuTx who were not hospitalized. The participants were consecutively included from the two thoracic transplant centres in Sweden. The main reasons for exclusion were language barrier or poor medical condition. The data were collected during the period February 2014 to October 2015, where 204 LuRs were due for their annual follow-up. Of those, 128 (63%) were included, 55 LuRs from Lund and 73 from Gothenburg. The final sample size was affected by practical inclusion difficulties at the out-patient transplant clinics and these participants were considered to be missing

at random. Nine LuRs were included twice in different follow-up years due to an inclusion error, but were subsequently excluded from one of the data collection occasions. Two LuRs were identified as both heart *and* lung recipients and thereby did not meet the inclusion criteria and were removed from the sample. Thus, the final sample consisted of 117 LuRs who were due for follow-up at 1 year (n=35), 2 years (n=28), 3 years (n=23), 4 years (n=20) and 5 years (n=11) as displayed in Figure 3.

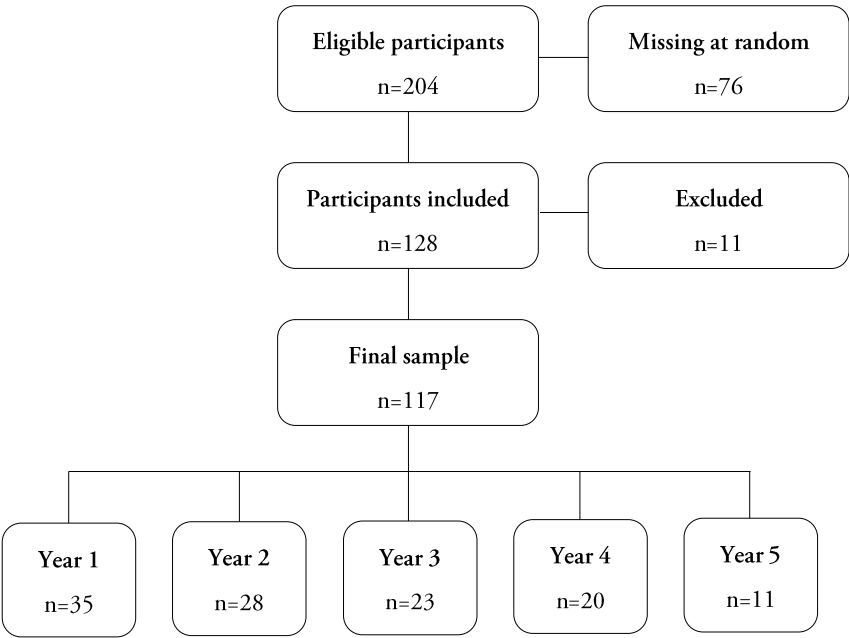


Figure 3. Overview of the sample selection in Paper III.

Data collection by means of self-report questionnaires

The self-reported questionnaires were utilized in paper format and handed out by nurses at the transplant clinics in pre-coded envelopes. After completing the questionnaires the LuRs returned them to the nurses in the pre-coded envelopes, either directly at the clinic or by post afterwards. Perioperative data such as time on a ventilator and length of ICU stay were gathered from the patients’ records after they had granted permission.

Three different instruments were used to measure the degree of recovery, symptoms, health and well-being;

- The Postoperative Recovery Profile (PRP)
- The Organ Transplant Symptom and Well-Being Instrument (OTSWI)
- The Psychological General Well-Being Index (PGWB)

Two different dimensions of well-being were measured, transplant specific well-being by means of the OTSWI instrument and psychological well-being by means of the PGWB instrument. General health was measured by one sub-dimension in the PGWB instrument.

The psychometric properties of the Post-Operative Recovery Profile

The PRP was designed in Sweden to evaluate patient-reported progress of post-operative recovery and the long-term follow-up after different surgical procedures, both on individual and group levels (Allvin et al., 2009). The conceptualization of recovery and item definitions are based on a theoretical framework (Allvin et al., 2007) and the description of post-operative recovery is from the perspectives of patients, registered nurses and surgeons (Allvin et al., 2008). Five dimensions (physical symptoms, physical functions, psychological, social, activity) and 19 items were identified as part of the post-operative recovery process (Allvin et al., 2009). To determine the content validity of the items, eight nurses, seven surgeons and 19 patients systematically judged their relevance and usefulness. The content validity of the instrument was high, where on average 85% (range 71-97%) of the participants considered the items essential in the recovery process. A total of 25 patients participated in the evaluation of the intra-patient reliability of the instrument and the percentage agreement ranged between 72-100%, hence a vast majority of the items showed a high level of intra-patient reliability (Allvin et al., 2009).

The degree of recovery was graded from *fully recovered*, *almost fully recovered*, *partly recovered*, *slightly recovered* or *not recovered at all* (Allvin et al., 2011). The 19 questions in the instrument cover different physical and mental symptoms, but also possible limitations in daily occupation and social life. The responses are given on a four point scale, i.e. none, mild, moderate and severe (Allvin et al., 2011). The timeframe is specified as how the participants felt when completing the instrument. The level of recovery is based on the number of “none” responses, where 19 (out of 19) equals fully recovered, continuing with a descending gradient down to < 7 “none” responses, which equates with not recovered at all.

The questionnaire has been further developed regarding its ability to discriminate recovery profiles between different groups, where repeated measurements were performed up to 12 months after surgery (Allvin et al., 2011).

The psychometric properties of The Organ Transplant Symptom and Well-Being Instrument

The OTSWI was developed among Swedish solid organ recipients to measure symptom prevalence, symptom distress and transplant specific well-being after organ transplantation (Forsberg et al., 2012). The outcome criterion of the OTSWI is well-being by means of HRQoL involving physiological, emotional, social and behavioural components. In the development of the instrument, questionnaires were sent to 229 organ recipients (kidney, liver, heart and lung) and 185 responded. The instrument development and testing steps suggested by Juniper, Guyatt and Jaeschke (1996) were utilized and the Swedish version of the SF-36 questionnaire was used to validate the OTSWI.

There were eight factors verified by the psychometric tests developed to measure transplant well-being; *fatigue, joint and muscle pain, cognitive functioning, basic activities in daily life* (BADL), *sleep problems, mood, foot pain* and *economy* (Forsberg et al., 2012). All eight factors had satisfactory internal convergent validity as well as good item-scale discriminatory validity. Together the eight factors accounted for 86% of the variance. Each response relates to the discomfort of a situation or problem, assessed on a five-point scale from “*not at all*” (0), “*a little*” (1), “*somewhat*” (2), “*quite a bit*” (3) to “*very much*” (4). Time was specified as the previous seven days. The scale also has a summary score of 0-80 where lower scores indicate higher well-being. In addition, symptom distress was measured by degree of discomfort from twenty transplant specific symptoms graded from *not at all, a little bit, somewhat, quite a bit* to *very much* (Forsberg et al., 2012).

The psychometric properties of the Psychological General Well-Being Index

The Swedish version of the Psychological General Well-Being (PGWB) index was used to measure subjective psychological well-being and distress (Wiklund & Karlberg, 1991). The original English version of the index was developed in 1984 by Dupuy for the purpose of “*providing an index that could be used to measure self-representations of intrapersonal affective or emotional states reflecting a sense of subjective well-being or distress*” (Dupuy, 1984, p 170). The original PGWB index was translated into Swedish in a study by Wiklund and Karlberg (1991) following standard principles. The alpha-coefficients obtained in the Swedish version were presented in the study.

The instrument comprises 22 items, which constitute six dimensions; *anxiety, depressed mood, positive well-being, self-control, general health* and *vitality*. The maximum PGWB index score is 132 (best subjective well-being) where higher scores indicate better health status and psychological well-being, while the minimum score is 22 (poorest subjective well-being). A normal sum-score falls in the range of 100-105 and women generally tend to report lower well-being than men (Dimenas, Carlsson, Glise, Israelsson & Wiklund, 1996). When originally developed, the psychometric properties of the

instrument suggested that the items in the subscales are internally consistent and that the subscales are therefore validated (Dimenas et al., 1996; Dupuy, 1984).

The 22 items forming the PGWB index show very high internal consistency reliability (.94) and can be used to construct an overall index score. The psychometric properties also suggest that the PGWB index is sensitive to changes in an individual's psychological well-being and has good test-retest reliability (Dupuy, 1984).

Sample selection, participants and data collection Paper IV

Sample selection and participants

The selection of participants in Paper IV was partly performed in accordance with the four steps described by Morse (2011), although the sample selection was pre-decided due to the prospective design of the study. This constituted *convenience sampling* and can also be called primary selection. The *purposeful sampling* in the study involved the option of re-interviewing the LuRs at three years post-transplant in order to capture intermediate-term experiences while still minimising the risk of losing participants due to long-term mortality. *True theoretical selection* was not employed in this study as it prospectively follows the initial 15 participants included, although all participants had extensive experience of the phenomenon of interest. Theoretical group interviews can be used to expand on and verify the emerging model (Morse, 2011). However, this was not performed in the present study as the emerging main concerns and strategies used were evident, thus targeted questions were posed to verify the grounded theory.

The sample consisted of 14 LuRs, ten men and four women with a mean age of 56 years. The participants had been interviewed previously at their 1-year follow-up and were now re-interviewed at their third annual follow-up. One female LuR could not be re-interviewed due to mortality. The participants were originally selected at their 1-year interview from the two transplant units in Sweden where LuTx is performed, thus the same selection was predetermined. All participants had undergone bilateral LuTx except one who had received bilateral lungs and a heart.

Data collection by means of interviews

The interviews were performed face-to-face (n=11) or by telephone (n=3) between June 2016 and February 2017 by the same interviewer at both the one and three-year follow-up. The three interviews conducted by phone were due to logistic difficulties (n=2) and to the participant's poor medical condition, which led to the postponement of the

three-year follow up (n=1). The interviews were arranged either by a nurse at the transplant clinic or by the interviewer, who asked if the participants were willing to participate in a follow-up interview three years post-transplant. The interviews began by asking the participants to describe their experiences and well-being since the first interview one year post-transplant up to present day. They were asked to narrate freely and follow-up questions were posed to encourage them to elaborate on their answers, clarify their experiences and compare experiences described during the first interview with their present condition. The grounded theory in Paper I was also briefly explained and discussed with the participant's. The interviews lasted on average 59 minutes (range 29-95 minutes), were digitally recorded and transcribed verbatim. In accordance with the GTM, data collection and preliminary analysis were conducted simultaneously. Memos were written after each interview, which became more theoretically focused later in the process. Eventually a theory started to emerge, which was further developed and confirmed by the final analysis.

Analysis of the data (Papers I-IV)

Preunderstanding

My personal preunderstanding is based on several years' experience as an intensive care nurse within the context of heart- and LuTx, although this is limited to the early post-operative phase in the thoracic intensive care unit (TICU).

The intensive care of LuRs is often strenuous and influenced by many complications that might have affected my perspective on the post-transplant well-being of the LuRs. I had no long-term experience of post-transplant care but based on my short-term experience of the often complicated post-operative care, my presumption was that LuRs experienced reduced well-being due to symptoms and complications.

The research group consisted of another intensive care nurse with heart- and LuTx experience as well as two other nurses with extensive experience within solid organ transplantation.

Qualitative method by means of grounded theory (Papers I & IV)

The inductive method based on GT was chosen due to the specific aim of Paper I *to investigate lung recipients' main concerns and how they dealt with these concerns* but also because a *process* was explored during the first year post-transplant. The assumption that a process of change occurred post-transplant was based on clinical experience. In

Paper IV, which was prospective, changes in the researchers' pre-understanding between the two data collection occasions had to be considered. Consequently, it was decided to continue with Constructivist Grounded Theory, which considers the research context and the researcher's perspectives as well as emphasizing how data, analysis and methodological strategies are constructed. This means that categories and theory are developed from the patterns revealed by the researchers' theoretical constructions of the participants' narrative (Charmaz, 2014).

The GTM originates from the social sciences and comprises a systematic, inductive and comparative method for the purpose of constructing theory based on empirical findings (Bryant & Charmaz, 2011). Data collection and analysis proceed simultaneously. For the sake of simplicity, the GTM can be divided into the Glaserian school, the Strauss and Corbin School and Constructivist Grounded Theory, where the latter was used in this thesis.

A grounded theory is a conceptually abstract explanation of a latent pattern or behaviour in the social setting under study. It must explain, not merely describe, what is happening in a social setting (Bryant & Charmaz, 2011). The GTM tries to account for people's actions from the perspective of those involved by first discovering their main concern and then the individual behaviour designed to resolve it (Polit & Beck, 2010). Conceptualization is a core process in this method, thereby making it a theory-generating rather than a descriptive method.

As recommended, a literature review was conducted before performing the interviews to establish whether previous studies with a grounded theory approach had been made on this particular topic (Hallberg, 2010), but no such study was found. A second reason for a literature review is to provide a background to and motivate interest in the research area under investigation as well as placing the study into a context (Glaser, 2010).

In the GTM the process of analysing the interviews consists of *initial coding*, *focused coding* and *theoretical coding* as well as the *constant comparative method* (Charmaz, 2014). Initial coding of the interviews was conducted by reading the interviews line by line and focusing on the main concern as well as the strategies used to deal with it. Words, phrases or processes indicating important categories related to the research question were highlighted (Charmaz, 2014). Reflections and questions that emerged during the analysis and coding process were logged for each interview. Focused coding was conducted in order to detect and explain the most frequent and significant codes that illuminated the tentative main categories. This also explained the strategies used by the LuRs in relation to their main concern. Specific relationships between the categories generated from the focused coding were developed in the theoretical coding. The main concern and the categories were conceptualized.

The constant comparative method was used throughout the analysis. By comparing data and concepts from the various interviews, commonalities and differences can be

detected, which allows the researchers to develop and refine the categories. The process ceases when the content of each source has been compared with the others (Polit & Beck, 2010). Theoretical saturation was achieved in accordance with the GTM when no new sub or main categories emerged from the data (Charmaz, 2014).

Qualitative method by means of deductive content analysis (Paper II)

The findings from Paper I resulted in several hypotheses concerning the concept of recovery after a LuTx, which needed further exploration. The interview data obtained was rich and part of the material was not used in Paper I. This enabled a second analysis of the material but from a different perspective, hence deductive content analysis inspired by Hsieh and Shannon (2005) was employed. Content analysis consists of three different approaches; *conventional*, *directed* or *summative*, all with the purpose of interpreting subjective meaning from the content of text data through a systematic classification process of coding and identifying themes (Hsieh & Shannon, 2005). Directed content analysis, which was used in Paper II, starts with a theory or relevant research findings as guidance for the initial codes (Hsieh & Shannon, 2005). In this case the concept analysis by Allvin et al. (2007), which explores post-operative recovery after general surgery, was employed. The purpose of using a directed approach to content analysis is to extend a theoretical framework or conceptually validate it (Hsieh & Shannon, 2005). The LuRs' own experience of the post-operative recovery process was compared to the existing concept analysis by Allvin et al. (2007) with the aim of developing it further in the context of LuTx.

The process of analysing the data began by identifying key concepts or variables as initial coding categories (Potter & Levine-Donnerstein, 1999). By using the sub-dimensions in the concept analysis by Allvin et al. (2007), definitions were determined for each category. Text representing the different dimensions was highlighted in the transcript and then coded using pre-determined codes. Text that could not be categorized was given a new code based on the content. Two of the authors collaborated in comparing the meaning units as well as the additional data specific to the context of LuTx. All the authors discussed the final result. The findings from a directed content analysis can either support or contradict the pre-existing theory, thereby contributing to its further development, but in a different context such as recovery after LuTx.

Non-parametric statistical analysis (Paper III)

In Paper III, non-parametric analyses were mainly performed due to the nature of the sample, which comprised ordinal data (Polit & Beck, 2010). The SPSS Statistics (SPSS Inc., IBM Corporation, Armonk, N.Y., USA) was used for analysing the data. The analyses were performed step-wise as follows;

1. Proportions such as symptom prevalence, symptom distress and degree of recovery and psychological well-being 1-5 years after LuTx were explored and described.
2. Possible differences between two unpaired groups were explored.
3. Possible relationships between recovery and well-being were explored.
4. Analyses of possible explanatory factors by means of hierarchical multiple regression were conducted.

The Chi Square was used to test differences in proportions of recovery between male and female LuRs and in LuRs older/younger than 50 years. The independent T-test was employed to determine that there were no differences between LuRs who were *not recovered* and those who had made a *reasonable recovery* regarding time on a ventilator, length of ICU stay and total duration of hospital stay.

The Mann-Whitney-U-Test was used to explore statistically significant difference between two unpaired groups (Maltby, Day & Williams, 2007). This is a non-parametric alternative to the t-test, but instead of comparing the means of two groups, the Mann-Whitney-U-Test compares medians by converting the scores on the continuous variable to ranks across the two groups. It then evaluates whether the ranks for the two groups differ significantly (Pallant, 2016). The Spearman rho correlation, which is also a non-parametric test, was used to explore whether a statistically significant relationship occurs between two continuous variables with a rho value between -1.00 and +1.00 (Maltby et al., 2007).

In order to test how well the OTSWI-sum and PGWB-sum explain the variation in recovery, hierarchical multiple regression was utilized. Multiple regression can be used to explore the relationship between one continuous dependent variable and a number of independent variables or predictors (Pallant, 2016). It is based on correlation but allows an exploration of the interrelationship among a set of variables. In hierarchical multiple regression, the researcher specifies in which order the independent variables are entered into the model, based on theoretical grounds. Variables are entered in steps and once all variables are entered the overall model is assessed in terms of its ability to predict the dependent measure and the relative contribution of each block of variables (Pallant, 2016).

The following questions guided the hierarchical multiple regression analysis:

- How well do the PGWB-sum and OTSWI-sum predict recovery? How much variance in recovery can be explained by scores on these two scales?
- Which is the best explanatory factor of perceived recovery: the PGWB instrument or the OTSWI?
- If we control for the possible influence of age and sex is this set of variables still able to explain a significant amount of the variance in recovery?

Ordered category data were presented with medians and percentiles (P_{25} , P_{75}). Values of $p < 0.05$ (two-tailed) were considered statistically significant. Recovery was dichotomized into two groups, i.e., reasonably recovered patients represented by the levels fully recovered, almost fully recovered and partly recovered in the PRP instrument and those not recovered represented by the levels slightly recovered and not recovered at all. Age was dichotomized into two groups, younger or older than 50 years. Length of stay in the ICU was dichotomized into longer or shorter than seven days.

Ethical considerations

The studies in the thesis were approved by the Regional Ethics Board in Lund, Sweden (Dnr. 2014/670 for the qualitative studies in Papers I, II & IV and Dnr. 2014-124 for the quantitative study in Paper III) and conform to the ethical principles for medical research involving human subjects outlined in the Declaration of Helsinki (WMA, 2013) and the Swedish research ethics legalisation (SFS, 2003:460). The declaration of Helsinki states that research involving human subjects should meet the prerequisite of being valuable to mankind as well as protecting the health, dignity, integrity, right to self-determination, privacy and confidentiality of personal information of research subjects. It further prescribes the need for informed consent and the possibility to end participation at any time (WMA, 2013).

In order to minimize the risk of the participants feeling obliged to take part in the study, they were first contacted by nurses working at the follow-up clinic for both the qualitative interview studies and the quantitative study involving questionnaires. The purpose of the study was explained and the potential participants were asked if they wanted to take part. Information about the confidentiality of the study, protection of their identity and their right to withdraw at any time was provided by both by the nurses at the follow-up clinics and the researcher who performed the interviews. In the quantitative studies the same procedure was adhered to by the nurses at the follow-up clinics who handed out the questionnaires. The researchers had no contact with the participants except for sending them a reminder letter with a copy of the questionnaire where necessary. Potential participants only received one reminder in order not to pressure them into participating or add a possible burden. The information was provided both verbally and in writing together with contact information for the researcher in charge of the study in case they had questions or wished to withdraw from the study. The participants who were interviewed were offered a copy of the final version of the articles so that they could read the content of the research after publication in scientific journals, which was requested by two participants. The location of the interview, either at the transplant clinic or at home, was chosen by the participants in order to provide an environment where they would feel relaxed and safe, which might contribute to a more open interview.

The Regional Ethical Review Board in Lund granted permission to carry out interviews with LuRs one year post-transplant. According to the same Ethical Review Board, no additional ethical permission was needed to conduct follow-up interviews three years

post-transplant. The GTM used in the qualitative studies enables the possibility of approaching the same participants again with follow-up questions for the purpose of further developing the theory. At the end of the interviews at the one-year follow-up, each participant was asked for permission to be contacted again for further questions if necessary, to which all agreed. When it was decided to re-interview the participants at their three-year follow-up, they were approached by the nurse at the transplant clinic and asked to participate again. They were given verbal information about the study and the possibility to withdraw at any time.

The potential psychological risk and burden to the participants were perceived to be low and the possible benefits generated from the studies were considered to outweigh any negative aspects. A medical social worker was available at each transplant clinic in case the interviews in the qualitative study became too emotionally demanding, but this situation never occurred. When analysing the questionnaires, if answers were detected that indicated a serious threat to the health status of the LuR in question, the transplant team was notified in order to ensure assistance to the LuR. This occurred in eight cases and concerned severe pain and non-adherence.

The results of all four studies are presented at group level and the quotations included in the qualitative studies are anonymous, which rules out the possibility of identifying a specific individual.

The questionnaires, personal ID, code-keys and data provided in the studies were kept confidentially in accordance with the Swedish personal data act (PuL, [1998:204]) and stored in a locked and fireproof cabinet. Raw data were stored in an external hard drive separately from the code-keys. Data were gathered from the LuRs' records after permission was granted in accordance with regulations and stored confidentially.

Results

The findings in this thesis illuminate several different aspects of the recovery process after LuTx but from the overall perspective of the LuRs themselves. The result will be presented in two different sections, starting with a short summary of each paper followed by a description of the overall understanding of all four papers.

Summary

Health Transition and Reconstructing Daily Occupation (Paper I)

During the first year, the recovery process was understood as a health transition starting pre-transplant and proceeding over the course of the following 12 months. The main concern in the grounded theory was *Reconstructing Daily Occupation*. This core category consisted of four main categories; *Restricting*, *Regaining*, *Reorganizing* and *Enriching Daily Occupation*, as well as several sub-categories, which described in detail the strategies used to reconstruct daily occupation. The phase of *Restricting daily occupation* occurred pre-transplant and involved a constant struggle to breathe due to the pulmonary disease, resulting in restrictions in daily occupations. This was described as facing a severely limited everyday life and the participants tried to endure their illness and the symptoms they experienced. In the post-transplant *Regaining* phase vital functions were restored, making it possible to perform many daily occupations. The sometimes overwhelming feeling of being able to breathe more easily was a driving force and the main focus was on regaining physical health to enable the performance of daily occupations. Goal setting was an important strategy used by the participants post-transplant. *Reorganising* daily occupations involved adapting and adjusting to their current condition and learning how to perform daily occupations in new ways due to the prevalence of symptoms and complications. The *Enriching* phase was characterized by an experience of health and a deep appreciation for being able to perform most daily occupations. The participants expressed an overwhelming joy and appreciated small things in everyday life such as being able to ride a bike or play with their children. They had a remarkable ability to adopt a positive approach throughout the health transition. The result of the study contributed to an understanding of the huge importance of

daily occupation and the necessity of including an occupational therapist in the transplant team in order to support and change occupational patterns post-transplant.

A Post-transplant Framework and a New Definition (Paper II)

The post-operative recovery concept analysis developed by Allvin et al. (2007) for general surgery was used as guidance when analysing the LuRs' narratives. The result revealed that the concept analysis was partly applicable in the context of LuTx. This paper further developed Allvin's concept of recovery by removing some of the original sub-dimensions and adding others. The sub-dimensions added in the new post-transplant framework were *symptom management*, *adjusting to physical restraints*, *emotional transition*, *achieving an optimum level of psychological well-being*, *social adaptation* and *reconstructing daily occupation*. Management of symptoms due to surgical complications as well as side-effects of the immunosuppressive treatment was a substantial part of the recovery process. When symptom management was insufficient, adjusting to physical restraints was necessary. The emotional transition was described as re-evaluating life, prioritizing differently and changing their perception of themselves. Social adaptation involved changes in social life, partly due to recommendations prescribed by healthcare professionals. The reconstruction of daily occupation outlines the habitual changes that were necessary post-transplant. The recovery trajectory was described as well as critical junctures in terms of positive and negative factors affecting the post-transplant recovery process as reported by the LuRs. Recovery after a LuTx differed from recovery after general surgery as described by Allvin et al., (2007) due to the LuRs' contradiction of returning to pre-operative standards constituted by their illness and pre-operative standards. This implied that a new perspective on recovery in post-transplant management was essential. Based on the findings a definition of post-transplant recovery was developed;

"Post-transplant recovery is a dynamic, demanding process involving a transition from pre-transplant severe illness to a state of experienced health, achieved by adjusting to regained physical, psychological, social and habitual functions. Essential parts of the transitional recovery process consist of symptom management, achieving an optimum level of psychological well-being, social adaptation and reconstructing daily occupations." (Lundmark, Lennerling, Almgren & Forsberg, 2016 p. 3123)

Recovery, Symptoms and Well-being (Paper III)

In this quantitative paper, 117 LuRs were included although the response rate varied between the different instruments utilized. The result in Paper III revealed that very few LuRs perceive themselves as fully recovered 1-5 years post-transplant (5.7%), while 27.6% were not recovered at all. However, the result showed that it was possible

to be partly recovered with the presence of symptoms and still experience good psychological well-being and health. A majority (69%) was reasonably recovered 1-5 years after LuTx, constituted by fully (5.7%), almost fully (17.2%) and partly recovered (46%) in the PRP-instrument. Furthermore, there was a strong correlation between recovery and both transplant specific well-being ($r_s=0.741$) and psychological well-being ($r_s= - 0.720$) 1-5 years after LuTx. A strong correlation was also found between the sub-dimension of general health and recovery for each year, with the strongest correlation after five years ($r_s= - .886$). The OTSWI sum score and PGWB sum score together explained 54.4% of the variance in recovery after controlling for age and sex, where transplant specific well-being measured by the OTSWI makes the largest single contribution to perceived recovery.

LuRs who were not recovered spent a longer time on the ventilator in the TICU, had a longer length of ICU stay and total hospital stay. They were characterized by lower psychological and transplant specific well-being as well as a higher symptom burden.

The PGWB sum score was reported as good or above for all years except the fourth, where the median was 93.5 and 70% ($n=14$) reported poor psychological well-being. The PGWB sum score was also dichotomized into good psychological well-being (> 100), which was reported by 55.6% of the LuRs ($n=65$) and poor psychological well-being (<100), which was reported by 41% of the LuRs ($n=48$) 1-5 years post-transplant.

The most prevalent symptoms were tremor (66%), breathlessness (62%) and decreased libido (60%). The symptoms perceived as the most distressing were embarrassment about appearance, decreased libido and poor appetite. There was no or only a weak relationship identified between present lung-function (FEV_1 and BOS) and self-reported recovery and well-being.

Grounded Theory of Adaptation to a New Normality (Paper IV)

The interviews in Paper IV deepened the understanding of the grounded theory developed in Paper I. The core category in Paper IV, *Adaptation to a new normality*, described a process which contained three main categories; *Compare*, *Accept* and *Adjust*, which were used as strategies. Several sub-categories outlined in detail the strategies used to adapt to a new normality. A prerequisite for adapting to a new normality is an understanding on the part of the LuRs that their previous life no longer exists and that a new way of living requires adaptation.

The adaptation was enabled by the participants' acceptance of their current condition as well as their limitations, which was facilitated by comparing their present condition to life pre-transplant, leaving them with a feeling of improvement. The participants also compared their current condition to their health status in earlier post-transplant stages, resulting in satisfaction when progress was noticed. The participants used the

strategies to varying extents in line with the prevalence of symptoms and complications, while higher or lower degrees of adjustment were necessary depending on the symptom burden.

Adaptation was described as changing one's behaviour and everyday life to make them compatible with the new normality after a LuTx. The findings indicate that adaptation is a *process* during recovery as well as the *outcome* and goal in terms of achieving health, which occurred if the adaptation was perceived as successful by the participants. If the symptom burden was high and required many adjustments that restricted everyday life, the process of adaptation was difficult and a strong sense of illness emerged. The findings led to the conclusion that despite symptoms and complications LuRs can experience health by adapting to a new normality. However, a new normality was initially undefined by the participants. The adaptation process is individual, beginning post-transplant and continuing throughout life in conjunction with the experienced health status.

The overall understanding of recovery based on the result (Papers I-IV)

The purpose of merging the results is to demonstrate how these four papers complement each other, which common denominators they share and how in some sense they describe recovery after LuTx in a similar way although with different methods.

The overall understanding of the findings will demonstrate that;

- Recovery after a LuTx differs from recovery after general surgery. Many LuRs were only partly recovered and still had symptoms although they experienced health.
- From a patient perspective post-transplant life in terms of recovery is a process of adaptation to a new normality that enables health and well-being.

The experience of health despite not being fully recovered

Paper I demonstrates a health transition starting with illness pre-transplant and ending (in the study) one year afterwards with the experience of health, although the transition is probably an on-going process. The participants stated that they did not always feel recovered as they had many symptoms, side effects and complications but still experienced health. This is consistent with the results found in Papers II, III and IV. The new definition of post-transplant recovery states that the process involved a

transition with the goal of experiencing health and an optimum level of psychological well-being (Paper II). The findings in Paper III revealed that few LuRs perceived themselves fully recovered after one year (n= 2.8%) although psychological well-being, transplant specific well-being as well as general health were considered to be above or within the normal range. Thus, quantitative data confirm that it is possible to be partly recovered with the presence of symptoms and still experience good well-being and health. Moreover, the result in Paper IV showed that acceptance was a key strategy for the ability to adapt to a new normality, which involved accepting the fact that they would never recover fully and focusing on experiencing health instead.

Although it was possible to experience health despite the prevalence of symptoms and complications (Papers I and III), Paper IV revealed that a moderate or high degree of adjustment was often necessary three years after LuTx due to the symptoms. This led to challenges in the adaptation process and difficulties experiencing good health and well-being. The findings in Paper III are in line with this by demonstrating a deviation in both transplant specific well-being as well as psychological well-being during the fourth year. This might be a result of the high level of adjustment required due to severe symptoms, making it difficult to adapt and culminating in deteriorating health and well-being.

Breathlessness was experienced by 62% (n=69) of the LuRs and the need to rest due to breathlessness was experienced by 49% (n=55) 1-5 years after LuTx. Of those, 25% found this highly distressing (Paper III). In the interviews, the participants described breathlessness and the resulting need to rest as one of the symptoms that strongly affected their ability to perform daily occupations (Paper I). Many habitual adjustments were required due to breathlessness, which sometimes increased the symptom burden and made it difficult to adapt to a new normality, thus causing a feeling of illness (Paper IV). This finding reveals that breathing problems are still common post-LuTx and cause restrictions in everyday life. In addition to medical treatment and exercises with a physiotherapist, this demands self-management support from an occupational therapist in order to adjust and reconstruct daily occupations.

The illumination of the process of recovery as adaptation

The two grounded theories in Papers I and IV are intertwined. The grounded theory in Paper IV presented a comprehensive understanding of the overall main concern during recovery after LuTx, which was *Adaptation to a New Normality*. The theory deepened the understanding of the core category Reconstructing Daily Occupation in Paper I and further developed the grounded theory. During the first year, the participants' main focus was on Reconstructing Daily Occupation, although the underlying overall process was one of adaptation to a new normality. Thus, the new understanding recognizes the core of Reconstructing Daily Occupation as a detailed

description of one of the sub-categories in Paper IV, habitual adjustment, and actually describes how the LuRs adjust habitually during the first year in order to Adapt to a New Normality.

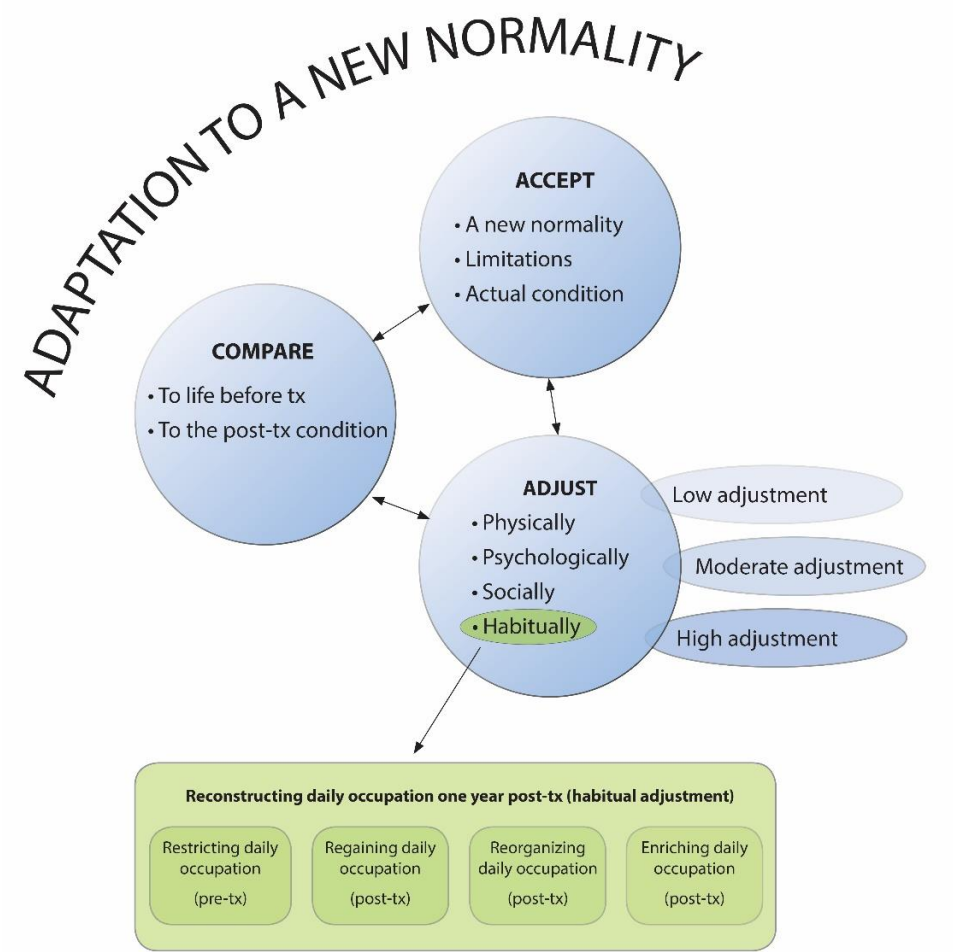


Figure 4. The process of Adaptation to a New Normality based on the overall understanding of Papers I and IV.

Figure 4 presented above differs somewhat from Figure 3 presented in Paper IV and will be described in the following section. The overall understanding in this thesis generates insights into how the strategies of Accept, Compare and Adjust used by the LuRs are related to each other. This understanding is described in the result section of Paper IV although not illustrated clearly in the figure presented in the paper. As stated in Paper IV, the LuRs used the strategies in order to adapt but to differing extents depending on their health status. The inter-relation between the strategies used was not linear in time but instead intertwined. The use of the strategies was related to the actual onset of various symptoms and experienced restrictions. Often the first strategy employed was acceptance of a certain symptom or restriction, which enabled the strategy of adjusting in different areas of life. The strategy of comparing was often used as a means of experiencing health when the comparison resulted in positive outcomes. However, as described above and in Figure 4, the strategies were often used simultaneously as well as back and forth depending on fluctuations in the health condition.

Paper IV describes the three different trajectories of low, moderate or high adjustment as starting one year post-transplant after the Enriching phase in the developed GT in Paper I. However, this should not be viewed as an absolute point in time but rather as illustrating the three possible trajectories of adjustment described by the LuRs at the three-year follow-up. A more accurate description is that the strategy of adjustment as well as the other strategies used start immediately post-transplant in the same way as the process of Adaptation. When high levels of adjustment were needed due to chronic rejection and symptoms, adaptation to a new normality was difficult and resulted in deteriorating health. This was experienced as returning to square one, i.e. the pretransplant period of illness and restricted daily occupations.

As already described, Paper IV provided an understanding of how adaptation to a new normality begins immediately post-transplant. The first year consists of extensive adjustment of daily occupations (Paper I), which occurs simultaneously with the adaptive process involving physical, psychological, social as well as habitual adjustments in the LuRs' lives. Several sub-categories in the grounded theory in Paper I (accepting, adjusting, adapting, comparing) involve strategies used by the participants to reconstruct daily occupations but which could actually be viewed as encompassing the strategies used for adaptation to a new normality described in Paper IV.

Adaptation to a new normality was based on the understanding that life after LuTx required a new way of living. Adaptation and especially adjustments were described by the participants as occurring in all areas of life, physically, psychologically, socially and habitually. This process is intertwined with the post-transplant recovery framework described in Paper II. The main dimensions in the framework of *physiological*, *psychological*, *social* and *habitual* recovery could be viewed as dimensions in which adjustments and adaptation occur. The emerging categories in the new transplant

specific framework, *symptom management*, *adjusting to physical restraints*, *emotional transition*, *achieving an optimum level of psychological well-being*, *social adaptation* and *reconstructing daily occupations* can all be considered different strategies for adjusting and adapting to a new normality. Further on in Paper II, critical junctures are presented as positive and negative factors affecting the post-transplant recovery. Some of these factors were also discussed by the participants three years later in Paper IV but as mediators of adaptation to a new normality, for example “comparing” and “expectations” as well as obstacles to adaptation such as “complications and setbacks”.

When adaptation to a new normality was successful from the participants’ own point of view, e.g., when the adjustment to symptoms and complications was acceptable, the experience of health and well-being was achieved. However, if optimal adaptation and adjustment was impossible due to the high prevalence of symptoms and restrictions, a profound sense of illness occurred (Paper IV). This result is consistent with the findings in Paper III. The LuRs who were not recovered, e.g., experienced numerous symptoms and restrictions in everyday life, reported lower transplant specific well-being and psychological well-being compared to those who were reasonably recovered. There was also a strong correlation between transplant specific well-being and recovery 1-5 years after LuTx ($r_s=0.741$) as well as between recovery and psychological well-being ($r_s= -0.720$).

The terminology used in the papers regarding the post-transplant period known as the recovery process has changed and evolved in conjunction with the increased understanding gained from each paper. After analysing the result from Paper I, the recovery process during the first year was understood as a health transition that continued beyond the first year. The result from Paper IV deepened the understanding of the recovery process and health transition by revealing that they actually constitute a process of adaptation. How the terminology of recovery, transition and adaptation should be viewed is not the primary focus of this thesis. However, one could argue that they are all parallel or similar processes. A successful transition is accomplished when distress is replaced by a sense of well-being and the mastering of a changed situation (Schumacher & Meleis, 1994). This is similar to Roy’s definition of a successful adaptation as an effective response to the changing environment where health can be experienced (Roy, 2009). In conclusion, the concepts share many similarities and in a sense describe the same thing, although a more comprehensive exploration which is beyond the scope of this thesis is needed in order to understand exactly how these terms and processes relate to each other.

To summarize the overall understanding, the findings reveal why it is of great importance for transplant professionals to change from focusing on the original meaning of the term recovery to instead focusing on how to facilitate the process of adaptation. The term recovery is widely used within healthcare but it might be less appropriate within the field of LuTx given the findings presented in Paper III as well

as the fact that during recovery the participants primarily focused on adaptation as a means of restoring health. Adaptation is a major part of the post-transplant period and should be the main focus when supporting self-management with the goal of facilitating health. Thus, the discussion will focus on how to facilitate adaptation as well as the essence of a new perspective on post-transplant management.

Discussion

Based on the understanding of the findings, the patient perspective on recovery will be illuminated with focus on the importance of adaptation. Adaptation is viewed as a self-management strategy, leading to the question of how healthcare professionals can use this new knowledge in post-transplant care when providing self-management support in order to restore health and optimize well-being.

The key findings in this thesis that will be discussed are;

- Few recipients perceived themselves as fully recovered 1-5 years post-transplant in terms of being symptom free, although it was possible to be partly recovered and experience good psychological well-being and general health (Papers I, III and IV). There was a strong relationship between recovery and well-being where decreased well-being is an area of concern (Paper III).
- There was no or only a weak relationship identified between lung function and perceived recovery as well as well-being (Paper III).
- Many LuRs experienced numerous symptoms (Papers I-IV) and a high symptom burden had a negative effect on the adaptation process (Paper IV).
- Everyday life and reconstructing daily occupation were important, especially during the first year. The term “new normality” was individually defined (Papers I and IV).
- Adaptation was used as a self-management strategy by the LuRs in their pursuit of health and overall well-being (Paper IV).

The relationship between recovery, symptoms, well-being and health

All four papers demonstrate the often demanding process occurring after a LuTx where very few LuRs ever perceive themselves as fully recovered and 28% were not recovered at all 1-5 years post-transplant. This might have consequences for whether it is reasonable to strive for full recovery, how recovery after LuTx should be defined as well as how it is possible to experience health and well-being despite numerous symptoms.

At the same time, the result demonstrated that a majority (69%) of the LuRs were fully, almost fully or partly recovered but still experienced good psychological well-being and general health 1-5 years post-transplant. This finding in combination with the described health transition occurring during the first year as well as the outcome of health through adaptation demonstrates the LuRs' remarkable ability to focus on and experience health. The LuRs' health perspective should be enhanced and emphasized as a self-management strategy by healthcare professionals.

In a study including 64 LuRs, positive psychological benefits and post-traumatic growth (PTG) were explored in a long-term perspective > 5 years after LuTx (Fox et al., 2014). According to existing theories, PTG develops in response to specific powerful life experiences and as a result of the struggle with highly challenging life crises (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004) such as before and after a LuTx. It can be manifested as, for example, an increased appreciation of life in general, an increased sense of personal strength or changed priorities (Tedeschi & Calhoun, 2004). The result of the study found that PTG exceeded levels observed in other chronic diseases, suggesting that LuTx uniquely generates positive psychological changes (Fox et al., 2014). This occurred despite physical and psychiatric morbidities (Fox et al., 2014) thus PTG might be a contributing factor that should be acknowledged when discussing the positive approach to and experience of health by the LuRs in this thesis.

Psychosocial aspects and decreased well-being post-transplant

There was a strong relationship between recovery and both psychological general well-being and transplant specific well-being. In Paper III, the result demonstrated good psychological well-being except in two cases, which should be highlighted as possible areas of concern. Firstly, during the fourth year, psychological well-being decreased with 70% (n=14) reporting poor psychological well-being. Secondly, the LuRs who were not recovered were characterized by lower psychological and transplant specific well-being, a longer time on a ventilator and a longer intensive care stay as well as a higher symptom burden. These results might be indicative of the crucial need for timely post-transplant support as well as the importance of identifying and focusing on those LuRs who are not recovered. The decreased psychological and transplant specific well-being might be a sign of depression and psychological distress and previous research has revealed that depression is a predictor of increased mortality (Dew et al., 2015; Smith et al., 2017) as well as morbidity (Rosenberger et al., 2016). This highlights the importance of identifying those who are slightly or not at all recovered in order to screen them for possible depression. However, given the findings in this thesis the focus should

not be on measuring the level of recovery but rather the symptom burden and well-being, which might affect the ability to adjust and adapt to a new normality.

In line with this, previous research demonstrates a correlation between psychological distress and the level of self-care agency, indicating the need to reduce psychological distress not only to improve well-being but also to enable self-management behaviours (Hu, Lingler, DeVito Dabbs et al., 2017), in this case the process of adaptation. Furthermore, the odds are three times greater that depressed patients will be non-adherent to treatment recommendations compared with non-depressed patients (DiMatteo et al., 2000). In addition, it is already recommended that healthcare professionals should evaluate the LuRs' psychological well-being and screen for depression (Dew & DiMartini, 2005; Dew et al., 2015). The identification of LuRs with a high symptom burden, decreased well-being and poor medical status might also serve as a point of departure for the change from timely self-management support to a focus on palliative care.

A study exploring psychosocial aspects before and up to two years after heart- or LuTx revealed that the recipients' coping ability and self-perceived health improved over time post-transplant, although in terms of HRQoL, depression and stress, LuRs recovered more slowly compared to heart recipients (Agren, Sjoberg, Ekmehag, Wiborg & Ivarsson, 2017). For example, the stress levels of LuRs were only comparable with those of the heart recipients after two years (Agren et al., 2017). Similar recovery trajectories have been found in another study where the perceptions of QoL of 199 lung- versus heart transplant recipients were longitudinally compared during the first year (Myaskovsky et al., 2006). Several QoL domains were higher among heart recipients shortly after transplant, while LuRs' QoL improved at a slower pace but was equivalent to that of the heart recipients after one year. However, on perceptions of general health, the LuRs had consistently poorer scores than heart recipients on all measurement occasions (Myaskovsky et al., 2006). This could be due to the fact that LuRs have higher rates of medical complications compared to heart recipients and their physical recovery is often of longer duration (Rosenberger, Dew, DiMartini, DeVito Dabbs & Yusen, 2012).

In a review including 73 studies, clinically meaningful and significant improvements were found in HRQoL after LuTx, which continued for up to one year post-transplant (Singer et al., 2013). When comparing with other solid organ recipients, the review suggested that LuRs may derive greater HRQoL benefit. This could be attributed to the extremely poor pre-operative HRQoL (Singer et al., 2013), which is supported by one of the results in this thesis where the adaption strategy of comparing the current situation to life pre-transplant resulted in a positive outcome. Nevertheless, when compared to population norms, the LuRs exhibited substantial residual impairments (Singer et al., 2013).

In another review of psychosocial issues facing LuTx candidates, LuRs and family caregivers, it was concluded that although transplantation may improve quality of life, physical functioning and psychiatric status, all LuRs do not experience the same degree of improvement nor as quickly as anticipated (Rosenberger et al., 2012). Many LuRs expect the transplant to restore health and QoL to a level comparable with that pre-illness. Instead, post-transplant life requires adjustment and coming to terms with the burden of medical illness and continued reliance on caregivers (Rosenberger et al., 2012). This is in line with the result of the present thesis. Patients' level of psychosocial outcomes often plateau and do not return to levels equivalent to those of the general population, although the review emphasizes the importance of supporting the often dramatic improvement in psychosocial status post-transplant by optimizing adherence, symptom management and preventing complications (Rosenberger et al., 2012).

The discrepancy between lung function and perceived well-being

To our surprise, there was no relationship identified between objective lung-function, e.g. FEV₁ and BOS, and self-reported recovery or well-being (Paper III). Medical parameters are often measured post-transplant but this suggests that objective parameters might not accurately represent the LuRs' experience of health. This discrepancy should be taken into consideration when designing post-transplant follow-up and emphasizes the importance of using self-report screening tools in addition to objective medical measurements. Despite their poor lung function, LuRs might perceive their health as good and their positive approach should be encouraged when providing self-management support. This also emphasizes the importance of including both the inside patient perspective and the outside professional perspective when assessing LuRs' chronic condition.

The importance of symptom management support

The importance of self-management support is evident given the psychosocial aspects, possible decreased well-being as well as the discrepancy between objective and subjective well-being. The results suggest that symptom management is an important area to target in order to reduce symptom burden, increase well-being and facilitate the process of adaptation. The grounded theory in Paper IV reveals that a high symptom burden with severe complications and limitations requires a high level of adjustment, making it difficult to adapt to a new normality. This in turn leads to deterioration in

health and decreased well-being, which is also supported by the findings in Paper III, hence highlighting the fact that supporting symptom management is of the utmost importance in order to reduce adjustment difficulties and thereby facilitate the process of adaptation.

As in this thesis, previous research shows that LuRs suffer from many different symptoms (Forsberg et al., 2012; Kugler et al., 2007; Kugler et al., 2009; Lanuza et al., 2012) as well as the fact that the most frequent symptoms were not always the most distressing ones (Lanuza et al., 2012; Lanuza et al., 1999). In our study trembling hands was the most frequently reported symptom, which was experienced by 66% of the LuRs. This is similar to another study including 287 LuRs where 70% reported tremor (Kugler et al., 2007). In the same study, Cushingoid appearance was reported as the most distressing symptom by 39% (experienced by 33%), which could be compared to the most distressing symptom in our study, namely feeling embarrassed by one's appearance and reported by 33% of those experiencing that symptom (experienced by 26%).

Comparisons between different studies should be understood in light of the fact that the results may vary depending on the choice of instruments, time since transplantation, type of LuTx (single/double), gender, age and immunosuppressive medications, which makes comparisons complicated. This might explain why some of the symptoms reported in our study were consistent with those in other studies, while some were not and several were not even measured in other studies.

Another newly published study including 117 LuRs at 1-5 years post-transplant from the SMATT project revealed high levels of fatigue as a prominent self-reported symptom with a strong relationship to both psychological and social well-being, requiring symptom management support (Forsberg, Lundmark, Kisch, Lennerling & Jakobsson, 2019). The LuRs with the most intense fatigue considered themselves to be only slightly recovered or not recovered at all. The more intense fatigue was associated with lower psychological well-being and also negatively related to impaired self-efficacy. The link between self-efficacy and self-management is well established and the ontological assumption is that a person's behaviour is changeable through specific external actions (Bandura, 1977). Symptom management with special focus on fatigue might be a target area for support and nursing interventions due to a high level of fatigue and impaired self-efficacy leading to a risk of reduced self-management ability (Forsberg et al., 2019). This result was not entirely consistent with the findings in Paper III, where fatigue was not reported as a specific problem. This could be due to methodological considerations where different instruments were used to evaluate fatigue, as the OTSWI is not designed to solely measure fatigue, which was the case in the reported study.

The term “new normality” and daily occupation

The term “new normality” is defined by the LuRs themselves based on experienced symptoms, complications and personal conditions, which is why person-centred care is essential. Our result demonstrates the importance of adjusting habitually by reconstructing daily occupations during the first year as part of adapting to a new normality. In a qualitative study exploring LuRs’ expectations of a supervised exercise rehabilitation programme, it was perceived as a highly valuable tool that assisted them to return to “normal life” and perform everyday activities (Fuller et al., 2014). Rehabilitation in terms of exercising was an important mechanism for achieving this (Fuller et al., 2014). The desire to return to normalcy has also been described in another qualitative study with the aim of describing the psychosocial process of the symptom experience associated with the threat of organ rejection after LuTx (De Vito Dabbs et al., 2004). With regard to the importance of reconstructing daily occupations, a qualitative study explored the experiences of everyday life after LuTx (Thomsen & Jensen, 2009). The result highlighted the need to address LuRs’ experience of gratitude, positive life orientation and support for their situation and daily life (Thomsen & Jensen, 2009).

In an interview study including 40 LuRs, the most frequently mentioned concerns during the first 6 months post-transplant were physical complaints, fear of organ rejection, side-effects of medication and restrictions in everyday life, although a majority experienced considerable improvements in physical health (Seiler et al., 2016). The result of the study described LuTx as a life changing event and a journey to relative normality that affected physical, psychological, social and behavioural aspects of the LuRs’ lives (Seiler et al., 2016), a result similar to that of this thesis. Furthermore, the authors conclude that adjusting to life post-transplant requires acceptance of medical illness and underscores the importance of support in decreasing symptoms and optimizing self-management strategies (Seiler et al., 2016).

The use of the term new normality has also been found in populations other than those within the context of transplantation. In a qualitative study illuminating patient experiences after a myocardial infarction it was found that when faced with a dramatic life event, most patients managed to achieve a new normality where their life changed but was still satisfying (Petricek, Buljan, Prljevic & Vrcic-Keglevic, 2017). During the process of adjustment, the patients’ state of normality changed and three main themes emerged; good adjustment – the new normality, maladjustment – a continuous search for the new normality and perceived needs in searching for the new normality. The adaption process was described as a convoluted path of trial and error (Petricek et al., 2017). Another qualitative study described partners’ and patients’ experiences of life in the first year after colorectal cancer surgery (Ohlsson-Nevo, Andershed, Nilsson & Anderzen-Carlsson, 2012). The interviews revealed one theme; “Life is back to normal

and yet not”, where the participants described living a normal but different life than before. The similarities of these results with the findings of the thesis suggest that adaptation to a new normality might be generic.

Adaptation as a self-management strategy post-transplant

The findings discussed above indicate that it is possible to be partly recovered with numerous symptoms and restrictions in everyday life but with the overall experience of good psychological well-being and general health. A plausible explanation of how the LuRs can experience health could be found by applying The Roy Adaptation Model. This section of the discussion presents a short summary of The Roy Adaptation model and explains how adaptation can be viewed as a self-management strategy. The findings pertaining to the LuRs’ experience of health and well-being will also be explored as an outcome of adaptation.

Summary of The Roy Adaptation Model

Adaptation is a key concept in Callista Roy’s theory, where adaptive “means that the human system has the capacity to adjust effectively to changes in the environment and, in turn, affects the environment.” (Andrews & Roy, 1986 p.22). Adaptation is described as a process of responding positively to environmental changes.

Key concepts in The Roy Adaptation Model are person, goal, health, environment and nursing activities (Andrews & Roy, 1986). The person is described as an adaptive system where human behaviour is viewed as the output of this system. Adaptive behaviour is evidence of an effective response to stimuli, while ineffective behaviour indicates concerns. A person’s behaviour is influenced by the surrounding environment, which is constituted by different focal, contextual or residual stimuli as well as the person’s ability to deal with these stimuli. Roy categorizes the person’s adaptive response to these stimuli in four different modes; physiological, self-concept, role function or interdependence (Andrews & Roy, 1986).

Health and well-being as an outcome of adaptation

In the context of LuTx, each LuR’s adaptation level is unique and constantly changing, representing her/his ability to cope with the changing environment in a positive manner. Roy views adaptation as both a process and a product or end-state (Roy, 2009), which is consistent with the findings in Paper IV. Adaptation to a new normality is described as a *process* where adjustments take place within physical, psychological, social

and habitual areas of life depending on the changing environment, e.g. symptoms, complications and restrictions. Adaptation is also described as a desired *outcome* in terms of making it possible to achieve health and well-being.

In the process of adaptation, stressors produce a reaction called stress, which triggers the use of coping behaviours to reduce or alleviate it. Depending on the ways of coping, adaptive or ineffective responses will be produced (Roy, 2009). An adaptive response will contribute to health whereas ineffective or maladaptive responses will not contribute to health (Roy, 2009). This reasoning is consistent with the overall understanding of the findings in Papers I, III and IV. The findings in Paper III where a majority of LuRs were reasonably recovered although symptoms were present, e.g. stressors, revealed that they had an overall experience of health, which might be a result of their adaptive response. This may also explain why LuRs suffering from a high symptom burden whose responses were ineffective lacked the experience of health.

Thus, in accordance with Roy's theory, all stimuli are part of the LuRs' environment, which comprises external and internal stimuli that act as stressors, serving as input and provoking a response (behaviour) (Andrews & Roy, 1986). How a person responds is a combination of both input stimuli and the level of adaptation. Focal stimuli are internal or external, which immediately confront a person and demand attention (Andrews & Roy, 1986), for example the symptoms experienced by LuRs. Contextual stimuli are all other stimuli present in the situation that contribute to the effect of the focal stimuli, for example the process of recovery, immunosuppressive medications, as well as the entire context and consequences inherent in living with a chronic condition such as after LuTx. Residual stimuli are general, vague or ambiguous factors that may affect a person's behaviour but their effects are not obvious and the person might not be aware of them (Andrews & Roy, 1986), for example prior experiences and coping strategies pre-transplant.

By applying Roy's model, LuRs respond to the changing environment by using innate or acquired coping mechanisms to maintain adaptation. The result revealed the key coping mechanisms used by the LuRs in order to maintain adaptation, namely Compare, Accept and Adjust (Paper IV). Stimuli and adaptation levels are input that activates the coping mechanisms, which act as controllers and assist a person in adapting to the environment.

In Roy's theory, the coping mechanisms produce behavioural responses relative to the four adaptive modes where the adaptation level can also be observed;

- physiological mode (how a person responds physically to stimuli from the environment)
- self-concept mode (psychological and spiritual aspects of a person)
- role function mode (the roles a person occupies in society)
- interdependence mode (focuses on interactions related to love, respect and value)

These four modes might be represented in the grounded theory by the four areas in which the LuRs adjust, physiologically, psychologically, socially and habitually (Paper IV).

The LuRs did not explicitly differentiate between “health” and “well-being”, which were often seen as intertwined and in the literature health is described as being central to the concept of well-being (Linton et al., 2016). If the experience of health increases so too does overall well-being. Why the LuRs managed to successfully adapt to a new normality and experience health and well-being might be partly explained by their pre-transplant illness as well as their self-management strategies of accepting and comparing in order to adjust. By constantly comparing their post-transplant experience with their pre-transplant severe illness and constant struggle to breathe, the fundamental difference was being able to breathe again. The comparison resulted in acceptance of their current situation and the formulation of realistic expectations. All four papers also revealed the LuRs’ remarkable ability to maintain a positive approach, which facilitated the process of adaptation and thereby the experience of health. This is a highly important self-management strategy that should be encouraged and supported by healthcare professionals. Focus should be on health promotion while emphasizing positive factors for adaptation in order to restore well-being and health.

Factors inhibiting or facilitating the adaptation process

Understanding which stimuli act as stressors and influence the LuRs’ post-transplant condition and situation as well as which factors facilitate the adaption process is vital. Such factors affect how a person perceives and responds to stimuli during the adaptation process after LuTx. Paper II reveals critical junctures affecting post-transplant recovery, which could be viewed as possible stressors. Examples of positive factors were physical exercise pre- and post-transplant, social support, a positive approach, no expectations and comparison with the pre-transplant condition. The LuRs’ early understanding of the fact that their old way of life was gone forever and that a new normality was necessary facilitated the adaptation process. Examples of negative factors were complications and setbacks, poor physical condition, fatigue and depression. These are concrete areas where transplant professionals can provide support by changing the LuRs’ own adaptation level to deal with challenges in everyday life in a positive way in order to enhance health and well-being. This reasoning is based on Roy’s theory, which states that a person, e.g., a LuR, is not passive in relation to her/his environment and challenges in everyday life, but instead an active participant interacting with the environment and formulating adaptive responses (Lutjens, 1991).

A clinical example of the use of Roy’s Adaptation Model can be found in the investigation of adaptation after liver transplantation (Ordin, Karayurt &

Wellard, 2013). Deductive content analysis was used and the findings indicated that the recipients needed information and support regarding their ineffective behaviour in all modes of The Roy Adaptation Model. The use of a nursing model when providing care for liver transplantation recipients was supported by the findings (Ordin et al., 2013). These findings might be transferrable to the context of LuTx.

Comprehensive understanding

The comprehensive understanding is based on the overall understanding of Papers I-IV as well as the Roy Adaptation Model, which provides a new perspective on recovery after LuTx.

A new perspective on recovery after lung transplantation

As stated in the overall understanding, recovery after LuTx differs from the original meaning of recovery in the sense of not regaining one's pre-transplant condition. The recovery process is actually a process of adaptation. Although the papers in this thesis focus on LuRs, other solid organ transplantations share many common denominators such as the life changing event, the new chronic condition inherent in transplantation, immunosuppressive treatment followed by symptom experiences, which is why these results might be transferrable to other transplant recipients.

The post-transplant definition in Paper II could be the foundation of a modified definition of the process of adaptation. Using the term adaptation instead of recovery after LuTx might be an important change of mind-set. The findings clearly state that full recovery is difficult to achieve and that the purpose of LuTx from a patient perspective is to experience health and well-being. For that reason healthcare professionals should consider focusing less on recovery in the sense of its original meaning of returning to the pre-transplant condition and instead recognize how recovery is perceived from a patient perspective where the focus is on adapting to a new normality.

Irrespective of whether a LuR experiences complications, symptoms and set-backs post-transplant, there is always a need to adapt to a new normality. A LuR who perceives her/himself as fully recovered without symptoms still needs to adjust her/his life in accordance with hygiene recommendations, immunosuppressive medications and the fact that a LuTx is considered a chronic condition. The question is just how much adjustment is required in order to adapt to the new normality. This is also why person-centred care is of the utmost importance post-transplant considering that "a new normality" is defined by the recipients themselves depending on personal circumstances and health status.

The further developed definition of post-transplant recovery might be;

“Post-transplant recovery after lung transplantation is a continuous process of adaptation to a new normality, involving a transition from pre-transplant severe illness to a state of experienced health and well-being, achieved by using the strategies of comparing, accepting and adjusting to a new normality, defined individually by each recipient. Essential parts of the adaptation process consist of symptom management, achieving an optimum level of psychological well-being, social adaptation and reconstructing daily occupations.”

Methodological considerations

The discussion regarding methodological considerations will address;

- Sample selection and participants
- Chosen methods and analysis
- How to ensure trustworthiness & validity

Sample selection and participants

Papers I, II and IV

The sample selection and participants are the same in Papers I, II and IV, although in Paper IV the data collection occurred two years after that in Papers I and II. Although the data in all three papers were analysed by different methods, it could be argued that the similarities in the findings are due to the same participants.

The advantages of performing a longitudinal GT study are the possibilities to follow the process of change over time and being able to gain a comprehensive understanding of the phenomena of interest. By performing follow-up interviews, the understanding of the process can be deepened by further exploring previously mentioned themes and experiences. At the same time, it must be acknowledged that the same informants are interviewed twice, albeit on two separate occasions. The fact that the statistical analysis performed in Paper III in some sense supports the theories in the qualitative studies regarding the possibility to experience health with the presence of symptoms should be viewed as a strength.

The sampling in the qualitative studies was performed according to the GTM and the consecutive sampling meant that more men than women were interviewed. When analysing the data there was no obvious difference in the narratives between men and women or due to age. When using the GTM and selecting informants it is important to find individuals who are proficient in verbal communication, reflective and willing to share their experiences rather than focusing on gender, age or ethnicity (Morse, 2011). The number of eligible LuRs is limited due to the relatively low number

of LuTx performed, which is why consecutive sampling was employed to capture potentially eligible informants. The consecutive sampling meant that some informants were less reflective and proficient in verbal communication than others, which is why the sampling continued until the analysis was completed in accordance with the GTM. A guiding principle in sampling is data saturation where sampling continues until no new information is obtained (Morse, 2011). The number of informants required to achieve saturation depends on several factors, for example, the broader the scope of the research question, the more informants are needed. Another factor is the quality of the data, e.g., how reflective and communicative the informants are regarding their experiences (Morse, 2011).

The data collection in accordance with the GTM as well as certain deviations from the recommendations are described in the Method section. The deviations were due to the clinical reality of a limited population of LuRs in Sweden as well as the need to prospectively follow the same LuRs in Papers I and IV. This is not believed to have led to any negative consequences for the developed grounded theories. When performing the analysis and the follow-up interviews three years post-transplant the number of included participants was believed to be sufficient to achieve saturation both in terms of the emerging core categories and the strategies employed.

One of the strengths throughout the thesis is the inclusion of LuRs from the only two transplantation centres in Sweden that perform LuTx. It is considered an advantage that LuRs from the whole country were selected and that not only one single centre, medical or caring tradition was reflected on. However, it should be acknowledged that the context, as well as the medical and post-transplant differences at each centre could affect the result and also its transferability to an international setting.

Fortunately only one LuR was lost at the second interview due to mortality. This provided the opportunity to follow the social process of change by means of adaptation in-depth.

As noted in Paper I and Paper II, the inclusion of participants is described somewhat differently. Due to the purpose of the study in Paper I, namely to perform a GT study, the sampling in accordance with the GTM was thoroughly described. As Paper II had a different purpose and method, the sampling was not described in the same way. However, it is clearly stated in Paper II that the data included were derived from another inductive study and the inclusion of informants ended when data saturation was achieved in accordance with the GTM used originally. The aim of Paper II was to re-analyse the interviews, which is why the description of the sample selection differs between the two papers.

Paper III

In terms of inclusion of participants in Paper III, the intention was to employ consecutive sampling. However, in reality all eligible informants were not included due to practical difficulties at the outpatient transplant clinic, which might have affected the sample in this paper. This loss of inclusion is considered missing at random and no further analysis of the sample was conducted. There is also an ethical aspect of performing an analysis of LuRs who were not included due to the fact that they did not consent to participate.

The exclusion of non-Swedish speaking and hospitalized LuRs in addition to the loss of informants due to transplant mortality resulted in a fairly small sample in the fifth year. The decision to exclude non-Swedish speaking LuRs was taken for practical reasons and the impossibility of providing an official interpreter to assist. When comparing the sample in Paper III with the broader LuTx population nationally and internationally, it is representative regarding type of LuTx (single/double), indications for transplantation, age etc.

As stated in the sample section of the qualitative studies, the number of eligible LuRs is limited due to the fact that relatively few transplantations are performed, which is also the reason for the inclusion of LuRs from both LuTx centres in Sweden.

The choice of methods and analysis

Preunderstanding during the analysis

In qualitative studies, the researchers themselves are the data collection instruments, which is the reason why their credibility should be considered in terms of preunderstanding and experience within the field. If this is not done the analytic process and trustworthiness might be affected (Polit & Beck, 2010).

The interviews generated personal reflection when my short-term perspective and experience as an intensive care nurse caring for LuRs did not match the participants' positive experience and feeling of well-being one year post-transplant. This was discussed continuously within the research group during the data collection and analysis. Although it is plausible that prior experience and preconceptions affected the interviews, efforts were made to ask open questions and let the participants lead the interviews. Researcher credibility was enhanced during the data analysis by constant self-reflection and awareness of possible prejudices and perspectives, which were discussed within the research group.

The participants were not dependent on me for their follow-up. I was not involved in their care nor had I any experience of post-transplant care outside of the TICU. The fact that my preunderstanding and clinical experience only concerned the early post-transplant period might have contributed to an open mind and enabled an inductive approach when asking about the participants' long-term experiences. My preunderstanding and experience of caring of LuRs was sometimes acknowledged by the participants and facilitated the encounter with them.

Papers I & IV

In order to understand and obtain a holistic and comprehensive picture of life after LuTx, an inductive, qualitative method seemed to be the most relevant choice in Papers I and IV. One assumption based on clinical experience was that a process occurred during the first year and when combined with the specific aim of investigating the LuRs' main concerns and how they dealt with them it made GT appear to be an appropriate method. We also wanted to investigate how the main concerns and strategies used by the LuRs evolve over time, which is why a longitudinal prospective design was chosen for Paper IV with the analysis by means of the GTM.

When asking the participants to describe previous experiences and thoughts there is always a risk of recall bias. However, LuTx was considered to be a major life-changing event and therefore remembered with ease. The participants described many events in great detail even though one or two years had passed.

A potential bias was acknowledged when performing the analysis in Paper IV due to the fact that previously developed theories and concepts in Paper I might direct the further analysis. This is why the Constructivist GTM used in Papers I & IV was chosen because it considers the research context and pre-understanding. Glaser (2010), who advocates classic GT, argues that previously known concepts might hamper the researchers' ability to develop new concepts and theories. However, Hallberg (2010) states that the importance lies in not being consciously directed by earlier theories and furthermore adds that in order to think conceptually, a prerequisite is to continually read the literature within the area and become immersed in previously developed theories and concepts. Efforts were made to ensure that the theories developed were truly grounded in the data by writing memos and by using the comparative method. This was done by repeatedly reading and analysing the material, discussing possible main concerns and categories within the research group as well as in some cases validating the theories with the participants. This final step confirmed the relevance of the theories to the LuRs.

Paper II

A deductive qualitative method was chosen in Paper II. After analysing the interview data in Paper I, some data were not included in the developed grounded theory. Descriptive, qualitative studies offer new ways of approaching previously collected data (Polit & Beck, 2010), which is why a second analysis was performed on the data from Paper I. The participants' narrative involved the concept of recovery to a great extent and the decision was made to re-analyse the dataset. However, it is not possible to be inductive twice, thus another qualitative method was chosen, directed content analysis. The use of directed content analysis in Paper II has some inherent limitations, as when analysing the result the researchers should be aware of a possible bias where it might be more likely to find supportive evidence for a theory rather than non-supportive (Hsieh & Shannon, 2005). This was reflected upon and acknowledged by the researcher but the use of directed content analysis for post-operative recovery ensured that significant parts of the post-transplant recovery process were illuminated. In the result in Paper II it is also stated that some parts of the original concept analysis could not be used in the context of LuTx. A strength when using directed content analysis is that a theory can be further developed in another context than that for which it was originally intended.

Paper III

In Paper III, a quantitative cross-sectional design was chosen. The previous qualitative studies provided us with a deeper understanding of life after LuTx, which required further explanations by means of quantitative methods. The use of a cross-sectional design has some inherent limitations as well as strengths that must be considered when performing the analysis. For example, it prevents the determination of any causal relationships, there is a risk of sampling biases and no timeline is shown among the variables of interest (Kazdin, 2014). Although correlations can be demonstrated, the direction or possible causal relationships cannot be determined. However, the advantages of a cross-sectional design are the efficiencies in terms of resources and time, no attrition due to assessment at one point in time and the possibility to study the magnitude and type of relationships among the variables. (Kazdin, 2014). For these reasons a cross-sectional study was performed despite the above-mentioned limitations, to be used as a first step to comprehend what relationships exist, to explore the well-being of the LuRs and to understand which symptoms should be further investigated. The next step, which is on-going in the SMATT project and outside of this thesis, is to prospectively and longitudinally explore over five years how recovery, well-being and symptoms evolve over time after a LuTx.

The difficulties in measuring a process such as recovery or symptoms that change over time should be acknowledged. Nevertheless, it is believed that a cross-sectional

explorative design is valuable as a first step and can provide knowledge about the health status at certain points in time after LuTx.

Non-parametric analyses were mainly performed due to the nature of the sample (ordinal data). When analysing the findings, results from the different instruments are presented both at group level for all 117 LuRs one to five years post-transplant as well as yearly in some cases. The findings in Paper III could have been presented in a more structured way and the sometimes unclear description of whether the analysis concerned the whole population one to five years post-transplant or on a yearly basis is considered a limitation.

The use of non-parametric statistics made it possible to analyse fairly small samples on a yearly basis. The decision to differentiate some of the result by year was made in order to scrutinize recovery, symptoms (by means of the OTSWI sum score) and well-being after, for example, one year and three years given that the qualitative findings were based on these time points. Instead of presenting all 20 symptoms measured by the OTSWI each year (which would have provided an overload of data to the reader) it was decided to instead analyse the OTSWI sum score on a yearly basis. A second purpose of analysing the data each year was to explore if any particular year post-transplant strongly deviated in terms of the explored outcome measures. When performing analysis at group level one to five years post-transplant, it was possible to explore the proportions of the perceived level of recovery. However, it was not possible to explore the trajectory of the recovery process or the time point at which the onset of rejection occurred, causing symptoms and restrictions in everyday life that would be measured by the PRP instrument. Having said that, the instruments in the study measure self-reported symptoms, well-being and recovery but whether the origin of these symptoms and restrictions in everyday life stems from not being recovered after the transplantation, the onset of chronic rejection or side-effects from the immunosuppressive medication is unclear. However, this was not the primary purpose of the study given the chosen cross-sectional design.

When analysing the LuRs' level of perceived recovery it should be noted that in order to be fully recovered, the number of none responses must be 19/19. This means that there can be no experienced symptoms at all and no limitations in everyday life, which might be considered a very high standard to achieve and should be considered when discussing the fact that so few LuRs were fully recovered.

Besides analysing recovery, symptoms and well-being as stated in the aim of the study, several additional parameters were also explored, although in relation to the posed research question. Some of the standard evaluation parameters in transplant medicine are time on a ventilator, length of ICU stay and time in hospital. Standard measures of graft functions are FEV₁ and grade of chronic rejection measured by BOS, thus we chose to explore self-perceived recovery, symptoms and well-being in relation to the so-called objective markers of graft function. Although the cross-sectional design prevents

us from exploring any casual relationship, it was still believed to be valuable to state whether there were any relationships between these parameters. The overall purpose of this thesis is to measure how the LuRs themselves perceive their recovery, symptoms and well-being, which is why self-report questionnaires were used. However, as self-report instruments are rarely used in post-transplant follow-up care while objective medical parameters are measured, it is of clinical value to explore whether well-being and symptoms experienced by the LuRs are consistent with the standard parameters that are actually measured.

The data were partly dichotomized into different groups such as levels of recovery, age and length of ICU stay. These dichotomizations were based on clinical experience as well as how the data emerged. The mean age in the sample was close to 50 years, which is why it was decided to divide the sample into two groups, older and younger than 50 years. A length of ICU stay of longer than one week is clinically regarded as a more complicated course of events. Thus, the length of the ICU stay was divided into longer or shorter than seven days. The dichotomization of recovery into two groups instead of five was deemed useful based on clinical relevance and also to obtain a clearer description of the proportions between reasonably recovered LuRs and those not recovered at all.

When analysing quantitative results and testing various hypotheses two different errors can occur (Pallant, 2016). *Type I error* refers to the rejection of the null hypothesis when it is in fact true and occurs when it is believed that there is a difference between groups but in reality there is none. This possibility was minimized in Paper III by selecting an appropriate alpha level, in this case 0.05. The numbers of analyses performed and hypotheses tested were also carefully considered before analysing the data in order to avoid Type I error. *Type 2 error* occurs when the null hypothesis is not rejected when in fact it is false, i.e. believing that groups do not differ when in fact they do (Pallant, 2016).

How to ensure trustworthiness and validity

There are several issues when it comes to the terminology surrounding the quality of qualitative studies (Polit & Beck, 2010). Some believe that rigor and validity are appropriate in qualitative studies, while others argue that these are quantitative terms (Polit & Beck, 2010). The following discussion of qualitative studies and the GTM will be based on Lincoln and Guba (1985) as well as Charmaz (2014). Paper III will be discussed in terms of reliability and validity.

Qualitative studies (Papers I, II & IV)

In order to develop trustworthiness throughout the qualitative studies, four criteria were used and reflected upon; *credibility*, *dependability*, *confirmability* and *transferability* as suggested by Lincoln and Guba (1985) (Polit & Beck 2010).

Credibility is viewed as an overriding goal and refers to confidence in the truth and interpretation of the data. To achieve credibility, a broad perspective was captured by interviewing LuRs with explicit experience of the research question, namely the recovery process after LuTx. The analysis of the interviews was initially performed partly independently by M.L, who conducted the interviews, as well as by the main supervisor. The final analysis was then conducted in collaboration with and discussed by the research group. In order to enable the reader to judge credibility, the findings were illustrated by quotations. The grounded theory developed in Paper I was confirmed by four validation interviews, which also ensured the credibility of the result. The grounded theory in Paper I was later confirmed by the follow-up interview performed two years later. Credibility also concerns whether there is sufficient data to answer the research question, where information about the mean time of the interviews as well as the number of participants included can guide the reader in judging credibility.

Dependability refers to the stability of data over time and conditions. Dependability was achieved by discussing how to interpret the result within the research team and reflecting on possible alternative outcomes. All of the interviews were performed by the same person and efforts were made during the interviews to ensure that the meaning of questions and answers was captured accurately by discussing it with the participants. It is believed that the findings of the studies could be replicated if the inquiry was repeated within the same context but at a different time.

Confirmability refers to objectivity, i.e. the potential for congruence between two or more independent people about the accuracy, relevance or meaning of the data. This was achieved by making sure that the analysis reflected the participants' voices, was grounded in the data and in Paper II by comparing the data from the original concept analysis with the interview data. Discussions within the research group regarding the analysis, categorisation and interpretation of the results took place throughout the process and consensus was achieved. When performing the interviews one year post-transplant, there was no intention to deductively use the concept analysis by Allvin et al. (2007) in Paper II. This was decided at the end of the process of developing the grounded theory in Paper I and might enhance the conformability of the studies.

Transferability refers to the extent to which qualitative findings can be transferred to other settings or groups. As previously stated, the qualitative findings are based on the same participants, which should be acknowledged when discussing transferability. However, given that the recruitment of the sample was performed on two different

occasions, varying methods were used to analyse the data and the theories developed are believed to be grounded in the data, the findings should be transfereable. Due to the implicit chronic condition inherent in LuTx as well as the immunosuppressive treatment, the findings should also be transferrable to a broader population of LuRs both nationally and internationally as well as possibly other solid organ recipients. By interviewing LuRs from both transplant centres in Sweden, a broad perspective of the recovery process was captured and possibly not influenced by the medical or caring treatments and strategies of a single centre. Transferability was also ensured by providing a description of the study context as well as the inclusion and exclusion criteria.

Authenticity is a concept related to developing trustworthiness and refers to the extent to which the researchers present a fair range of different realities (Polit & Beck, 2010). The authenticity was partly strengthened due to the statistics in Paper III, which to some degree confirmed the grounded theory in Papers I & IV. In Paper I, the final theoretical construct was not confirmed by all of the participants, although confirmation of the theory was evident during the follow-up interviews performed in Paper IV three years post-transplant.

When evaluating a grounded theory, *originality*, *resonance* and *usefulness* might be considered in addition to credibility (Charmaz, 2014). Originality was evident given that the grounded theories developed demonstrated a new perspective on post-transplant recovery and provided new insights from a patient perspective. Resonance was ensured by presenting the grounded theory to the participants to ascertain that it made sense to them. The analysis also offered a deeper insight into how the participants were able to experience health post-transplant by means of adaptation. The usefulness of the grounded theories has been substantial in changing the post-transplant follow-up to include an occupational therapist as well as providing healthcare professionals with important strategies for how to provide self-management support. A strong combination of originality and credibility increases the resonance, usefulness and overall contribution of the theory (Charmaz, 2014). A grounded theory that conceptualizes and conveys what is important is considered a valuable contribution (Charmaz, 2014).

The fact that how the strategies in the developed GT in Paper IV were inter-related was not visualised in the figure in the paper could be regarded as a limitation. However, how these strategies were used simultaneously was described in the result and the new Figure 4 in this thesis might be considered more distinct in conveying this information. As previously stated, a GT is not static and can thus be further developed and changed when new data and understanding emerge, which do not necessarily have to be based solely on interviews.

Reliability and validity in quantitative research (Paper III)

Reliability and validity are major terms used within quantitative research, where reliability refers to the degree of consistency with which an instrument measures an attribute (Polit & Beck, 2010). Validity assesses the degree to which an instrument measures what it is intended to measure and important aspects are face validity, content validity, criterion-related validity and construct validity (Polit & Beck, 2010).

The psychometric properties of the instruments have been described earlier in the Method section. The choice of using a combination of both generic instruments (PRP and PGWB) as well as a transplant-specific instrument (OTSWI) in the study is considered a strength. The OTSWI is designed to specifically capture common and relevant symptoms after transplantation. Both the PRP and the OTSWI are constructed to measure PRO and were used to obtain the patient perspective. Furthermore, the PRP and OTSWI were constructed and tested in a Swedish population, as were the norm-values in the PGWB instrument.

When discussing the validity of the study, there could be selection bias due to our exclusion of non-Swedish speaking, hospitalized LuRs and the loss of informants due to transplant mortality, which resulted in a fairly small sample in the fifth year. However, mortality reflects the clinical reality and the survival rates after LuTx. Furthermore, LuRs in poor medical condition might not have been included, although given the findings where 28% were not recovered at all one to five years post-transplant it can be assumed that many LuRs in poor medical condition did participate. A possible threat to internal validity was discovered when some LuRs were included twice although in different follow-up years and two were both heart- and LuRs and should not have been included at all. These participants were removed from the database, thus the findings were not affected.

When generalising our result, the selection bias described above should be taken into account. In addition, the context of medical care, follow-up care and immuno-suppressive treatment should also be considered as they might vary internationally and affect the prevalence of symptoms and well-being. It could be argued that the cross-sectional inclusion of LuRs one to five years post-transplant might be affected by changes in the medical treatment or follow-up care during the timeframe. The inclusion of participants from two transplant centers minimizes this concern as well as the relatively short timeframe of five years where the follow-up care from a clinical point of view has not changed notably. However, despite these concerns it should be possible to generalize the findings from Paper III to a broader LuTx population, both nationally and internationally. One aspect of a study's external validity concerns the adequacy of the sampling, as the generalizability of the result is enhanced if the characteristics of the sample are representative of the population (Polit & Beck, 2010). When studying the demographics and characteristics of the sample in Paper III it was considered

representative of the broader population. For example, our sample consisted of 85% double LuTx and in Sweden double LuTx constituted 84% of all LuTx surgery in 2018 (OFO, 2019), while the equivalent Scandinavian statistic was 90% double LuTx (Scandiatransplant, 2019). Furthermore, demographics such as indications for transplantation and mean age were similar to the international situation as our sample was 50/50 in terms of the proportion of male and female LuRs, while internationally 56% of LuRs were men in the period 1995-2017 (ISHLT, 2018).

Another strength of the study is that no contact between the participants and the researchers occurred during the recruitment process, which minimized possible influence. The recruitment was instead carried out by clinical nurses at the outpatient clinics. As in all clinical research, there is a risk that they unintentionally selected suitable LuRs. However, despite stringent instructions to the nurses, that part of the research process was beyond the researchers' control.

Conclusion

In conclusion, this thesis contributes an increased understanding of the post-transplant recovery process after LuTx, identified as a process of adaptation. Important health and illness trajectories have been revealed, which demonstrates the LuRs' highly developed ability to adapt to a new normality, a process that begins immediately post-transplant and continues thereafter. When the adaptation is perceived as successful, it enhances health and well-being although when optimal adaptation is not possible due to too many symptoms or restrictions, there is a strong sense of illness.

Recovery after LuTx differs from that after general surgery in the sense of not desiring to regain one's pre-transplant condition and also due to the implicit chronic condition and immunosuppressive treatment. Consequently, irrespective of whether a LuR experiences complications and symptoms post-transplant, adaptation to a new normality is a necessity. When caring for LuRs, use of the term adaptation instead of recovery post-transplant might signal an important change of mind-set to the recipients. The strategy of adjusting expectations of post-transplant life in line with the LuRs' actual health condition is crucial and facilitates the process of adaptation. Adjusting and balancing expectations as well as discussing adaptation to a new normality is a process that should be initiated even before the actual transplantation as a preparation for post-transplant life

A new post-transplant framework and definition of post-transplant recovery have been developed for use by healthcare professionals in follow-up care. Few LuRs recover fully and a low degree of recovery and high symptom distress might be a marker of impaired well-being and health. For this reason the focus of transplant nursing should be on both health management by means of supporting the process of adaptation as well as identifying those LuRs in need of increased support and interventions. Given the finding that the most prevalent symptoms were not always perceived as the most distressing ones as well as the discrepancy between objective lung function and perceived well-being, the importance of self-reported measurements of symptom frequency, symptom burden and well-being is evident.

Each LuR's adaptation level is unique and constantly changing, where her/his approach to goal setting might be an important cornerstone for achieving health. An understanding of the importance of person-centred care is also essential due to the fact that the new normality is based on personal circumstances. Essential strategies used by

LuRs to adapt to a new normality and experience health have been identified. Understanding this and which stimuli act as stressors or facilitate the process of adaptation are key elements of health promotion after LuTx as well as for providing self-management support.

Clinical implications

The patient perspective on recovery after LuTx in this thesis provides healthcare professionals with clinical implications regarding how post-transplant follow up could be designed and areas of importance for self-management support. The following clinical implications are suggested and will be described below;

- Post-transplant follow-up based on the inside perspective
- The inclusion of an occupational therapist in the transplant team
- The importance of implementing self-report screening tools
- How transplant nurses can support adaptation as a self-management strategy

Post-transplant follow-up based on the inside perspective

In order to design post-transplant follow-up, the purpose of post-transplant recovery as well as how this can be achieved should be considered. The findings provides healthcare professionals with a unique insight into how LuRs themselves perceive their recovery and thereby which areas should be in focus when designing post-transplant care. The findings show that supporting the process of adaptation in order to enhance health and well-being is of the utmost importance to the LuRs. This process should be initiated in the pre-transplant period in discussions with potential recipients regarding expectations and the actual reality that LuRs might face afterwards. The information provided pre-transplant should include details of the implicit chronic condition following LuTx, the importance of adjusting expectations and how the post-transplant period can be viewed as a process of adaptation to a new normality.

Healthcare professionals as well as LuRs must recognize that LuTx is a chronic condition and therefore the post-transplant follow-up as well as self-management support should be designed accordingly. The care provided should be research-based but also acknowledge the LuRs' own complementary knowledge concerning their chronic condition, health and response to treatment and interventions.

In a study of healthcare professional support for self-care management in chronic illness, it is stated in the clinical implications that the illness experience trajectory must be understood in order to provide support (Thorne & Paterson, 2001). The most critical knowledge comes from the patients themselves in terms of bodily responses and

the findings challenge the traditional compliance models of chronic disease education. In addition, the authors emphasize the importance of long-term partnerships in which healthcare professionals can guide patients towards skill development (Thorne & Paterson, 2001).

As also stated in the Conclusion section, it is essential to change the existing mindset from a focus on recovery post-transplant to one of adaptation to a new normality, a process that should be initiated when discussing the option of Tx with a potential candidate.

The inclusion of an occupational therapist in the transplant team

Due to the extensive need for adjustments in all areas of life demonstrated in Paper IV, post-transplant follow-up should consist of a multi-professional team with the overall aim of supporting the process of adaptation. The result from Paper I emphasizes the importance of including an occupational therapist in the transplant team with the aim of supporting habitual adjustments and changing occupational patterns. Furthermore, a psychologist or psychiatrist might support LuRs to adjust psychologically and a physiotherapist and a physician with specific competence in the area of Tx should also be included. This multi-professional team should preferably be led by a transplant nurse in charge of planning nursing interventions as well as support in targeted areas of interest. Specially trained transplant nurses have proven to be key players in the management and coordination of care for chronically ill patients in order to improve health outcomes (Busse, Blümel, Scheller-Kreinsen & Annette Zentner, 2010).

The interaction and communication between the transplant team and the LuR is crucial for promoting self-management and well-being. The use of a mobile application for organ recipients enables communication with the transplant team and facilitates an extensive platform of knowledge and self-management support. This might be an optimal tool in addition to the face-to-face caring encounter with the transplant team. Such a tool has now been implemented within Swedish transplant care.

The American Nurses' Association and International Transplant Nurses' Society define transplant nursing practice as; "Specialized nursing care focused on the protection, promotion and optimization of the health and abilities of both the transplant recipient and the living donor across the life span" (ANA & ITNS, 2009). This thesis provides transplant nurses with a possible approach for how to promote and optimize health after LuTx by supporting the process of adaptation.

The importance of implementing self-report screening tools

The findings in this thesis suggest the need for changes in follow-up care such as systematic measurement of symptoms and symptom burden, well-being and possible levels of adaptation. In order to support the process of adaptation within all areas of life, the first step is to map out where the greatest need of self-management support lies. This can preferably be accomplished by self-report screening tools in order to comprehend when and in which areas nursing interventions and support are necessary. It is vital to evaluate which stimuli and behaviours act as stressors and negatively influence the post-transplant condition, as well as to understand facilitating factors. According to the findings, symptom management and adaptation to symptoms and restrictions in everyday life are of great importance to the LuRs. Other areas of concern include psychological adaptation involving an emotional transition.

In 2014, the National Institute of Health in the US started a large measurement project, The Patient-Reported Outcome Measurement Information System (PROMIS) with the aim of providing clinicians and researchers with efficient and valid measures of health and well-being (Health, 2019). The Psychological Adaptation Scale (PAS) is a validated tool where four domains of adaptation were identified and items were selected from the PROMIS “positive illness impact” data bank (Biesecker et al., 2013). The intention of the PAS is to evaluate and facilitate comparisons of adaptation across conditions, for example in prospective studies that aim to enhance coping efficacy in chronic conditions. The tool can also generate understanding of the relationship between health outcomes such as QoL and psychological well-being (Biesecker et al., 2013).

The 15-item Coping and Adaptation Processing Scale (CAPS) – Short Form is another tool that effectively measures coping and adaptation (Roy, Bakan, Li & Nguyen, 2016). It can be used in both research and clinical practice for patients with chronic and acute health conditions (Roy et al., 2016).

The screening tools should be used during the entire post-transplant period due to the fact that many LuRs experienced a high symptom burden and decreased well-being after four years (Paper III). It is also plausible that many LuRs experience an increased symptom-burden and psychological distress in the long-term when graft rejection begins. Furthermore, it is necessary for transplant professionals to comprehend the point at which self-management support should be replaced by a focus on palliative care.

How transplant nurses can support adaptation as a self-management strategy

Understanding the three different adjustment trajectories required by LuRs in order to adapt to a new normality can enable self-management support as well as individually

tailored interventions. When supporting LuRs in their process of adaptation, transplant professionals can use the key concept of nursing activities described as the nursing process. These consist of six steps; *assessment of behaviour*, *assessment of stimuli*, *nursing diagnosis*, *goal setting*, *intervention* and *evaluation* (Andrews & Roy, 1986).

When assessing adaptive behaviour, the use of self-report screening tools might provide a first indication of possible areas of concern as well as specific stimuli and stressors that demand further interventions or support from transplant professionals. LuRs' behaviour as well as adherence to self-management regimes might serve as an indicator of how well they are adapting or managing to cope with changes in their health status. However, our results also reveal that LuRs' ability to adapt depends on the levels of adjustment required and that successful adaptation is determined by the individual in terms of the desired health outcome and well-being.

To summarize, the clinical implications state that post-transplant follow-up should consist of health management by means of supporting the process of adaptation, symptom management and identification of those LuRs in need of increased support. The multi-professional transplant team should include an occupational therapist and be led by a transplant nurse in charge of nursing interventions. Self-report screening tools should be employed post-transplant. Person-centred care should be mandatory, due to the knowledge that the new normality is based on personal circumstances.

Future research

The following areas are proposed for future research;

- Prospective long-term studies are of importance and currently ongoing within the SMATT project in order to explore the post-transplant trajectory in terms of symptoms, well-being and health in addition to identifying predictors of both a complicated and a more straightforward course. This might reveal the point at which early interventions are crucial as well as which areas transplant professionals should focus on.
- An initial post-transplant management regime should be implemented in the ICU. Special focus should be placed on prospective studies of if and how the length of time on the ventilator and in the ICU affects LuRs' long-term well-being, health and occurrence of symptoms. If factors during the ICU stay are found to have a long-term effect, early interventions by nurses such as respiratory care, non-invasive ventilator treatment, early tracheal extubation and mobilization should be explored to establish whether they might have an effect on long-term outcome.
- Due to the knowledge of the huge impact of symptoms on adaptation and self-management ability, intervention studies on symptom management are vital. Can interventions and symptom management support increase well-being and health in addition to reducing psychological distress?
- This thesis highlights the complexity of the concept of recovery and the need for new theoretical frameworks in the context of Tx. Further research is needed on changing the post-transplant focus from recovery in its original sense to exploring rehabilitation medicine in terms of adaptation as a post-transplant strategy.
- Finally, the developed grounded theories need to be tested psychometrically to evaluate the relevance of each concept.

Summary in Swedish/Sammanfattning på svenska

Avhandlingen består av fyra publicerade delarbeten och har den svenska titeln: Återhämtning efter lungtransplantation – Adaption till en ny normalitet

Transplantation av lungor är idag en etablerad behandlingsform vid svår lungsjukdom och organskada och genomförs som en sista behandlingsmöjlighet då all annan medicinsk behandling är utförd. Utan en transplantation hade den drabbade personen annars avlidit inom ett till två år. De vanligaste orsakerna till lungtransplantation är cystisk fibros, lungfibros och kronisk obstruktiv lungsjukdom (KOL). Operations-teknik, medicinsk utveckling och omhändertagandet efteråt har succesivt förbättrats, de största hoten mot överlevnad är akut eller kronisk avstötning samt primär dysfunktion av transplantatet. Idag, 2019 överlever i Sverige omkring 88 % av patienterna ett år efter lungtransplantation, 65 % efter 5 år och efter 10 år lever 50 %. Av lika stor vikt är dock hur kvaliteten på det liv man överlever till ser ut och där det idag finns stora förväntningar på delaktighet i vård och behandling av dem som mottar organ.

En lungtransplantation och livet som följer efteråt räknas som ett kroniskt sjukdomstillstånd med livslång immundämpande läkemedelsbehandling för att undvika avstötning av organet. Denna läkemedelsbehandling är nödvändig men medför samtidigt en mängd olika biverkningar och följsjukdomar som ger symptom och som kan minska välbefinnandet hos lungmottagaren. Förutom livslång medicinering krävs också att mottagaren av organet följer olika rekommendationer och behandlingar från sjukvården såsom riktlinjer för kost och motion, olika hygienrestriktioner på grund av infektionskänslighet samt undvikande av sol, alkohol-intag, vissa miljöer, resor etc.

Termen self-management refererar till hur den transplanterade personen hanterar sitt liv, följsamhet till ovanstående riktlinjer men också psykologiskt och socialt bemästrande av livet som transplanterad.

Vi vet idag inte hur self-management påverkas av postoperativ återhämtning eller upplevda symtom och välbefinnande. För thoraxtransplanterade patienter i Sverige är detta i princip outforskat och internationellt är tidigare forskning sparsam. För att

kunna rikta vårdinsatser och skapa uppföljningsprogram krävs systematiskt och vetenskapligt framtagna kunskap som kan bidra till en djupare förståelse för thoraxtransplanterade patienters self-management vilket är avgörande för stabilt goda långtidsresultat.

Det övergripande syftet med avhandlingen är att från ett patientperspektiv utforska, förstå och förklara återhämtningsprocessen, symptom och välbefinnande efter en lungtransplantation.

Artikel I genomfördes med hjälp av vårdvetenskaplig grundforskning där syftet var att undersöka vad som var viktigast för lungmottagare under det första året samt vilka strategier de använde för att hantera de utmaningar som följde med transplantationen. Femton lungtransplanterade personer från Lund och Göteborg intervjuades och materialet analyserades med *Grounded Theory Method*. Resultatet visar ett teoretiskt ramverk där vikten av att återuppbygga sitt vardagsliv, *Reconstructing Daily Occupation*, betonades. Vidare beskrivs en process där lungmottagarna upplevde en bra hälsa efter ett år trots förekomst av symptom och biverkningar från själva operationen men också den immundämpande läkemedelsbehandlingen. Dessa symptom och biverkningar ledde ofta till begränsningar i det dagliga livet där lungmottagarna återtog, omorganiserade och återuppbyggde sitt dagliga liv beroende på sina omständigheter. Resultatet har fått kliniska implikationer i form av förståelsen av vikten att inkludera en arbetsterapeut i transplantationsteamet för att stödja de lungtransplanterade i denna process.

Artikel II utgör en fördjupning av vad återhämtning är efter en lungtransplantation där ett nytt ramverk utvecklades med nya definitioner och begrepp. Materialet bestod av samma intervjuer som användes i artikel I men analyserades med hjälp av innehållsanalys. En tidigare gjord begreppsanalys angående postoperativ återhämtning efter allmän kirurgi användes som mall och jämfördes med hur lungtransplanterade personer upplevde sin återhämtning. Resultatet visade att återhämtning efter en lungtransplantation skiljer sig åt på flera plan jämfört med återhämtning efter annan kirurgi, således vidareutvecklades den tidigare begreppsanalysen och anpassades till en transplantationskontext. Det nya framtagna ramverket visar att återhämtning sker inom fyra olika dimensioner, fysiskt, psykologiskt, socialt och habituellt med målet att uppleva hälsa. Områden av särskild vikt var att hantera sina symptom, anpassa sig efter fysiska begränsningar, emotionell transition, att uppnå ett optimalt välbefinnande, social adaption samt att återuppbygga sitt vardagsliv. I artikeln föreslås också en ny definition på vad återhämtning efter lungtransplantation innebär.

Artikel III är kvantitativ i sin design och där studerades återhämtning, symptom och välbefinnande i form av en tvärsnittsstudie baserat på en kohort av 117 lungmottagare 1-5 år efter transplantationen. Tre olika självskattnings-instrument delades ut till lungmottagarna som därefter analyserades med olika statistiska metoder. Resultatet visade att väldigt få lungmottagare upplever sig helt återhämtade, endast 5,7 %, och nästan 27,6 % var inte alls återhämtade 1-5 år efter transplantationen. En majoritet av

lungmottagarna, 69 % upplevde sig helt, nästan helt eller delvis återhämtade. Det fanns ett starkt samband mellan upplevd återhämtning och välbefinnande. Det var möjligt att uppleva sig delvis återhämtad men ändå uppleva bra hälsa. De vanligaste symtomen som rapporterades var skakningar i händer 66 %, andfåddhet 62 % och sänkt libido 60 % medan de symtom som upplevdes som jobbigast var generande förändringar i utseendet, sänkt libido och nedsatt aptit. Det fanns inget samband mellan upplevd återhämtning samt välbefinnande och objektivt uppmätt lungfunktion. Vidare framkom att de lungmottagare som var sämst återhämtade upplevde sämre välbefinnande och hade en större symptombörda. Tidigare forskning har visat ett samband mellan depression och ökad mortalitet och morbiditet vilket visar vikten av att upptäcka lungmottagare med ett försämrat välbefinnande. Kliniska implikationer baserat på studien är att uppföljningen efter lungtransplantation behöver förändras för att systematiskt mäta symptombördan och välbefinnandet med syfte att ge extra stöd och behandling till lungmottagare med till exempel sänkt välbefinnande.

Artikel IV är en kvalitativ uppföljningsstudie av de intervjuer som genomfördes av lungmottagare efter ett år och som nu åter inkluderades tre år efter transplantationen. Syftet med studien var att fördjupa förståelsen för den hälsoprocess som tidigare visats samt vidareutveckla den grundade teorin. Fjorton lungmottagare intervjuades igen (en informant hade avlidit) och materialet analyserades med *Grounded Theory Method*. En ny grundad teori togs fram som visade att kärnan efter en lungtransplantation handlar om att adaptera till en ny normalitet, *Adaptation to a New Normality*. Detta sker via tre olika strategier: genom att jämföra (*Compare*), anpassa (*Adjust*) och acceptera (*Accept*) sina nya förutsättningar. Adaptionen till en ny normalitet bestod i att komma till insikt om och acceptera att livet som det var före sjukdomen och transplantationen inte skulle komma tillbaka utan det nya livet efter transplantationen krävde en adaption. Adaption till en ny normalitet är individuellt baserad på de omständigheter, symptom och komplikationer som varje unik lungmottagare upplever och är en kontinuerlig och föränderlig process som börjar direkt efter transplantationen. Om lungmottagaren kan anpassa sig efter sin situation och lyckas adaptera upplevs hälsa och välbefinnande men om livet består av för många begränsningar i vardagen på grund av en hög symptombörda uppstår svårigheter i anpassningen och adaptionen. Ett minskat välbefinnande och upplevelsen av en dålig hälsa infinner sig då. Det krävs alltid en anpassning efter en lungtransplantation på grund av det kroniska tillstånd som en transplantation i sig utgör samt den immundämpande läkemedelsbehandlingen, men graden av anpassning som krävs beror på lungmottagarens tillstånd och påverkar utfallet av adaption, hälsa och välbefinnande. Vidareutvecklandet av den grundade teorin som beskrevs i artikel I visade att under det första året efter en lungtransplantation ligger stort fokus på att återuppbygga sitt vardagsliv men detta är egentligen en habituell anpassning och en del i den stora övergripande processen som pågår nämligen att adaptera till en ny normalitet.

Sammanfattningsvis belyser denna avhandling viktiga aspekter av hur lungmottagare upplever sin återhämtning i form av en adaptionsprocess, hur symtombilden och välbefinnandet ser ut efteråt samt komplexiteten som ligger i begreppet återhämtning från ett transplantationsperspektiv.

Lungmottagarnas anmärkningsvärda förmåga att adaptera till en ny normalitet efter sin transplantation bidrar till upplevelsen av hälsa och välbefinnande, trots förekomst av symtom och begränsningar i det dagliga livet. Få lungmottagare upplever sig helt återhämtade och detta i kombination med en hög symtombörda kan vara en indikation på minskat välbefinnande vilket måste uppmärksammas. Uppföljningen bör delvis bestå i att systematiskt mäta symtom, symtombörda och välbefinnande genom självskattningsinstrument för att möjliggöra stöd och interventioner från vårdpersonal.

Resultaten i avhandlingen ger möjliga kliniska implikationer angående hur vårdpersonal kan utforma uppföljningen efter en lungtransplantation samt hur self-management stödet ska riktas. Fokus bör riktas mot att främja hälsa efter en lungtransplantation genom att stödja adaptionsprocessen samt hanteringen av de symtom och komplikationer som kan uppkomma. Eftersom en lungtransplantation kräver anpassning inom många olika dimensioner bör transplantationsteamet vara tvärprofessionellt, ledas av en sjuksköterska och bestå av en sjukgymnast, en psykolog, en psykiatriker, en medicinläkare med inriktning mot transplantationsmedicin och givet vikten av att återuppbygga vardagslivet, en arbetsterapeut. Att som vårdpersonal i transplantationsteamet arbeta personcentrerat är av yttersta vikt då lungmottagarens adaptionsnivå är individuell och en ständigt pågående föränderlig process.

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Paper I



ORIGINAL ARTICLE

Health transition after lung transplantation – a grounded theory study

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Aims and objectives. To investigate lung recipients' process of transition from prior the transplantation to one year afterwards, as well as what their main concerns are and how they deal with these concerns.

Background. During the last three decades, lung transplantation has been established as an effective treatment for patients with end-stage pulmonary disease. Towards the end of the 20th century, the concept of survival expanded to also include improving health-related quality of life (HRQoL). Although many studies have been published regarding lung recipients' HRQoL, aspects of health and everyday life remain understudied. Lung transplantation demands some kind of transition. However, very little is known about this transitional process.

Design. A qualitative inductive approach using Grounded Theory (GT) was used.

Methods. A total of ten adult males and five adult females ($n = 15$) with a mean age of 55 years were included in the study and interviewed one year after transplantation. The open-ended interviews were digitally recorded and transcribed verbatim after each interview. The analysis of the material was performed consistent with Charmaz constructivist approach of GT.

Results. The core category *Reconstructing daily occupations* summarises a process wherein the generated GT is present through four main categories: *Restricting*, *Regaining*, *Reorganising* and *Enriching*. The process of reconstructing daily occupations is necessary to regain health.

Conclusions. A trajectory of health transition is evident, starting pretransplant with the lung disease and severe illness and proceeding at least up to one year after the transplantation with experienced health.

Relevance to clinical practice. The result enables a unique possibility to enhance the lung recipients' striving for everyday life and thereby promote health. There is a need for change in the existing multidisciplinary transplant team to also include an occupational therapist to support and guide the lung recipients in changing their occupational patterns.

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

- An understanding of the strong relationship between the lung recipients' reconstruction of daily occupations and their ability of restoring health.
- An understanding of the trajectory of the health-transition which enables a target oriented guidance and support of the lung recipients.
- An understanding of the importance of including an occupational therapist in the transplant team.

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Introduction

During the last three decades, lung transplantation (LUTx) has been established as an effective treatment for patients with end-stage pulmonary disease (Yusen *et al.* 2013). A transplantation may allow a complete recovery of health (Singer *et al.* 2013). The primary clinical goal is defined by survival. In recent years, the long-term survival after lung transplantation has increased, with one-year survival of 79% and five-year survival of 53% internationally (ISHLT 2015). In Sweden the equivalent statistics present a one-year survival of 85% and a five-year survival of 66% (Scandiatriplant 2015). Prior to receiving a LUTx, these patients are facing an acute or chronic life-threatening disease with severe illness and less than one year left to live. Having an end-stage pulmonary disease means a constant struggle to breathe and the breathing problems are followed by physical limitations, poor health-related quality of life (HRQoL) and a severely impaired daily life (Singer *et al.* 2013). Lung transplantation is a demanding type of transplantation and they have a longer recovery period and more recommended restrictions post-transplantation, for example, 6 months of quarantine instead of three, compared to other groups of organ recipients. During the first post-transplant year, the medical follow-up is intense.

Background

Based on our clinical experience, the basic assumption behind this study is that lung transplantation demands some kind of transition. However, no studies have so far been performed aiming at investigating this supposed transitional process. A transition occurs when a person's current reality is disrupted, that is, by a lung transplantation, causing a process of convoluted passage during which people redefine their sense of self and redevelop self-agency in response to these disruptive life events (van Loon & Kralik 2005). An individual in transition tend to be more vulnerable to risks that may in turn affect their health (Meleis *et al.* 2000). Because of this knowledge gap a deeper understanding of this process is vital to support the lung recipients in their necessary adaptation (Cavallini *et al.* 2015 & Forsberg *et al.* 2015).

Towards the end of the 20th century the concept of survival expanded to also include improved health and HRQoL (Singer & Singer 2013 & Singer *et al.* 2014). The concept of health alone focuses on the ability to perform activities of daily living and emphasise themes of well-being and quality of life (Singer & Singer 2013 & Singer *et al.* 2014). The concept of HRQoL is a thoroughly established and defined parameter within the healthcare science. Extensive research and studies have been made regarding lung transplant recipients' HRQoL, which has improved greatly in recent years (Singer *et al.* 2013). The greatest improvements can be seen in physical health and functioning domains with the largest improvements within the first six months continuing up to one year. Thereafter, HRQoL trajectories are less stable and negatively affected by Bronchiolitis Obliterans Syndrome (BOS) and comorbidities (Kugler *et al.* 2010 & Singer *et al.* 2013). Although many studies have been published regarding lung recipients' HRQoL, this remains understudied compared to other solid organ transplants recipients (SOTRs) (Singer *et al.* 2013). In addition to the studies made regarding HRQoL, there are also a few studies focusing on LUTx recipient's experiences after transplantation (De Vito *et al.* 2004, Thomsen & Jensen 2009, Fuller *et al.* 2014).

From a clinical perspective, we believe that the process of transition, one way or another, is linked to experiences of health. Since the process of health transition after lung transplantation is mainly unexplored, the aim of this study was to investigate lung recipients' process of transition from before transplantation to one year afterwards, as well as studying what their main concerns are and how they deal with these concerns.

Methods

An inductive approach using Grounded Theory (GT) according to Charmaz (2010) was used. The scope of the phenomena of interest was the lung transplant recipients' transitional experience of recovery and health from being severely ill prior to transplantation until one year after. We aimed at enable a comprehensive description of the trajectory of recovery and health over time by means of a constructivist perspective. This method acknowledges the

researcher's ontological assumptions and pre-understanding involving previous record of caring for lung transplant recipients.

Design

The inclusion criteria were adult LUTx recipients who were due for their 12 months' follow-up after transplantation and who were medically stable and considered themselves physically fit for the interview. Patients medically unstable or with difficulty speaking Swedish were excluded. Participants were selected from the two only transplant units in Sweden where lung transplantation is performed and the selection of informants was performed in four steps as described by Morse (Morse, 2011):

- 1 *Convenience sampling.* Accessible adult lung recipients due for their one-year follow-up at both transplant units were recruited by the transplant coordinator to identify the scope, major components and the trajectory of the overall process. After five interviews, we moved on to the next sampling step.
- 2 *Purposeful sampling.* During this step we wished to maximise variation of meaning. These five new interviews revealed more in-depth how the participants themselves were weaved in the emerging phenomena of daily occupation. They spoke for themselves and a conceptual scheme as well as the trajectory identified during the convenience sampling was now confirmed as it emerged more clearly.
- 3 *Theoretical sampling.* First we recoded the data according to the identified trajectory and illuminated critical junctures, that is, the points between the stages. Then we let the emerging categories and our increasing understanding direct the final sampling. We therefore posed targeted questions to five more informants concerning the meaning of each concept to enable grounded definitions as well as clarifying the linkages between the categories. No true negative cases, that is, participants who have not responded in the anticipated way were identified.
- 4 *Validation interviews.* Four validation interviews were performed where we worked deductively and asked the participants if the analysis made sense to them and if there was a match between their experiences and the emerging theoretical model. These informants were recruited by the researcher performing the interviews (ML).

After including 15 LUTx recipients, we were convinced that we understood what we saw, could identify its relevant forms and that it appeared culturally consistent. Therefore, the sampling ceased. A total of ten adult males and five adult females with a mean age of 55 years (range 26–70 years) were included. All but one had under-

gone bilateral lung transplantation. The one exception had received bilateral lungs and a heart at the same time. The participants gave informed written consent and the interviews took place at the hospital where the informant had the one-year follow-up visit.

Ethical approval

This study was approved by the Regional Ethical Board in Lund (Dnr 2014/670). There were no specific ethical concerns present. We had prepared for emotional support by a social worker at each Transplant unit if the interviews would be emotionally demanding. However, the situation never occurred and no informants needed this consultation. After the written consent was obtained, all the selected informants remained in the study.

Data collection

The collection of data was done during 2014–2015. The open-ended interviews were digitally recorded and transcribed verbatim after each interview. Thoughts, emotions and actions from the time the participant became seriously ill to transplantation and the first year after were recalled during the interview. The open-ended questions enabled the informants to more vividly relate memories during their first year after transplantation and elaborate on their experiences. The interviews lasted on average 49 minutes (range 35–83 minutes). All interviews were performed by one researcher (ML). Written memoranda were collected during the interviews. Demographic data were collected and consisted of age, diagnosis and social status.

Data analysis

Initially we conducted a literature review as recommended by Hallberg (2010) and Glaser (2010) to establish whether previous studies with a grounded theory approach had been made with this particular focus. No such study was found. We performed initial coding of the interviews, line by line to find words or phrases indicating important categories, qualities or contexts related to the research question (Charmaz 2010). Reflections and questions that emerged during the analysis and coding process were logged for each interview. We then conducted focused coding to detect and explain the most frequent and significant codes, which illuminated the main concern experienced by the informants. Theoretical coding specified relationships between the generated codes from the focused coding and simultaneously the constant comparative method (CCM) (Charmaz 2010) was used on data, codes and categories. Finally, the process

of change and the ways the informants dealt with it was identified.

Results

The core category *Reconstructing daily occupations* summarises a process wherein the generated grounded theory is present through four main categories: *Restricting*, *Regaining*, *Reorganising* and *Enriching*. Our result demonstrates a strong relationship between reconstructing daily occupations and experiencing good health. An occupation is defined as the outcome of a person performing a task in a context (Persson *et al.* 2001). The individual takes on a task and when doing it, it becomes an occupation (Erlandsson & Eklund 2001). The common denominator for all the informants was their active efforts to regain and reorganise, that is, reconstruct their daily occupations and thereby experience good health. Through this generated process a trajectory of health transition is evident starting pretransplant with the lung disease and severe illness and ending in this study one year after the transplantation, with health. The trajectory of the health transition moved forward with small shifts back and forth between illness-health depending on the course of their recuperation, complications and medical treatment. Additionally, the main categories contain several subcategories. The outline of the results is presented in Fig. 1. In the following text, sub categories will be presented in bold *italics* and quotes in *italics*.

Restricting

The pretransplant illness trajectory could either be chronic or acute. A majority had endured their pulmonary disease with a steady deterioration the last couple of years prior to transplantation. Restricting daily occupations was defined as facing a severely limited everyday life due to the symptoms of the pulmonary disease and a constant struggle to breathe. This constant struggle to breathe had a strong negative impact on the informants' ability to perform their daily occupations and this was described as a substantial restriction in their lives. The informants tried to endure their illness and adjusted their life thereafter.

Before the informants were diagnosed with their pulmonary disease and were accepted for transplantation, many kept *denying* the seriousness of the situation. They blamed their condition and symptoms on anything else but the disease. The informants were constantly *struggling* to breathe, with or without being dependent on oxygen. Due to their inability to breathe properly they all struggled to manage daily occupation, which was heavily impaired. Eventually they came to *accepting* their disease and thereby gradually accepted the limitations in their daily occupations. The phase of acceptance also involved accepting their destiny and the course that their life had taken. The informants described a life pretransplant that mainly focused on *adjusting* their lives and daily occupations according to the illness and their symptoms. The adjustments involved many things such as reducing physical activity, working with

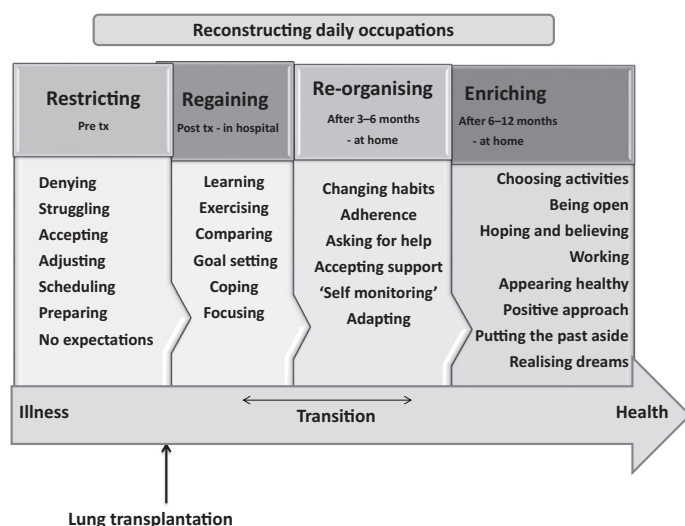


Figure 1 The grounded theory of reconstructing daily occupation after lung transplantation evidenced as a transitional process from illness to health.

oxygen and decimate social relationships. Due to their physical limitations, many informants expressed the importance of *scheduling* their daily occupations to save their strength. This planning also involved handling the illness practically rather than emotionally.

"Then one had to adjust, well to what one could manage, what one could do. If it was dusty or the floor was dirty, so what?" (female, 68 years)

Many informants began *preparing* for dying, making arrangements for a will (testimony) and closing a business. After being approved for transplantation and put on the wait list some started preparing for the recuperation afterwards by exercising. They had *no expectations* on the transplantation and were mainly fatalistic. They had no choice regarding transplantation since the only alternative was to die. A majority of the informants described the time before transplantation as a state of simply enduring the severe illness and its consequences.

"You never had any idea of what better meant...all my life I had this deterioration and couldn't breathe and had very low oxygen levels so I didn't know what better meant? You can't have something you don't know of." (male, 26 years)

Regaining

This phase involved regaining vital functions after the transplantation which was done mainly at the hospital but also at home. Breathing without a constant struggle is a key prerequisite for being able to perform many daily occupations. The ability to breathe in a normal way again, made it possible to regain basic functions such as walking, getting dressed and restoring their physical strength. This overwhelming sensation of being able to breathe was a driving force during this phase. The main focus during their hospital stay was to regain their physical strength. This regaining phase of basic functions could last shorter or longer, depending on the prevalence of complications and setbacks. Some felt that they had regained their physical strength after a couple of weeks, and some had not restored it fully after one year. However, the majority experienced a turning point after approximately 6 months.

Initially after the transplantation they managed recuperation by *learning* new skills. This involved many physical aspects like learning how to breathe again and to walk but also mental aspects like comprehending that they actually could do things after transplantation that they hadn't done for a very long time. All the informants were strongly focused on *exercising*. They went from fatalistic to focusing

on restoring their everyday life and they all understood the importance of exercising.

"The exercise, I think that is very important. That I have been motivated to keep going. And it (exercise) is really important in the future as well." (female, 41 years)

During the regaining phase with the focus on exercising, a key strategy was a constant *comparing* with their pre-transplant condition and noticing the progress post-transplant. In doing so they heightened the awareness of their progress and comparisons helped them to master setbacks and complications.

"Yes, but they are not so big these problems (complications), compared to what you had before, they become trivial after a while when you live with it." (male, 67 years)

Many used the strategy *goal setting* and worked hard to achieve their goals. The goal setting could involve anything from riding a bike, taking long walks or being able to enjoy a hockey game with friends. The informants used different types of *coping*, for example, confronting the demand for exercise, noticing progress or accepting restrictions. They encouraged themselves and accepted their situation by making the best of it. A few informants were coping by surrendering and letting others take over responsibilities. All of the informants were strongly *focusing* on their recuperation but in different ways. They turned to positive role-models, that is, were inspired by other organ transplant recipients who had recovered successfully and regained health. Despite various setbacks and complications, they did not let anything turn them down or stop them from reaching their primary goal of restoring and enjoying everyday life.

Reorganising

When still admitted to the hospital, the healthcare professionals were in charge of the informants' recuperation but at hospital discharge they were responsible themselves. This meant an insight of the need for reorganising their everyday life, that is, daily occupations. The common denominator of all informants was their ability to adapt to their present condition and the recommended restrictions. Adaptation in this context is constituted by their ability to adjust to their constantly changing situation and being able to experience good health regardless of different complications and setbacks.

After the transplantation many faced a new everyday life which meant *changing habits*. This included different things like shopping when there was a minimum of people and to avoid crowded places. They also faced a positive relief not having to adjust to a lethal illness anymore. Most

of the informants demonstrated a strong *adherence* to training programs, medications, hygiene rules and food restrictions. A strategy when facing complications was *asking for help*. All of the informants were willing to *accept support*, regardless if the support came from healthcare members or family and friends. They were all careful about their new lungs and wanted to take care of them. This involved *self-monitoring* especially in the beginning by noticing high temperature, infections and declining respiratory function as recommended by the healthcare professionals. All of the informants had to relate to several adjustments in their new life as lung recipients and they were willing to do so by *adapting* to new conditions. This adaptation involved adjusting their daily occupations depending on complications and symptoms and doing things in new ways.

"Well of course it strengthens you when you notice the results getting better, so that has been positive." Regarding complications "but that are things that, well I can still live a normal life so to speak." (female, 62 years)

Enriching

The reorganisation of daily occupations preceded the enriching phase where the informants started to direct themselves towards enjoying their restored everyday life and even more, appreciating breathing which enabled health. The enriching phase contains more than regaining and reorganising daily occupations. After six to twelve months at home, most of the informants also experienced good health. With their ability to breathe came the possibility to manage and enjoy everyday life.

"I imagine that we who suffer from a lung disease and can't breathe properly, we can never imagine how it is to breathe properly. It is somehow such a utopian feeling, you can't describe it in words. Now you understand how easy it's supposed to be to breathe. You had no idea about that before. It's supposed to be this way and you kind of get used to it. You adjust after your own capability. And this I can't do and this I can, but now, there are no limits at all. I can do whatever I want." (male, 57 years)

After the informants had regained their physical strength, they valued their newfound capability of *choosing activities* in life. They expressed an overwhelming joy of being able to do anything they wanted to and appreciated small things in everyday life like riding a bike, playing with their children and cleaning the house.

"Now I do things I dreamt about before." (male, 54 years)

Many expressed a different mental state of mind by *being open* to their surroundings, both friends and people in

general but also regarding gaining new perspective in life. They embraced their new personality and the feeling of gratitude of being alive. In this phase most of the informants started to make plans ahead and *hoping and believing* became new strategies for the future.

"Now I feel as if life, now it has started." (male, 70 years)

Many of the informants wanted to start *working* again. Some went back to work almost right away and some started later. The ability to work again was an important factor during the health transition process. Some felt that by working they could forget about the transplantation and the feeling of being different. This feeling of being different was mentioned by numerous informants and was expressed through the informants' desire and strategy of *appearing healthy*. Sometimes the informants tried to hide symptoms from the transplantation, for example, breathing problems, from their surroundings and sometimes they did not want to talk about being transplanted. This was explained as not wanting to be viewed as sick by others or avoiding to be stigmatised.

Throughout the health transition process all of the informants had a remarkable ability of adopting a *positive approach* as a key coping strategy. One year after LUTx, several informants still had problems with breathing, fatigue, pain or infections but they all experienced good health despite their complications and side effects from medical treatment. When the informants looked back on the time before the transplantation, many felt as it was a bad dream and they wanted to *put the past aside*. This was also expressed by sometimes being reluctant to talk about their present complications and symptoms with their friends, but focusing on their perceived good health instead. By putting the past aside, they now wanted to move forward beyond their identity as transplanted and *realising dreams*. This could involve different things like attending a course, go skiing or hiking in the mountains.

"I focus on health and don't think that much about my illness." (female, 56 years)

Discussion

Methodological considerations

We performed this study consistent with the four criteria of good quality in GT-research described by Charmaz (2010), that is, originality, trustworthiness, resonance and usefulness. We tried to ensure credibility by judging and criticising the interview guide independently of each other while still in the research team. During data collection and

data analysis, theoretical overload was clearly evident after 15 interviews. By the end of the analysis process, the sub-categories and the main categories confirmed the analysis rather than adding new data. One of the strengths in this study is the inclusion of informants from the only two transplantation centres in Sweden performing lung transplantation. We consider this an advantage that participants from the whole country was selected and that not only one single centre or medical or caring tradition was reflected on. There are also limitations. The final theoretical construct was not confirmed by the informants and the study was not performed prospectively.

Reflection on the findings

To our knowledge this is the first study to use a truly inductive method to understand the process of health transition after lung transplantation. The findings revealed a distinct, and from a time perspective, linear process of health transition starting from illness pretransplant and ending one year afterwards with the informants' experience of good health. However, the health transition most likely continues beyond one year even if that time span wasn't covered by our data collection. While life transitions may have a distinct beginning and end, transition for people with chronic illness may not be complete as their health and well-being status fluctuates (Shaul 1997). Research done by Kralik (2002) & van Loon and Kralik (2005) suggests that transition is an intricate and convoluted process with forward and backward movement.

The key approach through the process of change was adjustment to various physical demands, complications and changes in everyday life. We also identified a trajectory of transition from a severely restricted life through regaining and reorganising daily occupations to a state of enriching daily occupations and enjoying everyday life which enhanced their experience of good health. This trajectory was unexpected in several ways. First, the huge importance of daily occupations was underestimated. In the post-transplant out-patient clinic, healthcare professionals focus more on self-management than on daily occupations, which unfortunately might be viewed as self-evident instead of vital. Second, the goal oriented approach by the informants while regaining and reorganising was impressive. The informants put a great value in the fact that they could breathe and this physiological state acted as a constant inspiration and gave hope during the whole health transition. While the healthcare professionals take the respiratory function for granted after transplantation and fail to acknowledge this as a mediator for hope and recovery, the lung recipi-

ents are overwhelmed by their new health condition and explain all their achievements by the fact that they can breathe.

The informants went through a very explicit transitional process as defined by van Loon and Kralik (2005). The transplantation disrupted the current reality for the sick person and is a point of departure for the lung recipients, which marks the beginning of their transition from illness to experiencing good health. Transition is the way people respond to change over time and entails change and adaptation but not all change engages transition (Kralik *et al.* 2006). The informants responded to change over time by reconstructing their daily occupations. A person needs to acknowledge that a prior way of living/being has ended, or a current reality is under threat and that change needs to occur before the transition process can begin (Kralik *et al.* 2006). A successful transition is one where feelings of distress are replaced with a sense of well-being and to master a changed event (Schumacher & Meleis 1994). The person develops an increasing confidence in coping with change and mastering new skills and new ways of living (Meleis *et al.* 2000) which in our findings correspond with the last phase *enriching*.

The recipients' prior life with severe breathing difficulties had ended. They realised this already when they woke up in the thoracic intensive care unit (TICU). Furthermore, reconstruction of a valued self-identity is essential for transition. Time is also an essential element in transition and therefore longitudinal studies are required to explore the initial phase, midcourse experience and outcome of the transition experience (Kralik *et al.* 2006). Even if this study was performed retrospectively the result in our study emphasises the longitudinal aspect and the trajectories within the transition is well described by the informants. An individual in transition tend to be more vulnerable to risks that may in turn affect their health (Meleis *et al.* 2000). This is why it is of great importance to describe the transitional process after lung transplantation in an already vulnerable group due to immunosuppressive medication.

One of the main findings was the informants' desire to regain their daily occupation. The everyday life is a phenomenon that many people think they know everything about. However, few really understand the depth and importance of it (Erlandsson 2013). It is in everyday life that the consequences of sickness and disabilities become most obvious which often means that the ability to manage everyday life is lost or reduced. Previous research demonstrates a clear relationship between daily occupation and health (Erlandsson & Håkansson 2009, Erlandsson *et al.* 2011). Thus, if we understand the complexity of everyday life and the various relationships to health, we also understand how to alter

aspects of our daily occupations to maintain and enhance health (Erlandsson 2013). The core of our result presents the lung recipients' active strategy to regain health by reconstructing daily occupations. Our findings add to the existing guidelines by providing a theoretical framework that might guide the lung transplant recipient as well as the healthcare professionals in the post-transplant health trajectory. Existing guidelines do not emphasise enough the importance of regaining daily occupations or acknowledge the importance of enrolling an occupational therapist to the transplant team.

If a person may be hindered from accessing a certain repertoire of occupations, because of loss of capacity and functional limitations, this may constitute a considerable risk for developing illness (Wilcock 2006). This was clearly seen pretransplant when their constant struggle to breathe and physical limitations heavily impaired their ability to perform their daily occupations and thereby caused a feeling of illness. The exclusion of meaningful occupation from a person's occupational repertoire may affect the global meaning of life (Persson *et al.* 2001). This demonstrates the great impact daily occupation has on everyday life and the meaning of life.

Since the lung recipients have endured the struggle to breathe and a strongly reduced physical capacity pretransplant, they are very aware of what kind of limitations there can be in everyday life and what kind of restraints there can be in performing daily occupations. Some informants expressed that if you had not had problems breathing yourself, you could never understand the anxiety and the strong impact it has on everyday life and health. You have to experience it yourself to grasp the essence of it. The informants further stated that if you don't have problems breathing, you do not think about performing daily occupations. However, when your ability is lost or reduced, difficulties in performing daily occupations become very evident. The meaning of daily occupations is subjective. What seems to be trivial for healthy people can be perceived as extraordinary for lung recipients due to their pretransplant history. This was a significant finding in our study. After the transplantation they had the energy to do other things except struggling to breathe and that created an overwhelming feeling of joy and experience of good health.

The power of occupation lies in its impact on health. Disorganisation of occupations can lead to illness but the same occupation can be reorganised and thereby promote well-being and health (Erlandsson 2013). The informants all used physical exercise to regain their physical strength and thereby enable the reconstruction of daily occupations. In a qualitative study by Fuller *et al.* (2014) the patients' expectations of a supervised exercise rehabilitation pro-

gramme following lung transplantation was explored. One of the theme findings in the result was the recipients' desire for normalcy, including resuming family roles and performing everyday activities, that is, daily occupation, which is consistent with our findings. Post-transplant exercise rehabilitation was perceived as a highly valuable tool that assisted recipients to return to a "normal life".

After the LUTx the recipients faced the need to implement major changes in everyday life due to recommended restrictions regarding hygiene rules, food restrictions but also due to different complications and symptoms from the surgery and side effects of the immunosuppressive medication. Our findings reveal the lung recipients' unique ability to reorganise their daily occupations, learn new tasks and perform old occupational patterns in a new way. They adapt to their new lives and conditions in a remarkable way and can thereby experience good health, regardless of different set-backs and complications. This is consistent with a study by Anand-Kumar *et al.* (2014) who investigated the positive effects of organ transplantation where heart, liver and lung transplant recipients were included. The result demonstrated positive experiences in the whole group but the lung recipients reported significantly greater improvements in health compared to liver- and heart recipients. Similar results are presented in studies of Goetzmann *et al.* (2010) and Fox *et al.* (2014).

Our informants defined good health as the ability to being able to do whatever they wanted such as being able to spend time with friends and family and to feel good physically and mentally. This is consistent with previous studies showing that it is important for health not to have too many interruptions in everyday occupations and to be able to do what one intend to do (Erlandsson *et al.* 2010). Individuals that are denied access to what they want to do may as a consequence gradually develop a situation that implies an even greater challenge in their strive towards regaining a health bringing repertoire of daily occupations (Erlandsson 2013). This is why everyday life is of utmost importance for the lung recipients, since a functioning everyday life, promotes well-being and health.

Conclusion

There might be a relationship between the lung transplant recipients' reconstruction of daily occupations and their ability of restoring health relevant for those 79% surviving the first year. A trajectory of health transition is evident, starting pretransplant with the lung disease and severe illness and proceeding at least up to one year after the transplantation with experienced health.

Relevance to clinical practice

With this new grounded theory and the understanding of the strong connection between health and reconstructing daily occupation, we now have a unique possibility to enhance the lung recipients' striving for everyday life and thereby promote health. There is a need for changing the existing multidisciplinary transplant team to also include an occupational therapist. The lung recipients are restoring their health by reconstructing daily occupations; hence an occupational therapist is a key resource to initiate, support and guide the recipients in changing their occupational patterns.

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Contributions

Study conception/design, data collection, analysis and drafting of manuscript: ML; data analysis and critical revision for important intellectual content: LKE; study conception/design, drafting of manuscript, critical revision for important intellectual content and supervision: AL; data analysis and drafting of manuscript: MA; study conception/design, data analysis, drafting of manuscript, critical revision for important intellectual content and supervision: AF.

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Paper II



ORIGINAL RESEARCH: EMPIRICAL RESEARCH –
QUALITATIVERecovery after lung transplantation from a patient
perspective – proposing a new framework

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Abstract

Aims. The aims of this study were two-fold:

- to develop the concept analysis by Allvin *et al.* from lung recipients' perspective of their post-transplant recovery process and
- to identify the recovery trajectories including critical junctions in the post-transplant recovery process after lung transplantation.

Background. Lung transplantation is an established treatment for patients with end-stage lung disease. The recovery process after lung transplantation is very demanding. Today, patients are expected to play an active role in their own recovery but require ongoing support during the process.

Design. A deductive, retrospective interview study using directed content analysis and Allvin's recovery concept analysis.

Method. Fifteen adult lung transplant recipients who were due their 12-month follow-up were consecutively included and interviewed during 2015. Patients who were medically unstable or had difficulties speaking Swedish were excluded from this multi-centre study.

Findings. Allvin's concept analysis is partly applicable to the context of lung transplantation. The recipients' experience of the post-transplant recovery process could be confirmed in the main dimensions of the concept analysis, while several sub-dimensions were contradictory and were excluded. Six new sub-dimensions emerged; symptom management, adjusting to physical restraints, achieving an optimum level of psychological well-being, emotional transition, social adaptation and reconstructing daily occupation.

Conclusion. The concept analysis by Allvin *et al.* was possible to expand to fit the lung transplantation context and a new contextual definition of post-transplant recovery after solid organ transplantation was developed. Recovery and health were viewed as two different things.

Keywords: adaptation, adjustment, concept analysis, framework, lung transplantation, nursing, postoperative recovery, post-transplant recovery, qualitative, transition

Why is this research needed?

- Few frameworks exist that support transplant nurses in promoting recovery after solid organ transplantation (SOT). No previous study has explored recovery after lung transplantation from a patient perspective.
- Exploring the postoperative recovery process from a patient perspective makes it possible for healthcare professionals to support and guide lung transplant recipients, which might improve patient self-management.
- Recovery after lung transplantation is a demanding process due to lifelong immunosuppressive medication involving increased risk of infections and numerous restrictions.

What are the key findings?

- The concept analysis by Allvin *et al.* cannot be applied as a whole but some parts are useful and we expanded the analysis to cover lung transplant recipients.
- A new contextual definition of post-transplant recovery after solid organ transplantation was formulated, which might enable healthcare professionals to support and guide transplant recipients.
- The lung transplant recipients viewed recovery and health as two different things.

How should the findings be used to influence policy/practice/research/education?

- By adopting this post-transplant definition and its sub-dimensions to promote a healthy and constructive recovery process.
- Acknowledge that lung transplant recipients do not equate full recovery with the experience of good health.
- Allowing self-management support to be guided by a post-transplant recovery definition.

Introduction

Lung transplantation is an established treatment for patients with end-stage lung disease (Arcasoy & Kotloff 1999). During 2013, 4139 lung transplantations were performed worldwide (ISHLT 2015). The equivalent figure in Scandinavia was 137 lung transplantations in 2013 (Scandiatransplant 2015). Over the course of the last two decades, considerable advances have been made regarding organ preservation, surgical techniques, immunosuppression and antibiotic therapy, which have contributed to improved postoperative survival (Langer 2015). The following two pre-conditions characterize solid organ transplant recipients in general and lung recipients in particular: (1) Before transplant surgery the recipients were suffering from an end-stage disease

inevitably leading to death and their goal is not to recover to pre-operative levels of independence/dependency; (2) The goal of transplantation is not to completely cure a disease or repair a surgical problem but rather to move from a life-threatening disease to sustainable survival and better health, albeit with lifelong medication. These two pre-conditions have a crucial impact on healthcare professionals' approach to transplant recipients' recovery process.

The rationale behind this study is that we know from a clinical perspective and a previous inductive analysis of this interview data (Lundmark *et al.* 2016) that the recovery process after lung transplantation is very demanding. To the best of our knowledge, this is the first attempt to explore the postoperative recovery process after lung transplantation from a patient perspective. Today, much of the responsibility for postoperative recovery has shifted from the hospital to the patients and their families (Allvin *et al.* 2008). The importance of daily occupations is also highlighted (Lundmark *et al.* 2016). An occupation is defined as the outcome of a person performing a task in a context (Persson *et al.* 2001). The individual takes on a task and when doing it, it becomes an occupation (Erlandsson & Eklund 2001). If patients are expected to play an active role in their own recovery they require ongoing support during the process, both in the hospital and after discharge. Therefore, it is important to increase our knowledge and understanding of postoperative recovery. Exploring the postoperative recovery process makes it possible for transplant professionals to organize support for and guide lung transplant recipients, identify negative recovery markers and increase patient participation, which might ultimately improve patient self-management.

Background

To the best of our knowledge, no framework exists that supports transplant nurses in promoting recovery after solid organ transplantation (SOT). However, a concept analysis of postoperative recovery that might be useful after SOT is the one developed by Allvin *et al.* (2007), where postoperative recovery is defined as:

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

The understanding of a concept should be considered a dynamic and ongoing process that is responsive to new

knowledge and experiences (Meleis 2005, Allvin *et al.* 2007). Lung transplantation is considered as major surgery, which is why a definition pertaining to the postoperative process was chosen as opposed to a model concerning recovery in general. In the study by Allvin *et al.* (2007) four dimensions of postoperative recovery were identified from their literature review; physiological, psychological, social and habitual recovery (Table 1) which founded their definition of postoperative recovery. Formulating a definition of postoperative recovery as a concept promotes understanding of its use in postoperative care and the factors that influence it (Allvin *et al.* 2007).

The recovery process includes turning points defined as recovery trajectories (Allvin *et al.* 2007). ‘Critical junctions in the trajectory can be identified as either improvements or setbacks in relation to the expected outcome. Each particular trajectory corresponds with the progression and control of bodily functions as patients move towards recovery and these shifts in control are defined as recovery markers’ (Allvin *et al.* 2007, p 554). Critical junctions and turning points are therefore viewed as the same in this study and can be perceived as both positive and negative.

Postoperative recovery is a commonly used concept in health care. However, there is a need to obtain a deeper understanding of the course of events during recovery, as otherwise there is a risk that the concept will be used without

reflection (Allvin *et al.* 2008). Although many studies imply that recovery is a staged process where the goal is to achieve resolution and return to normal (Johnson & Morse 1990, Tobin 2000, Allvin *et al.* 2007), others challenge the fact that recovery has an end-point and instead define it as a process without an end-point or destination (Kelly & Gamble 2005).

The study

Aims

The aims of this study were two-fold:

- to develop the concept analysis by Allvin *et al.* (2007) from lung recipients’ perspective of their post-transplant recovery process and
- to identify the recovery trajectories including critical junctions in the post-transplant recovery process after lung transplantation.

Design

A directed content analysis influenced by Hsieh and Shannon (2005) was conducted using the content of the concept analysis by Allvin *et al.* (2007). This qualitative study has a retrospective cross-sectional design and a deductive approach was employed where Allvin’s concept analysis acted as a point of departure for several hypotheses regarding the recovery process after lung transplantation. These hypotheses were:

- the recovery process involves several dimensions
- it is possible to identify critical junctions and the overall recovery trajectory and
- side effects and set-backs might act as critical junctions

Re-analysis of the material was used since we already were familiar with the interviews from a previously inductive analysis published elsewhere (Lundmark *et al.* 2016), enabling us to perform another extensive analysis but from a different and deductive perspective. Descriptive qualitative studies neither have a formal name, nor are embedded in a disciplinary tradition which enables new ways of approaching previously collected data as in our study (Polit & Beck 2010). The data in our study were very rich. The advantage is that it was possible to explore the interviews again in a more in-depth way covering new aspects of recovering after lung transplantation. According to Hsieh and Shannon (2005), a directed content analysis starts with a theory or relevant research findings as guidance for the initial codes, in this case the concept analysis by Allvin *et al.* (2007). The goal of a directed approach to content analysis is to

Table 1 Dimensions of postoperative recovery found in the literature (Allvin *et al.* 2007, p.555).

Physiological	<ul style="list-style-type: none"> • Regain control over reflexes and motor activities • Normalize and control bodily functions • Loss of pain and fatigue • Conservation of energy • Experience of passivity
Psychological	<ul style="list-style-type: none"> • Experience of passivity • Return to psychological well-being • Return to wholeness • Reinstate integrity • Transition from illness to health • Loss of depression, anger, anxiety, fatigue and passivity
Social	<ul style="list-style-type: none"> • Experiences of pressures and cues • Becoming independent • Stabilize at full social function
Habitual	<ul style="list-style-type: none"> • Functioning in interaction with other people • Stabilizing the full range of activities • Take responsibility for and controlling activities in daily care • Restoration of normal eating, drinking and toilets habits • Returning to work and driving

conceptually validate or extend a theoretical framework or theory (Hsieh & Shannon 2005), which is consistent with our first aim in this study. We have added the lung transplant recipient's own experience of the postoperative recovery process to the existing concept analysis by Allvin *et al.* (2007) and thereby developed the concept analysis further in the context of lung transplantation.

Participants

The inclusion criteria were adult lung transplant recipients who were due their 12-month follow-up after transplantation and could participate in an interview. Patients who were medically unstable or had difficulties speaking Swedish were excluded. This multi-centre study involves the only two transplant units in Sweden. The recipients that met the inclusion criteria were asked to participate by the transplant nurse at the transplant centre and were also given information about the study and the possibility to terminate their participation at any time in the study. A total of ten men and five women with a mean age of 55 years (range 26–70 years) were consecutively included. All but one had undergone solely bilateral lung transplantation. The one exception had received bilateral lungs and a heart transplantation at the same time. The inclusion of participants ended when data saturation was achieved that is, when no new information occurred in relation to the first grounded theory analysis. That the data were sufficient also for this second analysis became evident during both the first and second analysis since the interviews were extensive and rich. The demographics of the transplanted participants are presented in Table 2.

Data collection

Data collection took place in the period 2014–2015. The open-ended interviews lasted for an average of 49 minutes (range 35–83 minutes) and were digitally recorded and transcribed verbatim after the conclusion of each interview. All the interviews were performed by one of the authors (M.L.) who were not involved in their present care nor had any knowledge about their present condition. The location of the interview was chosen by the informants and as a result, all of the interviews were conducted at the transplant centre in connection to their 12-month follow-up visit. The interviews began with an open-ended question where the participants were asked to describe their recovery experience after the transplantation. Themes that were elaborated involved critical junctions, symptoms, side effects and set-backs as well as consequences in everyday life. Follow-up questions were posed for clarification and to avoid misunderstanding.

Table 2 Indications for lung transplantation and demographic characteristics of the 15 participants.

Characteristics	Number of patients
Female	5
Male	10
COPD (Chronic Obstructive Pulmonary Disease)	4
Pulmonary fibrosis (cystic, idiopathic)	8
Pulmonary hypertension	1
Rheumatoid arthritis	1
Langerhans cell histiocytosis	1
Married/Cohabitant	9
Employed pre-transplant	9
Working post-transplantation	6
Retired	3
Studying	1

Ethical considerations

The study was approved by the Regional Ethics Board (Dnr. 2014/670-14/10). The participants gave their informed, written consent and the interviews took place at the hospital in connection with the 12-month follow-up visit. There were no specific ethical concerns present. We had prepared for emotional support by a social worker at each Transplant unit if the interviews would be emotionally demanding. However, the situation never occurred and no informants needed this consultation. After the written consent was obtained, all the selected informants remained in the study.

Analysis

The data analysis process began by identifying key concepts or variables as initial coding categories (Potter & Levine-Donnerstein 1999). In the concept analysis by Allvin *et al.* (2007) this was equivalent with the main dimensions of 'physiological, psychological, social and habitual recovery'. Next, operational definitions were determined for each category using the sub-dimensions in the concept analysis by Allvin *et al.* (2007). After reading the transcript and highlighting text representing the different dimensions, all the highlighted passages were coded using predetermined codes. Text that could not be categorized by the initial coding scheme was given a new code (presented in single quote marks in the Result section).

Rigour and trustworthiness

The concepts of credibility, dependability, confirmability and transformability can be used to ensure trustworthiness

in a qualitative study (Polit & Beck 2010). To achieve credibility, we tried to capture a broad perspective by interviewing lung recipients from the only two transplant units in Sweden that perform lung transplantation. We interviewed more men than women due to the consecutive sampling. The use of directed content analysis has some inherent limitations in that researchers approach the data with an informed, but nonetheless, strong bias. The results are illustrated by quotations to enable the reader to judge the credibility of our interpretation regarding the recovery process. We achieved dependability by jointly reflecting on the analysis and discussing different ways of interpreting the results in relation to the concept analysis. We believe that the findings are transferrable to other lung transplant recipients in particular and solid organ transplant recipients in general in developed countries. By using the concept analysis for post-operative recovery, we ensured that significant parts of the post-transplant recovery process were illuminated. In the analysis, it was obvious that the concept analysis could be further developed by the addition and subtraction of several sub-dimensions to fit the transplant setting, which was done in this study.

Findings

The findings are presented in two parts in line with the two-folded aim. First we present the development of the concept analysis, which stem from the main dimensions in the postoperative recovery concept analysis by Allvin *et al.* (2007). The new data and sub-dimensions that emerged are labelled post-transplant recovery and are presented below in single quote marks. Secondly we present the findings regarding the recovery trajectories including critical junctions in the post-transplant recovery process after lung transplantation.

Development of the concept analysis

Based on the lung transplant recipients' view of their recovery process our result shows that recovery from a lung transplantation takes place in a unique context and differs from recovery after other surgical procedures on which the concept analysis by Allvin *et al.* (2007) is based. Therefore, it was essential to develop and expand the former concept of postoperative recovery to fit the context of lung transplantation and also create a new definition of post-transplant recovery which is presented under Discussion.

It was nonetheless clear that the participants' experiences of the post-transplant recovery process could be confirmed in the main dimensions found in the literature review made

by Allvin *et al.* (2007). In our result below, we will present those sub-dimensions that were found in the literature review in the concept analysis by Allvin *et al.* (2007) but which did not fit in the context of lung transplantation. These sub-dimensions are removed from the new post-transplant framework presented in Table 5. In our analysis, we also discovered a need for developing new sub-dimensions that were specific in the context of lung transplantation which are presented below in single quote marks.

One of Allvin's physical recovery sub-dimensions is loss of pain and fatigue. None of the participants in our study reported pre-transplant pain, but for many, the transplantation itself led to pain and fatigue, that could last for at least up to a year. Most of the participants initially experienced various forms of thoracic pain involving the sternum, the ribs or from the surgical incision. A majority of the participants also suffered from muscle weakness, which was mainly located in the lower limbs and sometimes the arms. However, loss of pain and fatigue was not a recovery marker because the participants experienced health despite these problems, which is the reason why this sub-dimension is not directly applicable to lung recipients.

A new sub-dimension that emerged was 'symptom management', which represented a substantial part of the recovery process. Support from healthcare professionals was needed to limit the impact of these symptoms and complications but self-management by the patients themselves was also required. This could involve self-care such as breathing exercises, pain-management strategies or resting due to fatigue. Another new sub-dimension that emerged was 'adjusting to physical restraints', which was necessary when symptom management was insufficient. This was evident throughout the recovery process, although they generally adjusted to their limitations and adopted new ways of performing the activities of everyday life given their physical restraints.

Psychological recovery meant dealing with a range of different feelings. The participants went through a clear transition from illness to health, despite the fact that even after a year, many had to adjust to complications and remaining restraints. Most of the participants expressed intense feelings of happiness, thankfulness and joy that emerged during the early postoperative phase. They felt they had received a second chance in life. Many tried to describe their feelings of joy and stated that no healthy person could ever understand what it was like to be terminally ill and then regain your life. The participants strived after 'achieving an optimum level of psychological well-being' instead of returning to psychological well-being and wholeness, which is not relevant in the present context because the participants' condition pre-transplant was not desirable.

According to Allvin *et al.* (2007), an important part of psychological recovery is to reinstate integrity. However, during the recovery process, some of the participants suffered from various psychological problems such as depression, anxiety and anger. It is reasonable to assume that these conditions might compromise their psychological integrity, although this sub-dimension was poorly defined in the original concept analysis by Allvin *et al.* (2007). The sub-dimension loss of depression, anger, anxiety, fatigue and passivity could not be directly applied to the data because many of the participants developed these conditions. Another redundant sub-dimension was experience of pressures and cues, which the participants did not mention.

A new sub-dimension emerged during the psychological recovery. The participants went through an 'emotional transition' and started to re-evaluate life, prioritize in a different way and many became very emotional and cried easily. This was experienced as a positive change because they were more aware of their own feelings. After transplantation they viewed their future in a different way, became happier, more hopeful and believed that they could plan ahead. The transplantation also meant changing their perception of themselves as they could now live their life in a different way. However, the changed feelings were not always positive and could also mean becoming more agitated, giving up on things and having difficulty starting projects. Some also suffered from panic attacks, anxiety, depression, fear of rejection and existential thoughts.

Most of the participants had reached a plateau of stabilizing at full social function, although this sub-dimension took on a new meaning in the post-transplantation context due to hygiene restrictions, complications from surgery and side effects of the medication. Instead of returning to their previous social function, a new sub-dimension called 'social adaptation' emerged, which involved changes in their social life and included functioning in interaction with other people. For example, breathing problems made them unable to participate in social activities or take strenuous walks, while fatigue could limit their social life as they did not have sufficient energy to play with their children or take part in various activities. Social adaptation also involved adjusting to hygiene restrictions by avoiding crowds and people with infections. During their social recovery, the participants expressed the importance of support, which could involve both instrumental and emotional support from family and friends, and guidance from healthcare professionals. Most of the participants experienced very supportive surroundings but some were disappointed in their friends and family, who they considered had failed them. The latter stated that their real friends emerged after the

transplantation. A few participants separated from their spouse, which was challenging. Others described being more open to their social surroundings afterwards.

Many participants wanted to take responsibility for and control activities in daily care, which was a major part of their recovery, but the original sub-dimensions in the concept analysis by Allvin *et al.* (2007) did not cover all aspects in this context and thus a new sub-dimension emerged, 'reconstructing daily occupation'. This included the sub-dimensions from the original analysis. The participants had to adjust their habits by going to the supermarket in the morning when there were few customers there, avoiding crowded places and going to the hospital at specific times. Besides going back to old habits, new ones also emerged. Monitoring health at home was an important habit, as were breathing exercises and being alert for signs of infection. Although many of the participants were used to taking medication before the transplantation, having to take the immunosuppressive medicines at specific times was a new habit that required adjustment. The reconstruction of daily occupation during recovery was described as first regaining one's daily occupations after transplantation, thereafter reorganizing them in accordance with the new life situation and finally enjoying one's daily occupations.

Recovery trajectory and critical junctions

Presented below are the sub-dimensions from the literature review in the concept analysis by Allvin *et al.* (2007) that did fit in the context of lung transplantation. Our new version of the post-transplant framework is presented in Table 5 where old and new sub-dimensions are listed. We will also describe the recovery trajectory and critical junctions found in the analysis.

Physiological recovery

Initially, physical recovery involved regaining control over reflexes and motor activities and normalizing and controlling bodily functions such as learning how to breathe again, manage personal hygiene and walk. This is consistent with the sub-dimensions found in the literature by Allvin *et al.* (2007). A majority of the participants had to start from scratch to rebuild their physical strength and in general, they were very motivated to exercise. They emphasized the importance of training programmes and support from a physiotherapist as a means of regaining control over bodily functions. Improvement in their physical performance was a confirmation that the recovery process was progressing, which encouraged them to increase their efforts. All of the

participants described the sensational feeling of being able to breathe again, which was also a prerequisite for physical recovery:

Now I don't think about breathing. Before, I had to think about every breath I took. (male, 26 years)

The participants adjusted to fatigue by resting for a couple of hours when necessary, thereby enabling conservation of energy, which is one sub-dimension in the concept analysis by Allvin *et al.* (2007). Two participants described experiences of passivity and feelings of relief when others took control but most played a very active role in their recuperation. However, a few disliked exercising as they experienced a great deal of pain after exercise and felt little motivation to continue training.

Turning points

The physiological recovery process lasted from the inpatient post-transplantation period until up to 1 year afterwards, depending on the prevalence of complications and setbacks, defined as critical junctions. Distinct turning points occurred after approximately three weeks, three months and six months. Three weeks after lung transplantation several participants had regained independence in terms of managing personal hygiene and being able to walk without assistance. After three months they had regained enough physical strength to be discharged from the hospital to their own home. The third turning point occurred after approximately six months when the recommended restrictions in daily life were less demanding. Throughout the physical recovery process, recovery markers consisted of improvements in their exercise level and the results of their self-monitored micro spirometry values. Other important markers were gaining weight after being malnourished or being able to perform previous daily occupations.

The postoperative recovery process was influenced by diverse factors that could affect recovery positively or negatively. Critical junctions in the recovery process, as reported by the informants, are presented in Table 3. The early post-transplant phase was characterized by several anticipated physical symptoms that often occur immediately after lung transplantation. Complications and side effects after transplantation are described in Table 4:

So it was those kinds of problem (complications such as broken ribs, sternum wound, infections) but the lungs work really well!...

(About complications:) 'Setbacks are there to be overcome and you have to make the most of your life. And you don't get any

Table 3 Critical junctions affecting the post-transplant recovery process reported by the participants.

Positive factors	Negative factors
<ul style="list-style-type: none"> • Physical exercise pre-transplantation • Physical exercise after transplantation • Being in good shape pre-transplantation • Social support from friends and family • Support from healthcare professionals, continuity • Being stubborn and a 'fighter' • Positive approach • Noticing small improvements → moving forward • Comparing with the pre-transplant condition → makes you positive and appreciative • Positive role models • No major expectations of recovery • Seeing the wholeness, both physically and psychologically • Having worked pre-transplant and returning to work 	<ul style="list-style-type: none"> • Complications and setbacks → negatively affects exercise capability • Not interested in physical exercise • Poor physical shape pre-transplant • Abandoned by friends and family • Isolation • Fatigue • Depression • Role models who are negative or report many complications

better just sitting there, becoming depressed and feeling sorry for yourself, that has never, never been my cup of tea. (female, 68 years)

Psychological recovery

Critical junctions were apparent when many psychological issues emerged directly after the transplantation, when the participants were discharged to their home and after about six months, when they felt mentally stronger. To manage the emotional transition, the lung transplant recipients used different coping strategies and goal setting to cope with setbacks, complications and pain. Despite complications, they succeeded in maintaining a very positive approach throughout the recovery process. Many believed this resulted from comparing how terrible they felt before the transplantation with how much better everything was afterwards:

Well, now there's nothing negative at all. If feels like I could catch the moon or whatever! Once again, it's probably really hard for you healthy people to actually understand what it feels like...turn back the clock and I was more or less dying and now I feel so damn lively. (male, 57 years)

Table 4 Side effects, setbacks and complications experienced by the lung recipients.

Main recovery dimensions	Manifestation/obstacles to recovery
Physiological	Cardiac-pulmonary <ul style="list-style-type: none"> • tachycardia • low blood pressure → dizziness • atrial fibrillation • pulmonary constriction → breathing difficulties → expand with stents • pulmonary fluid → breathing difficulties → drainage • pulmonary embolism → breathing difficulties • sleeping with breathing mask/home ventilator Side effects of medication <ul style="list-style-type: none"> • pain in legs and feet → problems walking • burning pain in hands/cold hands • tremor in hands and legs • constipation • increased facial hair growth • moon-face • leukocytopenia • dry mouth Infections/virus/fungal infections <ul style="list-style-type: none"> • breathing problems • infected sternum/rib → prolonged hospitalization • fever • tiredness/fatigue Musculoskeletal <ul style="list-style-type: none"> • difficulties walking • poor balance → fall accidents • pain in legs, hip, chest and arms • fragile ribs → crack/break → pain • instable sternum → pain → immobilized • tender breast • muscle soreness • muscle weakness Motor sensory <ul style="list-style-type: none"> • muscle spasm • restless legs/pins and needles → sleep problems Other <ul style="list-style-type: none"> • rejections → fever, breathing problems, tiredness • stomach surgery • diaphragm paralysis → home ventilator • nerve damage → numbness • decreased kidney function • loss of appetite

Table 4 (Continued).

Main recovery dimensions	Manifestation/obstacles to recovery
Psychological	Cognitive <ul style="list-style-type: none"> • fatigue • hallucinations • sleep disorders • concentration problems • memory problems • difficulties in reading comprehension • depression Social <ul style="list-style-type: none"> • social restrictions • limitations in social activities Habitual <ul style="list-style-type: none"> • difficulties performing daily occupations

Social recovery

During the social recovery all the participants strived to become independent of health care and hospitalization, although some still had to rely on their family and friends for instrumental support. Most felt they could function in interaction with other people:

It's probably easier to talk to me nowadays than it was before, because at that time I was so focused on being unwell and didn't want to participate. It's not always easy keeping a happy face when you're feeling really shitty. (male, 57 years)

With the exception of one, all participants were very careful to avoid sick persons and crowded places and also regularly used hand sanitizer. They described this as a precaution that they were more than willing to take to avoid infection and did not consider it an obstacle to social recovery. For some of the participants, it was very important to appear healthy in the eyes of people in their social environment. They stated that they did not want to be viewed as ill, be stigmatized or obtain sympathy. Furthermore, they had no wish to explain their situation to others and tried to hide symptoms such as breathing problems. A recovery trajectory became evident during the first six months of isolation when the participants kept to themselves. Some were relieved when the six-month isolation period was over and they could attend social functions again, while others preferred to remain isolated at home.

Habitual recovery

In addition to physical recovery, the participants were very focused on their habitual recovery. Their goal was to take responsibility for and control activities in daily care which was a sub-dimension in the concept analysis by Allvin *et al.* (2007). Most of them could quickly return to normal

eating, drinking and toilet habits, although after a year, a few still had difficulty managing everyday life and needed support from their family. Many stressed that returning to work and driving were strong recovery markers. Some worked from home almost immediately after the transplantation and others began working part-time. All of the informants had to handle various restrictions:

It's the thing with all the medicines...the thing about time, that it's so important to take them...I feel it's a great deal to have to remember...there are more rules now... (female, 41 years)

The participants' insider perspective on their recovery trajectory and remaining illness resulted in the conclusion that recovery and health should be viewed as two different things because many of the participants were not fully recovered but still experienced good health. The recovery process was far from linear and instead moved back and forth. Most of the participants felt better than they had expected and were able to adjust to the complications and remaining restraints after the transplantation.

Discussion

Development of the concept analysis

Our study shows that the concept analysis by Allvin *et al.* (2007) is very useful, in parts. However, it is also possible to further develop it in the context of lung transplantation. The participants' experience of the post-transplant recovery process could be confirmed in the main dimensions of the concept analysis, while several sub-dimensions are rather irrelevant for lung transplant recipients. The sub-dimensions that differed from the original concept analysis were loss of pain and fatigue, loss of depression, anger, anxiety, fatigue and passivity, experiences of pressures and cues and return to psychological well-being and wholeness. These have been removed from the new post-transplant framework, see Table 5. The social and habitual recovery sub-dimensions from Allvin's original concept analysis are now included in the new sub-dimensions of social adaptation and reconstructing daily occupation. New sub-dimensions also emerged from the informant's experiences such as symptom management, adjusting to physical restraints, emotional transition, achieving an optimum level of psychological well-being, social adaptation and reconstructing daily occupation.

The use of the phrase returning to normality in the definition presented in the concept analysis by Allvin *et al.* (2007) also needs to be addressed because the term normality is complex and can have numerous different meanings.

Table 5 New framework of post-transplant recovery after SOT, including sub-dimensions.

Physiological	<ul style="list-style-type: none"> • <i>Regaining control over reflexes and bodily functions</i> • <i>Conserving energy</i> • <i>Experiencing passivity</i> • <i>Symptom management</i> • <i>Adjusting to physical restraints</i>
Psychological	<ul style="list-style-type: none"> • <i>Transition from illness to health</i> • <i>Reinstating integrity</i> • <i>Emotional transition</i> • <i>Achieving an optimum level of psychological well-being</i>
Social	<ul style="list-style-type: none"> • <i>Becoming independent</i> • <i>Social adaptation</i>
Habitual	<ul style="list-style-type: none"> • <i>Reconstructing daily occupations</i>

The bold italics represent new sub-dimensions developed from this study while the sub-dimensions in italic represent the original concept analysis developed by Allvin *et al.* (2007).

For lung transplant recipients, returning to normality does not mean a return to their pre-operative condition.

The concept analysis presented by Allvin *et al.* (2007) is developed mainly for tissue surgery. While lung transplant recipients undergo an extensive surgical procedure, a recovery framework for such patients needs to contain more dimensions and be more contextualized. Extensive research has been conducted on recovery after non-surgical procedures (Tobin 2000, Kelly & Gamble 2005) and perhaps these and other studies should be included in a future recovery framework to understand the depth and special circumstances surrounding transplantation. One conclusion from our study is that a new contextual recovery framework after transplantation is needed to support and guide transplant recipients.

In a qualitative study by Allvin *et al.* (2008) patients and staff who were interviewed described postoperative recovery as: A dynamic process in an endeavour to continue with everyday life. The essence of the recovery process was a desire to reduce unpleasant physical symptoms and achieve a level of emotional well-being, and regain functions and re-establish activities. Everyday life after the recovery process was not always comparable to that before surgery (Allvin *et al.* 2008). This is consistent with the result of the present study and the investigation by (Lundmark *et al.* 2016).

Previous research on social function after SOT highlights the importance of social adaptation during recovery (Cavalini *et al.* 2015, Forsberg *et al.* 2015) and habitual recovery requires reconstructing daily occupation (Lundmark *et al.* 2016). In the light of these previous studies regarding social and habitual recovery, and the increased knowledge of

physiological and psychological recovery generated by this study, we now believe that the scientific knowledge is sufficient to develop a new definition of post-transplant recovery after SOT. Therefore, we propose a first definition of post-transplant recovery:

Post-transplant recovery is a dynamic, demanding process involving a transition from pre-transplant severe illness to a state of experienced health, achieved by adjusting to regained physical, psychological, social and habitual functions. Essential parts of the transitional recovery process consist of symptom management, achieving an optimum level of psychological well-being, social adaptation and reconstructing daily occupations.

Recovery trajectory and critical junctions

Some recovery trajectories in these sub-dimensions were contradictory because during the post-transplant process the participants developed anxiety, depression and psychological problems, in addition to suffering many complications and side effects from the medication. Although some sub-dimensions could not be applied directly, all the participants had clear recovery processes in the main dimensions, which could therefore be used by healthcare professionals to support recovery after lung transplantation. Adjusting to physical restraints was a constant theme during recovery. Transplant recipients do not proceed from being terminally ill to healthy without lifelong medication, side effects and complications, which cause various symptoms. For recipients to experience good health, they have to manage these symptoms themselves and adjust to the physical restraints. The emotional transition is described in the result and involves an altered state of mind. It can be hindered or prolonged if transplant recipients are unable to embrace their emotional transition, for example, due to experiencing uncertainty and lack of support from healthcare professionals (Almgren *et al.* 2016). The required social adaptation, which is partly due to transplant specific restrictions associated with immunosuppressive medications, is an important part of recovery and regaining social function after transplantation (Cavallini *et al.* 2015, Forsberg *et al.* 2015).

In previous research reconstructing daily occupation during habitual recovery has proven to be the core of returning to everyday life after lung transplantation and thereby experiencing good health (Lundmark *et al.* 2016). Lung recipients define health and normality as their ability to perform daily occupations, for example, everyday life (Lundmark *et al.* 2016) and not as full recovery. However, this striving for normality implied by the definition of postoperative recovery might also become a stress factor for transplant recipients

and create feelings of uncertainty (Almgren *et al.* 2016). Recovery is not a process of 'getting over' uncertainty but rather learning to live with and manage it. In a study concerning recovery after myocardial infarction, the informants' sense of difference afterwards is emphasized in the results (Tod 2008). Acknowledging the importance of difference also highlights the inappropriateness of defining recovery as 'returning to normal'. If someone is different, 'returning to normal' is clearly an unachievable goal (Tod 2008).

Today there is a lack of studies that explore postoperative recovery from a long-term perspective. In our study, the recovery process constituted a path starting immediately after transplantation and continuing beyond the 1-year follow-up since many participants did not consider themselves recovered after 1 year. There might be patients who, due to transplant surgery complications or the side effects of medication, will never return to a subjectively satisfying level of independence or dependence in their everyday life. This makes it difficult to define an endpoint for recovery. However, one important conclusion from our study is that the participants did not equate being fully recovered with the experience of good health. Many participants who suffered multiple complications and symptoms from the surgery and medication did not consider themselves recovered but still experienced good health. For this reason, the goal does not have to be achieving a full recovery but should instead focus on the ability to experience subjective health.

Our result also demonstrates that there are several ways both healthcare professionals and lung transplant recipients themselves can influence the post-transplant recovery process (Table 3). According to the participants, exercising before transplantation can have a positive effect, in the same way as support from family, friends and the transplant team. This knowledge could be used to generate strategies for support and follow-up activities during postoperative recovery. In a study by Allvin *et al.* (2008), several factors were described as important for influencing recovery. Antecedents to recovery, the time required to recover, support and encouragement, regular and appropriate information, in addition to setbacks during recovery were all considered to affect the recovery process in a positive or negative manner (Allvin *et al.* 2008). This is consistent with the result of our study.

All the participants emphasized the importance of exercising both before and after transplantation as a means to promote recovery. Outpatient rehabilitation programmes that include supervised exercise training have been shown to be effective in improving limb muscle dysfunction, exercise capacity and quality of life both before and after transplantation (Langer 2015). A review study revealed similar

results, indicating that structured exercise training after transplantation has a positive effect on exercise capacity, skeletal muscle function and lumbar bone mineral density (Wickerson *et al.* 2010). Rehabilitation also plays an important role in the pre-operative management of patients (Rochester 2008) and could be a mediating factor in the transition from illness to health. Based on the results of a randomized control trial studying exercise training after lung transplantation, patients should be strongly encouraged to participate in an exercise training intervention. These patients exhibited improved functional recovery and increased participation in daily physical activities (Langer *et al.* 2012).

Limitations

Most of the participants were born in Sweden, which limits the finding to a solely western perspective. However, we selected participants from the two transplant units in Sweden where LuTx is performed to cover various parts of the country. By using only one source of data in the study, there was a risk of incubating a focus solely on the informants lived experience and not on the postoperative recovery. Because the framework is intended to establish dimensions that exist among data it is not to be perceived as an absolute truth; rather, it is a cautious explanation of the recovery process after lung transplantation. The study does not fully reflect the gender distribution in the lung transplant population due to the consecutive sampling.

Conclusions

The concept analysis presented by Allvin *et al.* (2007) was possible to expand to fit the context of lung transplantation and a new contextual definition of post-transplant recovery after solid organ transplantation was developed. It is possible to experience good health without being fully recovered after lung transplantation, that is, recovery and health are two different things. Our study contributes with an increased understanding of the post-transplant recovery process after lung transplantation, highlighting the complexity of the concept of recovery and the need for new theoretical frameworks in the context of transplantation. Future research should focus on the development of a middle-range theory concerning post-transplant recovery.

Our result in combination with our previous research and clinical experience suggests that the need for a framework, and the new definition of post-transplant recovery, is relevant for all solid organ recipients. This could contribute to more person-centred care for recipients and guidance for

healthcare professionals in their efforts to provide self-management support.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contribution

Martina Lundmark: study conception/design, data collection, analysis and drafting of manuscript.

Annette Lennerling: study conception/design, drafting of manuscript, critical revision of important intellectual content and supervision.

Matilda Almgren: data analysis and drafting of manuscript.

Anna Forsberg: study conception/design, data analysis, drafting of manuscript, critical revision of important intellectual content and supervision.

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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Paper III



Recovery, symptoms, and well-being one to five years after lung transplantation – A multi-centre study

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Recovery, symptoms, and well-being one to five years after lung transplantation – A multi-centre study

Background: In recent years, survival after lung transplantation has remained largely unchanged despite improvements in short- and intermediate-term survival, indicating the need to identify factors associated with recovery and long-term survival. Very little is known about how lung recipients recover after lung transplantation and whether such factors are related to symptom distress and well-being. This constitutes the rationale of the study.

Aim: The aim was to explore symptom prevalence and distress as well as the degree of self-reported perceived recovery and well-being 1–5 years after adult lung transplantation.

Method: This multicentre, cross-sectional nationwide study includes 117 lung recipients due for follow-up at 1 year (n = 35), 2 years (n = 28), 3 years (n = 23), 4 years (n = 20) and 5 years (n = 11). Three different self-assessment instruments were utilised; The Postoperative Recovery Profile, the Organ Transplant Symptom and Well-Being Instrument, and the Psychological General Well-Being Instrument. Ethical approval of the study was obtained.

Results: Few (5.7%) lung recipients were recovered 1–5 years after lung transplantation and 27.6% were not recovered at all. No relationship was identified between present lung function and self-reported recovery or well-being. There was a strong relationship between recovery and well-being. It is possible to be partly recovered and experience good health. The most prevalent symptoms were tremor 66%, breathlessness 62%, and decreased libido 60%, while the symptoms perceived as most distressing were embarrassment about appearance, decreased libido, and poor appetite.

Limitations: The cross-sectional design prevents identification of any causal relationships. Patient loss due to transplant mortality and inclusion difficulties resulted in a fairly small sample.

Conclusion: Our findings suggest the need for changes in follow-up care such as systematic measurement of the degree of self-reported recovery and symptoms. This entails self-management support tailored to the recipients' symptom-management and health-management requirements.

Keywords: lung transplantation, nursing, posttransplant follow-up, recovery, self-management, symptoms, well-being.

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Introduction

During the past three decades, lung transplantation (LuTx) has become an established and effective treatment for patients with end-stage pulmonary disease, (1, 2) and more than 50 000 single and double lung transplantations (LuTxs) have been performed worldwide (3). Very little is known about how lung recipients (LuTRs)

perceive their recovery after transplantation. This study aims to address a knowledge gap regarding the extent to which lung transplant recipients recover after transplantation and whether factors such as symptom distress are related to the state of posttransplant recovery. To the best of our knowledge, this multicentre, cross-sectional nationwide study is the first of its kind to explore LuTRs' self-reported, perceived degree of recovery in relation to perceived symptoms and well-being.

What is already known is the fact that posttransplant follow-up is extensive in order to optimise medical therapy. It involves bronchoscopies, biopsies, lab tests, chest radiographs and clinical examinations (2) but also active

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patient engagement in a variety of health behaviors (4), i.e., self-management. This include intake of medication, regular physical activity, reducing the use of alcohol, smoking cessation, sun-protection, keeping medical appointments (4) as well as self-monitoring of lung function, vital signs and symptoms (5, 6). Based on a clinical perspective, healthcare professionals expect LuTRs to play an active role in their recovery process. This includes symptom-management, which is part of the concept of self-management. As part of posttransplant care, LuTRs must adhere to a complex self-management regime (7) due to their high rates of infection and acute or chronic rejection (3, 8).

Previous qualitative studies suggest that the goal after LuTx is not necessarily full recovery without the presence of symptoms, but instead to achieve the experience of health by learning how to adjust to and manage one's symptoms (9, 10). Therefore, one hypothesis is that it is possible to experience well-being and health despite not being fully recovered in terms of being symptom free.

Symptom experience is a critical posttransplant outcome, possibly affecting self-management. During the recovery process, LuTRs suffer from many different symptoms (11–14). Posttransplant symptoms may vary in frequency, time of onset and duration as well as perceived distress but also due to immunosuppressive treatment (11). There is an association between side-effects from immunosuppressive medications, symptom experience and nonadherence as patients try to decrease their symptom burden by reducing dosage or taking drug-holidays (11).

Previous research also reveals that depressive and anxiety-related disorders are common after LuTx (15, 16). In a study including 178 LuTRs, 30% suffered from major depression that developed gradually during the first 2 years posttransplant (17). Depression at an early stage posttransplant increases the risk of long-term transplant-related mortality (18–20) and morbidity (15) with an elevated risk of Bronchiolitis Obliterativ Syndrom (BOS), patient death and graft loss (15). No evidence-based practice guidelines are available to support LuTRs during recovery. What remains unknown is whether or not a relationship exists between well-being, symptoms and recovery, especially after LuTx, and there is a lack of knowledge regarding the recovery process from a patient perspective as well as the possible impact of symptoms, well-being and health. Despite improvements in short- and intermediate-term survival, long-term survival after LuTx has remained largely unchanged (3). This indicates an urgent need to identify and improve factors associated with long-term survival. Thus, the aim was to explore symptom prevalence and distress, as well as the degree of self-reported recovery and well-being 1–5 years after adult lung transplantation.

Methods

Study population and ethical approval

This cross-sectional study is part of the Swedish national multicentre study; Self-Management After Thoracic Transplantation (SMATT). Adult LuTRs due for their annual follow-up 1–5 years after transplantation were consecutively included from the two thoracic transplant centres in Sweden. Inclusion criteria were transplant recipients receiving only lungs, Swedish speaking, mentally lucid and not hospitalised at the time of the data collection. The reasons for exclusion were inability to speak Swedish, declining participation or transplanted with both lungs and a heart.

During the data collection period from February 2014 to October 2015, 204 LuTRs were eligible for an annual follow-up and 128 (63%) were included. Practical inclusion difficulties at the outpatient transplant clinics affected the final sample size. Due to inclusion errors nine recipients were included twice in different follow-up years, which were subsequently corrected. Another two recipients were identified as both heart and lung recipients after the inclusion was made and were thereby removed from the final sample. Thus, the final sample consisted of 117 LuTRs who were due for follow-up at 1 year ($n = 35$), 2 years ($n = 28$), 3 years ($n = 23$), 4 years ($n = 20$), and 5 years ($n = 11$).

The Regional Ethical Review Board of southern Sweden granted permission to carry out this study (D-nr. 2014-124). The information provided was kept confidential and stored in accordance with the Swedish personal data act; (21). Data were gathered from the patients' records after permission was granted in accordance with regulations.

Data collection and instruments

The lung recipients were approached by the nurse at either of the two outpatient transplant clinics with verbal and written information about the study. After consent was obtained the three different self-report instruments (Table 1) were utilised in paper form and handed out by nurses. The participants could either answer the questionnaires while waiting for the examinations and lab results or bring the instruments home and return them in a pre-paid and pre-coded envelope. The Postoperative Recovery Profile (PRP) was used to measure the degree of perceived recovery, graded from *fully recovered*, *almost fully recovered*, *partly recovered*, *slightly recovered* or *not recovered at all* (22). The Organ Transplant Symptom and Well-Being Instrument (OTSWI) was used to measure symptom prevalence, symptom distress, and transplant specific well-being (13). The Swedish version of the Psychological General Well-Being (PGWB)

Table 1 Self-assessment instruments employed

PRP: The 19 questions in the instrument cover different physical and mental symptoms, but also possible limitations in daily occupation and social life. The responses are given on a four point scale, i.e., none, mild, moderate, and severe. The timeframe is specified as how the recipients felt when completing the instrument. The level of recovery is based on the number of 'none' responses, where 19 (out of 19) 'none' responses equal fully recovered continuing with a descending gradient down to <7 'none' responses which equates with not recovered at all. The content validity of the instrument was high and a vast majority of the items showed a high level of intra-patient reliability (30)

OTSWI: The 20 questions in the instrument consist of eight factors measuring transplant well-being, fatigue, joint and muscle pain, cognitive functioning, basic activities of daily life (BADL), sleep problems, mood, foot pain, and economy. All eight factors had satisfactory internal convergent validity as well as good item-scale discriminatory validity. Together the eight factors accounted for 86% of the variance. Each response relates to the discomfort of a situation or problem, assessed on a five-point scale ranging from 'not at all'(0), 'a little'(1), 'somewhat'(2) and 'quite a bit'(3) to 'very much' (4). The timeframe was specified as the previous 7 days. The scale has a summary score of 0–80 where lower scores indicate higher well-being. In addition, symptom distress was measured by the degree of discomfort from twenty transplant specific symptoms graded from 'not at all'(0), 'a little'(1), 'somewhat'(2) and 'quite a bit'(3) to 'very much' (4) (13)

PGWB: The instrument contains 22 questions constituting six dimensions, anxiety, depressed mood, positive well-being, self-control, general health, and vitality. The timeframe was specified as the previous 7 days. The maximum PGWB-index is 132 (best subjective well-being) where higher scores indicate better health status and psychological well-being with a minimum score of 22 (poorest subjective well-being). A normal sum-score is in the range of 100–105, where women generally tend to report lower well-being than men (31). The instrument has good internal consistency as well as test-retest reliability and validity

instrument was employed to measure psychological well-being and distress (23).

Statistical analysis

The SPSS Statistics 24 (SPSS Inc., IBM Corporation, Armonk, N.Y., USA) was used for analysing the data, which were mostly ordinal. Ordered category data are presented with medians and percentiles (P_{25} , P_{75}). We used the following statistical analysis to test hypothesis regarding differences between two un-paired groups and relationships between different aspects of well-being and recovery: Chi Square, *T*-test, Mann Whitney *U* and Spearman's rho. Also Hierarchical multiple regression was used to answer the question, if we control for the possible effect of age and sex, are the PGWB- sum score and the OTSWI-sum score still capable of predicting a significant amount of variance in recovery? Values of

$p < 0.05$ (two-tailed) were considered statistically significant. The analysis was performed in a step-wise manner.

Perceived recovery was dichotomised into two groups, i.e., reasonably recovered patients represented by the levels *fully recovered*, *almost fully recovered* and *partly recovered* in the PRP-instrument and those not recovered represented by the levels *slightly recovered* and *not recovered at all*. Age was dichotomised into two groups, younger or older than 50 years. Length of stay in the ICU was dichotomised into longer or shorter than 7 days. Lung function was defined by Forced Expiratory Volume in 1 second (FEV_{10}) and the grade of chronic rejection i.e., Bronchiolitis obliterans syndrome (BOS). The BOS grade ranged from 0–3 and was dichotomised into two groups, with or without BOS. Hierarchical multiple regression was used to assess the ability of the PGWB-sum and OTSWI-sum to predict levels of recovery after controlling for the influence of age and sex.

Result

Patient characteristics

Demographics, indication for transplantation and immunosuppressive medications are presented in Table 2. The mean age of the participants was 54 years (SD 12.5) (range 18–74 years). At the two transplant units, the median time on a ventilator was 12 hours ($p_{25} = 3$; $p_{75} = 41$), median intensive care stay was 4 days ($p_{25} = 2$; $p_{75} = 8$), and median total hospital stay was 32 days ($p_{25} = 25$; $p_{75} = 46$). During the first year posttransplant 21.1% ($n = 4$) worked full time and 42.1% ($n = 8$) worked part-time. There were no gender differences regarding lung function (FEV_{10}) ($p = 0.111$) or BOS grade ($p = 0.072$).

Recovery

The PRP instrument response rate was 74% ($n = 87$), where 5.7% ($n = 5$) were *fully recovered* and 17.2% ($n = 15$) were *almost fully recovered* 1–5 years after LuTx. The recipients who were *partly recovered* and *slightly recovered* constituted 46% ($n = 40$) and 3.4% ($n = 3$) respectively. In total 27.6% ($n = 24$) were *not recovered at all*. Figure 1 presents the degree of recovery on a yearly basis 1–5 years posttransplant. The proportions of recovered LuTRs did not differ between men and women nor between patients younger or older than 50 years.

Characteristics of patients who were not recovered

The response rate on the OTSWI-instrument varied between 93% and 97% ($n = 109$ –113). The LuTRs who were not recovered reported lower transplant specific well-being compared to those who were reasonably recovered in all eight dimensions of the OTSWI instrument

Table 2 Demographics of the 117 included lung recipients.

	Frequency n and proportions (%)
Demographics	
Gender	
Female	59 (50)
Male	58 (50)
Median Age	57
≥50 years	85 (73)
≤49 years	32 (27)
Married/Cohabitant	75 (68)
Living arrangement, N = 110	
Living with children	27 (24)
Living without children	69 (63)
Other	14 (13)
Education, N = 111	
Primary	25 (23)
Secondary/Vocational education	59 (53)
University	27 (24)
Perceived ability to work, N = 110	
Unable to work	57 (52)
Full time	26 (24)
Part time	27 (24)
Type of graft	
Double lung transplantation	98 (85)
Single lung transplantation	18 (15)
Re-transplantation	12 (10)
Indications for transplantation	
Chronic Obstructive Pulmonary Disease (COPD)	29 (25)
Lung fibrosis	24 (21)
Cystic fibrosis	19 (16)
Lack of Alpha 1-antitrypsin	19 (16)
Other	12 (9)
Pulmonary Arterial Hypertension (PAH)	7 (6)
Emphysema	4 (3)
Bronchiectasis	3 (3)
Immunosuppressive medications ^a	
Mycophenolate mofetil (MMF)	79 (75)
Steroids	63 (59)
Cyclosporine	61 (57)
Tacrolimus	45 (43)
Rapamycin	34 (32)
Azathioprine (AZA)	12 (11)

Data regarding type of graft is missing for one patient.

^aMany recipients had a triple combination of immunosuppressive drugs, which is why frequency is larger than total n included in the study.

($p \leq 0.001$). The p-value for sleep problems was 0.012. The OTSWI sum-score differed between the two recovery groups ($p < 0.001$). The recipients who were not recovered suffered from more distress in all symptoms except increased appetite, dyspepsia and headache ($p < 0.001$ –0.034). Recipients who were not recovered were a longer time on the ventilator ($p = 0.005$) and also had a longer intensive care stay ($p = 0.001$) and total hospital stay

($p = 0.005$). Among the 27 recipients who were not recovered, 14.8% ($n = 4$) worked full or part-time.

One year after LuTx, there was a moderate correlation between recovery and time on the ventilator, (r_s 0.472), as well as between recovery and length of intensive care stay (r_s 0.390). This relationship between recovery and length of time in the intensive care unit was also apparent after 2 and 3 years (r_s 0.492 and 0.540).

There were 67% ($n = 77$) without BOS and 33% with BOS grade 1–3 ($n = 38$) and two patients where the BOS-grade was missing. Among those with BOS, 12 had grade 1, 16 had grade 2 and 10 grade 3. Thus a majority didn't suffer from chronic rejection. The proportion of LuTRs with BOS were not significantly higher among those not recovered than among those reasonably recovered ($p = 0.558$). A weak relationship ($r_s = -0.262$) was identified between recovery and lung function (FEV_1) while no relationship was found between BOS and recovery ($r_s = 0.018$).

Recovery in relation to symptoms and transplant specific well-being (OTSWI)

There was no relationship between lung function (FEV_1) and OTSWI-sum ($r_s -0.109$). The lowest transplant specific well-being, with a possible score ranging from 0 to 80, was reported 4 years after transplantation, median 22 ($p_{25} = 11$; $p_{75} = 32$). There were no differences between male and female recipients in overall transplant specific well-being. In the second and fourth year medians of 4 and 5.5 respectively were reported (min 0, max 12) in the sleep problem dimension. The highest median of fatigue was reported on the fourth year 4.0 (min 0, max 12). Female lung recipients reported worse joint and muscle pain (JMP) ($p = 0.012$) and sleep problems (SP) ($p = 0.04$) than their male counterparts.

As shown in Tables 3 and 4, the five most prevalent symptoms 1–5 years after LuTx were not always experienced as the most distressing ones. Female LuTRs reported worse headache ($p = 0.05$), nausea ($p = 0.02$), and dizziness ($p = 0.026$) than male LuTRs who reported more problems with trembling hands ($p < 0.001$). The only relationship identified between BOS grade and the 20 investigated symptoms were with dyspnoea ($r_s = 0.221$) and dyspnoea while resting (r_s 0.216).

There was a strong correlation between transplant specific well-being (OTSWI-sum score) and recovery 1–5 years after LuTx ($r_s = 0.741$). This correlation was evident each year ($r_s = 0.655$ –0.821) with the strongest correlation after 1 year.

Recovery in relation to psychological well-being (PGWB)

The response rate on the PGWB-instrument was 97% ($n = 113$). A normal PGWB-sum score is in the range of

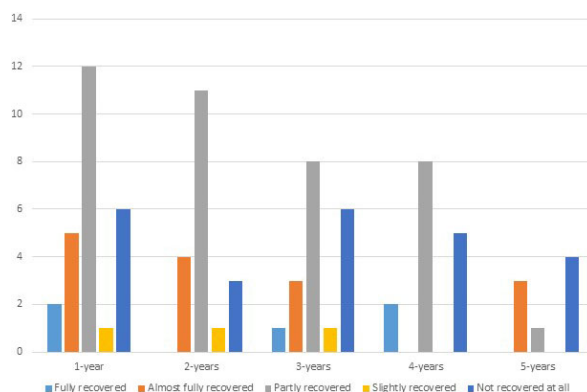


Figure 1 The frequency (N) of lung recipients at each level of recovery at each yearly follow-up.

Table 3 The ten most prevalent symptoms reported by the recipients 1 to 5 years after transplantation

Symptoms (prevalence)	Total n	Not at all	A little	Somewhat	Quite a bit	Very much
My hands are trembling (66%)	113	38	42	19	8	6
I am breathless (62%)	112	43	37	20	4	8
My libido is decreased (60%)	111	44	31	17	11	8
I have headache (59%)	113	46	34	19	8	6
I need to rest because I am breathless (49%)	112	57	24	17	7	7
I have diarrhoea (47%)	112	59	31	12	4	6
I feel sad (47%)	111	59	31	11	6	4
I'm swollen (46%)	112	60	31	11	4	6
I have increased appetite (44%)	113	63	23	22	5	0
I feel dizzy (34%)	113	74	33	4	1	1

Table 4 The ten most distressing symptoms reported by the recipients 1–5 years after lung transplantation

Symptoms	Total n	Not at all	A little	Somewhat	Quite a bit	Very much	High distress
My looks make me embarrassed (26%)	113	83	17	3	3	7	33%
My libido is decreased (60%)	111	44	31	17	11	8	28%
I have decreased appetite (24%)	113	86	14	6	2	5	26%
I need to rest because I am breathless (49%)	112	57	24	17	7	7	25%
I have headache (59%)	113	46	34	19	8	6	21%
My hands are trembling (66%)	113	38	42	19	8	6	19%
I have diarrhea (47%)	112	59	31	12	4	6	19%
I feel sad (47%)	111	59	31	11	6	4	19%
I'm swollen (46%)	112	60	31	11	4	6	19%
I feel nauseous (29%)	113	80	20	7	2	4	18%

100–105. PGWB-sum scores were within or above the range of normal values, indicating good psychological well-being and health status for all years except the fourth, where the median was 93.5 ($p_{25} = 79.5$; $p_{75} = 109$). At the 4-year follow-up 70% ($n = 14$) reported poor psychological well-being, whereas a

majority had reported good psychological well-being at all other annual follow-ups, ranging from 57.1% to 72.7%. When dichotomising the PGWB-sum-score into good psychological well-being (>100) and poor psychological well-being (<100), 55.6% ($n = 65$) reported good psychological well-being and 41% ($n = 48$) poor

psychological well-being 1–5 years after LuTx, while 3.5% ($n = 4$) were missing. There was no relationship between lung function (FEV_1) and recovery ($r_s = 0.117$).

The median of the general health sub-dimension was good in all years, range 14–16 (max 18). Patients treated on the ventilator for more than 30 hours reported lower general health ($p = 0.036$). There was no difference regarding age, sex or length of intensive care stay in the dimensions of general health and overall psychological well-being.

There was a strong relationship between recovery and psychological well-being after 1–5 years ($r_s -0.720$). This correlation ranged between $r_s -0.662$ to 0.806 for each individual year with the strongest correlation after 4 years ($r_s -0.806$). There was also a relationship between the sub-dimension of general health and recovery for each year in the range of $r_s -0.583$ to 0.886 , with the strongest correlation after 5 years ($r_s -0.886$).

LuTRs who were *slightly recovered* or *not recovered at all* reported decreased psychological well-being, median 96 and 79, respectively ($p < 0.001$). Recipients who were *partly*, *almost* or *fully recovered* reported good psychological well-being and general health (Table 5).

Together, the OTSWI-sum score and PGWB-sum score explained 54.4% of the variance in recovery after controlling for age and sex (R square change = 0.544 , F change (2.81) = 49.79 , $p < 0.001$), with the OTSWI-sum score recording a higher beta value ($\beta = 0.45$, $p < 0.001$) than the PGWB-sum score ($\beta = -0.34$, $p = 0.006$).

Discussion

The key findings in this study were:

- Few LuTRs perceive that they are recovered 1–5 years after LuTx.
- There is a strong relationship between perceived recovery and both psychological general well-being and transplant specific well-being.
- No or weak relationship was identified between lung function and perceived recovery as well as both

psychological general well-being and transplant specific well-being.

- Transplant specific well-being makes the largest unique contribution to perceived recovery.
- It is possible to be partly recovered and experience good health.

To the best of our knowledge, this is the first study to explore the degree of recovery and well-being after LuTx, and the findings imply that changes are required in follow-up care. First, very few (5.7%) LuTRs perceived themselves to be *fully recovered* and 28% were *not recovered at all* 1–5 years after transplantation. This raises questions as to whether it is reasonable to expect full recovery in terms of being symptom free, how recovery after transplantation should be defined, and what kind of self-management support is required by the recipients. A previous qualitative study provides transplant nurse practitioners with a framework for the recovery process, as well as the following definition of posttransplant recovery from a patient-perspective;

Posttransplant recovery is a dynamic, demanding process involving a transition from pre-transplant severe illness to a state of experienced health, achieved by adjusting to regained physical, psychological, social and habitual functions. Essential parts of the transitional recovery process consist of symptom management, achieving an optimum level of psychological well-being, social adaptation and reconstructing daily occupations. (10)

The framework and definition together with the result of this present study might serve as a guide for the type of self-management support required after LuTx.

One of the most important goals of transplantation is to improve and promote health related quality of life (24). Our findings demonstrate that the recipients often had a very complicated recovery process characterised by the prevalence of many symptoms and setbacks, where the support of healthcare professionals in the promotion of well-being and health is a key element.

Although LuTx is a life-saving treatment, the goal is not to completely cure a disease or repair a surgical

Table 5 Median total score of the well-being in the five recovery groups

Level of recovery (n)	PGWB sum-score ^a median (p_{25} p_{75})	General health ^b median (p_{25} p_{75})	OTSWI sum-score ^c median (p_{25} p_{75})
Fully recovered (5)	118 (113, 121.5)	16 (16, 17.5)	3 (1,6)
Almost fully recovered (15)	115 (113, 118)	17 (16, 17)	5 (3,9)
Partly recovered (40)	105 (96, 111.8)	15 (14, 16.8)	15 (10, 23)
Slightly recovered (3)	96 ($p_{25} = 63$)	12 ($p_{25} = 9$)	21 ($p_{25} = 10$)
Not recovered at all (24)	79 (66.5, 94.3)	9.5 (8, 11.8)	32 (20.3, 38)

^aIn the Psychological General Well-being instrument (PGWB) max is 132 and higher scores indicate higher well-being.

^bIn the subscale General Health (GH) max score is 18 with higher score indicating better health.

^cIn the Organ Transplant Symptom and Well-being Instrument (OTSWI), maximum score is 80 and the higher the score, the lower the well-being.

problem but rather to move from an end-stage disease to better health and well-being, albeit characterised by a chronic condition requiring life-long medication that causes side-effects and complications. Health systems and health care today are organised around an acute and reactive model of care that does not meet the needs of patients with chronic conditions and multiple pathologies (25) such as LuTRs. This important fact is often disregarded (25) and therefore follow-up care after LuTx should be reorganised to a multi-professional team approach based on patients' own experience of the recovery process and their chronic condition.

The fact that recipients who were not recovered were characterised by lower psychological and transplant specific well-being, as well as higher symptom burden must be acknowledged during the posttransplant follow-up. As depression has proven to be a predictor of an increased risk of mortality (19, 20) and morbidity (15), it is of the utmost importance to identify those recipients who are *slightly or not recovered at all*, after which the follow-up care should be specifically designed to find recipients with lower well-being and screen them for depression. In two review studies it is recommended that healthcare professionals should assess transplant recipients' psychological well-being and screen for depression as part of routine clinical care (16, 20).

A majority of the recipients were *partly recovered* and despite the presence of numerous symptoms still reported well-being and good general health. In a previous qualitative study the LuTRs described several symptoms and complications, yet experienced health (9). Furthermore, the most frequent symptoms were not always the most distressing ones, thus both symptom frequency and burden must be measured posttransplant. One symptom that is thoroughly investigated is chronic pain after LuTx, which might further affect recovery and requires pain assessment during follow-up (26, 27).

To our surprise there is only a weak relationship with the present lung function, presence of chronic rejection and recovery. Also no relationship was identified between lung function and well-being. Thus it suggests that objective measures of recovery by means of lung function might not be enough as a recovery marker. The question as to why LuTRs can experience health despite the presence of symptoms might be explained by the fact that an adaptation process occurs. Adaptive responses contribute to health, whereas ineffective or maladaptive responses do not (28). When tailoring follow-up care for LuTRs, adaptation as a means for achieving health should be considered and supported by the transplant team. One of the most important goals of transplant nursing is health-promotion (24), which consists of both support provided by healthcare professionals at the clinics and hospitals and self-management support, which is a major part of self-care when at home. Self-management support

is a key component of effective chronic illness management and improves patient outcomes (29). Understanding the recovery process is a prerequisite for the development of guidelines to enable healthcare professionals to conduct health promotion and enhance well-being. Transplant nurses involved in the follow-up care should emphasize symptom-management support in order to minimise symptom burden, but a focus on health management is equally important. In the light of our study where a majority of the recipients experienced well-being and good health, the key mission for transplant nurses should be health promotion, preferably at an outpatient clinic led by advanced nurse practitioners.

Future prospective studies are important in order to investigate the recovery process trajectory and identify predictors of both a complicated and a positive course of recovery. Furthermore, greater focus should be placed on the recipient's adaptive strategies for attaining well-being and health.

Methodological considerations

The cross-sectional design of our study prevents us from identifying any causal relationships. A selection bias may be apparent due to our exclusion of non-Swedish speaking, hospitalised recipients and the loss of patients due to transplant mortality, which resulted in a fairly small sample in the fifth year. In addition to the above-mentioned selection bias, the context of medical care context should be taken into consideration as it might not only differ internationally but also nationally at the two transplant centres in Sweden.

Conclusion

In conclusion, there is a high frequency of symptoms after LuTx. Despite the fact that few recipients achieve full recovery after LuTx, well-being can still be experienced. Objective signs such as lung function is not enough as recovery markers since they are not related to the lung recipients' illness experience. The low degree of perceived recovery is related to poor psychological well-being while high symptom distress might be a marker of an increased need for self-management support.

Clinical implications

- The degree of self-perceived recovery and symptom distress should be systematically evaluated after LuTx in order to identify recipients with impaired well-being.
- The goal of posttransplant follow-up after LuTx should be health promotion by supporting recipients' symptom- and health management as well as adaptive strategies.

- Long-term follow-up should include health promotion at an outpatient clinic, preferably managed by a multi-professional team led by advanced nurse practitioners.

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Author contributions

Martina Lundmark: study conception/design, data collection, analysis and drafting of manuscript. Annette Lennerling: study conception/design, drafting of manuscript, critical revision of important intellectual content and

supervision. Matilda Almgren: data analysis and drafting of manuscript. Anna Forsberg: study conception/design, data analysis, drafting of manuscript, critical revision of important intellectual content and supervision.

Ethical approval

The Regional Ethical Review Board of southern Sweden granted permission to carry out this study (D-nr. 2014-124).

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Paper IV



Developing a Grounded Theory on Adaptation After Lung Transplantation From Intermediate-Term Patient Experiences

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Abstract

Background: Previous research revealed that it is possible for lung recipients to experience health 1 year posttransplant, despite not being fully recovered. However, an in-depth, long-term perspective on how lung recipients' health transition evolves over time is lacking. Thus, the aim of this study was to further develop a grounded theory of health transition by exploring the process of change 1 to 3 years after lung transplantation. **Methods:** The grounded theory method was used prospectively to analyze the narratives of 14 adult lung recipients who were included at their 1-year follow-up and reinterviewed 2 years later. **Results:** This novel study contributes an in-depth understanding of the adaptation process after lung transplantation. The greatest concern in the 3 years after lung transplantation was adaptation to a new normality, which was achieved by 3 main strategies: compare, accept, and adjust. Adaptation to a new normality involved understanding that one's previous life no longer exists and that a new way of living requires adaptation. Successful adaptation resulted in the experience of health and well-being, whereas too many symptoms and limitations in everyday life led to difficulties and a profound sense of illness. **Conclusions:** Lung recipients can experience health, despite symptoms and complications by adapting to a new normality. This individual process begins post-transplant and continues throughout life.

Keywords

lung transplantation, adaptation, grounded theory, qualitative, posttransplant follow-up, recovery, nursing

Background

The rationale behind this study is the lack of in-depth knowledge of the long-term health transition after lung transplantation. The first posttransplant year has been covered in detail,¹ resulting in the question "How is it possible for lung transplant recipients to experience health and well-being despite numerous symptoms and complications?" Lung transplantation is an established treatment for patients with end-stage pulmonary disease.^{2,3} More than 50 000 single and double lung transplantations have been performed worldwide.⁴ Recovery after transplantation is demanding, requiring adherence to a complex self-management regime leading to a risk of nonadherence.⁵ Lung recipients are considered to deal with a chronic condition requiring lifelong medication that causes side effects and comorbidities. It is essential to take the recipients' own experience and knowledge into account when organizing long-term follow-up. The starting point is to identify their main concerns after lung transplantation and in the long term. Lung transplant recipients have many different symptoms during the recovery process, partly due to immunosuppressive treatment.⁶⁻⁹

A recent study of 117 lung recipients 1 to 5 years posttransplantation revealed that very few perceived themselves to be fully recovered without symptoms or restrictions in everyday life.¹⁰ There was no relationship between perception of recovery, forced expiratory volume in 1 second, and bronchiolitis obliterans syndrome (BOS), a way to grade chronic rejection. Lung transplant recipients with BOS did not experience

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significantly less recovery than those without BOS. Only 6% of the recipients reported full recovery, and 28% had not recovered at all 1 to 5 years after transplantation. A majority reported being partly recovered with good well-being and general health, despite numerous symptoms. The 3 most prevalent symptoms were tremor (66%), breathlessness (62%), and decreased libido (60%), while the symptoms perceived as most distressing were embarrassment about appearance, decreased libido, and poor appetite.¹⁰ Lundmark et al., demonstrated that despite various setbacks and complications, a health transition occurs during the first year posttransplant.¹ To gain a longitudinal understanding of the transition process as well as recipients' main concerns and how they deal with them up to 3 years posttransplant, the aim of the study was to further develop a grounded theory of health transition by exploring the process of change 1 to 3 years after lung transplantation.

Materials and Methods

As this study was prospective, changes in the researchers' pre-understanding between the 2 data collection occasions had to be considered. Consequently, Constructivist Grounded Theory¹¹ was used because it emphasizes how data, analysis, and methodological strategies are constructed and takes the research context and the researchers' perspectives into account. Data collection started 1 year after lung transplantation, and the interviews were analyzed by Lundmark et al.¹ The present study reports interviews with the same recipients performed 3 years posttransplant. The findings cover the transition process 1 to 3 years after lung transplantation. The regional ethical review board of southern Sweden granted permission for the study (D-nr. 2014-124).

Setting and Selection

Due to the prospective study design, the selection of the informants (N = 14), 10 men and 4 women with a mean age of 56 years, was predecided. They had all been interviewed at their 1-year follow-up and were due for their third annual follow-up at the 2 transplant units in Sweden where lung transplantation is performed. One female recipient could not be reinterviewed due to mortality. We chose not to replace her with a new informant. All participants except 1 had undergone bilateral lung transplantation. The one exception had received bilateral lungs and a heart. The second interview was arranged either by a nurse at the transplant clinic or by the first author (M.L.). Demographic characteristics are presented in Table 1.

Data collection

The individual face-to-face (n = 11) and telephone interviews (n = 3) took place between June 2016 and February 2017. The interviews began with an open-ended question asking the informants to describe their experiences and recall thoughts, emotions, and actions, since the first interview 1 year

Table 1. Demographic Characteristics of the 14 Informants and Their Indications for Lung Transplantation.

Characteristics	Number of Patients
Demographics	
Female/male	4/10
Double lung transplantation	13
Double lung transplantation and heart transplantation	1
Working	5
Retired	6
Sick leave	2
Studying	1
Married or cohabiting	6
Single	8
Indications for transplantation	
Chronic obstructive pulmonary disease	4
Lung fibrosis	4
Cystic fibrosis	4
Pulmonary arterial hypertension (PAH)	1
Other	1

Initial coding was performed through line by line coding when reading the interviews with focus on the main concern of the recipients as well as strategies used to deal with the main concern. Words or phrases, actions and processes indicating important categories related to the research questions were highlighted.

Focused coding was conducted to detect and explain the most frequent and significant codes which illuminated the tentative main categories as well as strategies used by the recipients in relation to their main concern.

In the theoretical coding specified relationships between the generated categories from the focused coding was developed and the main concern as well as the categories was conceptualized.

Throughout the analysis, the constant comparative method was used on data i.e. comparing incidents to incidents, incidents to concepts and concept to concept throughout the dataset. A constructivist approach was used, meaning that the categories and theory were developed from the patterns revealed by the researchers' theoretical constructions of the informants' narrative, in line with the constructivism of Charmaz.¹¹ When no new sub or main categories emerged from the data, theoretical saturation was achieved in accordance with Grounded Theory Method.¹¹

Figure 1. The coding analysis according to Grounded Theory Method.

posttransplant. Examples of questions are Could you please tell me what has happened since the last interview? What happened next? and How do you feel now? Follow-up questions were posed to encourage the informants to expand their answers and clarify their thoughts and experiences, including those expressed in the previous interview. The interviews were digitally recorded, transcribed verbatim, and lasted on average 59 minutes (range: 29-95 minutes). Both the 1- and 3-year interviews were performed by the first author (M.L.) who was not involved in caring for the informants and had no information about their medical condition.

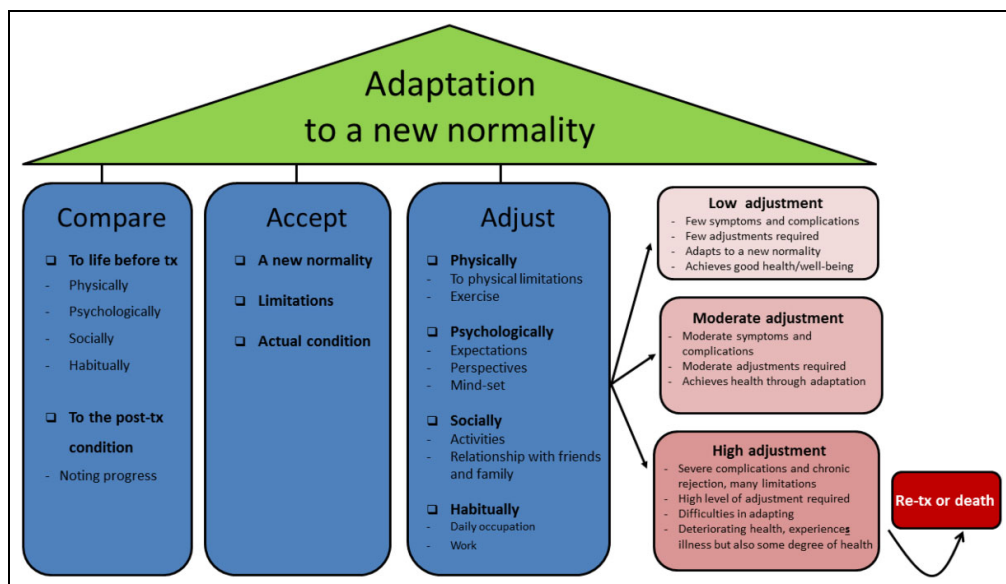


Figure 2. The process of adaption to a new normality in the first 3 years after lung transplantation as experienced by 14 lung transplant recipients.

Data Analysis

The grounded theory method analysis consists of initial coding, focused coding, and theoretical coding as well as the constant comparative method¹¹ described in Figure 1. Data collection and preliminary analysis were conducted simultaneously. After each interview, memos were written. Later in the interview process, the memos became more theoretically focused as a theory started to emerge, which was later confirmed by the final analysis.

Results

The generated grounded theory revealed the main concern up to 3 years after lung transplantation and is summarized in the core category, adaptation to a new normality. The core category comprises 3 main categories illuminating the process of adaptation to a new normality, namely, compare, accept, and adjust (Figure 2). The main categories contain several subcategories and provide a detailed description of the adaptation strategies used by the transplant recipients. Quotations (Q1-Q17) from the informants are presented in Table 2.

Adaptation was described as changing one's behavior and everyday life to make them compatible with the new normality of being a lung recipient with or without symptoms and complications (Q1). Adaptation was both a process and an outcome of health and included all conditions, circumstances, and influences that affected the behavior of the recipient. In

this context, conditions were immunosuppressive medications and the chronic condition caused by transplantation. Circumstances and influences were symptoms and complications as well as the psychological, social, and habitual context of the recipients (Q2).

Higher or lower degrees of adjustment were necessary depending on the symptom burden. The ability to adjust and adapt was limited by physiological and psychological conditions. Health was achieved when the adaptation was experienced as successful. A profound sense of illness occurred when optimal adaptation was impossible due to too many complications or restrictions. Although illness was present in particular situations, it was still possible to experience some degree of health and well-being in other parts of life (Q3).

A new normality was initially undefined by the recipients. It was a continuous individual process, where the recipient tried to adapt to living with a chronic condition and constantly changing environment. The recipients possessed their own unique ability to create a new normality based on their life situation and how much adaptation is required (Q4).

Adaptation to a new normality was a physical, mental, social, and habitual process based on the understanding that one's previous life no longer exists and that a new way of living requires adaptation (Q5).

All informants used the main strategies compare, accept, and adjust in order to adapt but to a different extent depending on their condition. Accepting their condition and the necessary

Table 2. Quotations From the Informants.

Categories	Quotations From the Informants
Core category: Adaptation to a new normality	<p>Q1: "I think it's amazing how you adapt and adjust to your condition when there is no other alternative. In that way you learn how to live with it." (Male, 65 years)</p> <p>Q2: "Everything is constantly changing. You have to adapt all the time when new things occur." (Male, 27 years)</p> <p>Q3: "... You had your old normality when you were sick and adapted to manage your life with the restraints and now you are in a new situation that you have to adapt to... You adapt to the restraints you experience so that you feel normal again, or adjusted to the new normality." (Male, 27 years)</p> <p>Q4: "It is impossible to return to where you were... You simply have to adapt to the new reality." (Male, 71 years)</p> <p>Q5: "Well, I feel that I have adapted already. And yes, it is a different life. But it's a good life... Your life has changed, everything is different. You have to process the whole thing and find a way of existing. And there is the mental process, you have to, sort of, be true to yourself and then find a reasonable way of living." (Female, 60 years)</p>
Main categories: Compare, accept, adjust	<p>Q6: "Well, the fact is that I would be dead if I hadn't received this opportunity. That's why I only see things in a positive way, the life I had before wasn't a life. I was completely limited and everything was demanding, you can't compare to how I am now... And despite the fact that I've had many set-backs and complications, it is worth it." (Female, 63 years)</p>
Compare	<p>Q7: "I have absolutely no complaints. For once I've got a life. I never had a life before. My whole life was focused on breathing exercise, mobilizing mucus, coughing... there was no spare time. Now I have six hours of extra time every day to do whatever I want, instead of doing breathing exercises." (Male, 59 years)</p> <p>Q8: "... I feel that even if I don't have full capacity it is fantastic compared to my previous condition... And I do compare (with my life pre transplant) and that's why I appreciate and value the life I have today... To be honest, I'm not sure I would be still alive... You see life in a completely different way, you appreciate and value life in a different way, you don't take things for granted anymore." (Female, 63 years)</p> <p>Q9: "When I compare the life I have now with life pre-tx, with all the complications I still have a better life now, that's the way you have to see it." (Female, 63 years)</p> <p>Q10: "So it's like, if your strength increases, then you push harder, you want to push yourself all the time... it strengthens your confidence, it feels positive when you notice progress and then you push yourself even harder to see if you can do more." (Female, 63 years)</p>
Accept	<p>Q11: "I accepted my situation then [pre-transplant] and I accept my situation now as well. No anxiety, nothing dramatic. Life has different sides and I want to focus on the bright ones." (Female, 60 years)</p> <p>Q12: "... I just accept that I have to forget certain things [being able to travel to certain places]. You have to realize that you can't keep longing for things that aren't going to work, there's no point!" (Male, 69 years)</p> <p>Q13: "We all know that life is limited and people around me die. Many times I feel I'm in the waiting room of death. But, so what? If that's the case then so be it. We will all die and I'm not afraid. When you're in pain and everything is miserable, death might be a blessing." (Male, 71 years)</p>
Adjust	<p>Q14: "The human being has an incredible ability to adapt and so have I. When I couldn't run anymore I walked, when it was harder to breathe, well, then I had to walk even more slowly, you adjust!... so of course, you can have a lot of complications but the quality of life is so much better than before." (Female, 43 years)</p> <p>Q15: "When your strength is gone it's gone. When you get breathless while putting on your shoes. And you don't know how to get up from the chair and how to reach the door and to go out. It is unbelievable how bad it can be. But I have learnt to take it easy, I simply take it easy. I might be late but who cares? It's better than not getting there at all..." (Male, 71 years)</p> <p>Q16: "I can't deny that I expected to feel fine afterwards. I sort of believed that everything would be fine. But later, well with my medical history and everything, I have always been more cautious, thought that everything might not be perfect after all." (Male, 27 years)</p> <p>Q17: "I suffer from chronic rejection. It is unlikely that it will improve, but you never know. In half of the cases it helps. If it doesn't work, it doesn't work. And then there is no rescue plan B." (Male, 71 years)</p>

adjustment enabled adaptation. The process was facilitated by constant comparison of their pre- and posttransplant condition, which enabled realistic expectations and acceptance of the situation. A positive outcome and sense of health emerged when expectations were adjusted to what can actually be accomplished (Q6).

Main Categories

Compare

The recipients compared their present condition to life pre-transplant within all dimensions of life: physical, psychological, social, and habitual. Within the physical dimension, the

informants concluded that daily life posttransplant contained less breathing problems, coughing, breathing exercises, fatigue, and fewer limitations (Q7). Within the psychological dimension reflective thoughts were common posttransplant, where gratefulness and appreciation of having received a second chance emerged. Sadness about not experiencing the health they had before the lung disease also occurred. However, comparison with the alternative of not having had the chance to receive new lungs made them appreciate life, despite not being fully recovered (Q8). Within the social dimension, the comparison to the often very restricted social life pretransplant made them aware of a positive improvement despite adjustments and limitations. When facing chronic rejection, adjustment by means of deconstruction of social life was necessary, which was comparable with life pretransplant. Within the habitual dimension, most recipients enjoyed a far more enriching everyday life, despite limitations and required adjustments. The possibility of performing daily activities, sometimes impossible pretransplant, was positive and resulted in a feeling that they had better health and well-being than before. The positive outcome of the comparison facilitated adaptation.

Besides comparison to their condition pretransplant, the recipients also compared their present situation with the early phases of rehabilitation posttransplantation, which frequently resulted in satisfaction with their improved condition (Q9). They used goal setting and reflection as active strategies for noting progress. Constantly comparing and reflecting on physical accomplishments increased their motivation, self-confidence, and well-being. The recipients' goals were often modest and based on everyday life tasks or basic physical functioning, thus making them possible to accomplish (Q10).

Accept

Acceptance involved submitting to a new normality, limitations, and one's actual condition.

The acceptance of a new normality was an individual process that involved different components depending on the prevalence of symptoms and complications as well as how much they affected everyday life. In some cases, the adjustments were small, such as taking medications, exercising, and avoiding exposure to possible infections, while in others the adjustment was far greater and limited everyday life. They did not expect to recover fully and accepted this fact, thus focusing on experiencing health instead.^{Q11} The informants' new normality included acceptance of the possibility of graft rejection, which they coped with by being aware of it without letting the fear control their life. They also accepted certain limitations such as the forms of transport they could use and the places they could go to as part of their new normality.

The new normality involved individual limitations to varying degrees, such as being unable to perform the same activities or travel as before and acceptance of diminished physical ability (Q12). Limitations were also related to immunosuppressive medications and restrictions inherent in transplantation. Comparison with pretransplant breathing difficulties was common,

resulting in the conclusion that the less intrusive symptoms and complications posttransplant were easier to accept and affected everyday life to a lesser degree. A fatalistic approach was adopted, where the actual condition and life course were accepted. Informants facing chronic rejection accepted the possibility of death or retransplantation as well as the fact that life might be shorter than expected (Q13).

Adjust

Adjustment is defined as a small change made to something or way of doing something. When recipients adjusted to a new situation, they changed their behavior or ideas, often involving all aspects of life. The 4 subcategories describe in detail how the recipients adjusted physically, psychologically, socially, and habitually.

Physically

Adjusting physically involved adjusting to physical limitations and adjusting exercise. Most necessary physical adjustments were perceived as acceptable and resulted in health and well-being. The one exception was adjusting to respiratory failure, which often restricted daily life to a greater extent and was thus more intrusive (Q14).

Many of the adjustments involved physical limitations due to symptoms and complications. Symptoms originating from respiratory failure such as chronic rejection, narrowed or collapsed anastomoses in the bronchus, often limited the recipients' physical performance as evidenced by dyspnea, tachypnea, coughing, and fatigue. This required a slower walking pace, rest during activities, or performing daily occupation in a different way. Resting due to fatigue or breathing difficulties was another common form of adjustment as well as performing all activities step by step in order to accomplish them (Q15). Respiratory failure also resulted in an increased breathing workload and thereby a need for greater energy intake. Recipients adjusted their diet accordingly, exercised to gain strength, and ensured sufficient energy intake.

Other physical conditions that required adjustment were the side effects of immunosuppressive medications, comorbidities such as blindness due to fungal infection, osteoporosis, muscle weakness due to steroids, skin cancer, and cognitive disorders. The complications and associated limitations were often accepted as part of the new normality and adjustments made. Despite their prevalence, health and well-being could be achieved.

Exercise was adjusted by exercising at certain times of the day, resting between exercises, or choosing appropriate activities. However, exercise was often restricted due to respiratory complications.

Psychologically

Psychological adjustment included several strategies such as adjusting expectations, perspectives, and mind-set. When

psychologically adjusting to the new normality, a transition process took place that involved changing perspectives on life as well as acknowledging its fragility and finiteness. Different strategies were used when adjusting expectations, such as lowering, balancing, or changing expectations.

The often very complicated posttransplant care forced the lung transplant recipients to lower their expectations. This could involve not expecting a full recovery, not expecting to be symptom free, or not striving for full life expectancy. When facing chronic rejection, expectations were lowered to a basic level of managing daily activities due to physical restrictions.

The lung transplant recipients continually balanced their expectations based on what kind of physical accomplishments they achieved or failed to achieve. The ability to balance their expectations was sometimes a product of an extended period of illness pretransplant as well as a complicated postoperative course (Q16). It was often necessary to change the entire perspective on life.

Focusing on health and well-being became more important than focusing on a full recovery, which was often impossible to achieve. They also adjusted perspectives on life by prioritizing differently, living in the here and now, and filling life with meaningful activities and people. Insignificant or trivial things that had seemed important pretransplant were replaced by more meaningful ones. The changed focus and adjusted mind-set were part of the psychological transition process when adapting to the new normality.

Recipients were often fatalistic, and while they believed in the future, they were aware of possible complications and adjusted their life goals. Those dealing with chronic rejection or many symptoms and complications also had to adjust psychologically to coping with negative emotions, stress, and fear of graft rejection (Q17). This could involve concrete actions such as taking walks when feeling down or handling emotional stress by planning social activities. They also adjusted their personality traits to the new normality due to less ability to handle stress, agitation, emotional, and cognitive changes.

Socially

Social adjustment involved adjusting activities and adjusting the relationship with friends and family due to their condition and the effect of immunosuppressive medications. Many activities in the informants' lives had to be adjusted due to their condition or the recommended restrictions intended to prevent infections. Some activities were easily and willingly adjusted while others were not. Adjusting activities included planning ahead in order to carry them out. Recipients avoided crowded places, public transportation, and some social activities. They adjusted their travel habits, avoiding flying or spending holidays in remote areas.

Social adjustment among friends and family was achieved by choosing the social context and avoiding sick people, day care, and sick grandchildren. Significant others adjusted activities carried out together, which could involve visiting the recipient in her or his home instead of meeting in a café or choosing

a café close to the recipient's home in order to avoid a strenuous walk. Families often adjusted to daily habits such as using a hand sanitizer and reminding the recipients to take their medications. Positive social adjustment was also present when the recipients had the energy to expand their social context.

Habitually

Habitual adjustment involved adjusting daily occupation and work. Adjustment of daily occupation included healthy eating, using sun protection and hand sanitizer in addition to adjusting sleep habits based on medication intake. Due to symptoms, the informants had to adjust daily activities, for example, planning shopping or asking for help carrying shopping bags. Some informants sat down while preparing food or adjusted in other ways. Adjusting work included changing work assignments to less physically demanding jobs, avoiding sick people at work, avoiding certain environments due to the risk of infection as well as not shaking hands, working less hours, or working from home.

The Longitudinal Process of Change From 1 to 3 Years Posttransplant

The grounded theory developed 1 year posttransplant revealed that lung transplant recipients' main concern was reconstructing daily occupation (1) for which the main strategies were restricting, regaining, re-organizing, and enriching, as presented in Figure 3. A health transition trajectory was evident up to 1 year posttransplant when most informants experienced health.

The developed grounded theory reveals 3 different trajectories starting 1 year posttransplant after the Enriching phase, presented in Figure 3. Depending on the symptoms and complications experienced, low, moderate, or high adjustment was required as described in Table 3 and Figure 2. Informants requiring a high level of adjustment often returned to square one, that is, the pretransplant period of restricted daily occupation.

The present findings have deepened our understanding of the analysis of the interviews conducted at 1-year follow-up, which actually provides a detailed description of how the lung transplant recipients adjust habitually during the first year to adapt to a new normality. The overall understanding after 3 years is that adaptation to a new normality begins immediately posttransplant by extensive adjustment of daily activities, followed by an adaptive process involving all areas of the recipients' lives. This continuous process is never-ending.

Discussion

Methodological Considerations

We opted to follow Charmaz's evaluation criteria for rigor in grounded theory methodology studies.¹¹ Grounded theory method emphasizes the importance of not being consciously directed by earlier theories and concepts when interpreting

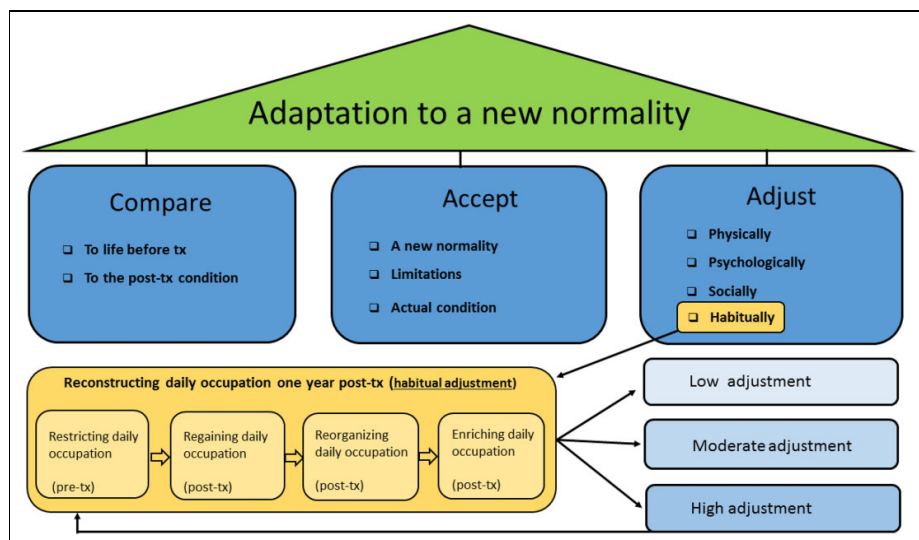


Figure 3. The process of adaption to a new normality in the first 3 years after lung transplantation including the detailed process of reconstructing daily occupation identified during the first year.

Table 3. Three Categories of Lung Recipients Based on their Adaptation and Their Current Health Condition 3 Years After Lung Transplantation.

Low adjustments required

Lung recipients with few symptoms and complications that demand few adjustments. The adjustments made have a minor impact on daily occupations. Physical as well as psychological abilities are perceived as good. The process of adaptation is focused on adjusting to the specific chronic condition of a transplantation, adjust work, studies, and travels as well as adjust to a new normal with friends and family. Little self-management support is needed

Moderate adjustments required

Lung recipients with many symptoms and complications requiring moderate adjustments in many different dimensions of life. They use the strategy of comparing to pretransplant condition to a greater extent than the first group resulting in a positive comparison. They accept possible limitations and manage to adapt to their new normal life and to achieve health and well-being with the need of a fair amount of self-management support

High adjustments required

Severely limited lung recipients who experience many limitations, often due to chronic rejection. Symptoms experienced were often respiratory failure that had a severe and restricting impact on the recipients' everyday life. A very high level of adjustments are required, and adaptation to a new normality is difficult to achieve resulting in deteriorating health and a profound experience of illness. In some sense, they accept their situation and try to adjust their expectations while facing the reality of possible retransplantation or death. Palliative care is required or preparations for a retransplantation if possible.

data. This potential bias was acknowledged when performing the analysis of data from the same informants 1 and 3 years posttransplant. The influence of preunderstanding and interpretative prerogative can be avoided by maintaining theoretical sensitivity through constant comparison. A limitation is the inclusion of only Swedish-speaking informants, which means that the results stem from a narrow cultural and ethnic context. Since we asked the informants to recall what has happened during the last 2 years, recall bias might have affected their statements.

Reflections on the Findings

To the best of our knowledge, this is the first study to prospectively investigate long-term experiences after lung transplantation in-depth by means of the grounded theory methodology. The theory provides a reasonable explanation of how adaption makes it possible to experience health and well-being, despite the presence of numerous symptoms. A key factor in the process of adaptation was the lung transplant recipients' early understanding that their pretransplant life would never return and that adaption to a new way of living, that is, the creation of a new normality, was inevitable.

The findings are confirmed by Lundmark et al., where a majority of lung transplant recipients experienced several symptoms and restrictions 1 to 5 years posttransplant but still reported good well-being and general health.¹⁰ Another study revealed that the majority of lung transplant recipients experienced considerable improvement in physical health and well-

being, despite reporting physical complaints and restrictions in everyday life.¹² It was concluded that adjusting to posttransplant life required acceptance of ongoing illness and that health-care providers should act as mediators to facilitate the journey to relative normalcy. Our study adds knowledge about how the lung recipients define this relative normalcy, the new normality as well as the strategies they use to enable this journey.

Adaptation occurs when a person responds positively to environmental changes.¹³ Adaptive responses contribute to health, whereas ineffective or maladaptive responses do not,¹³ which is consistent with the findings in our study. Each transplant recipient's adaptation level was unique and constantly changing, representing her or his ability to cope with the changing environment in a positive manner. Our result revealed the lung transplant recipients' experience of health and well-being when achieving an adaptive response to the new normality, and the experience of illness when the burden of symptoms and complications was too severe, an ineffective response.

The new understanding has clinical implications for chronic illness management and follow-up care after lung transplantation. Self-management is a vital concept in chronic illness management. Research has revealed that self-management support is a key component of effective chronic illness management and improves patient outcomes.¹⁴ A prerequisite for developing self-management strategies is an understanding of what is important for individuals living with chronic conditions.¹⁵

The adjustments required in the low adjustment category were considered easy and a small sacrifice in relation to the chance of a new life. With a small amount of self-management support, the informants adapted to a new normality with different routines and experienced good health and well-being. Recipients' requiring moderate adjustment and having many symptoms and complications have the greatest need of self-management support to increase the possibility of positive outcomes. For recipients' requiring a high level of adjustment, self-management support should be replaced by palliative care or preparation for retransplantation.

Based on our grounded theory, we recommend the following clinical approach. Lung recipients' individual adaptation process and strive for health and well-being should be facilitated by health-care professionals. Understanding the 3 different adjustment trajectories required by recipients in order to adapt to a new normality can enable self-management support as well as individually tailored interventions and resources. Person-centered care should be mandatory due to the knowledge that the new normality is based on personal circumstances. Health-care professionals can promote health by evaluating stimuli and behaviors that have a negative effect on adaptation and plan supportive activities accordingly as well as evaluate their effectiveness.

Conclusion

Lung recipients possessed a highly developed ability to adapt to a new normality and experienced health and well-being, despite symptom burden and complications. Adaptation to a new normality involved acknowledging that one's previous

life no longer exists and that the new lifestyle required adaptation. Adaptation to a new normality began immediately posttransplant and was an individual and never-ending process. When the adaptation was perceived as successful, health was experienced. However, when optimal adaptation was not possible due to too many symptoms or restrictions, there was a strong sense of illness.

Authors' Note

Martina Lundmark contributed to study conception/design, data collection, analysis, and drafting of the article; Annette Lennerling contributed to drafting of the article and critical revision of important intellectual content and supervision; and Anna Forsberg contributed to study conception/design, data analysis, drafting of the article, and critical revision of important intellectual content and supervision. This study was performed within the Swedish Multicenter Study Self-management after Thoracic Transplantation.

Declaration of Conflicting Interests

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