

**The Perceived Threat
of the Risk of Graft Rejection among
Organ Transplant Recipients**

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ABSTRACT

Transplantation is an established and successful treatment for critically ill patients. For many of the organ transplant recipients (OTR) it is the only option for survival. When OTRs are asked about what they fear the most, the most common answer is graft rejection. Graft rejection is a real threat against an OTR since it is the body's natural way, through its immunological defence, to protect itself against foreign bodies or unknown substances.

Aim: The primary aim of this thesis was to explore the risk of graft rejection from the perspective of OTRs by describing the characteristics of the threat experience. A secondary aim was to investigate the relationships between the perceived threat of the risk of graft rejection, by means of a domain specific questionnaire, and selected associated factors such as coping strategies and Health Related Quality of Life (HRQoL).

Methods: The efforts to acquire scientific knowledge included seeking the unique in each individual case as well as group correlations. For this reason, the data collection methods were both inductive and deductive and included interviews and questionnaires. The study group consisted of 1) 16 adult OTR, 2) 8 adolescent OTR, 3) 185 adult OTR, 4) 185 adult OTR. The instruments used to collect data were SF-36, General Coping Questionnaire (GCQ) and the Perceived Threat of the risk of Graft Rejection (PTGR) which was developed for the purpose in this thesis. Data analysis was performed mainly by descriptive and parametric statistical methods as well as by the use of phenomenography.

Results: Adult OTRs perceived graft rejection in various ways involving five domains; *abstract threat to life, concrete threat to health, trust in the body, striving to control the threat and one's identity*. There were also various ways of learning about graft rejection involving three domains; *experience of graft rejection that was accompanied by symptoms and personal observations, experience of graft rejection in the absence of physical symptoms and personal observations and no experience of graft rejection*. The adolescents' perceptions were grouped into seven domains: *tests and examinations, transplantation, medication, graft rejection as a condition, graft rejection and its consequences, friends and oneself as an organ transplant recipient*. It was possible to develop an instrument for measuring the perceived threat of graft rejection and three homogenous and psychometrically sound factors were identified. These were labelled *intrusive anxiety, graft-related threat and lack of control*. A majority (74 %) reported a low level of *intrusive anxiety*. The kidney transplant recipients reported more *graft related threat* than other OTRs. The differences between the transplanted organ groups in their use of coping strategies were small. Likewise, coping related very weakly with sex, age, time since transplantation and whether they had experienced graft rejections or not. The respondents tended in general to use more of 'positive' coping strategies (strategies related to positive well-being).

Conclusion: OTRs perceive the risk of graft rejection in various ways, from nothing to worry about to the threat of death. It was possible to measure the perceived threat of graft rejection among OTRs with an instrument comprising twelve items. Perceptions and coping seem to be independent of demographic and clinical variables such as type of organ transplanted, time since transplantation and experiences of graft rejection, age and sex.

Keywords: Organ transplantation, graft rejection, adolescents, perceptions, psychometric evaluation, health related quality of life, coping

ORIGINAL PAPERS

This thesis is based on the following papers, identified in the text by their roman numerals:

- I. Nilsson M, Persson L-O, Forsberg A. (2008). Perceptions of experiences of graft rejection among organ transplant recipients – striving to control the uncontrollable.
Journal of Clinical Nursing, 17, 2408–2417.
- II. Nilsson M, Persson L-O, Olausson M, Swerkersson S, Forsberg A. (2010). Perceptions of experiences of the risk of graft rejection among organ transplanted adolescents.
Submitted.
- III. Nilsson M, Forsberg A, Bäckman L, Lennerling A, Persson L-O. (2010). The perceived threat of the risk for graft rejection and health related quality of life among organ transplant recipients.
Journal of Clinical Nursing. In press.
- IV. Nilsson M, Forsberg A, Bäckman L, Lennerling A, Persson L-O. Coping in relation to perceived threat of the risk of graft rejection and Health-Related Quality of Life among organ transplant recipients'.
In manuscript.

ABBREVIATIONS

ANOVA	Analysis of variance
HLTR	Heart or lung transplant recipient
HTR	Heart transplant recipient
HRQoL	Health related quality of life
GCQ	General coping questionnaire
KTR	Kidney transplant recipient
LDLT	Living donor liver transplantation
LTR	Liver transplant recipient
LUTR	Lung transplant recipient
OTR	Organ transplant recipient
PRCI	Psychological reactions to chronic illness
PTGR	Perceived threat of the risk for graft rejection
QoL	Quality of life
SF-36	Short form health survey
SPSS	Statistical package for the social sciences
Tx	Transplantation
WHO	World health organization

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INTRODUCTION

When Organ Transplant Recipients (OTRs) are asked about what they fear most, the most common answer is graft rejection. However, we know very little about the meaning and essence of this fear. Does it concern the risk of deterioration of health and prolonged dependency on healthcare, or maybe the fear of death? In a study by Gubby (1998), one of the main stressors after a liver transplantation was identified as the possibility of graft rejection or repeated hospitalization. According to Gubby, the potential for graft rejection remains an ever-present threat (Gubby, 1998). A Liver Transplant Recipient (LTR) expressed the following thoughts in a study by Forsberg (2002, p. 11):

“Sometimes you think about how long it all will last. For how long will a transplanted liver work. Those moments come and I actually be sad... To get some extra time. I can have quality of life, in spite of living overtime. The difference between me and others is that we all have return ticket booked, but mine is already printed out. I often think about that”.

Transplantation is now an established and successful treatment for critically ill patients. In some situations it is the only option for survival. The number of organ transplants has increased considerably over the years and in 2008 it was estimated that 100 900 transplantations were performed all over the world (<http://www.transplant-observatory.org>). At the same time the expected survival in the short-term has also increased (Busuttil, et al., 2005; Yaby & Vincenti, 2009; Yun & Gonzales-Stawinski, 2009).

In 1954 the first successful kidney transplantation was performed between identical twins (Harrison, Merrill, & Murray, 1956; Merrill, Murray, Harrison, & Guild, 1956; Murray, Merrill, & Harrison, 2001). In 1963 the first liver transplantation (Starzl, et al., 1963) and also the first lung transplantation took place (Hardy, Webb, Dalton, & Walker, 1963). A few years later, in 1967, the first heart transplantation was performed (Barnard, 1967, 1968) and fifteen years later, the first combined heart and lung transplantation (Reitz, et al., 1982). Prior to the 1980s, survival after transplantation was relatively poor. The discovery of cyclosporine® in 1972 (Calne, 1979; Calne, et al., 1979), meant a tremendous breakthrough and thereafter several medications have been developed in order to prevent as well as cure graft rejection. However, the history of transplantation is short and the challenge of dealing with graft rejection still remains. Great efforts are continuously being made to develop new immunosuppressive drugs that will facilitate individualized protocols for OTRs and at the same time maintain graft function with as few side-effects as possible.

From a clinical viewpoint, graft rejection is, in addition to infections, the greatest threat against an OTR. It is the body's natural way, through its immunological defence, of protecting itself against foreign bodies or unknown substances. After transplantation, the treatment consists of medications intended to subdue the immune system defences in order to prevent graft rejection (Wood, 1995). The transplanted patient has to submit to an extensive follow-up programme for the purpose of early identification of graft

rejection, infection or other complications. The patient is also expected to develop an adequate self-care capacity regarding medication, observing signs of graft rejection as well as dealing with new demands and changes in daily life. A common intervention in different transplant settings worldwide is patient education before as well as after discharge from the transplant unit. The aim is to provide tools and strategies to help the OTRs not to expose themselves to risks that could lead to infections or graft rejection. However, a key message in most education is also that the recipient should live as normally as possible, in spite of the fact that he/she has received a transplant. The life of the OTR is transformed from suffering from a life-threatening disease to a hopefully more healthy one compared to the situation before the transplantation, but he/she has to undergo life-long treatment.

Although OTRs are advised preoperatively to expect at least one episode of graft rejection, they are nevertheless surprised and frightened when it occurs (Forsberg, Bäckman, & Möller, 2000). Surman (1989) suggests that anticipatory anxiety may precede the first graft rejection. Once the anti-rejection therapy routine is mastered, OTRs are generally more at ease. When describing psychiatric aspects of organ transplantation, Surman (1989) reported that graft rejection is often accompanied by withdrawal, depression and reactivation of feelings associated with the previous health impairment. According to Surman et al. (1987), depression is associated with early graft rejection or infection. House et al. (1983) reported that knowledge of laboratory evidence of liver homograft malfunction after liver transplantation often resulted in anger directed towards the surgical team and nursing staff for not doing enough to prevent the graft rejection.

Today, research focuses not only on primary survival, but also on issues such as Health Related Quality of Life (HRQoL), adherence and how to reduce the side-effects of the medication. Knowledge about patients' reactions to and understanding of the transplantation is a necessary foundation for individualized care and its quality. Nursing interventions should be tailored in order to increase patients' ability to constructively handle various stressors, thereby allowing them to experience a good HRQoL. In order to give person-centred care and provide for the needs of the whole person, more information is required about perceptions, reactions and coping strategies among OTRs. Today, the knowledge of OTRs' perceived threat of graft rejection is limited, e.g. how it is related to age, sex, type of organs transplanted, time since transplantation and experiences of graft rejection. The basic idea of this project was therefore to investigate how transplanted patients perceive and react to the risk of graft rejection.

BACKGROUND

Organ transplant recipient (OTR)

The indications for organ transplantation differ, but in both adult and paediatric care, the OTR is a person whose health condition has for some reason deteriorated to a level where the only option for survival is organ transplantation. The number of organ transplants performed is shown in Table 1.

Table 1. Number of organ transplants during 2004-2009

Year	USA	Euro-transplant	Scandia-transplant
2009	28 463	7569	1659
2008	27 965	7296	1635
2007	28 369	7517	1581
2006	28 941	6969	1511
2005	28 116	6738	1422
2004	27 040	6335	1515

<http://www.unos.org>; <http://www.eurotransplant.org>
<http://www.scandiatransplant.org>

Chronic renal failure occurs when the Glomerular Filtration Rate (GFR) is below normal range. GFR is classified on a five-grade scale where grade five represents end-stage renal disease. At this level, renal replacement therapy is required (K/DOQI, 2002; Rees, Webb, & Brogan, 2007). End-stage renal disease occurs when the renal dysfunction has progressed to the point when maximal medical management is no longer sufficient. Dialysis or transplantation is then necessary. A kidney transplantation from a living related donor, quite early in the process, is considered to be the optimal treatment of end-stage renal disease among children (Kliegman, Behrman, Jenson, & Stanton, 2007). In the case of adults, kidney transplantation is also the treatment of choice for end-stage renal disease. The risk of death for Kidney Transplant Recipients (KTRs) is less than half of that for dialysis patients (Wolfe, et al., 1999). The prognosis for children with chronic kidney disease has improved dramatically due to advances in medical management, dialysis techniques and kidney transplantation (Kliegman, et al., 2007). The main diagnosis leading to paediatric kidney transplantation is congenital disease. In the Nordic countries between 1994-2004, sixty-nine per cent of paediatric KTRs were diagnosed as suffering from congenital diseases, such as malformations and hereditary disorders, while the other thirty-one per cent had acquired diseases (<http://www.scandiatransplant.org>).

In Sweden, between 2000-2009, the main diagnoses for all kidney transplantations were cystic kidney disease, diabetic nephropathy and glomerulonephritis (<http://www.medscinet.net/snr/>).

Liver transplantation in paediatrics is a procedure for children with end-stage liver disease, life-threatening hepatic metabolic disorder, severe drug or toxin mediated hepatic failure and localized cancers of the liver. The most common indication is extra-hepatic biliary atresia, metabolic liver disease and acute hepatic necrosis (Kliegman, et al., 2007). As in children, liver transplantation among adults is a procedure for patients suffering from chronic end-stage liver disease and acute liver failure. In the Nordic countries in 2009, the most common indication for liver transplantation among adults was primary sclerosing cholangitis, post-hepatitis C cirrhosis and alcoholic liver cirrhosis (<http://www.scandiatransplant.org>).

Heart transplantation is a procedure for patients with end-stage heart failure. The most common diagnosis among adults is Dilated Cardiomyopathy (DCM), Ischemic Heart Disease (IHD) and congenital heart disease (<http://www.scandiatransplant.org>). Lung transplantation is an option for patients with end-stage lung disease (Chabot, et al., 2000; Tamm, Bolliger, Solèr, & Perruchoud, 1995). The most common diagnosis among adults leading to lung transplantation is chronic pulmonary disease caused by alpha 1-antitrypsin deficiency or by smoking and fibrosis (<http://www.scandiatransplant.org>).

Graft rejection

Our immune system protects us from foreign substances and the transplanted organ is recognized as foreign, therefore the immune system will try to destroy it (Williams, Grady, & Sandford-Guttenbeil, 1991). As medical research has progressed, the prevalence of graft rejection has decreased, but OTRs are advised preoperatively to expect at least one episode of graft rejection. There are three types of graft rejection; hyper-acute, acute and chronic. Hyper-acute graft rejection occurs minutes to hours after transplantation and is prevented by screening blood groups and Human Leukocyte Antigens (HLA) prior to transplantation, thus it is a very rare condition. Nevertheless, the risk of acute and chronic graft rejection remains. Acute graft rejection occurs within days or weeks after transplantation (Nairn & Helbert, 2002). The mechanism of acute graft rejection is a cell-mediated response by the fact that tissues are infiltrated by macrophages and lymphocytes (Goldsby, Kindt, Osborne, & Kuby, 2002).

Regardless of the type of organ transplantation, acute graft rejection is most common during the first year, occurring in 10-50% of all KTRs (Dickenmann, Nickleit, Tsinialis, Gurke, & Mihatsch, 2002) and in 20-40 % of liver transplant recipients (LTRs) (Benten, Staufer, & Sternbeck, 2009). Among heart transplant recipients (HTRs), acute graft rejection occurs in 20-30 % of cases (Taylor, et al., 2009), while 36 % of lung transplant recipients (LUTRs) experience at least one episode of acute graft rejection (Christie, et al., 2009).

Chronic graft rejection occurs months or years after transplantation and is a condition that gradually breaks down the graft (Nairn & Helbert, 2002). The mechanism behind chronic graft rejection includes both cell- and humoral mediated responses (Goldsby, et al., 2002).

This immunosuppressive treatment is sustained as long as the recipient is alive or the transplant is functioning in the recipient's body. The immunosuppressive protocols differ over time, between transplant units and between types of organ transplantation. There are many side-effects associated with immunosuppressive therapy, causing various symptoms and distress in OTRs. Few systematic approaches to incorporating symptoms or the impact of side-effects from medication after organ transplantation have been documented (Kugler, et al., 2007; Winsett, et al., 2004; Winsett, Stratta, Alloway, Wicks, & Hathaway, 2001). Kugler et al. (2009) reported that symptoms due to the side-effects of medication are related to Health Related Quality of Life (HRQoL) and non-adherence.

Definitions of concepts

This thesis involves studies on the subject of threat, coping and HRQoL, which will be defined and described in the following text.

Threat

As reported previously, graft rejection is a real threat to the OTR and something that many report as the main stressor after transplantation. Definitions of threat have been provided by, among others, Lazarus and Folkman (1984, p. 32) who describe it as:

“harms or losses that have not yet taken place but are anticipated. Even when harm/loss has occurred, it is always fused with threat because every loss is also pregnant with negative implications for the future”.

Lazarus also extended this definition by describing threat as (Lazarus, 1991, p. 18):

“a threatening encounter that makes one feel uneasy (anxious), which is connected with a strong effort to protect oneself from anticipated danger”

These definitions may cover some of the perceptions of the threat of graft rejection reported by OTRs and also be implicit in the actions taken by them to cope with the situation.

According to Carpenter (2005), perceived threat is based on a perception of some anticipated harm. The harm can be in forms such a perceived loss, interference with needs or goals and perceived loss of control. It is the individuals' perception of the cue or event that is meaningful, rather than the kind or quality of the anticipated harm. Carpenter argues, firstly, that threat is based on a perception. This is important as perceptions are culturally constructed, a function of one's social milieu and can be specific to the individual. Secondly, he claims that threat is based on the perception of anticipated harm. The quality or type of perceived harm is not important; it is the individual's perception of the event or cue that is significant in terms of threat. Thirdly, the perceived threat comes from a cognitive appraisal of an event or cue. Carpenter writes (Carpenter, 2005, p. 194):

“In the event of a perceived threat, the individuals’ perception of a threatening event is based on a cognitive appraisal to that event. What is appraised as threatening to one individual may be appraised as challenging to another. And finally, perceived threat exhibits itself as an emotional response that is part of an individual’s stress response”

Health Related Quality of Life (HRQoL)

HRQoL has emerged as an important outcome measure in organ transplantation. According to Shumaker and Naughton (1995), the concept refers to a person’s subjective evaluation of his/her health status and ability to achieve and maintain a level of overall functioning that allows him/her to pursue valued life goals and is reflected in their general well-being. HRQoL is determined by physical, social and emotional well-being as well as cognitive functioning (Shumaker & Naughton, 1995). Applying Shumaker & Naughton’s definition of HRQoL to the OTR might lead to the following result, as described by Forsberg (2002) in relation to LTRs. The OTRs’ current health status, i.e. the presence of graft rejection, infections or surgical complications, influences, and is influenced by, the health care provided, including medication, patient education and mental support. The individual’s ability to perform health promoting activities, for example physical exercise and adherence to medication, influences the possibility of achieving and maintaining a level of overall functioning. The result of this process may finally affect the person’s chances of pursuing valued life goals that indicate his/her general well-being after organ transplantation.

Coping

Much research has attempted to identify and describe those psychological processes that explain why some individuals fare better emotionally than others when afflicted by severe medical conditions. These psychological processes have generally been described in the literature as “coping”, which concerns our ability to deal with stress-inducing events. It has become a relatively central concept in psychology and caring research and has gained acceptance in the terminology of society in general. The most widely adopted coping theory, presented by Richard Lazarus in the late 1960s, is transactional theory, where coping is described as (Lazarus & Folkman, 1984, p. 141):

“constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”

PREVIOUS RESEARCH

Few studies have examined the perceived risk of graft rejection from the perspective of OTRs. Earlier studies asked OTRs what they are most afraid of or feel most stressed about. The common theme that emerged in these studies was rejection (Dabbs, et al., 2004; Fallon, Gould, & Wainwright, 1997; Forsberg, et al., 2000; Gubby, 1998; Kong & Molassiotis, 1999; Luk, 2003; White, Ketefian, Starr, & Voepel-Lewis, 1990).

White et al. (1990) found that the stressor that received the highest score among KTRs was uncertainty about the success of the transplantation. In the study by Fallon et al. (1997), the aim was to identify specific stressors among KTRs at different time intervals after transplantation; at six months, from one to five years and after five years. Irrespective of time since transplantation, the most common stressor was the possibility of rejection. It was shown that although fear of rejection decreased over time, it nevertheless remained as the main stress factor. Gubby (1998) studied thirty LTRs and concluded that the threat of graft rejection was the single most significant stress factor. Similar results were reported by Kong and Molassiotis (1999). The study involved 101 KTRs and data were collected within one year and more than one year after transplantation. The fear of rejection was identified as the most stressful concern in both groups, but to a lesser degree for those with a longer follow-up. Forsberg et al. (2000) described that LTRs with a follow-up of one year experienced the threat of graft rejection as a shift from no big deal to fear of death, involving a constant awareness of the body, constant fear, an invisible threat and as a betrayal of the body. Luk (2003) asked KTRs, with a mean time of 5.5 years since transplantation, what they found most difficult. The most common experience was the risk of rejection and always having to take medication to prevent it.

Dabbs et al. (2004) reported that LUTRs were striving for normality after transplantation. Striving for normality was the core process and involved the symptom experiences and interpretation associated with rejection. In the first stage, they expected normality, which began when they realized that they had normal objective signs. At this point in time, most patients did not acknowledge that they were ill. The longer they experienced no rejection, the longer they remained at this stage and ignored the fact that rejection might be inevitable. However, the development of rejection marked the beginning of the stage of vulnerability. When rejection occurred, recipients expressed surprise and disappointment. Now they were forced to admit that they were not normalized, that they were still vulnerable and thus paid greater attention to symptoms. With the development of insight, a greater acceptance emerged regarding ups and downs after the transplant. At this level they routinely monitored their condition and checked a variety of parameters every day.

Concerning adolescent OTRs, there is a lack of qualitative studies regarding the perceived risk of graft rejection. One behavior commonly discussed as a possible cause of graft rejection among adolescents is non-adherence in relation to medication and several studies have focused on this issue. The overall message from these studies is that the adolescent developmental period is associated with a high risk of non-adherence (Annunziato, et al., 2007; Annunziato, et al., 2008; Berquist, et al., 2008; Bullington,

et al., 2007; Dobbels, Decorte, Roskams, & Damme-Lombaerts, 2010; Fredericks, et al., 2008; Rianthavorn & Ettenger, 2005; Shemesh, et al., 2008; Simons, Gilleland, et al., 2009; Simons, McCormick, Mee, & Blount, 2009; Stuber, et al., 2008; Venkat, Nick, Wang, & Bucuvalas, 2008; Zelikovsky, Schast, Palmer, & Meyers, 2008). In order to address the various aspects of medication and graft rejection in adolescents, there is a need for understanding, from the adolescent perspective, of how graft rejection is perceived during this stage of life.

There are few studies about adolescents' strategies for mastering daily life as OTRs in relation to the risk of graft rejection. In earlier studies a common theme that emerged was normality (Olausson, et al., 2006; Wise, 2002). Wise (2002) interviewed adolescents and children aged between seven and sixteen years, who were between three and nine years old at the time of a liver transplantation. A major theme in that study was the strive for a normal life or to live in the same way as healthy children. Olausson et al. (2006) found a similar motivation in their study, in which children, aged between four and eighteen years, who had been transplanted with heart, lung, liver or kidney, were interviewed. It was revealed that a major concern for the children was to live a normal life, i.e. to be able to do what they wanted to do, go to school, be with friends and make plans for the future.

HRQoL has been extensively assessed since it emerged as an important outcome measure in transplantations (Bownik & Saab, 2009; Butler, et al., 2003; Karam, et al., 2003; Karam, et al., 2003; Vermeulen, et al., 2003). Several studies have examined HRQoL in relation to different types of transplanted organs (Baiardi, et al., 2002; Benten, et al., 2009; Forsberg, Lorenzon, Nilsson, & Bäckman, 1999; Grady, 1999; Grady, et al., 2007; Habwe, 2006; Hellgren, et al., 1998; Plas, et al., 2003; Rutherford, et al., 2005; Stilley, Miller, Manzetti, Marino, & Keenan, 1999; Terada & Hyde, 2002). These studies have in general demonstrated that OTRs experience improved HRQoL after transplantation compared to before, although compared to healthy people, their scores are generally lower in most health domains, particularly physical health. In studies using the Short Form-36 questionnaire (SF-36), mental health was excellent the first five years after liver transplantation (Forsberg, et al., 1999; Hellgren, et al., 1998). Using the same instrument, Rutherford et al. (2005) studied LUTRs who were found to score lower than healthy people in all areas except mental health and bodily pain. They also scored lower than chronically ill people in physical functioning, role-physical, role-emotional and general health.

Forsberg (2002) reported the experienced meaning of health and Quality of Life (QoL) among LTRs, as "*the sense of freedom to choose to do whatever you want to do and being able to do it*" (p 9). Health was experienced as physical and mental well-being. Factors supporting the experience of health and QoL were; courage to live, hope for the future, having a job and feeling mentally well. Health was not considered the same as being totally medically healthy. The meaning of QoL was sometimes expressed as equal to experiencing general good health and was strongly associated with a stable financial situation. A poor financial position was considered a strong obstacle to achiev-

ing good QoL. However, although the studies of HRQoL have contributed valuable information about health status in different domains, they do not provide specific information in relation to the perceived risk of graft rejection among OTRs.

There are a some studies that focus on coping in the post-transplant period (Forsberg, Bäckman, & Svensson, 2002; Kaba, Thompson, & Burnard, 2000; Lindqvist, Carlsson, & Sjöden, 2004; Liu, Feurer, Dwyer, Shaffer, & Pinson, 2009; O'Connor, et al., 2009). Studying KTRs, Lindqvist et al. (2004) found that the most frequent coping style was an optimistic approach. The least used coping styles were emotive and evasive. There were no differences in the use of coping styles between women and men, but the men regarded confrontative coping as more efficient. Kaba et al. (2000) found similar results in a qualitative study focusing on HTRs. They suggested eight styles of coping, grouped in three categories, which they termed positive coping, negative coping and seeking to cope. O'Connor et al. (2009) also found a positive and optimistic coping style among HTRs which involved facing the problems, not giving up and continuing the struggle. Liu et al. (2009) compared two groups of KTRs, one that was transplanted less than one year before, and the other, one to three years earlier. The first group used more engagement coping, reported a higher degree of perceived self-efficacy and more social support compared to the group transplanted one to three years earlier. In a prospective study, Forsberg et al. (2002) evaluated the change in the sense of coherence and coping among LTRs before and during the first year after transplantation, where the most common strategy was confrontational coping.

In conclusion, previous research has demonstrated that the risk of graft rejection is perceived as a major stressor among organ transplant recipients. Thus, the perceived risk of graft rejection is prominent in the lives of OTRs. Earlier studies indicate that this risk has a negative impact on the patients' everyday lives (House, Dubovsky, & Penn, 1983; Surman, 1989; Surman, Dienstag, Cosimi, Chauncey, & Russels, 1987). Despite this, research on OTRs' perceived risk of graft rejection is a neglected field. Both adult and adolescent OTRs seem to strive for normality and a regular daily life. HRQoL improves after transplantation compared to before, however there are long-term limitations, especially in the area of physical functioning. Health is not considered equal to being totally medically healthy, and the most commonly used coping strategy seems to be confrontational coping.

RATIONALE

Although there have been great advances in the understanding of the physiological mechanisms behind graft rejection and the biomedical treatment of the immunological processes causing graft rejection (Ekberg, et al., 2009; Frei, et al., 2010; KDIGO, 2009), knowledge of OTRs' perceptions and experiences of the risk of graft rejection is still poor. For example, it is still unclear how OTRs in various age groups perceive this risk. There is no specific instrument available to measure the perceived risk of graft rejection among OTRs. The different characteristics of this threat are rarely described. The absence of systematic and structured measurements also hampers the possibility of making comparisons between groups of OTRs to evaluate effects of various interventions.

The rationale behind this study was to describe the characteristics of the experienced risk of graft rejection, HRQoL and coping among OTRs. As already described, the general definitions of threat comprise an overall expectation of harm (Lazarus & Folkman, 1984). Threat can be viewed as something that makes one feel uneasy and which is connected to efforts to protect oneself from anticipated danger (Lazarus, 1991). However, we do not know whether responses to the experience, consequences in everyday life and strategies to master the perceived threat are unique in OTRs. In addition to developing a domain-specific instrument for self-assessment of the perceived risk of graft rejection, there is also a need to expand the current view of the threat experience and deepen our understanding of its nature. The intention was to illuminate some specific clinical and demographic characteristics of OTRs that might affect the perceived threat of the risk of graft rejection, i.e. follow-up time, age, sex, type of organ and number of graft rejections.

A second rationale was to investigate the relationship between the perceived risk of graft rejection and HRQoL and coping in OTRs. At present there are no specific intervention strategies in relation to OTRs' perceived risk of graft rejection. However, some of the hypothesized related factors, i.e. coping strategies, could be influenced in order to indirectly relieve intrusive anxiety caused by the perceived threat, thus diminishing the consequences in the OTRs' daily life.

In order to alleviate the consequences, the concept of threat is of importance for nurses who face the challenge of caring for those experiencing threat-induced emotions. Whether the threat is perceived or real, i.e. a graft rejection proven by biopsy, it induces various negative emotional responses. The foremost reason for this thesis is to increase our knowledge from the perspective of OTRs for use in the care and education of patients who suffer from the perceived threat of graft rejection. Such knowledge can also serve as a basis for future longitudinal and intervention studies.

AIM

The primary aim of this thesis was to explore the risk of graft rejection from the perspective of OTRs by describing the characteristics of the threat experience. A secondary aim was to investigate the relationships between the perceived threat of graft rejection, by means of a domain specific questionnaire, and selected associated factors such as coping strategies and HRQoL.

The specific aims were to;

- I The aim was to investigate perceptions of graft rejection as well as different methods of obtaining knowledge about graft rejection among adult organ transplant recipients.
- II The aim was to investigate adolescent organ transplant recipients' perceptions of the risk of graft rejection and how they obtain knowledge about this risk.
- III The aim was to develop and test a valid and reliable instrument that measures the perceived threat of the risk for graft rejection after organ transplantation. A secondary aim was to obtain descriptive data regarding graft rejection and HRQoL.
- IV The aim of the study was to explore types of coping strategies used to handle the threat of graft rejection among organ transplant recipients and to investigate relations between coping and perceived threat as well as HRQoL.

METHOD

Perspective and viewpoints

This thesis is based on the assumption that the OTR is a person who tries to make meaning out of and gain knowledge and understanding of the phenomenon of organ transplantation. An important supposition was that OTRs attempt to understand the phenomenon of graft rejection, as the central part of education during post transplantation care deals with what graft rejection is, signs to watch out for and how it is treated. The care focuses on preparing OTRs by creating situations that enable learning. Surman (1989) argues that a supportive and behaviourally oriented nursing approach should be facilitated.

The efforts to acquire scientific knowledge included seeking the unique in each individual case (I and II) as well as group correlations (III and IV). For this reason, the data collection methods were both inductive and deductive and included interviews and questionnaires (Table 2). The inductive approach in Studies I and II was chosen because the area in focus had been poorly investigated and there was a lack of specific knowledge about the perceived risk of graft rejection among OTRs. The deductive approach in Study III was motivated by the absence of a method for measuring the perceived risk of graft rejection. In Studies III and IV, numerical data were collected to allow comparison and enable statistically significant relationships. The measurements and questionnaires were used to evaluate and map OTRs' perceptions of the risk of graft rejection as well as their strategies for coping with it, in relation to HRQoL.

Table 2. Research design overview

Study	Focus	Data collection	Participants	Analysis
I	Transplanted adults' perceptions of graft rejection.	Interviews	16 patients, 19-65 years, transplanted with kidney, liver, heart or lung.	Phenomenography
II	Transplanted adolescents' perceptions of graft rejection.	Interviews	8 patients, 13-19 years, transplanted with kidney or liver.	Phenomenography
III	Perceptions related to health related quality of life.	Questionnaires GCQ, SF36	185 patients, 19-65 years, transplanted with kidney, liver, heart or lung.	Statistical analyses
IV	Coping related to perceptions and health related quality of life.	Questionnaires PTGR, GCQ, SF36	185 patients, 19-65 years, transplanted with kidney, liver, heart or lung.	Statistical analyses

PTGR=Perceived Threat of the risk of Graft Rejection, GCQ=General Coping Questionnaire, SF 36=Short Form Health Survey

Study I

Inclusion criteria

- Age 19-65
- Organ transplanted at Sahlgrenska University Hospital
- At least three months since transplantation
- Not being admitted to the hospital during the time the study was carried out
- Swedish speaking
- Mentally lucid

Selection procedure

A start date was agreed for the interviews. Participants were then strategically selected in order to include patients receiving one of the four most common types of organ: kidney, liver, heart or lung, as well as to obtain variation in terms of age and follow-up time. All respondents were informed by letter and asked to participate when they arrived at the outpatient clinic. Written consent was requested before the interview. One patient declined participation.

Participants

Sixteen patients, six males and ten females, four from each organ group, aged between twenty-one and sixty-three years (mean 47 years) and with a follow-up time of between three months and ten years (mean 4 years), participated. The patients had received organs from either a deceased or a living donor. Demographics are presented in Table 3.

Table 3. Demographic data of sixteen adult OTRs

Organ	Sex	Age	Time since transplantation	Number of rejections
Lung	M	58	7 yr and 3 yr	2-3
Lung	F	53	9 yr	2
Lung	F	57	2 yr	2
Lung	F	50	1 yr	3
Heart	M	49	8 yr	7-8
Heart	M	26	1 yr	2
Heart	F	54	2 yr	0
Heart/Kidney	M	48	6 m	0
Kidney	M	57	5 yr	1
Kidney	F	55	4 yr	1
Kidney	F	36	4 yr	0
Kidney	F	52	10 yr	0
Liver	F	45	3 m	0
Liver	F	35	6 m	1
Liver	M	21	3 yr	1
Liver	F	63	1 yr	0

Data collection in Studies I and II

Data were collected by unstructured interviews that were audio-taped and transcribed verbatim. All interviews were performed by the first author (M.N) at the hospital during a follow-up visit to the outpatient clinic. The interviews were conducted as an open dialogue. Questions were not pre-formulated. The interview started with some general questions, after which the main research question was posed: “When I say graft rejection – please tell me about your thoughts”. Follow up questions were asked when necessary, i.e. “what does graft rejection mean to you”? In Study I the interviews lasted ten to thirty minutes and in Study II ten to fifteen minutes.

Study II

Inclusion criteria

- Age 13-19
- Organ transplanted at Sahlgrenska University Hospital
- At least two months since transplantation
- Not being admitted to the hospital during the time the study was carried out
- Swedish speaking
- Mentally lucid

Selection procedure

Participants were strategically selected in order to include adolescents who received one of the three most common types of organ; kidney, liver or heart, as well as to obtain variation in terms of age, sex and time since transplantation. At the time of inclusion there was a total of thirty-three liver transplanted children being followed up at the paediatric hospital. Among these were fourteen who fulfilled the age criterion. One was excluded because he/she was transplanted with a multi-visceral graft and the interviewer had been deeply involved in his/her care. An additional three patients were excluded because of mental retardation. Finally, ten patients remained who fulfilled the inclusion criteria, six of whom had scheduled follow-up visits during the time of the study and were asked to participate. All six patients accepted. During the same period there were in total twenty-five kidney transplanted children followed-up at the clinic. Thirteen of them fulfilled the age criterion, but four were excluded due to psychosocial reasons. Finally, nine eligible kidney transplanted adolescents remained. Four of these patients were asked to participate and two accepted. The last group of interest was the heart transplanted group. In total there were twenty-two heart transplanted children available and eight fulfilled the age criterion. Four were excluded due to language problems or social issues. Finally, there were four eligible patients. Since one of them did not have a follow-up visit during the period of the interviews, three heart transplanted adolescents were asked to participate. Unfortunately, the health of one heart transplant recipient deteriorated, leading to exclusion, and the rest declined participation. There were no lung transplanted patients available during this period.

All adolescents were contacted by a letter to their parents and one to themselves containing relevant information. They were then contacted by phone and asked to partici-

pate. Signatures from both guardians were requested as well as the written consent of the participating adolescent.

Participants

The final study group comprised eight recipients, five boys and three girls, who agreed to participate and who obtained consent from their parents. Two had received a kidney and six a liver. They were aged between thirteen and eighteen (mean 15 years) and with a follow-up time of five months to fourteen years (mean 7 years). Demographics are presented in Table 4.

Table 4. Demographic data of eight adolescent OTRs

Age	Sex	Organ	Age when transplanted
13 yr	F	Kidney	6 yr
13,8 yr	M	Liver	3 yr
14 yr	F	Liver	3 yr
14,5 yr	M	Liver	1 yr
15 yr	M	Liver	9 months
15,5 yr	F	Liver	15 yr
15,7 yr	M	Liver	13 yr
18 yr	M	Kidney	14 yr

Analyses in Studies I and II

The phenomenographic method was used in Studies I and II. Phenomenography has similarities with phenomenology. Both methods focus on exploring how humans make sense of and transform experience into consciousness (Patton, 2002). However, the purpose differs in that phenomenology tries to extract the essence or the most invariant meaning of a phenomenon, while phenomenography tries to find variation in the way in which individuals experience the world. Perception has a central position in phenomenography (Sjöström & Dahlgren, 2002). Phenomenography assumes that phenomena in the world have different meanings to different people (Uljens, 1989) and studies the various ways in which people experience and conceptualize phenomena in and aspects of the world around us (Marton, 1981). The ontology is non-dualistic; the assumption is that the only world we can communicate about is the world that we experience. These differences can be described, communicated and understood by others (Sjöström & Dahlgren, 2002). Phenomenography distinguishes between first and second order perspectives. The first order perspective focuses on reality itself and the second order concentrates on the human perceptions of reality (Svensson, 1984). Central concepts in phenomenography are ‘what’ and ‘how’, the ‘what’ question setting out the conditions for the “how” question (Uljens, 1989). The domains are formed by “what” the informants actually talk about, and “how” they talk

about the “what” constitutes the qualitatively different variations in perceptions. The categories are formed by descriptions at a more collective level. Finally, the essence comprises a description of the unique character of each category in a more phenomenological sense.

The main and preferred method for collecting phenomenographic data is through individual interviews. The respondents’ statements are used for developing different categories describing how the phenomenon is experienced. These outcome categories constitute people’s various ways of thinking about their experiences. The interviewer has to make it clear to the respondents that the interview is open and that they are allowed to think aloud, to be doubtful and to pause. There are two main problems associated with using interviews as a data collection method. The first concerns the respondent’s motivation for participating in the study. The second is related to our understanding of what the respondent is trying to tell us. It is important for the interviewer to immediately interpret what the respondent is saying in order to be able to decide whether to probe and pose further questions. Any misunderstanding may jeopardize the quality of the interview data (Sjöström & Dahlgren, 2002).

All interviews were audio taped and transcribed verbatim. The transcripts were analysed separately and then compared, in Study I by three of the authors (M.N, A.F L-O-P) and in Study II by two (M.N, A.F). The analysis of data followed seven steps in accordance with Sjöström and Dahlgren (Sjöström & Dahlgren, 2002):

1. Familiarization; researchers read through the transcripts.
2. Compilation; summarize the answers to a certain question from all respondents.
3. Condensation; reduction of individual answers to find the central parts of longer answers or dialogue.
4. Grouping; classification of similar answers.
5. Comparison; compare categories in order to try to establish borders between them.
6. Naming; emphasize the essence.
7. Contrastive comparison; description of the unique character of each category and of resemblances between categories.

Studies III and IV

Inclusion criteria

- Age 19-65 year
- Organ transplanted at Sahlgrenska University Hospital
- Out-patients during the study period
- Understanding of written and spoken Swedish

Selection procedure

Participants were recruited through the Transplant Unit register of all OTRs. Patients with a follow-up time of 1 year \pm 3 months and 3 years \pm 3 months after transplantation were included. These criteria were applied in order to capture those with a relatively recent transplantation as well as those who had had their transplant for a longer time. The study group included 229 OTRs between 19-65 years old, transplanted with a kidney (n=147), a liver (n=50) or a heart and/or a lung (n=32). This distribution between organ transplantation reflects the reality; KTRs are the largest group of transplanted patients followed by LTRs, while HTRs and LUTRs constitute the smallest group.

Data collection

A set of questionnaires was sent in February 2008 to OTRs transplanted at the Sahlgrenska University Hospital in Gothenburg, Sweden, resulting in 162 responses. A reminder was sent in May 2008, which increased the number of responders to 185, giving a final response rate of 81% (185 of 229). Clinical and demographic data were collected by means of the questionnaires and included type of organ transplanted, date of transplantation, number of graft rejections, age, sex, marital and occupational status.

Participants

The study group had received either a kidney (n=117), a liver (n=39), a heart or a lung (n=29). Demographics are presented in Table 5.

Table 5. Demographics of 185 OTRs n (%)

Male	114 (62 %)
Female	71 (38 %)
Age < 50 yr	77 (42 %)
Age > 50 yr	108 (58 %)
Working	85 (46 %)
Studying	3 (2 %)
Retired	2 (1 %)
Disability pension	64 (35 %)
Sick-leave	22 (12 %)
Unemployed	4 (2 %)
Other	4 (2%)
Single	61 (34 %)
Co-habitant/Married	122 (66 %)
Kidney transplant recipients	117 (63 %)
Liver transplant recipients	39 (21 %)
Heart/Lung transplant recipients	29 (16 %)
Time since transplantation: 1 yr \pm 3 months	107 (58 %)
Time since transplantation: 3 yr \pm 3 months	78 (42 %)
Number of respondents who experienced rejection	70 (38 %)

Statistical analysis Study III

Data were analysed with SPSS version 15.0 and the Multi-trait Analysis Program – version 2 (Hays, Hayashi, Carson, & Ware, 1998). Scale reliability was estimated using the Cronbach's alpha coefficient for each of the modified hypothesized scales of the Perceived Threat of the risk of Graft Rejection (PTGR) questionnaire. According to the conventional rule, this coefficient should exceed at least 0.70 (Nunnally & Bernstein, 1994). In order to investigate differences between three groups due to type of organ, univariate ANOVA with post hoc analysis was performed. When analysing differences between two unpaired groups (sex, follow up-time), an independent *t*-test was employed. In order to investigate relationships between perceived threat of the risk of graft rejection and HRQoL, parametric (Pearson) correlations were calculated. A significant difference was considered to exist when $p < .05$. If possible, data were also tested with corresponding nonparametric statistics. However, since no major differences in results were found, parametric statistics are presented throughout.

Statistical analysis in Study IV

Data were analysed with SPSS version 15.0. Scale reliability was estimated using the Cronbach's alpha coefficient for each of the scales in the General Coping Questionnaire (GCQ) and the Perceived Threat of the risk of Graft Rejection (PTGR) questionnaire. Univariate ANOVA with post hoc analysis was performed to investigate differences between three groups related to type of organ. When analysing differences between two unpaired groups (sex, follow up-time), an independent *t*-test was used. In order to investigate relationships between perceived threat of the risk of graft rejection and ways of coping, Pearson correlations were calculated. A significant difference was considered to exist when $p < .05$. If possible, data were also tested with corresponding nonparametric statistics. However, since no major differences in results were found, parametric statistics were presented throughout.

Measurement and instrument

Perceived Threat of the risk of Graft Rejection (PTGR)

The PTGR questionnaire was developed from interviews with sixteen OTRs who had been transplanted with a kidney, a liver, a heart or a lung (Study I). The core questions in the interview study concerned perceptions of and strategies aimed at mastering the situation of living with the threat of graft rejection (Nilsson, Persson, & Forsberg, 2008). The item pool in the primary version of the PTGR consisted of twenty-three authentic statements covering the domains revealed in the interviews. The domains obtained in this qualitative study were labelled *abstract threat to life (9 items)*, *concrete threat to health (3 items)*, *trust in body (3 items)*, *control (7 items)* and *adjustment (5 items)*. A pilot study was conducted involving ten participants which resulted in a reduction of five items due to lack of clarity. The respondents rated the degree to which each item applied to them on a 5-point Likert scale with response alternatives “strongly disagree” (1) to “strongly agree” (5).

General Coping Questionnaire (GCQ)

The GCQ consists of 40 items concerning thoughts and actions that patients have experienced in trying to deal with problems and distress caused by their physical condition. These items cover ten dimensions of coping; *self-trust, fatalism, problem reducing actions, resignation, change of values, protest, social trust, isolation, minimization and intrusion*. The GCQ is based on in-depth interviews with persons with different somatic illnesses and disabilities (Persson & Rydén, 2006) and has been tested for validity and reliability among patients with myocardial infarction (Brink, Persson, & Karlson, 2009) and diabetes (Persson, Erichsen, Wändell, & Gåfväls, 2010). In the present study, eight of ten items were reformulated to fit the specific conditions faced by transplanted patients. The respondents rated each item on a six-point response scale ranging from “I always think or act like this” to “I never think or act like this”. In order to facilitate comparisons, all scales were transformed to 0-100, following the procedure suggested by Ware et al. (1994). This transformation converts the lowest and highest possible scores to zero and 100, respectively. Scores between these values represent the percentage of the total possible scores achieved.

Short Form Health Survey SF-36 (SF-36)

The Swedish version of the SF-36 questionnaire, which measures health status, was used as an indicator of HRQoL (Ware, 1987). The SF-36 is constructed to measure the eight most important health areas which are presumed to be universal and which represent basic human function and well-being. The areas are: *Physical Functioning (PF), Role limitations due to Physical problems (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role limitations due to Emotional problems (RE) and Mental Health (MH)*. The questions refer to effects during “the past four weeks”. The SF-36 scale has been psychometrically tested and validated in a Swedish population (Sullivan, Karlsson, & Ware, 1994; Persson, Karlsson, Bengtsson, Steen, & Sullivan, 1998; Sullivan & Karlsson, 1998; Sullivan, Karlsson, & Ware, 1995). The SF-36 also provides two summary measures; *Physical Component Score (PCS)* and *Mental Component Score (MCS)* (Ware, Kosinski, & Keller, 1994). Possible scores for the eight health areas of the SF-36 range from 0-100, with higher scores indicating a better HRQoL. The PCS and MCS scales are scored using norm-based methods. The means, standard deviations and factor score coefficients used in the scoring are derived from the general U.S. population. A linear *t*-score transformation method is employed so that both the PCS and MCS have a mean of 50 and a standard deviation of 10 in the general U.S. population.

Rigour and trustworthiness in qualitative research

Lincoln and Guba (1985) suggested four criteria for developing the trustworthiness of a qualitative inquiry: credibility, dependability, confirmability and transferability. These criteria represent parallels to the positivists’ criteria of internal validity, reliability, objectivity and external validity, respectively.

Credibility refers to confidence in the truth of the data and interpretations of them. This involves two aspects. Firstly, to carry out the study in a way that enhances the believability of the findings and, secondly, taking steps to demonstrate credibility to external readers (Lincoln & Guba, 1985). To enhance the credibility (Studies I and II) and prevent retrospective distortion or misinterpretation, the participants' statements were followed-up by new questions. The interviewer was familiar with the context and could therefore enter into the participants' descriptions and experiences. Quotations were used in order to illustrate the participants' perceptions, thus allowing the reader to decide whether our descriptions and interpretations are reasonable as well as to reflect on the meaning of the participants' statements.

Dependability refers to the stability of data over time and conditions. The main question for establishing dependability is: Would the study findings be repeated if the inquiry was replicated with the same (or similar) participants in the same (or a similar) context? Credibility cannot be attained in the absence of dependability (Lincoln & Guba, 1985). With regard to dependability (Studies I and II), the data collection was performed during regular routine follow-ups at the hospital, thus not involving any "set up" settings or environmental conditions that would prevent replication.

Confirmability refers to objectivity. It concerns the potential for congruence between two or more independent people about the accuracy, relevance and meaning of the data. To achieve this criterion, the findings must reflect the participants' voice and conditions of the inquiry and not the biases, motivations or perspectives of the researcher (Lincoln & Guba, 1985). With regard to confirmability (Studies I and II), the full text of the interviews was considered by all authors, and only statements relevant to the aim of the study were included in the final analysis.

Transferability could be viewed as analogous to generalizability and refers to the extent to which qualitative findings can be transferred to, or have applicability in, other settings or groups (Lincoln & Guba, 1985). The transferability (Studies I and II) to other OTRs outside the study group is considered good, since the main focus of the study is perceptions of graft rejection, which is a common phenomenon in the mind of every OTR. The participants were also of various ages, both sexes and had received various solid organs.

Validity and reliability in quantitative research

Validity is a quality criterion referring to what extent an instrument measures what it is intended to measure. The key question with regard to an instrument's validity is: What is this instrument really measuring and does it measure the abstract concept of interest properly? (Polit & Beck, 2010)

The expected scale dimensionality of the PTGR questionnaire was examined both by the confirmatory multi-trait analysis program and by explorative principal component analysis (with oblique, varimax rotation). In the multi-trait analysis program, the hypothesized internal item-scale structure is examined, i.e. to establish convergent and discriminatory validity. Convergent validity refers to the consistency of the items ex-

pected to measure a scale (factor). This was tested by computing the item correlations with their expected factor, corrected for overlap. A common criterion is item-scale correlations of at least 0.40 (Hays, et al., 1998). Discriminatory validity was tested by computing the proportion of items that correlated higher or significantly higher with their expected (hypothesized) scale compared with the other scales (success rate). In the explorative principal component analysis, three strategies were used interactively to determine the number of tentative factors to be retained; Cattell's scree plot, absorption of variance and meaningfulness of factors (Gorsuch, 1983). The item-scale structure that was the best compromise between the results of the multi-trait analysis and the explorative factor analysis was finally retained. Scale reliability was further estimated using Cronbach's alpha. According to the conventional rule, this coefficient should exceed at least 0.70 (Nunnally & Bernstein, 1994).

Reliability refers to the degree of consistency or dependability with which an instrument measures an attribute (Polit & Beck, 2010). In Paper III, scale homogeneity was estimated using Cronbach's alpha, resulting in values of 0.81-0.91, which suggest good scale reliability for the PTGR. In Paper IV, the scale homogeneity was tested for the adjusted version of the GCQ in relation to OTRs and their psychological reactions to graft rejection.

ETHICAL CONSIDERATIONS

The project was approved by the Research Ethics Committee at Gothenburg University (Paper I: 497-05, Paper II: 568-07, Paper III and IV: 569-07). The respondents were informed of the aim, utility and confidentiality of the study, of their right to integrity and they decided themselves whether to participate. Informed consent, both oral and written, was obtained in Studies I and II; in Study II from both the adolescent and the parent, or if possible, both parents. In Studies III and IV, only written consent was obtained. The respondents were informed that they could withdraw their participation at any time during the study.

The researcher is not connected to the clinic in which Studies I, III and IV were performed, thus no impact on the relationship between patients and care providers could be expected. The researcher is connected to the clinic in which Study II was performed, but not to the outpatient clinic where the respondents had their follow-up visits.

In this project, the risk of injury or unethical treatment was judged to be minimal. However, there is always a risk of arousing feelings that might be difficult for the patient to handle. In order to deal with such eventualities, there was a back-up with a medical doctor, psychologist or almoner. There were no economic interests involved.

RESULTS

The main findings of these studies can be summarized as follows:

- Among adults, the perceptions varied from nonthing to worry about to the threat of death.
- Among adolescents, the main perception was that graft rejection was something completely unknown or just vaguely familiar.
- Adolescents tended to describe their different ways of learning in a vague way.
- *Intrusive anxiety* was a PTGR factor suggesting that life as a whole was considered to be threatened by a possible graft rejection.
- *Graft related threat* was a PTGR factor with less emotional content and more cognitive reflection implying that a graft rejection is a life-threatening event.
- *Lack of control* was a PTGR factor involving a perception of having no influence on the risk of graft rejection.
- The majority of the OTRs reported a low level of *intrusive anxiety* in relation to the perceived threat of graft rejection.
- The KTRs reported more *graft related threat* than other OTRs.
- The most common coping strategies were related to positive well-being.
- Perceptions and coping did not seem to be related to demographic and clinical variables such as type of organ transplanted, time since transplantation or experiences of graft rejection, age and sex.

A further description of the perceptions and differences identified between groups can be found below.

Perceptions of graft rejection

One main finding in both interview studies was that there were extensive variations in perceptions of the risk of graft rejection among adult and adolescent OTRs. Among adults (Study I), the perceptions varied from nonthing to worry about to the threat of death. Among adolescents (Study II), the main perception of graft rejection was that it was something completely unknown or just vaguely familiar. In the adult study, the perceptions could be grouped into five domains. In the *abstract threat to life* domain, the risk of graft rejection was perceived as constant. The perceptions varied from viewing graft rejection as something manageable to a condition leading to serious illness and even death. The *concrete threat to health* domain revealed that the biopsy and blood tests resulted in a high level of emotional stress due to fear that the diagnostic procedure would confirm graft rejection. The immunosuppressive medications also acted as a reminder. In the *trust in the body* domain, the OTRs strived to trust their own body as a means of gaining control over the threat. *Striving to control the threat* meant that they had developed various strategies for mastering the process, based on

the perception that graft rejection was something controllable. The domain labeled *one's identity* involved the perceptions of ability to master the situation and being empowered to act upon experience based knowledge.

In the adolescent study, the perceptions were grouped into seven domains. The *tests and examinations* domain revealed perceptions of the need to check the graft function and the importance of blood levels as an indicator of health status. In the *transplantation* domain, the various perceptions involved a basic understanding that the transplantation was something inevitable. The adolescents talked about the medication, and their perceptions in the *medication* domain revealed that it was an important part of their daily lives. The *graft rejection as a condition* domain involved various perceptions, indicating that graft rejection is considered fairly insignificant, not worthy of attention and something that these adolescents had never heard of. Within the *graft rejection and its consequences* domain, the perceptions were in line with a more biomedical explanation and reflected a deterioration leading to graft loss, the need for dialysis, hospitalization and, in a worst case, re-transplantation. The perceptions in the *friends* domain indicated that friends and class mates were familiar with their condition and situation. The perceptions in the *oneself as an organ transplant recipient* domain focused on normality. The adolescents perceived themselves as living a normal life.

In Study III, an instrument for measuring the perceived threat of the risk of graft rejection was developed and three homogenous and psychometrically sound factors were identified. These were labelled *intrusive anxiety*, *graft related threat* and *lack of control*. *Intrusive anxiety* comprised six items involving an abstract component, where life as a whole was considered to be threatened by a possible graft rejection. As the threat of graft rejection always seemed to be present, the participants experienced no peace and rest. It also included fear of the future and how it will end. Concrete reminders of the risk such as laboratory tests and medication formed a part of this fac-

Table 6. Rotated Component Matrix (Varimax with Kaiser Normalization)

PTGR factors	Item	Item Scale Correlation	Cronbach's alpha
Intrusive anxiety	Graft rejection is almost always on my mind	0.840	0.91
	Nothing can distract me from worrying	0.819	
	I think of graft rejection every day	0.811	
	I experience great fear about how it will end	0.811	
	I fear graft rejection when awaiting the lab results	0.788	
	I think of graft rejection whenever I take my medication	0.773	
Graft related threat	Graft rejection means that I will be as ill as before the transplantation	0.840	0.81
	Graft rejection means that my original disease will return	0.825	
	Graft rejection means losing my graft	0.766	
Lack of control	I can't personally influence graft rejection	0.899	0.82
	I can't influence the outcome	0.862	
	I doubt that I can do anything about it	0.720	

tor. *Graft related threat* comprised three items. This factor contained less emotional content and more cognitive reflection that graft rejection is a life threatening event. It involved items such as the fear of becoming as ill as before the transplantation, that the original disease would return and losing the graft. Lack of control comprised three items indicating that the patients perceived having no influence over the risk of graft rejection (Table 6).

Ways of learning

We also analysed the various ways of learning about graft rejection. In Study I, which focused on adults, this part of the result comprised three domains; *experience of graft rejection that was accompanied by symptoms and personal observations*, *experience of graft rejection in the absence of physical symptoms and personal observations* and *no experience of graft rejection*.

In the first domain, *experience of graft rejection that was accompanied by symptoms and personal observations*, the OTRs declared that they experienced symptoms at the time of the graft rejection. Some of the OTRs had paid attention to the signals from their body, searched for information by discussing graft rejection with other OTRs and learned from the latter's experiences. The other OTRs within this domain ignored the signals from their body, did not search for information and avoided discussing the matter with other OTRs. Despite these differences, the essence of the lived experience of graft rejection in this domain was security, since both groups felt safe and comfortable with their health situation. In the second domain, *experience of graft rejection in the absence of physical symptoms and personal observations*, the OTR had also experienced graft rejection and its treatment, but with the difference that he/she did not notice any symptoms. Afterwards, the OTR did not know what to watch out for, which gave rise to a situation where the OTR, due to fear and lack of knowledge, was constantly aware of physical symptoms, but did not know what to attend to. The third domain, *no experience of graft rejection*, included the OTRs who had not suffered this phenomenon. One approach was that OTRs with experience of graft rejection and its treatment became their role models. However, they did not actively seek information. A second strategy was not to discuss graft rejection with other OTRs but to learn about it solely by means of written information provided by the transplant unit.

In Study II the focus was on adolescents, and eight participated. Two were not familiar with the concept of graft rejection. One adolescent believed that information about graft rejection was provided by means of an information brochure sent by the hospital prior to transplantation. Two reported that they had received information from doctors or other health care professionals. None of the participants had actively searched for information, for instance on the Internet and, when asked about what treatment is necessary in the event of rejection, none of them could provide an answer.

Differences and relations between groups

Type of organ transplanted

The results of Study III revealed that the OTRs did not differ in *intrusive anxiety* and *lack of control*. The majority (74 %) reported a low level of *intrusive anxiety*. Regarding *graft related threat*, the OTRs' scores were more widely spread, as 33 % of the patients perceived a low level of *graft related threat* (score < 2), 40 % were uncertain and 33 % reported a high level (score > 4). There was a significant difference in the *graft related threat* dimension ($p < .000$) between KTRs and those who had received a liver, a heart or a lung. This difference remained significant after controlling for sex differences between the groups. A high level of *lack of control* was experienced by 47.5 %. Basic descriptive data regarding perceptions of *intrusive anxiety*, *graft related threat* and *lack of control* are presented in Table 7.

Table 7. Basic descriptive data regarding perceptions of intrusive anxiety, graft related threat and lack of control among organ transplant recipients (n=185).

Factors in PTGR	High level (Score > 4)	Uncertain (Score 3)	Low level (Score < 2)
Intrusive anxiety			
KTR (n=109)**	6 (5 %)	27 (25 %)	76 (70 %)
LTR (n=38)*****	2 (5 %)	7 (18.5 %)	29 (76.5 %)
HLTR(n=29)	1 (3.5 %)	3 (10.5 %)	25 (86 %)
Graft related threat			
KTR (n=109)**	39 (36 %)	44 (40 %)	26 (24 %)
LTR (n=37)*****	5 (13.5 %)	15 (40.5%)	17 (46 %)
HLTR (n=29)	3 (10%)	11(38%)	15 (52 %)
Lack of control			
KTR (n=109)**	51 (47 %)	38 (35 %)	20 (18 %)
LTR (n=39)*****	18 (46 %)	11 (28 %)	10 (26 %)
HLTR (n=29)	15 (52 %)	6 (21 %)	8 (27 %)

KTR=kidney transplant recipients, LTR=liver transplant recipients, HLTR=heart/lung transplant recipients. Different levels represent scores on a 5-point Likert scale for each item. *missing response

There were no differences between the organ types in HRQoL except for the domains of *Physical Functioning* (PF), *Role limitations due to Physical problems* (RP) and *Physical Component Score* (PCS). In the *Physical Functioning* (PF) domain, the HTRs and LUTRs scored lower than the other two groups while in the RP domain, the LTRs scored lowest. KTRs had a significantly higher *Physical Component Score* (PCS). These differences remained significant when controlling for sex differences between the groups (Table 8).

In terms of coping strategies (Study IV), no statistically significant differences between the organ groups were found.

Table 8. Differences in experienced health related quality of life (HRQoL) among patients 1 year +/- 3 months and 3 years +/- 3 months, respectively, after a kidney, liver or heart/lung transplantation (n=185)

Health areas (SF-36)	HLTR (n=29) mean (SD)	KTR (n=111) mean (SD)	LTR (n= 45) mean (SD)	p-values
PF	66.03(23.75)	79.55(21.64)	73.65 (21.77)	p<.05
RP	64.65 (39.25)	66.51 (39.85)	43.42(44.52)	p<.05
BP	71.17 (27.23)	72.49 (26.55)	61.63 (30.45)	ns
GH	57.96 (19.27)	59.59 (22.75)	60.00(22.21)	ns
VT	62.44 (24.18)^	61.97 (26.08)	51.71 (26.62)	ns
SF	80.17 (22.78)	82.34 (24.00)	75.66 (26.47)	ns
RE	78.16 (34.82)	74.31 (37.85)	66.66(44.52)	ns
MH	81.42 (15.44)^	76.22(22.63)	72.42 (22.55)	ns
PCS	40.95 (11.13)^	44.90 (10.12)	40.61 (11.44)	p<.05
MCS	50.99 (9.88)^	47.21 (12.41)	45.18 (12.59)	ns

^Missing response, PCS=physical component summary, MCS=mental component summary.

Time since transplantation

Intrusive anxiety, graft related threat and lack of control were not related to follow-up time after transplantation. Time since transplantation showed no significant relation with any of the coping dimensions.

Experiences of graft rejection

When comparing patients with no graft rejection to those who had experienced a graft rejection, there were no significant differences in *intrusive anxiety, graft related threat* or *lack of control*. Furthermore, there was no correlation between perceptions of *graft related threat* and the number of rejections. When the two groups were compared, the difference in the use of coping strategies was small, although there were significant correlations between the number of rejections and *isolation* (Table 9).

Age

OTRs over and under fifty years of age were compared. The analysis revealed that the younger group perceived significantly more *intrusion* compared to the older OTRs (Table 9).

Sex

Women experienced significantly more *intrusive anxiety* (p= .014) and less *lack of control* (p=.038) than men, but there was no difference in the *graft related threat* dimension. A significant difference was found in terms of coping strategies, where females tended to use more *fatalism* (Table 9).

Table 9. Comparisons in use of coping strategies measured by the instrument General Coping Questionnaire (GCQ) between females/males, below/above 50 years of age, no rejection/one or several rejections and transplantation (tx) within 1 year/within 3 years^{ab}. Mean values and standard deviations within parentheses.

Coping dimensions	Females n=71	Males n=113	Under 50 yrs n=76	Over 50 yrs n=108	No rejection n=111	Rejection n=58	1 yr since tx n=108	3 yrs since tx n=76
Social trust	75.3 (27.4)	68.0 (28.3)	72.0 (28.1)	70.0 (28.2)	71.1 (28.0)	70.8 (28.8)	71.8 (27.1)	69.4 (24.6)
Minimization	74.5 (17.9)	71.4 (21.5)	70.7 (19.0)	73.8 (20.4)	74.8 (19.2)	69.0 (21.0)	73.6 (20.0)	71.0 (19.6)
Problem-reducing actions	75.6 (20.3)	70.6 (21.6)	69.1 (19.6)	74.9 (22.0)	71.9 (23.0)	73.4 (18.6)	73.5 (20.6)	71.1 (22.0)
Self-trust	55.7 (25.6)	55.2 (26.0)	53.6 (24.2)	56.7 (27.0)	55.6 (27.0)	56.2 (27.3)	56.3 (25.9)	54.2 (25.8)
Fatalism	57.9 (29.8)	47.9 (28.0)*	47.4 (28.7)	54.8 (29.0)	51.2 (29.2)	49.1 (30.3)	54.0 (29.6)	48.5 (28.1)
Change of values	50.0 (24.6)	48.3 (24.9)	46.0 (21.2)	51.0 (26.8)	46.2 (24.1)	52.7 (26.6)	49.4 (20.6)	48.3 (25.1)
Resignation	28.0 (21.2)	23.4 (19.1)	23.5 (19.0)	26.4 (20.6)	23.2 (18.8)	27.8 (22.6)	25.7 (20.5)	24.5 (19.3)
Isolation	19.7 (19.1)	16.1 (16.3)	17.4 (18.5)	17.6 (16.9)	13.9 (14.6)	20.6 (19.9)*	17.4 (17.0)	17.8 (18.4)
Intrusion	19.9 (21.5)	15.5 (18.3)	20.7 (14.8)	14.8 (17.9)*	15.0 (16.4)	19.1 (21.7)	17.9 (19.8)	16.3 (19.6)
Protest	18.3 (22.0)	15.1 (17.5)	18.9 (21.8)	14.6 (17.4)	15.1 (18.3)	16.8 (20.1)	17.2 (20.4)	15.1 (17.9)

^aScale values range from 0-100, with high levels indicating higher incidence of use. ^bIndependent samples t-test. *p<0.05.

Relations between PTGR, HRQoL and coping

Intrusive anxiety in the PTGR correlated particularly strongly with the *intrusion*, *protest* and *isolation* coping dimensions and moderately with *resignation* and *minimization*. A high correlation was also found between the PTGR dimension *lack of control* and the coping dimension *fatalism* as well as a moderate correlation with *problem-reducing actions* and *resignation*. The *graft related threat* dimension did not show any substantial correlation with any of the coping dimensions (Table 10).

When exploring the relationship between PTGR and SF-36, moderate to weak relations were found, particularly between *intrusive anxiety* and dimensions indicating various aspects of mental health, *Social Functioning* (SF), *Role limitations due to Emotional problems* (RE), *Mental Health* (MH) and *Mental Component Score* (MCS). The *graft related threat* dimension had low correlations with all SF-36 domains (Table 11).

Table 10. Correlations between coping dimensions measured by the General Coping Questionnaire (GCQ) and the dimensions in the Perceived Threat of the risk of Graft Rejection (PTGR) instrument

Coping dimensions	PTGR dimensions		
	Intrusive anxiety	Lack of control	Graft related threat
Self-trust	.12	.02	.01
Fatalism	.21**	.97**	.10
Problem-reducing actions	.22**	.36**	.10
Resignation	.39**	.31**	.15*
Change of values	.09	.25**	.14
Protest	.72**	.26**	.22**
Social trust	.02	.08	-.10
Isolation	.64**	.15	.27**
Minimization	-.37**	.19*	-.18*
Intrusion	.91**	.21	.21*

*p<0.05. **p<0.01.

Table 11. Relationship (Pearson's moment correlation) between perceived threat of graft rejection measured by PTGR and health related quality of life (HRQoL) measured by SF-36.

Health areas (SF-36)	Intrusive anxiety	Graft related threat	Lack of control
PF	-.178*	-.064	-.259**
RP	-.267**	-.093	-.265**
BP	-.224**	.014	-.174*
VT	-.255**	-.157*	-.225**
GH	-.293**	-.133	-.189*
SF	-.373**	-.105	-.297**
RE	-.331**	-.114	-.217**
MH	-.396**	-.187*	-.173*
PCS	-.168*	-.017	-.242**
MCS	-.402**	-.174*	-.201**

PCS=physical component summary, MCS=mental component summary. *Correlation is significant at the 0.05 level (2-tailed). **Correlation is significant at the 0.01 level (2-tailed).

Weak correlations were found between the ‘positive’ coping dimensions (*self-trust, problem-reducing actions, change of values, social trust and minimization*) and the SF-36 health dimensions. Stronger correlations were found with the ‘negative’ coping dimensions. *Mental Health (MH)* correlated as expected with *fatalism, resignation, protest, social isolation and intrusion*. These types of coping were related to poor *mental health*. *Resignation* and *isolation* in particular showed significant correlations with all dimensions of subjective health status, including the physical one (Table 12).

Table 12. Correlations between coping dimensions and the SF-36 dimensions

Coping dimensions	SF-36 dimensions							
	PF	RP	BP	GH	VT	SF	RE	MH
Self-trust	.10	-.03	-.06	.02	.08	-.03	-.10	-.06
Fatalism	-.27**	-.30**	-.17*	-.24**	-.27**	-.33**	-.26**	-.24**
Problem-reducing actions	-.10	-.23**	.11	-.11	-.06	-.14	-.17*	-.05
Resignation	-.18*	-.16*	.28**	-.17*	-.21**	-.20**	-.37**	-.31**
Change of values	-.05	-.17*	-.17	.08	-.05	-.04	-.17*	-.10
Protest	-.11	-.22*	-.25**	-.32**	-.27**	-.30**	-.34**	-.44**
Social trust	.04	-.02	.02	.05	.15*	.06	.03	.14
Isolation	-.20**	-.35**	-.28**	-.43**	-.37**	-.50**	-.42**	-.54**
Minimization	.03	.04	.01	.30**	.19*	.15*	.11	.27**
Intrusion	-.14	-.26	-.23**	-.38**	-.31**	-.38**	-.37**	-.50**

*p<0.05. **p<0.01.

DISCUSSION

Methodological considerations

Phenomenography was chosen since it is the empirical study of the different ways in which people experience, perceive, apprehend, understand and conceptualize the various phenomena in and aspects of the world around them. The interviews were short. Both the adult and the adolescent informants condensed their narratives in a way that was unexpected. The interviewer is very familiar with the area of organ transplantation with experience in the field of professional nursing involving both adolescent and adult OTRs and had previously performed several research interviews. Some respondents elaborated on their perceptions and experiences, but overall the statements were remarkably short without giving the impression that information was withheld due to lack of confidence in the interviewer. A possible reason among the adults is that they did not believe that graft rejection was worth talking about, which contradicts a review of earlier research where graft rejection was the main cause of fear or threat. An important difference might be that earlier research was based on the question of what the OTR most feared, felt threatened or stressed by, while the interview question in Studies I and II did not include any values or pre understanding of graft rejection such as fear, threat and stress. Among the adolescents, a plausible reason for the fairly short interviews is that it is difficult to talk about a phenomenon that one is not very familiar with. As described by Berg-Kelly (1998), a large group of adolescents are not verbal when visiting the hospital. They show difficulties in expressing themselves and their descriptions are often vague in spite of sometimes considerable problems both physical and mental (Berg-Kelly, 1998). The interviews always ended with a question as to whether there was something that the respondent felt had not been said. The interviews ended when there was nothing more to say about the subject. When the interviews tended to be longer, the respondents drifted away from the subject.

The analysis resulted in a large number of variations in adult OTRs' perceptions of experiences of the risk of graft rejection. The categories were then developed from the ways the respondents described their strategies for acting upon their perceptions, which in retrospect led to categories too far removed from the genuine perceptions. In Paper II, involving adolescents, the categories were more closely related to the different variations in perceptions. Another crucial aspect to address is our choice of exploring the essence of each category. Phenomenology searches for the essence or the most invariant meaning of a phenomenon, while the aim of phenomenography is to discern and describe ways of experiencing phenomena in the surrounding world. We have actually moved from maximum variation to invariance in one and the same data analysis process and described this performance in steps five to seven in the analysis, as suggested by Sjöström and Dahlgren (Sjöström & Dahlgren, 2002). We found that comparing categories in order to try to establish borders between them and naming their essence can result in a description of the unique character of each category, i.e. the essence. We argue that our interpretation of steps five to seven in the analysis has provided a deeper understanding of both the variations in the perceptions and the presumed deeper experienced meaning behind them. Moreover, the core objective of Sjöström and Dahlgren's method is the exploration of *perceptions of experiences*

of something as opposed to perceptions per se (Sjöström & Dahlgren, 2002). This implies that the respondents' perceptions stem from experiences of the phenomenon, in this case graft rejection, and that they presumably attribute some meaning to these experiences, which in turn shapes the perceptions. The chosen method was applied by Sjöström and Dahlgren to fit nursing research (Sjöström & Dahlgren, 2002). The first and second order perspectives were adequately revealed in steps one to four. There may still be disagreement regarding whether or not the categories reflect the variations in perceptions in a correct way and whether or not steps five to seven of the analysis should have been interpreted to reflect a phenomenological direction.

In Paper III, the aim was to develop and psychometrically test an instrument to capture the perceived threat of the risk of graft rejection at a level that can be generalized. This resulted in the Perceived Threat of the risk of Graft Rejection (PTGR) instrument. When increasing the use of questionnaires designed to assess health care outcomes or other aspects from the patient perspective, it is essential to consider their properties when evaluating quality and applicability for clinical use.

Researchers have defined quality criteria regarding the properties of health status questionnaires (Andresen, 2000; Fitzpatrick, Davey, Buxton, & Jones, 1998). These are, apart from evaluation of validity and reliability, a clear description of the concept of interest, item selection, item reduction and the workload required of respondents to complete the questionnaire. When scrutinizing the quality of the PTGR, it should be noted that evaluation of validity and reliability has been performed to some extent, but many tests still remain to, e.g. test-retest and responsiveness. Concept validation of questionnaires is increasingly obvious in recent studies and is not something that is established once and for all. We carried out a test of concept validity by examining the relationships between the PTGR and SF36. Those who perceive the threat to be greater could be assumed to report poorer mental health. In a way, we also investigated the validity of PTGR in Study IV, as we related it to coping and found that the expected correlation existed.

Furthermore, we could have elaborated on the theoretical framework. The item selection has been reasonably described. However, Paper III lacks a clear description of the estimated workload required from the respondents. This workload is expected to be low since the PTGR contains a small number of items (Appendix 1).

The instrument used in Paper IV, the GCQ, was not a transplant specific instrument but originally developed to focus on general coping among populations with serious medical conditions (Brink, et al., 2009; Gåfvvels & Wändell, 2007; Persson, et al., 2010; Persson & Rydén, 2006; Wändell & Gåfvvels, 2004). However, the items were adjusted to be applicable to OTRs and the perceived threat of the risk of graft rejection. A strength of this approach was that the persons involved, i.e. OTRs, performed the measurement by means of self-rating scales, which is suitable due to the subjective nature of the data. A disadvantage was the fact that the instrument had not been tested for validity or reliability in this group of patients. However, the scale reliabilities computed in the present population were acceptable except for one dimension – resignation (Cronbach's alpha 0.60). This suggests that the GCQ questionnaire has a stable

factor structure across populations and settings and can thus be used to assess coping in various populations with somatic conditions including OTRs.

Finally, there is a need to discuss the selection of participants and its relevance to the studies in this project. The selection procedure in Study I began with a start date on which it was planned to commence the interviews. Participants were then strategically selected to fulfill the inclusion criterion. The aim was to find variations in perceptions. We decided that the first priority was to include an even number of participants who had received the four most common types of organs; kidney, liver, heart and lung. The next priority was to achieve a balanced distribution in terms of age and follow-up time. The data collection included a fairly large number of participants.

The selection procedure in Study II was the same as in Study I. It can be argued that there could have been a more balanced distribution between the two groups; kidney and liver transplanted adolescents. However, in the light of the result from Study I, where there were large variations in perceptions of graft rejection and no indication of differences between the types of organ transplanted, we believed that a balanced age distribution was of greater importance in the adolescent group. Therefore, when including adolescents in the study, the inclusion criterion of age was the main priority. It could be argued that the sample size is small. The limited number of adolescents who fulfilled the inclusion criterion and the short data collection period made it difficult to increase the number of participants.

The data collection in Studies III and IV included a fairly large sample of transplanted recipients. The study group included 229 OTRs aged between 19-65 years, transplanted with a kidney (n=147), a liver (n=50) or a heart and/or a lung (n=32). Seven belonged to a small group; axillar liver-kidney transplantation patients. As a result of the low number, this group was not included when analysing differences between groups related to the type of organ received. The distribution between transplanted organs is representative from a clinical perspective; KTRs are the largest group of transplanted patients followed by LTRs, while the smallest group consists of HTRs and LUTRs. We decided to recruit one group with a fairly recent transplantation (about one year after tx) and one group with a moderate time interval since transplantation (about three years after tx). All patients within these two groups were included. It could be argued that we should have selected different time intervals. However, we did not want to include patients too soon after the transplantation in order to allow them to gain some lived experience.

General discussion of the result

Perceptions and perceived threat of graft rejection

Previous studies have shown that graft rejection may give rise to fear and it is considered a major stressor among OTRs. This thesis contributes more knowledge about what constitutes this threat as perceived by OTRs. The basic idea behind the thesis was not the assumption that graft rejection always involves experiences of fear or threat. The baseline was the OTRs' perceptions of the phenomenon of graft rejection and the risk involved, without any preconceived values. Thus, the understanding of

the risk of graft rejection from an inside perspective has become more nuanced. The inside perspective involves the patient's view of the disease and the consequences for his/her daily life, while the outside perspective represents the symptoms of the disease based on pathophysiology (Thorne & Paterson, 2000). According to Toombs (1992), the outside and inside perspectives can also be termed the professional and the personal understanding of disease. These perspectives differ from each other in four respects:

- the focus on the current situation
- attitude towards the disease
- relevance, i.e. what is important
- perception of time

Both outside and inside perspectives are important and valid. There is no contradiction between them (Toombs, 1992). It is evident in the results of Studies I and II that there are major differences between the inside and the outside perspective in the area of graft rejection.

Graft rejection may be perceived as an abstract threat to life but also as a concrete threat to health. Living with the risk might be interpreted as being at risk of losing the graft. According to O'Byrne, risk can be defined as being exposed to the likelihood of a negative event, and being an "at-risk person" means being unintentionally at risk. The mere thought of the risk could lead to stress and anxious feelings (O'Byrne, 2008). This thesis also tells us more about what it means to be an "at-risk person" after organ transplantation. The adult OTRs strived to control the uncontrollable by taking various actions involving adherence with medication, maintaining a positive frame of mind and adopting healthy behaviour as a way of treasuring the gift of the graft. This was also described by Forsberg et al. (2000), where the LTRs tried to honour the donor by living a healthy life and not doing anything to harm the graft. In the light of previous research, where graft rejection was described as causing fear, it is encouraging that the majority of the OTRs (74%) did not experience *intrusive anxiety* as reported in Paper III.

The adolescents seemed rather unfamiliar with the phenomenon of graft rejection. It is an interesting finding that some adolescents had actually never heard of it. The explanation for the result of Study II could partly be found in adolescent development. According to Erikson, there are eight developmental stages, from infancy to old age (Erikson, 1968, 1985). The fifth stage is the period of adolescence, comprising the ages between twelve and twenty (Hwang & Nilsson, 1995). The stage is described as a transition from childhood towards adulthood and involves learning to be independent of one's parents. Adolescence implies a feeling of invulnerability and risk-taking is a characteristic behaviour. For the young person in this period, it is important to be normal and not to differ from the peer group (Berg-Kelly, 1998).

There are extenuating circumstances due to adolescent development, and it is important to be aware that the perceptions of graft rejection reflect normal adolescent

behaviour. Adolescents strive for normalcy and this part of the result is in line with previous studies (Olausson, et al., 2006; Wise, 2002). However, the result is worrying and gives rise to concern. From an outside perspective, as transplant professionals we need to underline the fact that the adolescents' knowledge might be on a very low level, which can lead to several risks. In addition, our knowledge of non-adherence to medical regimens in this age group makes such awareness even more important. The period of adolescence is a well-known risk factor for non-adherence (Kahana, Frazier, & Drotar, 2008; Kelly, 2006; Simons, McCormick, et al., 2009). Adherence is defined as

“the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (World Health Organization, p 3.).

The aim of Study II was not to investigate or explore adherence among adolescents. However, one might reflect on whether it is possible to expect them to adhere to the medical regimen if they have never heard of the risk of graft rejection. Several of the adolescents in Study II were vaguely familiar with the phenomenon of graft rejection. Adolescents' perceptions of graft rejection might be of paramount importance in the light of the finding that forty percent of transplanted adolescents lose their grafts within thirty-six months after the transition from a pediatric to an adult unit (Rianthavorn & Ettenger, 2005).

The PTGR factor labels are based on the respondents' statements with respect to the different items. Within *intrusive anxiety*, graft rejection seemed to be always more or less present, allowing no rest or peace of mind. According to definitions of fear and anxiety, there is a difference between these concepts. Fear can be defined as

“a response to a threatening event or dangerous situation when the person expresses fright, cardiac excitation, and motoric responses of fight, flight or freeze for an adaptive purpose: to protect his/her existence. Its expression is more immediate and the result of exposure to innate stimuli, to suitably intense aversive conditions, or to an environment reminiscent of an original fear experience” (Bay, 1999, p. 110).

Anxiety is a more generalized state consisting of a perceived mismatch and a subjective feeling of dread of impending doom that might be transformed to a more objective behavioural state and can be defined as

“a heightened state of uneasiness to a potential nonspecific threat that is inconsistent with the expected event and results when there is a mismatch between the next likely and the actual event” (Bay, 1999, p. 105).

Graft related threat involved being as ill as before the transplantation, or that the basic disease would return, leading to loss of the graft. This is in accordance with Lazarus and Folkman's (1984) description of threat as harms or losses that have not yet taken place but are anticipated. *Lack of control* implied that the OTRs perceived that they

had no influence on the risk of graft rejection. This could be interpreted as either positive or negative. If *lack of control* is driven by anxiety, it will be negative for the OTR, but if it is perceived not to affect graft rejection and at the same time enables the patient to feel safe, it can be viewed as positive.

Ways of learning

One intention in this thesis was to understand more about various ways of learning about graft rejection among OTRs. Which sources are available to them in their strive for knowledge and understanding of graft rejection and related symptoms? The present result indicated that the adult OTRs had received both verbal and written education. It should be noted that, irrespective of age, none of the participants had actively searched for information, e.g. on the Internet. There were, as expected, differences in the way in which the informants discussed graft rejection with other OTRs. The present results revealed three groups with different experiences of graft rejection. One group that should receive particular attention is OTRs with *experience of graft rejection in the absence of physical symptoms and personal observations*. The data analysis in Study I revealed that they seemed particularly vulnerable and exposed, as they had actually experienced graft rejection but without any symptoms to detect or learn from. These persons tried to constantly listen to their body and be alert to any change that could signal rejection. As they had not experienced any signs in connection with the graft rejection, they lived with constant uncertainty and insecurity in relation to this risk. This situation appeared as a state of suffering due to constant fear of rejection that could occur without warning and perhaps without the organ recipient him/herself being aware of it. From a nursing perspective, these patients need special support by numerous educational conversations aimed at providing an understanding of graft rejection and reducing the perceived stress.

The great variation in perceptions of the risk of graft rejection and differing ways of obtaining knowledge about it leads to several clinical implications in terms of patient education. A challenge for health care professionals will be to identify those OTRs with a high level of *intrusive anxiety* or *graft related threat* and take measures to decrease the level. One suggestion is educational conversations as part of regular follow-up visits at a nurse led out-patient clinic. These visits should be person centred and tailored from a patient perspective, as well as offering support and providing tools and advice in line with the OTRs' personal perceptions of graft rejection and complement the explanation from the biomedical model of the disease.

Differences and relations between groups

This thesis has added knowledge about whether the perceived threat of the risk of graft rejection was influenced by the type of organ, age, time since transplantation, number of graft rejections and sex. The results indicated that correlations are weak. However, some interesting findings should be highlighted.

The KTRs reported more *graft related threat* than other OTRs. Why? If we look at the factor *graft related threat* within the PTGR, its content includes; becoming as ill as before the transplantation, that the basic disease will return and loss of the graft. Perhaps the explanation for the higher level among KTRs is that they had experienced

a longer period of disease and even dialysis prior to transplantation and therefore felt more threatened. Another plausible explanation is that there may be a link to the type of donor, i.e. living or deceased. Luk (2004) found that KTRs experienced constant fear of graft rejection, especially those who received a graft from a living donor. Nevertheless, the reason as to why KTRs score higher on *graft related threat* needs further exploration.

There was no relation between the time since transplantation and the PTGR. Thus, it would be wrong to assume that follow-up time is an important aspect in relation to the perceived threat. It can be argued that the longer follow-up, the more stable the graft function, leading to a balanced approach to graft rejection from the OTRs' perspective. One issue is whether the perceived threat is stable or increases or decreases over time, and such a study requires a longitudinal design. In contrast, Fallon (1997) reported that the possibility of graft rejection was the main stressor, irrespective of time since transplantation.

There were no differences in PTGR when comparing those with no graft rejection to informants who had experienced a graft rejection. In addition, when investigating coping; there was a significant correlation between the number of graft rejections and *isolation*. If we look at the items that make up the factor *isolation* in the GCQ, their content concerns withdrawing and isolating oneself as well as difficulties talking about graft rejection. This suggests that one cannot draw the conclusion that if an OTR has experienced a graft rejection, he/she is less afraid or less threatened by this risk. Instead, there are indications that the greater the experience of graft rejection, the more difficult it is to talk about it, thus increasing the risk of withdrawal.

When comparing OTRs in terms of age, the analysis revealed that the younger group perceived significantly more *intrusion* compared to the older one. No other study has been found to which this part of the findings can be compared. The content of the factor *intrusion* is an inability to keep the threat of graft rejection at a distance, catastrophizing and allowing the threat to rule one's life. Perhaps the result is reasonable considering that younger people are more unwilling to be restricted in everyday life.

Finally, women experienced significantly more *intrusive anxiety* and less *lack of control* than men. Since women reported more intrusive anxiety, it is reasonable from a clinical perspective to detect those female OTRs who suffer the most, as they are at risk of experiencing poorer HRQoL, affecting everyday life in various ways. According to Kugler et al. (2009), females tend to experience life as more risky and perceive more emotional distress. Further studies are needed regarding female OTRs' strategies for mastering *intrusive anxiety*. As expected, there was a significant difference in coping strategies, with women tending to use more *fatalism*. The content of *fatalism* within the GCQ is beliefs that the outcome of graft rejection is dependent on fate, luck or by others.

Relations between the PTGR, HRQoL and coping

There were strong correlations between *intrusive anxiety* and the coping strategies *protest* and *intrusion*. This result seems reasonable, since these dimensions involve

the same content and aspects measured by two different questionnaires. The graft related threat dimension correlated strongly with the coping strategy *fatalism*. We found this interesting, since it implies that the perception of graft rejection involving becoming as ill as before the transplantation as well as a return of the original disease leading to graft loss is based on beliefs that the outcome of graft rejection depends on fate, luck or by others. This raises the question of whether health care professionals should support this fairly relaxed approach or increase the OTRs' understanding of the phenomenon of graft rejection.

It was encouraging to find overall weak correlations between the dimensions in PTGR and HRQoL, suggesting that *intrusive anxiety* and *graft related threat* do not necessarily affect HRQoL in a negative way. Regarding coping and HRQoL, there were moderate correlations between *isolation* and the dimensions *General Health* (GH), *Social Functioning* (SF), *Role limitation due to Emotional problems* (RE) and *Mental Health* (MH). Coping strategies involving withdrawal and isolation due to fear of graft rejection, but also as a form of protest, most likely impair mental health to some extent. It is therefore important to detect those with ineffective coping in order to prevent illness or suffering due to fear that has not been worked through.

CONCLUSION AND CLINICAL IMPLICATIONS

The conclusions from these studies are:

- Organ transplant recipients perceive the threat of the risk of graft rejection in various ways, from nothing to worry about to the threat of death.
- Adolescents might have no knowledge of graft rejection or are merely vaguely familiar with the phenomenon.
- It was possible to measure the perceived threat of the risk of graft rejection among organ transplant recipients with an instrument comprising twelve items.
- It was possible to adapt an established instrument to study coping in relation to graft rejection.
- The most common coping strategies seem to be positive in nature (strategies related to positive well-being).
- Perceptions and coping seem to be independent of demographic and clinical variables such as type of organ transplanted, time since transplantation and experiences of graft rejection, age and sex.

We assimilate information and learn in different ways. In Studies I and II, OTRs described the various ways in which they had learnt about graft rejection. Almost all of them stated that they had received written information and an implication is therefore that we should continue to provide it. However, written information does not take account of individual variations in perceptions of graft rejection. We propose that the educational conversation with the OTR about graft rejection should be conducted on the basis of his or her own perception. This can be done by asking; when I say graft rejection – what do you think of? In this way, the OTRs' own experiences are captured. Several of the OTRs stated that they talked to fellow patients and thus shared their experiences. It seems a good idea to arrange opportunities for OTRs to discuss the topic with each other in organised conditions, e.g. in study circles. This would benefit the OTR group members who learn about graft rejection through role models. However, there may be other ways in which learning can be facilitated. Although no OTR stated having actively searched for information on the Internet, the question can be asked if the learning situation can be shifted to new arenas such as computer games or information provided on CD/USB. Technical development is rapid and probably opens up an infinite number of possibilities to stimulate learning about graft rejection among OTRs of all ages.

FURTHER RESEARCH

Further research should address the following areas:

- To clarify the underlying cause of the high level of perceived *graft related threat* among KTRs
- To perform a concept analysis of graft rejection
- A longitudinal study to measure perceived threat of the risk of graft rejection over time
- Interventions among adolescents in order to increase their knowledge of graft rejection
- To explore whether there is any relation between perception of the risk of graft rejection and adherence, and, if so, to what extent they are related

SVENSK SAMMANFATTNING

Sammanfattningsvis bidrar denna avhandling till en ökad förståelse för hur organtransplanterade patienter uppfattar hotet att leva med risken för avstötning samt att det i mycket begränsad omfattning har relation med ålder, kön, vilket organ som var transplanterat, tid sedan transplantation och erfarenhet av avstötning eller inte.

Alla patienter som genomgår en organtransplantation löper risk för avstötning, rejektion, av det transplanterade organet. Det är kroppens naturliga sätt att via immunförsvaret försvara sig mot en främmande kropp eller främmande ämnen. Behandlingen efter transplantationen består därför av att med läkemedel dämpa immunförsvaret och därmed förhindra en avstötning. Denna läkemedelsbehandling är livslång eller så länge man har det transplanterade organet kvar. Tidigare forskning har genomförts där forskarna har studerat vad de transplanterade patienterna upplever som mest hotande eller stressande efter transplantation. Samstämmigt har denna forskning kommit fram till resultatet att avstötning av det transplanterade organet är det som den transplanterade patienten uppper som det största hotet, rädslan eller det de är mest stressade för.

Det övergripande syftet med denna avhandling var att kvalitativt och kvantitativt studera transplanterade patienters uppfattningar om risken för avstötning, samt om dessa var relaterade till ålder, kön, vilket organ som var transplanterat, tid sedan transplantation och erfarenhet av avstötning eller inte. Vidare studerades hur uppfattningarna var relaterade till hälsorelaterad livskvalitet och coping. Datainsamlingen har skett genom intervjuer och enkäter.

I studie I ingick sexton deltagare som var transplanterade med njure, lever, hjärta eller lunga. Tid sedan transplantation var mellan tre månader och tio år. Deltagarna var sex män och tio kvinnor i åldern tjuogoett till sextiotre år. Syftet vara att studera variationer av uppfattningar utifrån upplevelser av risken för avstötning och av den anledningen användes metoden fenomenografi. Genom intervjuerna med sexton transplanterade patienter framkom tjugosju uppfattningar. Uppfattningarna grupperades i följande fem domäner: *det abstrakta hotet mot livet*, *det konkreta hotet mot hälsan*, *tillit till kroppen*, *strävan efter att kontrollera hotet* och *identitet*.

Inom domänen *det abstrakta hotet* varierade uppfattningarna mellan att avstötning var något hanterbart till att det leder till att bli så sjuk som före transplantationen eller till och med död. Domänen *det konkreta hotet mot hälsan* innehöll uppfattningar som var relaterade till provtagning, biopsi och medicinering. Domänen *tillit till kroppen* innebar att kroppen signalerar att en avstötning har uppkommit. I domänen *strävan att kontrollera hotet* hade den intervjuade olika strategier för att hantera avstötning som baserades på tron att avstötning var något kontrollerbart. Inom den femte och sista domänen *identitet* varierade uppfattningarna mellan att avstötning är något normalt, en nyttig erfarenhet samt att man mår som provsvaren visar. Studien har även analyserat på vilka olika sätt patienterna har lärt sig om avstötning. Denna del omfattade tre domäner: *erfarenhet av rejektion med symtom och egna observationer*, *erfarenhet av rejektion utan symtom* samt *egna observationer och ingen erfarenhet av rejektion*.

I studie II ingick åtta deltagare, fem pojkar och tre flickor i åldern tretton till arton år som var transplanterade med njure eller lever. Tid sedan transplantation var mellan fem månader och fjorton år. Liksom i studie I var syftet att studera variationer av uppfattningar utifrån upplevelser av risken för avstötning och även här användes metoden fenomenografi. Genom intervjuerna med åtta transplanterade ungdomar framkom fyrtiofyra uppfattningar. Uppfattningar grupperades i följande sju domäner: *tester och undersökningar*, *transplantation*, *medicinering*, *avstötning som ett tillstånd*, *avstötning och dess konsekvenser*, *vänner och sig själv som transplanterad*. Uppfattningarna inom domänen *tester och undersökningar* handlade om att det var nödvändigt och viktigt med blodprover och kontroller av deras hälsa. I domänen *transplantation* visade uppfattningarna att transplantationen varit nödvändig och ofrånkomlig. Inom domänen *medicinering* hade ungdomarna uppfattningar om att mediciner var en viktig del av deras dagliga liv. Domänen *avstötning som ett tillstånd* omfattade uppfattningar om avstötning som något som inte var betydelsefullt och inte behövde någon uppmärksamhet, samt något som man inte hade hört talas om. Domänen *avstötning och dess konsekvenser* innehöll uppfattningar som beskrev en försämring av hälsan som kunde leda till att transplantatet förlorades. Domänen *vänner* indikerade att vänner och klasskamrater kände till att ungdomarna vara transplanterade. Domänen *sig själv som transplanterad* fokuserade på normalitet och ungdomarna uppfattade sig själv som normala. Studien har även undersökt på vilka olika sätt patienterna hade lärt sig om avstötning. Två av ungdomarna kände inte till begreppet avstötning. De övriga var bekanta med begreppet och uppgav att de fått information på sjukhuset.

I studie III och IV var deltagarnas ålder nitton till sextiofem år. Den tillfrågade gruppen utgjordes av 229 patienter som var transplanterade med njure, lever, hjärta samt lunga. Samtliga patienter som hade uppföljningstid 1 år \pm 3 månader och 3 år \pm 3 månader sedan de transplanterats inkluderades. Den slutliga svarsfrekvensen blev 81% (n=185).

Syftet med studien var att utveckla, validitets- och reliabilitetstesta ett instrument som mäter transplanterade patients upplevda hotet av risken för avstötning, samt att studera samband med och konsekvenser för hälsorelaterade livskvalitet. I resultatet av den explorativa analysen framkom tre faktorer, *påträngande oro*, *graftrelaterat hot* och *brist på kontroll*. Vidare visar resultatet att majoriteten av de tillfrågade uppger en låg nivå av *påträngande oro*. Angående *graftrelaterat hot* var det en mer jämn fördelning över skalan. En hög nivå av *brist på kontroll* uppfattades av nära hälften av de tillfrågade. När det gäller *påträngande oro* och *brist på kontroll* var det ingen skillnad mellan grupperna av organtransplanterade. Däremot var det en signifikant skillnad i uppfattat *graftrelaterat hot*, där njurtransplanterade uppfattade mer *graftrelaterat hot* än lever-, hjärt-, eller lungtransplanterade. Det var ingen skillnad mellan könen i uppfattat *graft relaterat hot*, men kvinnor uppfattade signifikant mer *påträngande oro* och mindre *brist på kontroll*. Uppfattningarna påverkades inte av tid sedan transplantation. Likaså hade inte heller erfarenhet av att ha en eller flera avstötningar någon inverkan.

Syftet med studie IV var att studera coping av avstötning i relation till symptombörda, hälsorelaterade livskvalitet och konsekvenser i dagligt liv. Ytterligare ett syfte var att reliabilitetstesta instrumentet Psychological Reactions to Chronic Illness (PRCI) i relation till fenomenet avstötning. Resultatet visade att transplanterade patienter generellt mest använde sig av positiva copingstrategier, strategier relaterade till positivt välbefinnande. De enda skillnaderna som hittades mellan grupperna vara att kvinnor använde sig mer av *fatalism* än män, den yngre gruppen upplevde mer *intrusion*, och slutligen de som erfarit avstötning upplevde mer *isolation*. Dimensionen *påträngande oro* korrelerade starkt med coping dimensionerna *intrusion*, *protest* och *social isolation*. Det fanns även en stark korrelation mellan dimensionen *brist på kontroll* i Perceived Threat of the risk of Graft Rejection (PTGR) och coping dimensionen *fatalism*.

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REFERENCES

- Andresen, E. (2000). Criteria for assessing the tools of disability outcomes research. *Archives of Physical Medicine and Rehabilitation*, 81(12 Suppl 2), 15-20.
- Annunziato, R., Emre, S., Schneider, B., Barton, C., Dugan, C., & Shemesh, E. (2007). Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatric Transplantation*, 11, 608-614.
- Annunziato, R., Emre, S., Shneider, B., Dugan, C., Aytaman, Y., McKay, M., et al. (2008). Transitioning health care responsibility from care givers to patient: A pilot study aiming to facilitate medication adherence during this process. *Pediatric Transplantation*, 12, 309-315.
- Baiardi, F., Esposti, E. D., Cocchi, R., Fabbri, A., Sturani, A., Valpiani, G., et al. (2002). Effect of clinical and individual variables on quality of life in chronic renal failure patients. *Journal of Nephrology*, 15(1), 61-67.
- Barnard, C. (1967). The operation. A human cardiac transplant: an interim report of a successful operation performed at Groote Schuur Hospital, Cape Town. *South African Medical Journal*, Dec 30;41(48), 1271-1274.
- Barnard, C. (1968). What we have learned about heart transplants. *The Journal of Thoracic and Cardiovascular Surgery*, Oct;56(4), 457-468.
- Bay, E. J. (1999). Fear and Anxiety: A Simultaneous Concept Analysis. *Nursing Diagnosis*, 10(3), 103-111.
- Benten, D., Stauffer, K., & Sternbeck, M. (2009). Orthotopic liver transplantation and what to do during follow-up: recommendations for the practitioner. *Gastroenterology & Hepatology*, 6(1), 23-36.
- Berg-Kelly, K. (1998). *Adolescent medicine [In Swedish]*. Stockholm: Liber AB.
- Berquist, R., Berquist, W., Esquivel, C., Cox, K., Wayman, K., & Litt, I. (2008). Non-adherence to post-transplant care: Prevalence, risk factors and outcomes in adolescent liver transplant recipients. *Pediatric Transplantation*, 12, 194-200.
- Bownik, H., & Saab, S. (2009). Health-related quality of life after liver transplantation for adult recipients. *Liver Transplantation*, Nov;15(Suppl 2), 42-49.
- Brink, E., Persson, L.-O., & Karlson, B. (2009). Coping with myocardial infarction: evaluation of a coping questionnaire. *Scandinavian Journal of Caring Sciences*, Dec; 23(4), 792-800.
- Bullington, P., Pawola, L., Walker, R., Valenta, A., Briars, L., & John, E. (2007). Identification of medication non-adherence factors in adolescent transplant patients: The patient's viewpoint. *Pediatric Transplantation*, 11, 914-921.
- Busuttil, R. W., Farmer, D. G., Yersiz, H., Hiatt, J. R., McDiarmid, S. V., Goldstein, L. I., et al. (2005). Analysis of Long-term Outcomes of 3200 Liver Transplantations Over Two Decades. A Single-Center Experience. *Annals of Surgery*, 241(6), 905-918.
- Butler, J., McCain, N., Feurer, I., Speroff, T., Davis, S., Chomsky, D., et al. (2003). Modeling the effects of functional performance and post-transplant comorbidities on health-related quality of life after heart transplantation. *Journal of Heart and Lung Transplantation*, Oct;22(10), 1149-1156.

- Calne, R. (1979). Immunosuppression for organ grafting. *International Journal of Immunopharmacology*, 1(3), 163-164.
- Calne, R., Rolles, K., White, D., Thiru, S., Evans, D., McMaster, P., et al. (1979). Cyclosporin A initially as the only immunosuppressant in 34 recipients of cadaveric organs: 32 kidneys, 2 pancreases, and 2 livers. *Lancet*, Nov 17;2(8151), 1033-1036.
- Carpenter, R. (2005). Perceived threat in compliance and adherence research. *Nursing Inquiry*, 12(3), 192-199.
- Chabot, F., Vial, B., Siat, J., Robert, V., Borrelly, J., & Polu, J. (2000). Lung transplantation: indications, techniques and results. *Revue de Pneumologie Clinique*, Nov;56(5), 301-312.
- Christie, J. D., Edwards, L. B., Aurora, P., Dobbels, F., Kirk, R., Rahmel, A. O., et al. (2009). The Registry of the International Society of Heart and Lung Transplantation: Twenty-six Official Adult Lung and Heart-Lung Transplantation Report-2009. *The Journal of Heart and Lung Transplantation*, 28(10), 1031-1049.
- Dabbs, A. D. V., Hoffman, L. A., Swigart, V., Happ, M. B., Dauber, J. H., McCurry, K. R., et al. (2004). Striving for normalcy: symptoms and threat of rejection after lung transplantation. *Social Science & Medicine* 59, 1473-1484.
- Dickenmann, M., Nicleleit, V., Tsinalis, D., Gurke, L., & Mihatsch, M. (2002). Why do kidney grafts fail? A long term single-center experience. *Transplant International*, 15, 518-514.
- Dobbels, F., Decorte, A., Roskams, A., & Damme-Lombaerts, R. (2010). Health-related quality of life, treatment adherence, symptom experience and depression in adolescent renal transplant patients. *Pediatric Transplantation*, 14, 216-223.
- Ekberg, H., Bernasconi, C., Tedesco-Silva, H., Vitko, S., Hugo, C., Demirbas, A., et al. (2009). Calcineurin inhibitor minimization in the Symphony study: observational results 3 years after transplantation. *American Journal of Transplantation*, Aug;9(8), 1876-1885.
- Erikson, E. (1968). *Identity: Youth and Crisis*. New York: Norton & Company, Inc.
- Erikson, E. (1985). *The completed life cycle [In Swedish]*. Stockholm: Natur och Kultur.
- Eurotransplant International Foundation <http://www.eurotransplant.org>
- Fallon, M., Gould, D., & Wainwright, S. P. (1997). Stress and quality of life in the renal transplant patient: a preliminary investigation. *Journal of Advanced Nursing*, 25, 562-570.
- Fitzpatrick, R., Davey, C., Buxton, M., & Jones, D. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess*, 2(14), 1-74.
- Forsberg, A., Bäckman, L., & Möller, A. (2000). Experiencing liver transplantation: a phenomenological approach. *Journal of Advanced Nursing*, 32(2), 327-334.
- Forsberg, A., Bäckman, L., & Svensson, E. (2002). Liver transplant recipients' ability to cope during the first 12 months after transplantation. *Scandinavian Journal of Caring Sciences*, 16, 1-8.
- Forsberg, A., Lorenzon, U., Nilsson, F., & Bäckman, L. (1999). Pain and health related quality of life after heart, kidney, and liver transplantation. *Clinical Transplantation*, 13, 453-460.
- Fredericks, E., Magee, J., Opipari-Arrigan, L., Shieck, V., Well, A., & Lopez, M. (2008). Adherence and health-related quality of life in adolescent liver transplant recipients. *Pediatric Transplantation*, 12, 289-299.

- Frei, U., Dalozé, P., Vitko, S., Klempnauer, J., Reyes-Acevedo, R., Titiz, I., et al. (2010). Acute rejection in low-toxicity regimens: clinical impact and risk factors in the Symphony study. *Clinical Transplantation*, *Jul*; 24(4), 500-509.
- Goldsby, R., Kindt, T., Osborne, B., & Kuby, J. (2002). *Immunology* (Fifth ed.). New York: WH Freeman and Company.
- Gorsuch, R. (1983). *Factor analysis*: Hillsdale NJ: Lawrence Erlbaum Associates.
- Grady, K. (1999). Predictors of quality of life in patients at one year after heart transplantation. *The Journal of Heart and Lung Transplantation*, *18*, 202-210.
- Grady, K. L., Naftel, D. C., Kobashigawa, J., Chait, J., Young, J. B., Pelegrin, D., et al. (2007). Patterns and Predictors of Quality of Life at 5-10 Years after Heart Transplantation. *Journal of Heart and Lung Transplantation*, *26*(5), 535-543.
- Gubby, L. (1998). Assessment of quality of life and related stressors following liver transplantation. *Journal of Transplant Coordination*, *2*, 113-118.
- Gåfvéls, C., & Wändell, P. (2007). Coping strategies in immigrant men and women with type 2 diabetes. *Diabetes Research and Clinical Practice*, *72*, 269-278.
- Habwe, V. Q. (2006). Posttransplantation Quality of Life: More Than Graft Function. *American Journal of Kidney Diseases*, *47*(4), 98-110.
- Hardy, J., Webb, W., Dalton, M. J., & Walker, G. J. (1963). LUNG HOMOTRANSPLANTATION IN MAN. *The Journal of American Medical Association*, *Dec 21*(186), 1065-1074.
- Harrison, J., Merrill, J., & Murray, J. (1956). Renal homotransplantation in identical twins. *Surgical Forum*, *6*, 432-436.
- Hays, R., Hayashi, T., Carson, S., & Ware, J. (1998). *User's guide for the multi-trait analysis program (MAP)*: The Rand Publication series.
- Hellgren, A., Berglund, B., Gunnarsson, U., Hansson, K., Norberg, U., & Bäckman, L. (1998). Health-Related Quality of Life After Liver Transplantation. *Liver Transplantation and Surgery*, *4*(3), 215-221.
- House, R., Dubovsky, S., & Penn, I. (1983). Psychiatric aspects of hepatic transplantation. *Transplantation*, *36*, 146-150.
- Hwang, P., & Nilsson, B. (1995). *Developmental psychology from fetus to adult [In Swedish]*. Stockholm: Natur och Kultur.
- K/DOQI. (2002). Clinical Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification and Stratification *American Journal of Kidney Diseases*, *Feb*;39(suppl 1), 1-266.
- Kaba, E., Thompson, D. R., & Burnard, P. (2000). Coping after heart transplantation: a descriptive study of heart transplant recipients' method of coping. *Journal of Advanced Nursing*, *32*(4), 930-936.
- Kahana, S., Frazier, T., & Drotar, D. (2008). Preliminary quantitative investigation of predictors of treatment non-adherence in pediatric transplantation: A brief report. *Pediatric Transplantation*, *12*, 656-660.
- Karam, V., Castaing, D., Danet, C., Delvart, V., Gasquet, I., Adam, R., et al. (2003). Longitudinal prospective evaluation of quality of life in adult patients before and one year after liver transplantation. *Liver Transplantation*, *Jul*;9(7), 703-711.

- Karam, V., Gasquet, I., Delvart, V., Hiesse, C., Dorent, R., Danet, C., et al. (2003). Quality of life in adult survivors beyond 10 years after liver, kidney, and heart transplantation. *Transplantation, Dec 27;76(12)*, 1699-1704.
- KDIGO. (2009). Clinical Practice Guideline for the Care of Kidney Transplant Recipients. *American Journal of Transplantation, 9(Suppl 3)*, 1-155.
- Kelly, D. (2006). Current issues in pediatric transplantation. *Pediatric Transplantation, 10*, 712-720.
- Kliegman, R., Behrman, R., Jenson, H., & Stanton, B. (Eds.). (2007). *Nelson TEXTBOOK of PEDIATRICS* (18th Edition ed.): SAUNDERS ELSEVIER.
- Kong, I. L. L., & Molassiotis, A. (1999). Quality of life, coping and concerns in Chinese patients after renal transplantation. *International Journal of Nursing Studies, 36*, 313-322.
- Kugler, C., Fischer, S., Gottlieb, J., Tegtbur, U., Welte, T., Goerler, H., et al. (2007). Symptom experience after lung transplantation: impact on quality of life and adherence. *Clinical Transplantation, 21*, 590-596.
- Lazarus, R. (1991). *Emotion and adaptation: A new synthesis*. New York: Springer.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverley Hills: Sage.
- Lindqvist, R., Carlsson, M., & Sjöden, P. (2004). Coping strategies of people with kidney transplants. *Journal of Advanced Nursing, 45(1)*, 47-52.
- Liu, H., Feurer, I. D., Dwyer, K., Shaffer, D., & Pinson, C. W. (2009). Effects of clinical factors on psychosocial variables in renal transplant recipients. *Journal of Advanced Nursing, 65(12)*, 2585-2596.
- Luk, W. S.-C. (2003). The HRQoL of renal transplant patients. *Journal of Clinical Nursing, 13*, 201-209.
- Marton, F. (1981). PHENOMENOGRAPHY - DESCRIBING CONCEPTIONS OF THE WORLD AROUND US. *Instructional Science, 10*, 177-200.
- Merrill, J., Murray, J., Harrison, J., & Guild, W. (1956). Successful homotransplantation of the human kidney between identical twins. *Journal of the American Medical Association, Jan 28;160(4)*, 277-282.
- Murray, J., Merrill, J., & Harrison, J. (2001). Renal homotransplantation in identical twins. 1955. *Journal of the American Society of Nephrology, Jan;12(1)*, 201-204.
- Nairn, R., & Helbert, M. (2002). *Immunology For Medical Students*: Mosby.
- Nilsson, M., Persson, L.-O., & Forsberg, A. (2008). Perceptions of experiences of graft rejection among organ transplant recipients – striving to control the uncontrollable. *Journal of Clinical Nursing, 17*, 2408-2417.
- Nunnally, J., & Bernstein, I. (1994). *Psychometric Theory (3rd edition)*. New York: McGraw-Hill Publishing Company.
- O'Byrne, P. (2008). The dissection of risk: a concept analysis. *Nursing Inquiry, 15(1)*, 30-39.
- O'Connor, K., Janelle, C., Coutu, M.-F., Rouleau, A., Lessard, M.-J., Kirouac, C., et al. (2009). "I'm Cured But ...?": Perceptions of Illness Following Treatment. *Journal of Health Psychology, 14*, 278-287.

- Olausson, B., Utbult, Y., Hansson, S., Krantz, M., Brydolf, M., Lindström, B., et al. (2006). Transplanted children's narratives of daily living: children's narratives about their lives following transplantation. *Pediatric Transplantation*, 10(5), 575-585.
- Organizacion Nacional de Transplantes <http://www.transplant-observatory.org>
- Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods*. London: Sage.
- Persson, L., Erichsen, M., Wändell, P., & Gåfvells, C. (2010). Psychometric evaluation of a questionnaire assessing coping with chronic illness in two independent samples of people with diabetes. *Submitted*.
- Persson, L., Karlsson, J., Bengtsson, C., Steen, B., & Sullivan, M. (1998). The Swedish SF-36 Health Survey II. Evaluation of clinical validity: results from population studies of elderly and women in Gothenborg. *Journal of Clinical Epidemiology*, 51(11), 1095-1103.
- Persson, L., & Rydén, A. (2006). Themes of effective coping in physical disability: an interview study of 26 persons who have learnt to live with their disability. *Scandinavian Journal of Caring Sciences*, 20(3), 355-363.
- Plas, S. V. d., Hansen, B., Boer, J. d., Stijnen, T., Passchier, J., Man, R. d., et al. (2003). Generic and disease-specific health related quality of life in non-cirrhotic, cirrhotic and transplanted liver patients: a cross-sectional study. *BMC Gastroenterology*, 3(33), 1-13.
- Polit, D., & Beck, C. (2010). *Essentials of Nursing Research 7 ed*. Philadelphia.: Lippincott Williams & Wilkins.
- Rees, L., Webb, N. J., & Brogan, P. (2007). Oxford specialist handbook in paediatrics. Paediatric Nephrology. New York: Oxford University Press, Inc.
- Reitz, B., Wallwork, J., Hunt, S., Pennock, J., Billingham, M., Oyer, P., et al. (1982). Heart-lung transplantation: successful therapy for patients with pulmonary vascular disease. *New England Journal of Medicine*, Mar 11;306(10), 557-564.
- Rianthavorn, P., & Ettenger, R. (2005). Medication non-adherence in adolescent renal transplant recipient: A clinician's viewpoint. *Pediatric Transplantation*, 9, 398-407.
- Rutherford, R. M., Fisher, A. J., Hilton, C., Forty, J., Hasan, A., Gould, F. K., et al. (2005). Functional Status and Quality of Life in Patients Surviving 10 years After Lung Transplantation. *American Journal of Transplantation*, 5, 1099-1104.
- Scandiatransplant <http://www.scandiatransplant.org>
- Shemesh, E., Annunziato, R., Schneider, B., Dugan, C., Warshaw, J., Kerkar, N., et al. (2008). Improving adherence to medications in pediatric liver transplant recipients. *Pediatric Transplantation*, 12, 316-323.
- Shumaker, S., & Naughton, M. (1995). *The international assessment of health related quality of life: a theoretical perspective*. In: *The international assessment of health related quality of life. Theory, translation, measurement and analysis*. New York: rapid communications.
- Simons, L., Gilleland, J., Blount, R., Amaral, S., Berg, A., & Mee, L. (2009). Multidimensional Adherence Classification System: Initial development with adolescent transplant recipients. *Pediatric Transplantation*, 13, 590-598.
- Simons, L., McCormick, M., Mee, L., & Blount, R. (2009). Parent and patient perspectives on barriers to medication adherence in adolescent transplant recipients. *Pediatric Transplantation*, 13, 338-347.

- Sjöström, B., & Dahlgren, L. O. (2002). Applying phenomenography in nursing research. *Journal of Advanced Nursing*, 40(3), 339-345.
- Starzl, T., Marchioro, T., Kaulla, K. V., Hermann, G., Brittain, R., & Waddell, W. (1963). Homotransplantation of the liver in humans. *Surgery Gynecology & Obstetrics* 117(6), 659-676.
- Stilley, C., Miller, D., Manzetti, J., Marino, I., & Keenan, R. (1999). Optimism and coping styles: a comparison of candidates for liver transplantation with candidates for lung transplantation. *Psychotherapi and Psychosomatics*, 68, 299-303.
- Stuber, M., Shemesh, E., Seacord, D., Washington, J., Hellemann, G., & McDiarmid, S. (2008). Evaluating non-adherence to immunosuppressant medications in pediatric liver transplant recipients. *Pediatric Transplantation*, 12, 284-288.
- Sullivan, M., Karlsson, J., & Ware, J. (1994). *SF-36 Hälsoenkät: Svensk Manual och tolkningsguide (Swedish manual and interpretation guide) [in Swedish]*. Göteborg: Health Care Research Unit, Medical Faculty, Gothenburg University and Sahlgrenska Hospital. Gothenburg, Sweden.
- Sullivan, M., & Karlsson, J. (1998). The Swedish SF-36 Health Survey III. Evaluation of criterion-based validity: results from normative population. *Journal of Clinical Epidemiology*, 51(11), 1105-1113.
- Sullivan, M., Karlsson, J., & Ware, J. J. (1995). The Swedish SF-36 Health Survey--I. Evaluation of data quality, scaling assumptions, reliability and construct validity across general populations in Sweden. *Social Science & Medicine*, 41(10), 1349-1358.
- Surman, O. (1989). Psychiatric aspects of organ transplantation. *American Journal of Psychiatry* 146, 972-982.
- Surman, O., Dienstag, J., Cosimi, B., Chauncey, S., & Russels, P. (1987). Liver transplantation: Psychiatric considerations. *Psychosomatics*, 12, 615-618.
- Swedish Renal Registry <http://www.medscinet.net/snr/>
- Svensson, L. (1984). *Människobilden i INOM-gruppens forskning: Den lärande människan*. Göteborg: Göteborgs universitet, Institutionen för pedagogik.
- Tamm, M., Bolliger, C., Solèr, M., & Perruchoud, A. (1995). Lung transplantation. *Schweizerische Medizinische Wochenschrift*, Jun 3;125(22), 1092-1102.
- Taylor, D. O., Stehlik, J., Edwards, L. B., Aurora, P., Christie, J. D., Dobbels, F., et al. (2009). Registry of the International Society for Heart and Lung Transplantation: Twenty-sixth Official Adult Heart Transplant Report-2009. *The Journal of Heart and Lung Transplantation*, 28(10), 1077-1022.
- Terada, I., & Hyde, C. (2002). The SF-36: an instrument for measuring quality of life in ESRD patients. Review. *EDTNA ERCA J*, 28(2), 73-76, 83.
- Thorne, S., & Paterson, B. (2000). Two decades of insider research: What we know and don't know about chronic illness experience. *Annual Review of Nursing Research*, 18, 3-25.
- Toombs, K. (1992). *The meaning of illness: A phenomenological account of the different perspectives of physicians and patients*. London: Kluwer Academic Publishers.
- Uljens, M. (1989). *Fenomenografi - forskning om uppfattningar*. Lund: Studentlitteratur.
- United network for organ sharing <http://www.unos.org>

- Ware, J. (1987). Standards for validating health measures: Definitions and contents. *Journal of Chronic Disease, 40*, 473-480.
- Ware, J., Kosinski, M., & Keller, S. (1994). *SF-36 Physical and Mental Health Summary Scales: A User's Manual*. Boston: MA: New England Medical Center.
- Venkat, V., Nick, T., Wang, Y., & Bucuvalas, J. (2008). An objective measure to identify pediatric liver transplant recipients at risk for late allograft rejection related to non-adherence. *Pediatric Transplantation, 12*, 67-72.
- Vermeulen, K., Ouwens, J., Bij, W. v. d., Boer, W. d., Koëter, G., & TenVergert, E. (2003). Long-term quality of life in patients surviving at least 55 months after lung transplantation. *General Hospital Psychiatry, Mar-Apr;25(2)*, 95-102.
- White, M., Ketefian, S., Starr, A., & Voepel-Lewis, T. (1990). Stress, coping and quality of life in adult kidney transplant recipients. *American Nephrology Nurses Association Journal 6*, 421-425.
- WHO (2003). Adherence to long-term therapies. Evidence for action. Chapter 1, p. 3.
- Williams, B. A. H., Grady, K. L., & Sandford-Guttenbeil, D. M. (1991). *Organ Transplantation. A manual for Nurses*. New York: Springer Publishing Company.
- Winsett, R., Arheart, K., Stratta, R., Alloway, R., Wicks, M., Gaber, A., et al. (2004). Evaluation of an immunosuppressant side effect instrument. *Progress in Transplantation, Sept;14(3)*, 210-216, 240.
- Winsett, R., Stratta, R., Alloway, R., Wicks, M., & Hathaway, D. (2001). Immunosuppressant side effect profile does not differ between organ transplant types. *Clinical Transplantation, 15(Suppl 6)*, 46-50.
- Wise, B. V. (2002). In Their Own Words: The Lived Experience of Pediatric Liver Transplantation. *Qualitative Health Research, 12(1)*, 74-90.
- Wolfe, R., Ashby, V., Milford, E., Ojo, A., Ettenger, R., Agodoa, L., et al. (1999). Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *New England Journal of Medicine, Dec 2; 341(23)*, 1725-1730.
- Wood, K. (Ed.). (1995). *The handbook of TRANSPLANT IMMUNOLOGY*. Oxford: Med Sci Publications.
- Wändell, P., & Gåfvels, C. (2004). Patients with type 2 diabetes aged 35-64 years at four primary health care centres in Stockholm County, Sweden. Prevalence and complications in relation to gender and socio-economic status. *Diabetes Research and Clinical Practice, 63*, 195-203.
- Yaby, J., & Vincenti, F. (2009). Kidney transplantation: the ideal immunosuppression regimen. *Advances in Chronic Kidney Disease, 16(4)*, 226-233.
- Yun, J., & Gonzales-Stawinski, G. (2009). Heart transplantation. Review. *Minerva Chirurgica, 64(1)*, 23-35.
- Zelikovsky, N., Schast, A., Palmer, J., & Meyers, K. (2008). Percieved barriers to adherence among adolescent renal transplant candidates. *Pediatric Transplantation, 12*, 300-308.

Appendix

Att leva med risken för att få en avstötning - Percieved Threat of the risk of Graft Rejection, (PTGR)- Swedish version

Att leva med risken för att få en avstötning av sitt transplanterade organ kan innebära problem, både fysiska och psykiska. Vi vill genom detta frågeformulär få information om hur just Du upplever risken för avstötning.

Nedan finner Du ett antal påståenden som berör hur **Du kan tänka och känna kring avstötning och risken för detta**. Det finns inga svar som är rätt eller fel – det vi vill veta är just Dina känslor och tankar.

Det finns 5 möjliga svarsalternativ på varje påstående enligt nedan. Besvara varje påstående genom att markera det svarsalternativ som bäst stämmer med hur just Du **för närvarande** tänker kring Din situation:

Stämmer precis	Om påståendet helt och hållet stämmer med Din uppfattning
Stämmer ganska bra	Om påståendet stämmer till stor del med Din uppfattning
Osäker	Om Du är osäker på påståendet
Stämmer inte särskilt bra	Om påståendet stämmer dåligt med Din uppfattning
Stämmer inte alls	Om påståendet inte alls stämmer med Din uppfattning

		Stämmer inte alls 1	Stämmer inte särskilt bra 2	Osäker 3	Stämmer ganska bra 4	Stämmer precis 5
1	Avstötning innebär att min grundsjukdom kommer tillbaka.	1	2	3	4	5
2	Avstötning innebär att jag blir lika sjuk som jag var innan transplantationen.	1	2	3	4	5
3	Avstötning innebär att jag förlorar mitt transplantat och måste transplanteras igen.	1	2	3	4	5
4	Jag tänker på avstötning varje dag.	1	2	3	4	5
5	Jag tänker på avstötning varje gång jag tar mina mediciner.	1	2	3	4	5
6	Jag är rädd för att det är en avstötning när jag väntar på svaren från blodproverna	1	2	3	4	5
7	Risken för avstötning upptar större delen av mina tankar och styr väldigt mycket i mitt liv.	1	2	3	4	5
8	Jag känner stor ångslan för hur det kommer att sluta	1	2	3	4	5
9	Jag tänker på avstötning nästan hela tiden	1	2	3	4	5
10	Jag tvivlar på min förmåga att kunna göra någonting själv för att påverka risken för avstötning	1	2	3	4	5
11	Jag tror inte jag kan styra hur det blir när en avstötning uppstår	1	2	3	4	5
12	Jag tvivlar på att jag kan påverka detta över huvud taget	1	2	3	4	5

