

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

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av

Madeleine Nilsson

Fakultetsopponent:

Professor Henrik Ekberg

Kliniken för njurmedicin och transplantation, Skånes Universitetssjukhus, Malmö

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- 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*.

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UNIVERSITY OF GOTHENBURG

# THE PERCEIVED THREAT OF THE RISK OF GRAFT REJECTION AMONG ORGAN TRANSPLANT RECIPIENTS

Madeleine Nilsson

Queen Silvia's Childrens Hospital, Sahlgrenska University Hospital, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden

## 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