



An overview performed by the ETAHP board

Transplant Nursing Research in Europe



Summary

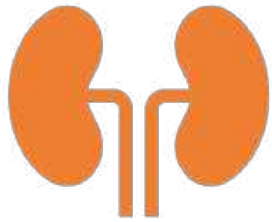


There are three strong research traditions in Europe:

1. Living donation of solid organs (kidney & liver) or stem cells
2. Non-adherence and solid organ transplantation
3. Symptom management and self-management after solid organ transplantation

The Scandinavian tradition involves person centered care and qualitative methods within a hermeneutic research perspective.

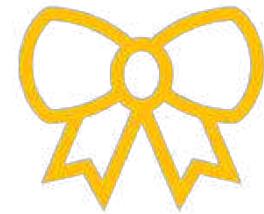
Introduction



This presentation only includes transplant nurses performing transplant nursing research in Europe.



The presentation does not claim to be complete.



The purpose of this overview is to present the magnitude of transplant nursing research going on in Europe.




Nursing research

Nursing research is systematic inquiry designed to develop trustworthy evidence about issues of importance to the nursing profession, including nursing practice, education, administration and informatics (Polit & Beck, 2008).

Clinical Nursing Research

Clinical nursing research is designed to guide nursing practice and to improve the health and quality of life of nurses' clients (Polit & Beck, 2008).



The art and science of transplant nursing

The art and science of transplant nursing is health promotion by supporting acceptance and adaption after solid organ transplantation as a process towards health.

The transition from life threatening illness to health and quality of life with a new organ is facilitated when uncertainty is relieved and self-efficacy is strengthened.

The Swiss Transplant Research Group



- Sabina de Geest. Professor of Nursing and Director of the Institute of Nursing Science of the Faculty of Medicine at the University of Basel, Switzerland
- Professor of Nursing at the Center for Health Services and Nursing Research at the KU Leuven
- Adjunct Professor at the John Hopkins University (USA)

The Swiss Research Focus

- Behavioral and psychosocial issues with the ultimate goal of improving clinical outcomes in chronically ill populations (e.g. solid organ & stem cell transplantation).
- The prevalence, determinants and consequences (both clinical and economic) of non-adherence to medication regimens, and on testing the efficacy of adherence enhancing interventions.





The BRIGHT-study

- Lut Berben, R.N., PhD
- University of Basel

The Swiss research group

Kris Denhaerynck

Research Fellow, Phd

Institute of Nursing Science, University of Basel

Research topic: Applied statistics



University of Basel



- Dr.sc.med. Sabine Valenta
- Postdoctoral Research Fellow and Advanced Practice Nurse
- Institution: Nursing Science, Department Public Health, University of Basel (Switzerland) and Department of Hematology, University Hospital Basel (Switzerland)
- Research topic: Development, implementation and evaluation of a new integrated care model facilitated by eHealth for allogeneic stem cell transplanted patients in Switzerland – the SMILe study; research on self-management support in cancer outpatients and their family caregivers



University of Basel

- Janette Ribaut
- PhD student/Research assistant
- Institute of Nursing Science, Department of Public Health, Faculty of Medicine, University of Basel
- **Research topic:** Implementation of eHealth-facilitated medication adherence interventions in transplant populations



Research focus in Switzerland

Chronic illness management and adherence
in transplantation (BRIGHT) study.

Patterns relating to chronic illness
management.

Prevalence and variability of non-adherence
to the treatment regimen.

Determine the multi-level factors related to
immunosuppressive medication
non-adherence.



Transplant Nursing Research in Germany

- Christiane Kugler, R.N., PhD
- Professor in Nursing
Science and Head of the
Institute of Nursing Science
at the University Freiburg.



The German Research Focus

Patient-centered care for patients and families with chronic conditions. Specific emphasis is given the patient reported outcomes research with the development, validation, and use of psychometrically sound assessment instruments.

Symptoms and patient self-management after cardio thoracic transplantation.



Research in organ donation

- Professor Maggie Sque PhD, BSc (Hons), Dip.N.Ed, RN1, LPE, FHEA
- Professor in Clinical Practice and Innovation at the University of Wolverhampton's Faculty of Education, Health and Wellbeing and The Royal Wolverhampton NHS Trust.



British Research Focus

Psychological and social issues that concern bereavement, organ and tissue donation and post mortem organ use

Critical care experiences and bereavement among families of organ donors.

Factors influencing bereaved families' decisions about organ donation

Research with bereaved families: A framework for ethical decision-making



University Medical Center in
Groeningen

and

Erasmus University in
Rotterdam

The Netherlands



- Coby Annema-de Jong R.N., PhD
- University of Groeningen (UMCG)
- Health Sciences- Nursing
Research



Research focus

- Anxiety and Depression after Liver Transplantation
- Psychological problems in general after liver Transplantation

Thesis: [Annema-de Jong, C. \(2017\). *What's on your mind? Emotions and perceptions of liver transplant candidates and recipients*](#)
[Groningen]: Rijksuniversiteit Groningen



Marion J Siebelink

R.N., PhD

University Medical Center in
Groeningen

Research focus:

Pediatric donation and
transplantation



- Mirjam Tielen
- R.N., PhD, Nurse
Practitioner
- Erasmus Medical Center in
Rotterdam



Research focus

Medication adherence after kidney transplantation

Illness perceptions after kidney transplantation

Adolescents' experience of kidney transplantation



- Marleen van Buren- Advanced Nurse Practitioner, PhD-student
- Department of Internal Medicine
- Erasmus University in Rotterdam



Research focus

Self-management
among kidney
transplant
recipients

Nurse-led self-
management
support

Pregnancy in
kidney transplant
recipients

Belgium

- Nathalie Duerinckx R.N., PhD
- Clinical Nurse Specialist
- Heart transplantation at
University Hospital Leuven





Research focus

Thesis: The dark clouds that surround heart transplantation, depressive symptoms and smoking (2017).

Medication adherence and heart transplantation.



Turkey
transplant nurse
researchers



Yaprak Sarıgöl Ordin, Assoc. Prof.

Dokuz Eylul University

Nursing Faculty

İzmir

Research area:

Liver transplant recipients care

Kidney transplant recipients care

Medication adherence

Live donation psychosocial assessment

Pediatric liver transplant recipients care

Organ donation



Arzu Kader HARMANCI SEREN, Assoc. Prof.

University of Health Sciences, Hamidiye Faculty of Nursing

Head of the Department of Nursing Administration

International Transplant Nurses Society

Member of the Board of Directors (Int. Director)

İstanbul

Research area:

Deceased donor assessment

Family interview

Organ donation

Organ transplant coordination

Live donation psychosocial assessment



Zeliha Özdemir Köken, Assist. Prof.

Hacettepe University

Nursing School

Ankara

Research area:

Deceased donor assessment

Organ donation

Medication adherence

Kidney transplant recipients



Özgül Karayurt, Prof.

İzmir University of Economics

Faculty of Health Sciences

Research area:

Liver transplant recipients care

Kidney transplant recipients care

Medication adherence

Live donation psychosocial assessment

Pediatric liver transplant recipients care



Fatma Cebeci, Prof.
Akdeniz University
Nursing Faculty
Antalya



Nilgün Mutlu Aksoy, Assist. Prof.
Akdeniz University
Nursing Faculty
Antalya



Özge İşeri, Assist. Prof.
Ondokuz Mayıs University
Health Science Faculty
Samsun

Research area:
Liver transplant recipients care
Adaptation after transplantation
Education of liver transplant recipients

Polish transplant nursing research



Liver transplantation in Warszaw



- **Marta Hreńczuk, RN, PhD, MSc**
Medical University of Warsaw

Research area

- Liver Transplantation, kidney transplantation – quality of life,
- Quality of nursing care in transplant setting
- Nursing care in liver & kidney transplantation



Thoracic transplantation in Krakow

- **Prof. Irena Milaniak, RN, MSN, PhD**
- Andrzej Frycz Modrzewski Krakow University
- John Paul II Hospital – Cardiovascular Surgery & Transplantology Department
- **Research area**
- Quality of life of heart & kidney transplant recipients
- Psychological assessment of transplant recipients
- Non-adherence
- Attitudes towards organ donation and transplantation
- Device therapy in heart failure

**Transplant Nursing Research in
Scandinavia**

Person-centred
care of solid organ
transplant
recipients

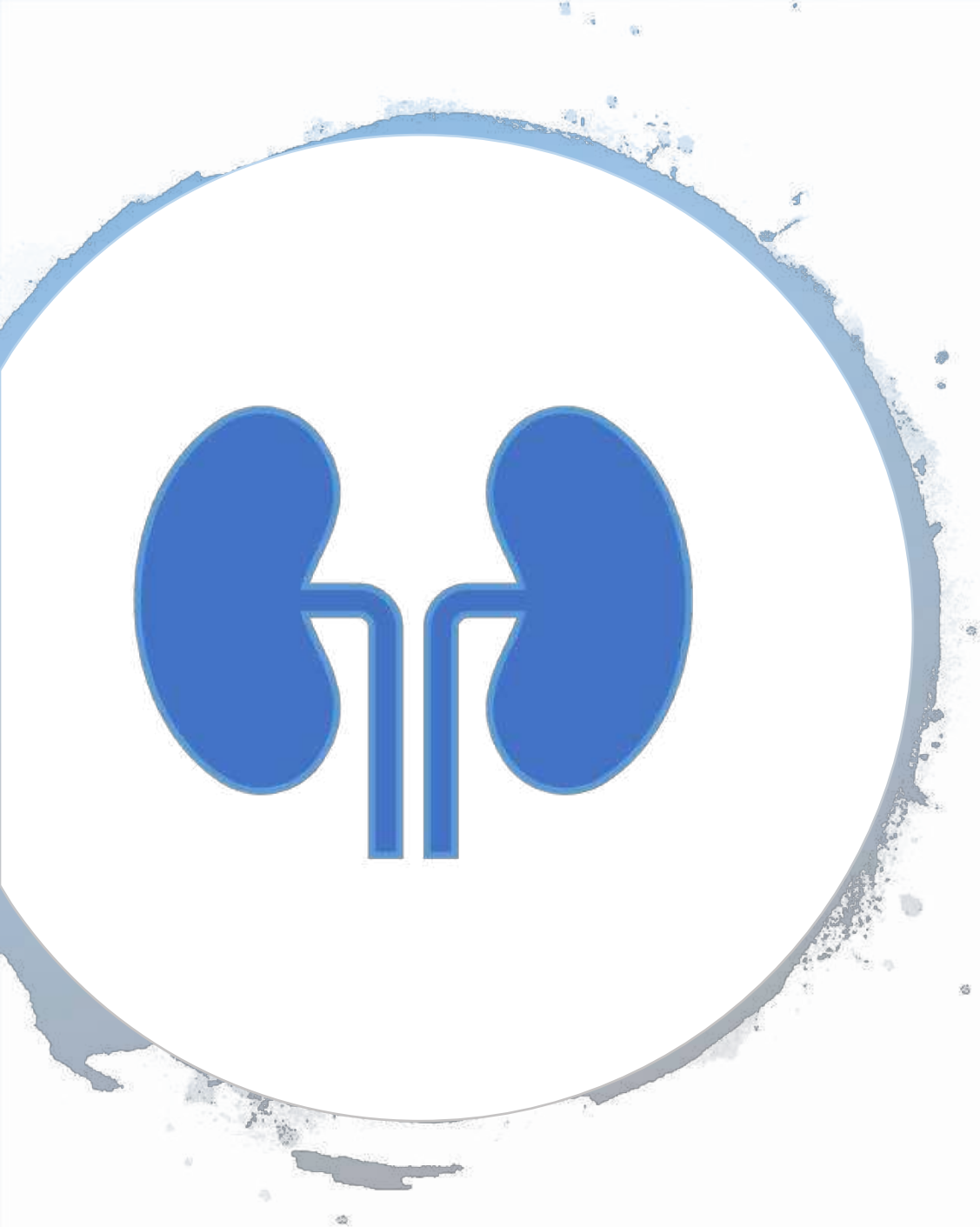




The Norwegian group

- Käthe Meyer R.N., PhD
- Oslo University
- Rikshospitalet, Oslo





Living kidney donors

- Long-term health outcomes in kidney donors
- Relationships between clinical, self-reported and donation specific outcomes
- Long-term experiences of Norwegian live kidney donors



Transplantation Nursing Research in Norway

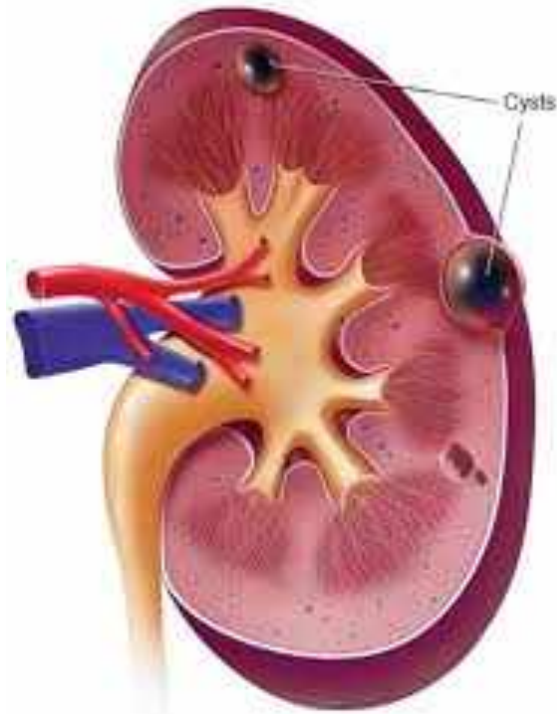
- Doctor Marit Helen Andersen R.N., PhD
- Oslo University Hospital
- Research Group for Quality of Life and Health Economy.
- Quality of Life Research



The Danish group

- Doctor Hanne Agerskov R.N., PhD,
- University of South Denmark, Odense
- Institute of Clinical Research
- Clinical nephrology
- Nursing Science

The Danish perspective on kidney donation



- Living kidney donors' experience during evaluation for donation
- Experiences three months after donation
- Experiences during the whole donation process

A large, irregular blue ink splash or watercolor blotch serves as the background for the title text. The splash is centered and has a textured, painterly appearance with various shades of blue and some white highlights. The text is white and centered within the splash.

Swedish Transplant Nursing Research

Research focus in Sweden



- Self-management after thoracic transplantation (The SMATT-study)
- The perceived threat of the risk of graft rejection
- Patient learning
- Social adaptation after organ transplantation
- Recovery and transition after lung transplantation
- Symptoms, health related quality of life and adherence
- Health literacy
- Theory development in transplant nursing



Perspective and viewpoints

- A central perspective is that the starting point is the person who has a disease or symptoms and not the disease in the person.
- Focus on the transplanted persons experiences and beliefs in relationship to illness, disease and suffering as well as the recovery and maintenance of health.

Perspective and viewpoints



- The projects in the Swedish research groups are primary based on a hermeneutic perspective.
- The projects stem from the ontological assumption that the human being is a subject driven by motives.



Research questions

- The research interest is directed towards how the person – in relation to organ donation- comprehend, experience, perceive and cope with the situation and the phenomenon organ donation.
- Organs can be donated from either a live donor or a deceased donor and we embrace both ways in our research.

Research questions



- The research questions are mainly from a nursing perspective, aiming at the person's interpretation of and reaction to the entire life situation rather than the disease itself.

Research methods



- Content analysis
- Phenomenological hermeneutics
- Grounded Theory
- Phenomenography
- Hermeneutics
- Various statistical methods
- Psychometric evaluation and instrument development

The logo of the University of Gothenburg features a large, light gray circle. Inside the circle, the text "University of Gothenburg" is written in a black, sans-serif font. To the right of the text, there is a small gray dot and a thick, green, curved line that starts below the dot and curves downwards and to the left.

University of
Gothenburg

Sahlgrenska University
Hospital



Living Kidney Donation

- Assistant professor Annette Lennerling R.N., PhD
- University of Gothenburg
- The Transplant Centre at Sahlgrenska University Hospital



Research focus

- Living donation
- Non adherence after solid organ transplantation
- Patient education
- Self-management after solid organ transplantation
- Health literacy



Organ donor advocacy

- Anne Flodén, R.N., PhD
- Attitudes towards organ donor advocacy among ICU-nurses



Percieved threat of the risk of graft rejection

- Madeleine Eriksson (fd Nilsson).
- R.N. PhD, Clinical Nurse Specialist in pediatric nursing
- The inside perspective on graft rejection among solid organ recipients.
- Middle range theory on how to support transplant recipients with a fear of graft rejection.



Adaptation after liver transplantation

- Anna Brantmark
- R.N., MSci, PhD-student
- The Transplant Center at Sahlgrenska University Hospital and University of Gothenburg
- Clinical specialist in liver and intestinal transplantation

The logo for Lund University is a light gray circle. Inside the circle, the words "Lund" and "University" are written in a black, sans-serif font, stacked vertically. To the right of the text, there is a small gray dot above a thick, green, curved line that starts from the bottom and curves upwards towards the dot.

Lund
University

Care in high tech
environments
and

Skane University Hospital,
Department of Thoracic
Surgery



Primary investigator

- Anna Forsberg
- R.N., PhD
- Clinical professor in Transplant Nursing at Lund University, Sweden
- Director of the Care in High-tech Environments Research Group



Adaptation after lung transplantation

- Martina Lundmark
- R.N. PhD, Clinical Nurse Specialist in intensive care, post doc
- Recovery after lung transplantation- adaptation to a new normality
- Theory development regarding how to adapt and reconstruct daily occupation after lung transplantation.



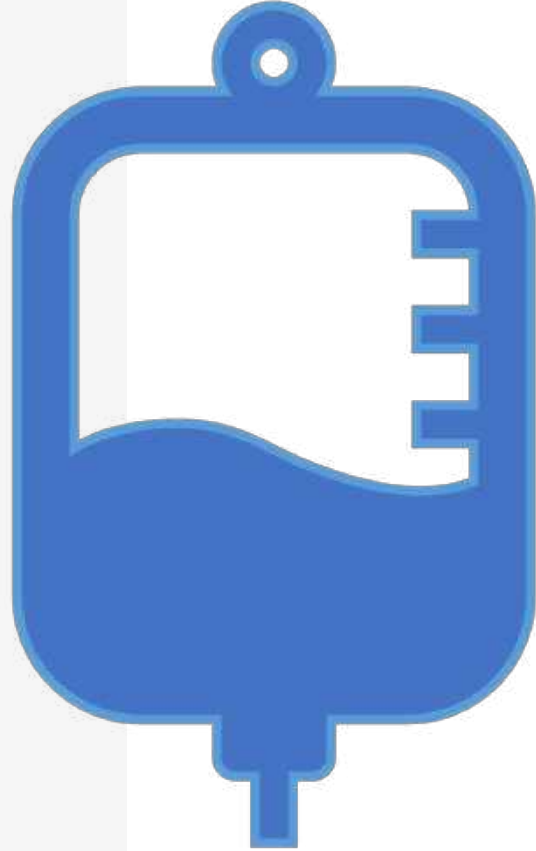
Self-efficacy after heart transplantation

- Matilda Almgren,
- R.N., PhD, Clinical Nurse Specialist in intensive care, post doc
- Self-efficacy after heart transplantation
- Focus on uncertainty and self-efficacy in relation to heart transplantation as a chronic condition.

Sibling Stem Cell Donation & Stem Cell Transplantation



- Annika Kisch
- R.N., PhD
- Post doc at Lund University, Care in High tech environments
- Clinical Nurse Specialist in Stem Cell Donation and Transplantation at Skåne University Hospital



Allogenic Stem Cell Transplantation

- Sibling donation of stem cells
- Patients' experiences before and after allogenic hematopoietic stem cell transplantation
- Grounded Theory of Having a Stem Cell Donor



Symptom occurrence and symptom distress after heart transplantation

- Marita Dalvindt
- R.N., Msci, PhD-student in Care in High tech environments at Lund University
- Clinical Nurse Specialist in cardiac nursing
- Department of Thoracic surgery and transplantation at Skane University Hospital