

EHPS Networking Grant Application

'Development of standardized screening for living organ donors in Europe'

Abstract

Living kidney and liver donation is one way of helping alleviate the worldwide shortage of organs for transplantation. In order to maximize donor safety and minimize negative outcomes thorough psychosocial screening of donor candidates is required. However there is currently no gold-standard to do so. In order to fill this gap we initiated this research project. Firstly, we reviewed the literature on current screening practices which revealed large variation and a lack of consensus regarding the concept of 'psychosocial'. Secondly, we mapped the concept of 'psychosocial' in the context of living donor screening and identified essential elements of a screening tool. Thirdly, we developed a screening tool combining validated instruments and additional semi-structured interview questions. In the proposed study we will assess content validity and pilot the tool. We are applying for funding for a consortium meeting with international partners to design and plan this study.

Proposal

Theoretical Rationale and Aims: Over the past decades there has been an exponential growth in living organ donation programmes as a way of helping to alleviate the worldwide shortage of organs for transplantation. The current state-of-the-art indicates that when donors are appropriately screened and selected long-term consequences for physical or mental health appear limited (1-3). Interpersonal relationships are unaffected or improved (2), regret is low (4), and personal growth and interpersonal benefit are also reported (5). However, a minority experience negative psychosocial outcomes: post-donation depressive or anxiety symptoms has been reported in 5-23% and 6-14% of cases respectively (2); 6-22% report finding the surgery stressful (2); concerns/worries include living with one kidney and potential kidney failure, surgical complications, deterioration of own health, medical costs and loss of income, acquisition of insurance and recipient outcomes (2). In cases of poor recipient outcomes, studies showed 13% felt it had been a waste, 11% experienced suicide ideation, 5% felt guilty, and in cases where the recipient had died only 50% felt it had been worth it. Thorough psychosocial screening of donor candidates is essential (and often mandatory) in order to minimize potential negative consequences and maximize donor safety. To date, a number of psychosocial screening guidelines and protocols have been published (6-23). These guidelines, however, are very broad and tend to list 'what' needs to be addressed rather than providing concrete recommendations on 'how' screening should be performed (13). Consequently, the interpretation of these guidelines varies substantially leading to large differences in screening practices and differential treatment of potential donors (24, 25). In order to address this issue, the psychological working group of the ELPAT (European platform for Ethical, Legal and Psychosocial aspects of Transplantation) initiated a research project. Firstly, in a systematic review we identified 197 unique criteria used psychosocial screening of living kidney or liver donors (10). Secondly, we clustered these criteria using a rigorous Concept Mapping methodology (Ismail et al, submitted). Analyses resulted in six clusters: (1) motivation and decision-making; (2) personal resources; (3) social resources; (4) psychopathology; (5) information and risk processing; and (6) ethical and legal factors. Thirdly, we developed a

battery of validated psychological tests chosen for the purpose of screening of living donors along-side specifically developed in-depth semi-structured interview questions to test those aspects for which no validated measures exist. Each section is accompanied by ‘red flags’ (yes/no) warranting further assessment, intervention or exclusion from donation. This has the following advantages: a) it supports the standardization of an internationally accepted psychosocial screening protocol for prospective donors; and b) it allows generation of comparative data for monitoring of benefits and risks for donors over time. In order to disseminate this tool for use in clinical practice, its validity, feasibility and acceptability need to be assessed in a pilot study. In this grant application we request financing for a consortium meeting to develop a research protocol for a prospective study. The aim of the study is to test our innovative psychosocial screening instrument empirically in several European transplant centers.

Design & Methods: The proposed study will incorporate 2 stages. Firstly, validity screening will be conducted whereby experts from the field will rate the instrument on content validity using the approach outlined by Polit and Beck (26). Secondly, the instrument will be implemented in clinical practice in a minimum of three countries.

Research participants: Participants to be included in the pilot of the screening tool will be potential living liver or kidney donors.

Partners: The team are members of ELPAT, a subdivision of the European Organ Transplant Society (ESOT). Emma Massey (psychologist), Erasmus MC, the Netherlands, will coordinate this study and has been an active member of EHPS since 2004. Co-investigators are Fabienne Dobbels (psychologist), University of Leuven, Belgium; Nathalie Duerinckx (clinical nurse specialist), University of Leuven, Belgium; Sohal Ismail (psychologist), Erasmus MC, the Netherlands; Hannah Maple (surgeon), Guys & St. Thomas, UK; Ines Mega (psychologist), Portugal; Chistina Papachristou (psychologist), Charité University Hospital Berlin, Germany; Lotte Timmerman (psychologist), Erasmus MC, the Netherlands.

Budget: We have no other existing resources to facilitate a research meeting or to support conducting the proposed research. The table below shows estimated costs, budgeted for 7 participants as one member will host the meeting and will therefore not incur travel and accommodation costs.

Type of cost	Euros
Flights *7 (€250 p.p.)	1750
Accommodation 2 nights *7 (€100 per night)	1400
Venue and audiovisual hire	200
Catering *8	1000
Total	4350

Research timeline: We propose to hold the research meeting in June 2015. Prior to the meeting we will conduct the validity screening and after the meeting we will implement the pilot study in clinical practice. A manuscript on the development and piloting of the tool will be written and submitted to a journal for publication by November 2015. Should EHPS be willing to support the organization of this meeting, EHPS will be mentioned on both publications.

Curriculum Vitae

Emma K. Massey

Personal details

Name Emma K. Massey
Date of birth 18.01.1980
Address Erasmus MC
Department of Internal Medicine, Nephrology & Transplantation.
Room NA-510
Postbus 2040
3000 CA Rotterdam
The Netherlands
Telephone +31 (0) 643081685 / +31 (0) 10 70 32442
E-mail e.massey@erasmusmc.nl
Personal website <http://nl.linkedin.com/pub/emma-massey/>

Education

Doctorate PhD in Health Psychology
04/2009
Well-being and headache in adolescents: A self-regulation perspective
Prof. Stan Maes, dr. Winnie Gebhardt, dr. Nadia Garnefski
Leiden University, the Netherlands

Master's degree MSc in Health Psychology (cum laude)
09/2004
Application of the Health Behavior Goal Model to Smoking Cessation in
Pregnancy.
Dr. W. Gebhardt
Leiden University, the Netherlands

Bachelor degree BSc in Psychology (2:1)
06/2002
University of Birmingham, UK

Work experience

Assistant professor (11-2014 – present)
Erasmus MC, Department of Internal Medicine, Nephrology & Transplantation.
In this position I lead the research line on psychosocial aspects of giving and
receiving a kidney for transplantation. Main tasks include conducting research,
obtaining research grants, dissemination of finding, supervising phd students,
and undergraduate and post-graduate teaching.

Post-doc (10/2008 – 11/2014)
Erasmus MC, Department of Internal Medicine, Nephrology & Transplantation.

PhD thesis supervision

Sohal Ismail (PhD graduation 10-06-2014)
Lotte Timmerman (2011 – present)
Jan Willem Grijpma (2013 – present)
Dorthe Slaats (2013 – present)

Grants

Principal investigator Dutch Kidney Foundation (Nierstichting). Donors' and patients' perspective on

Anonymity and social media in LIVE donation: an ELPAT initiative. 2015-2017.

Dutch Kidney Foundation (Nierstichting). Self-management after kidney transplantation: Development and pilot-testing of an innovative nurse-led self-regulation intervention (€130,000). 2013-2015.

Dutch Kidney Foundation (Nierstichting). Patient education on renal replacement therapy for pre-dialysis patients and their families (€188,000). 2010-2013.

Dutch Kidney Foundation (Nierstichting). Living kidney donation among patients of non-Dutch origin (€227,000). 2010-2013.

Co-investigator

ZonMw tussen weten en doen II. NURSE-CC: Rotterdam Consortium for Nursing Research into Self-management and Empowerment in Chronic Care. PI: AnneLoes van Staa, RN, MD, MA (€750,000).

Evidence Based Care for Nurses Erasmus MC. Psychological predictors of non-Adherence after Kidney Transplantation (PAKT study). (€20,000). PI: Mirjam Tielen, M-ANP.

ZonMW (PP4). The promotion of adequate goal striving as a strategy to improve psychological well-being among at-risk adolescents of vocational schools (€499,490). PI: Pepijn van Empelen, Phd.

Publications

International articles

Rakké YS, Zuidema WC, Hilhorst MT, Erdman RA, **Massey EK**, Betjes MG, Dor FJ, IJzermans JN, Weimar W. Seriously Ill Patients as Living Unspecified Kidney Donors: Rationale and Justification. Transplantation 2014 epub ahead of print. **IF = 3.7**

Ismail SY, Luchtenburg AE, Timman R, Zuidema WC, Boonstra C, Weimar W, Busschbach JJ, **Massey EK**. Home-based family intervention increases knowledge, communication and living donation rates: a randomized controlled trial. Am J Transplant. 2014; 14: 1862-9. **IF=6.2**

Tielen M, van Exel J, Laging M, Beck DK, Khemai R, van Gelder T, Betjes MG, Weimar W, **Massey EK**. Attitudes to medication after kidney transplantation and their association with medication adherence and graft survival: a 2-year follow-up study. J Transplant. 2014;67530.

Duerinckx N, Timmerman L, Van Gogh J, van Busschbach J, Ismail SY, **Massey EK**, Dobbels F; ELPAT Psychological Care for Living Donors and Recipients working group. Predonation psychosocial evaluation of living kidney and liver donor candidates: a systematic literature review. Trans Int. 2014;27:2-18. **IF = 3.2**

Timmerman L, Zuidema WC, Erdman RA, Kranenburg LW, Timman R, IJzermans JN, van Busschbach JJ, Weimar W, **Massey EK**. Psychologic functioning of unspecified anonymous living kidney donors before and after donation.

Transplantation. 2013;15:1369-74. **IF = 3.7**

Mamode N, Lennerling A, Citterio F, **Massey E**, Van Assche K, Sterckx S, et al. Anonymity and Live-Donor Transplantation: An ELPAT View. Transplantation. 2013;95:536-41.

Ismail SY, Luchtenburg AE, Kal-V Gestel JA, Zuidema WC, Weimar W, Busschbach JJ, **Massey EK**. Modifiable factors in access to living-donor kidney transplantation among diverse populations. Transplantation. 2013;96:586-90. **IF = 3.7**

Massey EK, Tielen M, Laging M, Beck DK, Khemai R, van Gelder T, Weimar W. The role of goal cognitions, illness perceptions and treatment beliefs in self-reported adherence after kidney transplantation: a cohort study. J Psychosom Res. 2013;75:229-34. **IF = 3.3**

Ismail SY, Timmerman L, Timman R, Luchtenburg AE, Smak Gregoor PJ, Nette RW, van den Dorpel RM, Zuidema WC, Weimar W, **Massey EK**, Busschbach JJ. A psychometric analysis of the Rotterdam Renal Replacement Knowledge-Test (R3K-T) using item response theory. Trans Int. 2013;26:1164-72. **IF = 3.2**

Ismail SY, Claassens L, Luchtenburg AE, Roodnat JJ, Zuidema WC, Weimar W, Busschbach JJ, **Massey EK**. Living donor kidney transplantation among ethnic minorities in the Netherlands: a model for breaking the hurdles. Patient Educ Couns. 2013;90:118-24. **IF = 2.4**

Ismail SY, Luchtenburg AE, Zuidema WC, Boonstra C, Weimar W, **Massey EK**, Busschbach JJ. Multisystemic engagement and nephrology based educational intervention: a randomized controlled trial protocol on the KidneyTeam At Home study. BMC Nephrol. 2012 23;13:62. **IF = 1.6**

Ismail S, **Massey EK**, Luchtenburg A, Claassens L, Zuidema W, Busschbach JJ, Weimar W. Religious attitudes towards living kidney donation among Dutch renal patients. Med Health Care Philos. 2012;15:221-227. **IF = 0.7**

Roodnat JJ, Laging M, **Massey EK**, Kho M, Kal-van Gestel JA, Ijzermans JN, van de Wetering J, Weimar W. Accumulation of Unfavorable Clinical and Socioeconomic Factors Precludes Living Donor Kidney Transplantation. Transplantation. 2012;15:18-23. **IF = 3.7**

Dor FJ, **Massey EK**, Frunza M, Johnson R, Lennerling A, Loven C, et al. New Classification of ELPAT for Living Organ Donation. Transplantation. 2011;91(9):935-8. **IF = 3.7**

Massey EK, Hilhorst M, Nette R, Smak Gregoor P, van den Dorpel M, van Kooij A, Zuidema WC, Zietse R, Busschbach JJ, Weimar W. Justification for a home-based education programme for kidney patients and their social network prior to initiation of renal replacement therapy. J Med Ethics. 2011;37:677-81. **IF = 1.4**

Massey EK, Garnefski N, Gebhardt WA, van der Leeden R. A daily diary study on

the independent and interactive effects of headache and self-regulatory factors on daily affect among adolescents. *Br J Health Psychol.* 2011;16(2):288-99. **IF = 2.3**

van Buren M, **Massey EK**, Maasdam L, Zuidema WC, Hilhorst M, IJzermans J, Weimar W. Attitudes towards financial incentives amongst actual living kidney donors. *For Love or Money? Am J Transplant.* 2010;10:2488-92. **IF = 6.0**

Massey EK, Kranenburg L, Zuidema WC, Hak G, Erdman R, Hilhorst M, IJzermans J, Busschbach JJ, Weimar W. Encouraging psychological outcomes after altruistic donation to a stranger. *Am J Transplant,* 2010;10:1445-52. **IF = 6.0**

Roodnat J, Zuidema WC, de Wetering J, de Klerk M, Erdman R, **Massey EK**, Hilhorst M, IJzermans J, Weimar W. Altruistic donor triggered domino-paired kidney donation for unsuccessful couples from the kidney-exchange program. *Am J Transplant,* 2010;10:821-827. **IF = 6.0**

Gebhardt WA, van der Doef M, **Massey EK**, Verhoeven C, Verkuil B. Goal commitment to finding a partner and satisfaction with life among female singles: the mediating role of rumination. *J Health Psychol.* 2010;15:122-130. **IF = 1.5**

Massey EK, Garnefski N, Gebhardt WA, van der Leeden R. Daily frustration, cognitive coping and coping efficacy in adolescent headache: A daily diary study. *Headache.* 2009; 49(8):1198-1205. **IF = 2.6**

Massey EK, Garnefski N, Gebhardt WA. Goal frustration, coping and well-being in the context of adolescent headache: A self-regulation approach. *Eur J Pain.* 2009;13:977-984. **IF = 3.8**

Massey EK, Gebhardt WA, Garnefski N. Self-generated goals and goal process appraisals: Relationships with sociodemographic factors and well-being. *J Adolesc.* 2009;32:501-518. **IF = 1.6**

Massey EK, Gebhardt WA, Garnefski N. Adolescent goal content and pursuit: a review of the literature from the past 16 years. *Dev Rev.* 2008;28:421-460. **IF = 6.8**

National articles

Massey EK. De arts als poortwachter? *Tijdschrift voor gezondheidszorg en ethiek.* 2009;19:40-41.

Contribution to books

Ismail SY, Luchtenburg AE, Zuidema WC, Weimar W, **Massey EK**, Busschbach JJ. Let's Talk About Living Donor Kidney Transplantation: Breaking the passive deadlock on living donation. In: *Public engagement in Organ Donation and Transplantation.* Randhawa G, Schicktanz S (Eds). Pabst Science Publishers, 2013.

Massey EK, Kranenburg L, Zuidema WC, Hak G, Erdman R, Hilhorst M, IJzermans J, Busschbach JJ, Weimar W. Altruistic donation to strangers: donor motivation and interpersonal values. In: *Organ Transplantation: Ethical, Legal and*

Psychological Aspects. Expanding the European Platform. Pabst, 2011. Weimar W, Bos MA, Busschbach JJ (Eds).

Massey EK, Dobbels F, Dew MA. Issues in Adherence to Lifestyle and Medication Regimen after Solid Organ Transplantation. In: Organ Transplantation: Ethical, Legal and Psychological Aspects. Expanding the European Platform. Pabst, 2011. Weimar W, Bos MA, Busschbach JJ (Eds).

Massey EK, Gebhardt WA, Garnefski N. Goals. In: Encyclopaedia of Adolescence. Springer. Levesque RJR (Ed.). 2012.

Invited (plenary) lectures

Self-management after kidney transplantation: challenges and chances.

EuroTransplant Winter Meeting, Alpbach, Austria, Jan 2015.

Psychological aspects of the recipient. Specialty update symposium ELPAT.

European Society for Organ Transplantation (ESOT), Vienna, Austria, Sept 2013.

The psychological aspects of unspecified donation. State of the Art 5: Ethical challenges in Transplantation. European Society for Organ Transplantation (ESOT), Vienna, Austria, Sept 2013.

Psychological Aspects of Altruistic Donation to a Stranger (ETCO/ELPAT Joint Session). European Organ Donation Congress, 22nd ETCO, Cardiff, UK, Sept 2011.

Psychosociale aspecten rond donatie bij leven. Mini-symposium, Medisch Ethische Commissie Nederlands Transplantatie Vereniging, Utrecht, Oct, 2010.

Astellas Symposium 'Optimising Patient Management Post-Transplantation', Zeist, NL. Jan 2010.

Memberships

Member

- **European Health Psychology Society (EHPS) (2004 – present)**

- National Workgroup Social Science Research Nephrology (2009 – present)

- Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) (2008 – present)

- European Society for Organ Transplantation (ESOT) (2009 – present)

- Netherlands Transplantation Society (2008 – present)

- Research Institute for Psychology & Health (P&H) (2004 – 2009)

Board member

- Secretary of National Workgroup Social Science Research Nephrology (SWON) (2012 – present)

- Chairperson ELPAT workgroup 'Psychological Care of patients and donors', ELPAT, a subdivision of ESOT (2011 – present)

- Chairperson ELPAT workgroup 'Diverse-populations' ELPAT, a subdivision of ESOT (2008 – 2011)

- PhD representative on the Daily Management Board (DB), Clinical, Health and Neuropsychology Unit, Leiden University

- **Secretary of CREATE, a subdivision of the European Health Psychology Society (2005 – 2007)**

Fabienne Dobbels

POSITION TITLE Assistant professor	HEALTH SERVICES AND NURSING RESEARCH UNIVERSITY OF LEUVEN (KU Leuven), Belgium		
EDUCATION/TRAINING			
INSTITUTION AND LOCATION	DEGREE	MM/YY	FIELD OF STUDY
University of Leuven (KU Leuven), Belgium	Master	1996	Psychology
University of Leuven (KU Leuven), Belgium	Post-graduate	1997	Academic teaching
University of Leuven (KU Leuven), Belgium	Post-graduate	1999	Psychotherapy
University of Leuven (KU Leuven), Belgium	PhD	2005	Social Health Sciences

A. Personal statement

Prof. Dr. Fabienne Dobbels is a psychologist and psychotherapist, who worked at the heart transplantation program of the University Hospitals of Leuven, Belgium from 1996 until 2006. She defended her PhD in 2005, focusing on pre-transplant psychosocial screening, adherence and long-term post-transplant outcomes. Afterwards, she received a 6-years post-doctoral scholarship of the Scientific Research Foundation Flanders (FWO). Appointed as full-time assistant professor, Dr. Dobbels is currently a senior researcher within the Center for Health Services and Nursing Research, Department of Public Health and Primary Care of the University of Leuven, Belgium (KU Leuven). Key research topics include patient adherence, psychosocial issues and patient reported outcomes predominately in the field of organ transplantation, but also in other chronic illness populations. Dr. Dobbels is a reviewer for many international journals and has presented at numerous national and international conferences, with over 130 peer-reviewed articles and 10 book chapters to her name, and is the principal or co-investigator of several research grants. Given her clinical and research expertise on behavioural change, Dr. Dobbels is particularly well placed to collaborate in the planned research program.

B. Positions and honors

Positions and employment

<i>Dec 1996-30 Sept 2006:</i>	Psychologist: Cardiac rehabilitation and Transplantation University Hospital Leuven: Part-time (50%)
<i>Aug 1998-30 Sept 2006 :</i>	Research fellow (part time 50%) Health Services and Nursing Research, School of Public Health and Primary Care; University of Leuven (KU Leuven) (Belgium)
<i>Oct, 2005-present:</i>	Lecturer (20%) Master in Nursing and Midwifery (chronic illness management course in the Master's program) Health Services and Nursing Research, University of Leuven (Belgium)

- Oct, 2006-Sept 30, 2012:* *Post-doctoral fellow with scholarship of “Fonds voor Wetenschappelijk Onderzoek Vlaanderen (FWO)” (3 years mandate from 2006-2009; Second term 2009-2012)*
- Health Services and Nursing Research, School of Public Health and Primary Care (University of Leuven)
- Sept 2011-present:* Visiting professorship (reader) at Florence Nightingale School of Nursing, King’s College, London (UK)
- Oct, 2012-present:* Assistant Professor (100%), Health Services and Nursing Research, School of Public Health and Primary Care, University of Leuven (KU Leuven), Belgium
- June, 2014-present:* Visiting professor at the Institute of Nursing Science, University of Basel, Switzerland

Other experience

- 2007-2014: Associate Director for Outcome Analyses, Registry of the International Society for Heart and Lung Transplantation
- 2008-present: Co-chair of the Psychosocial Aspects of Transplantation working group of the Ethical, Legal and Psychosocial Aspects in Organ Transplantation (ELPAT) task force of the European Society for Organ Transplantation (ESOT)
- 2009-present: Chair Transplant360, a European task force developing educational and training materials to improve patients’ adherence and post-transplant self-management
- 2009-present: Associate editor Pediatric Transplantation
- 2014-present: Founding member of the European Transplant Allied Health Professionals Committee (ETAHP) as part of the European Society for Organ Transplantation (ESOT)

Reviewer

Journal of Heart and Lung Transplantation, Pediatric Transplantation, American Journal of Transplantation, Clinical Transplantation, Transplantation, Transplantation International, Progress in Transplantation, Journal of Cardiovascular Nursing, European Respiratory Journal, European Heart Journal (non-exhaustive list)

Membership of professional organizations and patient organizations

European Society for Organ Transplantation
 International Society for Heart and Lung Transplantation
 International Pediatric Transplant Association
 International Transplant Nurses Association
 Membership of transplant patient organizations of the University Hospitals of Leuven: LLT, HaTrActief, HALO

C. Selected Peer-reviewed Publications

Total number of publications:

- 131 Medline cited peer reviewed international publications (129 published; 2 in press; h-index= 34, citations > 4200, average citation rate= 28)
- 15 book chapters & numerous abstracts of presentations at international meetings published in conference proceedings or Journal supplements

Most recent publications (2014 only)

1. Claes A, Decorte A, Levchenko E, **Dobbels F**. Facilitators and barriers of medication adherence in pediatric liver and kidney transplant patients: a mixed-methods study. *Prog Transplant* 2014, in press.
2. **Dobbels F**, Wong S, Min Y, Sam J, Kalsekar A. Beneficial effect of Belatacept on health-related quality of life and perceived side-effects: results from the BENEFIT and BENEFIT-EXT trials. *Transplantation* 2014; 33(4):347-9.
3. **Dobbels F**, Mauthner O, Milisen K. Frailty in LVAD destination therapy: putting a new motor in a rickety old car running out of gas? *J Heart Lung Transplant*, in press.
4. Vanhoof J, Delcroix M, Vandevelde E, Denhaerynck K, Wuyts W, Belge C, **Dobbels F**. Emotional symptoms and quality of life in patients with pulmonary arterial hypertension. *J Heart Lung Transplant* 2014; 33(8):800-8.
5. Murray P, **Dobbels F**, Lonsdale D, Harden P. Impact of end-stage kidney disease on academic achievements and employment in young adults: a mixed methods study. *J Adolesc Health* 2014; 55(4):505-12.
6. Berben L, Russell C, Engberg S, **Dobbels F**, De Geest S. Development, content validity and inter-rater reliability testing of the CIMI-BRIGHT: an instrument to assess the level of chronic illness management implemented in solid organ transplant programs. *International Journal of Care Coordination*, in press.
7. Kirsch M, Götz A, Halter JP, Schanz U, Stüssi G, **Dobbels F**, De Geest S. Differences in health behaviours between recipients of allogeneic haematopoietic stem cell transplantation and the general population: A matched control study. *Bone Marrow Transplantation* 2014; 49(9):1223-30..
8. Kirsch M, Mitchell SA, **Dobbels F**, Stussi G, Basch E, Halter JP, De Geest S. Linguistic and content validation of a German-language PRO-CTCAE-based patient-reported outcomes instrument to evaluate the symptom experience in survivors of allogeneic haematopoietic stem cell transplantation. *European Journal of Oncology Nursing* 2014, Sep 1: e-pub ahead of print.
9. Temmerman F, **Dobbels F**, Ahn Ho T, Pirson Y, Vanslebrouck R, Coudyzer W, Bammens B, van Pelt J, Pirenne J, Nevens F. *Journal of Hepatology* 2014; e-pub ahead of print.
10. **Dobbels F**, de Jong C, Drost E, et al. PROactive's innovative conceptual framework on physical activity. *European Respiratory Journal* 2014, e-pub ahead of print.
11. Berben L, Denhaerynck K, **Dobbels F**, Engberg S, Vanhaecke J, Crespo-Leiro M, Russell C, and De Geest S for the BRIGHT study team. Building research initiative group: chronic illness management and adherence in transplantation (BRIGHT) study: rationale, design and methodology. *Journal of Advanced Nursing* 2014, Sept 26, e-pub ahead of print.
12. **Dobbels F**. Intellectual disability in pediatric transplantation: pitfalls and opportunities. *Pediatr Transplant*. 2014 Nov;18(7):658-60
13. Benden C, Goldfarb SB, Edwards LB, Kucheryavaya AY, Christie JD, Dipchand AI, **Dobbels F**, Levvey BJ, Lund LH, Meiser B, Yusen RD, Stehlik J; International Society for Heart and Lung Transplantation. The registry of the international society for heart and lung transplantation:

seventeenth official pediatric lung and heart-lung transplantation report-2014; focus theme: retransplantation. J Heart Lung Transplant. 2014 Oct;33(10):1025-33.

14. Yusen RD, Edwards LB, Kucheryavaya AY, Benden C, Dipchand AI, **Dobbels F**, Goldfarb SB, Levvey BJ, Lund LH, Meiser B, Stehlik J; International Society for Heart and Lung Transplantation. Society for Heart and Lung Transplantation: Thirty-first Adult Lung and Heart-Lung Transplant Report-2014; Focus Theme: Retransplantation. J Heart Lung Transplant. 2014 Oct;33(10):1009-24.
15. Lund LH, Edwards LB, Kucheryavaya AY, Benden C, Christie JD, Dipchand AI, **Dobbels F**, Goldfarb SB, Levvey BJ, Meiser B, Yusen RD, Stehlik J; International Society of Heart and Lung Transplantation. The Registry of the International Society for Heart and Lung Transplantation: Thirty-first Official Adult Heart Transplant Report-2014; Focus Theme: Retransplantation. J Heart Lung Transplant. 2014 Oct;33(10):996-1008.
16. Dipchand AI, Edwards LB, Kucheryavaya AY, Benden C, **Dobbels F**, Levvey BJ, Lund LH, Meiser B, Yusen RD, Stehlik J; International Society of Heart and Lung Transplantation. The registry of the international society for heart and lung transplantation: seventeenth official pediatric heart transplantation report-2014; focus theme: retransplantation. J Heart Lung Transplant. 2014 Oct;33(10):985-95.

Ongoing projects

- 2009-2014: Troosters T, **Dobbels F**, Decramer M. The PROactive project: developing patient reported outcome tools to measure physical activity in patients with COPD. KU Leuven as managing entity of the Innovative Medicines Initiative IMI
- 2009-2014: De Geest S, **Dobbels F**. The BRIGHT study: building research initiative group on adherence in transplantation. Unrestricted research grant from a pharmaceutical company
- 2013-2017: **Dobbels F**, De Geest S. Is there a preference for interactive health technology applications to support self-management in solid organ Tx recipients? Special Research Fund (BOF) KU Leuven

Completed projects

- 2009-2012: **Dobbels F**, De Geest S. The ABC project: Ascertain barriers for compliance: policies for safe, effective, and and cost-effective use of medicines in Europe. KU Leuven as partner in a 7th framework EU-funded project
- 2010-2012: **Dobbels F**, De Geest S. The EULOD project: Living organ donation in Europe. KU Leuven as partner in a 7th framework EU-funded project (coordination action)
- 2011-2012: Bollen H, Meyns B, **Dobbels F**. Emotional distress, quality of life and care burden in patients with left ventricular assist devices and their partners: a prospective study. Nursing and Social Sciences research grant of the International Society of Heart and Lung Transplantation
- 2011-2013: Kirsch M, Halter J, Stüssi G, **Dobbels F**, De Geest S. PROVIVO: Patient reported outcomes in view of symptom experience and self-management of adult long-term survivors after haematopoietic stem cell transplantation: a Mixed methods study. Swiss Krebsliga
- 2012-2013: Berben L, **Dobbels F**, Russell C, De Geest S. Chronic Illness management. Implementation in Heart Transplant Centers Study. Nursing and Social Sciences research grant of the International Society of Heart and Lung Transplantation

Nathalie Duerinckx

Personal details:

Health Services and Nursing Research

Department of Public Health and Primary Care

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Education

2012 – present	University of Leuven, Leuven, Belgium, Doctoral school Biomedical Sciences PhD program Patient Related and public health research
2007 – 2009	Katholieke Universiteit Leuven, Leuven, Belgium Master's Degree in Nursing and Midwifery (Cum laude)
2004 – 2007	Katholieke Hogeschool Leuven, Leuven, Belgium Bachelor Degree in Nursing (Magna cum laude)

Master's thesis

Is there a relationship between improper eye drop administration skills and non-adherence to eye drop treatment in patients with glaucoma? A cross-sectional observational study.

Defended in June 2009 – Promotor: Professor Dr. T. Zeyen

Winner of the award for best thesis - Professor Evers for Nursing and Midwifery 2011

Professional experience

Jan 2012 – present	Assisting Academic Personnel (AAP) (50%) University of Leuven, Leuven, Belgium, Department of Public Health and Primary Care Health Services and Nursing Research
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July 2009 – Dec 2011	Research Associate (research project EULOD) (50%) Katholieke Universiteit Leuven, Leuven, Belgium, Center for Health Services and Nursing Research
July 2014 – present	Clinical Nurse Specialist Heart Transplantation (50%) University Hospitals of Leuven, Leuven, Belgium, Department of Cardiology & Heart Transplantation
July 2011 – June 2014	Specialist nurse heart transplantation (50%) University Hospitals of Leuven, Leuven, Belgium, Department of Cardiology & Heart Transplantation
July 2009 – 2011	Staff Nurse (50%) University Hospitals of Leuven, Leuven, Belgium, Department of Cardiology & Heart Transplantation

Involvement in international research projects

2011 – present	B-SERIOUS project (Funded by the Brocher Foundation) Subgroup leader smoking group
2010 – 2012	EULOD project (Living Organ Donation in Europe) , EU-funded research project (FP7) Involvement in work packages 2 (scientific work package) and 5 (dissemination of the research project results): http://www.eulod.org

Publications in international, peer-reviewed journals

- **Duerinckx N**, Timmerman L, Van Gogh J, Busschbach JJ, Ismail SY, Massey EK, Dobbels F, on behalf of the ELPAT Psychological Care for Living Donors and Recipients working group. Pre-donation psychosocial evaluation of living kidney and liver donor candidates: a systematic literature review. *Transplant International*, *In press*.
- De Geest S, Dobbels F, Schönfeld S, **Duerinckx N**, Sveinbjarnardottir EK, Denhaerynck K. Academic Service Partnerships: What do we learn from around the globe? A systematic literature review. *Nursing Outlook*. 2013 Mar 9. doi:pii: S0029-6554(13)00012-2. 10.1016/j.outlook.2013.02.001.

- Lennerling A, Lovén C, Dor FJ, Ambagtsheer F, **Duerinckx N**, Frunza M, Pascalev A, Zuidema W, Weimar W, Dobbels F. Living organ donation practices in Europe - results from an online survey. *Transplant International* 2013 Feb;26(2):145-53. doi: 10.1111/tri.12012. Epub 2012 Dec 1.
- De Geest S, Burkhalter H, De Bleser L, Berben L, **Duerinckx N**, De Bondt K, Dobbels F. Non-adherence to immunosuppressive drugs in transplantation: What can clinicians do? *Journal of Renal Nursing* 2010; 2: 59-63.
- Dobbels F, **Duerinckx N**, Breunig C, De Geest S. What every nurse should know about depression. *Journal of Renal Nursing* 2010; 2(1):6-11.

Professional memberships

International organizations

- Member of ISHLT (International Society of Heart and Lung Transplantation) (since 2013)
- Member of ITNS (International Transplantation Nursing Society) (since 2011)
- Member of ESOT (European Society of Organ Transplantation) (since 2011)
- Member of EULOD (Living Organ Donation in Europe) (since 2010)
- Member of ELPAT (Ethical, Legal and Psychosocial Aspects of Organ Transplantation) (since 2009)

Christina Papachristou

PERSONAL INFORMATION

Birthdate **26.08.1974**
Telephone **+49-179 925 2006**
Email **christina.papachristou@charite.de**

AREAS OF EXPERTISE

- Mental health
- Social determinants of health
- Health policies and health services research
- Health promotion
- Qualitative Research Methods
- Organ transplantation

PROFESSIONAL EXPERIENCE

- Date 2001 – to date
- Employer **Charité University Hospital Berlin, Medical Clinic for Internal Medicine and Psychosomatics**
- Position **Clinical and Research Associate**

- Date 2014 – to date
- Employer **COFS – Coalition for Organ Failure Solutions**
- Position **Advisor and Program Specialist**

- Date 2010 - 2012
- Employer **EU-funded Research Project ELIPSY – 7th Framework Programme**
- Position **Researcher www.eulivingdonor.eu**

- Date 01/2002
- Employer **University of Essen, Germany & German Ministry for Family, Gender, Youth and Third Age Issues (BMFSFJ)**
- Position **Expert Interviewer**

- Date 2001 – 2002
- Employer **Charité – Medical School of Berlin German, Medical Sociology Department**
- Position **Tutor (Health systems and Health Policy)**

- Date 08-10/1999
- Employer **NGO Flora Tristan, Lima, Peru - Division Sexual and Reproductive Health -**
- Position **Internship – Health Policy Research – Field study**

EDUCATION

- Date 2002 – 2006
- Institution **Charité - Medical School Berlin, Germany**
- Degree **PhD in Health Sciences – Medicine**

- Thesis “The decision of undergoing living donor liver transplantation – legal standards and subjective experience. An empirical qualitative research methods study for the improvement of the psychosocial evaluation and the support of living liver donors”.

- Date 2009 – 2011
- Institution **London School of Economics and Political Science (LSE)**
- Degree **MSc in Health Economics, Policy and Management**

- Date 1998 – 2000
- Institution **Technical University of Berlin, Germany**
- Degree **Master in Public Health (MPH)**
- Specialisation Health Promotion in the Community and the Working Environment

- Date 1992 – 1997
- Institution **Department of Psychology**
Aristotle University of Thessaloniki, Greece
- Degree **Degree in Psychology (Clinical & Social Psychology)**

CONTINUOUS PROFESSIONAL DEVELOPMENT

- Date 2013 – 2016
- Institution **Berlin Academy for Psychotherapy**
Training in Psychodynamic Psychotherapy

- Date 09/2006
- Institution **London School for Hygiene and Tropical Medicine & Institute of Psychiatry, Kings College London, UK.**
- Title **Short Course „International Mental Health Research - Methods & Applications“**

- Date 07/2005
- Institution **Department of Tropical Hygiene and Public Health, University of Heidelberg, Germany**
& German Development Cooperation (GTZ)
- Title **Postgraduate course in „Quality Management in International Health“**

- Date 02/2003
- Institution **London School of Hygiene & Tropical Medicine, UK**
- Title **Short course „Evaluation of health promotion interventions“**

- Date 04 – 12/1998
- Institution **Free University Berlin, Germany**
- Title **Postgraduate seminars in“ Qualitative Research Methods in the Social Sciences“**

- Date 2000-2003

- Institution **Institute for Systemic Therapy (IST), Berlin, Germany**
- Title **Training in Systemic Theory, Counselling and Psychotherapy**

REVIEWS

- Reviewer for a research proposal - Research Grants Council of Hong Kong, China
- Journal for Psychosomatic Research
- American Journal of Transplantation
- Liver Transplantation
- American Journal for Psychiatry in Medicine

FUNDS/AWARDS

- **7th Framework Programme Fund – European Union (60.000 Euro)**
- Internal Research Fund – Charité University Medicine (2007,2009, 2012)
- Hertha Narthoff Award for Best Master Theses in Public Health 2001(Medical Association Berlin and Technical University Berlin)

MEMBERSHIPS

ESOT (European Society for Organtransplantation)

ELPAT (Ethical, legal and psychosocial aspects in Transplantation)

LIDOBS (Living Donor Observatory)

PUBLICATIONS

- Papachristou C, Marie-Andrée Jacob. Matching organs with donors: legality and kinship in transplants. **Journal of the Royal Anthropological Institute**. 2014 Dec;20(4)
- [Mohsen Naghavi](#), [Haidong Wang](#), [Rafael Lozano](#), [Adrian Davis](#), et al. Global, regional, and national age-sex specific all-cause and cause-specific mortality for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. **Lancet**. 2014 Dec 17 (Epub)
- Tong A, Hanson CS, Chapman JR, Halleck F, Budde K, Papachristou C, Craig JC. The preferences and perspectives of nephrologists on patients' access to kidney transplantation: a systematic review. **Transplantation**. 2014 Oct 15;98(7):682-91
- Murray CJ, Ortblad KF, Guinovart C, Lim SS, et al. [Global, regional, and national incidence and mortality for HIV, tuberculosis, and malaria during 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013](#). **Lancet**. 2014 Sep 13;384(9947):1005-70
- Kassebaum NJ, Bertozzi-Villa A, Coggeshall MS, Shackelford KA, et al. [Global, regional, and national levels and causes of maternal mortality during 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013](#). **Lancet**. 2014 Sep 13;384(9947):980-1004
- Duerinckx N, Timmerman L, Van Gogh J, van Busschbach J, Ismail SY, Massey EK, Dobbels F; ELPAT Psychological Care for Living Donors and Recipients working group. [Predonation psychosocial evaluation of living kidney and liver donor candidates: a systematic literature review](#). **Transpl Int**. 2014 Jan;27(1):2-18
- Papachristou C, Klapp BF. The psychological evaluation of the living liver donor. **Acta Gastroenterologica belgica** 2010 Jul-Sep;73(3):383-8
- Papachristou C, Walter M, Frommer J, Klapp BF. Decision-making and risk assessment in living liver donation - How informed is the informed consent of donors? A qualitative study. **Psychosomatics** 2010 Jul;51(4):312-9
- Hermann H, Klapp BF, Danzer G, Papachristou C. Gender-specific differences associated with living donor liver transplantation – a review study. **Liver Transplantation** 2010 Mar;16(3):375-86
- Papachristou C, Frommer J, Walter M, Klapp BF. Living donor liver transplantation and its impact on the donor-recipient relationship – Results of a qualitative interview study with donors. **Clinical Transplantation** 2009;23(3):382-91

- Papachristou C, Walter M, Frommer J, Klapp BF. A model of risk and protective factors influencing the postoperative course of live liver donors. **Transplantation Proceedings** 2009; 41(5):1682-6
- Papachristou C, Walter M, Frommer et al. „I would consider it thrice...“; „Ich würde es mir dreimal überlegen...“ - Problemkonstellationen biographischer Arbeit vor und nach Leberlebendspenden. **Psychotherapie und Sozialwissenschaft** 2006; 8:71-93
- Papachristou C, Walter M, Dietrich et al. Motivation for living donor liver transplantation from the donors' perspective: an in depth qualitative research study. **Transplantation** 2004;78(10):1506-1514
- Walter M, Papachristou C, Pascher A et al. Impaired psychosocial outcome of donors after adult-to-adult living donor liver transplantation: An in-depth qualitative research study. **Clinical Transplantation** 2006;20(4):410-5
- Walter M, Pascher A, Papachristou C et al. Psychische und somatische Aspekte der Leberlebendspende: Präoperative Evaluation und postoperativer Verlauf. **Dtsch Med Wochenschr** 2005;130(30):1749-55
- Walter M, Papachristou C, Danzer G et al. Willingness to donate: an interview study before liver transplantation. **J Med Ethics** 2004;30(6):544-50
- Walter M, Papachristou C, Danzer G et al. Die Entscheidung potentieller Spender zur Leberlebendspende: Eine inhaltsanalytische Untersuchung zur Ambivalenz und Motivation in präoperativen Interviews. **Z KLIN PSYCHOL PSYCH** 2004;52 (2): 150-167
- Walter M, Papachristou C, Pascher A et al. Leberlebendspende: Entwicklung psychosozialer Parameter bei Spendern nach Resektion und Transplantation eines Leberlappens. In: Erim Y, Schulz KH (Eds.): Beiträge der Psychosomatik zur Transplantationsmedizin. Pabst Science, 2003;148-158
- Walter M, Dammann G, Papachristou C et al. Quality of life of living donors before and after living donor liver transplantation. **Transplant Proc** 2003;35(8):2961-3
- Walter M, Papachristou C, Fliege H et al. Psychosocial stress of living donors after living donor liver transplantation. **Transplant Proc** 2002;34(8):3291-

Lotte Timmerman

personal information

name	Lotte Timmerman
date of birth	18 maart 1987 in Zierikzee, The Netherlands
nationality	Dutch
adress	Coolhaven 30 B, 3024 AC Rotterdam, The Netherlands
telephone	+316 12 81 59 17
e-mail	lottetimmerman@xs4all.nl

profile professional

I am an ambitious psychologist who wants to brige the gap between scientific research and clinical practice. My passion is to conduct research and translate the results into clinical practice.

experience

- | | |
|--------------|---|
| 2011-present | <p>PhD-student / psychologist at the department of internal medicine at Erasmus Medical Center in Rotterdam, in collaboration with the department of psychiatry. conducting a prospective cohort study on the impact of living kidney donation on donors' mental health</p> <ul style="list-style-type: none">. writing a grant. member of the ELPAT (Ethical, Legal and Psychosocial Aspects of Organ Transplantation) working group 'psychological care for living donors and recipients'. teaching. tutor at the course 'medical psychology'. teaching at the course 'organ transplantation'. supervision on individual master thesis. presentations at international conferences. 'Changes in mental health among living kidney donors after donation: A matched control study' (ECPD 2014). 'Predictors of change in donors' mental health three months after living kidney donation' (EHPS 2014). 'Who has high expectations of donation? Exploring the psychological profile of living kidney donors' (ELPAT 2013, ESOT 2013). 'Knowledge about dialysis, transplantation, and living donation among prospective living kidney donors and recipients' (ELPAT 2013). 'Psychological functioning of unspecified anonymous living kidney donors before and after donation' (ETCO 2012, ELPAT 2013) |
| 2014 | <p>Trainee as psychologist at the department of psychiatry at Erasmus Medical Center in Rotterdam</p> <ul style="list-style-type: none">. conducting psychological examinations. co-therapist in psychological therapy groups for depression and psychological complaints during pregnancy |

- 2010 Volunteer at Onyame foundation in Ghana
 . supporting different projects aiming to improve health, education, and agriculture
- 2010 Research assistant at different research projects at the department of public health of Erasmus Medical Center in Rotterdam
- 2009 Research assistant at GGZ Delfland in Delft
- 2007-2008 Research assistant at Erasmus University in Rotterdam

publications

Timmerman L, Laging M, Westerhof GJ, Timman R, Zuidema WC, Beck DK, et al. Mental health among living kidney donors: A prospective comparison with matched controls from the general population. *American Journal of Transplantation* 2015 (in press)

Timmerman L, Ismail SY, Luchtenburg AE, Zuidema WC, IJzermans JNM, Busschbach JJV, et al. Exploring knowledge about dialysis, transplantation, and living donation among patients and their living kidney donors. *International Journal of Behavioral Medicine* 2015 (in press)

Timmerman L, Weimar W. An argument to abolish legal restrictions on unspecified living kidney donation. *Transplantation* 2014; 98: 1145-6. Timmerman L, Zuidema WC, Erdman RA, Kranenburg LW, Timman R, IJzermans JNM, et al. Psychologic functioning of unspecified anonymous living kidney donors before and after donation. *Transplantation* 2013; 95: 1369-74

Timmerman L, Laging M, Zuidema WC, IJzermans JNM, Betjes MGH, Busschbach JJV, et al. Who has extreme expectations of donation? Exploring the psychological profile of living kidney donors. In: Weimar W, Bos MA, Busschbach JJV, editors. *Organ transplantation: Ethical, legal and psychosocial aspects. Global issues, local solutions.* Lengerich, Germany: Pabst Science Publishers, 2014; p. 230-39

Duerinckx N, **Timmerman L**, van Gogh J, Busschbach JJV, Ismail SY, Massey EK, et al. Predonation psychosocial evaluation of living kidney and liver donor candidates: A systematic literature review. *Transplant International* 2014; 27: 2-18

Ismail SY, **Timmerman L**, Timman R, Luchtenburg AE, Smak Gregoor PJ, Nette RW, et al. A psychometric analysis of the Rotterdam Renal Replacement Knowledge-Test (R3K-T) using item response theory. *Transplant International* 2013; 26: 1164-72.

education

- 2008-2010 Master Clinical Psychology, Erasmus University Rotterdam, graduated in 2010
 . research internship: November 2009 – July 2010, grade: 7,8
 PsyQ Rijnmond in Rotterdam conducting a study on the effectiveness of metacognitive group therapy for generalized anxiety patients
 . clinical internship: February – October 2009, grade: 8
 GGZ Delfland in Naaldwijk and Delft
 . diagnosing and treating adults with mood disorders, anxiety, personality disorders, ADHD, and trauma

- 2005-2008 Bachelor Psychology, Erasmus University Rotterdam, graduated in 2008
 - . conducting three psychological examinations in order to receive my basic annotation psychodiagnostics (basisaantekening psychodiagnostiek)
 - . bachelor thesis: June – July 2008, grade: 8,3
 - Sophia Children’s Hospital Rotterdam literature research on the impact of stress on somaform disorders among children and adolescents
- 1999-2005 Pre-university secondary education, Buys Ballot College in Goes, graduated in 2005
 - . profile: culture and society with biology and extra mathematics

courses and qualifications

- 2011-2012 Netherlands Institute for Health Sciences (NIHES) courses:
 - . conceptual foundation of epidemiologic study design
 - . cohort studies
 - . courses for the quantitative researcher
 - . repeated measurements in clinical studies
- 2011 English Biomedical Writing and Communication
- 2009 Basic Annotation Psychodiagnostics (Basisaantekening Psychodiagnostiek)

skills

- software SPSS, MS Office (Word, Excel, Powerpoint)
- languages Dutch, English, German (good), French (intermediate)

Inês da Natividade Mega

Personal details:

Centro Hepato-Bilio-Pancreático e de Transplantação
Hospital de Curry Cabral
Centro Hospitalar Lisboa Central
Rua da Beneficência, 8, 1069-166 Lisboa
Tel: (+351) 21 792 43 12
Email: inesmega18@gmail.com

Education:

2000 – 2005: Instituto Superior de Psicologia Aplicada, Lisbon, Portugal
Licentiate Degree in Clinical Psychology

2004 – 2005 Universidad Pontificia, Salamanca, Spain
Erasmus in Clinical Psychology

2007 – 2012 Sociedade Portuguesa de Psicoterapias Breves, Lisbon, Portugal
Training in Psychotherapy

Professional Experience:

2006 – present Private Practice, Lisbon, Portugal
Clinical Psychology, Psychotherapy

2007 – 2008 Mental Health and Psychiatry Department,
Hospital de Santa Maria, Lisbon, Portugal
Internship in Clinical Psychology

2009 – present Hepato-Biliar-Pancreatic and Transplantation Unit
Hospital de Curry Cabral, Lisbon, Portugal
Clinical Psychologist (full time)

2007 – present Participation as speaker and member in national and
International meetings and study groups

Publications in peer reviewed journals:

- **Mega I**, Telles-Correia D, Barroso E. Nonadherence in liver transplantation: how to improve it?. *Psychotherapy and Psychosomatics*. 2013 82(suppl1) 1-134, pag 65.
- Telles-Correia D, **Mega I**, Freire MJ, Barreira D, Cortez-Pinto H. Anxiety and depression symptoms in liver encephalopathy: are they psychiatric or organic? *Psychotherapy and Psychosomatics*. 2013 82 (suppl1) 1-134, pag 114.

- Telles-Correia D, Barbosa A, **Mega I**, Monteiro E. Psychosocial Predictors of adherence after liver transplant in a single transplant center in Portugal. *Progress in Transplantation*. 2012 Mar;22(1):91-4
- Telles-Correia D, Barbosa A, **Mega I**. Quality of life and transplantation. *Acta Med Port*. 2010 Nov-Dec;23(6):1091-100.
- Telles-Correia D, Barbosa A, **Mega I**, Monteiro E. Predictors of mental health and quality of life after liver transplant. *Psychotherapy and Psychosomatics*. 2011;80(1):60-1.
- Telles-Correia D, Barbosa A, **Mega I**. Personality and transplantation. *Acta Med Port*. 2010 Jul-Aug;23(4):655-62.
- Telles-Correia D, Cortez-Pinto H, Barbosa A, **Mega I**, Monteiro E. Quality of life following liver transplantation: a comparative study between familial amyloid neuropathy and liver disease patients. *BMC Gastroenterology*. 2009 Jul 15;9:54
- Telles-Correia D, **Mega I**, Barbosa A, Barroso E, Monteiro E. Coping in transplanted patients. *Acta Med Port*. 2008 Mar-Apr;21(2):141-8
- Telles-Correia D, Barbosa A, **Mega I**, Direitinho M, Morbey A, Monteiro E. Psychiatric differences between liver transplant candidates with familial amyloid neuropathy and those with alcoholic liver disease. *Progress in Transplantation*. 2008 Jun;18(2):134-9.
- Telles-Correia D, Barbosa A, **Mega I**, Monteiro E. Validation of multidimensional adherence questionnaire for liver transplanted patients. *Acta Med Port*. 2008 Jan-Feb;21(1):31-6
- Telles-Correia D, Barbosa A, **Mega I**, Barroso E, Monteiro E. Adherence in transplanted patients. *Acta Med Port*. 2007 Jan-Feb;20(1):73-85.
- Telles-Correia D, Barbosa A, **Mega I**, Barroso E, Monteiro E. Mental health and quality of life in alcoholic liver disease patients after liver transplantation: a prospective controlled study. *Transplant Proceedings*. 2011 43(1): 184-186.

Professional Memberships:

- Member of the Portuguese Board of Psychologists, since 2011
- Member of ESOT (European Society of Organ Transplantation), since 2013
- Member of ELPAT (Ethical, Legal and Psychosocial Aspects of Transplantation), since 2013

Sohal Ismail

Personal details

Dr. S.Y. (Sohal) Ismail, Neuropsychologist / Epidemiologist

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Telephone: 06-28 18 32 84 / 06- 81 43 71 78

E-mail: s.ismail@erasmusmc.nl, sohalismail2@gmail.com

Date of birth: 01-07-1985 Erigavo, Republic Somaliland

Relevant work experience

- | | |
|-------------------|--|
| 02-2014 – present | Researcher <i>Dutch Transplant Foundation</i> <ul style="list-style-type: none">• Research and policy on cadaveric donation• Communication skills training for IC-doctors and IC-nursing staff |
| 06-2010 – present | Researcher <i>Erasmus MC</i> <ul style="list-style-type: none">• Clinical psychologist in training (Piog)• PhD research: Home-based education for dialysis patients• Communication education for medical students: year 1-6.• Psychosocial screening of altruistic kidney donors• Member of NTV: Dutch Transplantation Foundation• Member of ELPAT: 'Psychological care' workgroup |
| 01-2010 – present | Enterprise: S.I. Neuropsychy <ul style="list-style-type: none">• Neuropsychological assessment regarding cognitive deterioration• Neuropsychological rehabilitation regarding cognitive deterioration• Consultant neuropsychopathology• Communication skills training• Member of NVN: Dutch Foundation for Neuropsychology |
| 12-2009 – 07-2011 | Neuropsychologist <i>IJsselland Ziekenhuis</i> <ul style="list-style-type: none">• Execution of (neuro) psychological assessment regarding cognition, pain, personality and ADHD• Coordinating and implementing the project: Psychosocial care in oncology• Providing training to doctors and nursing staff regarding psychosocial care (internal medicine, lung diseases and cardiology) |

- Neuropsychologist within the Stroke Unit team
- Outpatient consultations

11-2009 – 07-2011

Museum educator at the Museum for Psychiatry *Het Dolhuys*

- Providing a tour for professionals and students (12 to 17 year) in both the museum and the brain lab

07-2009 – 12-2009

Research assistant in Adolescent Psychiatry *Curium-LUMC*

- Questionnaire research in Adolescent psychiatry

03-2009 – 06-2009

Teacher workgroup Neurobiology *Leiden University*

- Teaching functional neuroanatomy and clinical neuropsychology

08-2007 – 08-2009

Student researcher in Epilepsy *SEIN (Stichting Epilepsie*

Instellingen Nederland)

- Approaching/informing/scheduling patients for research
- Neuropsychological test administration in patients (oral/written/digital)
- Coding, reading, analyzing, interpreting and reporting physiological and (neuro) psychological data

08-2007 – 08-2009

Student assistant in Statistics *Leiden University*

- Teaching theoretical and practical SPSS skills
- Assisting in interpreting and reporting scientific results
- Taking and reviewing statistical (final)tests and reports

Academic qualifications / Courses

06-2013

Recertification Neuropsychology

12-2011 – 05-2013

Communication on Donation

03-2011 – 05-2011

Basic course on regulation and organization of clinical research

- Good Clinical Practice (GCP) guidelines
- GCP-Exam: 30-03-2012

08-2010 – 04-2013

Multisystemic therapy (MST)

- Theoretical MST training day in Oslo
- MST in Practise at RINO
- 2 years of Multisystemic therapy supervision

- 01-2011 – 01-2013 **Master of Science in Health Sciences** Erasmus University Rotterdam
- Specialization: Epidemiology
 - Elective courses: Survival Analysis for Clinicians; Repeated Measurements in Clinical Studies; Bayesian Statistics; Ethnicity, Health and Health Care; Medical Demography, From Problem to Solution in Public Health, Missing Values in Clinical Research
- 09-2005 – 02-2010 **Master Clinical Neuropsychology** Leiden University
Bachelor Psychology (Cum Laude) Leiden University
- Certificate for psycho-diagnostics (BAPD) and NIP-member
 - Clinical internship IJsselland Ziekenhuis
 - Thesis: Titel: *Blood Pressure and White Matter Hyper-intensities in the Spectrum of Cognitive Decline in Old Age.*
 - Honors Research Bachelors Project: Title: *Avoidance deficits, trauma and stress in patients with Psychogenic Pseudo Epileptic Attacks*
 - Extra curricular: Intensive English, Disabled care & Arabic
- 09-2004 - 07-2005 **Pharmaceutical Science** Hogeschool Utrecht
- 09-1999 – 07-2004 **High school** Visser 't hooft lyceum

Scientific publications:

1. **Ismail SY**, Luchtenburg AE, Zuidema W, Weimar W, Busschbach JJ, Massey EK. Let's talk about living donor kidney transplantation: Breaking the passive deadlock on living donation. In: Randhawa G, Schickanz S, editors. Public Engagement in Organ Donation and Transplantation. Lengerich: Pabst Science Publishers; 2013. p. 136-44.
2. **Ismail SY**, Luchtenburg AE, Kal VGJA, Zuidema WC, Weimar W, Busschbach JJ, et al. Modifiable Factors in Access to Living-Donor Kidney Transplantation Among Diverse Populations. *Transplantation* 2013;96:586-590.
3. **Ismail SY**, Claassens L, Luchtenburg AE, Roodnat JJ, Zuidema WC, Weimar W, et al. Living donor kidney transplantation among ethnic minorities in the Netherlands: A model for breaking the hurdles. *Patient Education and Counseling* 2013;90:118-24.
4. Duerinckx N, Timmerman L, Van Gogh J, Busschbach J, **Ismail SY**, Massey EK, et al. Predonation psychosocial evaluation of living kidney and liver donor candidates: a systematic literature review. *Transpl Int* 2014;27:2-18.
5. **Ismail SY**, Massey EK, Luchtenburg AE, Claassens L, Zuidema WC, Busschbach JJ, et al. Religious attitudes towards living kidney donation among Dutch renal patients. *Med Health Care Philos* 2012;15:221-7.
6. **Ismail SY**, Luchtenburg AE, Boonstra AC, Zuidema WC, Weimar W, Busschbach JJ, et al. Multisystemic engagement & nephrology based educational intervention: a randomized controlled trial protocol on the kidney team at home-study. *BMC Nephrol* 2012;13:62.
7. **Ismail SY**, Knoop MM, Duerinkckx N, Timmerman L, Papachristou C, Aujoulat MS, et al. An ELPAT definition of the concept 'Psychosocial' in the context of Screening Living Organ Donors in Europe: A Concept Mapping approach. 2012; Available from: <http://hdl.handle.net/1765/38305>.
8. **Ismail SY**, Massey EK, Luchtenburg AE, Da Silva A, Smak Gregoor PJH, Nette RW, et al. Development of the Rotterdam Renal Knowledge-Test (R3K-T). 2011; Available from: http://repub.eur.nl/res/pub/23968/Manuscript_Development%20of_R3K-T.pdf.

9. **Ismail SY**, Luchtenburg AE, Massey EK, Claassens L, Busschbach JJ, Weimar W. Living kidney donation among ethnic minorities: A Dutch qualitative study on attitudes, communication, knowledge and needs of kidney patients. http://repub.beurnl/resource/pub_20862/indexhtml 2010.
10. **Ismail SY**, Duerinckx N, Knoop MM, Timmerman L, Weimar W, Dobbels F, et al. Towards a Conceptualization of Psychosocial Screening Criteria in Living Organ Donors: An ELPAT Consensus. Manuscript submitted for publication.
11. **Ismail SY**, Timmerman L, Timman R, Luchtenburg AE, Smak Gregoor PJ, Nette RW, et al. A psychometric analysis of the Rotterdam Renal Replacement Knowledge-Test (R3K-T) using item response theory. *Transpl Int* 2013;26:1164-1172.
12. **Sohal Y. Ismail**, Annemarie E. Luchtenburg, Charlotte Boonstra, Willij C. Zuidema, Willem Weimar, Jan J. V. Busschbach and Emma K. Massey. A Randomized Controlled Trial of a Home-based Family Educational Intervention: The Kidney Team at Home Study. *Am J Transplant.* 2014;14:1862-9.

Skills:

- MS Office
- Q-brain (*brain scan analysis*)
- Atlas.ti (*qualitative analysis*)
- ProMISe (*research data management*)
- SPSS, R-Software package (*quantitative analysis*)

Najma Hannah Maple

Personal details

39 Spring Plat, Crawley, West Sussex, RH10 7DG
07789765810 misshannahmaple@gmail.com

Qualifications

March 2010	MRCS	Royal College of Surgeons of England
July 2007	MBBS	Guy's, King's and St Thomas' Medical School, University of London Distinction in Special Study Modules Final Centile Ranking: 15
July 2004	BSc (Hons)	Clinical Healthcare Ethics and Law (2:1) King's College London, University of London

Employment history

Current position		
Oct 2014-2015	ST3 General Surgery	Lewisham University Hospital, London
Research		
Oct 2011 – 2014	Research Fellow	Renal Transplant Surgery Guy's and St Thomas' Hospital, London Phd title: Psychosocial Outcomes in Living Kidney Donors: Predictors and Processes King's College London

Publications (8)

1. **Maple H**, Chilcot J, Lee V, Simmonds S, Weinman J, Mamode N. "Stress predicts the Trajectory of Wound Healing in Living Kidney Donors as measured by High-Resolution Ultrasound". *Brain Behavior and Immunity*, 2015 Jan; 43C: 19-26
2. **Maple H**, Chilcot J, Burnapp L, Gibbs P, Santhouse A, Norton S, Weinman J, Mamode N. "Motivations, Outcomes and Characteristics of Unspecified (Non-Directed Altruistic) Kidney Donors in the United Kingdom" *Transplantation*, 2014 Dec 15; 98(11): 1182-9
3. Chilcot J, Spencer B, **Maple H**, Mamode N. Depression and kidney transplantation. *Transplantation*. 2014. 97 (7), 717-721 (PMID:24342977)
4. **Maple H**, Drage M. Horseshoe polycystic kidney. *Clinical Kidney Journal*. 2013 6: 102-102
5. Sood HS, Arya M, **Maple H**, Grange P, Haq A. Robotic Telemanipulating Surgical Systems for Laparoscopy: the story so far in the UK. *Expert Rev Med Devices*. 2010 Nov; 7(6):745-52 (PMID: 21050085)
6. **Maple H**, Tavakkolizadeh A. Iron Supplementation for Anaemia after Hip Fracture Surgery. *Journal of Bone and Joint Surgery (Electronic Letter)* August 2010.
<http://www.ejbs.org/cgi/eletters/92/2/265#12055>
7. **Maple H**, Hadjianastassiou V, Jones R, Mamode N. Understanding risk in living donor nephrectomy. *J Med Ethics* 2010 36: 142-147 (PMID: 20211992)
8. **Maple H**, Dasgupta P. The role of Notch in Urological Cancers. *BJU Int*. 2009 Jul; 104(1):1-2. (PMID: 19388999)

International oral presentations (5)

1. Regret in Unspecified Kidney Donation in the UK
European Society for Organ Transplantation Congress, Vienna.

Maple H , Chilcot J, Weinman J, Mamode N 2. Does Stress Impair Wound Healing Measured by High-Resolution Ultrasound in Living Kidney Donors? A Pilot Study American Transplant Congress, Seattle	Sept 2013
Maple H , Simmonds S, Tran M, Chilcot J, Weinman J, Mamode N 3. Anonymity in UK Unspecified Kidney Donors: A Nationwide Survey Ethical, Legal, Psychosocial Aspects of Organ Transplantation (ELPAT) Conference	May 2013
Maple H , Chilcot J, Burnapp L, Santhouse A, Gibbs P, Weinman J, Mamode N 4. Identifying Predictors of Psychosocial Outcomes After Living Kidney Donation Ethical, Legal, Psychosocial Aspects of Organ Transplantation (ELPAT) Conference	April 2013
Maple H , Chilcot J, Weinman J, Mamode N 5. Paediatric Live Solid Organ Donors: A No or a Yes? Ethical, Legal, Psychosocial Aspects of Organ Transplantation (ELPAT) Conference	April 2013
Maple H , Mamode N, Bagul A	April 2013
National oral presentations (5)	
1. Stress impairs wound healing measured by High-Resolution Ultrasound in Living Kidney Donors - UK Society of Behavioural Medicine, Annual Conference, Oxford.	
Maple H , Chilcot J, Simmonds S, Lee V, Tran M, Weinman J, Mamode N 2. Assessment of psychosocial characteristics and outcomes in 117 non-directed altruistic donors in the UK - British Transplantation Society Annual Congress, Bournemouth.	Dec 2013
Maple H , Chilcot J, Burnapp L, Santhouse A, Gibbs P, Weinman J, Mamode N 13.. Identifying Predictors of Psychosocial Outcomes after Living Donation - British Transplantation Society Annual Congress, Bournemouth.	March 2013
Maple H , Chilcot J, Weinman J, Mamode N 4. Is Enhanced Recovery Sustained from Surgery Through to Adjuvant Chemotherapy? - Royal Society of Medicine (Coloproctology Section), Manchester.	March 2013
Maple H , Farrah Malik E, Schizas A, Williams A, George M. 5. Living Donors Will Accept High Surgical Risks - British Transplantation Society Annual Congress, Edinburgh.	Jan 2011
Maple H , Halley A, Mamode N	March 2006
International poster presentations (12)	
1. Quality Of Life Outcomes After Transplantation Of Expanded Criteria Deceased Donor Kidneys – World Transplant Congress, San Francisco	
Maple H , Park KC, Turner S, Mamode N, Kessar N 2. Psychological Implications of Poor Communication between Living Donors and Recipients – World Transplant Congress, San Francisco	July 2014
Maple H , Chilcot J, Mamode N 3. Increased Psychological Distress in Living Donors with Primary Carer Status – World Transplant Congress, San Francisco	July 2014
Maple H , Chilcot J, Mamode N 4. Psychological outcomes in Living Donors and Recipients 3 months after surgery – World Transplant Congress, San Francisco	July 2014
Maple H , Chilcot J, Mamode N 5. Pre-operative stress and recovery in living kidney donors European Society of Organ Transplantation, Vienna	July 2014

Maple H , Simmonds S, Tran M, Chilcot J, Weinman J, Mamode N 6. Analysis of Motivation and Anonymity in 117 Unspecified (Altruistic) Donors in the UK. American Transplant Congress	Sept 2013
Maple H , Chilcot J, Burnapp L, Santhouse A, Gibbs P, Weinman J, Mamode N 7. Perioperative psychosocial factors and wound healing in living kidney donors Ethical, Legal, Psychosocial Aspects of Organ Transplantation (ELPAT) Conference	May 2013
Maple H , Simmonds S, Tran M, Chilcot J, Weinman J, Mamode N 8. The Use of Pre-Printed Operation Notes Leads to Better Data Collection - 24th International Congress of The Transplantation Society	April 2013
Maple H , Olsburgh J 9. Is Enhanced Recovery Sustained from Surgery Through to Adjuvant Chemotherapy? - Association of Surgeons of Great Britain and Ireland Surgical Congress	July 2012
Maple H , Farrah-Malik E, Schizas A, Williams A, George M 10. Small Bowel Obstruction Following Transabdominal Preperitoneal Inguinal Hernia Repair - American Hernia Society Conference, Florida	May 2011
Maple H , Rajendran N, Nizar S, Reddy M 11. Risk Communication and Perception in Living Organ Donation - Congress of the European Society for Organ Transplantation, Geneva	Mar 2010
Maple H , Halley A, Mamode N 12. Quality of Life after Laparoscopic vs. Open Living donor Nephrectomy - Congress of the European Society for Organ Transplantation, Geneva	Oct 2005
Halley A, Maple H , Mamode N	Oct 2005
National poster presentations (13)	
1. Entrapment In Living Kidney Donors British Transplantation Society Annual Congress, Glasgow	
Maple H , Chilcot J, Mamode N	Feb 2014
2 Three Month Psychological Outcomes In Living Kidney Donors And Recipients – A Lack Of Significant Morbidity British Transplantation Society Annual Congress, Glasgow	
Maple H , Chilcot J, Mamode N	Feb 2014
3. Well-being In Living Kidney Donors With Primary Carer Status Does Not Differ Significantly From Recipients On Haemodialysis British Transplantation Society Annual Congress, Glasgow	
Maple H , Chilcot J, Mamode N	Feb 2014
4. Transplantation of extended criteria deceased donor kidneys is not associated with inferior quality of life outcomes British Transplantation Society Annual Congress, Glasgow	
Maple H , Park KC, Turner S, Mamode N, Kessar N	Feb 2014
5. Stress and Wound Healing in Living Kidney Donors - A Pilot Study European Association of Psychosomatic Medicine, Cambridge	
Maple H , Simmonds S, Tran M, Chilcot J, Weinman J, Mamode N	July 2013
6. Psychosocial characteristics and outcomes in non-directed altruistic donors in the UK - European Association of Psychosomatic Medicine, Cambridge	
Maple H , Chilcot J, Burnapp L, Santhouse A, Gibbs P, Weinman J, Mamode N	July 2013
7. Predicting Psychosocial Outcomes after Living Donation European Association of Psychosomatic Medicine, Cambridge	

Maple H , Chilcot J, Weinman J, Mamode N 8. Does stress affect wound healing as measured by High-Resolution Ultrasound in Living Kidney Donors? A Pilot Study British Transplantation Society Annual Congress, Bournemouth	July 2013
Maple H , Simmonds S, Tran M, Chilcot J, Weinman J, Mamode N 9. Paediatric Live Solid Organ Donors: Yes or No? British Transplantation Society Annual Congress, Bournemouth	Mar 2013
Maple H , Mamode N, Bagul A 10. Predictors of Psychosocial Outcomes after Living Kidney Donation – A Qualitative Study - UK Society of Behavioural Medicine Conference, Manchester	Mar 2013
Maple H , Chilcot J, Weinman J, Mamode N 11. The Use of Pre-Printed Operation Notes Leads to Better Data Collection British Transplantation Society Annual Congress, Glasgow	Dec 2012
Maple H , Olsburgh J 12. Living Kidney Donors Will Accept Extreme Risks Irrespective of Pre-operative Education - British Transplantation Society Annual Congress, Manchester	Feb 2012
Maple H , Halley A, Mamode N 13. Is Quality of Life better after laparoscopic Living Donor Nephrectomy? British Transplantation Society Annual Congress, Edinburgh	Mar 2007
Halley A, Maple H , Mamode N	March 2006

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