

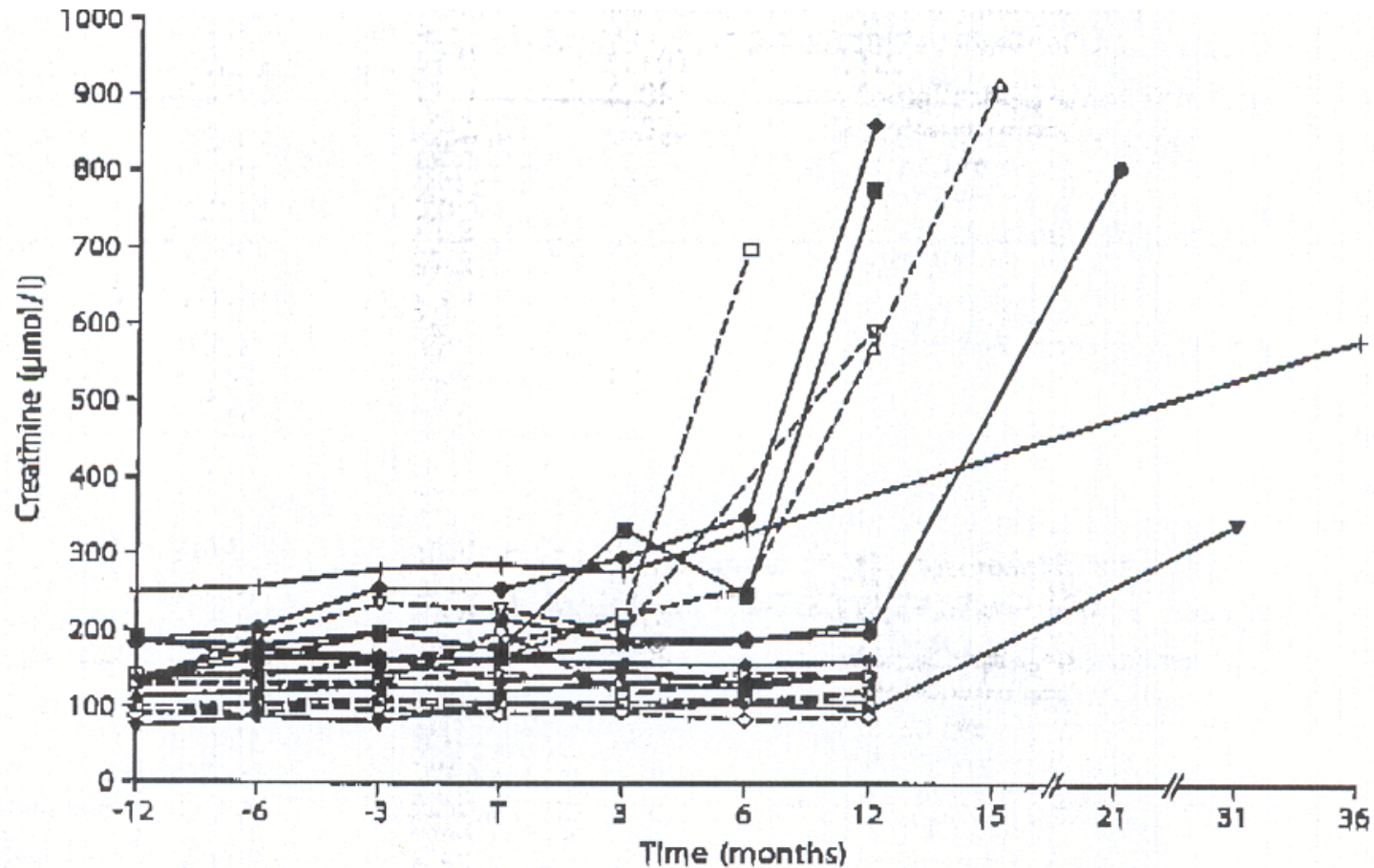
Transition in Nephrology



Medizinische Hochschule
Hannover

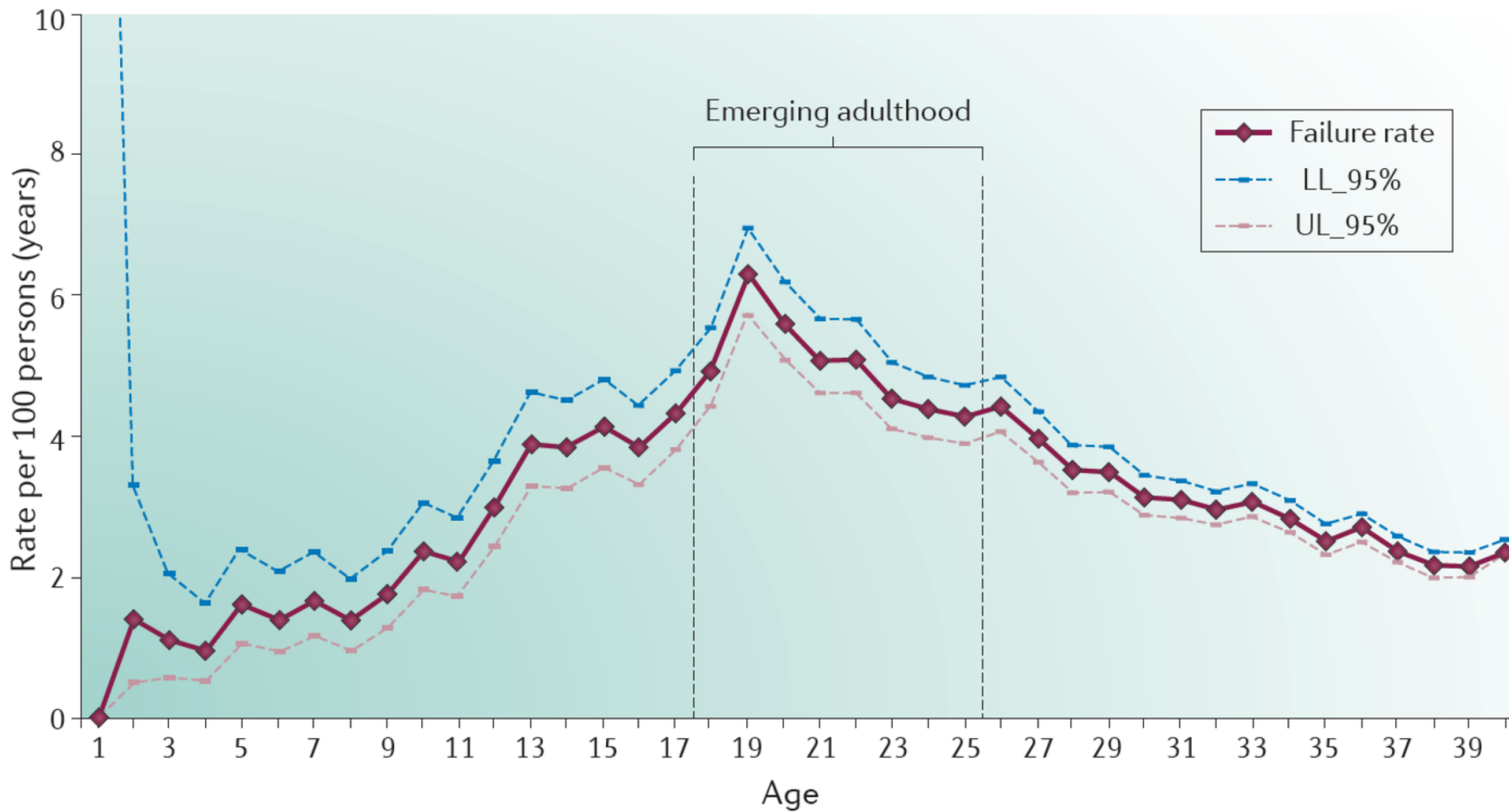


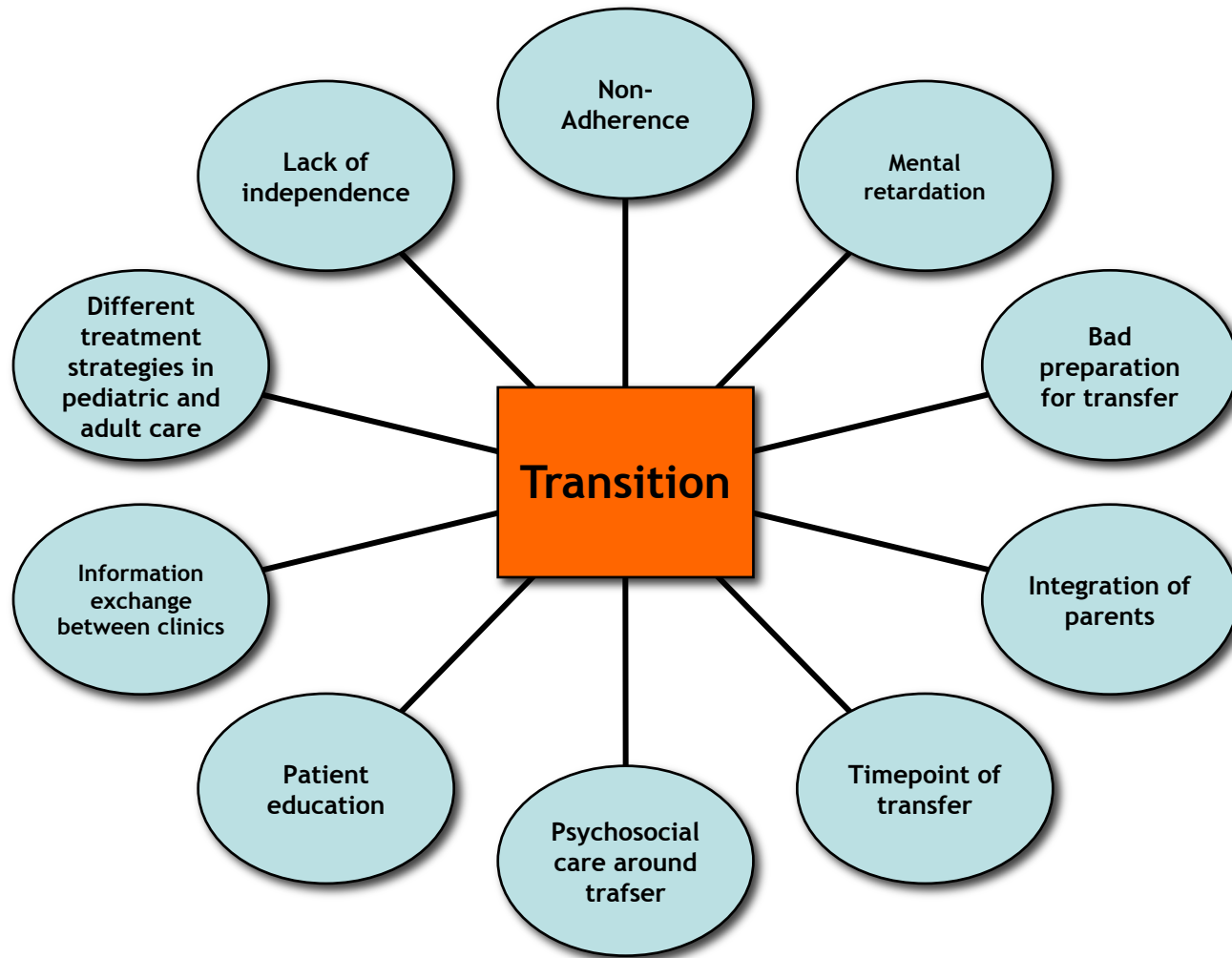
The problem



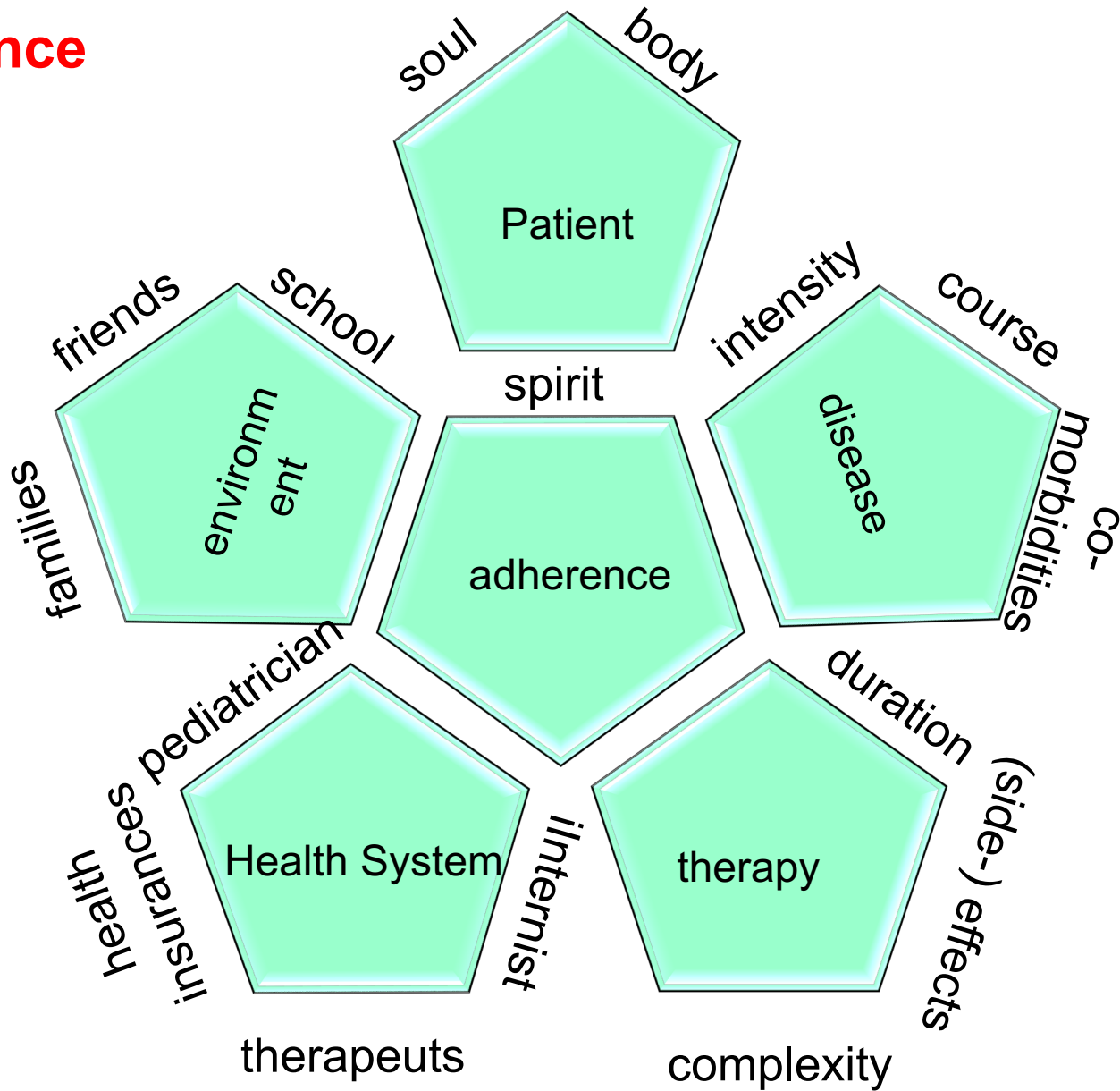
35% unerwartete Transplantatverluste

Transition and non-adherence





Adherence



Transition models

Pediatric Nephrology -> adult nephrology

Pediatric Nephrology -> transition clinic -> adult nephrology

Pediatric Nephrology -> adolescent clinic -> young adult clinic -> adult nephrology

Other examples: CF-centers (children and adults), adults with inborn heart disease

Different models of transition to adult care after pediatric kidney transplantation: A comparative study

Pape L, Lämmermühle J, Oldhafer M, Blume C, Weiss R, Ahlenstiel T.
Different models of transition to adult care after pediatric kidney transplantation: A comparative study.

L. Pape^{1,2,*}, J. Lämmermühle^{1,*},
M. Oldhafer², C. Blume³, R. Weiss² and
T. Ahlenstiel^{1,2}

Table 1. Different types of transition clinics

| Type of clinic | Provider | Frequency of appointments | Affiliation |
|------------------------------------|------------------------------------|---|---|
| Group 1 Transition clinic | One specialized adult nephrologist | Every 4 wk | On university campus but private provider |
| Group 2 Adult transplant clinic | Residents in surgery or nephrology | Every 3–6 months plus appointments at family doctor | Part of university clinics |
| Group 3 Office nephrologist | Several adult nephrologists | Depending on nephrologist every 4–12 wk | No university affiliation |

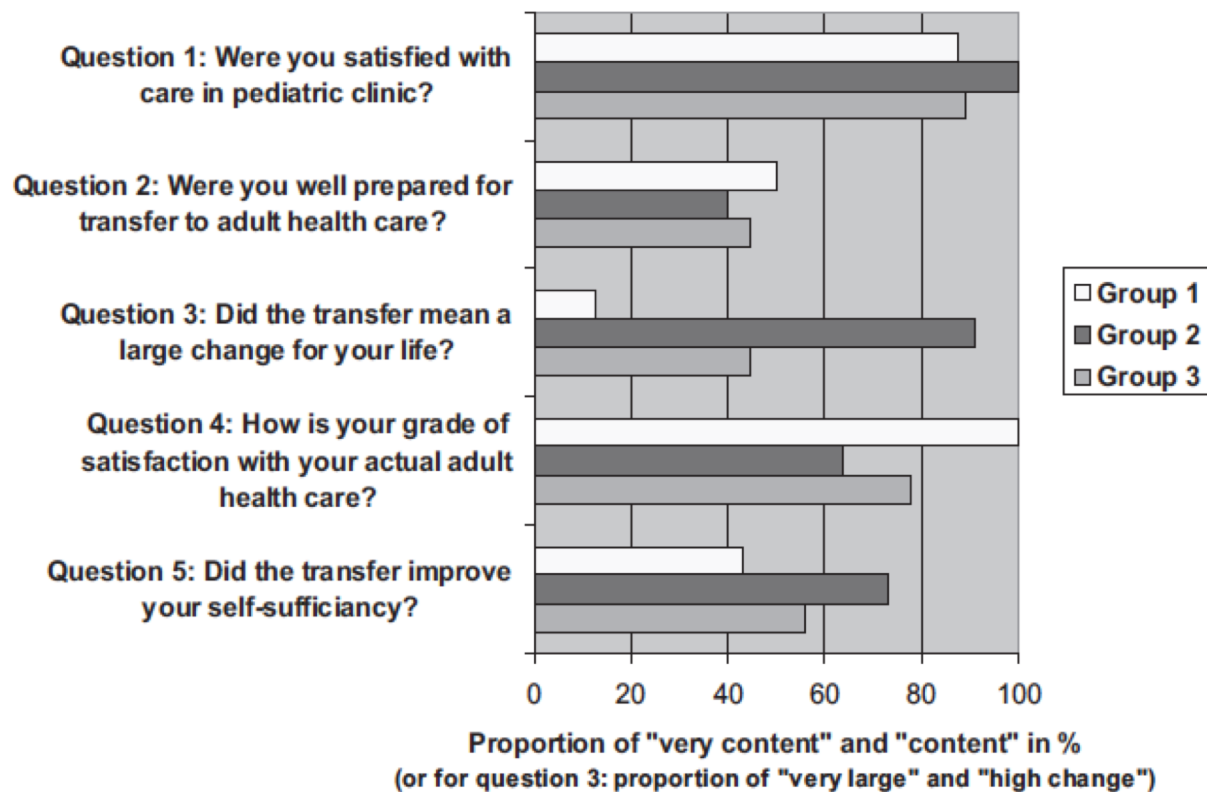


Fig. 2. Responses to the satisfaction questionnaire (response rate 69% in setting 1, 53% in setting 2 and 41% in setting 3). Group 1: transition clinic, group 2: adult transplant clinic, and group 3: office nephrologist.



OPEN

Survey on Management of Transition and Transfer From Pediatric- to Adult-based Care in Pediatric Kidney Transplant Recipients in Europe

Martin Kreuzer, MD,¹ Jenny Prüfe, PhD,¹ Burkhard Tönshoff, PhD,² Lars Pape, MD,¹ and Members of the Working Group 'Transplantation' of the European Society for Paediatric Nephrology

TABLE 1.

Components of transition and frequency of use in 31 pediatric nephrology centers in Europe (multiple choices permitted)

| Descriptions | Used by |
|--|---------|
| The concept of transition and goals in self-management to acquire are explained to the patient (and family) in early adolescence. | 27/31 |
| An unwritten plan for transition is made and communicated with the patient. | 26/31 |
| A written transition plan is made and communicated with the patient. | 7/31 |
| From a certain age the patient consults the nephrologist without a parent first—if applicable, the parent joins the consultation later on. | 18/31 |
| Individual in-house training courses of transition relevant skills. | 10/31 |
| Group training courses of transition relevant competencies at your center. | 11/31 |
| External training of transition relevant skills (including inpatient rehab programs). | 10/31 |
| Written information material about transition/transfer (eg, handout, magazine, flyer, book...). | 10/31 |
| Transition medical passport. | 4/31 |
| Computer-based training/education (eg, software, online/internet/intranet, app, etc). | 0/31 |
| Progress of self-management skills is monitored by nephrologist/social worker WITHOUT special tools. | 10/31 |
| Progress of self-management skills is monitored by a score-based system. | 1/31 |
| Progress of self-management skills is monitored by questionnaire. | 9/31 |
| Readiness of transfer is determined by using an appropriate tool (eg, transition scale, questionnaire, self-rating) | 6/31 |

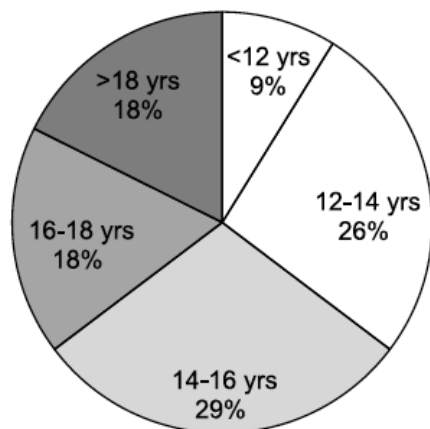


FIGURE 1. Age of introduction of the concept of transition to adolescents and young adults after KTx at 34 centers in Europe. The age groups marked in white are recommended by the 2011 ISN/IPNA consensus on transition.¹

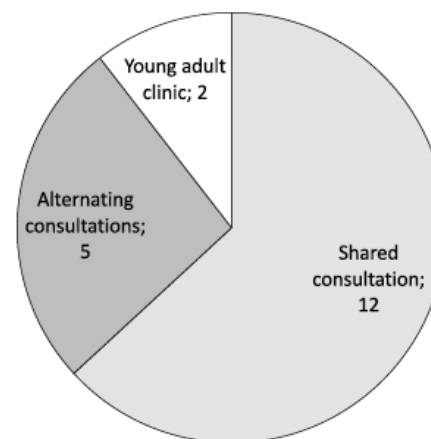
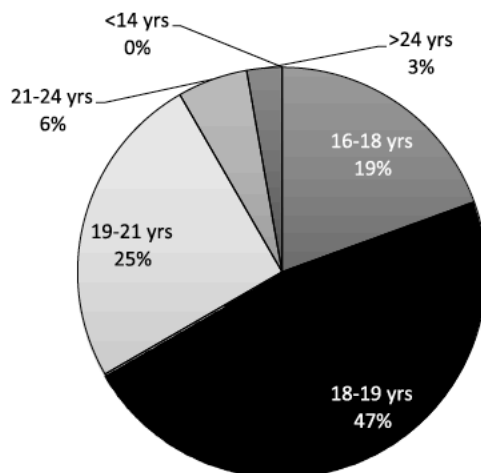


FIGURE 2. Types of transition clinics used by 15 European centers (multiple choices permitted).

A

commonly used



B

most appropriate

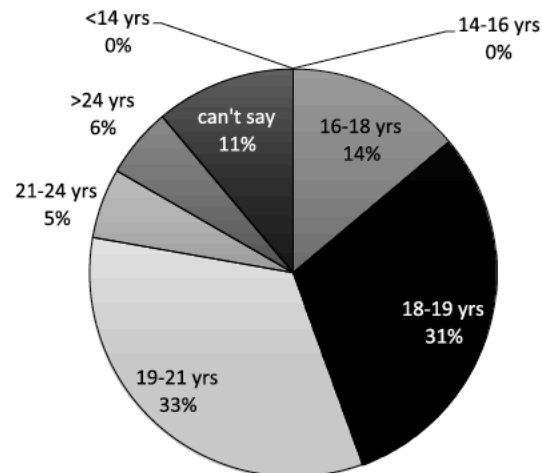


FIGURE 3. Transfer age. Comparison between the age when patients were most commonly transferred (A) and the opinion of the pediatric care provider on the most appropriate age for transfer (B) at 36 European centers.

TABLE 2.

Five-level Likert scale medians and ranges on transition policy statements of 31 pediatric nephrology centers in Europe

| Policy statement | Median (range) |
|--|----------------|
| "At our clinic information about transition is given to the patient in a gradual manner appropriate to developmental state." | 5 (3-5) |
| "The transition plan is individualized for each patient." | 4 (2-5) |
| "Progress of self-management skills is monitored on a regular basis." | 3 (1-5) |

TABLE 3.

Healthcare professionals actively involved within the transfer process to adult-based care at 34 European pediatric nephrology centers

| Profession | Involved by |
|------------------------------------|-------------|
| Pediatric nephrologist | 33/34 |
| Adult nephrologist | 31/34 |
| Family doctor/general practitioner | 3/34 |
| Pediatrician | 4/34 |
| Psychologist (pediatric) | 22/34 |
| Psychologist (adult) | 7/34 |
| Social worker (pediatric) | 19/34 |
| Youth worker | 2/34 |
| Social worker (adult) | 6/34 |
| Nutritionist (pediatric) | 14/34 |
| Nutritionist (adult) | 3/34 |
| Nursing staff (pediatric) | 25/34 |
| Nursing staff (adult) | 12/34 |

TABLE 4.

Five-level Likert scale medians and ranges on transition policy statements of 34 European pediatric nephrology centers

| Policy statement | Median (range) |
|--|----------------|
| "Transfer at our center is individualized for each patient after s/he has completed a transition plan; this will depend upon completion of physical growth and, where possible, educational, social and psychological attainment". | 4 (1-5) |
| "Transfer at our center is agreed upon jointly by the patient and his/her family/careers in conjunction with the pediatric and adult renal care teams." | 4 (2-5) |
| "Transfer at our center DOES NOT take place during a period of crises, especially if there is unstable social support." | 5 (2-5) |
| "Transfer at our center takes place after completing school education." | 3 (1-5) |
| "We take into account treatment plans by other subspecialties (eg, urological supervision)." | 4 (2-5) |

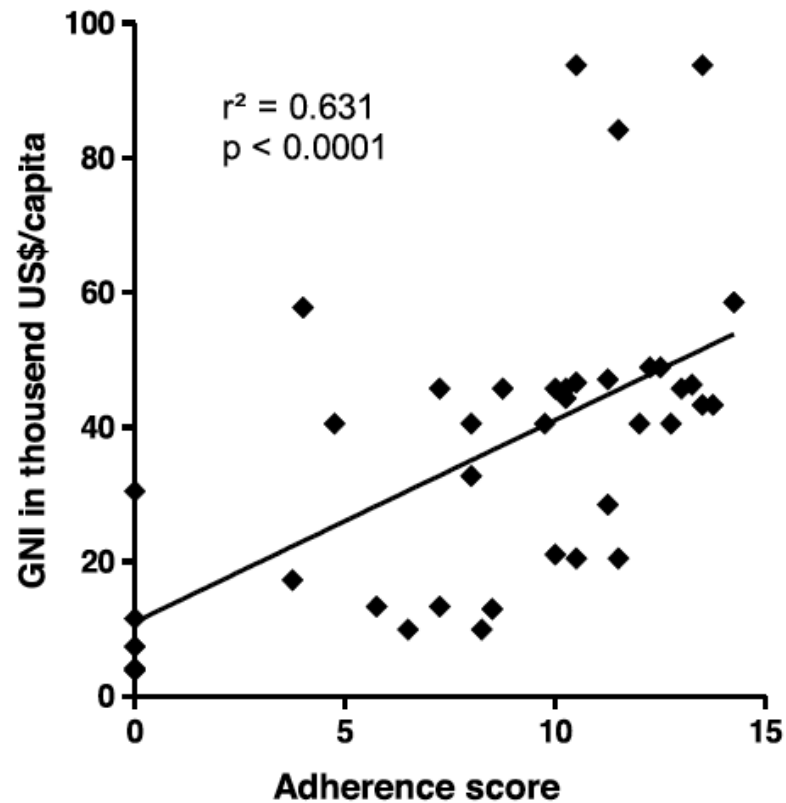


FIGURE 4. Spearman correlation between the GNI and the guidelines adherence score in 39 European pediatric nephrology centers. GNI, gross national income.

PRACTICE

QUALITY IMPROVEMENT REPORT

Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure

P N Harden *consultant nephrologist and transplant physician*¹, G Walsh *paediatric transplant nurse specialist*², N Bandler *adult transplant nurse specialist*¹, S Bradley *paediatric transplant nurse specialist*³, D Lonsdale *youth development worker*¹, J Taylor *consultant paediatric nephrologist*², S D Marks *consultant paediatric nephrologist*³

¹Oxford Kidney Unit and Transplant Centre, Churchill Hospital, Oxford OX3 7LJ, UK; ²Evelina Children's Hospital, London, UK; ³Great Ormond Street Hospital, London



Table 1| Outcomes for young adult kidney transplant recipients before and after introduction of integrated transition from paediatric nephrology care to adult care and a young adult clinic service

| | Model of transfer from paediatric to adult care | |
|--|---|---|
| | Direct transfer | Integrated transition and young adult service |
| Time period | 2000–05 | 2006–11 |
| Transfer process and adult care team | Single referral letter, 6 adult nephrologists | Young adult team (1 nephrologist, 1 nurse specialist, and 1 youth worker) |
| No of patients (male, female) | 9 (3 male: 6 female) | 12 (7 male: 5 female) |
| Median (range) age at transfer to adult care (years) | 18 (16–18) | 17.5 (16–18) |
| No (%) of late acute rejections | 3 (33) | 0 |
| No (%) of renal allograft loss | 6 (67) | 0 |
| Median (range) time to renal allograft loss | 40 (1–62) | — |
| No of deaths | 1 (due to miliary tuberculosis) | 0 |

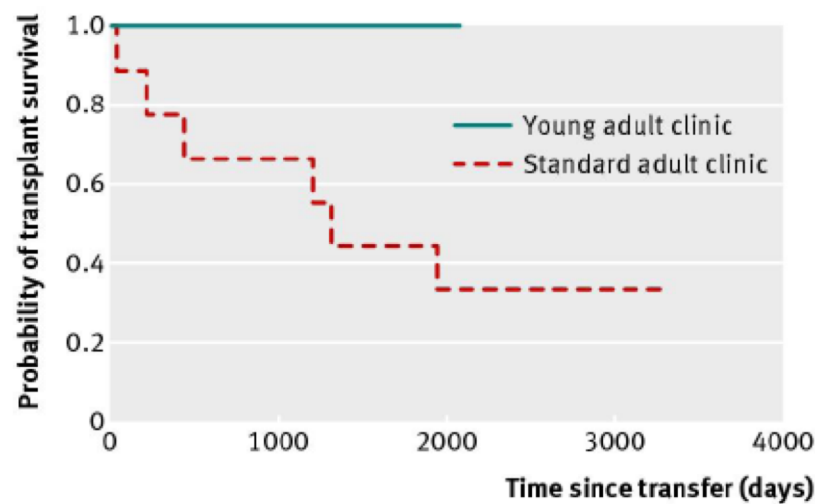
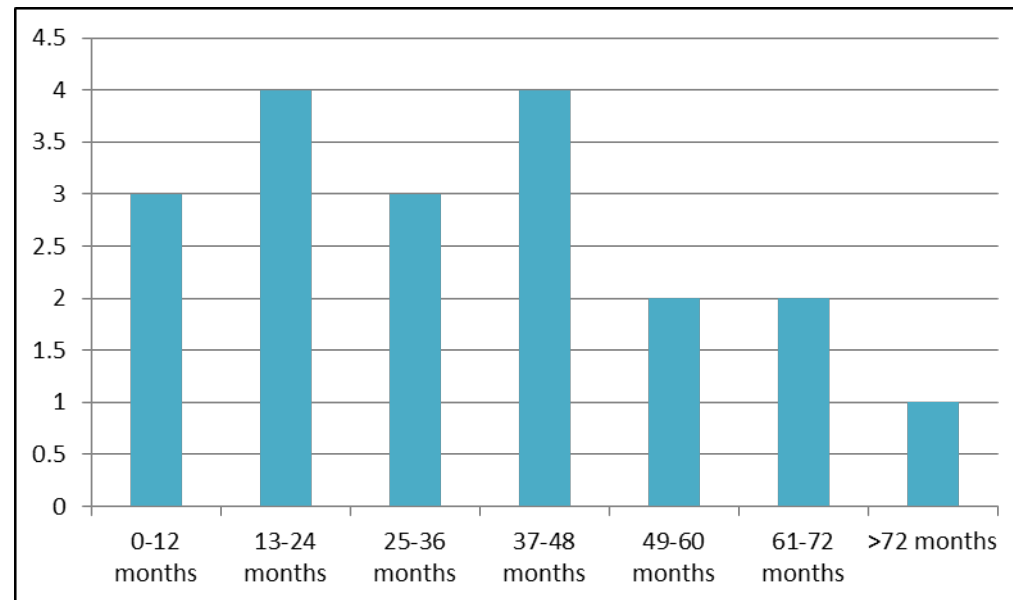


Fig 3 Renal allograft survival (days) before and after introduction of an integrated paediatric to adult transition and young adult clinical service for patients with end stage kidney disease (log rank test, P=0.015).

GOSH transition programme cohort: 25% (131/505 total) pRTR transferred

- Patient survival = 99%
- Graft survival = 83%
- Median age = 18 y
– range = 15 - 24 y
- 17% (19/112) grafts failed post-transition over 8 years
– 5 second grafts
- Graft survival = 9.7 y
– range = 0.0 - 20.6 y
- Median time to graft failure = 2.9 years





Shared Management Model

| Age and Time ↓ | Provider | Parent/Family → Youth | |
|-------------------|--|-----------------------|----------------|
| | Major responsibility | Provides care | Receives care |
| | Support to Parent/family & child/youth | Manages | Participates |
| | Consultant | Supervisor | Manager |
| | Resource | Consultant | Supervisor/CEO |

Transition Clinic

Information for Youth and Parents

What is the “Transition Clinic?”

Good 2 Go offers a weekly (Tuesday) clinic for SickKids patients (ages 12-17) who want to learn more about transitioning and develop skills to feel prepared. In some circumstances, we can also work with parents and caregivers on transition related concerns or include parents in discussions (with consent of the patient).

Transition Tools

Validated instruments created by the STARx Program to measure self-management and transition readiness.

Since 2006, our interdisciplinary STARx Team at UNC has created (and continues to validate) two tools to measure health care transition readiness - the provider-administered TRxANSITION Scale and the self-report STARx Questionnaire.

1. The TRxANSITION Scale™

The TRxANSITION Scale is a 10-domain, 32-item questionnaire measuring transitions readiness that is administered by a trained professional. Administering the instrument takes about 8 minutes and can be done either in person or over the phone. The TRxANSITION Scale™ Educational Handouts provide patient education that corresponds with each subdomain of the instrument.

2. STARx Transition Readiness Questionnaire

The STARx Questionnaire is a 3-domain, 18-item self-administered questionnaire measuring overall transition readiness. Patients can complete the STARx Questionnaire in 3 minutes on paper or on the computer.

3. Nephrology Medical Passport™

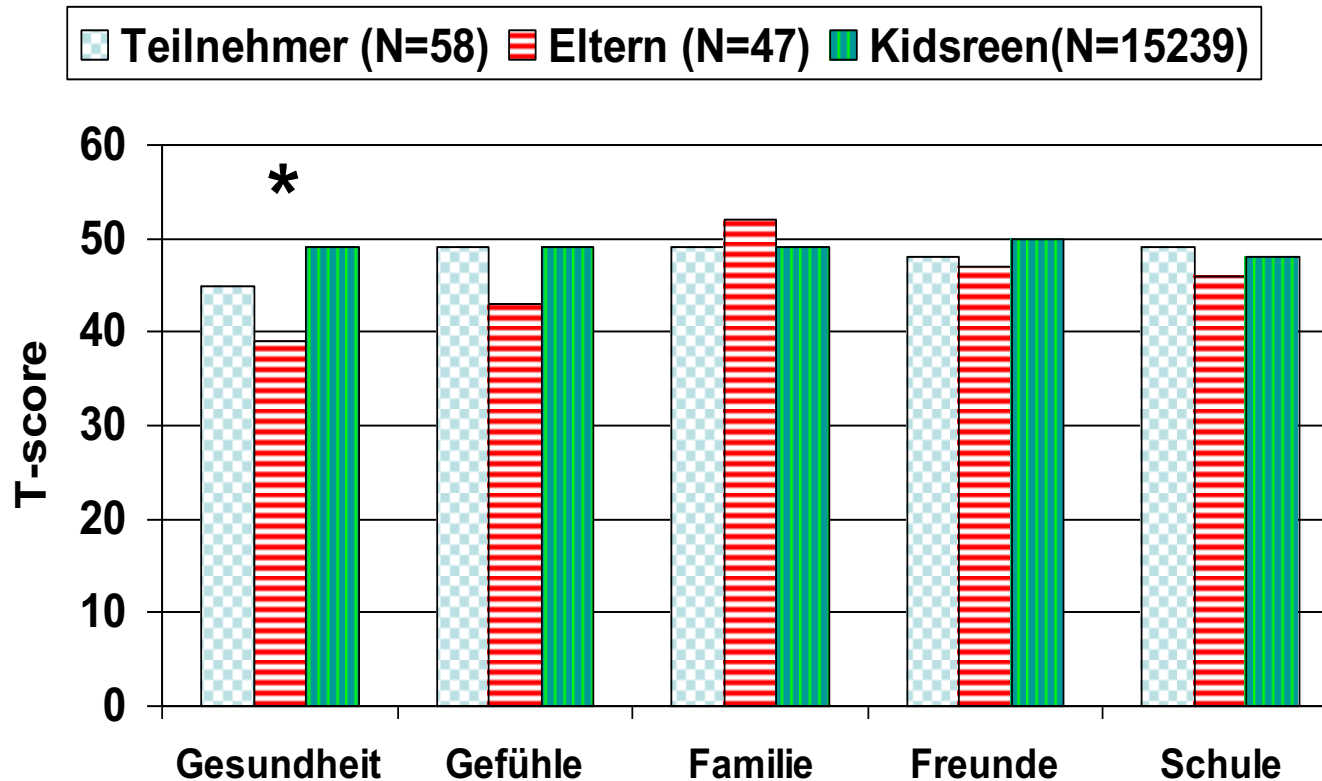
The Nephrology Medical Passport™ is a portable health summary the size of a driver's license that a patient can carry with them in their wallet. The passport can be used for patient education as well as a tool for communication between patient and provider.



Transition program „*endlich erwachsen*“ (finally adult) *started 2003*

- Primary one week seminar for adolescents > 16 years
- Workshops on different subjects for adolescents
- Weekend workshops for parents
- Pediatric dialysis workshop for nurses and physicians
- Communication: internet forum / homepage

Quality of life (HRQoL): Kidscreen 27

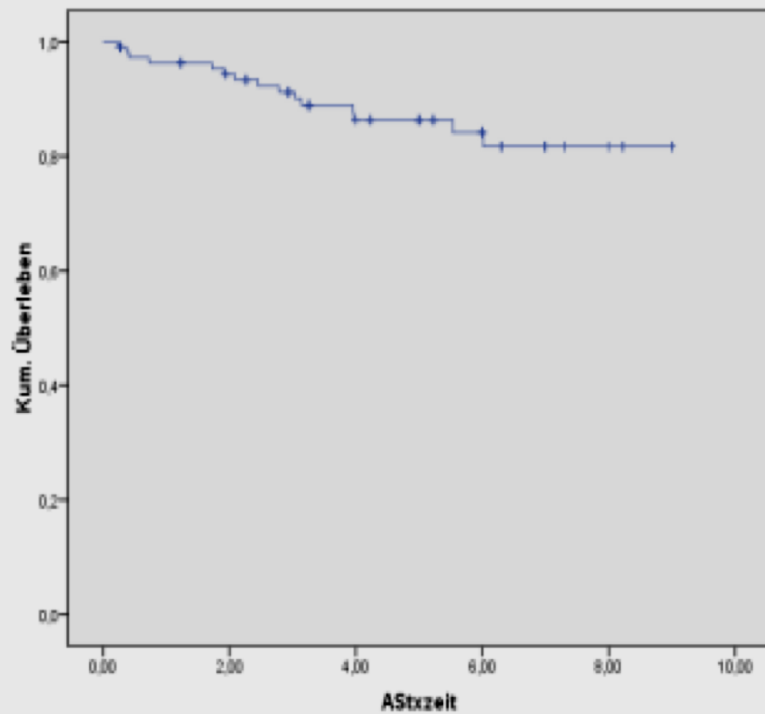


* Effect Size 0,43 Teilnehmer vs Kidscreen

Questionnaire 09/2007 – 01/2010

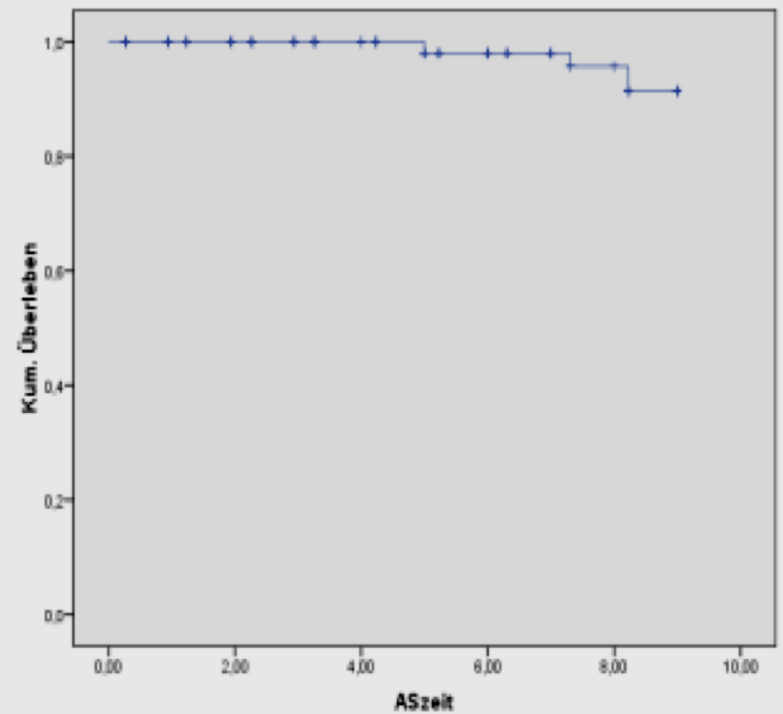
Survival

Tx-Kidneys n = 111



Tx lost = 15

Participants n = 184



Died n = 4

The Berlin Transition Program

Case-management

← 1st transition interview

Structured Epicrisis →

Transfer

Joint outpatient clinics
case conference

← 2nd transition interview

← closure interview

Internal Medicine



Pediatrics

M_{HH}

Medizinische Hochschule
Hannover



OPEN

Transitional Care and Adherence of Adolescents and Young Adults After Kidney Transplantation in Germany and Austria

A Binational Observatory Census Within the TRANSNephro Trial

Martin Kreuzer, MD, Jenny Prüfe, PhD, Martina Oldhafer, PhD, Dirk Bethe, Marie-Luise Dierks, PhD, Silvia Müther, MD, Julia Thumfart, MD, Bernd Hoppe, MD, PhD, Anja Büscher, MD, PhD, Wolfgang Rascher, MD, PhD, Matthias Hansen, MD, Martin Pohl, MD, PhD, Markus J. Kemper, MD, PhD, Jens Drube, MD, Susanne Rieger, MD, Ulrike John, MD, PhD, Christina Taylan, MD, Katalin Dittrich, MD, Sabine Hollenbach, MD, Günter Klaus, MD, PhD, Henry Fehrenbach, MD, Birgitta Kranz, MD, Carmen Montoya, MD, Bärbel Lange-Sperandio, MD, PhD, Bettina Ruckebrodt, MD, Heiko Billing, MD, PhD, Hagen Staude, MD, Krisztina Heindl-Rusai, MD, Reinhard Brunkhorst, MD, PhD, and Lars Pape, MD, PhD

Results

TABLE 2. Pediatric Nephrology Unit Staffing

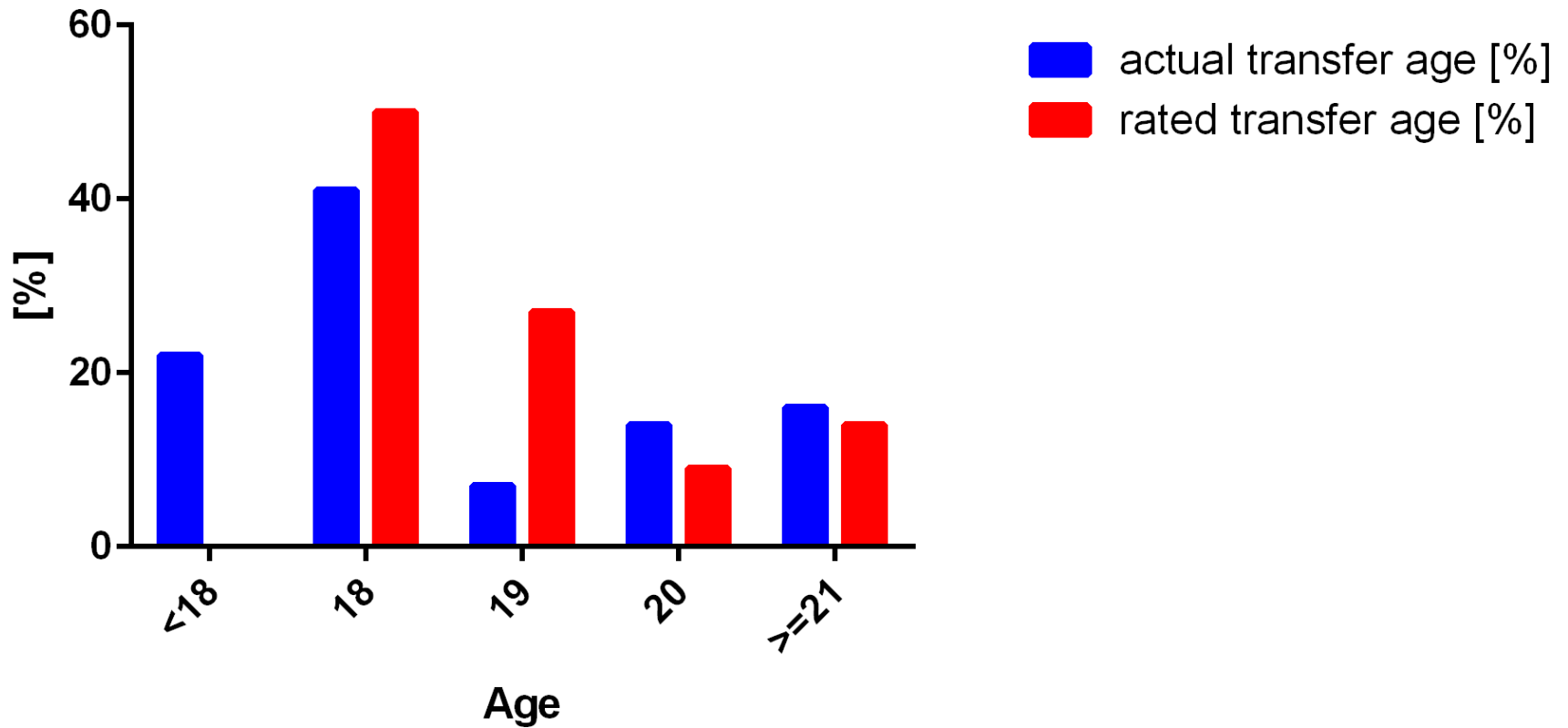
| Profession | Median Number | Range |
|---------------------------------|---------------|----------|
| Physicians | 1.9 | 0.6–4.0 |
| Nursing team | 3.25 | 0.25–8.5 |
| Psycho-social team [*] | 0.5 | 0–2.5 |
| Others [†] | 0.1 | 0–1 |

Data are given as proportion of one full-time position.

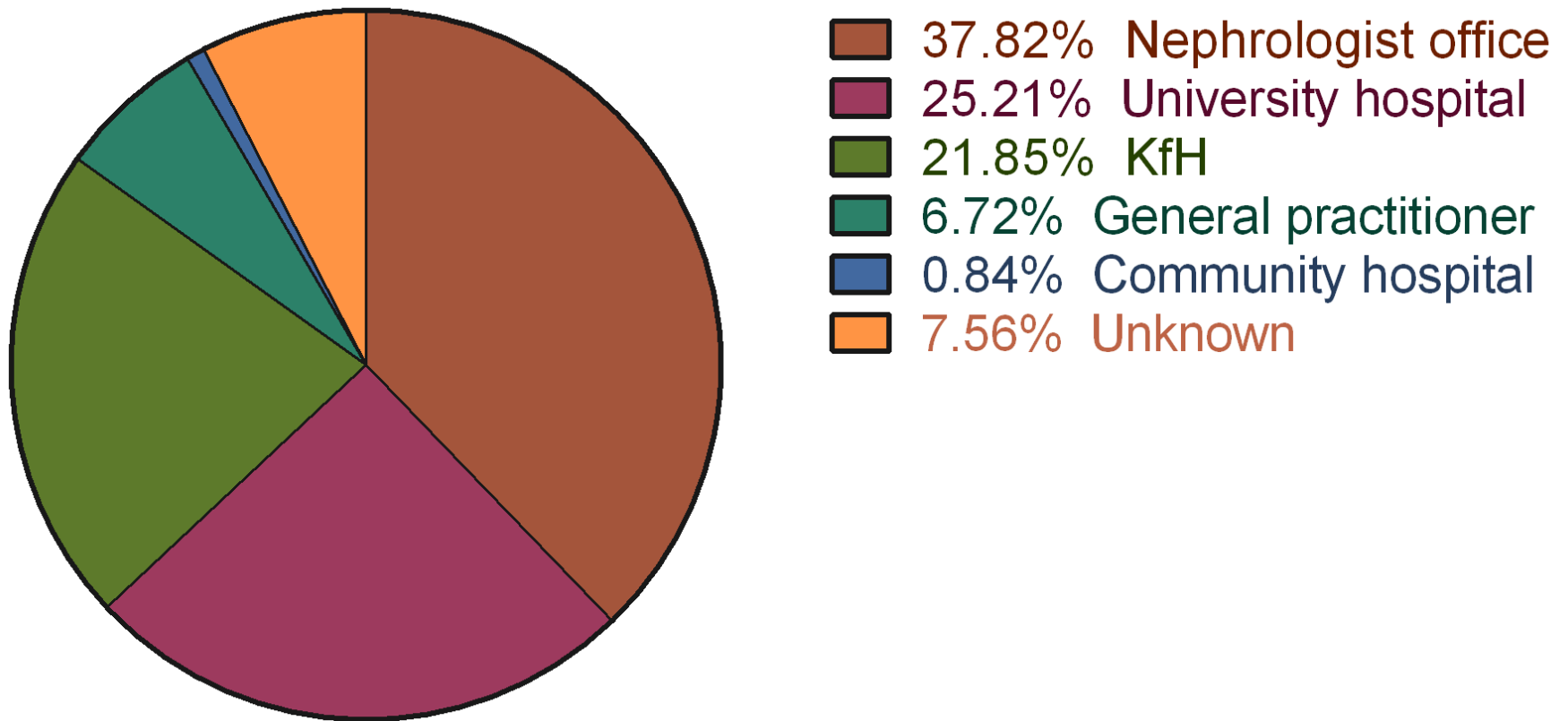
^{*} Psychologists and social workers.

[†] Total of other health care specialists, for example, nutritionist, educationalist.

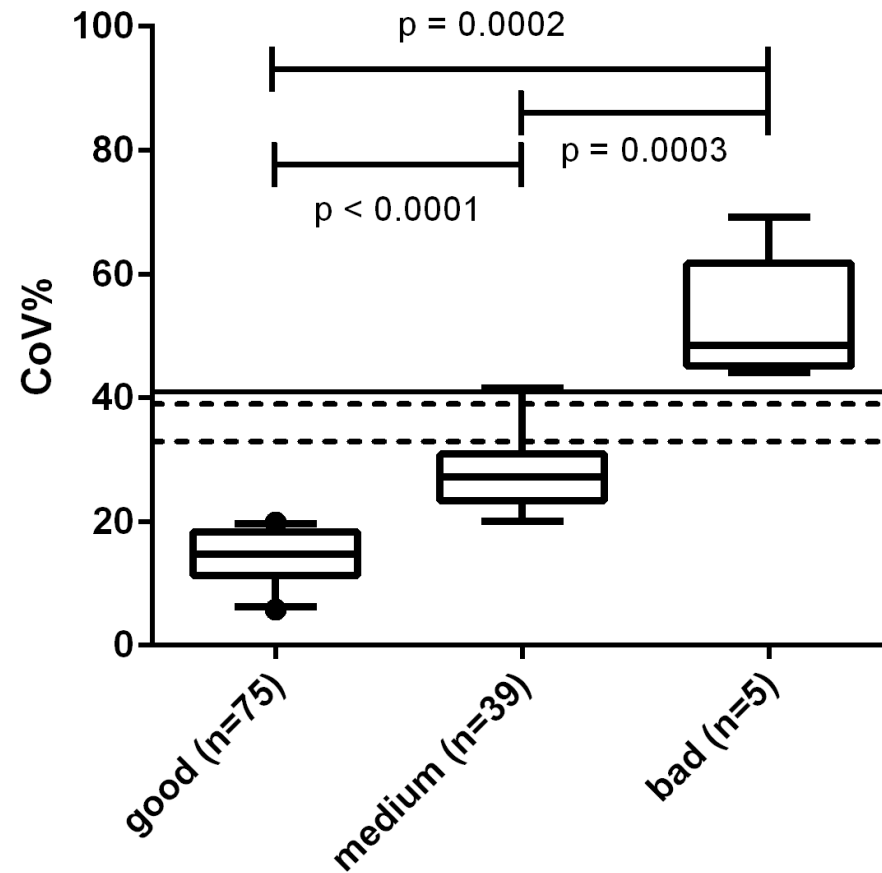
Results



Results



Results



Trough level variability and adherence

BMJ Open Transition structures and timing of transfer from paediatric to adult-based care after kidney transplantation in Germany: a qualitative study

Jenny Prüfe,¹ Marie-Luise Dierks,² Dirk Bethe,³ Martina Oldhafer,⁴ Silvia Mütter,⁵ Julia Thumfart,⁶ Markus Feldkötter,⁷ Anja Büscher,⁸ Katja Sauerstein,⁹ Matthias Hansen,¹⁰ Martin Pohl,¹¹ Jens Drube,¹ Florian Thiel,¹² Susanne Rieger,¹³ Ulrike John,¹⁴ Christina Taylan,¹⁵ Katalin Dittrich,¹⁶ Sabine Hollenbach,¹⁷ Günter Klaus,¹⁸ Henry Fehrenbach,¹⁹ Birgitta Kranz,²⁰ Carmen Montoya,²¹ Bärbel Lange-Sperandio,²² Bettina Ruckebrod,²³ Heiko Billing,²⁴ Hagen Staude,²⁵ Reinhard Brunkhorst,²⁶ Krisztina Rusai,²⁷ Lars Pape,¹ Martin Kreuzer¹

Table 1 IPNA consensus statement and its realisation in Germany

| 1. Transition to transfer | Aimed for by | Fully applied by |
|---|--------------|------------------|
| Delivery of necessary patient care information to the receiving adult service | 21/21 | 21/21 |
| 2. Transfer from paediatric to adult nephrology should... | | |
| be individualised for each patient after s/he has completed a transition plan depending on completion of physical growth and educational, social and psychological attainment | 21/21 | 1/21 |

Results This study highlights that professionals working within paediatric nephrology in Germany are well aware of the importance of successful transition. Key elements of transitional care are well understood and mutually agreed on. Nonetheless, implementation within daily routine seems challenging, and the absence of written, structured procedures may hamper successful transition.

| | | |
|--|---------|--|
| with specialist nurses for adult patients who liaise with specialist nurses from the paediatric unit can ensure continuity of care | no data | 0/21 |
| providing a comprehensive written and verbal summary of all the multidisciplinary aspects of the young person's care including medical, nursing, dietary, social and educational information | 21/21 | 0/21 (summary available but not as part of transition clinic) |
| offering a transition pathway to assert their autonomy and help provide the relevant information about themselves | 21/21 | 0/21 Not standardised |

IPNA, International Pediatric Nephrology Association.

Randomized trial

Hand out patient information

Consent of adolescent patients and their parents

Randomisation

Intervention group

Control group

Informed consent, gathering of baseline data ,
1st issuing of questionnaires (T0)

Gathering of clinical data
/ laboratory values for eCRF
2nd issuing of questionnaires (T1, 12 months)

T R A N S F E R

Recording and contacting of physicians
to whom transfers are made

Collection of clinical data
and laboratory values for eCRF
2nd issuing of questionnaires (T2, 24 months)

Pediatric outpatient clinic

Internist outpatient clinic

Participation in the „BerlinerTransitionsProgramm“
Transition by means of smartphone / app

Medical treatment according to normal center
standard

TRANSNephro 2nd phase



**Berliner
Transitions
Programm**



Task force Transition and quality of life

- Challenges and concepts for structured transition of patients with rare kidney diseases
- Survey on current transition practices in ERKNet centers based on TRANSNephro Survey
- Financing of transition in different European countries / health systems
- Survey on patient expectations and experiences
- Survey on parents expectations and experiences
- Survey on perspectives of adult nephrologists on transition



Next ERKnet webinar:

Feb 05 2019

"Management of X-linked hypophosphatemic rickets in children and adults"

by Dieter Haffner (Hannover, Germany)