

Pour une transition heureuse de la pédiatrie à la médecine adulte en dialyse

How to be successful in transition from pediatrics to adults

Johan Vande Walle
Ghent

- ➔ **The wrong subject**
 - ➔ Transition in dialysis : very limited data
 - ➔ To be happy during dialysis is???
- ➔ **The wrong title**
 - ➔ View of EBM pediatrician: How can anybody ever be happy to have to leave the pediatrician ?
 - ➔ View of non-EBM nephrologist : “pediatrie””adult medicine
 - ➔ Suggests already that it is a age-related topic
- ➔ **The wrong speaker**

When I was young and beautiful...

When I was young and beautiful...



When I was young and beautiful...

- ➔ **The patient was never “ready” to be send to the adult nephrologist**
- ➔ **Patients were kept untill 40 years on pediatrics?**

= archetypes

Identify Differences adult /pediatric care

Table 1 Differences between paediatric and adult units

Paediatrics	Adult
Family consultation	Individual consultation
Multidisciplinary team and psychosocial support	Limited team support (especially psychosocial)
Fewer patients	Large patient numbers
Specialist knowledge about rare genetic conditions, e.g. cystinosis	Lack of experience with rare 'paediatric' conditions
Shorter waiting lists	Longer waiting lists and pressure on dialysis 'spaces'
Peer support	No 'young adult' clinic
Medications usually free	Payment for medications

Pediatr Nephrol (2005) 20:113–117
 DOI 10.1007/s00467-004-1763-y

EDITORIAL COMMENTARY

Alan R. Watson

Problems and pitfalls of transition from paediatric to adult renal care


Identify Differences adult /pediatric care

➔ Children giving a life

- ➔ Normal school
- ➔ Normal psychosocial maturation
- ➔ Normal relationships
- ➔ Normal job later

➔ Adults : keeping in life

Identify Differences adult /pediatric care

- ➔ **Children giving a life**
 - ➔ Normal school
 - ➔ Normal psychosocial maturation
 - ➔ Normal relationships
 - ➔ Normal job later
- ➔ **AYA:** 
- ➔ **Adults : keeping in life**

transition

Transition : AYA = adolescents / young adults

A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. [Schwartz LA](#)¹, [Tuchman LK](#), [Hobbie WL](#), [Ginsberg JP](#) *Child Care Health Dev.* 2011 Nov;37(6):883-95.

A lot of literature with evidence, identifying that in the AYA-group,

- the “issue” of transition is more important
- than the diseased “organ”

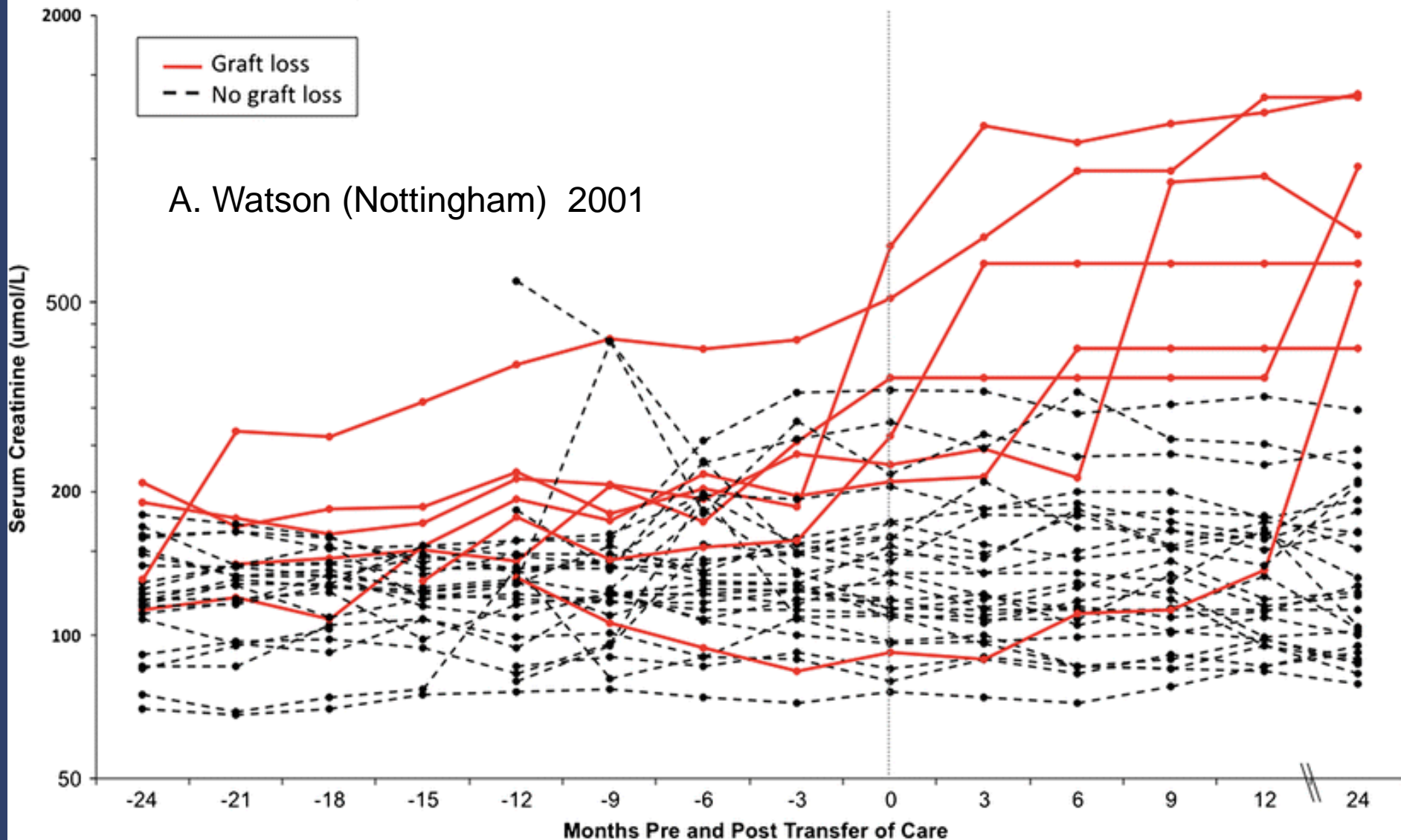
So hospital rather than subdiscipline strategy

Transition in nephrology

Alan Watson

Paul Harden

Allograft Function of PTC Patients Pre and Post Transfer of Care





From: **Age-Related Kidney Transplant Outcomes: Health Disparities Amplified in Adolescence**

JAMA Intern Med. 2013;173(16):1524-1532. doi:10.1001/jamainternmed.2013.8495

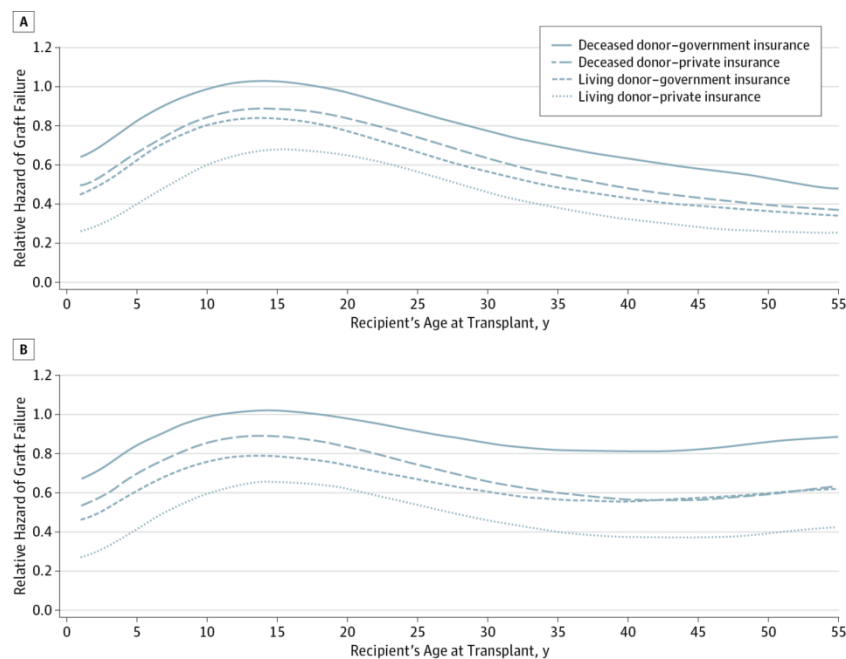


Figure Legend:

Graft Failure Relative Hazard According to Age at Transplant, Centered at 18 Years A, Death censored; B, non-death censored. Graphs were produced using the following covariate pattern: race was white, sex was male, recipient's and donor's histories were negative for diabetes mellitus and hypertension, HLA mismatch level was 3, and donor age was 36 years.

What's the problem?

- ➔ **ESRD is rare in paediatrics (9-50 ppm)**
- ➔ **Transplantation is the treatment of choice, as in addition to being the best 'treatment' for renal failure, it restores growth and pubertal development in children**
- ➔ **>80% of young adults transferred to adult services have a functioning renal transplant**
- ➔ **BUT up 35% of these patients will have lost their transplant 36 months after transferring to adult services**

When to send patients to an adult nephrologist?

- **Discussion comes out of discussion**
 - Recognition of pediatric nephrologist
 - “pampering” of the pediatric patient
 - Everybody can dialyse a patient > 30 kg.
 - Lack of collaboration between pediatric and adult nephrologists
 - Often in other hospital (London, Nottingham, Paris)
 - Always in other building
 - Defending territory
 - Not identifying interest of patient
- **Age**

Age for transfer ?

- > 15 year
- 18 year WHO
 - Patients with handicap ?
- after middle school : 18-19 y ?
 - Belgium convention
- On 25 year ?

transfer

- **Transfer to adult nephrologist**
 - Tx 30% rejection in first 6 month
 - CRF : 27 % loss for follow up
 - CKD : > 40% loss for follow up
- **Transfer is the period with the highest risk in the life of a patient with CKD**
- **Thus.. Keep patient longer on pediatrics**

No transfer

- **Keep patient longer on pediatrics = not taking in account**
 - the normal evolution to adulthood
 - Prolonging medical puberty
 - = comparable with puberty in own children

Transfer

- ➔ = not the discussion on technical capacity of dialysis
- ➔ **treat ex-children**
 - ➔ not as children
 - ➔ not as adults
 - ➔ Exc 18 y mild CKD + ACE-inhibitor
 - ➔ pediatrics = control / 3month
 - ➔ nephrologist 1 x/y
 - ➔ In between GP... but there is no GP
 - ➔ Living on rooms in city /weekend at home
 - ➔ 70 % loss for follow up

Transition = planned transfer = strategy

Phase 1: at 14 y and/or onset puberty start to talk on transition between 16 and 18 year

- Once grown up = positive stimulus
- Immediately defining ultimate limits
 - Better “achievements” than age as cornerstone
 - After finishing middle school, relationships, smoking.. anticonceptivis
- Is prepared over years
- Patient and parents have certain choice
- Possibility to ventilate wishes, concerns to other members of the pediatric team (psychologist, dietician, nurse)

Transition

- **Phase 1: at 14 y and/or onset puberty start to talk on transition between 16 and 18 year**
 - Making deal when definitely
 - Personal choice of child (not of parent)
 - Achievements = Acting as an adult
 - Own choice
 - No longer to school
 - smoking
 - “sexual intercourse”, anticonceptivs
 - Going out, going on holiday with friends
 - Dialysis > 16 – 18 y / transplantation
 - Definitely not earlier if the child does not want it
 - Not against the will of the child
 - Never during problem phase
 - Defining how transfer shall happen
 - Continuity of care

transition

➔ Phase 2:

- ➔ After team discussion = TEAM DECISION
- ➔ On 16 y talk with parents and child
 - ➔ Choice for transition
 - ➔ Room for negotiation until 18 y and/or leaving “middle” school
 - ➔ = exception
- Discussion with one target adult nephrologist = 1 person = very important
- ∞ Choice of adult nephrology center
 - ⑩ Take in consideration distance for the patient
 - ⑩ Possibility to go without parents on consultation
 - ⑩ Dependent of pathology

transition

- ➔ **Phase 3:**
 - ➔ Discussion in the staff / team
 - ➔ Combined pediatric/adult nephrology consultation 1 à 3x, also for peripheral centers
 - ➔ Adolescent policlinic
 - ➔ Making it clear that you are 1 team
 - ➔ That pediatric nephrologist remains informed (letters)
 - ➔ Fall back-possibility on
 - ➔ psychologist, dietician,
 - ➔ But not on pediatric nephrologist or hospitalisation
 - ➔ Orphan diseases

Distance pediatric nephrology / adult nephrology

1. Mentality
 - Identify this
2. Geography
 - Bridge it
3. Financial
 - Convention
 - Organisation
4. Attitude
 - “Outdoors visit” : Doctor-father with mother,.. And child is just sitting there
 - Need to change this attitude during puberty
5. Pathology

Transition from pediatric to adult renal services: a consensus

- ⇒ statement by the International Society of Nephrology (ISN) and
- ⇒ the International Pediatric Nephrology Association (IPNA)
- ⇒ **Alan R. Watson & Paul Harden** & Maria Ferris & Peter G. Kerr & John Mahan & Maher Fouad Ramzy *Pediatr Nephrol* (2011) 26:1753–1757

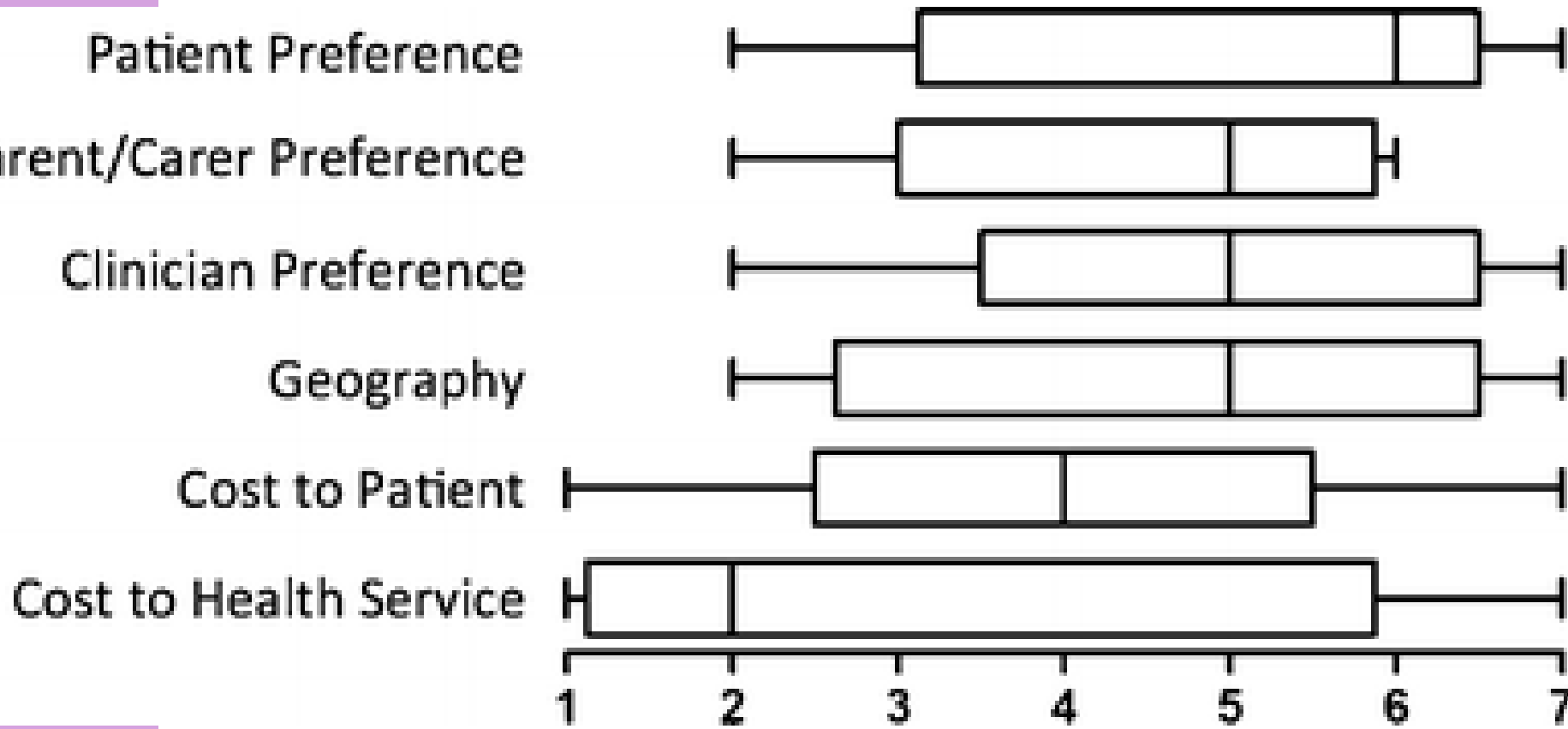
Adherence to transition guidelines in European paediatric nephrology units

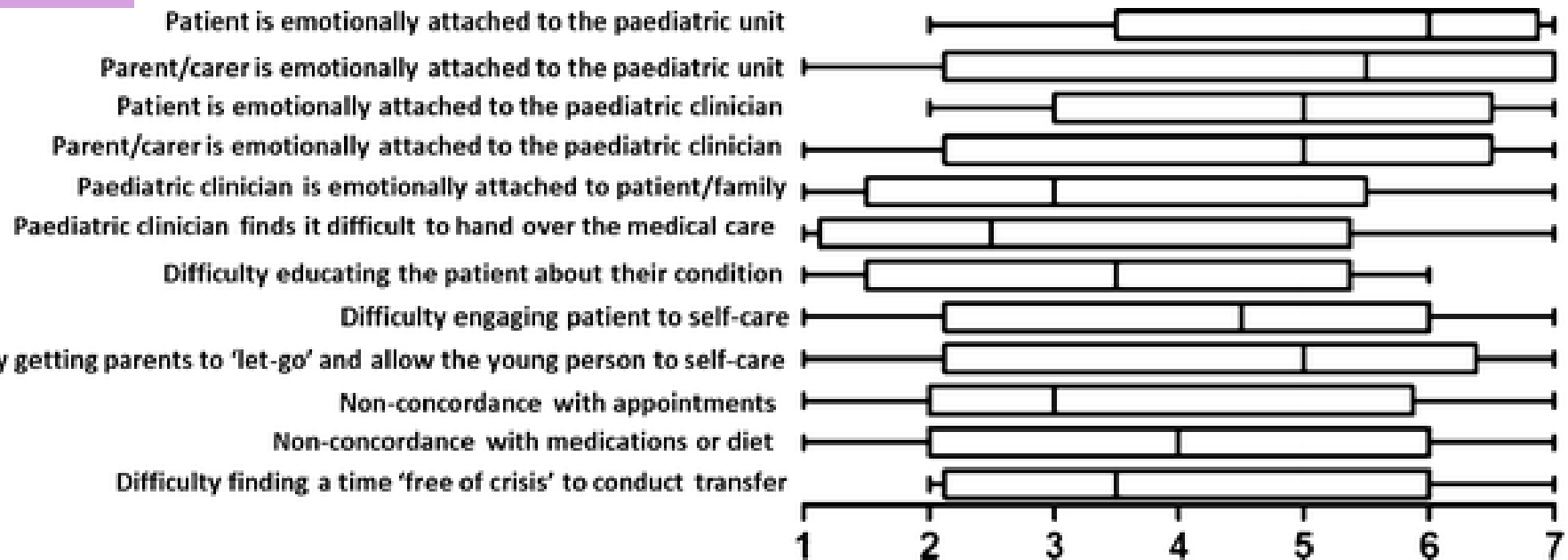
- ↻ **European Paediatric Dialysis Working Group Pediatr Nephrol (2014) 29:1617–1624**
- ↻ **Thomas A. Forbes & Alan R. Watson, Zurowska, Shroff, J. Van de Walle et al**

Table 1 Concordance with International Pediatric Nephrology Association/International Society of Nephrology (IPNA/ISN) Consensus Statements [4]

Statement	Concordance rates
Does your unit assess and prepare patients for transition to an adult service?	13 (86.7 %)
Does your unit have a lead nephrologist for transition (a 'transition champion')?	7 (46.7 %)
Do you give young adult patients the choice of which adult centre they wish to be transferred to?	12 (80 %)
Does your unit use a generic transition plan that is individualised for each young adult patient?	11 (73.3 %)
For patients with other medical and surgical specialties (e.g. urology) involved in care, does your unit co-ordinate transfer at an appropriate time considering treatment plans from these units?	13 (86.7 %)
Do young adults attend a special form of clinic for the purposes of managing transition or transfer?	7 (46.7 %)
Does your unit see young adult patients individually for at least part of their appointment without their parents being present?	14 (93.3 %)
Does the young person visit the adult unit (ward, clinic or dialysis unit, as appropriate) prior to transfer?	9 (60 %)
Does your unit routinely involve parents, other family members, boyfriends/girlfriends in the transition and education process with the patient's consent?	13 (86.7 %)
Does your unit provide the opportunity for patients to attend organised group support sessions with other young people in the process of transition?	4 (26.6 %)
Do young adults that have completed transfer also attend these group sessions?	2 (13.3 %)

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Do young adults that have completed transfer also attend these group sessions?	2 (13.3 %)
Does your unit provide group support sessions for parents of transitioning patients?	1 (6.7 %)
Does your unit use a transition scoring tool (e.g. TRxANSITION Score) to assess progress through the transition process?	0
Does your unit use a transition scoring tool to assess readiness for transfer?	0
Does your unit provide written information to the young person undergoing transition?	2 (13.3 %)
Do your transitioning patients receive tools to aid in the acquisition of disease self-management skills, such as the transition medical passport, electronic apps, or other patient-held tool?	3 (20 %)
Does your unit provide a written summary to the adult unit on transfer?	15 (100 %)
Do junior doctors at your hospital receive training in transition management/adolescent communication techniques?	3 (20 %)





choices : integrated care model

- ➔ Hemodialysis
- ➔ Peritoneal dialysis

- ➔ Pre-emptive renal transplantation
- ➔ Nocturnal hemodialysis
- ➔ Daily hemodialysis
- ➔ Home dialysis
- ➔ “dia”tel

- ➔ Reality
 - ➔ CRF.. Dialysis.. Tx ... Dialysis

If we want to “offer” the best

- ➔ = patient adapted
- ➔ = disease adapted...

Then we should offer all techniques in children and adolescents, but then are the pediatric nephrology centers too small

Should be collaborating /integrating with a large adult center

And resolve the problem of transition

Ghent's model

- ➔ **Distance between pediatric nephrology and adult nephrology is minimal**
 - ➔ Same nursing team PD / hemodialysis
 - ➔ Same localisation
 - ➔ see adult nephrologists already before transfer
 - ➔ Continue to see pediatric nephrologist afterwards.
- ➔ **It is not about “age”**
 - ➔ It is about “competences” of the adolescents
- ➔ **Referral from one pediatric to adult nephrology**
 - ➔ + with persistent help of dietician and psychologist

Table 3 Competencies to be achieved by the young adult before transfer

- I understand my condition and can describe it to others
- I can make decisions for myself about my treatment
- I know my medications and what they actually do
- I know what the adult clinic arrangements are and who will be my responsible consultant
- I know how to make and keep an appointment
- I can make my own transport arrangements to get to hospital appointments
- I am able to talk about my worries about blood tests and other treatments
- I know who to call in a medical emergency
- I know the restrictions that I have to follow including diet issues and advice on any activities
- I have sufficient knowledge about sexual health matters and have discussed alcohol, smoking and drug issues

➔ **A. Watson**

Core Elements of Transition

(Adapted: US Department of Health and Human Services)

