Preparation from early on and individual timing of transfer:
A need-adapted transition program after pediatric kidney transplantation

Dirk Bethe, Susanne Rieger, Burkhard Tönshoff
Center for Child and Adolescent Medicine
University Hospital, Heidelberg, Germany

European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure (EWOPA)
49th Annual Meeting, Visegrád, Hungary, June 14-16, 2018
Content

- Findings and recommendations
- Heidelberg transition program
- Conclusion
**Consensus statement** by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA) on

**Transition from pediatric to adult renal services** (Watson et al. 2011)

“**Young people are in transition from 14 to 24 years**”.

“**Transfer from pediatric to adult nephrology should:**

a.) be individualised for each patient after he/she has completed a transition plan; this will depend upon completion of physical growth and, where possible, educational, social and psychological attainment (A)(…) “

===> **Development of structured transition programs in many centers**
But what about transfer timing? Individualized?

Most pediatric centers have a policy of a fixed timing of transfer: at age 18 years
Findings and recommendations

Association between age and graft failure rate (Foster et al., 2011)

18 years = typical transfer age

= good timing of transfer?
Adolescent brains are different....

- Adolescence is a time of increase in connections between brain cells and pruning of brain pathways.

- Pre-frontal cortex – responsible for executive functioning (e.g. planning, problem solving, impulse control) - does not mature until about 25 years old.

(Durston et al. 2005, Giedd 2008)
Further findings:

- **Transfering before the age of 21 years** increases probability of graft loss in patients with a kidney transplant by 60%. (UNOS-Data) (Foster et al. 2011)

- **German Ped Neph professionals**: “In the interviews, every participant challenged the expected transfer age of 18 years. There was mutual agreement that such regulation was counterproductive and impeded an individualised care (...)” (Prüfe et al. 2017)
Findings and recommendations

==> Transition and transfer in Heidelberg:

Combining

Structured, need-adapted transition program

+  

Individual timing of transfer
Heidelberg transition program

Main elements:

- Transition process, until transfer to adult care, takes about 8-10 years

- **Individual timing of transfer to adult care**, possible from age 18. Usually at age 21-22, but timing is flexible. Transition readiness, medical and psychosocial aspects are taken into account.

- **Involved professions**: pediatric nephrologist, transplant nurse, psychologist, social worker, hospital teacher if needed. Transition process is coordinated by transition key worker (charity funded).

- Encouraging to participate in group activities with fellow patients, e.g. therapeutic camps with the Heidelberg team, or participation with national program „Endlich Erwachsen“ (= „Finally Adult“)
Heidelberg transition program

12-14 years old
Starting to train the medical knowledge. Occasional checking: „which drugs for which purpose?“, „When was the transplant?“, „Primary renal disease?“ „Do you help your parents in setting the drug organizer?“, „What is your creatinine base line, your target tacrolimus trough level?“

15-17 years old
Active introduction to the transition program and to the transition key worker. From 16: at the outpatient consultation: if possible first patient alone, then with parent. From 16: evaluation of adherence (doctor/nurse and/or psychologist) From 16-17: psychosocial exploration and counseling , also regarding legal changes with 18. Medical checklist at least once per year.
Heidelberg transition program

Checklist of medical knowledge at age 15-17 years:

- I know the names of my drugs and know which to take at what time
- I know the possible side effects of my drugs
- I take my drugs independently without recall by my parents
- I know the reasons for all examinations that are done
- I know my medical history
- I can call my doctor if needed and agree on an appointment by myself
- If I need medications, I take care about it by myself
- I spend most time without my parents with the doctor in the consulting hour
- I know about the risks of smoking, alcohol and other drugs for my illness
- I am informed about contraception
- I know my medical history
- I receive enough support from my family
- I have good friends whom I can contact any time
- I already know which type of vocational training course I will start after school
- I know that I must change my doctor when I am grown up
18 - 20 years
Intensive phase of transition
Regular discussion in multidisciplinary team
Regular checking medical knowledge, psychosocial situation (especially school, vocational training, drug adherence)
Issueing transition questionnaire
Questionnaire for the preparation for transition from the center for child and adolescent medicine to adult care

Dear...

You are currently being treated in the “Center for Child and Adolescent Medicine” of the University Hospital Heidelberg. You will be transferred to the adult nephrology center in the medium term. To prepare you we would like to ask you to fill in this questionnaire and to talk about with us in the next consulting hour. We hope to support you thereby in the transition to the adult center.

Name and first name: ________________________________  ________________________________
Date of birth: ________________________________
Date: ________________________________

Choose one of the following statements that applies best to you

<table>
<thead>
<tr>
<th></th>
<th>Agree</th>
<th>Agree partly</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know how my illness is called and I can explain it to someone else in a few sentences</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know the possible effects of my illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know the course of my illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know, why which examinations are executed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know the names of my drugs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know the effects and side effects of my drugs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take all drugs autonomously</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I recognize signs of deterioration of my disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know how to deal with health problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know to whom I can address health problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I make my doctor's appointments myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statement</td>
<td>Agree</td>
<td>Agree partly</td>
<td>Disagree</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>-------</td>
<td>--------------</td>
<td>----------</td>
</tr>
<tr>
<td>I answer most medical questions of my doctor myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take care myself of following recipes or regulations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I execute the treatments recommended by the doctor regularly (including drug intake)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If inevitably: I know the principle of my diet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If inevitably: I take care autonomously of the execution of my diet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know about the special effects of tobacco, alcohol and other drugs on my illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know about the connection between my illness and sexuality, prevention</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what to consider in case of pregnancy and birth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If applicable: I know the basics of the inheritance of my illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get enough support from my parents or other persons of trust</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In my home there is an adult person who is familiar with my disease and its treatment (e.g. parents)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My disease or its treatment represent a possible financial burden for me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have concrete plans for profession</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know about the peculiarities of my illness which I must consider with regard to the choice of career</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what I must tell my employer about my illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have questions about the impact of my illness on my job</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know about differences in adult medicine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I already had contact with the responsible persons in adult medicine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel ready for the transfer to adult medicine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish from the team of treatment ...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A. ... more information about my illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. ... support in questions about school, vocational training or university/college</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. ... more information about how to deal with authorities and about legal changes with reaching the age of majority (health insurance scheme, office, insurances)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. ... more support for the transition to adult medicine</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Heidelberg transition program

Transfer to adult care
- Individual timing! (usually at age 21-22)
  Prerequisites:
  • Completion of school, stable start of vocational training or university
  • Self sufficiency as a patient
  • Medically and psychosocially stable

- First contact with adult nephrologist: joint pediatric-adult transition clinic at the adult nephrology department of the Heidelberg University Hospital. Treatment responsibility is now in the adult unit, with a fixed (senior) doctor. Further pediatric advice is given on request (of patient or adult nephrologist).

- 6 weeks, 3 months, 6 months after the transfer: phone calls with the patient by the transition key worker
– Program still new (since July 2017), first experiences are encouraging. Patients appreciate the program.

– Problem: transition key worker is funded by charity. There are negotiations to get reimbursement by the health insurances.

– It has been revealing to discover the limited medical knowledge in quite a few patients.

– The age period 19-21 years is often a psychologically very vulnerable phase!
Take home message:

“The timing of transfer remains critical. Even the most effective transition program will not speed the biological process of brain maturation.” (Foster 2011)

Individual, criteria-dependent timing of transfer rather than age-dependent timing!
Thank you for your attention!