How to organize Transitional clinic (to adult nephrology)?

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Christer Holmberg
University of Helsinki
Children's Hospital
University of Helsinki

- Pediatric transplantations:
  - Kidney: 245
  - Liver (combined): 119 (13)
  - Heart: 68
  - Lung: 5
  - Intestinal: 3
Transition to adult clinic
(Helsinki)

Transition group for all patients (2–3 times/year)

- Transplantation/CRF-patients
  - 7y nurse first alone, 10y doctor first alone
  - Adolescent out-patient clinic 13y – chek list
  - Annual camp, parent seminars
  - Meeting with adult nurse and nephrologist
  - Patient summary
  - Patient with pediatric nurse to first adult visit
Adolescence

A period of personal development during which a young person must establish a personal sense of individual identity and feelings of self worth which include an alteration of his or her body image, adaptation or more mature intellectual abilities, adjustments to society's demand for behavioural maturity, internalising a personal value system and preparing for adult roles.

From 10-24 years (WHO)
Why is transition important?

- **Adolescence** = critical age: 10-18-24y

- **Puberty:**
  - rejection of authority, impulsive, risk taking
  - body image, cosmetic effects

- **Pediatric care:** big team and familiar own doctors and nurses

- **Adult clinic:** depends on patients own responsibilities and understanding

- Non-adherence - 53% - graft losses - 35% (expensive)

*Watson 2000*
ISN and IPNA consensus statement

Watson AR, 2011
Competencies before transition
Watson AR, 2011

I Understand:

- my condition and can describe it
- know my medication and why
- can make own decisions about treatment
- know the adult clinic and doctor
- to make appointments and arrangements
- who and where to call in emergency
- to discuss worries about blood tests and therapy
- about diet, sexual matters, alcohol and smoking
UK consensus statements
Webb et al., 2014

1. A formal national framework
2. Transition age individualized according to growth, development and education
3. An opportunity to a “young adult clinic”
4. Transition champions pediatric/adult
5. Planned with patient, parents & family
6. A “young adult support worker”
7. Develop standards for quality control
Multidisciplinary team perspectives
Webb et al., 2014

- pediatric and adult key champions
- the process of managing the patients', parents' and both units' expectations should start early, “confidence”
- key persons educated
- disparity in practice between pediatric and adult units resolved, “continuity”
- common guidelines and standards
10 studies showed significant improvement (DM):

- educational programmes, skills training
- transition coordinators
- joint clinics pediatric/adult
- service delivery (separate young adult clinics, out of hours phone support, enhanced follow-up)

- Patient education!!
- Transition clinics!!
Adherence to guidelines – barriers
Forbes et al., 2014

- 15 pediatric units, IPNA/ISN guidelines??
- 2/3 were aware - 1/3 had adapted!!

Factors:
- clinician preference
- geography

Barriers:
- emotionally attached (patient/parents)
- difficulties for parent to let go
HRQ of life??

- **Haavisto et al., 2013:**
  - 74 Tx patients, 7.2 y post-Tx
  - adolescents similar HRQOL as controls
  - risks: short follow-up, congenital disease, comorbidity

- **Kosola et al., 2012:**
  - 57 LT patients, follow-up 10.7 y
  - 68% excellent health, employment status correlated
  - 61% insufficient information on fertility, orgasm problems
  - embarrassed by scars, obesity
Transition when:

- Growth and puberty over
- Primary education finished
- Patient independant:
  - knows his/her disease and medication
  - knows adult clinic and doctor/nurse there
  - Knows how to act in acute situations
- Have been discussed:
  - infections, vaccinations, travel
  - sexual matters, fertility
  - sports, employment, studies
- Patient and parents are confident
Transition, now???