

Transition to adult care: not just a simple transfer

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transition of adolescents with chronic disorders from pediatric care to adult care is one of the biggest challenges for pediatric nursing



culture differences between pediatric and adult care

Pediatrics	Adult care
Family based care (parents involved)	Individual based care
Multidisciplinary team	Specialist orientation
Holistic care	Illness oriented care
Informal, relaxed approach	Formal and direct approach
Attention to developmental and learning issues, social functioning	Strong focus on treatment, complications and adherence

(adapted from Schidlow & Fiel 1990; Rosen 1995)



aim of the research

To explore experiences of adolescents with various chronic disorders, their parents and caregivers with transition from pediatric to adult care

To give recommendations to improve both preparation and coordination of transition



methodology

- case study design
- semi-structured interviews with 21 adolescents, 18 parents and 16 health care professionals
- all adolescents had been discharged from pediatric care (Sophia Children's hospital) in past year
- case studies were carried out between 2004-2006 by nursing students
- using similar interview protocol
- qualitative analysis using

ATLAS.ti



participants

	Male	Female	Age	Transferred Y / N
Haemophilia	3	-	18,17,18	3
Diabetes	1	2	18,20,18	3
Meningomyelocele (=spina bifida)	4	2	15,16,17 17,17,17	3 / 3
Congenital heart disorders	1	2	19,22,22	3
Cystic fibrosis	2	1	18,19,20	3
Rheumatoid arthritis	-	3	19,19,18	3
Total = 21	11	10	Ages 15-22	15 / 6

expectations of transition of those not yet transferred

- most adolescents do not worry about transition too much: "I'll wait and see"
- with the exception of those very ill
- they do not expect major changes in treatment or procedures, or approach by health staff
- in general, they have a positive, optimistic view on transition of care

experiences with transition: adolescents

- most adolescents had not been prepared for transition, but felt they were ready for it anyway
- for most, transition is more than a simple transfer: sometimes adjustment was harder than expected
- as health deteriorates, adolescents experience more difficulties in transition
- central theme for all adolescents is "living a normal life", implying flexible adherence to treatment regimes



experiences with transition: parents

- parents find it hard to adjust to their new role, to let go of their child and to gain trust in new caregivers
- parents experience more problems with leaving the children's hospital than their children



experiences with transition: health staff

- pediatric staff worry about quality of transition and sometimes express lack of confidence in adult care
- adult care seems not well prepared to deal with young patients
- adult care criticizes lack of independence and 'pampering' of adolescents
- most health professionals express concern about transition not being smooth and well structured



conclusion

- adolescents are generally positive about the fact that they will transfer to adult care when reaching adult age
- systematic preparation for the transitional process to adult care, however, is insufficient
- nurses should take the lead in coordinating transition



thank you!

