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TRANSITION OF ADOLESCENTS WITH CHRONIC DISORDERS FROM PEDIATRIC CARE TO ADULT CARE: NOT JUST A SIMPLE TRANSFER

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Introduction

Transition from pediatric care to adult care is becoming an important issue in pediatrics. In The Netherlands, transition programs for adolescents with chronic disorders are still rare. Care during transition does not seem well tailored to the needs of adolescents and parents.

Aim and material

Aim of this comparative study was to explore the experiences of adolescents with chronic disorders, their parents and caregivers. Semi-structured interviews were conducted with 21 adolescents (aged 17-21), 21 parents and 16 health care professionals. The interviews focused on the experiences of transition from pediatric to adult care of adolescents with hemophilia, diabetes, meningomyelocele, and congenital heart disorders (CHD), cystic fibrosis and rheumatoid arthritis. All interviews were analyzed using ATLAS-Ti, a computer program for qualitative analysis.

Results

Adolescents experienced transition as a positive step, yet adjustment was sometimes harder than expected. More difficulties in transition were experienced with deteriorating health. A central theme for adolescents is “living a normal life”, implying flexible adherence to treatment regimes. Parents reported they find it hard to adjust to their new role, to let go of their child and to gain trust in new caregivers. Pediatricians and nurses felt they were not always well prepared to deal with adolescents and they expressed concern about transitions not being smooth or well structured. Newly developed initiatives in the children’s hospital are protocols, nursing consultations and direct contact with adult health care professionals.

Conclusion

Systematic preparation for transition to adult care is insufficient. Nurses should take the lead in coordinating transition.

Transition to adult care: *not just a simple transfer*

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SLIDE 2 background

As a result of the improved pediatric care, 90% of all children in Western countries with a chronic illness of physical disability now survive into adulthood. This has implications for pediatrics and pediatric nursing. There are more adolescents with severe chronic disorders who need to prepare themselves for adult life. At the age of 18, they are expected to leave pediatric care and transfer to adult care. Transition from pediatric care to adult care is becoming a major challenge in pediatrics. In the Netherlands, there are very few transition programs for adolescents with chronic disorders. Care in the transition period does not seem well tailored to the needs of adolescents and parents.

SLIDE 3 differences between pediatric & 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

SLIDE 4 setting: the Sophia Children's hospital

Is part of Erasmus Medical Centre Rotterdam, largest pediatric hospital in the Netherlands. The bridge which is visible in the right side of the picture leads to the academic hospital for adults. The slogan of the Sophia Children's hospital is "In Sophia's the child is the focus".

SLIDE 5 Aim of the research

Aim of this comparative case-study was to explore the experiences of adolescents with chronic disorders, their parents and caregivers. Semi-structured interviews were carried out with 21 adolescents (age 17-21), 21 parents and 16 healthcare professionals.

SLIDE 6 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

All interviews were analyzed using ATLAS-Ti, a program for qualitative analysis.

SLIDE 7 Respondents

	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

Six patients had not been transferred yet, i.e. they had not visited the adult care provider yet. This was due to uncertainties with regard to the provider they were to visit.

Age of transferal varies among the specialties.

Six of all transferals had been made to non academic hospitals.

SLIDE 8 Results: expectations of transition of those not yet referred

- 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
- in general, they have a positive, optimistic view on transition of care

SLIDE 9 Results: experiences with transition adolescents

Those who have already experienced adult care, report that transition was more than a simple transfer. They sometimes found adjustment harder than expected. As their health deteriorates, they experienced more difficulties in transition. Adolescents find it hard to adjust to new health care provider; new routines and they experience a different, more business like approach. Some adolescents appreciate this 'adult like environment' in contrast to the children's hospital which they sometimes label as too childish.

A central theme for adolescents is "living a normal life" implying flexible adherence to treatment regimes.

SLIDE 10 Results: experiences with transition parents

Parents narrated that they find it hard to adjust to their new role, to let go of their child and to gain trust in new caregivers. They sometimes worry about the future and about lack of compliance and supervision.

SLIDE 11 Results: experiences with transition health staff

Pediatricians and nurses felt they were not always well prepared to deal with adolescents. In adult care, adolescents were sometimes seen as difficult patients and it was noted that some youngsters had been pampered too much in the children's hospital.

Most health care providers expressed concern about transition not being smooth or well structured. New initiatives are protocols, nursing consultations and direct contact with adult healthcare professionals.

SLIDE 12 Conclusions

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 is insufficient. Nurses should take the lead in coordinating transition. Coordination could be improved by developing and implementing protocols or clinical pathways.