

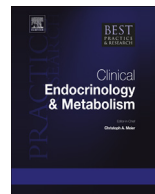


ELSEVIER

Contents lists available at ScienceDirect

## Best Practice & Research Clinical Endocrinology & Metabolism

Journal homepage: [www.elsevier.com/locate/beem](http://www.elsevier.com/locate/beem)



14

### Transition of adolescents and young adults with endocrine diseases to adult health care



Thomas M. Kapellen, MD, Consultant Pediatric Diabetologist  
and Endocrinologist<sup>\*</sup>,  
Wieland Kiess, Prof, Head of the Pediatric Department

*Hospital for Children and Adolescents, University of Leipzig, Germany*

#### ARTICLE INFO

*Article history:*

Available online 3 April 2015

*Keywords:*

transition  
transfer  
health care transition  
paediatric endocrinology  
endocrinology

The transition of adolescents with chronic endocrine diseases to adult care remains a major challenge for all those participating in the process. In paediatric endocrinology, a variety of diseases pose different challenges in the transitional process. The outcome of this transitional process is often judged by what happens after transfer. The young patient needs to be educated early on about continuing treatment into adulthood, resulting in full autonomy over their health care in early adulthood. Therefore, to optimize transition, paediatric and adult endocrinologists must work together to achieve continuity and to meet the needs of young patients.

© 2015 Elsevier Ltd. All rights reserved.

#### Introduction

Transition is defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems [1]. Children with chronic endocrine conditions need long-term paediatric care, but as patients reach adolescence and early adulthood, their care moves into adult medical management. This transition occurs at the same time as other phases of social adaptation, such as leaving home, vocational challenges or living with a new partner. Patients and their families are often concerned about potential differences between paediatric and adult approaches to endocrine care. An individual or family

<sup>\*</sup> Corresponding author. Hospital for Children and Adolescents University of Leipzig, Liebigstrasse 20 A, D-04103 Leipzig, Germany. Tel.: +49 3419726242; Fax: +49 3419712329.

E-mail address: [thomas.kapellen@medizin.uni-leipzig.de](mailto:thomas.kapellen@medizin.uni-leipzig.de) (T.M. Kapellen).

**Table 1**

Potential differences between paediatric and adult medicine.

Pediatrics		Adult medicine
Normal growth and development. Short-term perspective: avoiding acute complications	<b>Focus</b>	Long term perspective: avoiding long-term complications
Interaction with the whole family, strong emotional binding between patients, family and doctor. Empowerment.	<b>Strategy</b>	Responsibility of the young adult alone. Family is mostly not involved. Possibly more rational medication-oriented treatment
Multidisciplinary team is available.	<b>Multiprofessional team</b>	Individualized treatment, multiprofessional team not available in all cases.
Children and adolescents	<b>clients</b>	Adults, frequently older and multimorbid patients

approach is preferred to attending clinics full of elderly sick patients, which is often alienating to the young adult (Table 1).

Much published research has focused on transition within the field of diabetes [1–3]. Less research has been conducted in the area of transition in other endocrine diseases (see Table 2).

Transition clinics have been reported to be effective for a number of chronic diseases in improving compliance during the hand-over to adult services and aiding patient acceptance of adult services (e.g. diabetes mellitus, chronic renal failure and cystic fibrosis). Transition care requires a dedicated service with contributions from both paediatric and adult endocrinology. Local resources will determine the precise format of the service [1–3].

Some diseases tend to have significantly more implications for transition and follow up by an adult endocrinologist, especially if hormonal supplementation is essential for normal daily activity, such as chronic adrenal hyperplasia, Addison's disease or diabetes. In other cases, omission of hormonal replacement will lead to diminished quality of life, as in the case of growth hormone deficiency or congenital hypothyroidism. Several long-term consequences may result if hormonal replacement is not adequately followed up during adult life [2,4].

A typical case was reported by our department [4]. Combined pituitary hormone deficiency is a very rare disease that typically leads to impaired production of several hormones. In our case panhypopituitarism with loss of secretion of growth hormone, thyrotropin, adrenocorticotropin and gonadotropins was first diagnosed in the age of 13 years because of very short stature and delayed pubertal development. Hormonal replacement was initiated. However the patient was lost to follow up as an adult. With the age of 24 years the patient completely stopped all medication including hydrocortisone. He tended to have fatigue and pain in both knees. For the following years he felt comfortable although he had complete non treated panhypopituitarism as seen in lab controls resulting in low cortisol, gonadotropins, growth factors and hypothyroidism. In the age of 30 years he again presented in the paediatric endocrinology to restart treatment.

### The opinions of patients on transfer

Little is known about the specific needs of patients with endocrine diseases when transitioning to adult services. Polak et al. [2] surveyed patients to gather their opinions. Patients with congenital adrenal hyperplasia (CAH), hypogonadotropic hypogonadism and growth hormone deficiency (GHD) were interviewed using a general questionnaire addressing universal aspects of transition, and a disease-specific questionnaire. Of those eligible for inclusion, 73 (47.7%) responded: GHD:  $n = 33$ ; hypogonadotropic hypogonadism:  $n = 27$ ; CAH:  $n = 13$ . Transition to adult services was mainly arranged by the paediatric endocrinologist ( $n = 50$ ; 69%). Written summaries were available for the adult services in 70 cases (96%). A total of 13 (19%) patients reported that they had difficulties with scheduling their first appointment. The main concerns included change of clinician ( $n = 31$ ; 45%), being transferred to a different hospital ( $n = 17$ ; 25%) and possible modification of the treatment modalities (22%;  $n = 15$ ). Fifty-eight (79%), patients were accompanied to the first visit to the adult clinic by relatives, usually by their mother (55%) or their father (22%), or both (16%). The patients' spouse or other relatives rarely attended the first visit. A total of 71 (97%) young adults were satisfied with their

Download English Version:

<https://daneshyari.com/en/article/2791577>

Download Persian Version:

<https://daneshyari.com/article/2791577>

[Daneshyari.com](https://daneshyari.com)