



Review

Transition to adult medical care for adolescents with epilepsy



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ABSTRACT

Introduction: During transition to adult medical care, the adolescent with epilepsy is especially prone to emotional, mental, physical, and social developmental difficulties, leading to stigma and poor psychosocial and socioeconomic outcome in the long term.

Objectives: The aim of this review is twofold: to describe the psychosocial and medical transition from adolescence to adulthood and to evaluate the most effective model for transitional services in adolescents with epilepsy.

Methods: We searched PubMed for quantitative and qualitative data about transition from adolescence to adulthood in patients with epilepsy.

Results: A total of 49 articles were retrieved. We reviewed personal, psychosocial, and medical issues during transition and their long-term individual and societal consequences. Identifying risk factors for poor transition can lead to appropriate interventions for patients and their family. Although the concept of multidisciplinary transition care for adolescents with epilepsy is widely recognized, only a few transition clinics have been established. There is lack of evidence for their quality and cost-effectiveness.

Conclusion: In addition to medical problems, more attention should be paid to the risk of psychosocial problems during transition from pediatric to adult care. The implementation of transition care for adolescents with epilepsy is considered beneficial; however, its effectiveness should be further investigated.

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1. Introduction

Epilepsy is the most common childhood-onset neurological disorder transferring into adolescence, affecting 15 million children globally [1–4]. It is a disorder characterized not only by seizures but also by comorbid behavioral, social, physical, and intellectual disabilities, making it a heterogeneous and complex condition [1–6]. Both epilepsy and many of its associated comorbid disabilities can either continue or remit during adolescence and adulthood [6–8].

In addition to the normal age-related challenges, the adolescent with epilepsy is especially prone to emotional, cognitive, physical, and social developmental difficulties during transition to adulthood, influencing self-identity, autonomy, and thereby psychosocial outcome in the long term [3–5,9–17]. Moreover, leaving pediatric care during this transition often leads to discontinuity of chronic care [1,2,5,6,11,12,15]. Therefore, an emphasis on support during transition seems of utmost importance [1,6,7,13,18,19].

Although the problem of transition from pediatric to adult care and the concept of multidisciplinary transition care are widely recognized in chronic disease, little quantitative data are available about transition problems and required care in adolescents with epilepsy [1,6,11,13,15,19]. The aim of this review is therefore twofold: to describe the process of transition to adult medical care in adolescents with epilepsy and to evaluate the most effective model for epilepsy transitional services.

2. Methods

Since ‘transition in adolescents with epilepsy’ is a relatively new concept, found on PubMed since 1997 (Appleton et al. [4]), we chose to search PubMed instead of gray literature. It is unlikely that gray literature would provide additional information.

PubMed was searched for quantitative and qualitative data about transition from pediatric to adult care in adolescents with epilepsy (closing date: September 15th, 2014), using the MeSH terms epilepsy, seizure, convulsion, and transition to adult care and the text words epilepsy, seizure, and convulsion, combined with paediatric/pediatric, adolescents, teen, youth, underage, junior school, junior high, middle school, high school, senior high, boy/girl, puberty, young people, minors, combined with the text words transition and adult care and adult

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Table 1
Identified articles, study design, and topics.

Author(s) (year)	Title	Study design	Topic
Nabbout and Camfield [45] (2014)	Transition in adulthood: the challenge of epilepsies	Supplement <i>Epilepsia</i>	Introduction to special issue of <i>Epilepsia</i> : 'Transition of epilepsy care from children to adults'
Beghi et al. [8] (2014)	Epidemiologic aspects: lost in transition	Supplement <i>Epilepsia</i> Review	Long-term medical and psychosocial outcome in patients with epilepsy
Chiron and An [21] (2014)	Pharmacology aspects during transition and at transfer in patients with epilepsy	Supplement <i>Epilepsia</i> Review	AED treatment during transition
Scheffer and Dravet [22] (2014)	Transition to adult life in the monogenic epilepsies	Supplement <i>Epilepsia</i> Review	Psychiatric disorders, movement disorders, and epileptic encephalopathies during transition
Camfield et al. [23] (2014)	Transition issues for benign epilepsy with centrotemporal spikes, nonlesional focal epilepsy in otherwise normal children, childhood absence epilepsy, and juvenile myoclonic epilepsy	Supplement <i>Epilepsia</i> Review	Transition in patients with BECTS, NLFN, CAE, and JME
De Saint-Martin et al. [26] (2014)	Epileptic encephalopathy with continuous spike–waves during sleep: the need for transition from childhood to adulthood medical care appears to be related to etiology	Supplement <i>Epilepsia</i> Review	Transitional care for adolescents with ECSWS
Camfield et al. [24] (2014)	Transition issues for children with diffuse cortical malformations, multifocal postnatal lesions, (infectious and traumatic) and Lennox–Gastaut and similar syndromes	Supplement <i>Epilepsia</i> Review	Transition for children with diffuse cortical malformations, multifocal postnatal lesions, and LGS
Thiele et al. [27] (2014)	Transition into adulthood: tuberous sclerosis complex, Sturge–Weber syndrome, and Rasmussen encephalitis	Supplement <i>Epilepsia</i> Review	Transition for children with TSC, SWS, and RE
Cross and Duchowny [35] (2014)	Transition in lesional focal epilepsy, and following epilepsy surgery	Supplement <i>Epilepsia</i> Review	Epilepsy surgery during transition
Kossoff et al. [28] (2014)	Transition for patients with epilepsy due to metabolic and mitochondrial disorders	Supplement <i>Epilepsia</i> Review	Transition for patients with epilepsy with metabolic or mitochondrial disorders Ketogenic diet
Nashef et al. [34] (2014)	Transition: driving and exercise	Supplement <i>Epilepsia</i> Review	Driving and exercise in adolescents with epilepsy
Carrizosa et al. [40] (2014)	Models for transition clinics	Supplement <i>Epilepsia</i> Review	Models for transition clinics
Nabbout and Camfield [46] (2014)	Bringing the transition of epilepsy care from children to adults out of the shadows	Supplement <i>Epilepsia</i> Opinion	Need for transitional care
Devinsky [47] (2014)	Transition to adult care for children with epilepsy—a call for action	Supplement <i>Epilepsia</i> Opinion	Need for transitional care
Borlot et al. [6] (2014)	Epilepsy transition: challenges of caring for adults with childhood-onset seizures	Retrospective study Survey	Transition care for adolescents with epilepsy Neurologists' level of confidence in diagnosis and treatment
Camfield and Camfield [7] (2014)	What happens to children with epilepsy when they become adults? Some facts and opinions	Topical review	Seizure remission and social outcome in adults with childhood-onset epilepsy
Thomson et al. [9] (2014)	Life quality and health in adolescents and emerging adults with epilepsy during the years of transition: a scoping review	Scoping review	Challenging domains during transition to adulthood in adolescents with epilepsy
Ferro [43] (2013)	Adolescents and young adults with physical illness: a comparative study of psychological distress	Comparative study	Comparing psychological distress in adolescents with asthma vs. epilepsy
Schor [32] (2013)	Life at the interface: adults with "pediatric" disorders of the nervous system	Review	Childhood-onset neurological conditions, including epilepsy, compared to other chronic conditions
Lewis and Noyes [1] (2013)	Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adult services	Qualitative comparative embedded case study	Knowledge, information needs, and communicational skills in transitional services for adolescents with epilepsy
Kuchenbuch et al. [10] (2013)	Transition and transfer from pediatric to adult health care in epilepsy: a families' survey on Dravet syndrome	Survey	Process and satisfaction of transitional care for children with DS
Parachuri and Inglese [20] (2013)	Neurological problems in the adolescent population	Not available	Not available
Camfield and Camfield [44] (2013)	Help youth with epilepsy to become competent and happy adults: transition care	Editorial	Editorial (1 page) referring to Iyer and Appleton [11]
Iyer and Appleton [11] (2013)	Transitional services for adolescents with epilepsy in the U.K.: a survey	Survey	Presence and methods of a transition care for adolescents with epilepsy
Camfield et al. [16] (2013)	Transition from pediatric to adult epilepsy care: a difficult process marked by medical and social crisis	Review	Review importance of transitional care in children with epilepsy
Kossoff et al. [36] (2013)	Transitioning pediatric patients receiving ketogenic diets for epilepsy into adulthood	Case series/study	Studying process of transition to adult care in children with ketogenic diet
Camfield et al. [25] (2012)	Helping families cope with the devastation of Dravet syndrome	Review article	Optimizing quality of life during the different developmental stages of DS

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