

TRANSITION

NEWSLETTER



INDICE:

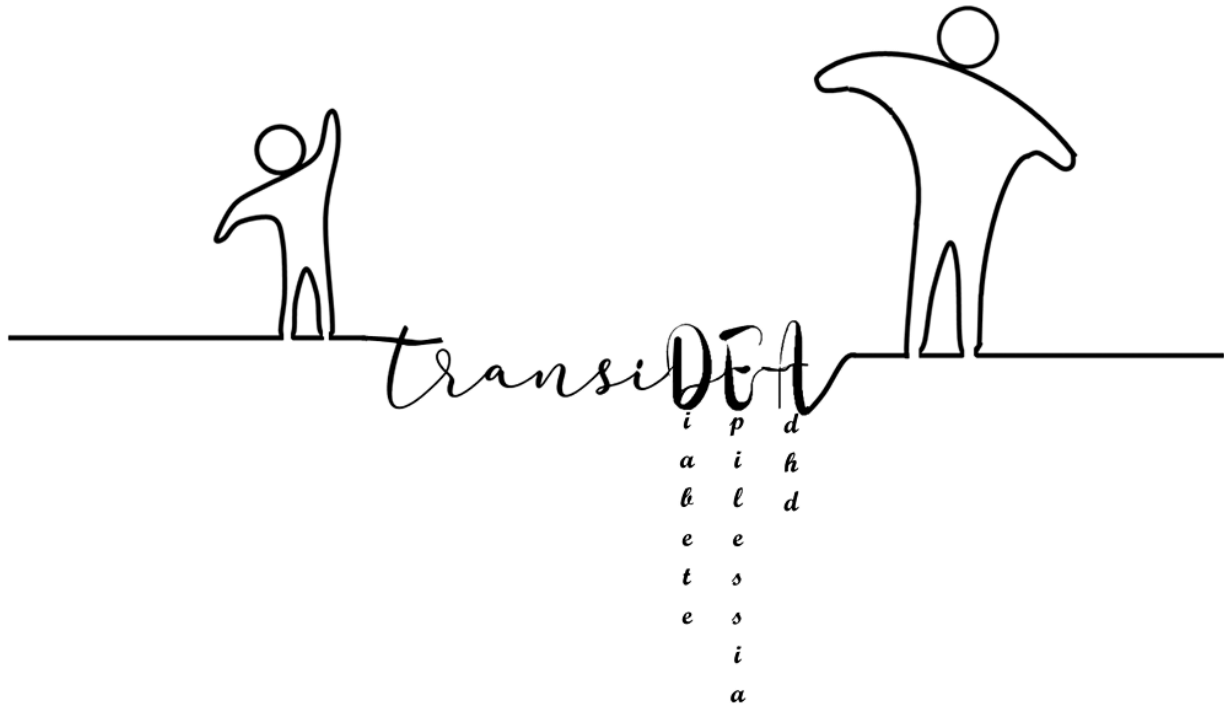
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GENERALE

Syst Rev. 2021 Feb;10:46.

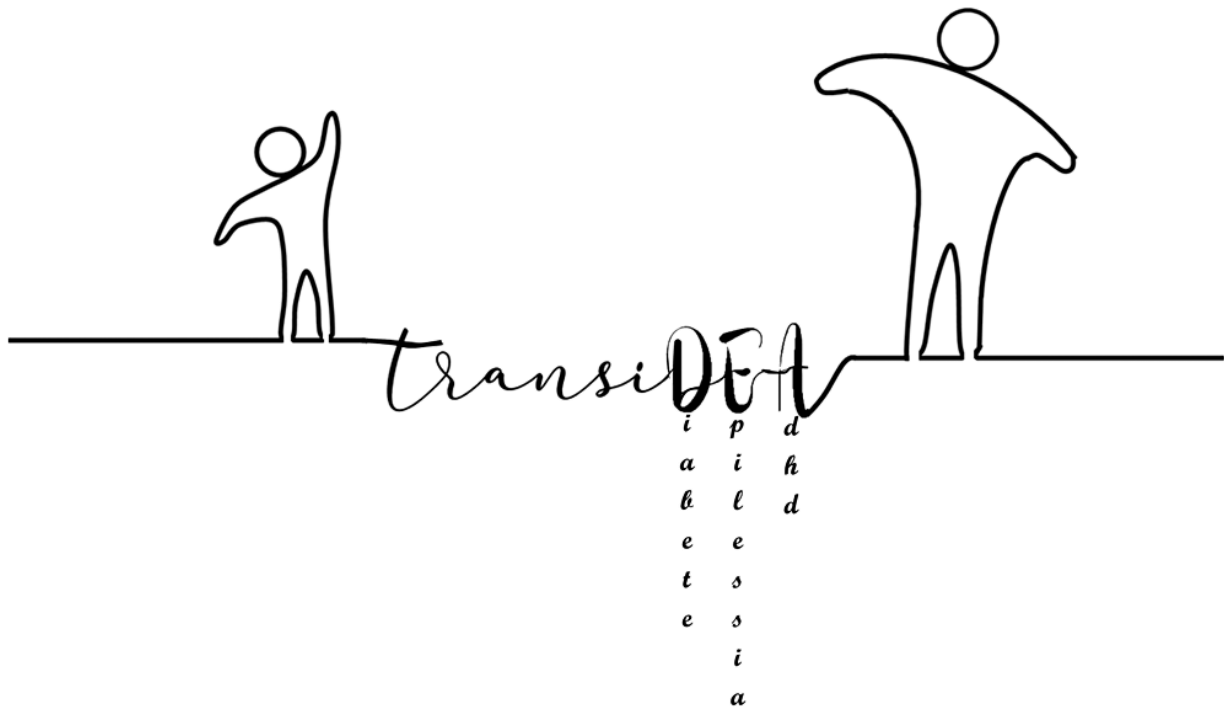
PRIMARY CARE DURING THE TRANSITION TO ADULT CARE FOR ADOLESCENTS INVOLVED WITH PEDIATRIC SPECIALTY SERVICES: A SCOPING REVIEW PROTOCOL.

Schraeder K, Allemang B, Scott C, et al.

BACKGROUND: Of the 15-20% of youth in North America affected by a chronic health condition (e.g., type 1 diabetes, cystic fibrosis) and/or mental health or neurodevelopmental disorder (e.g., depression, eating disorder, Attention Deficit-Hyperactivity Disorder), many often require lifelong specialist healthcare services. Ongoing primary care during childhood and into young adulthood is recommended by best practice guidelines. To date, it is largely unknown if, how, and when primary care physicians (PCPs; such as family physicians) collaborate with specialists as AYAs leave pediatric-oriented services. The proposed scoping review will synthesize the available literature on the roles of PCPs for AYAs with chronic conditions leaving pediatric specialty care and identify potential benefits and challenges of maintaining PCP involvement during transition.

METHODS: Arksey and O'Malley's original scoping review framework will be utilized with guidance from Levac and colleagues and the Joanna Briggs Institute. A search of databases including MEDLINE (OVID), EMBASE, PsycINFO, and CINAHL will be conducted following the development of a strategic search strategy. Eligible studies will (i) be published in English from January 2004 onwards, (ii) focus on AYAs (ages 12-25) with a chronic condition(s) who have received specialist services during childhood, and (iii) include relevant findings about the roles of PCPs during transition to adult services. A data extraction tool will be developed and piloted on a subset of studies. Both quantitative and qualitative data will be synthesized.

DISCUSSION: Key themes about the roles of PCPs for AYAs involved with specialist services will be identified through this review. Findings will inform the development and evaluation of a primary-care based intervention to improve transition care for AYAs with chronic conditions



EPILESSIA

Epilepsy Behav. 2020 Oct;111:107242.

PILOT DATA AND CASE EXAMPLE OF THE INITIAL VISIT IN A MULTIDISCIPLINARY TRANSITION-AGE PROGRAM (TAP). Hughes-Scalise A, Reger KL, Gergen MA.

The process of transition from pediatric to adult epilepsy care has received increased attention and emphasis in recent literature, particularly related to the assertion that effective transition is likely to lead to improved medical and psychosocial outcomes. However, the majority of current transition literature focuses on the structure of a transition program, with very little research providing relevant clinical data during the transition period and beyond. The current paper attempts to address this gap in the literature by providing pilot data on participants who engaged in the initial visit of a multidisciplinary transition-focused program housed in a level 4 epilepsy center in the Midwest. Pilot data are presented on 28 participants (36% female) who completed the initial transition appointment. All but one participant presented with a positive history for a neurobehavioral comorbidity, the most common of which included anxiety (61%), attention-deficit/hyperactivity disorder (ADHD; 39%) and depression (36%). Seventy-seven percent of participants further identified a current neurobehavioral comorbidity that was impacting their psychosocial functioning. Recommendations provided most frequently involved increased independence with epilepsy management (64%), increased independence with self-care/independent living (82%), psychological intervention (43%), and increased socialization (43%). A case example is also provided to further highlight program process and outcomes of the initial visit. Pilot results emphasize the value of multidisciplinary care involving psychosocial providers to facilitate a smooth transition between pediatric and adult healthcare

Per la ricerca degli articoli pubblicati nella letteratura scientifica nel mese in esame sono state consultate le banche dati Medline, Embase, PUBMED utilizzando le seguenti parole chiave (o i loro sinonimi): 'Transitional Care', 'Transitional to Adult Care', 'Children', 'Adolescent', 'Young'. Sono qui riportate le referenze considerate rilevanti e pertinenti.

Nervenarzt. 2022.

TRANSITION TO ADULT CARE FOR PATIENTS WITH EPILEPSY.

Brandl U.

The transition of children and adolescents with epilepsy to the adult healthcare system presents many challenges. The disease is frequently accompanied by cognitive and developmental impairments that make it difficult to achieve self-management of the disease. Seizures are often associated with a loss of consciousness; therefore, conversations regarding medical history often take place only between the physician and the parents. The children and adolescents then usually have a very little knowledge about their disease and do not learn to talk about their seizures and other disease-related problems. Childhood epilepsies are partly caused by rare genetic diseases, and neurologists usually have little experience with these diseases. In the past many of these etiologies were underdiagnosed in pediatrics and never reclassified during adulthood. An improvement of this situation requires long-term assistance over numerous years for the young patients to learn more about their own disease and the healthcare structures for adults. They should also be trained in how to talk about their medical problems with the doctor (physician-patient communication). At the medical level, a well-structured transfer of clinical findings, EEGs, imaging findings, etiologies, the current seizure situation, and the history of therapeutic measures is required. This article provides useful recommendations and information about existing programs and materials to support the management of transition

Seizure. 2022;96:43-45.

TREATMENT OUTCOME FOLLOWING THE TRANSITION TO ADULT EPILEPSY CARE IN CHILDHOOD-ONSET EPILEPSY.

Kwack DW, Lee H, Lee R, et al.

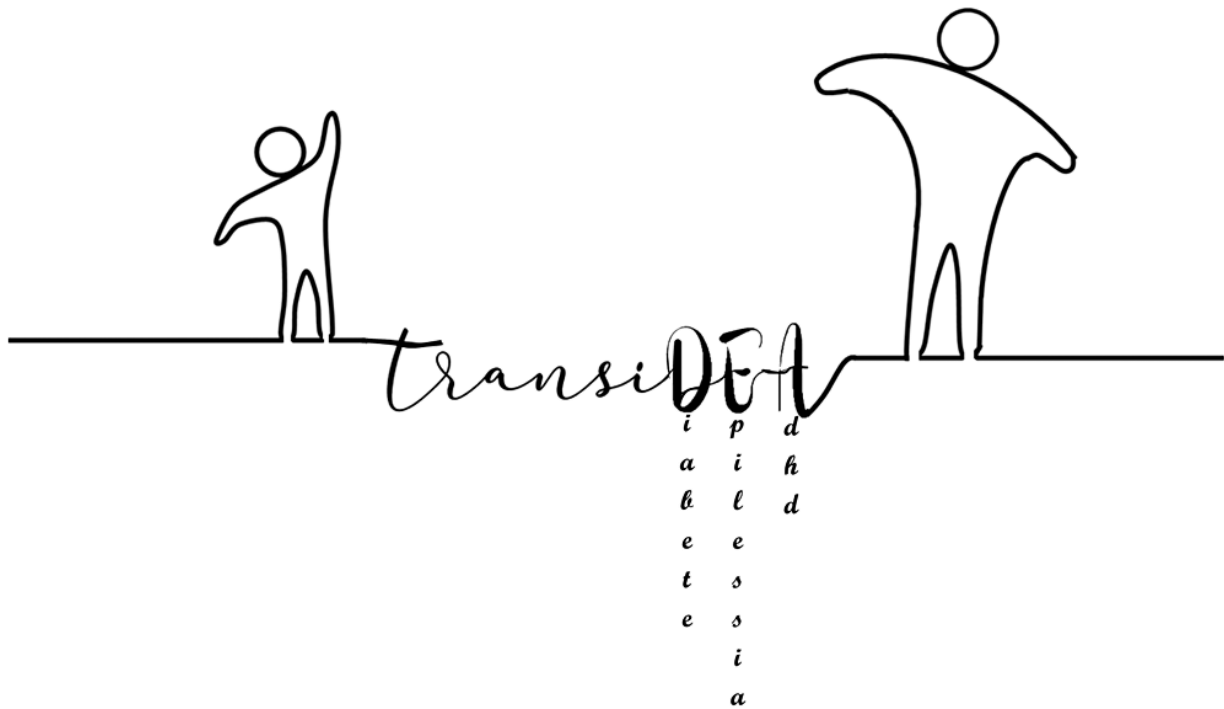
Introduction: Transition from pediatric to adult epilepsy care in patients with childhood-onset epilepsy can be challenging, and several aspects should be considered, including comorbidities, achieving social milestones, and adjustment of anti-seizure medications (ASMs). However, there is limited information regarding the treatment outcome following the transition to adult epilepsy care in childhood-onset epilepsy. Materials and methods: We performed a 13-year retrospective study of patients with childhood-onset epilepsy who had been transferred to our adult epilepsy clinic. Treatment outcomes were divided into two groups: seizure improvement (at least 50% reduction of seizure) and stationary or worsening seizures. Results: Among the 2,365 patients in our epilepsy cohort, 140 with childhood-onset epilepsy were transferred to adult epilepsy care. Forty-nine patients (35.0%) experienced improvement of seizures, whereas 91 patients (65.0%) reported stationary or worsening seizures following transition. Patients in the improvement group were younger at the time of transition than patients in the stationary or worsening group ($p = 0.004$) and had a lower number of ASMs before the adjustment ($p = 0.001$). Interestingly, patients in the improvement group had a greater chance of epileptiform discharges on EEG than patients in the stationary or worsening group (38/49 vs 54/91, $p = 0.03$). Conclusion: Our study shows that one-third of patients having childhood-onset epilepsy can experience seizure improvement following transition to adult epilepsy care, and the presence of epileptiform discharges on EEG may not necessarily mean a poor prognosis or drug-resistant epilepsy following the transition

Journal of Child Health Care. 2022.

STUCK IN TRANSIT: A QUALITATIVE STUDY OF THE TRANSITIONAL CARE NEEDS OF YOUNG PEOPLE WITH EPILEPSY AND JUVENILE IDIOPATHIC ARTHRITIS.

Wilson N, Whittaker K, Arnott J, et al.

Transition services for young people with long-term conditions often fall short. This qualitative study explored perspectives on service features that enable effective transition in epilepsy and juvenile idiopathic arthritis. Patients, parents, clinicians and service commissioners took part in semi-structured interviews ($n = 18$). Thematic analysis was used to identify key features, barriers and facilitators of effective transition across participant groups. Analysis led to the development of nine sub-themes which mapped to overarching domains of communication, capability, continuity and capacity. Findings include the need for age appropriate communication, the link between parental dependence, self-care and patient knowledge, the value of service integration for continuity and the impact of capacity on flexible and age appropriate transition services



DIABETE

BMJ Open Qual. 2022 Jan;11.

PATIENT AND FAMILY PERSPECTIVES OF A PRE-TRANSITION VISIT IN A PAEDIATRIC TERTIARY CARE DIABETES CLINIC.
Marr A, Tsampalieros A, Courtney J, et al.

INTRODUCTION: The need to better prepare youth with type 1 diabetes for the transition from paediatric to adult care is evident. As part of a regional quality improvement initiative, a novel Pre-Transition (Pre-T) Visit was developed and piloted at a paediatric tertiary care centre in January 2018 for patients aged 15-18 years to capture the status of their self-management skills, introduce transition tools and identify self-care goals and knowledge gaps to be addressed prior to transition.

PURPOSE: To evaluate patient and family satisfaction, visit relevance and patient engagement with a novel Pre-T Visit. **METHODS:** From May 2019 to March 2020 a survey was offered to all youth who attended a Pre-T Visit and their parent(s)/caregiver(s). Patient and family satisfaction with, relevance of and engagement with the Pre-T Visit were evaluated using a 5-point Likert scale. Multivariable regression was used to assess patient factors associated with patient level satisfaction.

RESULTS: Of the 63 youth who participated in a Pre-T Visit, 60 completed the survey. Mean age (SD) of participants was 16.7 (0.8) years; 47% were female. Mean (SD) haemoglobin A1C (A1C) was 8.2% (1.8). Patients reported high levels of satisfaction (95% quite or extremely satisfied) that were consistent across age, A1C, gender and disease duration. Visit relevance and engagement were also rated highly by youth. Parent participants (n=27) also reported high levels of satisfaction (89% quite or extremely satisfied) and relevance.

CONCLUSIONS: Pre-T Visits were rated highly by patients and their parents. Their impact on glycaemic control and health outcomes following transition requires further study

Diabetes Spectr. 2022 Feb;35:57-65.

OPPORTUNITIES FOR ENHANCED TRANSITION OF CARE PREPARATION FOR ADOLESCENTS AND EMERGING ADULTS WITH TYPE 1 DIABETES: USE OF THE READDY TRANSITION TOOL.

Kamoun C, Khoury JC, Beal SJ, et al.

There is an ongoing need to determine best practices for effective transition from pediatric to adult care for adolescents and emerging adults (EAs) with type 1 diabetes given the potential for poor health outcomes post-transfer. This study evaluated self-reported confidence ratings as measured by the Readiness of Emerging Adults with Diabetes Diagnosed in Youth (READDY) tool among adolescents and EAs with type 1 diabetes and the association of the confidence ratings with clinical and demographic characteristics, as well as provider documentation of relevant anticipatory guidance topics. The READDY is a diabetes-specific tool used to collect patient-reported confidence in transition preparation topics to target educational interventions. These interventions are divided into four domains: Diabetes Knowledge, Health System Navigation, Insulin Self-Management, and Health Behaviors. A retrospective chart review was conducted of patients 15-24 years of age with type 1 diabetes who completed the READDY survey between January 2017 and January 2018 at a single center. Overall patient-reported confidence levels were high. However, adolescents and EAs endorsed their lowest levels of confidence on items assessing knowledge of alcohol, tobacco, sexual health, and the impact of diabetes on pregnancy (females only), with the percentages of low scores of 20.7, 25.9, 35.9, and 42.9%, respectively. Documentation of provider counseling about screening and prevention of diabetes comorbidities, alcohol use, and tobacco use was associated with scores in the higher range for the corresponding item in the READDY survey. These findings highlight an opportunity to create interventions related to developmentally important topics for adolescents and EAs with type 1 diabetes to enhance successful transition preparation

J Child Health Care. 2022 Mar;13674935221074777.

STUCK IN TRANSIT: A QUALITATIVE STUDY OF THE TRANSITIONAL CARE NEEDS OF YOUNG PEOPLE WITH EPILEPSY AND JUVENILE IDIOPATHIC ARTHRITIS.

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Transition services for young people with long-term conditions often fall short. This qualitative study explored perspectives on service features that enable effective transition in epilepsy and juvenile idiopathic arthritis. Patients, parents, clinicians and service commissioners took part in semi-structured interviews (n = 18). Thematic analysis was used to identify key features, barriers and facilitators of effective transition across participant groups. Analysis led to the development of nine sub-themes which mapped to overarching domains of communication, capability, continuity and capacity. Findings include the need for age appropriate communication, the link between parental dependence, self-care and patient knowledge, the value of service integration for continuity and the impact of capacity on flexible and age appropriate transition services

J Prim Care Community Health. 2022 Jan;13:21501319221084890.

COMMUNITY BASED PRIMARY CARE FOR ADOLESCENTS AND YOUNG ADULTS TRANSITIONING FROM PEDIATRIC SPECIALTY CARE: RESULTS FROM A SCOPING REVIEW.

Schraeder K, Allemang B, Felske AN, et al.

BACKGROUND: Ongoing primary care during adolescence is recommended by best practice guidelines for adolescents and young adults (AYAs; ages 12-25) with chronic conditions. A synthesis of the evidence on the roles of Primary Care Physicians (PCPs) and benefits of primary care is needed to support existing guidelines. **METHODS:** We used Arksey and O'Malley's scoping review framework, and searched databases (MEDLINE, EMBASE, PsychINFO, CINAHL) for studies that (i) were published in English between 2004 and 2019, (ii) focused on AYAs with a chronic condition(s) who had received specialist pediatric services, and (iii) included relevant findings about PCPs. An extraction tool was developed to organize data items across studies (eg, study design, participant demographics, outcomes).

RESULTS: Findings from 58 studies were synthesized; 29 (50%) studies focused exclusively on AYAs with chronic health conditions (eg, diabetes, cancer), while 19 (33%) focused exclusively on AYAs with mental health conditions. Roles of PCPs included managing medications, "non-complex" mental health conditions, referrals, and care coordination, etc. Frequency of PCP involvement varied by AYAs; however, female, non-Black, and older AYAs, and those with severe/complex conditions appeared more likely to visit a PCP. Positive outcomes were reported for shared-care models targeting various conditions (eg, cancer, concussion, mental health).

CONCLUSION: Our findings drew attention to the importance of effective collaboration among multi-disciplinary specialists, PCPs, and AYAs for overcoming multiple barriers to optimal transitional care. Highlighting the need for further study of the implementation of shared care models to design strategies for care delivery during transitions to adult care

Pediatric Diabetes. 2022.

THE ASSOCIATION BETWEEN PEDIATRIC MENTAL HEALTH DISORDERS AND TYPE 1 DIABETES-RELATED OUTCOMES.

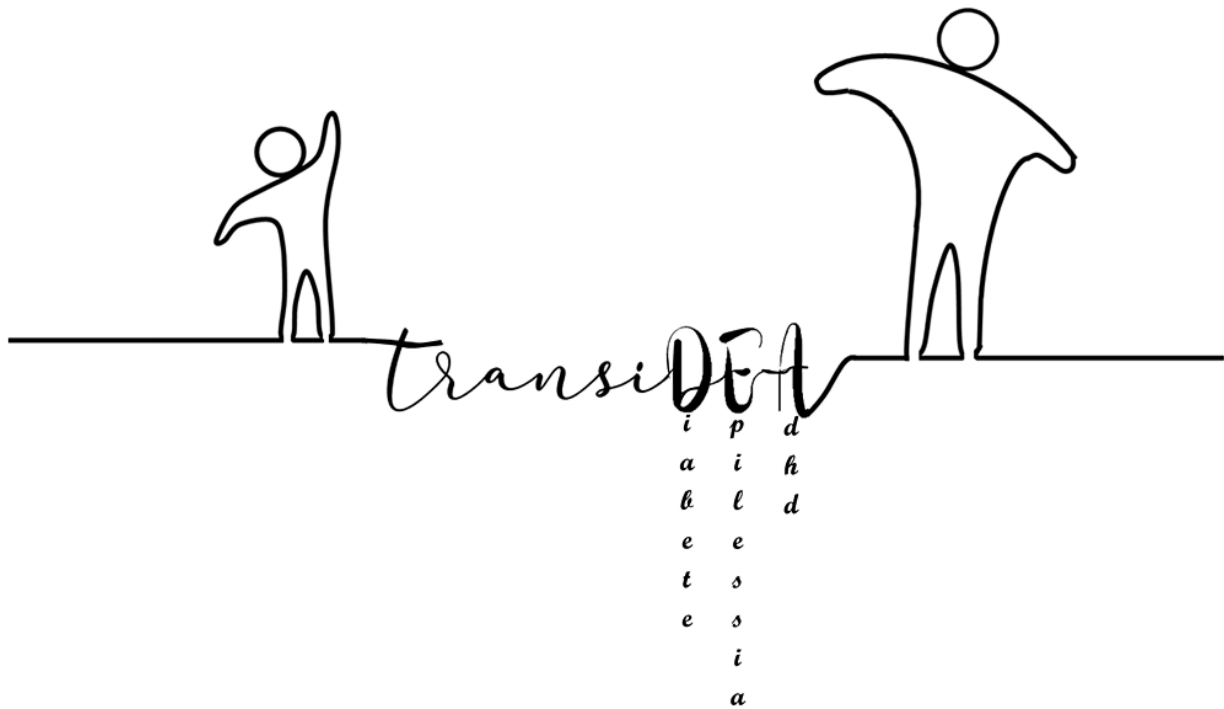
Hu TY, Price J, Pierce JS, et al.

Objective: Transition from pediatric to adult healthcare systems is a difficult process for young adults with Type 1 Diabetes (T1D) and most patients experience a deterioration in disease control. Mental health (MH) disorders are common in individuals with T1D and are believed to play a role in disease control and transition of care. We evaluated the association between the presence of pediatric MH disorder and measures of success in diabetes care in young adults who recently transitioned to adult care.

Research Design and Methods: Retrospective cohort study of young adults in a large adult endocrinology system who transitioned from a pediatric hospital system after 2009. MH disorders were diagnosed by clinical pediatric psychologists during routine care at the pediatric hospital. Measurements of Hemoglobin A1c, diabetes-related emergencies, clinic attendance and intervals in transition were assessed and compared between the pediatric and adult hospital systems.

Results: 237 young adults were identified and 100 (42%) of these were diagnosed with a MH disorder during pediatric care. Presence of a MH disorder was associated with higher Hemoglobin A1c levels prior to transition and increased rates of diabetes-related hospitalizations during the transition interval. Patients with a MH disorder were less likely to establish a pattern of consistent follow up after transition ($p = .021$).

Conclusions: MH disorders are common and predict greater challenges with diabetes management and less effective transition into the adult endocrinology system. Early recognition of MH disorders may allow for allocation of more proactive and intensive support for affected patients



ADHD

Autism. 2021 Apr;25:705-18.

HEALTHCARE SERVICE UTILIZATION AND COST AMONG TRANSITION-AGE YOUTH WITH AUTISM SPECTRUM DISORDER AND OTHER SPECIAL HEALTHCARE NEEDS.

Ames JL, Massolo ML, Davignon MN, et al.

Youth with autism spectrum disorder often have complex medical needs. Disruptions of healthcare during the transition from pediatric to adult healthcare may put youth with autism spectrum disorder at higher risk of medical emergencies and high medical costs. To understand healthcare utilization during the transition years, we conducted a study among transition-age youth (14-25 years old) receiving healthcare at Kaiser Permanente Northern California during 2014-2015. We examined differences in healthcare utilization and costs among youth with autism spectrum disorder (n = 4123), attention deficit and hyperactivity disorder (n = 20,6015), diabetes mellitus (n = 2156), and general population controls (n = 20,615). Analyses were also stratified by age and sex. Youth with autism spectrum disorder had the highest utilization of outpatient primary care, mental health, and psychotropic medications and the lowest utilization of obstetrics/gynecology and urgent care. Costs for youth with autism spectrum disorder were higher than those for attention deficit and hyperactivity disorder and general population peers and lower than for diabetes mellitus. Healthcare utilization patterns varied by age. Transition-age youth with autism spectrum disorder generally used healthcare at higher rates relative to attention deficit and hyperactivity disorder and general population peers but at similar or lower rates than diabetes mellitus peers, indicating this group's complex combination of psychiatric and medical healthcare needs. The relatively high utilization of psychiatric services and low utilization of women's health services in transition-age youth with autism spectrum disorder may have implications for long-term health and warrants additional research

Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2020 Jul;63:910-15.

ADHD IN THE TRANSITION TO ADULTHOOD: PREVALENCE, SYMPTOMS, RISKS, AND CARE.

Philipsen A, Döpfner M.

Attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental disorder. In contrast to earlier assumptions, ADHD at least partially persists into adulthood in 50-80% of the patients. This narrative review article highlights the risks, treatment options, and care requirements associated with the transition to adulthood. Available epidemiological and routine care data and guidelines are reviewed and screened for indications and recommendations to improve the health-care of adolescents with ADHD. Epidemiological and routine care data point to a care gap for adolescents with ADHD in the sensitive phase of transition from adolescence to adulthood. Specific transition concepts should be expanded and their effectiveness scientifically investigated

Epidemiol Psychiatr Sci. 2020 Jan;29:e87.

TRANSITIONAL CARE FOR YOUNG ADULTS WITH ADHD: TRANSFORMING POTENTIAL UPHEAVAL INTO SMOOTH PROGRESSION.

Ford T.

Increasing numbers of young adults need continued support for their attention deficit hyperactivity disorder (ADHD) beyond the age-boundary for children's services. The sparse literature on transition in general suggests patchy provision and huge gaps in transitional care, but also that young people with ADHD and other neurodevelopmental disorders fair particularly badly. Transition in health care coincides with many other important life-transitions while the difficulties associated with ADHD may make these challenges particularly hard to cope with. Parents or other advocates therefore often need to be involved, which can present problems in adult mental health services given that they tend to be less family oriented than children's services. Importantly, young people need help negotiating the transition from passive recipient of care to active self-management, and in building relationships with the adult team. In addition to patchy provision of adult ADHD services, transition is currently hampered by poor understanding of ADHD as a long term condition and uncertain knowledge of what services are available among young people and parents as well as the clinicians working with them. Guidelines recommend, and more importantly young people want, access to psycho-social interventions as well as medication. However, available evidence suggests poor quality transitional care and adult services that are highly focused on medication. Adult ADHD services need to undergo similar development to that experienced by Child and Adolescent Mental Health Services and community paediatrics over the last few decades. While we debate the relative merits of dedicated or specialist v. generic adult mental health services, for young adults with ADHD the training, experience and availability of professionals are more important than their qualifications or setting

Health Soc Care Community. 2021 Sep;29:1429-38.

EXPERIENCES OF TRANSITION FROM CHILDREN'S TO ADULT'S HEALTHCARE SERVICES FOR YOUNG PEOPLE WITH A NEURODEVELOPMENTAL CONDITION.

Shanahan P, Ollis L, Balla K, et al.

Previous research has highlighted a lack of continuity of care when young people with a neurodevelopmental condition make the transition from children's to adult specialist healthcare services. A lack of planning, consistency, and availability of adult services has been found to lead to; increased anxiety, poor health outcomes, reduced support and some young people not receiving healthcare. The majority of transition research has focused on what health professionals consider important in the transition process, rather than focusing on the experiences of the young people and those closest to them. Our objective was to gather evidence from young people (and their families) who had experienced transition from children's to adult specialist healthcare services through semi-structured interviews. Volunteers were recruited from two London boroughs. All young people were aged between 18 and 25 years with a neurodevelopmental condition (Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder and/or an Intellectual Disability). Overall, we interviewed six young people with support from a family member. Five further family members were interviewed on behalf of the young person. In total, ten semi-structured interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis. Four themes emerged from the analysis: (a) Parents as advocates, (b) Availability of adult's specialist health and social care services, (c) Lack of information sharing and (d) Transition as a binary, abrupt change. Our findings suggest the transition experience could be improved by changing service specifications to incorporate assessment and handover across the age range of 16-20 years. Additionally, statutory services should understand and provide the coordination role now offered by parents in transition. We suggest future research could evaluate the feasibility of a patient-owned online information sharing tool with information about relevant services for young people and their families

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