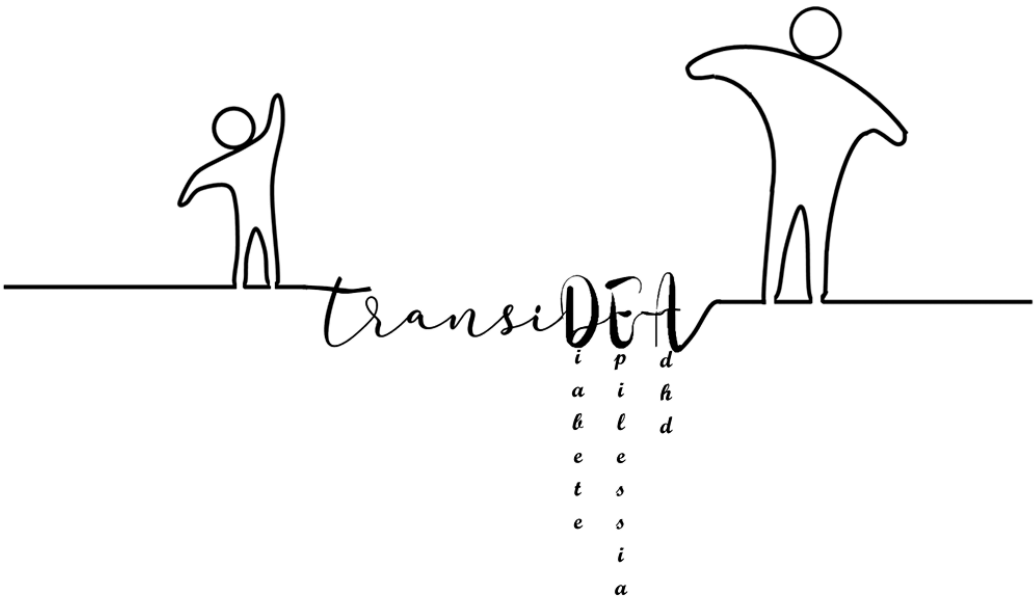
Indice:



GENERALE

Adv Chron Kidney Dis. 2022;29:219-20.
PEDIATRIC TO ADULT TRANSITION: IDENTIFYING IMPORTANT COMORBIDITIES AND CONSIDERATIONS FOR ADULT AND PEDIATRIC NEPHROLOGY HEALTH CARE TEAMS.
Raina R, Sethi SK.

Adv Clin Exp Med. 2022;31:157-63.
VARIOUS ASPECTS OF TRANSITION OF CARE FOR ADOLESCENTS WITH UROLOGICAL CONDITIONS.
Dobrowolska-Glazar B, Chrzan R, Bagłaj M.
Transition into adulthood is a common issue in many disciplines. However, urology faces additional difficulties due to different models of care and training as well as a wide diversity of pathologies. The goal of this paper is to discuss various aspects of the transition of urological care. This review provides some examples of pathologies that might require special attention of specialists. Most patients with rare diseases must be closely followed up in the long term. However, high-volume conditions may also have a huge impact on the well-being and quality of life in adulthood. Children who are cured due to oncological conditions will probably need additional attention in adulthood. The urological care during childhood is provided by a pediatric urologist, a pediatric surgeon or a urologist, depending on the local regulations and the organization of care. All patients are subsequently referred to a general urologist. Nowadays, a multidisciplinary approach is recommended in many cases, with a pediatric urologist as one of the team members. The patient, caregivers and healthcare professionals must be fully involved and focused on close cooperation to make the transition process smooth and successful

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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.

Ann Rheum Dis. 2022;81:1738.

TRANSITIONAL CARE IN JUVENILE IDIOPATHIC ARTHRITIS: TIMING, PREVALENCE OF SUBTYPES AND TREATMENT PROFILE IN A SPANISH TERTIARY HOSPITAL.

Pàvez Perales C, Torrat Novés A, Ivorra Cortés J, et al.

Background: Juvenile Idiopathic Arthritis (JIA) is the leading cause of chronic infammatory rheumatic disease in children. It's classifed into subtypes with different relative prevalences depending on geographical area (Oligarticular subtype predominates in Western Europe/North America. Enthesitis-related arthritis subtype predominates in Eastern Europe/Asia). To ensure continuity of care in adult rheumatology services, a systematic transition process is recommended. Various authors recommend that the process, of which pediatric and adult rheumatology teams should be part, begins around 14 years and ends around 18 years of age.

Objectives: We aim to study the age, relative prevalence and treatment profile in JIA subtypes at the beginning of the transitional care.

Methods: Descriptive and cross-sectional study of patients with JIA (according to ILAR criteria), diagnosed and treated in the pediatric rheumatology service and seen in the transitional care unit of the adult rheumatology service within the same tertiary hospital between January 2013 and December 2018. Demographic, clinical, analytical and treatment data were collected at the frst visit to the transitional care unit.

Results: 72 patients were included (46 women) mean age at diagnosis of 9.5 ± 4.6y and mean of 11.3 ± 4.36y from diagnosis to the frst visit at the transitional care unit. 27.7% were diagnosed with oligoarticular JIA, 20.8% with arthritis-en-thesitis JIA, 19.4% with Rheumatoid Factor negative (RF-) polyarticular JIA, 11.1% with systemic JIA, x9.7% with undifferentiated JIA, 5.5% with Rheumatoid Factor positive (RF+) polyarticular JIA and 5.5% of psoriatic arthritis. The mean age at the frst visit to the transitional care unit was 20.81 ± 2.96y (no differences between subtypes). Oral ulcers (20.8%), anterior uveitis (13.8%) and enthesitis (13.8%) were the most frequent extra-articular manifestations. 56.9% had antinu-clear antibodies (ANA) titers >1/160 at some point in course of disease (Table 1). 43% were treated with methotrexate, 38% with biological therapies, 11.% with glucocorticoids (GC) and 22.% had no treatment.

Conclusion: The oligoarticular form was the most prevalent subtype of JIA, similar to previously published series from Western Europe. The frst visit at the transition care unit occurred signifcantly later than recommended by various authors. The most frequent treatment was methotrexate. The use of biological therapies was high, with TNF alpha inhibitors being the most widely used, especially etanercept. The use of glucocorticoids was low. A non-negligible number of patients were treatment free

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Ann Rheum Dis. 2022;81:996.

JUVENILE IDIOPATHIC ARTHRITIS DISEASE ACTIVITY IN TRANSITIONAL CARE.

Carpio K, Burgeois Avella C, Lopez Robledillo JC, et al.

Background: Juvenile Idiopathic Arthritis (JIA) is a group of heterogeneous arthritis with onset earlier than 16 years old. According to previous studies, these patients experience an improvement of their disease activity, functionality and even remission probability as they become young adults.[1] Transitional care units aim to coordinate an uninterrupted follow-up in patients with chronic diseases in order to accomplished the objective of improving the ability of manage their own disease.[2] Our transitional care unit attend patients from 18 to 25 years old who have been previously diagnosed with any pediatric rheumatic disease Objectives: Our primary objective was to describe the disease activity of JIA patients at the transference to our unit and the remission maintenance during follow-up.

Methods: We conducted an observational retrospective longitudinal study from a cohort of patients with JIA who have been transferred to our transitional care unit. We selected patients with at least one clinical visit and active follow-up. We collected demographic data, JIA classifcation, previous treatments and the treatment at time of transfer, articular and ocular fares, remission defned by Wallace criteria3 and changes in treatment during follow-up. We calculated the percentage of patients who had active disease activity at the transference to the Unit and the proportion of patients who had an infammatory fare (ocular or articular) during the follow-up.

Results: From December 2016 to December 2021 we received 184 patients in our Transitional Care Unit, from them 127 had a JIA and 1 had asymptomatic chronic uveitis. Demographics of JIA patients is shown in Table 1. From 127 JIA patients, 34 (26,8%) were active at the transference and 53 (41,8%) had at least one fare during the follow-up. We calculated the percentage of patients who had active disease at the transference to the Unit and the percentage of patients who had an infammatory fare during the follow-up. Figures 1 and 2 showed the proportion of fares depending on the infammatory status at transference to the Transitional care unit and the use of biological therapy before transition.

Conclusion: JIA patients remain active in one quarter of the cases at the transference to the Transitional care unit and fares are twice frequent when they were active at the transference

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Arch Phys Med Rehabil. 2022;103:1013-22.

A SYSTEMATIC REVIEW OF THE EFFECTS OF COMMUNITY TRANSITION PROGRAMS ON QUALITY OF LIFE AND HOSPITAL READMISSIONS FOR ADULTS WITH TRAUMATIC SPINAL CORD INJURY.

Tschoepe R, Benfield A, Posey R, et al.

Objective: To investigate the effects of community transition programs for adults with traumatic spinal cord injury (tSCI) on hospital readmissions and quality of life (QOL). Data Sources: Seven databases (PubMed, Embase, Cumulative Index to Nursing and Allied Health Literature, Google Scholar, the Joanna Briggs Institute database, OTseeker, and PEDro) and reference lists of relevant articles were searched from inception through March 2020.

Study Selection: Original research studies were included that (1) evaluated interventions designed to support individuals aged 18-65 years with newly acquired tSCI in navigating the transition from subacute care to the community and (2) reported data for QOL or hospital readmission outcomes. Searches identified 4694 studies, and 26 of these met the selection criteria.

Data Extraction: Two reviewers independently screened and assessed all studies, extracting information about study type, methodological strengths and weaknesses, participant and intervention characteristics, comparator, and significant results. Any discrepancies were resolved by a third reviewer.

Data Synthesis: Studies were grouped according to primary intervention: peer mentoring (n=8), telehealth (n=5), education (n=5), independent living (n=3), occupational therapy (n=1), counseling (n=1), and patient navigation (n=4). Reviewers used the Let Evidence Guide Every Decision appraisal tool rubric to grade the body of evidence for each intervention type. Moderate level evidence supports the positive effects of peer mentoring, and low level evidence indicates positive effects of telehealth, education, independent living, and occupational therapy interventions. Peer mentoring, telehealth, and patient navigation were the only intervention types that included hospital readmission outcomes. Of these, peer mentoring had the most evidence, with 3 of the 4 studies that included hospital readmission outcomes demonstrating statistically significant improvements.

Conclusions: In general, there is a paucity of high-quality evidence with sufficiently similar characteristics to demonstrate and compare benefits from program participation. When high quality studies have been conducted, they have obtained mixed results. Of the different intervention types, peer mentorship has the strongest supporting evidence. Further research is needed to identify specific intervention components that are most effective in improving QOL and reducing hospital readmission for specific subgroups of individuals recovering from tSCI

Best Pract Res Clin Gastroenterol. 2022;56.

INHERITED PANCREATIC EXOCRINE INSUFFICIENCY AND PANCREATITIS: WHEN CHILDREN TRANSITION TO ADULT CARE.

Scheers I.

Hereditary pancreatitis (HP) encompasses two distinct disease groups: the first manifests as congenital exocrine pancreatic insufficiency (EPI), and the second includes hereditary forms of pancreatitis. EPI represents the ultimate expression of gland function loss. Cystic fibrosis is by far the most frequent aetiology of early-onset EPI; genetics and a growing understanding of the disease mechanisms have paved the way for innovative and personalized treatment approaches. Efforts are ongoing to further decipher the pathophysiology and explore new therapies for other causes of EPI. HP occurs in patients carrying mutations in genes encoding digestive proteases or proteins playing an important role in proper pancreatic function and homeostasis. Improved sequencing techniques have led to the discovery of several causal and disease promoting genes. Most forms of HP have a paediatric onset but complications usually manifest during adulthood. Surveillance in experienced centres is mandatory to diagnose and address these complications in a timely manner

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Best Pract Res Clin Gastroenterol. 2022;56.

WILSON'S DISEASE- MANAGEMENT AND LONG TERM OUTCOMES.

Socha P, Czlonkowska A, Janczyk W, et al.

Wilson's disease (WD) is an autosomal recessive genetic disorder of copper metabolism leading to liver or brain injury due to accumulation of copper. Diagnosis is based on: clinical features, biochemical tests including plasma ceruloplasmin concentration, 24h urinary copper excretion, copper content in the liver, and molecular analysis. Pharmacological therapy comprises chelating agents (penicillamine, trientine) and zinc salts which seem to be very effective. Still, poor compliance is a major problem. Adolescents and patients with psychiatric disorders usually have problems with adherence to treatment. As transition is a vulnerable period transition ”training” should start before the planned transfer, preferably already in early adolescence in cooperation between adult and pediatric clinics. Response to treatment is assessed based on physical examination, normal liver function tests and monitoring of copper metabolism markers. Liver transplantation has a well-defined role in Wilsonian acute hepatic failure according to the prognostic score. The long-term survival in WD patients

seems to be very similar as for the general population if disease is early diagnosed and correctly treated. WD patients with a longer delay from diagnosis to therapy and who present with neurological and psychiatric symptoms have worse quality of life

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BMJ Open Gastroenterol. 2022;9.

PERSISTENT SYMPTOMS ARE DIVERSE AND ASSOCIATED WITH HEALTH CONCERNS AND IMPAIRED QUALITY OF LIFE IN PATIENTS WITH PAEDIATRIC COELIAC DISEASE DIAGNOSIS AFTER TRANSITION TO ADULTHOOD.

Vuolle S, Laurikka P, Repo M, et al.

Objective To investigate the prevalence and associated factors of persistent symptoms despite a strict gluten-free diet in adult patients with coeliac disease diagnosed in childhood.

Design Medical data on 239 currently adult patients with paediatric diagnosis were collected from patient records. Also, patients completed structured study questionnaire. All variables were compared between those with and without persistent symptoms.

Results Altogether 180 patients reported adhering to a strict gluten-free diet. Of these, 18% experienced persistent symptoms, including various gastrointestinal symptoms (73%), arthralgia (39%), fatigue (39%), skin symptoms (12%) and depression (6%). Those reporting persistent symptoms had more often gastrointestinal comorbidities (19% vs 6%, p=0.023), health concerns (30% vs 12%, p=0.006) and experiences of restrictions on daily life (64% vs 43%, p=0.028) than the asymptomatic subjects. The patients with symptoms had poorer general health (median score 13 vs 14, p=0.040) and vitality (15 vs 18, p=0.015) based on a validated Psychological General Well-Being Questionnaire and more severe symptoms on a Gastrointestinal Symptom Rating Scale scale (total score 2.1 vs 1.7, p<0.001). Except for general health, these differences remained significant after adjusting for comorbidities. The groups were comparable in current sociodemographic characteristics. Furthermore, none of the childhood features, including clinical, serological and histological presentation at diagnosis, and adherence and response to the diet after 6-24 months predicted symptom persistence in adulthood.

Conclusion Almost one-fifth of adult patients diagnosed in childhood reported persistent symptoms despite a strict gluten-free diet. The ongoing symptoms were associated with health concerns and impaired quality of life

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Br J Haematol. 2022;197:260-70.

NEUROCOGNITIVE RISK IN SICKLE CELL DISEASE: UTILIZING NEUROPSYCHOLOGY SERVICES TO MANAGE COGNITIVE SYMPTOMS AND FUNCTIONAL LIMITATIONS.

Longoria JN, Heitzer AM, Hankins JS, et al.

Sickle cell disease (SCD) is an inherited blood disorder that is associated with developmental delays and neurocognitive deficits. This review details key findings related to neurocognitive outcomes for children and adults with emphasis on the impact of neurological correlates and disease severity. Associations between neurocognition, demographic factors and social determinants of health are also reviewed. Emerging literature has reported on the neurocognitive impact of SCD in children and adolescents in Africa and Europe, including children from immigrant communities. Neurocognitive deficits are linked to poor functional outcomes, including transition from paediatric to adult care, medication adherence and unemployment. Integrating neuropsychology into multidisciplinary care for individuals with SCD can assist with identification and management of neurocognitive concerns, intervention development, individualized care plan development and continued multidisciplinary research

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Can J Neurol Sci. 2022;49:S51-S52.

IMPROVING TRANSITIONING FROM PEDIATRIC TO ADULT CARE: A QUALITATIVE STUDY OF PATIENTS WITH HYDROCEPHALUS AND THEIR CAREGIVERS.

Fouladirad S, Cheong A, Singhal A, et al.

Background: Hydrocephalus is a common pediatric condition but many neurosurgeons cannot continue to care for patients into adulthood. Although gaps in care are thought to exist for youth transitioning to adult care, little is known about how patients/ caregivers feel about the process. This study examined the perceptions of adolescents and young adults transitioning from pediatric to adult care at a single centre.

Methods: We explored the perceptions of patients/caregivers with hydrocephalus about the transitioning process using semi-structured interviews and the qualitative research methodologies of grounded theory. 40 patient/caregivers (7 adolescents, 13 young adults, 20 parents) from BC Children's Hospital and the Hydrocephalus Clinic at Vancouver General Hospital. Interviews were transcribed verbatim and coded, with common themes identified.

Results: Four themes relating to transitioning from pediatric to adult care were identified: (1): Poor communiction; (2) Uncertainty relating to living life as an adult with hydrocephalus; (3) Anxiety and fear regarding navigating a new health care environment; (4) sadness in the loss of the relationship with the pediatric health care team.
Conclusions: We identified a general dissatisfaction with the transitioning process for hydrocephalus. Common themes and concerns identified may form the basis of an improved transitioning model for youth with hydrocephalus as they become adults

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Cardiol Young. 2022;32:S44-S45.

FACTORS PERCEIVED BY YOUNG ADULTS WITH CONGENITAL HEART DISEASE TO AFFECT CONTINUING FOLLOW-UP CARE AFTER TRANSFER.

Skogby S, Goossens E, Johansson B, et al.

Introduction: The growing population of young persons with congenital heart disease (CHD) needs appropriate follow-up care across their life-spectrum to safeguard future health. Among these patients, discontinuation of care is highly prevalent and associated with adverse outcomes, such as increased morbidity and need for urgent interventions. To develop preventive strategies for discontinuation, factors affecting continuing follow-up care from the patients' perspective should be explored. Settings characterized by a low prevalence of discontinuation of CHD care provide insights into facilitating factors for continuing care. The present study aimed to identify and explore factors perceived by young adults with CHD to affect continuing follow-up care.
Methods: This qualitative study included participants from seven Swedish university hospitals. All participants received follow-up at paediatric cardiology clinics and were transferred to adult healthcare facilities at 18 years of age. Both young persons with continued and discontinued follow-up were included. Sixteen interviews with young people aged 27y-29y were conducted a decade after their transfer to adult care. Interviews were transcribed verbatim and analysed with qualitative content analysis.
Results: Three main categories were identified describing factors perceived by participants to affect continuing follow-up: 1. Motivation for follow-up care;2.Participationin care and sense of connectedness with a healthcare provider (HCP); 3.Accessibility of care. (Figure 1). Multiple factors affected the participant's choice to continue or discontinue follow-up care. Their choice was often related to perceptions of CHD and follow- up care needs. Finding personal motivation was an important facilitator, as well as the interpersonal relationships with HCP's and a sense of belonging to the clinic. Behaviours and attitudes of HCP's were described as barriers and differences between paediatric and adult care were raised. Participants without follow-up care stressed the importance of encouragement and support in order to return to follow-up care.
Conclusions: To provide holistic care for this patient population, sufficient competencies among HCP's is required to carefully consider the specific health care needs of young people and in particular remaining transitional needs after transfer. Factors on three levels: patient-, hospital- and healthcare-system level were described by participants, indicating the need for holistic approaches to prevent discontinuation of follow-up care

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Cardiol Young. 2022;32:S18-S19.

TRANSITION CARE FOR CONGENITAL HEART DISEASE IN THE COVID- 19: ADAPTATIONS & IMPROVISATIONS IN A SUPRA REGIONAL CHD SERVICE IN THE UNITED KINGDOM.

Dua J, Ciotti G, Narayan A, et al.

Introduction: The COVID-19 pandemic resulted in prioritisation of healthcare resources to cope with the surge in infected patients, S18 Cardiology in the Young: Volume 32 Supplement 1 leading tosuspension of routine clinical services, including Transition Care Services (TCS). In these unprecendented times, our TCS decided to adapt and improvise so that we could continue with the transition process. We present our experience of the last few months of COVID-19.
Methods: The TCS is well established across the North West, North Wales & Isle of Man Congenital Heart Disease Network with the 2 weekly Transition Clinics in two major Children's Hospitals in Liverpool & Manchester. The team consists of 1 ACHD cardiologist, 3 paediatric cardiologists and 6 clinical specialist nurses. With the sudden shut down there was the expected pressure on the wait lists and with no clear end in sight, our Network Transition Service decided to go “fully“ virtual as soon aswe could set up this platform. We improvised 2 different models: 1. Initiallywe established “Fully Virtual Clinics“ on theNHS virtual platform “AttendAnywhere“,whereby the patient & family, the adult team and the paediatric team could “log-in“and conduct a virtual clinic. Each clinic had an initial 30 minutes of “TeamHuddle“ to reviewpatient data. Based on the status and recent investigations, future-plans were made. 2. Once guidelines were eased, we moved to a “Hybrid Clinic“ model, whereby the patientwould attend the children's hospital, have investigations and be seen by the paediatric team. The adult team would remotely log in, on “Attend Anywhere“.

Results: Over eighteen-week period during the pandemic, 106 patients were booked in for initially full virtual & subsequently hybrid clinics. 81 attended their appointments. 17 did not attend and 8 cancelled their appointments.
Conclusions: These models proved a big success, with good feedback from patients/families. Virtual clinics were particularly popular with youngsters. It took away the need to travel, helped maintaining social-distancing and reduced the risk of COVID- 19 in this vulnerable group. To our knowledge, there have been no studies in theUKlooking at the effect of the COVID-19 on the provision of TCS. This experience has been critical for us to provide our TCS in the future

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Cleft Palate-Craniofac J. 2022;59:101-02.
"GROWING UP AND TAKING CONTROL": YOUNG PEOPLES' NARRATIVES ON TRANSITION FROM CHILD-TO-ADULT CARE WITHIN UK CLEFT LIP AND PALATE SERVICES.
McWilliams D, Thornton M, Hotton M, et al.
Background/Purpose: Children born with cleft lip and/or palate (CL/ P) will often continue treatment into adulthood, at which point they become more involved in medical decision-making. Existing literature across CL/P and other health conditions indicates this can be a difficult transition for young people, and may result in dissatisfaction or disengagement with treatment if not well managed. The aim of this study was to qualitatively explore young people's experiences of moving from child to adult care within CL/P services in the United Kingdom (UK).
Methods/Description: Semi-structured interviews were carried out with 15 young adults born with CL/P aged 16-25. Data were analysed using inductive thematic analysis.
Results: Three overarching themes were identified. The first theme ('It's my time') explored the shift in responsibility from the caregiver to the young person, the participant's perceived level of involvement in their care, the role of the health professional, and the emotional impact of treatment. The second theme ('Creating a voice for myself') focused on young people's motivations for being involved in treatment, what empowered them to make their own decisions, and dynamics of control and power over their treatment. The third theme ('It's a bit late') explored instances of missed opportunity, where young people felt that they were not supported to make decisions or be heard, the importance of consistent care in transition, and the relationship that young people's experiences has on the trust they have in professionals. All participants reported feeling underprepared for being legally responsible for their own medical decisions upon reaching early adulthood.
Conclusions: Young adults born with CL/P in the UK may require significant support in the lead-up to and the period after they become responsible for their own medical decisions. CL/P teams should be mindful that young people may have questions and concerns throughout their transition and may need support to voice these. Future research could seek to triangulate these findings with similar data from healthcare professionals and caregivers, with a view to developing guidance and/or resources specifically aimed at supporting transition in CL/P services

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Clin Endocrinol. 2022;96:155-64.
PATIENT-PARENT PERCEPTIONS OF TRANSITION READINESS IN TURNER SYNDROME AND ASSOCIATED FACTORS.
Patel N, Klamer B, Davis S, et al.
Objective: Medical care transition to adult care presents challenges for individuals with complex medical conditions such as Turner syndrome (TS). The goals of this study were to: (1) identify factors associated with transition readiness; (2) examine associations and differences between patients' and parents' perceptions of readiness using Transition Readiness Assessment Questionnaire (TRAQ).
Methods: In a prospective cross-sectional study, girls with TS 12–25 years and one parent were recruited from 11/2019 to 12/2020. Three questionnaires were administered (demographic/clinical questionnaire, TRAQ, and TS Transition Readiness Assessment Questionnaire [TS-TRAQ]). Medical records were reviewed for karyotype and personal medical history. Descriptive statistics, Spearman's correlation, paired sample t tests, and linear regression were used to examine readiness and associated factors.
Results: Of 44 eligible patients, 35 patients and 30 parents completed the study. Patient age, education, and life skills were associated with a higher TRAQ score ($p < .001$). Greater TS knowledge was associated with higher readiness ($p < .05$). Readiness score for patient and parental perception of patient's readiness were correlated ($r = .83$; $p < .01$). Within patient-parent dyads, patients had higher readiness ($p < .01$). TRAQ and TS-TRAQ scores were correlated ($r = .69$; $p < .01$).
Conclusions: Increasing patient age, patient education, life skills, confidence, and higher social/emotional scores were associated with a higher total TRAQ. Patient and parent perceived readiness were correlated and scores within dyads were different. Patients had higher perceived readiness. Positive correlations between TRAQ and TS-TRAQ suggest this tool may be a useful resource. Given the unique neurocognitive profile and

social/emotional challenges among girls with TS, future research should include both patients and parents, and focus on validating TS-specific transition readiness tools

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Clin Nutr ESPEN. 2022;48:512.

PAEDIATRIC TRANSITIONAL CARE PROCESS WITHIN A HOMECARE PARENTERAL NUTRITION SERVICE.

Nobrega J, Marques R.

Working in partnership with the NHS as a national homecare nursing service supporting both adult and paediatric patients at home receiving parenteral nutrition, we developed a transition training programme with a major centre for young adults between the ages of 13-15yrs on long term parenteral nutrition. The programme was coordinated jointly with nursing leads from the homecare nursing service and clinical nurse specialists for children with intestinal failure. Using the knowledge and guidance of both institutions we developed a transition programme that supports both the young adult and the parent or carers through the process of training and independence. Demonstrating independence and increasing the two young adults' confidence through knowledge in self caring for their own lines and parenteral nutrition enables a positive transition process for all involved. We aimed to complete the programme before they commenced their GCSEs and allow the young adults time to socialize with their peer group in environments away from the home The first transitional programme was completed during summer 2019. During the project continuous reviews and analysis of the programme were conducted, enabling the development of different techniques for each individual young adult. Due to the success of the programme now the homecare nursing service can invite more young adults to be part of the transition programme. The programme is designed to commence during a school holiday to maximise focus time for the young adult and runs over one calendar year. Six hours of training is planned for each technique, these being disconnection from intravenous infusions, connection to intravenous infusions as well as dressing and needle free connector change. The young adult is trained using the applicable adult protocol from their base hospital. Over the course of the transition period, regular meetings are scheduled between the patient, homecare nursing service and discharging hospital. Long term, this programme will reduce the need for training within the hospital and therefore the use of hospital resources, need of admissions for carer relief and will enable the young adult to take full responsibility of their own care for parenteral nutrition. Young independent adults once trained will have the ability to socialise with their peers, move on to university or a apply for full time jobs. Parents or carers will be confident to start to transition themselves from having lived their lives around the young adult and caring for their parenteral nutrition to post transition stage being there for moral support and guidance only if needed. The transition programme has demonstrated through training in their own environment and at the pace that suits the individual and parent or carers, increased knowledge, confidence and a transition that gave all those involved the ability to live independently

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Clin Pediatr. 2022;61:669-73.

PUTTING THE GOOD IN GOODBYE: THE PEDIATRICIANS' ROLE IN FRAMING A POSITIVE TRANSITION TO ADULT CARE.

Fishman LN, Shanske S, McKenna KD.

Der Nervenarzt.. 2022;93:351-58.

FROM THE SOCIAL PEDIATRIC CENTER TO THE MEDICAL CENTER FOR ADULTS WITH DISABILITIES–TRANSITION IN ADULTS WITH COMPLEX DISABILITIES.

Bredel-Geißler A, Peters H.

The successful medical treatment of patients with complex disabilities requires care by multidisciplinary teams in social paediatric centers (German: SPZ) and medical centers for adults with disabilities (German: MZEB). These complement general outpatient medical care, which would be overwhelmed without this support. The quality of this care is crucial for the participation of patients and the prognosis of the disease. At the age of 18, this system requires a transition from the SPZ to the MZEB, which has not yet been satisfactorily regulated. The task and structural prerequisites for this are described. An inadequate or absent transition entails the risk of additional worsening of the course of the disease

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Dev Med Child Neurol. 2022.

HOW CLINICIANS CAN PROVIDE SUPPORT DURING THE TRANSITION TO ADULTHOOD FOR YOUNG PEOPLE WITH CEREBRAL PALSY: A PARENT AND HEALTHCARE WORKER'S PERSPECTIVE.

Fogel L.

Dev Med Child Neurol. 2022;64:73.

CHILDREN WITH CEREBRAL PALSY: HEALTHCARE COSTS AND TRANSITION FROM PAEDIATRIC TO ADULT HEALTHCARE.

Jarl J, Steskal D.

Objective: There is a concern that the healthcare sector fails to meet the healthcare needs of persons with cerebral palsy (CP) as they transition from the well-organized paediatric care into adult care. Due to discontinuation of services, young adults with CP might not access sufficient healthcare, resulting in worsening secondary conditions, such as pain and functional ability. We investigate how the healthcare costs for children/young adults with CP vary with age, sex, severity and subtype of CP as the child grows up and transitions from paediatric to adult care. Design: Population-based register study.

Method: We identified all persons with CP in Sweden and Norway using national patient registers, medical birth registers, and Cerebral Palsy Follow-Up Program (CPUP, Sweden only), the national follow-up surveillance programme for people with CP. We added all contacts with healthcare services in Norway and one Swedish healthcare administrative region (Sk+Ñne) during 2001-2018 to create a healthcare cost per person per year. We also linked demographic, socioeconomic and family characteristics information from other national registers. The effect of having CP at a given age on healthcare costs was analysed using Ordinary Least Square regression with individual-level clustered standard errors to correct for the panel structure of the data, controlling for various background characteristics. We stratified the analyses by type of healthcare and disability specific factors such as severity and subtype of CP.

Results: Preliminary results of this work in progress indicate that the healthcare costs for persons with CP compared to the general population are substantially higher in the first two years of life, primarily driven by inpatient care. In subsequent years, the cost difference is primarily driven by outpatient care, although the difference in costs gradually falls over the time. In the mid-twenties, there is no longer any excess healthcare cost for persons with CP. We also observe an increase in primary healthcare costs for persons with CP during adolescence.

Conclusion: We find no sharp drop in terms of healthcare costs as children age out of paediatric care into adulthood. Rather, there is a steady decline starting as early as in the first two years or life, with an increase in primary healthcare costs as individuals with CP enter adulthood. Subsequent analyses will both quantify the excess costs and investigate its distribution of disability specific factors

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Dev Med Child Neurol. 2022;64:93-94.

COMPARING THE EXPERIENCE OF KEY TRANSITIONAL CARE PRACTICES AMONG YOUNG PEOPLE WITH CEREBRAL PALSY AND SERVICE PROVIDERS IN IRELAND.

Fortune J, Walsh M, Walsh A, et al.

Objective: The transition from child to adult health services is a challenging process for young people with cerebral palsy (CP). Exposure to key practices may improve the experience and outcomes of transition. This study aimed to compare the experience of young people with CP and service providers against key practices.

Design: Cross-sectional Study

Method: Sixty-three young people with CP aged 16-22 years (mean [SD] age: 18.7y [5.1]; male n = 25; Gross Motor Function Classification System [GMFCS] level I [n = 25], II [n = 5], III [n = 8], IV [n = 8], V [n = 17]) and 107 service providers, were recruited from across Ireland via social media, disability organizations and professional networks. Service providers included disability managers, nurses, occupational therapists, physiotherapists, social workers and speech and language therapists who worked in a children's service (55%), adult service (16%) or a service that included both children and adults (28%). Participants completed an online or paper questionnaire describing if they received, or provided, a series of key practices identified as important for successful transition to adulthood including: a named worker, information on the transition process, promotion of health self-efficacy, meeting the adult team, and training in wider life skills. Descriptive statistics were used to report findings.

Results: Twenty-seven percent of young people had a named worker. Similarly, 27% of service providers ensured the young person had a named worker. Twenty percent of young people received information about the transition process and supports available. Of these, 11% received a written transition plan. However, 47% of service providers provided information on the transition process and 46% provided a written transition plan. Among young people, 33% received enough help to increase their confidence in managing their condition. Seventy-two percent of service providers supported young people to feel confident in managing their condition, with 7% of these having a written protocol for this. Fourteen percent of young people had met with a person who provides their healthcare in adulthood and 29% of service providers provided the opportunity to meet the adult team before transfer. Fourteen percent of young people received formal life skills training while 28% of service providers provided such training. Only 19% of service providers reported that a senior manager oversaw transition in their service.

Conclusion: Many young people with CP in Ireland do not receive support during transition. In particular, they report a lack of information, written transition plan and opportunity to meet with adult services. This may partly be explained by the lack of dedicated adult services for people with CP in Ireland

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Dev Med Child Neurol. 2022;64:92.

THE THREE E'S: EDUCATION, EMPLOYMENT, AND EVERYDAY LIFE IN ADULTS WITH CEREBRAL PALSY TRANSITIONING FROM PEDIATRIC HEALTH CARE.

Shrader W, Church C, Lennon N, et al.

Objectives: Transition to adult health care and society is a difficult time for many patients with cerebral palsy (CP), and the lack of support structures for this transition is well documented. Despite the common diagnosis of CP and the growing number of adults with CP, there is still a lack of understanding of how well our former patients are functioning in society. The purpose of this project was to assess patient education, employment, independence, activity levels, access to healthcare, and physical function in a cohort of adults with CP. Design: Retrospective cohort study with control group.
Method: We invited adults with CP who were former patients of our tertiary care paediatric CP centre to complete self-report outcomes (Patient-Reported Outcomes Measurement Information System Physical Function [PROMIS-PF] Satisfaction with Life Score [SWLS] and demographic information), and wear an electronic pedometer to monitor walking activity. We assessed levels of education, independent living, income levels, the use of Social Security Disability Income (SSDI), employment, access to health care, and chronic health problems. We evaluated correlations, stratified by Gross Motor Function Classification System (GMFCS) level, between walking ability and PROMIS physical function, SWLS, educational level, employment rate, and level of independent living.
Results: One hundred and nine adults with CP, age 29 (4) years, returned to participate. GMFCS levels: 20% I, 54% II, 22% III, and 4% IV. Educational levels (89% high school graduates, 37% bachelor's degree) were similar to the general population. Unemployment was higher than national levels at 46% and was associated with relatively high utilization of SSDI (51%). Thirty percent of participants lived with a caregiver. Mean daily walking activity correlated with PROMIS-PF scores ($r = 0.42$, $p < 0.000001$), employment level ($r = 0.27$, $p = 0.0046$), and independent living status ($r = -0.22$, $p = 0.02$). Employment status had a weak correlation with GMFCS level ($r = -0.32$). This cohort reported good to excellent health (91%) with outstanding access to primary care (99%). Sixty-nine percent reported some levels of chronic/musculoskeletal pain.
Conclusion: This assessment of adults with CP demonstrated similar levels of education to the general population and high levels of access to primary care, but relatively high rates of unemployment, the need for dependent caretakers, and SSDI utilization. Mean physical activity was correlated with GMFCS level, and negatively associated with employment. Chronic pain is an issue for most adults with CP. Increased focus on tools for better integration into the workforce and independent living may improve physical activity and health for adults with CP

Diagnosis. 2022;9:eA89-eA90.

TOWARDS UNDERSTANDING THE CONTRIBUTION OF COMMUNICATION FAILURES TO PROCESS-BASED MEDICAL ERROR IN ADOLESCENT TRANSITIONAL CARE.

Schepps S, Garbayo L.

Background: Adolescent transitional care for patients with chronic conditions is habitually associated with challenges to patient-centered decision-making and other system-level barriers for a successful transition. Medical error by “omission or commission in planning or execution that contributes or could contribute to an unintended result“ is studied herein in the context of adolescent transitional care of failed transitions that may lead to misdiagnosis of conditions. The project aims at identifying types of medical error associated with adolescent patients with chronic conditions going through transitions of care, clarifying how significant a role communication failures play under these conditions, and may inform how errors may be mitigated.
Methods: This work-in-progress is a patient-physician research partnership that combines literature review with a premedical student-patient self-ethnography. Literature was captured from PubMed using Boolean search terms between May 24th and May 29th of 2021.
Results: 84 articles were found, and 33 were considered relevant. Articles regarding medical error in adolescent transitional care for patients with chronic conditions provided a classification of two categories: errors in communication and errors in preparation. Both categories were found to be process-based errors. They were also found to be significant contributors to overall medical error for these patients. The unintended result of a failed transition was found often to be the product of a care team's failure to communicate or prepare a patient for transition. The self-ethnography in progress considers the patient-author experience and discusses whether both types of error may be at least partially mitigated through an improvement in patient-centeredness in care.

Conclusion: Given the relevance of patient-centeredness in healthcare, the study's preliminary analysis suggests that there is a need to extend patient-centeredness protocols to reduce process errors in adolescent transitional care due to miscommunication. Further research is needed to clarify how to better incorporate patient-centeredness in medical error studies and how its impacts on transitional care may be measured and evaluated for adolescents with chronic conditions

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Dig Dis Sci. 2022;67:3955-63.

LONG-TERM ADHERENCE TO A GLUTEN-FREE DIET AND QUALITY OF LIFE OF CELIAC PATIENTS AFTER TRANSITION TO AN ADULT REFERRAL CENTER.

Schiepatti A, Maimaris S, de Queiros Mattoso Archela dos Santos, et al.

Background: Modalities for the transition to adult care of celiac patients diagnosed during childhood/adolescence and their impact on long-term adherence to a gluten-free diet (GFD-A), quality of life (QOL) and maintenance of follow-up in adulthood are unknown. Aims: To evaluate whether timing of transition affects long-term GFD-A, QOL, and continuity of follow-up in adulthood and to identify predictors of long-term GFD-A.

Methods: Clinical and demographic data about pediatric care and adult follow-up at our center were retrospectively collected from clinical notes of celiac patients diagnosed during childhood/adolescence and then referred to our tertiary center. QOL and adult long-term GFD-A were prospectively evaluated with validated questionnaires. These parameters were studied by means of univariate and multivariate statistical analysis.

Results: 183 patients (130F, mean age at diagnosis 7.6 ± 5.8 years) were enrolled. Median age at transition to adult care was 20-áyears (IQR 17–25). There was no relationship between age at transition to adult care, long-term GFD-A, QOL, and continuity of follow-up. GFD-A tended to improve overall from pediatric care to adult referral (OR 2.92, 95% CI 1.13–7.87, $p = 0.02$) and also throughout adult follow-up (OR 9.0, 95% CI 4.2–19.7, $p < 0.01$). On multivariable logistic regression analysis, classical symptoms at diagnosis of celiac disease ($p = 0.02$) and good GFD-A at adult referral ($p < 0.01$) predicted good long-term GFD-A, while being lost to follow-up predicted poorer long-term GFD-A ($p = 0.02$).

Conclusions: Clinical characteristics can guide development of personalized strategies for implementing long-term GFD-A and ensure maintenance of regular follow-up in celiac patients diagnosed in childhood/adolescence and transitioning to adult care

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Eur Child Adolesc Psychiatry. 2022;31:805-18.

FACTORS ASSOCIATED WITH THE TRANSITION OF ADOLESCENT INPATIENTS FROM AN INTENSIVE RESIDENTIAL WARD TO ADULT MENTAL HEALTH SERVICES.

Pontoni G, Di Pietro E, Neri T, et al.

Transition of young people from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) is a complex process. Transition rates are heterogeneously reported, with wide definitions and ranges. Few data are available regarding predictive factors of a successful transition. We explored factors associated with transition in a cohort of former inpatients of a Children and Adolescents Intensive Treatment Ward (CAITW). Socio-demographic and clinical features of patients previously admitted to CAITW were matched to AMHS data for those patients having reached age requirements. We built multiple logistic regression models to identify factors associated with transfer to AMHS (either inpatient or outpatient) and with successful retention in treatment (RIT) at six (short RIT), 12 (intermediate RIT) and 24-ámonths after transfer (long RIT). From a cohort of 322 inpatients, 126 reached the age threshold for transfer to AMHS in the study period. The transfer rate was 50%. Two years after transition-age boundary, CAMHS-AMHS continuity of care was found in 40% and disengagement in 6% of cases. Longer and multiple hospitalizations, atypical antipsychotics prescription and a diagnosis of psychotic disorders were factors associated with short and intermediate RIT. A positive psychiatric family history was negatively associated with successful short and intermediate RIT. Diagnosis of psychosis and learning-supported school attendance were associated with long RIT. Young adults with a history of psychiatric inpatient admission as children or adolescents have a relatively high rate of transition to AMHS. A diagnosis of psychosis seems to be the strongest predictor for transition in these patients. Further research should focus on patients‘ schooling needs and on children of parents with mental health problems to enhance family and educational system engagement

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Eur Child Adolesc Psychiatry. 2020;29:41-49.

TRANSITION AS A TOPIC IN PSYCHIATRY TRAINING THROUGHOUT EUROPE: TRAINEES' PERSPECTIVES.

Hendrickx G, De Roeck V, Russet F, et al.

The majority of adolescents with mental health problems do not experience continuity of care when they reach the transition boundary of their child and adolescent mental health service. One of the obstacles for a smooth transition to adult mental health services concerns the lack of training for health-care professionals involved in the transition process. This study aims to seek psychiatric trainees' opinions regarding training on transition and the knowledge and skills required for managing transition. A survey was distributed to trainees residing in European countries. Trainees from 36 countries completed the questionnaire, of which 63% reported that they came into contact with youth and young adults (16ΓÇô26-áyears) during their clinical practice. Twenty-seven percent of trainees stated they have good to very good knowledge about the transition process. Theoretical training about transition was reported in only 17% of the countries, and practical training in 28% of the countries. Ninety-four percent of trainees indicated that further training about transition is necessary. The content of subsequent transition-related training can be guided by the findings of the MILESTONE project

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Eur J Hum Genet. 2022;30:571.

TRANSITION IN RARE DISEASES WORKSHOPS - DIFFERENT PERSPECTIVE OF PATIENTS, CARERS AND PROFESSIONALS MAY ADD AN IMPORTANT VALUE TO GUIDELINES OF CARE.

Sledzinska KM, Wierzba JM, Grybek T, et al.

Introduction: Rare diseases (RD) with its genetic background may affect up to 6-8% of the Europeans. As the life span of RD patients has recently increased, an issue of care during transition from pediatric to adult care has arisen. To better understand aspects of transition (so far there are no international guidelines available), Rare Disease Centre in Gdansk, Poland, organized workshops for patients and carers (P&C) and medical professionals (MP).

Materials and methods: Through the application process we chose 6 groups (6 people each): 3 MPs and 3 P&C. We asked every group 3 questions regarding challenges of transition that people with disabilities/the families of people with disabilities / specialists must face in adolescence. Then, we mixed groups (MP+P&C; 6 people each) to choose 3 most valuable MP's and P&C's answers separately. At the end, we asked participants to find solutions: imaginary ideal ones and real, possible to implement here and now.

Results: Interestingly, the answers of MPs and P&Cs were different. MPs focused on problems with education, difficulties in finding adequate medical care, random selections of specialist with not enough experience and knowledge needed, issues of family support, legal aspects of care. On the other hand, P&Cs addressed problems of infantilism, not adequate attitude towards adolescents, no independence, sexuality as taboo, lack of selfdeciding, including range of medical care needed.

Conclusions: It is important to create guidelines of transition care together with P&Cs, as their expectations towards transition may significantly differ from MPs' view

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Eur J Pediatr. 2022;181:2849-61.

ARE TRANSITION PREPARATION CONSULTATIONS FOR ADOLESCENTS WITH CHRONIC CONDITIONS VALUABLE? A MIXED-METHODS STUDY.

Mellerio H, Dumas A, Alberti C, et al.

Our objective was to assess the value of transition preparation consultations (TPC) offered by the AD'venir unit (R. Debré hospital, Paris) as a new service of transitional care, from the perspective of adolescents with chronic conditions (CCs) and their referring healthcare providers (RHCPs). TPCs included a face-to-face interview with pediatricians trained in adolescent medicine, exploring the adolescents' past (CC history), present (daily life, Treatment Burden Questionnaire, family/peer relationships, school, hobbies, sexuality, drugs), and future (global life project, transition, Good2Go questionnaire). The mixed-methods design included the following: a qualitative analysis within a multidisciplinary group (clinicians/sociologists/psychologist/public health researchers) of audio-recordings of TPCs (n = 27/girls = 56%/median age = 17.7 years) and phone interviews with adolescents 2 years post-TPC (n = 26); and a quantitative analysis of the Treatment Burden and Good2Go questionnaires and the benefits perceived by RHCPs (questionnaire 6-ámonths post-TPC). TPCs were a form of training for adult care, adolescents meeting a practitioner alone often for the first time. Naming their CC was difficult. All complained of limitations experienced in social life (diet, fatigue, laboratory/medical appointments), but not the treatment itself; most adolescents willingly talked about sexuality. Adolescents' feelings about transition were various, with poor representations of adult healthcare. Transfer was frequently unplanned. After TPCs, RHCPs modified their practices. Transition in the 2 years post-TPC was usually successful.

Conclusion What is Known: In adolescents with chronic conditions, it is advocated to personalize transition care according to the clinical and social context, pointed out as potentially impacting. Little is known about the most effective ways to prepare patients according to their needs.What is New: Based on a global approach to adolescent health, transition preparation consultations are delivered by specially trained physicians. They are a feasible and valuable way to highlight facilitators and barriers to successful transition and initiate the adolescents‘ own vision of their future

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Eur J Pediatr. 2022;181:1213-20.

FOLLOW-UP PRACTICES FOR CHILDREN AND ADOLESCENTS WITH CELIAC DISEASE: RESULTS OF AN INTERNATIONAL SURVEY.

Wessels M, Dolinsek J, Castillejo G, et al.

Adequate follow-up in celiac disease is important to improve dietary compliance and treat disease-related symptoms and possible complications. However, data on the follow-up of celiac children is scarce. We aimed to assess current pediatric celiac follow-up practices across Europe. Pediatricians and pediatric gastroenterologists from 35 countries in Europe, Israel, Turkey, and Russia completed an anonymous survey which comprised a 52-item questionnaire developed by the ESPGHAN Special Interest Group on Celiac Disease. A total of 911 physicians, the majority of whom exclusively worked in pediatric care (83%) and academic institutions (60%), completed the questionnaire. Mean age and mean experience with celiac care were 48.7 years (± 10.6) and 15.7-áyears (± 9.9), respectively. The vast majority (92%) always assessed anthropometry, dietary adherence, and tissue-transglutaminase IgA-antibodies at every visit, with the first visit being between 3 and 6-ámonths after diagnosis. Other parameters (% always tested) were as follows: complete blood count (60%), iron status (48%), liver enzymes (42%), thyroid function (38%), and vitamin D (26%). Quality of life was never assessed by 35% of the responding physicians. Transition to adult care was mostly completed via a written transition report (37%) or no formal transition at all (27%).

Conclusions: Follow-up of celiac children and adolescents in Europe may be improved, especially regarding a more rational use of (laboratory) tests, dietary and QoL assessment, and transition to adult care. Evidence-based advice from international scientific societies is needed. What is Known: Follow-up in celiac disease is important to treat disease-related symptoms, improve dietary compliance, and prevent possible complications. There is a lack of consensus about the appropriate follow-up. What is New: Almost all European physicians assess anthropometry, tissue-transglutaminase IgA-antibodies, and dietary adherence at every visit, but there are large variations in other follow-up aspects. Follow-up could be improved by a more rational use of (laboratory) tests, increased intention to dietary compliance, and quality of life together with transition programs to adult care

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Eur J Pediatr Surg. 2022.

THE TRANSITION OF CARE FOR PATIENTS WITH ANORECTAL MALFORMATIONS AND HIRSCHSPRUNG DISEASE: A EUROPEAN SURVEY.

Violani C, Grano C, Fernandes M, et al.

This study aimed at evaluating how transition of care is currently being organized in the European Reference Networks (ERNs) health care providers (HCPs) in pediatric areas and in the Anorectal Malformation Network (ARM-Net) Consortium hospitals. An online questionnaire was sent to a total of 80 surgeons, members of or affiliated members of three networks: ARM-Net Consortium, ERN eUROGEN, and ERN ERNICA. Complete information were obtained for 45 HCPs, most of which deal with transition and still see a few adult patients (ca. 10%). Gynecological, gastroenterological, urological, colorectal, and continence issues were the major problems described by adult patients to their physicians, and in line with these prevalent complaints, they are referred to the appropriate adult specialists. Forty percent of patients complain about sexual and fertility problems, but the percentage of andrologists and sexologists involved in the caring of adult patients with ARM/Hirschsprung's disease is low, just above 10.9%. Most hospitals deal with transition, but three basic criteria (i.e., presence of: [1] an official written transitional program, [2] a transitional coordinator, and [3] written information on transition to be handled to patients) are jointly met only by six HCPs. According to the responders, the most important issue requiring improvement is the lack of interest and of specific preparation by adult specialists. The overall results of this exploratory survey confirm the need for the development of comprehensive programs for transition in these rare and complex diseases, and identify the hospitals that, in collaboration with the networks, could share best practices in organizing structured transitional pathways and well follow-ups

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European Psychiatry, 2022; *64*(S1), S462-S463.

PROTRANSITION - AN ONLINE COURSE FOR PROFESSIONALS ON OPTIMIZING CARE DELIVERY FOR YOUNG PEOPLE WITH MENTAL ILLNESS IN TRANSITION FROM ADOLESCENCE TO ADULTHOOD.

König E, Stahl C, Reetz S, et al.

Objective An online course on transition psychiatry for mental health care professionals was created and evaluated to fill existing gaps in continuing education.

Material and methods Probands filled out an online-survey before starting and after finishing the online-course assessing subjective estimation of competences, transfer to practical work and satisfaction with the online course (N = 703). In addition, a dropout survey was conducted (N = 296).

Results There was an increase in competences and interdisciplinary understanding. Approximately 50 % indicated that the course has helped establishing standards of care for patients in transition. Satisfaction with the online course was very high. In the dropout survey, lack of time capacity was found to be the most important factor for dropping out of the course.

Conclusion The developed online course is a well-accepted and high-quality training possibility for a heterogeneous target group on the topic of transition psychiatry. Clinical relevance Appropriate, continuous psychiatric and psychosocial support for young people with mental illness is of great importance. The study points to the great potential of digital training offers in the field of transitionl psychiatry

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Front Endocrinol. 2022;13.

NAVIGATING DISRUPTED PUBERTY: DEVELOPMENT AND EVALUATION OF A MOBILE-HEALTH TRANSITION PASSPORT FOR KLINEFELTER SYNDROME.

Dwyer AA, Héritier V, Llahana S, et al.

Klinefelter syndrome (KS) is the most common aneuploidy in men and has long-term sequelae on health and wellbeing. KS is a chronic, lifelong condition and adolescents/young adults (AYAs) with KS face challenges in transitioning from pediatric to adult-oriented services. Discontinuity of care contributes to poor outcomes for health and wellbeing and transition programs for KS are lacking. We aimed to develop and test a mobile health tool (KS Transition Passport) to educate patients about KS, encourage self-management and support successful transition to adult-oriented care. First, we conducted a retrospective chart review and patient survey to examine KS transition at a university hospital. Second, we conducted a systematic scoping review of the literature on AYAs with KS. Last, we developed a mobile health transition passport and evaluated it with patient support groups. Participants evaluated the tool using the System Usability Scale and Patient Education Materials Assessment Tool (PEMAT). Chart review identified 21 AYAs diagnosed between 3.9-16.8 years-old (median 10.2 years). The survey revealed only 4/10 (40%) were on testosterone therapy and fewer (3/10, 30%) had regular medical care. The scoping review identified 21 relevant articles highlighting key aspects of care for AYAs with KS. An interprofessional team developed the mobile-health KS transition passport using an iterative process. Support group members (n=35) rated passport usability as 'ok ' to 'good' (70 ± 20, median 73.5/100). Of PEMAT dimensions, 5/6 were deemed 'high quality' (86-90/100) and participants knew what to do with the information (actionability = 83/100). In conclusion, many patients with KS appear to have gaps in transition to adult-oriented care. Iterative development of a KS transition passport produced a mobile health tool that was usable, understandable and had high ratings for actionability

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Front Neurol. 2022;12.

THE USE AND OUTCOMES OF MOTOR REHABILITATION SERVICES AMONG PEOPLE WITH CEREBRAL PALSY CHANGE ACROSS THE LIFESPAN.

Cornec G, Brochard S, Drewnowski G, et al.

Background and Aims: The provision of coordinated and multidisciplinary rehabilitation programs that adapt to the individual with cerebral palsy (CP) evolving rehabilitation needs throughout the different phases of life is highly challenging for healthcare systems. The aim of this study was to report the changes in motor rehabilitation (MR) environmental factors, service use and patient outcomes between children and adults with cerebral palsy and to identify if changes took place earlier or later than the standard division between pediatric and adult healthcare systems at 18 years.

Methods: We used data from the French ESPaCe survey to select a set of indicators for MR environmental factors, service use and patient outcomes, highlighted by patients and families in previous studies. We then compared the distribution of the indicator data between children and adults, as well as between four transition age groups: children under 12, adolescents up to 17 years, young adults, and adults over 25 years of age. We estimated odds ratios adjusted for motor involvement, associated impairments and informant type.

Results: A total of 997 respondents over 2 years of age were included in this study (484 children and 513 adults). Finding an available physiotherapist was very difficult for almost half of the children, and a greater proportion of adolescents and adults. Physiotherapy was provided in a private outpatient practice for twice as

many adults over 25 years as children and adolescents. The weekly amount of physical therapy decreased as outpatient practice increased. Multidisciplinary rehabilitation decreased sharply from adolescence and was halved at adulthood. Satisfaction with the MR program decreased from childhood into adolescence and adulthood. Perceived impact of physiotherapy on people with CP and their main carers were less positive in adolescents.
Conclusions: Healthcare policies should focus on accessibility issues at all ages, consider adolescents as a specific population, consider a wide transition phase (12–25 yo) and maintain a multidisciplinary approach at adulthood. There is a strong need for national rehabilitation strategies for individuals with CP

Front Oncol. 2022;12.
CANCER KNOWLEDGE AND HEALTH-CONSCIOUSNESS IN CHILDHOOD CANCER SURVIVORS FOLLOWING TRANSITION INTO ADULT CARE - RESULTS FROM THE ACCS PROJECT.
Otth M, Denzler S, Diesch-Furlanetto T, et al.
Background: Knowledge on chronic medical conditions in childhood cancer survivors (CCSs) is constantly growing and underlines that long-term follow-up (LTFU) care is often mandatory, also in adulthood. However, many CCSs discontinue follow-up care after transition to adult care. One reason might be that the current transition practices do not meet the needs of adolescent and young adult CCSs. We therefore aim to evaluate different transition models for Swiss CCSs by assessing their cancer knowledge, cancer worries, self-management skills, and expectations for LTFU care, following transition in two different hospital-based models.
Methods: Within the Aftercare of Childhood Cancer Survivors (ACCS) study, we performed a questionnaire-based survey with a cross-sectional and longitudinal part. We included 5 year CCSs aged >16 years at recruitment who were transitioned to adult care in two hospitals between 2014 and 2021. Here, we report the results of the cross-sectional part. We compared the survivors‘ cancer knowledge with medical record data and assessed cancer worries (6 questions), self-management skills (15 questions), and expectations (12 questions) by validated scales. We used descriptive statistics, chi-squared test, and t-tests to describe the results.
Results: We analyzed 57 CCSs (response rate 44%), 60% of those were female, had a median age of 9 years at diagnosis and 23 years at the questionnaire. Most CCSs recalled their diagnosis (95%) and exposure to treatment modalities (98%) correctly. CCSs worried the most about potential late effects (47%) and issues with having children in the future (44%). At least 75% of CCSs agreed to 12 of the 15 self-management questions, indicating high self-management skills. The top three expectations included that physicians know the survivors‘ cancer history, that visits start on time, and that physicians can always be called in case of questions.
Conclusion: CCSs receiving hospital-based LTFU care have good cancer knowledge and high self-management skills. The identified worries and expectations will help to improve the LTFU care of CCSs who transition to adult care, to further inform and educate survivors and healthcare professionals about and might be relevant for other countries with a similar healthcare system

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Front Pediatr. 2022;10.
EFFICACY OF A TRANSITIONAL SUPPORT PROGRAM AMONG ADOLESCENT PATIENTS WITH CHILDHOOD-ONSET CHRONIC DISEASES: A RANDOMIZED CONTROLLED TRIAL.
Morisaki-Nakamura M, Suzuki S, Kobayashi A, et al.
It is recommended that patients with childhood-onset chronic diseases (CCD) be transferred from pediatric to adult healthcare systems when they reach adulthood. Transitional support helps adolescents with CCD transition smoothly. Transition readiness is one of the key concepts to assess the efficacy of transitional support programs. This study aims to investigate the effect of a transitional support program on transition readiness, self-esteem, and independent consciousness among Japanese adolescents with various CCD using a randomized controlled trial. Adolescents with CCD aged 12–18 years participated in a randomized controlled trial evaluating the efficacy of a transitional support program. The patients in the intervention group visited transitional support outpatient clinics twice. They answered questionnaires regarding their disease and future perspectives to healthcare professionals and independently made a short summary of their disease. All the participants answered the questionnaires four times. Eighty patients participated in this study. Among those in the intervention group, transition readiness within one, three, and 6 months after interventions, and self-esteem within 1 month after interventions were higher than that of the control group. The scores on the “dependence on parents“ subscale at 6 months after interventions were lower for the intervention group as compared to the control group. This program is expected to help patients transition smoothly from pediatric to adult healthcare systems

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Front Pediatr. 2022;10.

MULTIDISCIPLINARY APPROACH FOR ADULT PATIENTS WITH CHILDHOOD-ONSET CHRONIC DISEASE FOCUSING ON PROMOTING PEDIATRIC TO ADULT HEALTHCARE TRANSITION INTERVENTIONS: AN UPDATED SYSTEMATIC REVIEW.

Wakimizu R, Sasaki K, Yoshimoto M, et al.

Introduction: Owing to improved prognosis, the number of adult patients with childhood-onset chronic disease (APCCD) has increased. In this systematic review, we evaluated a multidisciplinary approach toward APCCD, focusing on promoting pediatric to adult healthcare transition interventions and their effects.

Methods: We reviewed literature comparing the effects of pediatric to adult healthcare transition interventions in children and adolescents with childhood-onset chronic disease, using PubMed, MEDLINE, and CINAHL, from 2010 to 2021 (keywords: "transition", "children", "intervention", "healthcare", etc.). The inclusion criteria were as follows: (i) original studies, (ii) studies on pediatric to adult healthcare transition interventions in children with chronic disease, (iii) patients including "adolescents" aged 12 and older receiving intervention, and (iv) studies that included the four elements of the PICO model: Patient/ Problem, Intervention, Comparison and Outcome model.

Results: After evaluating 678 studies, 16 were selected, comprising topics such as "individual education programs"(n = 6), "group meetings" (n = 6), "active learning using information and communications technology" (n = 2), and "transition clinics" (n = 2). The effects obtained varied, depending on the contents and methods of the intervention. Additionally, there was no evidence of adverse outcomes from these interventions.

Conclusions: Pediatric to adult healthcare transition interventions provide systematic support for the transition, patient independence, and social participation; thus, they should be adopted based on their expected effects

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Front Pediatr. 2022;10.

TOWARD IMPROVING THE TRANSITION OF PATIENTS WITH CONGENITAL ADRENAL HYPERPLASIA FROM PEDIATRICS TO ADULT HEALTHCARE IN JAPAN.

Takasawa K, Kashimada K.

The transition of patients with childhood-onset chronic diseases from pediatric to adult healthcare systems has recently received significant attention. Since 2013, the Japan Pediatric Society developed working groups to formulate guidelines for transition of patients with childhood-onset chronic diseases from pediatric to their disease specialty. Herein, we report on the activities of the Japan Society of Pediatric Endocrinology (JSPE) and the current status of transition medicine for 21-hydroxylase deficiency (21-OHD) in Japan. The JSPE proposed roadmaps and checklists for transition and prepared surveys on the current status of healthcare transition for childhood-onset endocrine diseases. In Japan, newborn screening for 21-OHD started in January 1989; however, there is no nationwide registry-based longitudinal cohort study on 21-OHD from birth to adult. The current status and the whole picture of healthcare and health problems in adult patients with 21-OHD remain unclear. Thus, we conducted a questionnaire survey on JSPE members to clarify the current status of healthcare transition of 21-OHD and discuss future perspectives for the healthcare transition of patients with 21-OHD in Japan

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Front Pediatr. 2022;10.

THE PROCESS OF TRANSITION FROM PEDIATRIC TO ADULT HEALTHCARE SERVICES FOR NEPHROLOGICAL PATIENTS: RECOMMENDATIONS VS. REALITY. A SINGLE CENTER EXPERIENCE.

Scarponi D, Cangini G, Pasini A, et al.

Transitional care is an essential step for patients with kidney disease, and it is supported by policy documents in the United Kingdom and United States. We have previously described the heterogeneous situation currently found in Europe regarding certain aspects of transitional care: the written transition plan, the educational program, the timing of transfer to adult services, the presence of a coordinator and a dedicated off-site transition clinic. In line with the transition protocol "RISE to transition", the objective of this paper is to describe the experience of the Bologna center in defining a protocol for the management of chronic kidney disease and the difficulties encountered in implementing it. We apply this model to various chronic diseases along the process of transfer to adult services. It begins when the patient is 14 years old and is complete by the time they reach 18. The family is continuously involved and all the patients in transitional care receive continuous medical care and psychological support. We identified a series of tests designed to measure various criteria: medical condition, psychological state, quality of life, and degree of patient satisfaction, which are repeated at set intervals during the transition process. The organization of the service provided an adequate setting for taking charge of the patients in the long term. The transition program implemented by the adult and pediatric nephrology services of the Bologna center has lowered the risk of discontinuity of care and greatly improved the patients' awareness of responsibility for their own healthy lifestyle choices

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Headache. 2022;62:74.

NEEDS ASSESSMENT FOR TRANSITION TO ADULT HEADACHE SPECIALTY CARE FROM A TERTIARY PEDIATRIC HEADACHE CLINIC.

Patniyot I, Duggan D, LaRose M.

One sentence summary: An initial needs assessment on adolescent patients eligible for transition from the Pediatric Headache clinic to adult care providers revealed that the Headache Clinic continues to see a higher proportion of patients past the age of 18 when compared with the Pediatric Neurology division as a whole, and highlights the importance of identifying and partnering with adult headache providers beginning in mid teenage years for transfer of care.

Background: Transition of health-care from pediatric to adult-focused care can prove challenging for individuals with headache disorders. Barriers to transition of care can include adolescent patient unpreparedness in navigating their own healthcare needs, in addition to healthcare barriers to accessing appropriate care.

Methods: We sought to perform an initial needs assessment on adolescent patients eligible for transition from the Texas Children's Hospital Headache Clinic to adult care providers. The electronic medical record was searched for patients meeting the following criteria: age 18 and greater, Headache Clinic New, and Headache Clinic Established appointment types. This data was then compared to the same data for the entire pediatric neurology division. Further variables of interest included percentage of patients with Medicaid insurance, as well as proportion of teenage patients under age 18.

Results: For fiscal year 2021 there were a total of 431 patients (732 total visits) seen in Headache appointment visits, distributed amongst 3 pediatric headache specialists. Patients 18 and older comprised 7 new Headache Clinic visits (1.5% of total), and 91 follow up visits (21% of total), for a total of 98 visits. This number was increased from the previous yearly total of 83 patients 18 and older followed in Headache Clinic. The Pediatric Neurology division as a whole saw 1.2% new patients (all comers) over 18, and 11.5% established patients. Approximately 12% of all patients seen section-wide were between the ages of 16-18, while 54% of patients of all ages seen by the section were Medicaid insured.

Conclusion: Close to 100 patients per year are eligible for transition to adult headache providers based on age, a number that is increasing each year. The proportion of new headache patients seen is low and similar to section average, while the proportion of follow up patients seen after age 18 is higher and comprises 1/5th of the total headache clinic population. This analysis has identified areas of future focus in the process of establishing a headache transition clinic, such as identification of and partnership with adult headache providers for transfer of care, including those who accept Medicaid, and cultivating patient preparedness beginning in mid-teenage years for this transition process. (Table Presented)

Heart Lung Circul. 2022;31:544-48.

SURVEILLANCE OF END-ORGAN DAMAGE IN FONTAN PATIENTS PRIOR TO TRANSITION TO ADULT CARE: ARE WE THERE YET?

Wilson TG, Iyengar AJ, Zentner D, et al.

Background: Recently published guidelines and consensus statements have outlined recommended screening practices for monitoring of end-organ dysfunction in Fontan patients. We reviewed the current approach to end-organ screening in a local population of Fontan patients at the time of transition to adult care.

Methods: Patient data from the Australia and New Zealand Fontan Registry and patient medical records were used to review investigations performed in Fontan patients transitioned from The Royal Children's Hospital Melbourne to an adult centre between 1 July 2015 and 30 June 2020.

Results: A total of 32 patients were referred for transition to an adult centre between 1 July 2015 and 30 June 2020 at a mean age of 18.5±0.7 years (12.7±2.5 years post-Fontan). Liver function tests were performed in 22 patients (69%) within 5 years prior to transition and were abnormal in 15 patients (68%). Liver ultrasound was performed in 13 patients (41%) within 5 years prior to the date of transition, of whom 10 (77%) had abnormal findings (features suggestive of hepatic fibrosis in seven [54%], cirrhosis in two [15%], and portal hypertension in three [23%]). Fourteen (14) patients (44%) had no record of a liver ultrasound being performed between the date of the Fontan procedure and the time of transition to adult care. Hepatocellular carcinoma was diagnosed in one patient at 18 months following transition. A total of 24 patients (75%) had a serum creatinine measured within the 5 years prior to transition, and two (8%) had an estimated glomerular filtration rate (eGFR) less than 90 mL/min/1.73 m2. No patient had a urine protein-creatinine ratio measured between the date of the Fontan procedure and the time of transition to adult care.

Conclusions: In this study we have identified that the majority of patients transitioned from a tertiary paediatric centre to an adult centre within the last 5 years did not undergo routine surveillance for end-organ dysfunction. Routine screening for end-organ complications of the Fontan circulation should be incorporated into clinical practice and is an important part of Fontan patient care both pre- and post-transition to adult services

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Indian J Pediatr. 2022.

DESIGN OF A RHEUMATOLOGY TRANSITION CLINIC FOR A RESOURCE-CONSTRAINED SETTING.

Garcìa-Rodrìguez F, Arana-Guajardo AC, Villarreal-Treviño AV, et al.

Objectives: To describe the design process of a medical care program for adolescents with pediatric onset rheumatic diseases (PRD) during the transition from pediatric to adult care in a resource-constrained hospital.
Methods: The model of attention was developed in three steps: 1) the selection of a multidisciplinary team, 2) the evaluation of the state of readiness of patients and caregivers for the transition, and 3) the design of a strategy of attention according to local needs. The results of the first two steps were used in order to develop the strategy of attention.
Results: The transition process was structured in three stages: pretransition (at pediatric rheumatology clinic), Transition Clinic for Adolescents with Rheumatic Diseases (TCARD, the main intervention), and post-transition (at adult rheumatology clinic). Each stage was divided, in turn, into a variable number of phases (8 in total), which included activities and goals that patients and caregivers were to accomplish during the process. A multidisciplinary approach was planned by pediatric and adult rheumatologists, nutritionists, physiatrists, psychiatrist, psychologist, nurse, and social worker. During TCARD, counseling, education, nutritional, physical, and mental health interventions were considered.
Conclusions: The proposed transition model for patients with rheumatic diseases can be a useful tool in developing countries

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Int J Dent. 2022;2022.

CAREGIVERS' PERSPECTIVES ON TRANSITIONING DENTAL CARE FOR ADOLESCENTS WITH SPECIAL HEALTHCARE NEEDS-A CROSS-SECTIONAL STUDY.

Canares G, Clarke R, Caffrey E, et al.

Introduction. Few studies have investigated the concerns of caregivers of adolescents with special health-care needs (ASHCN) regarding the barriers and challenges of transitioning from a pediatric to an adult-based dental home. The purpose of this study was to assess these perceptions.
Methods. A 23-question survey was administered to guardians of ASHCN who presented to the pediatric dental clinic at the University of Maryland. Question types were either multiple choice, Likert scale responses, or open-ended. A descriptive analysis and Fisher's exact test were performed. Keywords were evaluated from the open-ended answers.
Results. Twenty-seven caregivers completed the survey over a six-month period. Sixty-six percent of caregivers were aware that dental needs change as child ages and thought that transitioning was a logical next step, 78% had concerns about transitional care, and 70% did not have the desire to transition. Fisher's exact analysis comparing awareness of transition versus the desire to transition was $p<0.10$.
Conclusion. Most caregivers were aware of the changing dental needs of ASHCN and believed transitioning was a logical step. Many caregivers lacked readiness and perceived multiple barriers to transitioning. Awareness of the need to transition from pediatric to adult-based dental homes was not correlated with the readiness to transition

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Intern Med J. 2022;52:15.

THE TRANSITION PROCESS FOR PAEDIATRIC RHEUMATOLOGY CLINIC PATIENTS AT A SINGLE TERTIARY PAEDIATRIC RHEUMATOLOGY CENTRE IN AUSTRALIA.

Huynh A, Buckle J, Cox A, et al.

Aim: This study aimed to examine the transition process of paediatric rheumatology patients from the Monash Children's Hospital (MCH) in Melbourne in order to identify areas that could be improved.
Method: Retrospective review of clinical data from the rheumatology database of paediatric rheumatology patients eligible for transition between January 2015 and September 2020.
Results: 165 patients were included. 57 patients were transitioned. 14 (33%) patients transitioned to adult rheumatology had active disease and 38 (88%) were on at least one medication. All patients transitioned to the GP had inactive disease off medication. Non-systemic Juvenile Idiopathic Arthritis (JIA) was the most common diagnosis in patients transitioned. The mean age at which transition was first discussed was 18.0 years, the first referral was made at a mean of 18.3 years. The mean age at first adult appointment was 18.5 years. 39 (91%) patients had a referral completed and 8 (19%) had a transfer letter. 13 (93%) patients transferred to the GP had a transfer letter. Transfer documents to an adult public rheumatology service rated 4.3 for quality, compared to 5.5 to the GP. Transfer of care was confirmed in 40 (93%) patients transitioned to an adult service, however correspondence was available for only 3 (7%).
Conclusion: Although the transition process at Monash Children's Hospital was adequate, it could be improved through earlier discussion of the process and improved referrals and documentation. A readiness to

transfer checklist and a young adult clinic have the potential to improve the process of transition to adult rheumatology care

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J Adolesc Health. 2022;70:S3-S4.

UNDERSTANDING THE ROLE OF INSURANCE IN THE TRANSITION TO ADULT CARE FOR ADOLESCENTS AND EMERGING ADULTS WITH SPECIAL HEALTHCARE NEEDS (AEASHCN): A QUALITATIVE STUDY.

Enzler CJ, Garland BH, Hergenroeder AC, et al.

Purpose: Adolescents and Emerging Adults with Special Healthcare Needs (AEASHCN) must develop self-management skills in preparation for transition to adult-based care. However, AEASHCN are not being adequately prepared for transition, resulting in poor health outcomes for some AEASHCN during the transfer period. These poor health outcomes are greater for AEASHCN who are underinsured (public insurance or self-pay). The purpose of this study is to qualitatively explore the role of insurance in the preparation, transfer, and engagement stages of transition for AEASHCN from three subspeciality services at a large, urban children's hospital.

Methods: This study included a convenience sample of participants from a cohort of 137 AEASHCN from the Gastroenterology, Rheumatology, and Renal clinical services who participated in a randomized control trial (RCT) designed to promote health self-management. Participants were 18-25 years of age. All genders and race/ethnic groups were included. One-to-one qualitative interviews were performed using open-ended, semi-structured questions to elicit the participant's experience with preparation for and experience with transition from pediatric- to adult-based care. Interviews were conducted until saturation was reached. Interviews were audio-taped, transcribed, and verified for accuracy. Demographic characteristics were summarized using descriptive statistics. Qualitative responses were analyzed using the Framework Method. All authors reviewed a subset of the transcripts to generate initial codes for repeated phrases and topics, which were applied to transcripts until no new codes were identified. Transcripts were read and coded independently by pairs of coders. Discrepant codes were discussed until consensus was reached. Using Atlas.ti, the codes were indexed and sorted into larger subthemes and final themes. All coded quotes were reviewed by the coders, and overarching themes were agreed upon.

Results: Twenty-eight AEASHCN participated in the study. Preliminary results indicate that underinsured AEASHCN were less satisfied with adult-based care than privately insured AEASHCN. Regardless of insurance status, AEASHCN discussed difficulties with affording adult-based care. Many AEASHCN who were underinsured described suddenly aging out of Medicaid and did not know how to obtain alternative insurance. AEASHCN did not report having discussions about insurance during the preparation to transition. When asked how the transition process could be improved, AEASHCN wanted recommendations for adult providers or assistance with transferring medical records, but did not cite needing better insurance information.

Conclusions: Regardless of insurance status, AEASHCN were surprised by the complexity and limitations of their insurance, and did not understand the role of insurance in transition challenges. Both insured and underinsured AEASHCN experienced financial barriers to receiving adult-based care. Being underinsured resulted in AEASHCN forgoing or being unable to secure adequate adult-based care. Insurance was perceived by AEASHCN as outside of their influence or locus of control; therefore, discussions about insurance prior to transfer should be facilitated by and assigned to key members of the clinic staff, such as social workers and pediatric providers. Materials to help AEASHCN better understand insurance as it applies to their specific adult-based care would benefit from a developmental lens that focuses on AEASHCN motivations and empowerment to transition to adult-based care. Sources of Support: Health Resources and Services Administration (R40MC30764)

J Adolesc Health. 2022;70:S103-S104.

THE UTILITY OF SELF-DETERMINATION THEORY IN PREDICTING FUTURE TRANSITION READINESS AMONG ADOLESCENTS AND EMERGING ADULTS WITH SPECIAL HEALTHCARE NEEDS (AEASHCN).

Enzler CJ, Hergenroeder AC, Durand CP, et al.

Purpose: Adolescents and Emerging Adults with Special Healthcare Needs (AEASHCN) must develop self-management skills (transition readiness) in preparation for transition to adult-based care. Health-promoting theories, such as Self-Determination Theory (SDT), may help identify factors that contribute to the development of transition readiness over time. The purpose of this study is to utilize a SDT framework to predict transition readiness among AEASHCN participating in a longitudinal study. We hypothesized that the SDT constructs of competence, autonomy, and autonomy support at baseline would predict AEASHCN transition readiness a year or more later.

Methods: AEASHCN from the Gastroenterology, Rheumatology, and Renal clinical services at a large, urban children's hospital were initially recruited to participate in a randomized control trial (RCT) of an intervention to promote self-management. Eligibility for the current study included completion of the 9-month follow-up

assessment (n=113). Eighty-one AEASHCN completed an additional assessment beyond the 9-month assessment an average of 17.0 months later. This additional assessment elicited transition readiness via the Readiness to Transition Questionnaire for Teens (RTQ-Teen), insurance status, school enrollment, transition status (having seen an adult provider, yes or no), and age. The SDT constructs of competence, autonomy, provider autonomy support, and parent autonomy support and demographic information (gender, race/ethnicity, randomization outcome) were extracted from the participant's 9-month RCT assessment. Bivariate analyses (t-tests and correlations) identified factors for entry into a linear regression model predicting transition readiness. Significant factors and those supported by the literature included: gender, age, race, ethnicity, insurance status, transition status, competency, autonomy, provider autonomy support, and parent autonomy support. Independent relationships between SDT constructs and transition readiness were evaluated using linear regression (simultaneous entry). Data were analyzed using SPSS, and statistical significance was tested at alpha=0.05.
Results: Participants were female (67.9%); Hispanic (38.3%); African-American (27.2%); privately insured (65.4%); and receiving care from an adult provider (72.8%). Findings of the final model suggest that increased competence (p=0.02), increased parent autonomy support (p<0.01), Hispanic ethnicity (p=0.05), and female gender (p=0.05) predict greater transition readiness (R2 = 0.329; F change=3.874; p<0.001). Factors not significantly related to the outcome included autonomy, provider autonomy support, age, race, insurance status, and transition status.
Conclusions: Findings from this longitudinal study support our hypothesis that the SDT constructs of competence and parent autonomy support predict AEASHCN transition readiness. Although hypothesized to be important predictors, autonomy and provider autonomy support did not predict transition readiness. This may be partially explained by most AEASHCN in the study having already transitioned to an adult provider; were not receiving support from their pediatric providers; were becoming more independent; and were likely to be reverting to parent support when needed. Prior to transfer, pediatric providers should target AEASHCN competency to self-manage, as well as encourage shared health self-management that ideally occurs between AEASHCN and their parents. These strategies may improve self-management among vulnerable AEASHCN as they transition from pediatric to adult-based care and could decrease the risk of poor health associated with lack of transition preparation. Sources of Support: Health Resources and Services Administration (R40MC30764)

J Adolesc Health. 2022;70:S103.
"I FEEL LIKE WE'RE APPROACHING A CLIFF": PERSPECTIVES ON HEALTH CARE TRANSITION AMONG PARENTS OF INTERNATIONALLY ADOPTED CHILDREN WITH HIV.
Fair CD, Glover F.
Purpose: The transition of youth with HIV from pediatric to adult care is associated with multiple adverse health outcomes including poor medication and appointment adherence. However, little is known about the experience of the growing population of internationally adopted children living with HIV (IACH). IACH may have adoption-related trauma and challenges that could impact their transition readiness. This qualitative project aims to understand parents' perspectives on care and preparation for transition of their IACH.
Methods: Twenty-three parents of IACH from 14 states in the United States completed hour-long audio-recorded semi-structured phone interviews focused on view of healthcare transition. The purposive sample was recruited from two pediatric infectious disease clinics and a private Facebook group. Interview transcripts were coded for emerging themes using standard qualitative methods.
Results: Most parents identified as white (n=22), female (n=22), and Christian (n=22), with a mean age of 42.7 years. On average each parent had 2 biological children and 2.8 adopted children. Of the 29 IACH (16 male, 13 female), all were virally suppressed. Sixteen IACH were adopted from countries in Africa. The mean age at adoption was 5.5 years (range 6 months-15 years). Mean age at time of parental interview was 12.7 (range 1-24 years) and two of IACH had transitioned to care in an adult infectious disease clinic. Findings indicated that health care transition is not often discussed; 20 did not have a transition plan with their provider. Many parents expressed apprehension regarding the transition to adult care. One parent noted, "I feel like we're approaching a cliff". Anxiety over the ability to communicate with their child's health provider and lack of comprehensive "one-stop shopping" were identified as concerns. Parents also felt their child may feel out of place in the adult infectious disease clinic due to their age. Indeed, one parent tried to establish care for her adolescent at an adult clinic and was told by a clinic scheduler that "it's maybe not the place you want to be with your young child". Parents emphasized the trusting relationship with pediatric providers due to the longstanding care received. One remarked "they've been through every stage of her life". Participants acknowledged that transition to another provider could be challenging for their child as adult providers may be less aware of adoption-related trauma.
Conclusions: Health care transition is an important, and inevitable, process in the lives of IACH. Parents do not feel well prepared for the transition to adult care. The transition represents not only a loss of access to

pediatric care, but also a shift in their relationship with their child. It is vital that physicians consider trauma-informed care throughout the transition process with IACH. Providers should scaffold health management-related independence of both IACH and their parents prior to transition. Coordination and communication with adult care providers is key to a successful health care transition. Future research should include longitudinal studies that follow IACH as they transition to adult care and directly account for their perspectives. Sources of Support: Elon Summer Undergraduate Research Experience, Elon Honors Fellows

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J Adolesc Young Adult Oncol. 2022;11:35-40.

A COMPARISON OF YOUNG ADULTS WITH AND WITHOUT CANCER IN CONCURRENT HOSPICE CARE: IMPLICATIONS FOR TRANSITIONING TO ADULT HEALTH CARE.

Mooney-Doyle K, Keim-Malpass J, Svynarenko R, et al.

Purpose: Concurrent hospice care provides important end-of-life care for youth under 21 years. Those nearing 21 years must decide whether to shift to adult hospice or leave hospice for life-prolonging care. This decision may be challenging for young adults with cancer, given the intensity of oncology care. Yet, little is known about their needs. We compared young adults with and without cancer in concurrent hospice care.

Methods: Retrospective comparative design used data from 2011 to 2013 U.S. Medicaid data files. Decedents were included if they were 20 years of age, enrolled in Medicaid hospice care, and used nonhospice medical services on the same day as hospice care based on their Medicaid claims activity dates.

Results: Among 226 decedents, 21% had cancer; more than half were female (60.6%), Caucasian (53.5%), non-Hispanic (77.4%), urban dwelling (58%), and had mental/behavioral disorder (53%). Young adults with cancer were more often non-Caucasian (68.7% vs. 40.4%), technology dependent (47.9% vs. 24.2%), had comorbidities (83.3% vs. 30.3%), and lived in rural (58.3% vs. 37.6%), southern (41.7% vs. 20.8%) areas versus peers without cancer. Those with cancer had significantly fewer live discharges from hospice (5.7 vs. 17.3) and sought treatment for symptoms more often from nonhospice providers (35.4% vs. 14.0%).

Conclusions: Young adults in concurrent hospice experience medical complexity, even at end-of-life. Understanding care accessed at 20 years helps providers guide young adults and families considering options in adult-focused care. Clinical and demographic differences among those with and without cancer in concurrent care highlight needs for research exploring racial and geographic equity

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J Asthma. 2022;59:956-66.

"IT IS KIND OF LIKE A RESPONSIBILITY THING": TRANSITIONAL CHALLENGES IN ASTHMA MEDICATION ADHERENCE AMONG ADOLESCENTS AND YOUNG ADULTS.

Zaeh SE, Lu MA, Blake KV, et al.

Objective: Nonadherence to asthma medications is prevalent among adolescents and young adults (AYAs) with asthma, leading to worsened control of asthma symptoms and more frequent exacerbations. AYAs have unique developmental transitional challenges that may alter medication adherence. We aimed to use a socio-ecological framework to explore the effect of transitional challenges from adolescence to young adulthood on asthma controller medication adherence and to identify possible strategies to promote medication adherence.

Methods: We conducted qualitative semi-structured interviews by phone with 7 adolescents (14 to 17 years), their respective caregivers, and 7 young adults (18 to 30 years). Participants were recruited from a respiratory clinical trial network and pulmonary clinics in 4 states at 6 different sites through convenience sampling. Interviews were audio recorded, transcribed and coded using thematic analyses.

Results: Participants identified personal challenges affecting adherence to asthma medications during the transition from adolescence to young adulthood including responsibility for asthma self-management, understanding of asthma condition and severity, embarrassment, and life demands. Health systems factors including medication cost, challenges with insurance, difficulties obtaining refills, and difficulty with access to medications at school also impacted asthma medication adherence. Participants recommended adherence strategies including improved access to inhalers, incorporating asthma medications into daily routines, and using reminders.

Conclusions: Focusing on the transitional challenges of AYAs during the time period from adolescence to young adulthood is necessary for supporting their asthma medication adherence and creating future interventions. Socio-ecological and systems factors should also be targeted for improved asthma medication adherence. Supplemental data for this article can be accessed online at https://doi.org/10.1080/02770903.2021.1897836

J Autism Dev Disord. 2022;52:2388-99.
DEVELOPMENT, FEASIBILITY, AND ACCEPTABILITY OF A NATIONALLY RELEVANT PARENT TRAINING TO IMPROVE SERVICE ACCESS DURING THE TRANSITION TO ADULTHOOD FOR YOUTH WITH ASD.
Taylor JL, Pezzimenti F, Burke MM, et al.
Many youth with autism spectrum disorder (ASD) face challenges accessing needed services as they transition to adulthood. The present study describes the development, feasibility and acceptability of a new intervention designed to teach parents of transition-aged youth with ASD about the adult service system and the most effective ways to access services and supports. As part of a randomized-controlled trial, the intervention named ASSIST was delivered to 91 participants in three states in the U.S. Results suggested that ASSIST is feasible and acceptable to participants. Though intended to be an in-person group-based program, due to COVID-19 restrictions ASSIST was primarily delivered online. Results and discussion explore the trade-offs and implications of these different treatment delivery modalities in relation to ASSIST

J Autism Dev Disord. 2022;52:4044-55.
PARENT PERSPECTIVES ON SUPPORTS AND BARRIERS FOR AUTISTIC YOUTH TRANSITIONING TO ADULTHOOD.
Hoffman JM, Kirby AV.
Knowledge is needed about specific supports and barriers for successful transitions to adulthood for autistic youth, especially from the perspective of parents, who are highly involved in transition preparation. We conducted a qualitative thematic analysis of previously conducted semi-structured interviews with 39 parents of 41 autistic adolescents to identify themes related to supports and barriers; we then used Bronfenbrenner's Ecological System's Theory to aid in interpreting the themes. We identified three main supports and four main barriers to the transition to adulthood from the parent interviews. The supports and barriers represent factors to consider at each theorized ecological level. Results point to opportunities to promote person-environment fit and support the transition to adulthood for autistic youth at multiple system levels

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J Autism Dev Disord. 2022;52:1051-65.
SERVICE USE AMONG TRANSITION-AGE YOUTH WITH AUTISM SPECTRUM DISORDER.
Ishler KJ, Biegel DE, Wang F, et al.
This study explored predictors of service use among 174 transition-age youth (age 16–30) with an Autism Spectrum Disorder using Andersen's (J Health Soc Behav 36(1):1–10, 1995) healthcare utilization model. Family caregivers were interviewed about past 6-month use of 15 services. On average, youth used 6.1 and needed 3.2 additional services. Greater service use was associated with two predisposing (caregiver college educated, caregiver not married/partnered), two enabling (youth has Medicaid waiver, youth in high school), and one need factor (lower adaptive functioning). Use of specific services was most strongly related to enabling (Medicaid waiver, in high school) and need factors (lower adaptive functioning, comorbid mental health diagnosis). Findings provide a snapshot of the "service cliff" faced by families and highlight the need for additional research

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J Autism Dev Disord. 2022;52:2575-88.
HEALTHCARE SERVICES DURING THE TRANSITIONS TO ADULTHOOD AMONG INDIVIDUALS WITH ASD AGED 15–25 YEARS OLD: STAKEHOLDERS' PERSPECTIVES.
Ghanouni P, Seaker L.
Although previous research has shown that the transition to adulthood may be challenging, there exists a lack of research regarding perspectives of stakeholders on the transition of individuals with Autism Spectrum Disorder (ASD). This study aimed to investigate stakeholders' experiences regarding healthcare services for youth with ASD during their transition. We involved 20 stakeholders, including 17 parents of youth with ASD as well as 3 services providers. The study yielded three major themes including: (a) accessibility and quality of care; (b) tensions and conflicts; and (c) navigation and integrated care. The findings can be used to direct change within the healthcare services towards better practices for youth with ASD and increasing the likelihood of positive health outcomes

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J Can Ass Gastroenterol. 2022;5:192-98.
DEFINING TRANSITION SUCCESS FOR YOUNG ADULTS WITH INFLAMMATORY BOWEL DISEASE ACCORDING TO PATIENTS, PARENTS AND HEALTH CARE PROVIDERS.
Bihari A, Hamidi N, Seow CH, et al.
Background: The transition from pediatric to adult care is associated with changes centered around the patient taking responsibility for their health. As the incidence of childhood-onset inflammatory bowel disease

(IBD) is increasing, it is important to address gaps in transition literature - specifically, the indicators signifying achievement of transition success. The study objective was to define transition success according to patients, parents, and health care providers involved in IBD transition.
Methods: This study used the method of qualitative description to conduct semi-structured interviews with patients, parents, and health care providers. During interviews, demographic information was collected, and interviews were recorded and transcribed. Data analysis was conducted independently of each group using latent content analysis. Participant recruitment continued until thematic saturation was reached within each group.
Results: Patients, parents, and health care providers all defined transition success with the theme of independence in one's care. The theme of disease management emerged within parent and provider groups, whereas the theme of relationship with/ trust in adult care team was common to patients and parents. Additional themes of care team management, general knowledge, care stability, and health outcomes emerged within specific groups.
Conclusion: This study demonstrated differences between how patients, parents, and health care providers view transition success. This finding reveals the value of using a multifaceted definition of transition success with input from all stakeholders. Further research should prioritize the identification of factors common to patients who do not reach transition success as defined by patients, their parents, and providers

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J Can Ass Gastroenterol. 2022;5:105-15.
Canadian Consensus Statements on the Transition of Adolescents and Young Adults with Inflammatory Bowel Disease from Pediatric to Adult Care: A Collaborative Initiative Between the Canadian IBD Transition Network and Crohn's and Colitis Canada.
Fu N, Bollegala N, Jacobson K, et al.
Objectives: With the increased prevalence of childhood-onset inflammatory bowel disease (IBD), there is a greater need for a planned transition process for adolescents and young adults (AYA). The Canadian IBD Transition Network and Crohn's and Colitis Canada joined in collaborative efforts to describe a set of care consensus statements to provide a framework for transitioning AYA from pediatric to adult care.
Methods: Consensus statements were drafted after focus group meetings and literature reviews. An expert panel consisting of 20 IBD physicians, nurses, surgeon, adolescent medicine physician, as well as patient and caregiver representatives met, discussed and systematically voted. The consensus was reached when greater than 75% of members voted in agreement. When greater than 75% of members rated strong support, the statement was rendered a strong recommendation, suggesting that a clinician should implement the statement for all or most of their clinical practice.
Results: The Canadian expert panel generated 15 consensus statements (9 strong and 6 weak recommendations). Areas of focus of the statements included: transition program implementation, key stakeholders, areas of potential need and gaps in the research.
Conclusions: These consensus statements provide a framework for the transition process. The quality of evidence for these statements was generally low, highlighting the need for further controlled studies to investigate and better define effective strategies for transition in pediatric to adult IBD care

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J Can Ass Gastroenterol. 2022;5.
TRANSITION PRACTICES FROM PEDIATRIC TO ADULT CARE OF CHILDREN LIVING WITH CROHN'S DISEASE IN QUEBEC.
Gong R, Kafyeke R, Bah B, et al.
Background: Nearly 25% of Crohn's disease cases are diagnosed during childhood. Among them, several adolescents may have extensive or complex disease implying specific needs during transition to adult care. Aims: The primary aim was to describe current transition practices from pediatric to adult care in patients diagnosed with Crohn's disease at CHU Sainte-Justine. The secondary aim was to determine factors that influenced the type of adult health centers (academic vs non-academic) to which patients were referred.
Methods: This single center study included patients diagnosed with Crohn's disease at CHU Sainte-Justine between 2009 and 2019. Adult centers were separated into five categories: academic centers in Montreal (CHU-Mtl) and outside of Montreal (CHU), non-academic centers in Montreal (CHG-Mtl) and outside of Montreal (CHG), and other centers. The following factors influencing the transfer to an academic center were analyzed in a multivariate logistic regression model: age at diagnosis, gender, disease location, disease activity: relapses, hospitalizations, emergency room (ER) visits, and place of residence.
Results: A total of 366 patients were included: 44% female, median (IQR) age at transfer 18.0 (17.9-18.4). Among them, 169 (48%) were transferred to CHU-Mtl, 144 (39%) to CHG, 22(6%) to CHU, 4 (1%) to CHG-Mtl, 27 (7%) to other centers. There was a significant increase in the annual number of patients referred to CHG and CHU-Mtl across the decade, compared to other centers. Patients transferred to CHU-Mtl had more

relapses per year (mean (SD) 0.8 (0.5) versus patients transferred to CHU, CHG and CHG-Mtl, p=0.0348), and 57% (N=97) of patients sent to CHU-Mtl had already visited the ER, as compared to 54%, 40% and 25% for CHU, CHG and CHG-Mtl respectively (p=0.0258). However, gender, age at diagnosis, maintenance treatment, number and duration of hospitalisations, extraintestinal manifestations, perianal inflammation or extensive disease location did not correlate with the type of adult center. Place of residence played a role in the choice of adult center: 56% (N= 95) of patients transferred to CHU-Mtl lived in Montreal (p<0.0001).
Conclusions: Clinical evolution and disease burden have an impact on the type of adult center. Efforts should be put to understand patient factors associated with the transfer to an academic vs non-academic center, for a better utilization of healthcare resources and adequate patient quality of life during transition

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J Can Ass Gastroenterol. 2022;5.
PREDICTING TRANSITION SUCCESS IN YOUNG ADULTS WITH INFLAMMATORY BOWEL DISEASE: PRELIMINARY RESULTS.
Bihari A, Goodman K, Wine E, et al.
Background: Patients diagnosed with inflammatory bowel disease (IBD) in childhood present more often with extensive disease, are more likely to be admitted to hospital and are less adherent with clinic appointments. Due to these risks, a smooth, uninterrupted transition from pediatric to adult care should be a priority. We have conducted interviews with providers, patients, and parents about their opinions on indicators of successful transition. Themes of successful transition that emerged included independence in seeking care and disease management. Characterizing successful transition based on stakeholder input makes it possible to monitor its achievement and identify its determinants.
Aims: This study aims to: 1) describe the frequency of success indicators in transitioned patients and 2) identify predictors associated with success indicators. We hypothesize that patients with more experience in pediatric care (e.g., younger age at diagnosis or on biologics) are more likely to achieve success.
Methods: We conducted a retrospective medical chart review to obtain data on patients who transitioned to adult care between January, 2014 - September, 2019 at the University of Alberta. We abstracted potential predictors, including social and disease factors, at first adult appointment which had notes on pediatric history. We chose available success indicators related to two themes: independence in seeking care (e.g., attending appointments, communicating for oneself) and disease management (e.g., lab work frequency and medication adherence). We abstracted selected success indicators within a two-year period from first appointment in adult care. We used Poisson and logistic regression to estimate incidence rate ratios (IR) and odds ratios (OR) for the association of potential predictors with success indicators.
Results: We reviewed medical charts of 99 patients. At first adult appointment, the median age at diagnosis was 14.5 years old (IQR: 13.2 - 15.9) and 57.6% of patients were on biologic agents. Within two years, 42.4% of patients required a change to a different therapy, 22.2% had at least two instances where a parent called on their behalf, and 16.2% had notes of medication nonadherence in adult care. Regression analysis (Table 1) estimated that patients who lived > 100km from clinic had a lab work incidence rate in the first year that was two-thirds that of patients who lived closer. Strong predictors of non-adherence in adult care included chart notes on pediatric medication non-adherence (OR~12) and, inversely, taking biologics (OR=0.34).
Conclusions: These results identified factors that could be used to identify patients likely to have poor outcomes following transition to adult care. These are preliminary results; we plan to analyze a total of 350 medical charts. (Table Presented)

J Child Heal Care. 2022.
PARENTS' VIEWS ON AND NEED FOR AN INTERVENTION DURING THEIR CHRONICALLY ILL CHILD'S TRANSFER TO ADULT CARE.
Thomsen EL, Hanghøj S, Esbensen BA, et al.
Parents of chronically ill adolescents play a significant role during their child's transition and transfer to adult care. Parents seek help and support, but appropriate initiatives are still lacking. Thus, there is an urgent call for knowledge regarding parents' needs and views on such support. The aim of this study was to examine, in relation to parents of chronically ill adolescents: 1) views and experiences regarding their child's transfer from paediatric to adult care, and 2) which initiatives parents preferred in relation to the transfer. The study was based on the interpretive description method, and data were collected through face-to-face or telephone interviews with parents of chronically ill adolescents aged 16–19 (n = 11). We found three overall findings: 'Feeling acknowledged vs. feeling excluded', 'Perceived differences between paediatric and adult care' and 'Feeling safe vs. entering the unknown', together with three preferred initiatives: 1) Joint consultations, 2) Educational events and 3) Online support/website. In general, we found that some parents were extremely worried about the transfer, while others were not. Our results suggest that transfer initiatives targeting parents

should focus on knowledge, expectations, relationships and goals in accordance with the social-ecological model of adolescent and young adult readiness to transition (SMART)

J Cyst Fibrosis. 2022;21:S137-S138.

USING QUALITY IMPROVEMENT TO DEVELOP TRANSITION TO ADULT CARE AT A UK CYSTIC FIBROSIS (CF) CENTRE.

Warnock L, Barnett T, Gates A, et al.

Objective: Following the creation of a quality improvement (QI) lead in the Oxford adult CF service, key areas for development were identified. Increased use of virtual care and CFTR modulators highlighted a need to adapt our transition process to meet the changing needs of young people with CF (pwCF). Our aim was to facilitate collaboration across adult and paediatric teams to identify areas for improvement.

Method: We led a process of stakeholder engagement including meeting with other CF and non-CF transition services. Multidisciplinary Team (MDT) QI meetings were held within the adult service to identify whatwas considered a successful transfer of care. We observed the first in-person transition clinic since the pandemic, and distributed electronic surveys of the clinic experience to pwCF, carers, and staff. Lastly, we held a virtual cross-service QI meeting to present findings, aiming to reach consensus on areas for change.

Results: 5/5 pwCF and 5/5 carers completed the clinic surveys. Both identified their main priorities: to meet the adult team and receive a clinical review. Comments identified anxiety discussing future life plans too young or repetitively. 3/5 pwCF and 3/5 carers preferred the carer to be present throughout the visit. 7/9 staff completed the survey. There was general agreement of clinic objectives that 6/7 felt were met. Comments were around clinic location, pre-meeting, and coordinating MDTreviewcontent. Holding a face-to-face clinic was perceived as important. Overall, the MDTs agreed on 5 areas for improvement: documentation; patient information; clinic meetings; individual profession handovers; and identifying pwCF requiring bespoke transition.

Conclusion: Protected time for QI provided a forum to bring paediatric and adult CF teams together to identify shared priorities for improvement of local transition care. A QI lead role has allowed us to drive service development during the COVID-19 pandemic and introduction of CFTR modulators

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J Cyst Fibrosis. 2022;21:S138.

Transition to adult care in children with cystic fibrosis – experience over a decade from a large tertiary centre in the northwest United Kingdom.

Maitra A, Tang Y, Myrtle A, et al.

Objectives: Cystic fibrosis (CF) care is delivered by a multidisciplinary team (MDT), and adolescence represents a challenging time, both in terms of growing patient independence and changing physiology. This is further complicated by the transition of most paediatric patients to adult services, which involves a completely new MDT team. As the transition is a lengthy and tortuous process, a coordinated effort is required for smooth processing and better patient outcomes. This study aimed at exploring the average age at transition, and the average duration of the transition process over a decade.

Methods: Royal Manchester Children's Hospital (RMCH) is involved in the tertiary CF care of 201 children in the northwest UK. RMCH has an established practice of transitioning all eligible children to adult services by their 18th birthday. This is achieved through a highly coordinated approach undertaken by all members of the CF MDT team and the creation of a common transition document. For the purpose of this study, this process was reviewed for all children transitioned to adult services between 2006 and 2018.

Results: Over the 13-year period, a total of 119 children with CF were transitioned to adult services, averaging 10/year (range 3–15/year). One record was excluded due to the missing date of MDT documentation. Overall, the average age at transitionwas 18.3 years (range 16.1–22.8 years). The average time for transition was 141 days (range 16–1,142 days).

Conclusion: Overall, RMCH performed well in a coordinated transitioning of most of its patients by the stipulated age, but it fell short with the time takenwith the actual process. The process itself needs to be reviewed for a transition undertaken in a timely manner

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J Heart Lung Transplant. 2022;41:S335.

PSYCHIATRIC COMORBIDITIES IN PEDIATRIC HT PATIENTS TRANSITIONING TO ADULT CARE.

Donald EM, Oren D, Jackson R, et al.

Purpose: The transition from pediatric to adult care occurs during a vulnerable time of emerging adulthood (between 18 and 25 years of age) for pediatric heart transplant (HT) recipients, and multiple factors can lead to poor health outcomes. Disorders of depression, anxiety and adjustment disorder are common in this population and are associated with medication non-adherence and adverse patient outcomes. The purpose of

this study is to explore the psychosocial history of pediatric HT recipients transferring to adult care in order to identify necessary areas for support when developing a formalized transition plan.
Methods: We retrospectively reviewed all patients who underwent transition from the pediatric to the adult HT program at our center between January 2011 and June 2021. We collected demographic characteristics at time of HT and adverse events including graft rejection, infection, hemodynamics and renal function before and after the transition. We also collected psychosocial history, work/educational status and reports of poor medication adherence at the time of transition.
Results: 72 patients were identified, 54.1% were male and 54.2% were white. Heart failure etiology was predominantly dilated cardiomyopathy (59.7%) and congenital heart disease (20.7%). The mean age at time of transplant was 13 years and the mean age at time of transition visit was 23 years. 76.3% were living with parents/fxandparents, 81.9% completed high school and 50% were employed at time of transition. 30% had reports of poor medication adherence during adolescence and 20.8% had a psychiatric diagnosis. 27.7% reported active substance use. Patients were followed for a median of 3.8 years following transition to adult care and overall survival was 90.3%. All seven patients that died following their transition had a history of psychiatric illness or substance use.
Conclusion: We observed relatively high rates of psychiatric illness, substance use and poor medication adherence in our population of adolescent and young adult HT recipients transferring to adult care, all of which can contribute to adverse patient outcomes. A formalized transition plan should focus on robust mental health services and substance use counseling in order to favorably influence outcomes following their transition

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J Heart Lung Transplant. 2022;41:S210-S211.
LONG-TERM OUTCOMES FOR PEDIATRIC HT PATIENTS TRANSITIONING TO ADULT CARE.
Donald E, Oren D, Jackson R, et al.
Purpose: Long-term survival rates for pediatric heart transplant (HT) recipients continue to improve, increasing the number that will transition care to adult specialists. There are limited data evaluating a transition plan specific to pediatric HT recipients. The purpose of this study is to describe the transition of pediatric HT patients to the adult HT program at a single large transplant center.
Methods: We retrospectively reviewed all patients who underwent transition from pediatric to adult HT program at our center between Jan 2011 and June 2021. We collected demographic characteristics at time of HT and adverse events including graft rejection, infection, hemodynamics and renal function before and after the transition. We also collected psychosocial and psychiatric history, work/educational status and reports of poor medical adherence.
Results: 72 patients were identified,54.1% were male. Mean age at time of transition was 23 (Table1) after a median of 11.6 years in the pediatric program. Patients were followed for a median of 3.8 years post-transition. Overall patient survival following transition was 90.3%. New graft dysfunction was demonstrated in 17 patients with a mean EF decrease of 19.8 % and 10 patients (13.8%) required re-transplant during the study follow up. Incidence of cellular rejection (2R,3R rejection) was 27.7% before transition, while none of the patients experience cellular rejection after transition. AMR rates were 13.6% and 12.3 % before and after transition. Incidence of depression or other psychological conditions was 20.8%.
Conclusion: Excellent patient outcome can be achieved although with higher rates of re-transplantation due to graft dysfunction following transition from pediatric to adult care. Because the transition period occurs during a vulnerable time of emerging adulthood, the development of a formalized transition plan has the potential to favorably influence outcomes through additional clinical and psychosocial support

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J Invest Dermatol. 2022;142:S62.
TRANSITION OF CARE IN PATIENTS WITH EPIDERMOLYSIS BULLOSA: A SURVEY STUDY.
Dykman M, Han J, Lunos S, et al.
Epidermolysis bullosa (EB) is a rare hereditary blistering condition with a wide spectrum of disease severity. Children with severe forms of EB have multi-disciplinary medical needs including wound treatments, infection management, nutritional maximization, and psychosocial support. These needs are initially addressed early on in the pediatric setting, but patients eventually age out of the pediatric sphere, transitioning to adult specialists. Furthermore, transition of care is fraught with emotional stress and logistical difficulties for patients and their families. There is little published data on transition of care in EB. We aimed to identify at what rate EB patients successfully transition to adult care and outline the barriers they face along the way. We conducted a survey study recruiting EB patients from the Dystrophic EB Research Association (Debra) website and centers caring for high numbers of EB patients in the United States and internationally from Sept 17, 2019 to Nov 3, 2021. Among adult patients (ΓëÑ18 years) nine percent of adults identified a pediatrician as their primary care provider. The majority of participants have not discussed transition of care with their healthcare providers nor the healthcare needs required as an adult. Ongoing pediatric subspecialty care was reported by

12% of adults, most commonly in pediatric dermatology and pediatric cardiology. Identified barriers to transition included the perceived lack of adult providers' knowledge about EB patient healthcare needs including challenges with physical activity, work, foot health, hot climate, oral health, and cost of care. Our study suggests the need for transition guidelines, early discussions with families about transition, and practical information for the adult providers accepting care

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J Med Genet. 2022;59:39-45.

PHENOTYPES IN ADULT PATIENTS WITH RETT SYNDROME: RESULTS OF A 13-YEAR EXPERIENCE AND INSIGHTS INTO HEALTHCARE TRANSITION.

Peron A, Canevini MP, Ghelma F, et al.

Background Rett syndrome is a complex genetic disorder with age-specific manifestations and over half of the patients surviving into middle age. However, little information about the phenotype of adult individuals with Rett syndrome is available, and mainly relies on questionnaires completed by caregivers. Here, we assess the clinical manifestations and management of adult patients with Rett syndrome and present our experience in transitioning from the paediatric to the adult clinic.

Methods We analysed the medical records and molecular data of women aged ΓëÑ18 years with a diagnosis of classic Rett syndrome and/or pathogenic variants in MECP2, CDKL5 and FOXG1, who were in charge of our clinic.

Results Of the 50 women with classic Rett syndrome, 94% had epilepsy (26% drug-resistant), 20% showed extrapyramidal signs, 40% sleep problems and 36% behavioural disorders. Eighty-six % patients exhibited gastrointestinal problems; 70% had scoliosis and 90% low bone density. Breathing irregularities were diagnosed in 60%. None of the patients had cardiac issues. CDKL5 patients experienced fewer breathing abnormalities than women with classic Rett syndrome.

Conclusion The delineation of an adult phenotype in Rett syndrome demonstrates the importance of a transitional programme and the need of a dedicated multidisciplinary team to optimise the clinical management of these patients

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J Neuromusc Dis. 2022;9:S29.

TRANSITION TO ADULT NEUROMUSCULAR CARE: THE PNEUMOLOGIST'S PERSPECTIVE.

Onofri A, Cutrera R.

Improvements in management of respiratory disorders coupled with improvements in standards of medical care are increasingly allowing young people with chronic respiratory diseases to survive into adulthood. The process of transition from the pediatric to the adult healthcare system is challenging and requires special attention. Particularly, patients on long-term ventilation tend to be patients with complex needs. Recent researches explored the transition experience of patients who had undergone the home mechanical ventilation (HMV) transition program of a tertiary children's hospital. Identified factors that aided transition included early transition discussion, joint pediatric - adult HMV clinic visits, written information about adult services, and communication training for the adolescents to improve their capacity to give accurate medical histories and discussions of their needs with the clinical team. The barriers identified included lack of referral to other medical specialists, difficulty co-ordinating appointments across multiple adult specialists and health care settings, inadequate information on adult community funding structures and limited involvement of family doctors. Similar to the situation in CF a few decades ago, only a limited number of adult physicians have experience in looking after these patients. Moreover, the multidisciplinary team set up which patients and their families are used to in paediatric care may only exist in a few tertiary centres. Some paediatric teams are therefore having to continue to look after these patients well into adulthood. As mentioned above, to being under the care of the pediatric pulmonologist who manages the respiratory and LTV aspects of his/her care, patients are often also under the care of several other specialties. For example, a neuromuscular patient will also typically be under the care of the neuromuscular pediatrician, spinal surgeons for scoliosis and orthopaedic surgeons if they have dislocated hips etc. The transfer to the respective adult clinicians ideally should be done sequentially rather than all at the same time and thus requires careful advance planning. In conclusion, transition is a process, not a single event of transference of care. The insights gained from examination of other chronic diseases highlight the absolute requirements, where possible, for better education and communication. For although all patients, whether manifesting complex needs or not, require some degree of individualized planning, this can only happen if there is a systemic recognition of the need for greater collaborative care partnerships between pediatric and adult clinicians

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J Neursurg Pediatr. 2022;29:371-78.

ESTIMATING THE PREVALENCE OF NEUROSURGICAL INTERVENTIONS IN ADULTS WITH SPINA BIFIDA USING THE HEALTH FACTS DATA SET: IMPLICATIONS FOR TRANSITION PLANNING AND THE DEVELOPMENT OF ADULT CLINICS.

Domino JS, Lundy P, Glynn EF, et al.

Objective: As the care of patients with spina bifida continues to evolve, life expectancy is increasing, leading to a critical need for transition planning from pediatric-based to adult-based care. The burden of neurosurgical care for adults with spina bifida remains unknown. In this study, the authors sought to use a large national data set to estimate the prevalence of neurosurgical interventions in adults with spina bifida.

Methods: This study utilized Health Facts, which is a de-identified proprietary data set abstracted from all Cerner electronic health records. It includes 69 million unique patients with > 500 million encounters in 580 centers. Validation, technical exclusions, and data filters were applied to obtain an appropriate cohort of patients. The ICD-9 and ICD-10 codes for all types of spinal dysraphism, as well as the Current Procedural Terminology (CPT) codes for hydrocephalus procedures, spinal cord untethering, and Chiari decompression, were queried and records were retrieved. Demographic variables along with differences in age groups and temporal trends were analyzed.

Results: Overall, 24,764 unique patients with ΓëÑ 1 encounter with a spinal dysraphism diagnosis between 2000 and 2017 were identified. The pediatric cohort included 11,123 patients with 60,027 separate encounters, and the adult cohort included 13,641 patients with 41,618 separate encounters. The proportion of females was higher in the adult (62.9%) than in the pediatric (51.4%) cohort. Annual encounters were stable from 2 to 18 years of age, but then decreased by approximately half with a precipitous drop after age 21 years. The sex distribution of adults and children who underwent procedures was similar (54.6% female adults vs 52.4% female children). Surgical interventions in adults were common. Between 2013 and 2017, there were 4913 procedures for hydrocephalus, with 2435 (49.6%) adult patients. Similarly, 273 (33.3%) of the 819 tethered cord procedures were performed in adults, as were 307 (32.9%) of 933 Chiari decompressions.

Conclusions: The Health Facts database offered another option for studying care delivery and utilization in patients aging with spina bifida. The median age of this population has now reached early adulthood, and a significant number of neurosurgical procedures were performed in adults. An abrupt drop in the rate of encounters occurred at 21 years of age, possibly reflecting transition issues such as access-to-care problems and lack of coordinated care

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J Neursurg Pediatr. 2022;30:1-7.

A QUALITATIVE STUDY OF TRANSITIONING PATIENTS WITH HYDROCEPHALUS FROM PEDIATRIC TO ADULT CARE: FEAR OF UNCERTAINTY, COMMUNICATION GAPS, INDEPENDENCE, AND LOSS OF RELATIONSHIPS.

Fouladirad S, Cheong A, Singhal A, et al.

OBJECTIVE Hydrocephalus is one of the most common condition treated by pediatric neurosurgeons. Many neurosurgeons are unable to continue to care for patients after they become adults. Although significant gaps in care are believed to exist for youth transitioning from pediatric to adult care, very little is known about how patients and their caregivers feel about the process. This qualitative study sought to examine the perceptions of adolescents, young adults, and their caregivers regarding transitioning from pediatric to adult care at a single Canadian center.

METHODS The authors explored the perceptions of patients with treated hydrocephalus and their caregivers using semistructured interviews and qualitative research methodologies. A convenience sample was recruited, composed of adolescent patients and their caregivers at the neurosurgery clinic of BC Children's Hospital, and patients and caregivers recently transitioned to adult care from the clinic. Interviews were transcribed verbatim and coded, with common themes identified.

RESULTS Four overarching themes relating to the process of transitioning from pediatric to adult hydrocephalus care for patients and their caregivers were identified from the data: 1) achieving independence, 2) communication gaps, 3) loss of significant relationships and environment, and 4) fear of uncertainty.

CONCLUSIONS Overall, patients with hydrocephalus and their families are dissatisfied with the process of transitioning. This study identified common themes and concerns among this cohort that may form the basis of an improved transition model for youth with hydrocephalus as they become adults

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J Parenter Enter Nutr. 2022;46:S187-S188.

TRANSITIONING IN AND TRANSITIONING OUT: PARENT AND ADULT PATIENT EXPERIENCES WITH HEALTHCARE FOR INTESTINAL FAILURE.

Neumann M, Kakani S, Allen J, et al.

Background: Survival for patients with intestinal failure (IF) has improved significantly, resulting in a growing number of patients with childhoodonset IF entering adulthood. Because of this trend, there is now great interest in the development of a model for successfully transitioning IF patients from pediatric to adult care. Patients

and families contribute invaluable insights and perspectives that can inform the development of a healthcare transition model for this population.
Methods: A mixed-methods disease-specific pilot survey was designed collaboratively by SBS/IF community members and clinicians to investigate quality of life concerns for this population. The survey was shared with a convenience sample of adult patients with pediatric-onset SBS/IF and parents of children with SBS/IF. Descriptive analyses of select open- and closed- ended questions were conducted to investigate adult patient and parent utilization of medical care, satisfaction with the medical care received, and perspectives on desired qualities of care.
Results: Twenty-five parents of children with IF and 13 adult patients with IF since childhood completed the survey. Eleven of the 25 parent respondents (44%) reported having transferred their child's medical care to a different institution, almost exclusively to access what they perceived as better or more specialized care (n=10). Parents who had transferred their child's care reported high satisfaction with the care their child was receiving much more frequently than those who did not (91% compared to 14% respectively). In contrast, eight adult patients (62%) reported having previously transferred their medical care to a different provider/institution, generally due to aging out of pediatric care (n=7). One adult patient remained in the pediatric system at the time of this survey, one was uninsured and no longer receiving any care, and three reported not receiving specialized GI care over long periods of time. Of the adult patients having transferred care, only half were highly satisfied with the care they were currently receiving. Reflecting on desired characteristics of their medical team, adult patients tended to value provider recognition of their expertise as patients (n=7) and the utilization of a knowledgeable but nuanced approach to care (recognizing the uniqueness of each IF case) that helps them live their desired lifestyle (n=7). Parent respondents most frequently highlighted a family-centered team approach that recognized parent expertise (n=16), the provision of whole-person, multidisciplinary care (n=9), and ease of access and responsiveness on the part of the provider or team (n=8).
Conclusion: While many families transition into specialized care to ensure optimized treatment for their child, young adult patients often transition out of this specialized, multidisciplinary care. These patients may experience barriers to accessing the care they desire, including finding knowledgeable providers experienced with adult IF patients and establishing a provider-patient relationship built on mutual trust. Better understanding the needs of adult patients with IF since childhood may help to inform the development of a transition model for this population

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J Pediatr Gastroenterol Nutr. 2022;74:609.
CLINICAL OUTCOMES TWO YEARS AFTER TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE IN INFLAMMATORY BOWEL DISEASE.
Gil Fernàndez P, Velasco Rodrìguez-Belvìs M, Palomino Pérez LM, et al.
Objectives and Study: Approximately 15-20% of Inflammatory Bowel Disease (IBD) cases are diagnosed during childhood and will eventually require to be transferred to an adult unit. It is recommended to carry out a prior transition process. However, there is no consensus on the ideal transition model and the number of optimal joint consultations. The objective of this study is to describe the clinical evolution of the patients after having undergone the process of transition to an adult unit from a pediatric tertiary hospital and analysing possible differences between the patients who had 1 or no transition consultations and those who performed more than 1.
Methods: Descriptive and retrospective bicenter study of patients diagnosed with IBD in pediatric age who followed the transition program prior to transition to the adult unit of a tertiary hospital between January 2017 and December 2020. The transition was carried out through consultations together with the patient and his family, as well as the physicians responsible for the corresponding pediatric and adult units. Demographic, clinical, and laboratory data were collected from these patients.
Results: A total of 30 patients were included, 18 (60%) were men. The mean age at diagnosis was 13 years. Of these, 15 were diagnosed with Ulcerative Colitis (UC), 14 with Crohn's Disease (CD) and 1 with unclassified IBD (uIBD). Only one patient (3.3%) underwent a change in diagnosis in the adult unit, from UC to CD. The mean number of transition consultations carried out was 2.4 ± 1.1 and the mean age at transfer was 17.5 ± 0.5 years. Up to 80% (20 patients) rated the transition as "useful". The clinical data before and for the two years after the transition are shown in Table 1. No significant differences were found between the patients who performed = 1 versus > 1 transition consultations in any of the variables compared.
Conclusions: An adequate transition process has benefits in controlling the disease. In our sample, the number of transition visits performed was not significantly related to better disease control. However, multicenter studies are necessary, with a greater number of patients, to allow us to analyse the global situation of the transition process from the different pediatric units, compare long-term results and draw conclusions about the efficacy of the different transition models

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J Pediatr Gastroenterol Nutr. 2022;74:193.

PERSISTENT SYMPTOMS ARE COMMON AND ASSOCIATE WITH HEALTH CONCERNS AND REDUCED QUALITY OF LIFE IN PAEDIATRIC COELIAC DISEASE PATIENTS AFTER TRANSITION TO ADULTHOOD.

Vuolle S, Laurikka P, Repo M, et al .

Objectives and Study: Persistent symptoms despite a strict gluten-free diet (GFD) have been frequently reported in adult coeliac disease patients. It remains unclear what are the prevalence and associated factors of such symptoms after long-term follow-up in patients diagnosed already in childhood.

Methods: Comprehensive medical data of 239 currently adult coeliac disease patients with a childhood diagnosis was collected. In addition, they responded to a study questionnaire and validated Gastrointestinal Symptom Rating Scale (GSRS) and Psychological General Well-Being (PGWB) questionnaires. All variables were compared between patients with and without persistent symptoms on a strict GFD in adulthood.

Results: Altogether 180 patients reported strict GFD. Of them, 18% experienced persistent coeliac disease-related symptoms, including gastrointestinal symptoms (73%), arthralgia (39%), fatigue (39%), skin symptoms (12%) and depression (6%). Those reporting symptoms had more often gastrointestinal comorbidities (19% vs. 6%, p=0.023), health concerns (30% vs 12%, p=0.006) and experiences of daily life restrictions due to GFD (64% vs 43%, p=0.028) than currently asymptomatic patients. The symptomatic patients also had lower PGWB general health (median 13 vs 14, p=0.040) and vitality (15 vs 18, p=0.015) scores and more severe gastrointestinal symptoms (GSRS total score 2.1 vs 1.7, p<0.001). Except general health, these differences remained significant after adjusting with gastrointestinal comorbidities. The groups did not differ in sex, current age, time from the diagnosis, work status, other than gastrointestinal comorbidities, BMI, smoking, regularity of physical exercise, use of oats, presence of children, family history for coeliac disease, self-experienced general health or regularity of follow-up in adulthood. Furthermore, the groups were comparable in all studied diagnostic features, including age, clinical presentation, severity of duodenal injury and tissue transglutaminase antibody values, and adherence and response to GFD after 6-24 months.

Conclusions: Almost one-fifth of adult coeliac disease patients diagnosed in childhood reported persistent symptoms despite a strict GFD. This inadequate clinical response was associated with health concerns, daily life restrictions and reduced quality of life. Later symptoms could not be predicted in childhood, emphasizing the importance of successful transition to adult care and personalized adulthood follow-up

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J Pediatr Genet. 2022;11:126-31.

X-LINKED HYPOPHOSPHATEMIC RICKETS: AWARENESS, KNOWLEDGE, AND PRACTICE OF PEDIATRIC ENDOCRINOLOGISTS IN ARAB COUNTRIES.

Deeb A, Juraibah FA, Dubayee MA, et al.

X-linked hypophosphatemic rickets (XLHR) is a genetic disease caused by inactivating pathogenic variants in PHEX, which results in reduced mineralization of bone, teeth, and renal phosphate wasting. XLHR is traditionally treated by phosphate and vitamin D analogs. Recently, burosumab, a recombinant anti-fibroblast growth factor-23 (FGF-23) monoclonal antibody was approved as specific XLHR therapy. We aimed to assess the awareness, knowledge, and management of XLHR among members of the Arab Society for Pediatric Endocrinology and Diabetes (ASPED). Of the 97 physicians who answered the online questionnaire, 97% were aware of XLHR, and while 90% screen family members of the index case, only 29% manage children with XLHR. In children with rickets, 40% of participants measure serum/urine phosphate routinely, and 31% request serum FGF-23 in suspected XLHR cases. Almost all responders use conventional XLHR therapy, and 4% used Burosomab. Only 14% were satisfied with the conventional treatment, and 69% reported therapeutic complications in up to 25% of their patients. Multidisciplinary care for XLHR is practiced by 94%, but 82% of providers did not have transition clinics. Pediatric endocrinologists in ASPED countries are aware of XLHR but have variable practice and are unsatisfied with its conventional treatment. Raising awareness of the recognition and modern management of XLHR is needed

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J Pediatr Hematol Oncol. 2022;44:E826-E832.

AGE OF TRANSITION READINESS OF ADOLESCENTS AND YOUNG ADULTS WITH CHRONIC DISEASES IN OMAN: NEED AN URGENT REVISIT.

Abdwani R, Al Saadoon M, Jaju S, et al.

Background: The Ministry of Health in Oman and some of Gulf regions set the cut-off age of "transfer" from child health care to adult health care at 13 years of age. Within the existing health system in this part of the world, there is paucity of evidence on the appropriate age for health care "transfer" of adolescents and young adults to adult health care. Similarly, there is lack of a structured health care "transition" program. The objective of the study is to indirectly determine the appropriateness of present cut-off age of transfer by studying readiness for transition among Omani patients suffering from chronic hematological conditions.

Methods: One hundred fifty adolescents and young adults with chronic hematological conditions were recruited from pediatric and adults clinics at Sultan Qaboos University Hospital. Participants were interviewed by a trained research assistant using the Arabic version of UNC TRxANSITION Scale to assess self-management skills and health related knowledge for transition. The score range is 0 to 10; the transition readiness of the patients is assessed as low (0 to 4), moderate (4 to 6), and high (6 to 10) respectively. The continuous variables were analyzed by parametric or nonparametric methods as appropriate. 2analysis was done to determine association of age groups within each sexes.
Results: The study recruited 150 subjects (52.7% males) with 50 patients in each of the 3 age groups of 10 to 13 years (lower), 14 to 17 years (middle), and 18 to 21 years (higher). The mean UNC TRxANSITION Scale scores of 5.14 (SD=1.27) in males in the total sample were significantly lower as compared with that of 5.67 (SD=1.50) in females (P=0.022). There is a steady increase in the overall median score with increase in age group, with median score of 4.42 in the lower, 5.26 in the middle and 6.81 in the higher age group (P<0.001). In section wise analysis, except for Adherence and Nutrition sections of the scale, all sections have statistically significant difference in the median scores across various age categories with lowest scores in the 10 to 13 age group and highest scores in the 18 to 21 years group. In the section related to reproduction, females had significantly higher mean ranks (31.52) and compared with 17.19 in males (P=0.001). The overall median transition score when analyzed separately for males and females across age groups showed that in the higher age group, 67% of males (P=0.008) and 90% females (P<0.001) have high transition scores compared with the other 2 groups.
Conclusions: Higher age was a significant predictor for transition readiness with median score being "moderate" in the lower and middle age groups, while the higher age groups scoring "high" on transition readiness. However, in the higher age group, the females (90%) showed better transition readiness than males (67%). The current age of transfer of 13 years is just at "moderate" levels. We recommend the need for establishing transition preparation program in Oman; increasing health transfer age in Oman to a cut-off age of 18 years and taking sex differences into consideration when providing interventions

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J Pers Med. 2022;12.
TRANSITION IN SICKLE CELL DISEASE (SCD): A GERMAN CONSENSUS RECOMMENDATION.
Alashkar F, Aramayo-Singelmann C, Böll J, et al.
Sickle cell disease (SCD) is considered a rare disease in Germany. Due to the increasing prevalence, the acute and chronic morbidities associated with the disease and the sharp increase in the mortality rate of young adults, a need-based transition structure for patients with SCD in Germany is explicitly required. This is the first multicenter German consensus statement addressing the importance of implementing a standardized transition guideline that allows adolescents and young adults to safely transition from pediatric to adult care. Early identification of medical needs and intervention remains important in the context of chronic diseases. Effective measures can improve health care in general, as they lead to a reduction in disease and the consequential economic burden. It is noteworthy that improving structural barriers remains a key challenge even in highly developed countries such as Germany. Inclusion of these transition services for patients with SCD into the regular care of chronically ill adolescents and young adults should be ensured, as well as the coverage of costs associated with a structured transition process

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J Transit Med. 2022;4.
PROTOCOL FOR READY2EXIT: A PATIENT-ORIENTED, MIXED METHODS STUDY EXAMINING TRANSITION READINESS IN ADOLESCENTS WITH CO-OCCURRING PHYSICAL AND MENTAL HEALTH CONDITIONS.
Allemang B, Samuel S, Sitter KC, et al.
Background: Up to 57% of adolescents and young adults (AYA) with chronic physical health conditions experience mental health conditions, the presence of which contributes to increased morbidity and poor quality of life. AYA with co-occurring physical and mental health conditions, therefore, may experience additional challenges as they transition from pediatric to adult services. While transition readiness - the acquisition of self-management and advocacy skills - contributes to successful transitions to adult care, this concept has not been adequately explored for AYA with co-occurring physical and mental health conditions. Research is needed to identify whether the presence of a mental health comorbidity is associated with transition readiness, and what the experiences of AYA with co-occurring conditions are as they exit pediatric services. This paper outlines the protocol for the Readiness and Experiences of ADolescents and Young Adults with Co-occurring Physical and Mental Health Conditions Exiting Pediatric Services (READY2Exit) study; the first study to address this gap using a patient-oriented, mixed methods design.
Methods: A sequential explanatory mixed methods design will be used to understand the transition readiness of 16-21 year olds with physical and mental health conditions using quantitative and qualitative data. First, Transition Readiness Assessment Questionnaire (TRAQ) scores will be compared among AYA with chronic

health conditions, with and without mental health comorbidity. Interviews will then be conducted with approximately 15 AYA with co-occurring health and mental health conditions and analyzed using qualitative description. The READY2Exit study will be conducted in collaboration with five Young Adult Research Partners (YARP) aged 18-30 with lived experience in the health/mental health systems across Canada. The YARP will partner in key tasks such as interview guide co-design, data interpretation, and knowledge translation tool development.
Discussion: AYA with co-occurring physical and mental health conditions may have unique needs as they prepare for health care transitions. The results of this study will inform the refinement of transition readiness practices to improve care for this group. The active involvement of the YARP across study phases will bring the critical perspectives of young adults to READY2Exit, ensuring the methods, research approaches and outputs align with their needs

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Mol Genet Metab. 2022;137:114-26.
MANAGEMENT OF EARLY TREATED ADOLESCENTS AND YOUNG ADULTS WITH PHENYLKETONURIA: DEVELOPMENT OF INTERNATIONAL CONSENSUS RECOMMENDATIONS USING A MODIFIED DELPHI APPROACH.
Burton BK, Hermida À, Bélanger-Quintana A, et al.
Background: Early treated patients with phenylketonuria (PKU) often become lost to follow-up from adolescence onwards due to the historical focus of PKU care on the pediatric population and lack of programs facilitating the transition to adulthood. As a result, evidence on the management of adolescents and young adults with PKU is limited.
Methods: Two meetings were held with a multidisciplinary international panel of 25 experts in PKU and comorbidities frequently experienced by patients with PKU. Based on the outcomes of the first meeting, a set of statements were developed. During the second meeting, these statements were voted on for consensus generation (≥70% agreement), using a modified Delphi approach.
Results: A total of 37 consensus recommendations were developed across five areas that were deemed important in the management of adolescents and young adults with PKU: (1) general physical health, (2) mental health and neurocognitive functioning, (3) blood Phe target range, (4) PKU-specific challenges, and (5) transition to adult care. The consensus recommendations reflect the personal opinions and experiences from the participating experts supported with evidence when available. Overall, clinicians managing adolescents and young adults with PKU should be aware of the wide variety of PKU-associated comorbidities, initiating screening at an early age. In addition, management of adolescents/young adults should be a joint effort between the patient, clinical center, and parents/caregivers supporting adolescents with gradually gaining independent control of their disease during the transition to adulthood.
Conclusions: A multidisciplinary international group of experts used a modified Delphi approach to develop a set of consensus recommendations with the aim of providing guidance and offering tools to clinics to aid with supporting adolescents and young adults with PKU

Mult Scler Relat Disord. 2022;68.
DEFINING THE EXPERIENCES OF ADOLESCENT PATIENTS WITH MULTIPLE SCLEROSIS IN TRANSITION FROM PEDIATRIC CARE TO ADULT CARE.
Yüksel Yılmaz D, Yardımcı F, Erdemir F, et al.
Background: The aim of this study was to evaluate the experiences of patients aged 18–24 years who were diagnosed with multiple sclerosis before the age of eighteen, during the transition from pediatric care to adult care.
Methods: This research was in the type of phenomenological qualitative research. Focus group interviews were conducted between December 2020 and October 2021 with seventeen participants who had been diagnosed with multiple before the age of eighteen, aged 18–24, voluntarily having agreed to participate in the study. The views of the participants were analyzed with Maxqda Plus v10 data analysis software, and thematic coding was created by the researchers.
Results: Of the participants, 58.9% were female, 76.5% had their first attack after the age of 13, and it was determined that 64.7% of them took oral tablets for therapeutic purposes. As a result of the content analysis; four thematic codes emerged: (a) Perceptions of the Illness and Pediatric Clinic Before Transition, (b) Perceptions of the Disease and Adult Clinic After Transition to the Adult Clinic, (c) Expectations from the Clinic They Received Service from During Their Childhood, (d) Expectations from the Clinic They Used in Adulthood.
Conclusion: This study revealed that individuals with multiple sclerosis did not receive any medical care regarding the transition from pediatric clinics to adult clinics. Describing the experiences of young adult patients with multiple sclerosis in pediatric clinics and their experiences in the transition to adult clinics allows for the definition of comprehensive, individualized and transitional nursing interventions

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Muscle Nerve. 2022;65:498-507.

MANAGEMENT OF SPINAL MUSCULAR ATROPHY IN THE ADULT POPULATION.

Rad N, Cai H, Weiss MD.

Spinal muscular atrophy (SMA) is a group of neurodegenerative disorders resulting from the loss of spinal motor neurons. 95% of patients share a pathogenic mechanism of loss of survival motor neuron (SMN) 1 protein expression due to homozygous deletions or other mutations of the SMN1 gene, with the different phenotypes influenced by variable copy numbers of the SMN2 gene. Advances in supportive care, disease modifying treatment and novel gene therapies have led to an increase in the prevalence of SMA, with a third of SMA patients now represented by adults. Despite the growing number of adult patients, consensus on the management of SMA has focused primarily on the pediatric population. As the disease burden is vastly different in adult SMA, an approach to treatment must be tailored to their unique needs. This review will focus on the management of the adult SMA patient as they age and will discuss proper transition of care from a pediatric to adult center, including the need for continued monitoring for osteoporosis, scoliosis, malnutrition, and declining mobility and functioning. As in the pediatric population, multidisciplinary care remains the best approach to the management of adult SMA. Novel and emerging therapies such as nusinersen and risdiplam provide hope for these patients, though these medications are of uncertain efficacy in this population and require additional study

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Neuro-Oncology. 2022;24:i181-i182.

STRUCTURED TRANSITION FROM PEDIATRIC NEUROONCOLOGY TO ADULT SURVIVORSHIP FOLLOW-UP CARE - CAN WE CLOSE THE GAP?

Krottendorfer K, Baumgartner AC, Boehm A, et al.

PURPOSE: Advances in treatment have increased survival rates and quality of life of pediatric CNS tumor patients leading to a growing number of long-term survivors. However, there is sufficient clinical and scientific evidence for the need of a highly specialized lifelong follow-up care due to multidimensional late effects. Furthermore, adolescence and young adulthood are challenging age periods when patients frequently get lost to follow-up potentially having severe impact on health and well-being. Since 2020, we have established a structured transfer of long-term survivors older than 18 years to a newly founded highly specialized adult care follow-up setting for childhood cancer survivors (IONA). The aim of this study was to evaluate the current transition process.

RESEARCH DESIGN: The standard of care transition process at the neuro-oncology unit of the MUV includes a joint appointment with the patient, a pediatric neuro-oncologist, psychologist and/or social worker and the team of the adult care facility (physician, psychologist). Different elements are used to end care safely in the pediatric structure and building trust in the upcoming out-patient-department at the same time. The transition process was evaluated statistically and analyzed qualitatively with regard to the factors that define a safe transition.

RESULTS: After two years (01/2020-12/2021) 114 patients had a joint transition appointment, two patients contacted IONA directly. Shortly after the joint appointment all patients had a scheduled follow-up meeting at IONA. 102 patients (87.9%) showed up, seven patients (6%) already had a planned appointment, two patients (1.7%) were in contact with IONA but had no possibility to show up in person. Only five patients (4.3%) did not attend the appointment and were lost to follow-up.

CONCLUSION: A structured interdisciplinary transition concept is a successful option to establish controlled and patient-safe transition from pediatric to adult care setting

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Nervenheilkunde. 2022;41:560-68.

SUPPORT OPPORTUNITIES FOR YOUNG ADULTS WITH A MENTAL ILLNESS AND CHALLENGES OF THE TRANSITION PHASE.

Ilgaz A, Fegert JM, Schulze UME, et al.

The transition from child and adolescent mental health care services (CAMHS) to adult mental health care services (AMHS) poses a challenge for young adults with mental disorders. This phase is associated with a lack of opportunities to support young adults after aging out from the CAMHS which put the continuity of their treatment at risk. Experience shows that only a small proportion of young adults undergo a smooth transition, while the majority fall into the alleged transition gap. The following article provides a review of previous research on the transition gap both in the health and social care systems and presents traditional as well as digital opportunities (the ProTransition-App) to support young adults during this critical phase

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Neuro-Oncology. 2022;24:i182.

SURVIVORSHIP: EDUCATION, CLINICAL GUIDELINES, AND TRANSITION TO ADULT CARE.

Hemenway M, Dorris K, Foreman N, et al.

As the cure rates of patients with pediatric brain tumors increases, the long term care needs of the survivors increase as well. Survivorship includes several facets of multidisciplinary care including education, clinical care guidelines, and transition to adult medical care. The neuro-oncology program at a large tertiary care hospital has developed a team to address survivorship needs. The Children's Oncology Group (COG) Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers was utilized as a backbone that was then customized for neuro-oncology patient education including disease type and treatment. The education was compiled into patient handouts as well as electronic medical record (EMR) statements that can easily be added to a clinic note or letter to referring providers. In addition, a diagnosis and treatment summary was placed both in the EMR as well as given to patients at various time points to ensure long term knowledge. Next, follow-up guidelines and roadmaps were developed and customized to tumor type and treatment received (surgery, radiation, chemotherapy). The roadmaps ensure patients are receiving high-quality comprehensive follow-up and screening from a large multidisciplinary team. Finally, patients will transition to adult care. With a large seven state catchment area, the adult care providers vary on local provider availability, knowledge, and medical complexity of the survivor. Each patient is evaluated based on their needs, availability of care locally, and ability to travel. The team developed relationships with the clinical team at the academic center adjacent to the pediatric hospital to support a smooth transition to adult care. The adult neuro-oncology care team can also serve as a consulting service for local adult providers. The survivorship team will continue to address the complex needs of brain tumor survivors and provide education for a smooth transition to adult care

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Neurol Res Practice. 2022;4.

ESSEN TRANSITION MODEL FOR NEUROMUSCULAR DISEASES.

Fleischer M, Coskun B, Stolte B, et al.

Background: With the optimization of medical care structures and the rapid progress in the development of new therapeutic methods, an increase in life expectancy is observed in patients with neuromuscular diseases. This leads to an expansion of the phenotypic spectrum, whereby new or previously less relevant disease manifestations in different organ systems gain more importance. The care of adolescents and young adults with neuromuscular diseases, therefore, requires increasingly close interdisciplinary collaboration within neuromuscular centers. Research question: How can the transition process from pediatric to adult care be structured so that the individual disciplines are efficiently integrated into the complex treatment and care process, and the patients' quality of life is improved?

Material and methods: A structured transition process was established at the University Hospital in Essen, Germany. Exemplarily, a comparable care concept was developed based on Pompe disease, Duchenne muscular dystrophy, and juvenile myasthenia gravis comprising four elements: (1) With the introduction of cross-department standard operating procedures, the logistical processes, as well as the diagnostic and therapeutic measures, are uniformly coordinated, and the transition process is bindingly defined. (2) To ensure a seamless transition, young patients are seen with their parents during joint consultations before they reach their 17th birthday. This creates an opportunity for patients to get to know the subsequent department structure and build a lasting relationship of trust. (3) A quarterly “transition board“ regularly brings together the participating disciplines from pediatric and adult care systems for a case-related interdisciplinary exchange and continuous optimization of the transition process. (4) A cross-department “Transition Database“, in which medical findings and parameters are recorded, was implemented as a common information platform and database.

Conclusion: The Essen Transition Model aims to close the gap in care for young patients with neuromuscular diseases during the critical transition from pediatric to adult medicine and to create a successful continuation of treatment in adulthood

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Neurourol Urodyn. 2022.

SCOPING REVIEW OF NEUROGENIC BLADDER PATIENT-REPORTED READINESS AND EXPERIENCE FOLLOWING CARE IN A TRANSITIONAL UROLOGY CLINIC.

Chua ME, Tse LN, Silangcruz JM, et al.

Objective: To generate a scoping review that summarizes thematically on all reported patient perceptions on readiness and experiences during transitional urologic care for patients with neurogenic bladder and or congenital genitourinary conditions that require continuity of care into adulthood.

Methods: A systematic literature search was performed in October 2021. Records were screened and identified for studies relevant to reported readiness and experience in urologic transitional care among patients

needing life-long urologic care. The methodological quality of the cross-sectional studies was assessed using AXIS. The included studies were clustered according to patient readiness in transition and patient experience satisfaction in the urologic transition process. This scoping review was part of a systematic review registered on PROSPERO CRD42022306229 and was conducted in compliance with the PRISMA extension for scoping reviews.
Results: A total of 12 articles were included that assessed patients with neurogenic bladder that reported either readiness or patient experience following the transitional care process. The patient readiness was assessed in six studies, determined using the TRAQ score with a range of 3–4/5. Older age, high health literacy, and parental or families' transition process awareness were associated with readiness. Generally, patients experience better satisfaction with pediatric care than with adult care facilities. Most patients felt that sexuality and fertility were not adequately tackled during the transition. The reported barriers to successful transition were patient, provider, and system factors, including lack of insurance coverage/financial management, patient preference, long-term bond with the pediatric providers, and communication by the adult provider. Based on AXIS, all of the studies identified for this scoping review did not determine the sample size, and most of the studies did not categorize the responders, which could introduce bias to the interpretation of their results.
Conclusion: This scoping review summarizes the readiness and experience of neurogenic bladder patients who underwent the urologic transitional process. Overall, understanding the patient, provider, and system factors associated with better readiness and enhancing the patient experience will ensure a better transition process

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Palliative Med. 2022;36:841-54.
VIEWS AND EXPERIENCES OF YOUNG PEOPLE, THEIR PARENTS/CARERS AND HEALTHCARE PROFESSIONALS OF THE ADVANCE CARE PLANNING PROCESS: A SUMMARY OF THE FINDINGS FROM A QUALITATIVE STUDY.
Hughes B, O'Brien M, Flynn A, et al.
Background: Advance care planning for young people is relatively new in the UK. There is a lack of understanding about the engagement of young people in their own planning process, optimal timing of discussions and the facilitators and barriers to the engagement of young people.
Aim: To explore the views and experiences of young people, their parents/carers and HCPs of the advance care planning process.
Design: A qualitative study, using semi-structured interviews with young people, their parents/carers and healthcare professionals across four case series. Data were analysed using thematic analysis.
Participants: Fifteen participants were interviewed: young people (n = 2), parents/carers (n = 5) and healthcare professionals (n = 8).
Results: Three themes were identified from the findings. Key findings related to barriers and facilitators of engaging young people in their own care planning were apparent in the following areas: misperception of terms; hierarchies of power in relationships; and a flexible and innovative organisational structure and culture.
Conclusion: Participants expressed a variety of views and experiences of advance care planning. Advance care planning was thought to be best initiated by a consultant when the young person is in their mid-teens, their condition is stable, and before they transition to adult care. Engagement was also considered to be facilitated by appropriate communication, developing relationships prior to initiating advance care planning, and written support for everyone involved in the process. These factors were supported by training and education for healthcare professionals and a flexible and innovative structure and cultures of organisations

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Pediatr Blood Cancer. 2022;69:S106.
DEVELOPMENT OF A TRANSITION-TO-ADULT-CARE CLINIC FOR PEDIATRIC ONCOLOGY TEENS AND YOUN ADULTS.
Rosenbaum AR, Reinman L, Casey R, et al.
Background: As many as 95% of pediatric oncology survivors will face at least one treatment-related chronic health condition by middle age. Transitioning from pediatric medical care to adult medical care can present a variety of challenges, including problems associated with accessing adult-appropriate health services and continued survivorship-specific care. In fact, only 32% of adult childhood cancer survivors report receiving cancer/survivorship-focused care. Objectives: To develop and evaluate a multi-disciplinary program aimed at improving the transition to adult care for pediatric oncology survivors and their families.
Design/Method: To develop our program, we 1) Conducted a literature review to identify the successes and difficulties encountered by similar transition clinics for children with chronic disease, and 2) Performed a needs assessment survey of both pediatric oncology survivors and guardians. Subsequently, a multi-disciplinary planning team, including physicians, nursing, and psychology specialists developed specific programing for the transition clinic, using both expert opinion and existing formats within the literature. Patient and guardian-reported effectiveness, acceptability and appropriateness are being collected via survey before, immediately

after, and 6 months following program participation. Results: The Pediatric-to-Adult Care Transition Program had its first quarterly clinic with four survivor participants and two parents. The pilot program consists of regular transition readiness assessments starting at age 16, attendance at a multidisciplinary, educational clinic at age 18-20, and a planned follow-up formal transition appointment one year later. The clinic consisted of a survivorship visit and specialized sessions for both survivors and guardians. Survivor sessions included practice relaying medical history, scheduling a doctor's appointment, and learning about mental health resources and school/work accommodations. Guardian sessions included sessions regarding communication with teenagers and fostering teenager independence. There were also joint sessions reviewing healthcare resource needs (e.g. insurance, transportation) and discussing genetics counseling. While based on few numbers to date, on 1-10 Likert scales, and survivors' level of preparedness of the transition to adult healthcare rose from an average 6 to 7, and guardians' rose from 5.5 to 6. Program usefulness was rated at 8.25 (patients) and 10 (guardians). There were no suggestions for modifications to the program.
Conclusion: Preliminarily, our pilot transition clinic was acceptable and well-received by both pediatric oncology survivors and their guardians. This program provides resources and skills development relevant to the transition from pediatric to adult medical care. As additional quarterly programs occur, we will continue to assess the utility of our transition program, while incorporating participant feedback

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Pediatr Blood Cancer. 2022;69.
MEASURING TRANSITION READINESS IN ADOLESCENTS AND YOUNG ADULTS WITH SICKLE CELL DISEASE USING THE TRANSITION READINESS ASSESSMENT QUESTIONNAIRE.
Oberoi AR, Patterson A, Sobota A.
Background/objectives: Adolescents and young adults (AYA) with sickle cell disease (SCD) face challenges related to the disease and its treatment. The Transition Readiness Assessment Questionnaire (TRAQ) is a self-report tool for assessing transition readiness for youth with special health care needs (YSHCN), including SCD. This study uses the TRAQ to understand transition readiness in patients with SCD treated at the Boston Medical Center and evaluates associations between TRAQ scores and transition outcomes (e.g., emergency department reliance [EDr] and emergency department utilization [EDu]).
Methods: We reviewed electronic medical records of AYA with SCD who completed the TRAQ in the pediatric hematology clinic between January 1, 2019, and March 1, 2020, and categorized healthcare encounters to calculate EDu and EDr. We used t tests and ANOVA models to analyze mean TRAQ scores, sex, age, genotype, EDu, and EDr.
Results: The sample was 45 AYA patients with SCD between 13 and 22 years old. The mean TRAQ score for the overall patient sample was 3.67. Mean TRAQ scores did not significantly vary by sex or genotype but did significantly increase with age. TRAQ scores did not correlate to EDu or EDr.
Conclusions: AYA patients with SCD have low transition readiness. The age of 18 may not be the most reliable attribute of readiness, though older patients do have higher readiness. The relationship between TRAQ scores, EDr, and EDu is not clear and requires further evaluation

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Pediatr Cardiol. 2022.
PLANNING TRANSITION OF CARE FOR ADOLESCENTS AFFECTED BY CONGENITAL HEART DISEASE: THE IRISH NATIONAL PATHWAY.
Bassareo PP, Mcmahon CJ, Prendiville T, et al.
At some point in their life, adolescent patients with a congenital heart disease (CHD) transition from paediatric services to adult care facilities. The process is not without any risks, as it is often linked with a significantly progressive deterioration in adolescents' health and loss of follow-up. In fact, transition patients often encounter troubles in finding a care giver who is comfortable managing their condition, or in re-establishing trust with the new care provider. Planning the rules of transition is pivotal in preventing these risks. Unfortunately, the American and European guidelines on CHD provide just generic statements about transition. In a recently published worldwide inter-societies consensus document, a hybrid model of transition, which should be adapted for use in high- and low- resource settings, has been suggested. Currently, in literature there are a few models of transition for CHD patients, but they are by far local models and cannot be generalized to other regions or countries. This paper describes the Irish model for transition of care of CHD patients. Due to the peculiarity of the healthcare organization in the Republic of Ireland, which is centralized with one main referral centre for paediatric cardiology (in Dublin, with a few smaller satellite centres all around, according to the “hub and spoke“ model) and one centre for adult with CHD (in Dublin), the model can be considered as a national one and the first to be released in the old continent

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Pediatr Nephrol. 2022.

TRANSITION OF YOUNG ADULT KIDNEY TRANSPLANT RECIPIENTS.

Matsuda-Abedini M, Marks SD, Foster BJ.

Survival of pediatric kidney transplant recipients has improved over the past six decades. However, adolescents and young adults still have the highest graft failure rates of any age group. There is a growing need for well-designed transition programs to ensure the successful integration of young adults into adult society with eventual transfer of care and management in adult transplant centers. In this review, we discuss the risk factors contributing to the high risk of kidney graft failure observed between 17 and 24-áyears of age, including the role of transfer from pediatric to adult care. We also address the unique challenges of adolescents with kidney transplant: the impact of chronic kidney disease on neurocognition, age-related changes in immune activity, and suboptimal adherence during the transition process. We then describe strategies to mitigate these risks by designing developmentally appropriate transition programs, and review the evidence supporting the benefits of well-designed multidisciplinary transition programs

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Pediatr Pulmonol. 2022;57:S22-S24.

TRANSITION TO ADULT CARE: WHAT ADULTS SHOULD KNOW ABOUT PEDIATRIC RESPIRATORY DISEASES.

Bush A.

There are many reasons why Pediatric and adult Pulmonologists need to talk to each other (including that adult pulmonologists care for pregnant women with chest disease which may affect the fetus, which is not covered here). This talk will present of some of the commonalities with adult respiratory physicians and their implications. 1. Early life events are pivotal causes of later adult life disease. - Early onset of Chronic Obstructive Pulmonary Disease (COPD): COPD is defined as a ratio of first second forced expired volume (FEV1)/forced vital capacity (FVC) < 0.70. Multiple birth cohort studies have demonstrated that early airflow obstruction tracks through life [1] and leads to early onset COPD as a result of failure of either or both to attain a normal growth plateau and accelerated decline in lung function [2]; 40% of airflow obstruction in middle age occurs before birth, and 60% in the preschool years [3]. A low FEV1 is a marker for early all-cause morbidity and mortality, including cardiovascular and metabolic [4], at least in a developed world setting; whether this is true in low and middle income (LMIC) contexts is unknown but highly likely. Finally, early life deprivation is associated with an accelerated decline in lung function [5] and sensitizes the patient to adverse adult factors such as smoking and occupational exposures [6]. – Early onset upper airway disease leading to over-diagnosis and overtreatment of asthma: Exercise-induced laryngeal obstruction (EILO) is associated with early laryngomalacia [7] and neonatal ligation of the ductus arteriosus in ex-preterm babies [8]. Failure to appreciate this leads to over-diagnosis of asthma with inappropriate prescription. - Differential diagnosis of a low FEV1/FVC ratio: COPD is an umbrella term describing this reduced ratio. Firstly, failure to understand the developmental changes in the ratio, specifically that many normal elderly people have FEV1/FVC < 0.70 means COPD is over-diagnosed [9]. Secondly, a ratio <0.70 has many causes and it would be na+»ve to suppose all should be managed differently. Is the pathophysiology of post-infectious obliterative bronchiolitis the same as that in a long-term smoker, and should they be treated the same way? It seems implausible. – Long-term consequences of interstitial lung disease (ILD): Neuroendocrine cell hyperplasia of infancy (NEHI) may lead to long term airflow obstruction, often treated as asthma, but with no evidence of atopic eosinophilic inflammation [10]. There may be long-term consequences of steroid therapy and alveolar underdevelopment necessitating careful follow-up, as well as genetic implications for the wider family in some ILDs. Furthermore, late relapse is an issue. Transition arrangements for ILD are fragmented and poor [11]. – LMIC infectious disease: Children with acquired immunodeficiency syndrome (AIDS) survive into adulthood with a high risk of airflow obstruction [12] and bronchiectasis [13], and likely an accelerated decline in lung function. In adults there is evidence of airflow obstruction post chemotherapy for tuberculosis [14]; there is much less evidence in children, but the long-term consequences of tuberculosis and its treatment in all age groups merit careful study. 2. Children with traditional 'pediatric diseases' need transition programs to adult care – Transition programs are really important to prepare young people for the adult clinic [15]. A planned process, with good communication, allows smooth transition. Adolescence is a time when there is a high risk of young people being lost to follow-up. The process will show regional variation and depend on the rarity of the disease. Joint transition clinics, with input from adult and pediatric chest physicians, are a great way to share expertise. 3. Long survivors of previously fatal childhood diseases are developing late complications in adulthood, which may need to change pediatric practice to inform treatment strategies – Study of adults with CF has led to a focus on bone health strategies and much early use of insulin in childhood. The next challenges will be whether pediatric strategies can reduce the risk of bowel cancer, and whether the traditional 'high calorie, high fat' diet will increase cardiovascular morbidity in these older survivors. – Neuromuscular disease - respiratory morbidity and mortality has been revolutionized by the aggressive use of nocturnal nasal mask ventilation, and airway clearance devices such as the cough assist [16]. Elective tracheostomy is also much more frequently offered. Furthermore, novel treatments such as gene therapy and nusinersin for severe spinal muscular atrophy show

the potential for completely changing the natural history of the condition. Now pediatricians need to address prevention of bone disease and pulmonary thromboembolism related to immobility, kidney disease related to hypercalciuria, and cardiac complications. – Premature birth: the detailed nature of the airway and parenchymal diseases, and the comorbidities, are varying over time as neonatology practices change leading to ever smaller and more premature babies surviving with airflow obstruction, parenchymal lung disease, disordered control of breathing, and potentially multiple extrapulmonary comorbidities [17]. Respiratory issues improve over time, but we know nothing of the rate of lung function decline in adult life in such patients. These young people need holistic care, especially if they have multiple handicaps, and this is totally lacking, at least in the UK, once they leave school. – Pulmonary toxicity of immunosuppression: pediatric cancer treatment and organ transplantation have been major successes in children. However, the toxicity of these treatments to the growing and developing lung will leave these children with lifelong vulnerability. They need careful follow-up in adult life, with feedback about how current practices may need to change as a consequence of long-term surveillance discovering new toxicities. 4. Childhood symptoms which we may have missed or under-rated may prove to be the harbingers of adult disease – Bronchiectasis: all children cough but most children are normal. However, more than half of adults with bronchiectasis had symptoms starting in childhood [18]. This underscores the need to take persistent chronic productive cough seriously, try to determine the underlying cause and institute energetic treatment with airway clearance and antibiotics to prevent progression to bronchiectasis while the airway disease is still reversible. – COPD: non-specific 'asthma-like' symptoms in the preschool years are a risk factor for COPD diagnosis and impaired spirometry in adult life [19]. It follows that we as pediatricians need to look beyond 'normal' childhood symptoms and ask whether the child is in fact at risk for significant adult disease. 1. Transgenerational: adults are the parents of the child! – Impaired spirometry in one or both parents is a risk factor for impaired spirometry in their offspring [4], and thus likely the attendant early increased extra-pulmonary, multisystem morbidity and mortality. – There is a transgenerational effect of smoking; asthma risk is increased in the children of the daughters of smoking grandmothers, even if the daughter does not herself smoke [20, 21]. Hence we need to join with adult doctors and urge them to recognize and communicate to adult patients the effect their health behaviors will have on their children, and to try to put health improvement measures in place early in their children, to try to break the trans-generational cycles of deprivation. Conclusion: we need to leave developmental silos and strengthen our vertical links with our adult colleagues. We need to unite with adult respiratory physicians to minimize early toxic exposures including smoking, vaping and indoor and outdoor pollution. Adult physicians need to be aware that a low FEV1 is a red flag to put in case strategies to minimize early all system complications, and also allow us to target the patient's children for disease prevention and health preservation strategies. We need to consider how adult and pediatric training programs should share relevant modules to ensure seamless academic research and optimal clinician input across the life course. For example, leaving our developmental silos to teaching days, grand rounds, journal clubs and ward rounds in adult thoracic medicine, and inviting adult trainees to ours, would be a good start. Even if we practice in a free-standing children's hospital, this could easily be accomplished at low cost with live streaming

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Pediatr Rheumatol Online J. 2022 Aug;20:62.

COMMENT ON: A NOVEL TRANSITION CLINIC STRUCTURE FOR ADOLESCENT AND YOUNG ADULT PATIENTS WITH CHILDHOOD ONSET RHEUMATIC DISEASE IMPROVES TRANSITION OUTCOMES.

Radić M.

Pediatrics. 2022;149.

THE FIRST LEAP TO ADULT CARE FOR A HISPANIC SICKLE CELL DISEASE PATIENT: LESSONS FOR ADEQUATE TRANSITION OF CARE.

Vilanova-Velez LR, Cintron-Lopez D, Lugo L.

Introduction: Transition from pediatric to adult medical care can be a high-risk period for youth with Sickle Cell Disease (SCD). Morbidity and mortality increase for patients with SCD in the United States after the age of 18 years. We present a case of a 21-year-old Puerto Rican female with SCD who presents for her first adult hospitalization due to an acute pain crisis complicated by acute chest syndrome (ACS).

Case Description: A 21-year-old Hispanic female with a diagnosis of SCD, with history of multiple pediatric hospitalizations due to pain crises, recurrent splenic sequestration, early childhood stroke, and ACS, presented to our adult hospital with acute and constant back pain. The patient admitted poor compliance with medication and with medical follow-up with her pediatric hematologist for the past two years. Her last visit to the hematologist was four months prior, during which a formal transfer to the adult hematology service was discussed. By the time of admission, the patient had never met with an adult hematologist. Her physical exam was remarkable for tenderness to palpation over the upper back, with later progression to dyspnea and fever. Laboratory findings were remarkable for a hemoglobin (Hgb) of 5.8mg/dL (baseline 8- 9mg/dL). Serial chest

X-rays showed progressive bilateral opacities. The patient was transferred to the medicine intensive care unit due to hypoxic respiratory failure and started on high- flow nasal cannula. The case was discussed with her primary pediatric hematologists, who recommended ACS management with aggressive intravenous fluids, pain medications, and antibiotics. She also received blood transfusions for a goal Hgb of 10mg/dL. The patient recovered, and prior to discharge, she was transferred to adult Hematology and Internal Medicine care.
Discussion: This case highlights the poor transition of a Hispanic young adult with SCD to adult care. In Puerto Rico, there is a predominantly Hispanic population with poor access to healthcare resources. This population has worse health outcomes when compared with other Hispanic subgroups. Currently, Puerto Rico does not have a transition of care clinic or a protocol for transitioning patients with chronic conditions to adult care. The challenges these patients experience has yet to be studied, and standardization of transition from pediatric to adult care in Puerto Rico needs to be discussed.
Conclusion: This case of an adult with SCD complicated by ACS shows the importance of transition of care for a pediatric patient into adulthood. Transition of care should be a part of the routine care for every child starting at approximately 12 years of age until the transition is complete. Minority groups have less access to quality health care. Understanding the challenges faced by these populations is essential to coordinate a structured process of transition of care that allows compliance and access to the needed services

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Transl Sci Rare Dis. 2022;6:13-23.
TRANSITION OF CARE OF PATIENTS WITH EOSINOPHILIC GASTROINTESTINAL DISEASES: CHALLENGES AND OPPORTUNITIES.
Hiremath G, Chapa-Rodriguez A, Katzka DA, et al.
Eosinophilic gastrointestinal disorders (EGID) are a group of allergen-mediated conditions which are characterized by eosinophilic inflammation affecting one or more parts of the gastrointestinal tract. A disproportionately higher number of EGID patients are diagnosed in the pediatric age group. Given the chronic course of EGIDs and lack of curative therapies at this time, majority of the pediatric EGID patients may require continued care well into their adulthood. However, to date, scant data are available regarding the health care transition (HCT), the transition of care (TC), and the effectiveness of transfer of care EGID patients from pediatric-oriented to adult-oriented providers. Herein, we review the lessons learnt from transfer of care of children with other chronic gastrointestinal and allergic conditions, analyze the current knowledge, potential barriers, the role of various stakeholders in successful transfer of care of EGID patients, propose a conceptual framework for HCT and TC of EGID patients, and identify outcome measures to ensure the quality of progression of care

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Value Health. 2022;25:S380.
COSTS OF IMPLEMENTING AN ADOLESCENT TRANSITION PACKAGE TO FACILITATE TRANSITION TO ADULT CARE FOR ADOLESCENTS WITH HIV IN KENYA.
Saldarriaga E, Beima-Sofie K, John-Stewart G, et al.
Background: Adolescents with HIV (AWHIV) in sub-Saharan Africa face challenges transitioning to adult HIV care including suboptimal disclosure of their HIV status, which is necessary for successful transition. Standardized tools and processes to facilitate transition are lacking. An Adolescent Transition Package (ATP) that combined HIV disclosure and transition tools recently was shown to improve transition readiness among AWHIV in Kenya in a cluster randomized trial (CRT). Understanding the costs associated with implementation of the ATP can inform future scale-up.
Methods: We estimated the average cost per patient of providing the ATP to adolescents enrolled in a CRT in 20 HIV clinics in Kenya. We used a micro-costing, activity-driven time estimation, from the provider perspective. We developed a flow-map, conducted healthcare worker (HCW) interviews, and completed time-and-motion observation. ATP costs were estimated as the difference in average cost for a visit in the intervention vs control clinics. We assessed uncertainty of costing estimates via Monte Carlo simulations.
Results: Thirty-seven HCWs (17 from control sites) were interviewed and observed. The incremental cost of providing one ALHIV visit with the ATP was 3.8USD (95%CI 3.6, 3.9), calculated as the difference in average cost per ALHIV visit of 33.6USD (95%CI 31.1, 37.4) in intervention and 29.8USD (95%CI 27.5, 33.4) in control clinics. The largest components of ATP intervention costs were development of the ATP educational materials and HCWs salary. Differences in the HCW cadre led the differences in costs – Counselors performed the largest proportion of activities in control sites, while Nurse Counselors did so among intervention sites.
Conclusion. The ATP can be feasibly implemented in HIV care clinics at a moderate increase in cost per clinic visit, which would be anticipated to decrease with wide scale-up. The low-cost of implementation increases the likelihood of the ATP to have a successful scale-up in Kenya

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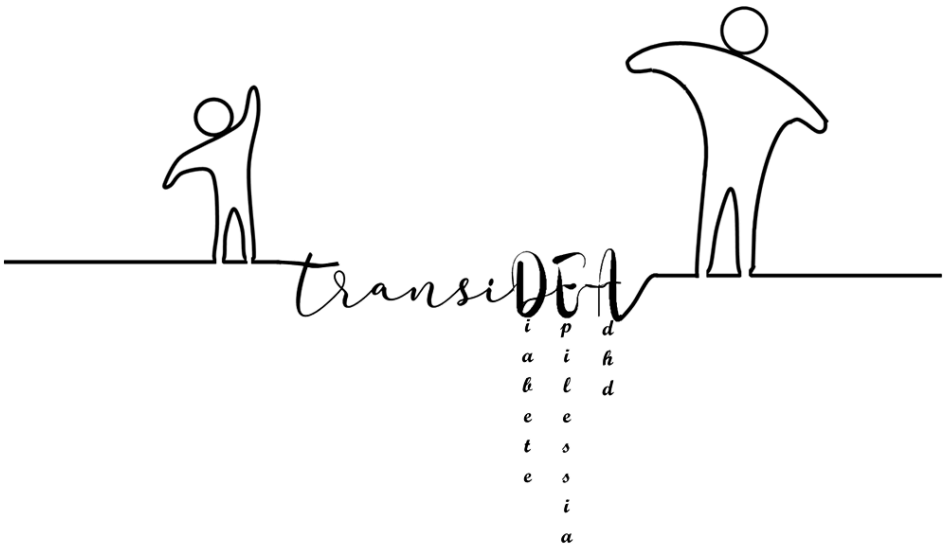


EPILESSIA

Epilepsia Open. 2022 Sep;7:452-61.

TRANSITION FROM PEDIATRIC TO ADULT CARE AMONG PATIENTS WITH EPILEPSY: CROSS-SECTIONAL SURVEYS OF EXPERTS AND PATIENTS IN KOREA.

Jung SY, Yu SW, Lee KS, et al.

OBJECTIVES: Many pediatric patients with epilepsy require treatment beyond the pediatric age. These patients require transition to an adult epilepsy center. Currently, many centers worldwide run epilepsy transition programs. However, a standardized protocol does not exist in Korea. The basic data required to establish a transition program are also unavailable. We aimed to assess the status and perceptions of patients and epilepsy care providers on transition.

METHODS: To assess the status of epilepsy transition, we retrospectively collected data from patients with epilepsy older than 18 years who visited our pediatric epilepsy clinic between March 1990 and July 2019. To assess the perception of transition, we surveyed patients, parents, pediatric neurologists (PN), and adult epileptologists (AE).

RESULTS: In a retrospective chart review, 39 of 267 (14.6%) patients visited the adult epilepsy clinic after consulting a pediatric neurologist, and three patients returned to the pediatric center. The average patient age at transition was 23.29 ±5.10 years. A total of 94 patients or their guardians and 100 experts participated in the survey. About half of the patients or guardians (44.7%) did not want to transition and emotional dependence was the commonest reason. Most patients (52.1%) thought that the appropriate age of transition was above 20 years. PNs had greater concerns about patients' compliance than AEs. Regarding the age of transition, AEs believed that a younger age (18 years) was more appropriate than PNs (20 years).

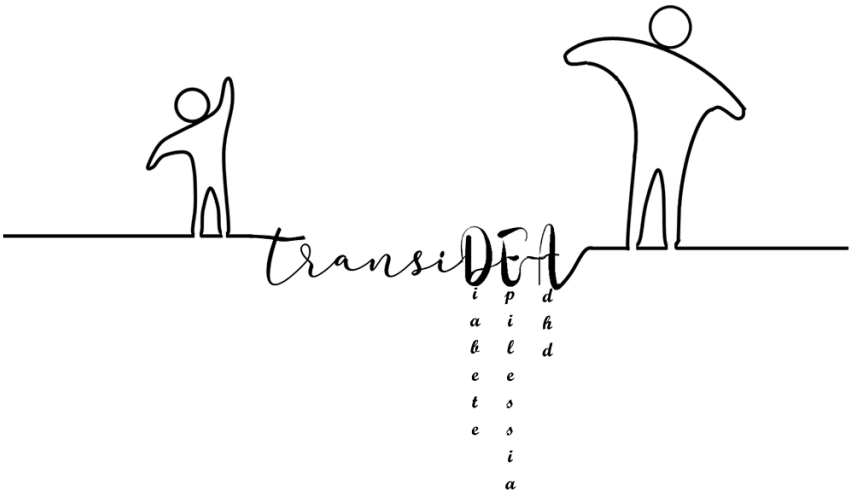
SIGNIFICANCE: This study describes difficulties in the transition from pediatric to adult epilepsy centers without appropriate support. There were differences in perspectives among patients, parents, and adult and pediatric epilepsy care providers. This study can assist in creating a standardized protocol in Korea

Seizure. 2022 Oct;101:52-59.

TRANSITION TO ADULT CARE IN EPILEPSY: A SYSTEMATIC REVIEW.

Goselink RJM, Olsson I, Malmgren K, et al.

The transfer from paediatric to adult care can be a complex process in children with epilepsy. Inadequate care during this phase can affect long-term medical and psychosocial outcomes. The aim of this study was to review studies on transitional care from paediatric to adult healthcare for young persons with epilepsy in order to synthesize evidence for best practice. We undertook a systematic review following PRISMA guidelines and employed narrative synthesis. A total of 36 articles were included, of which 11 were interventional studies and 25 observational studies. Study quality was rated as 'good' for only four studies. Interventions included joint or multidisciplinary clinics, education (patient and health professional education) and extended service provision (Saturday clinics, peer-groups). All studies observed a positive effect experienced by the participants, regardless of intervention type. Observational studies showed that transition plans/programmes are asked for but frequently not existing or not adapted to subgroups with intellectual disability or other neurodevelopmental conditions. The results of this systematic review on transitional care in epilepsy suggest that a planned transition process likely enhances medical and psychosocial outcomes for young people with epilepsy, but the body of evidence is limited and there are significant gaps in knowledge of what efficacious transition constitutes. More studies are needed employing qualitative and quantitative methods to further explore the needs of young people with epilepsy and their families but also robust study designs to investigate the impact of interventions on medical and psychosocial outcomes



DIABETE

Contemp Clin Trials. 2022 Aug;119:106830.

A MULTI-CENTER PEDIATRIC TO ADULT CARE TRANSITION INTERVENTION PROGRAM TO IMPROVE CLINIC VISIT ADHERENCE AND CLINICAL OUTCOMES AMONG ADOLESCENTS AND EMERGING ADULTS WITH TYPE 1 DIABETES MELLITUS [PATHWAY]: PROTOCOL FOR A RANDOMIZED CONTROLLED TRIAL.

Goyal A, Peerzada A, Sarteau AC, et al.

OBJECTIVE: This multi-center randomized controlled trial aims to evaluate the effectiveness of a context-specific transition intervention program to improve clinic visit adherence and clinical outcomes among emerging adults with type 1 diabetes mellitus (T1DM) in Delhi, India.

METHODS: We will recruit patients with T1DM of duration ≥1 year and age 15-19.5 years from the participating pediatric sites. After a baseline assessment and a "basic introductory session", which apprises participants about the concept of transition, study participants (proposed sample size =156) will be randomly allocated into an intervention and control arm. Participants in the intervention arm will receive a structured transition program delivered over 15 months. On the other hand, control arm participants will continue to receive usual care from the pediatric site till the time of transfer to the adult site. The study assessments will be done at baseline, at the time of transfer, and at 1 and 2 years following the transfer. The primary outcome is the difference in clinic attendance rate between intervention and control arms at the end of 1 year post-transfer. The secondary outcomes include the difference in clinic attendance rate at the end of 2 years, the difference in proportion of participants with a minimum of 4 visits in the first follow-up year, and process indicators such as diabetes knowledge and self-management skills, diabetes treatment satisfaction, overall quality of life, diabetes-related distress, hospitalization for acute complications and screening for chronic diabetes complications, and HbA1c.

CONCLUSION: This study will provide important new evidence about a potential strategy to improve clinical care among adolescents and emerging adults with T1DM in lower resource contexts during the vulnerable phase of transition from pediatric to adult healthcare. The trial is registered on the Clinical Trials Registry of India (http://ctri.nic.in) under the CTRI registration number CTRI/2020/10/028379

Diabet Med. 2022 May;39:e14781.

TOWARD A BETTER UNDERSTANDING OF TRANSITION FROM PAEDIATRIC TO ADULT CARE IN TYPE 1 DIABETES: A QUALITATIVE STUDY OF ADOLESCENTS.

Ladd JM, Reeves-Latour J, Dasgupta K, et al.

AIMS: Type 1 diabetes is associated with significant morbidity, with an increasing risk of acute diabetes-related complications in adolescence and emerging adulthood. Purposeful transition from paediatric to adult-oriented care could mitigate this risk but is often lacking. Detailed understanding of the perspectives of adolescents in their final year of paediatric care is essential to inform delivery of transition care programs.

METHODS: We conducted semi-structured interviews with adolescents (aged 17 years) with type 1 diabetes at an academic institution from April 2017 to May 2018. Participants were recruited through convenience sampling. Sixty-one interviews were transcribed for analysis. Coding followed the principles of thematic analysis.

RESULTS: Thirty-six percent of participants were male, and participants were from diverse socioeconomic backgrounds. We found three overarching themes in our analysis: first, difficulties navigating changing relationships with parents and healthcare teams; second, the need to increase type 1 diabetes self-management and differing comfort levels based on age of diagnosis; and third, perceived responsibilities for transition care preparation (for both the paediatric team and adolescents themselves) focused not only on type 1 diabetes-specific skills but also on healthcare system structures.

CONCLUSIONS: Our findings suggest that novel transition programs addressing changing inter-personal relationships, disease-specific self-management (adapted for age of diagnosis), and healthcare system navigation, supported by parents and peers, may be needed to improve transition care for adolescents with type 1 diabetes

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Patient Educ Couns. 2022 Jun;105:1510-17.

ACTIVE INVOLVEMENT OF YOUNG PEOPLE WITH T1DM DURING OUTPATIENT HOSPITAL CONSULTATIONS: OPPORTUNITIES AND CHALLENGES IN TRANSITIONAL CARE SERVICES.

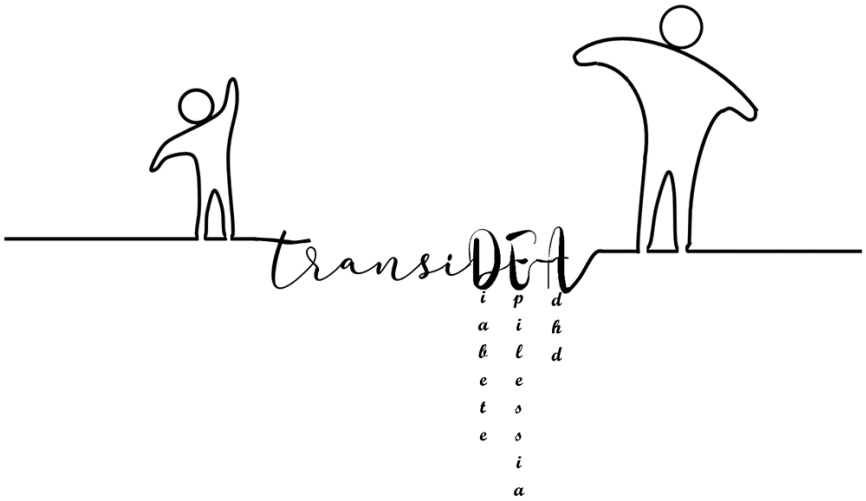
Peeters MAC, de Haan HG, Bal RA, et al.

OBJECTIVE: Little is known about active involvement of young people (YP) with type 1 diabetes (T1DM) in transitional care. This study aims to gain insight into patient-provider interactions during outpatient hospital consultations.

METHODS: Semi-structured observations (n = 61) of outpatient consultations with YP with T1DM (15-25 years) treated in 12 hospitals in the Netherlands. The consultations concerned pediatric care (n = 23), adult care (n = 17), and joint consultations (n = 21). Thematic data analysis focused on whether professionals engaged in open, in-depth conversations; used motivational interviewing techniques; involved YP in shared decision-making; and addressed non-medical topics.

RESULTS: Apart from some good examples, the healthcare professionals generally had difficulty interacting adequately with YP. They paid little attention to the YP's individual attitudes and priorities regarding disease management; non-medical topics remained generally underexposed. Conversations about daily life often remained shallow, as YP's cues were not taken up. Furthermore, decisions about personal and health-related goals were often not made together.

CONCLUSION: By adopting a more person-centered approach, professionals could empower YP to take an active role in their diabetes management. PRACTICE IMPLICATIONS: Using a structured conversation model combined with a tool to encourage YP's agenda-setting and shared decision-making is recommended for more person-centered transitional care in T1DM



ADHD

BMC Psychiatry. 2022 Apr;22:251.

IN TRANSITION WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD): CHILDREN'S SERVICES CLINICIANS' PERSPECTIVES ON THE ROLE OF INFORMATION IN HEALTHCARE TRANSITIONS FOR YOUNG PEOPLE WITH ADHD.

Price A, Mitchell S, Janssens A, et al.

BACKGROUND: National clinical guidelines emphasise the need for good communication of information by clinicians to young people and their parent/carers about what to expect during transition into adult services. Recent research indicates that of young people in need of transition for attention deficit hyperactivity disorder (ADHD), only a minority experience continuity of care into adulthood, with additional concerns about quality of transition. This qualitative analysis explored the role that information plays in the transition from child to adult mental health services for young people with ADHD, from the perspectives of clinicians working in children's services.

METHODS: Participants were recruited from National Health Service (NHS) Trusts located across the United Kingdom (UK), with varying service configurations. Twenty-two qualitative interviews were conducted with 15 paediatricians and seven psychiatrists working in child services and supporting young people with ADHD. The Framework Method was used to complete a thematic analysis of data related to the role of information in transitional care.

RESULTS: Two themes were identified in relation to the role of information in supporting transition and promoting continuity of care. Information for clinicians; about adult mental health services, the young person and their ADHD, and exchanged between services. Sharing information with young people; about transition processes, self-management, to support service engagement, and tailored to be accessible to young people with ADHD. Clinicians in children's services reported variable access to information. Clear protocols and being able to communicate about ADHD as a long-term condition, were described as having a positive impact on the transition process.

CONCLUSIONS: These findings illustrate that clear information on the transition process, and communication of evidence based and up-to-date information on ADHD as a long-term condition are essential components for clinicians supporting transition into adult services. Information exchange can be supported through transition discussions with young people, and joint meetings between services Discussions should be accompanied by accessible resources for young people and parents/carers such as leaflets and websites. Further efforts should be focussed on enabling clinicians to provide timely and appropriate information to young people with ADHD to support transition

Encephale. 2022 Oct;48:555-59.

TRANSITION FROM CHILD AND ADOLESCENT MENTAL HEALTH CARE TO ADULT SERVICES FOR YOUNG PEOPLE WITH ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD) OR AUTISM SPECTRUM DISORDER (ASD) IN EUROPE: BARRIERS AND RECOMMENDATIONS.

Maurice V, Russet F, Scocco P, et al.

Transition in mental health care is the process ensuring continuity of care of a young patient arriving at the CAMHS (Child and Adolescent Mental Health Service) age boundary within mental health services. Transition refers to a transfer to an adult mental health service (AMHS), to private care or other mental health community services. A transition plan can also lead to a managed end of specialized care with involvement of a general practitioner or social services. For young people with a diagnosis of ADHD (Attention Deficit Hyperactivity Disorder) or ASD (Autism Spectrum Disorder), two disorders that persist into adulthood, an optimal transition would ensure continuity of care or facilitate access to specialized care in the case of a discharge. Transition typically occurs during adolescence, a known sensitive period when young people may experience major changes at several levels: physiological, psychological and social. Any barrier in the transition process resulting in discontinuity of care may worsen the symptoms of ADHD or ASD and can ultimately adversely affect the global mental health of young people with such neurodevelopmental disorders. The objectives of this narrative review are: 1/to identify the barriers in the transition process in mental health services often faced by young people with these two disorders; 2/to highlight specific recommendations for strengthening the CAMHS-AMHS interface that have been proposed by various countries in Europe

Per ricevere la newsletter iscriversi al seguente indirizzo:
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Iniziativa nell'ambito del Progetto RF-2019-1237122
Il Progetto è realizzato con il contributo, del Ministero della Salute, Direzione Generale della Ricerca Sanitaria e Biomedica e della Vigilanza sugli Enti nell'ambito del Bando Ricerca Finalizzata 2019 esercizio finanziario anni 20118-2019