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Nr. 3 anno II – Nov2022/Genn2023

Per la ricerca degli articoli pubblicati nella letteratura scientifica nei mesi 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.

GENERALE

1. **TRANSITION TO ADULT HEALTH CARE: AN UNFINISHED BUSINESS.**
Aguerre, V.
Archivos Argentinos de Pediatría 120, 367–368 (2022) doi:10.5546/aap.2022.eng.367

2. **BRIDGING THE GAP- ARE WE GETTING IT RIGHT? AN AUDIT OF TRANSITION IN CRITICAL CARE.**
Ahmad, I. & Thomas, R.
Pediatric Critical Care Medicine 23, (2022) doi:10.1097/01.pcc.0000900548.83982.ac
 BACKGROUND AND AIM: We studied transition of young people (YP) with complex needs from paediatric critical care (PCC) to adult critical (ACC) services. METHOD: 1. Retrospective observational study of all YP with complex needs and PCC involvement transitioned/ eligible for transition from January 2019-July 2021. 2. Review of medical records, transition meetings, transition pathways (TP), and correspondence. RESULTS: 12 YP were identified, six female. Primary pathology was neurological in 11 and respiratory in one. 11/12 YP were non-ambulatory, 8 had severe learning difficulties, 3 had mental capacity; 9 were PEG fed, and 11 required respiratory support (6 tracheostomy and 5 noninvasively ventilated). Transition was initiated at 15years (14-17years); transfer was completed at 19years (17-20years) and was not simultaneous between teams with differences of more than a year in some. TP and advance care plan was completed in 9. Transition was paused during the pandemic. Participation in transition meetings: PCCU physicians 44%, nurses 33%, respiratory physicians 57% and neurologists in 63%; with 44%, 56%, 57% and 0% participation of corresponding adult professionals; GP/paediatricians 13% and parent(s)/YP 56%. 4/12 YP/families met ACC professionals. Parents' concerns: anxiety about their role, advocacy and bedside presence; changes in treatment, coordination of services and not knowing the GP. CONCLUSIONS: We identified delays in initiation of transition and transfer of care and inconsistent participation of professionals in meetings though communication via TP and correspondence was good. Parental involvement is fundamental to transition as many YP lacked mental capacity and there is no coordinator of care in adult services.

3. **TRANSITIONING YOUTH LIVING WITH HIV TO ADULT HIV CARE.**
Ayieko, J. & Thorp, M.
The Lancet HIV 9, e810–e811 (2022) doi:10.1016/S2352-3018(22)00303-4
 Comment on 'Transition to independent care for youth living with HIV: a cluster randomised clinical trial', Njuguna et al., 2022.

4. **CURRENT PERSPECTIVES ON PEDIATRIC INFLAMMATORY BOWEL DISEASE FOCUSING ON TRANSITIONAL CARE MANAGEMENT. WHAT SHOULD WE CONSIDER?**
Bay M, C., Núñez F, P., Quera, R. & Yarur, A. J.
Gastroenterología y Hepatología (2022) doi:10.1016/j.gastrohep.2022.10.003
 The prevalence of inflammatory bowel disease (IBD) continues to rise around the globe. Although the percentage of pediatric IBD patients seems to be increasing, rates are surprisingly heterogeneous among different populations. Although the pathogenesis of IBD is believed to be multifactorial, a genetic predisposition may be especially relevant in pediatric-onset IBD. Phenotypic characteristics can also be significantly different when comparing pediatric and adult-onset IBD. Patients that develop the disease at a younger age usually present with more extensive and more aggressive disease and develop complications faster when compared to those that develop it during adulthood. Children with IBD are found to have frequent mood disorders and have a higher risk of developing socio-economic hardship, failing to meet development milestones. Therefore, IBD management should always involve a multidisciplinary team that is

not limited to medical providers. Most institutions do not have an established transition protocol and lack the resources and training for transition care. Although there is no consensus on an optimal timing to transition the patient's care to an adult team, it is usually accepted they should be eligible for adult care when most of the key transition points have been met. Management strategies should be tailored to each patient's developmental level and environment. A successful transition can improve the long-term outcomes such as sustained remission, medication adherence, mental health and social and academic performance, while decreasing healthcare utilization. Every institution that manages pediatric IBD patients should have a well-established transition protocol in order to make sure to maintain continuity of care.

5. **MEDICAL SUMMARY TEMPLATE FOR THE TRANSFER OF PATIENTS WITH INFLAMMATORY BOWEL DISEASE FROM PEDIATRIC TO ADULT CARE.**

Benchimol, E. I. et al.

Journal of the Canadian Association of Gastroenterology 5, 3–11 (2022) doi:10.1093/jcag/gwab009

Background: The transfer of information is a key aspect of the transition of adolescent patients with inflammatory bowel disease (IBD) from pediatric to adult care. This is typically accomplished through the use of a consultation letter with a medical summary of the patient being transferred. To improve the quality and completeness of information included in a transfer letter, we developed a standardized medical summary template by integrating the feedback of adult and pediatric health care providers. Methods: To develop the letter template, we purposively sampled gastroenterologists or nurse practitioners caring for patients with IBD in four Canadian cities and invited them to take part in focus group discussions. Using a semi-structured approach, we explored the items deemed essential for inclusion in a transfer summary. Using the conventional content analysis framework, the focus group discussions were inductively coded to identify areas of priority for inclusion in the template. Results: Four focus groups were conducted, comprising 17 health care providers of 30 invited (56.7% participation). The resulting medical summary template included the following major headings: patient/disease characteristics, therapeutics history (including medications and surgeries), clinical history and current status, noteworthy investigations, history of complications (including hospitalizations), family history, immunization history and psychosocial history. The template also addressed health system process factors (i.e., urgency of transfer, mode of delivery and confidentiality) to ensure a seamless transfer to adult care. Conclusions: The standardized medical summary template should be used by pediatric providers to ensure that essential patient information and disease characteristics are sent to an adult provider.

6. **HEALTH-RELATED QUALITY OF LIFE, CONTINUITY OF CARE AND PATIENT SATISFACTION: LONG-TERM OUTCOMES OF FORMER PATIENTS OF THE TUEBINGEN TRANSITION PROGRAM (TTP) – A RETROSPECTIVE COHORT STUDY.**

Boeker, L. S. et al.

Pediatric Rheumatology 20, (2022) doi:10.1186/s12969-022-00776-6

Background: A significant number of patients in pediatric rheumatology suffer from ongoing disease activity into adulthood and thus need to be transferred into adult care. Transition as a structured individual process of preparation and patient empowerment can reduce risks of adverse long-term outcomes. The aim of this study was to measure long-term transition outcomes such as health-related quality of life (HR-QoL), patient satisfaction, and continuity of care in former patients of the interdisciplinary Tuebingen Transition Program (TTP). Methods: In an iterative team process, a standardized questionnaire was developed including the EQ-5D-5L to measure HR-QoL, visual analogue scales to measure various items of patient satisfaction, further questions on continuity of care and physical activity and physician global assessment (PGA) to determine disease activity. HR-QoL and physical activity were compared to data from the average German population. Data was analyzed descriptively, and a logistic regression analysis was performed to identify possible predictive factors for negative outcomes. Results: Response rate was 28.8% (85/295), 70.6% were female and median age was 24.1 years. 70.6% were diagnosed with juvenile idiopathic arthritis (JIA). Overall, HR-QoL was high (79.8 on the EQ VAS), yet lower than in the average population. The study cohort was more physically active than the respective average age groups. Mean patient satisfaction with pediatric care (8.4; standard deviation (SD) 1.7) and with the transition program (7.9; SD 2.6) was higher than with adult care (7.7; SD 2.2). 76.5% of participants received regular rheumatologic care after transfer.

After excluding all participants in remission, the drop-out rate was 4.7%. A low PGA at the time of transfer was associated with higher HR-QoL and patient satisfaction after transfer. Conclusions: HR-QoL of adult patients after successful transfer to adult rheumatology is reduced compared to the general population but physical activity and achievement of clinical remission could help to prevent negative long-term outcomes. Patient satisfaction and self-management of TTP patients were generally high, whereas youth-specific issues and their impact on the disease mandate greater attention. Treatment discontinuation rates were low and mostly due to remission. Further studies should focus on the identification of early predictors of long-term outcome to improve the process and outcome of transition.

7. **TRANSITION READINESS AMONG DUTCH ADOLESCENTS AND YOUNG ADULTS WITH HAEMOPHILIA: A QUESTIONNAIRE STUDY.**

Brands, M. et al.

Research and Practice in Thrombosis and Haemostasis 6, (2022) doi:10.1002/rth2.12788

Background: Around the age of 18 years, care for patients with a chronic disease, including haemophilia, is transferred from paediatric to adult care. This phase is often associated with a decrease in treatment adherence. To improve adherence and transition readiness, transition programmes were developed. These help guide adolescents through transition in a structured, comprehensive way, focussing on increasing self-management. The first Dutch transition programme was implemented in haemophilia care. Aims: To evaluate how adolescents and young adults with haemophilia in the Netherlands perceived their self-reported readiness to transfer to adult care, and to determine associated factors. Methods: In 2019, people with haemophilia evaluated various aspects of their life using a nationwide questionnaire. Adolescents aged 12-17 years and young adults aged 18-25 years completed age-specific questionnaires on their transition readiness and preparation. Possible determinants of readiness were assessed using validated questionnaires, including quality of life (CHO-KLAT), self-efficacy (HSES) and treatment adherence (VERITAS-PRO). Results: Data of 45 adolescents and 84 young adults with haemophilia (n = 60, 46.5% with severe haemophilia; n = 64, 49.6% using prophylaxis) were analysed. Of adolescents aged 12-14 years, 38.5% (10/26) reported to feel ready or almost ready to transition, which rose to 63.2% (12/19) for adolescents aged 15-17 years. Of young adults, only one participant (1.2%) reported he had not been ready to transition, and six (7.1%) did not know. Still, 13 young adults (15.5%) would have liked to receive more information on which professionals they would encounter in adult care, and 10 (11.9%) on healthcare costs. Prophylaxis use, joint bleeding rate and family history of haemophilia were not associated with readiness. Neither were quality of life, self-efficacy and treatment adherence, although positive trends were identified. Conclusion(s): Self-reported transition readiness in adolescents and young adults with haemophilia is relatively high and increases with age. Nevertheless, several improvements were suggested to further personalize and improve transitioning.

8. **CO-DESIGNED HEALTHCARE TRANSITION INTERVENTIONS FOR ADOLESCENTS AND YOUNG ADULTS WITH CHRONIC CONDITIONS: A SCOPING REVIEW.**

Bray, E. A., Everett, B., George, A., Salamonson, Y. & Ramjan, L. M.

Disability and rehabilitation 44, 7610–7631 (2022) doi:10.1080/09638288.2021.1979667

PURPOSE: To determine the scope of published literature on healthcare transition (HCT) interventions that have been co-designed with adolescents and young adults with chronic conditions, and to undertake feasibility assessments. METHODS: Using Scopus, CINAHL, Medline-Ovid, Cochrane and PsycINFO databases, publications that included a HCT intervention to support paediatric to adult healthcare transition were included. Study location, design, population, description of the intervention, co-design methods, feasibility evidenced using Bowen and colleagues' framework, and outcome measures were extracted for review. RESULTS: A total of 21 studies were included, relating to 17 co-designed HCT interventions that ranged across multiple medical specialties. There was no standard HCT intervention; characteristics, format and delivery mode varied. Only three studies reported a detailed description of the co-design method(s) used and none reported on the facilitators or barriers. Among the studies, five of Bowen and colleagues' eight dimensions of feasibility were measured. CONCLUSIONS: Despite the co-design process being neither described or evaluated extensively, all co-designed HCT interventions included in this review were considered to be feasible. Nevertheless, HCT interventions varied in their format and delivery method

making it difficult to compare between them. Furthermore, interventions were often condition-specific and not representative of the extensive range of chronic conditions. Implications for Rehabilitation: Healthcare transition interventions can improve adherence to care, health outcomes, ongoing rehabilitation, and quality of life of adolescents and young adults with chronic conditions. Healthcare transition interventions should maximise long-term functioning and prioritise rehabilitation aimed at enhancing independence and self-management skills, while reducing hospitalisations. The engagement of individuals with lived experience in the co-design of interventions has been strongly advocated as it brings unique knowledge and experience to the research process. Minimal attention has been given to the involvement of adolescents and young adults with chronic conditions in the development of healthcare transition interventions, however, healthcare transition interventions co-designed with adolescents and young adults with chronic conditions are both feasible and acceptable.

9. **TRANSITIONING BETWEEN PAEDIATRIC AND ADULT HEALTHCARE SERVICES: A QUALITATIVE STUDY OF THE EXPERIENCES OF YOUNG PEOPLE WITH SPINAL CORD INJURIES AND PARENTS/CAREGIVERS.**

Bray, E. A. et al.

BMJ Open 12, (2022) doi:10.1136/bmjopen-2022-065718

Objectives Healthcare transition (HCT) interventions are pivotal to paediatric rehabilitation. However, there has been limited research focusing on HCT in young people with spinal cord injury (SCI). To date, little has been reported on key factors that may contribute to a positive or negative transition experience and what, if any, are the gaps in the transition process. This study explored the experiences of transition from paediatric to adult healthcare for young people with SCI and parents/caregivers in pursuit of co-designing and developing an intervention to support transition. Design, setting and participants This qualitative study forms part of the planning phase of a larger participatory action research project. It supports obtaining a rich understanding of the phenomenon and the issues and actions necessary to achieve change. Semi-structured individual interviews were conducted online between April and June 2021 with young people with SCI and parents/caregivers who had transitioned or were preparing for the transition from paediatric to adult healthcare in NSW, Australia. The interviews were analysed using an inductive reflexive thematic analysis approach. Results The study recruited nine participants, five young people with SCI and four parents/caregivers. The interviews provided invaluable insight into young people with SCI and their parents'/caregivers' experiences of HCT. As HCT experiences were often less than optimal and needs were not adequately met, some recommendations were offered. These included a coordinated and streamlined handover from paediatric to adult healthcare providers, and a 'one-stop shop' for young people with SCI and their parents/caregivers to access transition information, such as how it occurs, who to call for ongoing support and advice, and tips on how to transition successfully. Conclusion Providing a coordinated and streamlined handover process as well as access to more context-related information could improve the transition experiences of young people with SCI and parents/caregivers, resulting in improved health outcomes and greater independence. Trial registration ACTRN12621000500853.

10. **DESCRIPTION AND DELAYS IN CARE IN THE BRIDGE TO ADULT CARE FROM CHILDHOOD FOR YOUNG ADULTS WITH RHEUMATIC DISEASE (BACC YARD) PROGRAM, A PEDIATRIC-TO-ADULT RHEUMATOLOGY TRANSITION PROGRAM.**

Bridges, J. et al.

Arthritis and Rheumatology 74, 3842–3844 (2022) doi:10.1002/art.42355

Background/Purpose: Children with chronic rheumatic conditions age and require transfer to adult rheumatologists for continued care. The transition period from pediatric to adult-oriented care is a high-risk time for disease flare and poor outcomes. Our objective was to design a structured transition program and determine the impact on time to first adult rheumatology appointment compared to historical controls. Methods: In 2020 we initiated a specialized transition program structure utilizing a dual adult/pediatric rheumatology clinician with the goal to improve transition outcomes, the Bridge to Adult Care from Childhood for Young Adults with Rheumatic Disease (BACC YARD) Program. Young adults who received the BACC YARD intervention were compiled into an observational registry. In this first phase of the program, an adult/pediatric rheumatologist joined the care team for the final pediatric rheumatology visit,

and then saw the patient with an adult rheumatology attending for the first visit in the adult rheumatology clinic. Requested timing for first adult rheumatology visit was determined by joint decision between the adult/pediatric rheumatologist and the pediatric attending at time of pre-transfer visit. The historical control cohort was obtained from the electronic records of Children's of Alabama and University of Alabama at Birmingham (UAB) between March 1, 2018 and March 1, 2020. All historical patients were identified who had at least two pediatric rheumatology visits prior to transfer and were successfully transferred to UAB rheumatology. Data harvest was supplemented by individual chart review to ensure that there was no documentation of visits with a rheumatologist outside of the Children's of Alabama/UAB system in the peri-transfer period. Table 1 Table 2 Results: The BACC YARD program included 86 participants from 7/2020-5/2022. 8% of participants were lost to follow-up at Children's of Alabama prior to the BACC YARD program but successfully re-established care at UAB through the BACC YARD program. 3.5% of participants were seen at other children's hospitals for a childhood-onset rheumatic disease but established adult care at UAB through the BACC YARD program. 19% of participants had upcoming appointments scheduled at UAB but not completed by time of this analysis. 65% of participants successfully completed a pre-transfer visit at Children's of Alabama and a post-transfer visit at UAB completed by 5/2022. 58% of the participants had a diagnosis of juvenile idiopathic arthritis and 30% had a diagnosis of systemic lupus erythematosus or similar connective tissue disease (-Table 1). Actual median transfer intervals were 129 days for JIA, 119 days for SLE, and 141 days for other diagnoses (-Table 2). There was a statistically significant shorter median interval between last pediatric and first adult visit in BACC YARD compared to the historical control cohort (141 days vs 261 days, respectively, $p < 0.001$; Figure 1). Conclusion: The BACC YARD Program cohort had a significantly reduced median time to first adult visit compared to historical controls. After further study, the BACC YARD intervention could be disseminated to other clinics for young adults with childhood onset rheumatic disease.

11. **MANAGEMENT OF EARLY TREATED ADOLESCENTS AND YOUNG ADULTS WITH PHENYLKETONURIA: DEVELOPMENT OF INTERNATIONAL CONSENSUS RECOMMENDATIONS USING A MODIFIED DELPHI APPROACH.**

Burton, B. K. et al.

Molecular Genetics and Metabolism 137, 114–126 (2022) doi:10.1016/j.ymgme.2022.07.012

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 ($\geq 70\%$ 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.

12. **ADOLESCENTS' AND YOUNG ADULTS' RECOMMENDATIONS FOR IMPLEMENTING HEALTHCARE TRANSITION IN RHEUMATOLOGY: A MIXED METHODS STUDY.**

Carandang, K. et al.

Arthritis Care and Research (2022) doi:10.1002/acr.24977

Objective: To elicit adolescents' and young adults' (AYAs') perspectives about how to implement the Six Core Elements of Healthcare Transition™ within rheumatology care. Methods: AYAs (16-28 years old) with self-reported rheumatic conditions were recruited through patient organizations and social media. In Phase One (QUAL), 90-minute focus groups were facilitated to elicit AYAs' reactions to Six Core Elements content. In Phase Two (QUAN), a national survey was conducted to determine generalizability of recommendations extracted from Phase One. Mixed methods analyses were conducted by a multi-disciplinary team of social science researchers, pediatric rheumatologists, and patients. Results: While focus group participants (n=39) were previously unfamiliar with the Six Core Elements, they reacted favorably to its format and content. Participants provided suggestions for how to logistically execute each component in clinic. Additionally, three overarching recommendations emerged that focused on motivating AYAs to engage: 1. Frame healthcare transition as an opportunity for empowerment, 2. Implement a structured education plan, and 3. Consider the role of parents. In line with qualitative findings, survey participants (n=137) reported that they would prefer to learn most transitional skills from and discuss developmentally specific topics with their rheumatology team. Participants reported they would likely complete programs to learn transitional skills from allied professionals, via patient portals, or in group settings. Conclusion: Incorporating patient perspectives into research and clinical practice is an opportunity to strengthen educational programs. AYAs emphasized the importance of gaining independence and becoming empowered through the healthcare transition process with structured support from their rheumatology teams.

13. **PILOT LONGITUDINAL KIDNEY TRANSPLANT TRANSITION PROGRAM PROMOTES PEER CONNECTIONS AND TRANSITION READINESS.**

Caron, R. & Richardson, K. L.

Pediatric Transplantation (2023) doi:10.1111/ptr.14468

Background: Adolescents who have received a kidney transplant are at high risk of graft rejection and transplant-related comorbidities around the time of transition from pediatric to adult care. While there has been a progress in tracking transition readiness, further work is needed to prepare adolescents for healthcare transitions. We describe a longitudinal cohort-based transition curriculum designed to prepare kidney transplant recipients for adult transplant care. Methods: Adolescent kidney transplant recipients aged 17 and older participated in the pilot cohort of the 2-year transition curriculum. Session topics included communication with the healthcare team, insurance, job skills, reflective practice, reproductive health, medications, and adult clinic introduction. Surveys were given to obtain narrative feedback, assess participant self-management behavior, and track curriculum knowledge. Results: Each participant attended an average of two sessions, with 18 out of 30 eligible adolescents participating in at least one session. After transitioning to a virtual platform, there was increased attendance of participants who live greater than 150 miles from the transplant center. Adolescents highlighted the value of the program's group structure to relate to and learn from other participants. Conclusions: The pilot transition program successfully provided adolescent kidney transplant recipients the opportunity to learn alongside their peers and gain interdisciplinary knowledge to prepare for healthcare transition. The program converted to a virtual platform during the COVID-19 pandemic, with increased accessibility for participants who live further from the transplant center. Group-based programming for adolescents should be enhanced to further prepare them for transitions to adult medicine.

14. **FACTORS RELATED TO THE READINESS OF BRAZILIAN CHRONIC PEDIATRIC PATIENTS TO TRANSITION TO CARE IN ADULT CLINICS.**

Carrara, F. S. A. et al.

Jornal de Pediatria (2022) doi:10.1016/j.jped.2022.10.006

Objective: Advances in medicine have increased the life expectancy of pediatric patients with chronic illnesses, and challenges with the guided transition of adolescents and young adults from pediatric clinics to adult clinics have grown. The aim of this study was to better understand readiness and factors related to this transition process in Brazil. Method: In this cross-sectional study of 308 patients aged from 16 to 21 years under follow-up in pediatric specialties, the degree of readiness for transition was assessed using the Transition Readiness Assessment Questionnaire (TRAQ) and its domains. Associations with demographic

data, clinical data, socio-economic level, medication adherence, family functionality, and parental satisfaction with health care were evaluated. Results: The median TRAQ score was 3.7 (3.2 – 4.2). Better readiness was associated with female patients, socio-economic class A-B, current active employment, higher level of education, not failing any school year, attending medical appointments alone, functional family, and a good knowledge of disease and medications. A low correlation was observed between TRAQ and age. TRAQ presented good internal consistency (alpha-Cronbach 0.86). In the multiple linear regression, TRAQ score showed a significant association with female gender, advanced age, socio-economic class A-B, better knowledge of disease and medications, and independence to attend appointments alone. Conclusion: TRAQ instrument can guide healthcare professionals to identify specific areas of approach, in order to support adolescents with chronic disease to set goals for their own personal development and improve their readiness to enter into the adult healthcare system. In this study, some factors were related to better TRAQ scores.

15. **IMPROVING THE TRANSITION FROM PAEDIATRIC TO ADULT HEALTHCARE: A SCOPING REVIEW ON THE RECOMMENDATIONS OF YOUNG ADULTS WITH LIVED EXPERIENCE.**

Cassidy, M., Doucet, S., Luke, A., Goudreau, A. & MacNeill, L.

BMJ open 12, e051314 (2022) doi:10.1136/bmjopen-2021-051314

OBJECTIVE: The goal of this review was to identify recommendations within the literature on how to improve the transition from paediatric to adult healthcare from the perspective of young adults (YAs) living with chronic conditions who have gone through the process. **DESIGN:** This review was conducted in accordance with JBI methodology for scoping reviews. **SEARCH STRATEGY:** We searched MEDLINE (Ovid), CINAHL (EBSCO), PsycINFO (EBSCO) and EMBASE (Elsevier) databases, and conducted a grey literature search for relevant material. The databases were searched in December 2019, and re-searched June 2020 and September 2020, while the grey literature was searched in April 2020. This scoping review focused on the recommendations of YAs with chronic conditions who have transitioned from paediatric to adult healthcare, in any setting (eg., hospital, clinic or community), and across all sectors (eg, health, education and social services). **RESULTS:** Eighteen studies met inclusion criteria for this review. These studies included YAs with 14 different chronic conditions, receiving primary health services in North America (67%) and Europe (33%). YAs' recommendations for improving the transition from paediatric to adult healthcare (n=number of studies reported) included: improving continuity of care (n=12); facilitating patient-centred care (n=9); building strong support networks (n=11) and implementing transition education preparedness training (n=7). **CONCLUSION:** Review findings can benefit service delivery by addressing important barriers to health, education, and social services for youth transitioning to adult healthcare.

16. **IMPLEMENTATION OF RHEUMATOLOGY HEALTH CARE TRANSITION PROCESSES AND ADAPTATIONS TO SYSTEMS UNDER STRESS: A MIXED-METHODS STUDY.**

Chang, J. C. et al.

Arthritis Care and Research 75, 689–696 (2023) doi:10.1002/acr.24822

Objectives: Despite poor health care transition outcomes among young adults with pediatric rheumatic diseases, adoption of transition best practices is low. We sought to understand how structured transition processes were operationalized within pediatric rheumatology practices and what factors were perceived to enable adaptations during a global pandemic. **Methods:** We conducted a mixed methods study of team leaders' experiences during an interim analysis of a pilot project to implement transition policy discussions at sites in the Childhood Arthritis and Rheumatology Research Alliance Transition Learning Collaborative. We combined quantitative assessments of organizational readiness for change (9 sites) and semistructured interviews of team leaders (8 sites) using determinants in the Exploration, Preparation, Implementation, Sustainment Framework. **Results:** Engagement of nursing and institutional improvement efforts facilitated decisions to implement transition policies. Workflows incorporating educational processes by nonphysicians were perceived to be critical for success. When the pandemic disrupted contact with nonphysicians, capacity for automation using electronic medical record (EMR)-based tools was an important facilitator, but few sites could access these tools. Sites without EMR-based tools did not progress despite reporting high organizational readiness to implement change at the clinic level. Lastly, educational processes were often superseded by acute issues, such that youth with greater medical/psychosocial complexity may not receive

the intervention. Conclusion: We generated several considerations to guide implementation of transition processes within pediatric rheumatology from the perspectives of team leaders. Careful assessment of institutional and nursing support is advisable before conducting complex transition interventions. Ideally, new strategies would ensure interventions reach youth with high complexity.

17. **TRANSITION TO ADULT SERVICES FOR YOUNG PEOPLE SUFFERING FROM LIFE-LIMITING NEURODEVELOPMENTAL DISABILITIES: A CASE SERIES.**

Cheng, H. W. B. et al.

Progress in Palliative Care 30, 364–370 (2022) doi:10.1080/09699260.2022.2066270

Due to advances in medical care, a growing number of young people with life-limiting neurodevelopmental disabilities (LLNDDs) are now surviving into adulthood. However, the traditional model of care between pediatrics and adult medicine was fragmented and did not match their multi-facet needs. A special working group that includes pediatricians, adult palliative care team, and representatives from non-governmental organizations (NGOs) was formed, providing a period of joint care of 12–24 months before transitioning to the adult palliative care team. A retrospective case series of 19 young adults with LLNDDs, recorded during the July 2015–June 2020 period at the study institution is presented. Recruited patients' age ranged from 18 to 38 (mean 26.2 [SD 6.1]). Majority of them (n = 14) require residential care at long-term care facilities (LTCFs) and high level of nursing care, which include artificial nutrition (n = 8) and home ventilator (n = 5). All patients referred to our palliative care (PC) program were engaged in a structured advance care planning (ACP) process. Seventeen patients (89.5%) had their Do-Not-Resuscitate (DNR) directives in place and two mentally competent patients completed their own advance directive (AD). All deceased (n = 10) had their DNR directives being honored. In conclusion, the palliative care needs of young adults suffering from LLNDDs should be properly addressed and implementation of a joint transitional care model between pediatrics and adult PC team is one possible method. Future research should encompass a better care model that addresses the multi-facet needs of young people suffering from LLNDDs, especially the transition from pediatrics to adult medicine.

18. **APPLYING INTERVENTIONS TO ADDRESS THE SOCIAL DETERMINANTS OF HEALTH AND REDUCE HEALTH DISPARITIES IN CONGENITAL HEART DISEASE PATIENTS.**

Cherestal, B., Hudson, Z. & Lopez, K. N.

Current Cardiovascular Risk Reports 16, 241–248 (2022) doi:10.1007/s12170-022-00710-1

Purpose of Review: Congenital heart disease (CHD) is associated with high expenditures, high complications, and the highest hospital readmissions among chronic pediatric diseases. Social determinants of health (SDOH) can further increase the burden of chronic disease on patients and families by reducing access to quality healthcare, safe neighborhoods, and healthy food. Strategies that seek to reduce disparities in the SDOH can have a positive impact on long term outcomes. This is particularly true for CHD patients where more adverse SDOH have been shown to have negative impact on patient outcomes. There is a need to determine if interventions focused on reducing disparities in SDOH utilized in other medical disciplines can be applied to pediatric cardiology. The purpose of our review is to determine how interventions implemented in other medical disciplines may be applied in pediatric cardiology populations to mitigate disparities in the SDOH. Recent Findings: There are community-based participatory research (CBPR) approaches and quality improvement (QI) initiatives that have been used to address disparities in the SDOH. Multi-disciplinary teams that incorporate community partners and have members dedicated to addressing out-of-hospital needs of patients have been trialed and successfully improved patient outcomes. These approaches focus on improving quality of care and mobilizing community resources to minimize access to care barriers. Patient and family empowerment and involvement also play an impactful role to inform research design and health policy questions to work toward promoting research and policies focused on delivering equitable care. Summary: SDOH play a major role in driving health inequities in the CHD population. Adapting interventions effective in mitigating SDOH inequities in other medical disciplines to pediatric cardiology provides the opportunity to improve access of care from the prenatal period through the transition and transfer to adult care and to reduce morbidity and mortality. Examples of intervention adaptations in pediatric cardiology include the following: (1) applying a community-based participatory research approach within interventions to improve detection of CHD and improve

perinatal outcomes, (2) developing and applying effective QI initiatives to mitigate disparities throughout the CHD lifespan, (3) meeting access to care needs of CHD patients and families for neurodevelopmental and mental health services, and (4) ensuring quality lifelong care (prenatal to adult congenital) and improving the transition and transfer to adult care.

19. **TRANSLATIONAL RESEARCH - HEALTHCARE TRANSITION READINESS, STRESS, AND RESILIENCE AMONG YOUTH WITH CHRONIC CONDITIONS AND DISABILITIES.**

Christian, B. J.

Journal of pediatric nursing 67, 172–175 (2022) doi:10.1016/j.pedn.2022.11.005

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

Chua, M. E. et al.

Neurourology and Urodynamics 41, 1650–1658 (2022) doi:10.1002/nau.25021

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.

21. **COMPARISON OF OUTCOMES BETWEEN DIRECT OR STRUCTURED PEDIATRIC-TO-ADULT HEALTHCARE TRANSITION IN COELIAC DISEASE.**

Ciacci, C., De Vivo, S., Di Feo, E. & Zingone, F.

United European Gastroenterology Journal 10, 573–574 (2022) doi:10.1002/ueg2.12290

Introduction: In celiac disease (CeD), the transition from paediatric to adult care should be a collaborative process involving patients, relatives, and physicians, to have the adolescent gradually take full responsibility for the disease. Aims & Methods: Our study aims to compare the structured transfer of care outcomes with a direct transfer from the pediatrician to adult care, in particular awareness and knowledge of CeD, adherence to the gluten-free diet, autonomy, and quality of life. In 2017, we guided the transition of a group of teenagers/young adults (YA) through a structured process with parents and the pediatrician. In January 2021, we interviewed a subgroup of them again and compared them with a similar group of CeD patients diagnosed at pediatric age who did not receive any transition of care. We evaluated the progress in knowledge of the disease, gluten-free diet (GFD) compliance, relationship with healthcare givers, autonomy in managing the disease's needs and quality of life, using standardized questionnaires in patients who underwent a transition and between this latter and those who did not perform a transition. Results: Of 58 YA

included in 2017, 38 were eligible for follow-up in 2021. Of them, we obtained complete answers in 20 (14 females, mean age 20.05±2.6 years). The remaining patients were not available or did not accept to participate. Twenty-five patients who did not receive any transition was also included (18 females, mean age 20.7±5.2 years). Those who underwent a transition, at follow-up in 2021 showed improvement only in the knowledge of the disease compared to findings in 2017. Patients who underwent a structured transition were more informed than those without transition. At the same time, as per adherence to the GFD, autonomy, and quality of life measured by the CDDUX questionnaire, the groups did not show any significant score difference. Conclusion: To our knowledge, the present study is the first to measure the outcomes of the structured vs. non-structured transition of care, showing that a structured transition improves the knowledge of the CeD but does not improve adherence, autonomy, or QoL of the young adults.

22. **TRANSITION FROM A RENAL PAEDIATRIC CLINIC TO AN ADULT CLINIC: PERSPECTIVES OF ADOLESCENTS AND YOUNG ADULTS, PARENTS AND HEALTH PROFESSIONALS.**

Crawford, K. et al.

Journal of Child Health Care 26, 531–547 (2022) doi:10.1177/13674935211028410

The management of chronic kidney disease is complex. With disease management being the responsibility of parents in the paediatric renal clinic, the responsibility is gradually shifted to adolescents and young adults during the transition to adult care. This multi-perspective qualitative study aimed to explore the experiences of adolescents and young adults, their parents and health professionals to gain an insight into transitional care. Focussing on the transition process and transfer to adult care, 18 adolescents and young adults and eight mothers participated in individual semi-structured interviews. Additionally, three focus groups were conducted with 20 multidisciplinary health professionals. Data were transcribed verbatim and analysed thematically. Similar responses from adolescents and young adults and mothers included the reluctance to leave the paediatric health service. Mothers found the transition to adult care more challenging than the adolescents and young adults. While health professionals acknowledged that engaging adolescents and young adults in their own care was challenging, they believed parents had an important role in facilitating their child's independence. This study highlights that health professionals in both paediatric and adult health services need to work collaboratively. However, importantly, health professionals need to be mindful that parents require an equal amount of engagement as adolescents and young adults, if not more, to mitigate parental barriers in achieving a successful transfer.

23. **TRANSITIONS FROM PEDIATRIC TO ADULT RHEUMATOLOGY CARE FOR JUVENILE IDIOPATHIC ARTHRITIS: A PATIENT LED QUALITATIVE STUDY.**

Currie, G. R. et al.

BMC Rheumatology 6, (2022) doi:10.1186/s41927-022-00316-5

Background: Juvenile idiopathic arthritis (JIA) is a childhood autoimmune disease that causes swelling and pain in at least one joint. Young people with JIA experience symptoms that persist into adulthood, and thus will undergo a transition including the transfer of care from a pediatric rheumatologist to an adult rheumatologist. Missing from the literature is research that centres the transition experience of young people with JIA in Canada. This goal of this patient-led research was to explore the experience young people with JIA through the process of transition. Methods: Qualitative study using the Patient and Community Engaged Research (PaCER) approach. Trained patient-researchers conducted three focus groups using the Set, Collect and Reflect PaCER process. Participants, recruited via purposive and snowball sampling using research/personal networks and social media, were young people with JIA in Canada between 18 and 28 years who had experienced with the process of transition to adult care. Recordings were transcribed verbatim. Patient researchers individually coded overlapping sections of the data, and thematic analysis was conducted. Results: In total, nine individuals participated in one or more focus groups. Three themes were identified, with sub-themes: preparedness for transition (readiness for the transfer of care, developing self-advocacy skills), continuity and breadth of care (changing relationships, culture shock, new responsibilities), need for support (social support, mental health support, and ongoing support needs – beyond the transfer of care. Peer support was a connecting concept in the support sub-themes. Transition was more than a change in primary physician but also a change in the care model and

breadth of care provided, which was challenging for young people especially if they had insufficient information. Conclusions: Transition from pediatric to adult care in rheumatology is a significant period for young people living with JIA, and this patient-led study provided insight into the experience from the perspective of young people with JIA which is critical to informing the development of supports for patients through the process. Patients, caregivers, pediatric and adult rheumatologists and members of the multi-disciplinary care team need to collaborate in terms of resources preparing for transfer, and support throughout the transition process to ensure a successful transition process.

24. **HEALTH CARE TRANSITION FROM PEDIATRIC- TO ADULT-FOCUSED CARE IN X-LINKED HYPOPHOSPHATEMIA: EXPERT CONSENSUS.**

Dahir, K. et al.

Journal of Clinical Endocrinology and Metabolism 107, 599–613 (2022) doi:10.1210/clinem/dgab796

Context: X-linked hypophosphatemia (XLH) is an inherited skeletal disorder that can lead to lifelong deleterious musculoskeletal and functional consequences. Although often perceived as a childhood condition, children and adults both experience the negative effects of XLH. Adolescents and young adults (AYAs) benefit from effective health care transition (HCT) preparation to support the transfer from pediatric- to adult-focused care. Whereas transition timelines, milestones, and educational tools exist for some chronic conditions, they do not meet the unique needs of patients with XLH. Evidence Acquisition: To produce the first expert recommendations on HCT preparation for AYAs with XLH developed by clinical care investigators and transition experts, a formal literature search was conducted and discussed in an advisory board meeting in July 2020. A modified Delphi method was used to refine expert opinion and facilitate a consensus position. Evidence Synthesis: We identified the need for psychosocial and access-related resources for disease education, genetic counseling, family planning, and AYA emancipation from caregiver-directed care. Additionally, we recognized that it is necessary to facilitate communication with patients through channels familiar and accessible to AYAs and teach patients to advocate for their health care/access to specialists. Conclusion: Clear HCT preparation guidelines and treatment-related goals are defined. Individualized timelines and practical strategies for HCT preparation are proposed to optimize health outcomes resulting from continuous clinical care throughout the patient lifecycle. We provide an expert consensus statement describing a tailored HCT preparation program specifically for AYAs with XLH to aid in the effective transfer from pediatric- to adult-focused health care.

25. **PLANNING TRANSITION IN TIMES OF TRANSITION: IS THERE A VIRTUAL PATHWAY FROM PEDIATRIC TO ADULT CARE?**

Danna, B., Maher, M., Gillispie-Taylor, M. & Vogel, T.

Arthritis and Rheumatology 74, 2568 (2022) doi:10.1002/art.42355

Background/Purpose: The BRIDGE (Baylor Rheumatology Initiative: Developing and Guiding Engagement) program is a quality improvement initiative to develop a safe, comprehensive pathway for our patients into adult rheumatology care. In designing this pathway, we utilized the core elements from gottransition.org. To accomplish elements 3 and 4, readiness and planning, our program utilizes a Transition Planning Tool (TPT), an electronic medical record (EMR)-based flowsheet that guides providers preparing patients for transition across multiple domains. In our prior analysis, components of the TPT correlated with improved transition outcomes. For both providers and patients, telemedicine is among the most profound changes stemming from the COVID-19 pandemic. Though telemedicine has made rheumatology care more accessible, we aimed to determine its impact on TPT use. Methods: TPT utilization is encouraged via a Best Practice Alert (BPA), which was incorporated into the EMR in January 2019. Provider use of the TPT for eligible patients is tracked via the BPA, allowing for quality improvement cycles to promote these important transition conversations. The visit type (telemedicine versus office visit) is also tracked. We compared how frequently providers addressed transition using the TPT in both office and telemedicine visits. We also analyzed TPT use across telemedicine visits throughout the pandemic. Results: From January 2020 to December 2021, transition planning was addressed using the TPT in 69% of all eligible visits, including both telemedicine and office visits. This was compared to 24% of eligible office visits in early 2019 when we began using the TPT BPA. Telemedicine began in May 2020, immediately comprising 36% of visits. This peaked in July 2020, wherein nearly 89% of all outpatients seen by pediatric

rheumatology were via telemedicine. Telemedicine continues to be regularly used for 20% of visits. When comparing all eligible outpatients seen in person to those seen virtually between May 2020 and December 2021, there is no statistically significant difference in how often the transition planning was addressed using the TPT ($p=0.215$). Conclusion: The pandemic created a significant pivot point in how rheumatology care is delivered. Fortunately for our patients, we found the introduction of telemedicine did not hinder the transition preparation conducted during eligible visits, as the TPT is addressed just as frequently during telemedicine as during office visits. The convenience that telemedicine affords is a tremendous benefit to our pediatric rheumatology patients. Going forward, we plan to investigate if telemedicine can be used for the sole purpose of addressing transition using dedicated virtual transition visits. As we continue to track the relationship between TPT use and successful transition into adult care, we can now investigate whether virtual transition planning leads to the same outcomes as in person.

26. **COLLABORATION BETWEEN MENTAL HEALTH AND VOCATIONAL REHABILITATION PROGRAMS FOR TRANSITION-AGE YOUTH VOCATIONAL OUTCOMES.**

Davis, M., Koroloff, N., Mizrahi, R. & Morrison, E.

Psychiatric rehabilitation journal 45, 303–313 (2022) doi:10.1037/prj0000539

Transition-age youth (TAY) with serious mental health conditions (SMHC) face many challenges as they establish adult employment. Mental health (MH) programs and vocational rehabilitation (VR) programs each provide key supports toward this goal, but collaboration is required. OBJECTIVE: The present study's objective was to assess the extent of collaboration between VR programs and MH programs that serve this age group and to identify interorganizational factors associated with collaboration levels. METHOD: Participants were 100 key informants from VR, and child mental health (CMH), transition-age youth MH (TAYMH), and adult mental health (AMH) programs in communities that received federal funding to improve services for TAY with or at risk of SMHC. Participants completed web surveys that queried four interorganizational factors and employed a modified social network analysis methodology to assess collaboration levels. RESULTS: The interorganizational factor, depth of knowledge, had a strong and consistent association with collaboration levels. There was little difference in MH-VR collaboration levels between MH programs serving different age groups. However, VR programs and CMH programs had both lower depth of knowledge of each other and lower collaboration levels, compared to TAY and AMH programs. CONCLUSIONS AND IMPLICATIONS FOR PRACTICE: Collaboration between VR and MH programs is instrumental to making sure that TAY with SMHC receive appropriate career development and employment services. Increasing the depth of knowledge that programs have about each other may enhance collaboration and appears particularly needed between VR and CMH programs. (Psycho Database Record (c) 2023 APA, all rights reserved).

27. **TRANSITIONS OF CARE IN CYSTIC FIBROSIS.**

DeFilippo, E. M. M., Talwalkar, J. S., Harris, Z. M., Butcher, J. & Nasr, S. Z.

Clinics in chest medicine 43, 757–771 (2022) doi:10.1016/j.ccm.2022.06.016

The development of formal transition models emerged to reduce variability in care, including cystic fibrosis (CF) responsibility, independence, self-care, and education (RISE), which provides a standardized transition program, including knowledge assessments, self-management checklists, and milestones for people with CF. Despite these interventions, the current landscape of health care transition (HCT) remains suboptimal, and additional focused attention on HCT is necessary. Standardization of assessment tools to gauge the efficacy of transfer from pediatric to adult care is a high priority. Such tools should incorporate both clinical and patient-centered outcomes to provide a comprehensive picture of progress and deficiencies of the HCT process.

28. **TRANSITION FOR TURNER SYNDROME: A ROLE FOR THE PRIMARY CARE PHYSICIAN.**

DeLacey, S., Berger, A., Shah, P., Brickman, W. & Habiby, R.

Hormone Research in Paediatrics 95, 242–243 (2022) doi:10.1159/000525242

Objectives Pediatric patients with Turner Syndrome often find their medical home within the Pediatric Endocrinology Clinic. However, as women transition to adult care, they typically require less endocrine

involvement, but continue to need educated providers to screen for and manage comorbidities. Several models for Turner Syndrome transition exist including transitioning care to an adult multidisciplinary clinic or adult/reproductive endocrinologist each of which present challenges. We sought to develop a process to improve transitions of care to local adult primary care providers. Methods In 2019 we began by identifying primary care providers in the home zip codes of our patients 14 years of age or older with Turner Syndrome. We then surveyed providers on their comfort with Turner Syndrome, access to common specialists, and preferred mode of education. Ultimately 16 different PCP locations were engaged to potentially receive patients. In November 2020 we initiated a comprehensive process for implementing transition including: educational documents for adult providers, a readiness assessment, patient educational materials, a release of information, and a transition policy. Results From 11/23/2020-7/30/2021, 26 patients 16 years of age or older had clinic visits, 15 of whom were 18 years old of age or older. A transition conversation was documented in 69% (18/26) of patients and the formal transition process was used with 46% (12/26) of patients. Identified barriers to using materials were inconsistent staffing, time, and integration into clinic flow. Thus far two women have completed transition to an adult provider. Conclusions Transition of care for women with Turner Syndrome has unique challenges. We have made modest progress on incorporating transition into routine care and finding adult medical homes for our patients. We have anecdotal evidence thus far on patient and adult provider satisfaction, but the active engagement between specialist and new primary care provider holds promise as a practical way to transition Turner Syndrome care that accommodates young adult patient needs.

29. **THE INPATIENT EXPERIENCE OF EMERGING ADULTS: TRANSITIONING FROM PEDIATRIC TO ADULT CARE.**

Driver, D. et al.

Journal of patient experience 9, 23743735221133652 (2022) doi:10.1177/23743735221133652

The pediatric-to-adult care transition has been correlated with worse outcomes, including increased mortality. Emerging adults transitioning from child-specific healthcare facilities to adult hospitals encounter marked differences in environment, culture, and processes of care. Accordingly, emerging adults may experience care differently than other hospitalized adults. We performed a retrospective cohort study of patients admitted to a large urban safety net hospital and compared all domains of patient experience between patients in 3 cohorts: ages 18 to 21, 22 to 25, and 26 years and older. We found that patient experience for emerging adults aged 18 to 21, and, to a lesser extent, aged 22 to 25, was significantly and substantially worse as compared to adults aged 26 and older. The domains of worsened experience were widespread and profound, with a 38-percentile difference in overall experience between emerging adults and established adults. While emerging adults experienced care worse in nearly all domains measured, the greatest differences were found in those pertinent to relationships between patients and care providers, suggesting a substantial deficit in our understanding of the preferences and values of emerging adults.

30. **A PAEDIATRIC-ADULT PROVIDER DYAD CARE MODEL IMPROVES TRANSITION FROM PAEDIATRIC TO ADULT HEALTH CARE FOR YOUTH WITH CHILDHOOD-ONSET SYSTEMIC LUPUS ERYTHEMATOSUS.**

El Tal, T., El Mutairi, A., Steiman, A. & Silverman, E.

Arthritis and Rheumatology 74, 2554–2555 (2022) doi:10.1002/art.42355

Background/Purpose: Systemic lupus erythematosus (SLE) is a chronic multi-system autoimmune disease affecting 1 in 1000 individuals, of whom 20% develop the disease in childhood. Childhood-onset SLE (cSLE) is typically more severe than adult-onset disease, with increased morbidity and mortality further amplified by risk of attrition on transfer from paediatric to adult care. Two key indicators for successful transition have been proposed: i) patient not being lost to follow up after transfer, and ii) attended all scheduled visits in adult care for at least a year after transfer. Studies have shown only 50% of paediatric rheumatology patients transition successfully to adult care. Recognizing this risk, we established a paediatric-adult provider dyad transition care model for youth with cSLE in Aug 2016. This begins with a transition clinic at The Hospital for Sick Children (Sickkids) for those turning 18, wherein patients first meet their adult care team, and then transition to Young Adult SLE (YASLE) clinic at Mount Sinai Hospital (MSH). This is a combined clinic staffed by both paediatric and adult rheumatologists that manage all patients

collaboratively until the age of 22 years, at which point patients are transferred to adult rheumatology clinic, staffed by the same adult rheumatologist. The purpose of this study was to evaluate the success of this unique transition model from paediatric to adult care. Methods: A comprehensive retrospective chart review of all cSLE (meeting 1997 ACR or 2012 SLICC Classification Criteria for SLE) graduates from Sickkids at 18 years was conducted since model initiation (Aug 2016) until Dec 2021. Based on the above indicators for “successful transition”, the following outcome measures were reviewed: number of cSLE patients who 1) graduated from Sickkids at 18 years during this time period, 2) attended transition clinic 3) planned to go to MSH vs. other clinic, 4) presented to MSH after transfer (first attrition metric) 5) continued to be followed at least a year after transfer (second attrition metric) and 6) graduated from YASLE clinic to adult rheumatology clinic. Descriptive statistics was used. Results: A total of 232 cSLE patients graduated from Sickkids over this timeframe. Of those, 58% (n=134) cSLE patients were slated for MSH (42% (n=98) for other clinics). Of 134 cSLE patients, two (1%) did not attend their SickKids transition clinic appointments yet later presented to MSH. One hundred thirty-two (99%) presented to MSH for their first visit, while 1% (n=2) were lost to follow up. Of these 132 cSLE patients, 91% (n=120) were seen within 1 year of transfer, and 99% (n=131) continued to be seen at least a year after transfer vs. one patient (1%) was lost to follow up. Of 66 YASLE clinic patients aged ≥ 22 years, 41% (n=27) graduated and transferred to adult rheumatology clinic, while the majority of the rest (n = 27, 75%) were booked for sometime in the future, or still attending a final YASLE clinic; a small number had moved away (n = 4, 11%). Conclusion: This unique transition care model rooted in a paediatric-adult provider partnership promotes timely and seamless transfer and transition, which ultimately optimizes healthcare transition outcomes.

31. **TRANSFER OF CONGENITAL HEART PATIENTS FROM PAEDIATRIC TO ADULT SERVICES IN ENGLAND.**

Espuny Pujol, F. et al.

Heart 108, 1964–1971 (2022) doi:10.1136/heartjnl-2022-321085

Objective This study assessed the transfer of patients from paediatric cardiac to adult congenital heart disease (ACHD) services in England and the factors impacting on this process. **Methods** This retrospective cohort study used a population-based linked data set (LAUNCHES QI data set: ‘Linking Audit and National datasets in Congenital Heart Services for Quality Improvement’) including all patients born between 1987 and 2000, recorded as having a congenital heart disease (CHD) procedure in childhood. Hospital Episode Statistics data identified transfer from paediatric to ACHD services between the ages of 16 and 22 years. **Results** Overall, 63.8% of a cohort of 10 298 patients transferred by their 22nd birthday. The estimated probability of transfer by age 22 was 96.5% (95% CI 95.3 to 97.7), 86.7% (95% CI 85.6 to 87.9) and 41.0% (95% CI 39.4 to 42.6) for severe, moderate and mild CHD, respectively. 166 patients (1.6%) died between 16 and 22 years; 42 of these (0.4%) died after age 16 but prior to transfer. Multivariable ORs in the moderate and severe CHD groups up to age 20 showed significantly lower likelihood of transfer among female patients (0.87, 95% CI 0.78 to 0.97), those with missing ethnicity data (0.31, 95% CI 0.18 to 0.52), those from deprived areas (0.84, 95% CI 0.72 to 0.98) and those with moderate (compared with severe) CHD (0.30, 95% CI 0.26 to 0.35). The odds of transfer were lower for the horizontal compared with the vertical care model (0.44, 95% CI 0.27 to 0.72). Patients who did not transfer had a lower probability of a further National Congenital Heart Disease Audit procedure between ages 20 and 30 compared with those who did transfer: 12.3% (95% CI 5.1 to 19.6) vs 32.5% (95% CI 28.7 to 36.3). **Conclusions** Majority of patients with moderate or severe CHD in England transfer to adult services. Patients who do not transfer undergo fewer elective CHD procedures over the following decade.

32. **TRANSITIONING ADOLESCENT MENTAL HEALTH CARE SERVICES: THE STEPS TO CARE MODEL.** **Farrell, M. L.**

Journal of child and adolescent psychiatric nursing: official publication of the Association of Child and Adolescent Psychiatric Nurses, Inc 35, 301–306 (2022) doi:10.1111/jcap.12377

TOPIC: A crisis exists regarding the number of children and adolescents who require psychiatric/mental health treatment. According to the 2018-2019 National Survey of Children’s Health, 24.4% of children, age 3-17 years, experienced one or more reported mental, emotional, developmental, or behavioral (MEDB) problems. **PURPOSE:** Transitioning from child/adolescent mental health services (CAMHS) to adult mental

health services (AMHS) requires a model of care that includes flexible policies and treatment options to accommodate individual developmental needs. Comprehensive and integrated psychiatric/mental health services are needed to improve the well-being of children and adolescents. **CONCLUSIONS:** The Steps to Care Model (STCM) provides a transition plan for adolescents into adult psychiatric/mental health services. The STCM consists of six overlapping segments: development of social and human capital, strategies for the promotion of mental health awareness and care, a shared electronic information system, comprehensive mental health care services in community-based settings, implementing education for all providers, and planned transitional services for youth.

33. **BUT WHAT DO WE MEAN BY ‘HEALTH’? A CRITICAL PERSPECTIVE ON THE CONCEPT OF HEALTH IN THE ADOLESCENT TRANSITION PROGRAM OF A NORWEGIAN UNIVERSITY HOSPITAL.**

Fløtten, K. J. Ø., Aujoulat, I., Wyller, V. B. B. & Solevåg, A. L.

BMC health services research 22, 1589 (2022) doi:10.1186/s12913-022-08903-5

BACKGROUND: To understand better what influences the practice of our transition program, we wanted to explore the underlying theory of health. **METHODS:** We performed a qualitative content analysis of the written material that guides the program, comprising a quality system guideline, two checklists, a guide to health professionals and managers, and three patient brochures. **RESULTS:** The analysis resulted in the formulation of three themes; ‘Being on top of medical management’, ‘Ability to promote own health’ and ‘Awareness of own goals and expectations’. **CONCLUSION:** Our analysis indicates that the program content revolves mainly around medical management and that other dimensions of health are not emphasised. We question what the goals of the program are and if these goals are explicit and shared among the program stakeholders. An explicit program theory is vital and needs to be evident in material supporting transition programs.

34. **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.

Developmental Medicine and Child Neurology 65, 156–157 (2023) doi:10.1111/dmcn.15342

35. **A MILESTONE STUDY OF YOUTH SERVICE TRANSITIONS IN EUROPE.**

Ford, T. & Anderson, J. K.

The Lancet Psychiatry 9, 930–931 (2022) doi:10.1016/S2215-0366(22)00371-6

36. **OPTIMISING CARE AND FOLLOW-UP OF ADULTS WITH ACHONDROPLASIA.**

Fredwall, S. et al.

Orphanet Journal of Rare Diseases 17, (2022) doi:10.1186/s13023-022-02479-3

Background: Achondroplasia is a genetic condition that can cause complications across the lifespan. While complications in childhood are well documented, the natural history of achondroplasia in adults has, until recently, been relatively lacking, and little is known about the care they receive or how they access it. The European Achondroplasia Forum undertook two exploratory surveys, one for healthcare professionals (HCPs) and one for patient advocacy group (PAG) representatives, to gain an understanding of current practices of the transition process of individuals with achondroplasia from paediatric to adult services and how adults perceive their care. **Results:** Most HCP respondents followed up more children than adults, and 8/15 responded that individuals did not transition to an adult multidisciplinary team (MDT) after paediatric care. Of 10 PAG respondents, none considered the experience of transition to adult services as good or very good and 50% considered it to be poor or very poor. A total of 64% (7/11) described the coordination of transition to adult services as “Not satisfactory” or “Poor”. HCPs and PAG representatives largely agreed on the core specialists involved in adult care (orthopaedic surgeons, physiotherapists, rehabilitation specialists, rheumatologists, clinical geneticists). However, there was a discrepancy in the understanding of healthcare needs outside of this, with PAG representatives selecting neurosurgeons and genetic counsellors, while HCPs selected pulmonologists and obstetricians/gynaecologists. There was agreement

between HCP and PAG respondents on the key barriers to effective care of adults with achondroplasia, with lack of an adult MDT, lack of interest from individuals in accessing care, and less experience in adult than paediatric MDTs ranking highly. Conclusions: This study indicates that the care and follow up of adults with achondroplasia is challenging. Individuals are often lost to, or decline, follow up as they leave paediatric care, and it is largely unknown how, where, and why adults with achondroplasia access care later in life. Lifelong, multidisciplinary specialist care led by an identified physician should be accessible to all individuals with achondroplasia. It is important to ensure barriers to optimal care are addressed to enable access to appropriate care for all individuals with achondroplasia.

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

García-Rodríguez, F. et al.

Indian Journal of Pediatrics 90, 29–37 (2023) doi:10.1007/s12098-022-04102-6

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.

38. **OUTCOMES OF TRANSITIONAL CARE PROGRAMS ON ADOLESCENT CHRONIC INFLAMMATORY SYSTEMIC DISEASES: SYSTEMATIC REVIEW AND META-ANALYSES.**

García-Rodríguez, F. et al.

Pediatric Rheumatology 20, (2022) doi:10.1186/s12969-022-00670-1

Background: Patients with juvenile chronic inflammatory systemic diseases (jCID) are vulnerable to many circumstances when transitioning to adult-centered healthcare; this increases the burden of disease and worsen their quality of life. Methods: MEDLINE, Embase, Web of Science and Scopus were searched from inception to March 16th, 2021. We included observational, randomized controlled trials and quasi-experimental studies that evaluated a transitional care program for adolescents and young adults with jCIDs. We extracted information regarding health-related quality of life, disease activity, drop-out rates, clinical attendance rates, hospital admission rates, disease-related knowledge, surgeries performed, drug toxicity and satisfaction rates. Results: Fifteen studies met our inclusion criteria. The implementation of transition programs showed a reduction on hospital admission rates for those with transition program (OR 0.28; 95% CI 0.13 to 0.61; I² = 0%; p = 0.97), rates of surgeries performed (OR 0.26; 95% CI 0.12 to 0.59; I² = 0%; p = 0.50) and drop-out rates from the adult clinic (OR 0.23; 95% CI 0.12 to 0.46; I² = 0%; p = 0.88). No differences were found in other outcomes. Conclusion: The available body of evidence supports the implementation of transition programs as it could be a determining factor to prevent hospital admission rates, surgeries needed and adult clinic attendance rates.

39. **A RANDOMIZED CONTROLLED TRIAL EVALUATING THE EFFECTIVENESS OF A SELF-MANAGEMENT PROGRAM FOR ADOLESCENTS WITH A CHRONIC CONDITION: A STUDY PROTOCOL.**

Gauci, J. et al.

Trials 23, (2022) doi:10.1186/s13063-022-06740-9

Background: Self-management support is increasingly viewed as an integral part of chronic condition

management in adolescence. It is well recognized that markers of chronic illness control deteriorate during adolescence. Due to the increasing prevalence of long-term chronic health conditions in childhood and improved survival rates of previously life-limiting conditions in children and adolescents, significant numbers of adolescents are having to manage their chronic condition effectively as they transition to adult health care. Therapy adherence has been identified as a major challenge for young people living with a chronic condition such as cystic fibrosis, diabetes, or asthma requiring long-term pharmacological therapy and/or lifestyle modifications. Most systematic reviews on self-management interventions address adult populations. Very few intervention studies are directed at adolescents with a chronic condition who are transitioning to adult health services. This protocol describes a prospective randomized controlled trial of a standardized self-management intervention program delivered to adolescents aged 15–18 years prior to their transfer to adult care. This study has been designed to provide evidence regarding self-management programs for adolescents and is the first study to use the Flinders Program with this important, under-researched age group. Methods: A randomized controlled trial is used to investigate the effectiveness of a modified adolescent-friendly version of an adult self-management program. This program is directed at improving self-management in an adolescent cohort 15–18 years of age with a chronic condition being treated in a specialist pediatric hospital. Participants will be randomized to either usual care or the modified Flinders Program plus usual care. Data collection will include measures of specific illness control, unscheduled hospital admissions, and questionnaires to record self-management competencies, quality of life, self-efficacy, and outcome measures specific to the chronic condition at baseline, 3 months, 6 months, and 12 months after delivery. Discussion: This study will provide a better understanding of the elements required for effective self-management programs in adolescents with a chronic condition and address some important knowledge gaps in current literature. The study will be carried out in collaboration with the Discipline of Behavioural Health at Flinders University, Adelaide, Australia, in order to inform the development of an adolescent version of the successful and validated Flinders Program™. Trial registration: Australian and New Zealand Clinical Trials Registry (ACTRN12621000390886). Registered on April 8, 2021.

40. **THE ROLE OF SELF-EFFICACY IN HIV TREATMENT ADHERENCE AND ITS INTERACTION WITH PSYCHOSOCIAL FACTORS AMONG HIV POSITIVE ADOLESCENTS IN TRANSITION TO ADULT CARE IN KENYA.**

Gitahi-Kamau, N., Wahome, S., Memiah, P. & Bukusi, E. A.

Vulnerable children and youth studies 17, 308–319 (2022) doi:10.1080/17450128.2021.1954736

Adolescents and young adults (15-24 yrs.) have poorer HIV clinical outcomes than adults. Despite this, there is minimal data on individual-level factors such as self-efficacy towards antiretroviral adherence among perinatally infected adolescents living with HIV in sub-Saharan Africa. Our study examined the interaction between antiretroviral treatment adherence self-efficacy and other psychosocial factors among adolescents receiving care in Nairobi, Kenya. We enrolled perinatally infected Adolescent Living with HIV (ALWHIV) 16-19 yrs. who were accessing care routinely at the HIV clinic. We measured self-reported ART adherence (7-day recall) and defined optimal adherence as >95%, and conducted a regression analysis to identify independently associated factors. Mediation analysis explored interactions between the psychosocial variables. We enrolled 82 ALWHIV median age 17 (IQR 16,18) who had been on ART for a median age of 11 yrs. (IQR 7,13). Sixty-four per cent (52) of the ALWHIV reported optimal adherence of >95%, and 15% reported missing doses for three or more months. After controlling for the other covariates, self-esteem, high viral load and an adherence level > 95% were significantly associated with adherence self-efficacy. Self-esteem was significantly associated with adherence self-efficacy and social support ($p < 0.001$ and $p = 0.001$), respectively. The paramed test indicated that the association between self-efficacy and adherence was mediated by self-esteem with a total effect of OR 6.93 (bootstrap 95% CI 1.99-24.14). Adherence self-efficacy was also mediated by self-esteem in developing adherence behavior. Interventions focused on increasing adherence among ALWHIV should include self-esteem building components.

41. **TRANSITION OF CARE IN PATIENTS WITH EPIDERMOLYSIS BULLOSA: A SURVEY STUDY.**

Han, J. et al.

Pediatric Dermatology (2022) doi:10.1111/pde.15232

There are little published data on the transition of care in EB. 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. The majority of participants had not discussed the transition of care with their healthcare providers, nor the healthcare needs to be required as an adult. Ongoing pediatric subspecialty care was reported by 12% of adults, most commonly in pediatric dermatology. Identified barriers to transition included the perceived lack of adult providers' knowledge about EB patient healthcare needs. The results suggest the need for transition guidelines, early discussions with families about transition, and practical information for the adult providers accepting care.

42. **ASSESSMENT OF TRANSITION READINESS TO PREDICT HEALTH CARE UTILIZATION DURING TRANSITION TO ADULT CARE IN SICKLE CELL DISEASE.**

Howell, K. E. et al.

Expert review of hematology 15, 1063–1072 (2022) doi:10.1080/17474086.2022.2144216

BACKGROUND: Transition-age patients with sickle cell disease (SCD) are at risk for poor outcomes associated with incomplete transition readiness and neurocognitive deficits. Study objectives were to: 1) test if a SCD-specific measure of self-management skills was associated with transition outcomes and 2) evaluate if caregiver-reported executive functioning was associated with self-management skills and transition outcomes among youth with SCD. **RESEARCH DESIGN AND METHODS:** Youth/caregivers were selected from a longitudinal cohort study. Caregivers completed the Behavior Rating Inventory of Executive Function (BRIEF); caregivers and youth completed the Self-Management Skills Checklist (SMSC) at a median age of 16.8 ± 0.6 years. Non-parametric tests compared SMSC and transition outcomes. Regression assessed the incremental validity of SMSC in predicting transition outcomes. **RESULTS:** In total, 95 participants (54% male, 55% severe genotype) completed the SMSC assessment. Most participants (87%) transferred to adult care within six months and 87% were retained for at least 12 months. BRIEF and caregiver-reported SMSC assessments were weakly, negatively correlated ($\rho = -0.25$, $p = 0.0392$) but were not significant in predicting transition outcomes ($p > 0.05$). **CONCLUSIONS:** The SMSC and executive function did not predict adult care engagement. Development of readiness assessments that predict care engagement and reflect self-efficacy is important for monitoring transition-aged patients with SCD.

43. **PSYCHOLOGICAL/SOCIAL FACTORS ASSOCIATED WITH TRANSFER READINESS IN YOUNG PEOPLE WITH JUVENILE IDIOPATHIC ARTHRITIS.**

Howsley, P. et al.

Clinical Rheumatology 41, 3777–3782 (2022) doi:10.1007/s10067-022-06237-5

The aim of this study is to investigate the relationships between psychological/social factors and transfer readiness from paediatric to adult rheumatology services in pre- and post-transfer young people (YP) with juvenile idiopathic arthritis (JIA). Participants completed questionnaires measuring a broad range of psychological/social factors (generalised anxiety, pain-specific anxiety, pain-related thoughts, depression, prosocial behaviours, problem behaviours, arthritis-related quality of life (QoL), social support, family functioning) and transfer readiness (transfer-related knowledge and skills, health-related self-efficacy). JIA disease activity was measured on the same day as the questionnaires. This study received all relevant ethical and regulatory approvals, and informed consent was received from or on behalf of all participants. In total, 40 pre-transfer YP with JIA aged 10–16 years ($M = 13.54$ years, 26 females) and their parents/guardians participated at Sheffield Children's NHS Foundation Trust, and 40 post-transfer YP with JIA aged 16–24 years ($M = 20.16$ years, 26 females) participated at Sheffield Teaching Hospitals NHS Foundation Trust. For both pre- and post-transfer YP, greater transfer readiness was associated with lower generalised anxiety levels, lower pain-specific anxiety levels, fewer pain-related thoughts, lower depression levels, fewer problem behaviours, better arthritis-related QoL, better social support, and better family functioning. Greater transfer readiness was also associated with less JIA disease activity for post-transfer YP only. A broad range of psychological/social factors were associated with transfer readiness in pre- and post-transfer YP with JIA. This highlights the importance of assessing and addressing YP's psychological/social well-being during their transition to adult services. **Key Points** • A wide range of

psychological and social factors may be associated with how ready young people with juvenile idiopathic arthritis feel to move from paediatric to adult rheumatology services. • Transition outcomes may be improved by comprehensively assessing and addressing young people's psychological and social well-being.

44. PEDIATRICIAN AND CHILD ADOLESCENT PSYCHIATRIST PERSPECTIVES OF COORDINATED CARE FOR EMERGING ADULTS.

Huginin, J. et al.

Journal of Adolescent Health (2023) doi:10.1016/j.jadohealth.2022.12.002

Purpose: To explore pediatrician and child/adolescent psychiatrists' perspectives of the role of coordinated care for emerging adults with serious mental health conditions, particularly as they transition to adult care. **Methods:** Semi-structured individual interviews of a purposive sample of 10 pediatricians and 11 child/adolescent psychiatrists in Massachusetts were used to explore coordinated care for emerging adults. Following verbatim transcription and double coding, we conducted a thematic analysis to identify key themes. Care coordination concepts explored included a case discussion, teamwork, communication methods, medication management, transition to adult care, the healthcare home, and youth and family role. Organizational and societal barriers were also discussed. **Results:** Providers described key barriers to continuous, coordinated care for youth with serious mental health conditions, including poor communication systems between providers, no organized process for the transition from pediatric to adult care, state licensing laws (particularly impacting college-age youth), inadequate connection to community supports, and poor reimbursement rates for psychiatric care. Termination of primary care in young adults and inadequate medication side effect monitoring were described as key gaps in care. **Discussion:** The current system of coordinated care for emerging adults with serious mental health conditions is a perfect storm of challenges that creates a vicious cycle of interconnected barriers which lead to fragmented, discontinuous, and sub-par care for this population.

45. HIV CARE CONTINUUM OUTCOMES AFTER TRANSITION TO ADULT CARE AMONG A PROSPECTIVE COHORT OF YOUTH WITH HIV IN ATLANTA, GEORGIA.

Hussen, S. A. et al.

Clinical infectious diseases: an official publication of the Infectious Diseases Society of America (2022) doi:10.1093/cid/ciac904

BACKGROUND: Healthcare transition from pediatric to adult-oriented clinical settings is often viewed as a high-risk time for care disengagement. However, there is a paucity of prospective, longitudinal research documenting HIV care outcomes after HCT. **METHODS:** We conducted a prospective, observational cohort study of healthcare transition among youth enrolled at an HIV care center in Atlanta, Georgia. Pediatric clinic patients (average age 24 years) were enrolled up to three months prior to expected transition, and followed to determine linkage, retention, and viral suppression in adult care through electronic medical record abstractions at: baseline, 6-, 12-, 18- and 24-months. **RESULTS:** The majority of our cohort (N = 70) was male (88.6%), Black (92.9%) and acquired HIV horizontally (80%). Most of our cohort was linked to adult care by 12 months (84%) after enrollment. Of those who linked to adult care by 12 months, retention rates were 86% (95% CI: 78-94%) at 6 months, 76% (95% CI: 66-86%) at 12 months, and 66% (95% CI: 55-78%) at 18- and 24-months. Once in adult care, the proportion with viral suppression was stable (73% at baseline, 74% at 6 months, 77% at 12 months, 67% at 18 months, and 78% at 24 months). **CONCLUSIONS:** Although most youth successfully linked to adult care, retention rates decreased over the 24-month follow up period. Rates of viral suppression were stable for those who remained in care. Strategies to support retention in adult care will be critical to optimizing transition for youth with HIV.

46. CURRENT TRANSITION PRACTICE FOR PRIMARY IMMUNODEFICIENCIES AND AUTOINFLAMMATORY DISEASES IN EUROPE: A RITA-ERN SURVEY.

Israni, M. et al.

Journal of Clinical Immunology 43, 206–216 (2023) doi:10.1007/s10875-022-01345-y

Background: Due to the absence of curative treatments for inborn errors of immunity (IEI), children born

with IEI require long-term follow-up for disease manifestations and related complications that occur over the lifespan. Effective transition from pediatric to adult services is known to significantly improve adherence to treatment and long-term outcomes. It is currently not known what transition services are available for young people with IEI in Europe. Objective: To understand the prevalence and practice of transition services in Europe for young people with IEI, encompassing both primary immunodeficiencies (PID) and systemic autoinflammatory disorders (AID). Methods: A survey was generated by the European Reference Network on immunodeficiency, autoinflammatory, and autoimmune diseases Transition Working Group and electronically circulated, through professional networks, to pediatric centers across Europe looking after children with IEI. Results: Seventy-six responses were received from 52 centers, in 45 cities across 17 different countries. All services transitioned patients to adult services, mainly to specialist PID or AID centers, typically transferring up to ten patients to adult care each year. The transition process started at a median age of 16–18 years with transfer to the adult center occurring at a median age of 18–20 years. 75% of PID and 68% of AID centers held at least one joint appointment with pediatric and adult services prior to the transfer of care. Approximately 75% of PID and AID services reported having a defined transition process, but few centers reported national disease-specific transition guidelines to refer to. Conclusions: Transition services for children with IEI in Europe are available in many countries but lack standardized guidelines to promote best practice.

47. **TRANSITION INTERVENTIONS FOR ADOLESCENTS ON ANTIRETROVIRAL THERAPY ON TRANSFER FROM PEDIATRIC TO ADULT HEALTHCARE: A SYSTEMATIC REVIEW.**

Jegede, O. E. & van Wyk, B.

International Journal of Environmental Research and Public Health 19, (2022) doi:10.3390/ijerph192214911
Globally, adolescents living with HIV (ALHIV) experience poor health outcomes such as low retention in care, ART non-adherence and viral non-suppression. These outcomes coincide with the period during and after their transition from pediatric to adult healthcare. This study aimed to systematically describe the compendium of transition interventions and synthesize the effects of such transition interventions on adherence to ART, retention in care and viral load suppression. Seven databases and Google Scholar were searched and the review findings were reported according to the Preferred Reporting Items Stipulated for Systematic Reviews and Meta-Analyses. The risk of bias and the strength of evidence were assessed using the National Institutes of Health quality assessment tool for observational cohort and cross-sectional studies. Seven studies (two cross-sectional, two retrospective cohort and three prospective cohort studies), with sample sizes ranging from 13 to 192, were included in the narrative synthesis. There was high-quality evidence that these interventions—Individualized care plans, communication, psychological support, and health and sexual education and mHealth—improved adherence, retention in care and viral load suppression at post-transition over the short and long term. In contrast, group transition intervention produced weak quality evidence. Hence, transition interventions including a combination of the high-quality evidenced interventions mentioned above can improve treatment outcomes for adolescents on ART.

48. **PEDIATRIC TO ADULT NEPHROLOGY TRANSITION PROGRAM: THE NORTHWESTERN EXPERIENCE.**

Kang, J. H., Nishi, L. & Ghossein, C.

Journal of the American Society of Nephrology 33, 437 (2022)

Background: Young adults (YA) with chronic kidney disease (CKD) transitioning care from pediatric to adult medical facilities face many obstacles. Six years ago, the Nephrology division at Northwestern Medicine (NM) implemented a transition program for YA with CKD. The initial transfer visit was led by an adult nephrology team in the pediatric nephrology space at Lurie Children's Hospital. Follow up care then occurred in the adult nephrology clinic at NM. Here we report on our outcomes. Methods: All patients that were seen in transition clinic between 2016-2021 were included. Successful transfer of care was defined as a completed transition clinic appointment. Successful transition was defined as one or more completed appointments in the NM adult nephrology clinic. An enhanced communication protocol of phone calls, texts, and emails from the adult nephrology team would be triggered for any patients who failed to show up for their follow up appointment. Results: There were 141 patients who completed their transfer visits. 67 (47%) were female and 74 (53%) were male, with the most common diagnoses being congenital kidney disease

(30%) and glomerular disease (24%). 82 patients (58%) were insured with private insurance, 54 (38%) with government insurance, and 5 (4%) had no insurance. Five patients were discharged from nephrology care at the initial transition clinic appointment. Six patients transitioned to external nephrology providers. Successful transition initially occurred in 93 patients (74%) with 32 (26%) patients missing their follow up appointment. Sixteen patients (13%) subsequently successfully transitioned after the enhanced communication protocol was activated, increasing our successful transition rate to 87%. Sixteen patients (13%) were lost to follow up. Conclusions: Based on our experience, successful pediatric to adult transition can be achieved with a dedicated transition program. Enhanced communication protocols for those missing their first adult nephrology clinic appointment can improve successful transition.

49. **CASE PRESENTATION AND PANEL DISCUSSION: TRANSITIONS IN CARE.**

Katz, J. et al.

JPEN. Journal of parenteral and enteral nutrition 47 Suppl 1, S35–S37 (2023) doi:10.1002/jpen.2438

There is evidence that significant quality problems arise as patients transition in care from one setting to another. Attention to nutrition during transitions of care is important to avoid complication. During the American Society for Parenteral and Enteral Nutrition 2022 preconference course, nutrition during transition of care from pediatric to adult care, from the intensive care unit to the hospital floors and from the hospital to home was addressed.

50. **VIRTUAL PEER-TO-PEER MENTORING FOR ADOLESCENTS WITH CONGENITAL HEART DISEASE: AN IMPLEMENTATION STUDY.**

Killackey, T. et al.

Canadian Journal of Cardiology 38, S227–S228 (2022) doi:10.1016/j.cjca.2022.08.220

Background/Purpose: Congenital heart disease (CHD) is the most common birth defect in Canada, affecting approximately 1 in every 100 children. Adolescents with CHD (AWCHD) must learn to independently manage their disease and transition to adult care, yet many young Canadians fail to attend an adult CHD clinic. Patients who do not receive follow-up care have increased risks of requiring urgent interventions and hospital admission. Interventions designed to support coping and self-management are key strategies to improve the ability of AWCHD to manage their health and successfully transition to adult care. Peer support is one intervention that has been shown to improve health outcomes and symptoms in people with chronic disease, however no study to date has examined the role of peer mentorship in supporting AWCHD. This project tailored an existing virtual peer-to-peer mentorship program (iPeer2Peer© (iP2P) program) to meet the needs of AWCHD. The study aims were twofold: (1) To determine whether the iP2P program can be sustainably integrated into clinical practice within the CHD Transition Program at The Hospital for Sick Children, and (2) To examine the impact of the iP2P program on self-management and quality of life. Methods/Results: A prospective feasibility study of the iP2P CHD program was conducted to determine whether the program could be integrated and sustained in practice (primary outcome) and to examine program effectiveness (secondary outcome). A mixed methods design was used to measure feasibility of implementation (i.e. acceptability, adoption, appropriateness, etc.) and effectiveness of the iP2P CHD program (i.e. self-management and transition readiness, quality of life, perceived social support, etc.). Semi-structured interviews were conducted to determine program satisfaction and engagement. At the time of submission, 8 peer mentors had been successfully recruited and completed the 3-day training program. Early analysis of implementation outcomes demonstrated that identification and recruitment of suitable mentors may be more challenging in this population than previous groups. This may be related to factors such as range of disease severity and the nature of co-occurring developmental, social and mental health challenges in this population. Conclusion/Implications for Practice: There is an urgent need to implement virtual support interventions as the COVID-19 pandemic has limited opportunities for AWCHD to receive social support. Preliminary results suggest that the iP2P CHD virtual peer support program can be feasibly implemented within the CHD Transition Program. Peer mentor recruitment and training is feasible, and participation in the peer mentorship program is of interest to both mentors and mentees.

51. **PROVIDER EDUCATIONAL NEEDS AND PREFERENCES REGARDING TRANSITION FROM**

PEDIATRIC TO ADULT CARE IN A PEDIATRIC HEALTH SYSTEM.**Kirkpatrick, L. et al.**

The Journal of continuing education in the health professions (2022) doi:10.1097/CEH.0000000000000479

INTRODUCTION: There is limited evidence on educational needs and preferences of pediatric health care professionals regarding transition from pediatric to adult health care. **METHODS:** We distributed an anonymous online survey to physicians and advanced practice providers at a large, free-standing children's hospital and associated primary care network to assess attitudes, practices, and educational preferences about transition. We analyzed data with descriptive statistics, chi-square, and logistic regression. **RESULTS:** A total of 178 providers responded (20% response rate) across 31 specialties (66% attending physicians, 19% fellows, and 15% advanced practice providers). Less than half (43%) were comfortable in their knowledge of transition, with fellows reporting significantly lower comfort than attendings ($P < .05$). In total, 47% reported annually discussing transition with their patients (fellows: 17% vs. attendings: 50%, $P < .05$). Educational topics of greatest interest included legal (71%) and financial concerns (69%), whereas preferred educational formats included Grand Rounds/lectures (68%) and webinars (63%). Facilitators to transition included lists of local adult providers for transition (89%), parent/family educational resources (88%), and a medical summary template in the electronic health record (85%). **DISCUSSION:** Major gaps exist in attitudes and practices related to transition. Identified educational strategies may serve as targets to improve the transition process through educational interventions.

52. **EDITORIAL: CHILDHOOD ENDOCRINE AND GENETIC DISORDERS: IMPROVING ADULT OUTCOMES.****Levitsky, L. L.**

Current Opinion in Endocrinology, Diabetes and Obesity 30, 14–15 (2023)
doi:10.1097/MED.0000000000000786

The Growth and Development section of Current Opinion this year brings you a review of an important element of care of young people with growth disorders – transition to adult care.

53. **PARENTAL PERSPECTIVES ON HEALTH CARE TRANSITION IN ADOLESCENT AND YOUNG ADULT SURVIVORS OF PEDIATRIC CANCER.****Loecher, N., Tran, J. T. & Kosyluk, K.**

Journal of adolescent and young adult oncology (2022) doi:10.1089/jayao.2022.0097

The health care transition (HCT) from pediatric to adult care is pivotal for childhood cancer survivors (CCS) and their parents. However, there is little research examining parental needs during HCT, despite this being a key predictor of successful HCT. The goal of this study was to investigate the needs of parents of CCS during HCT. Using an integrative review of the literature structured around the social-ecological model (SEM) of CCS transition readiness yielded 454 articles, including three hand-searched articles. Six articles were included in the final analysis. Data were extracted into nine factors derived from SEM. Articles were published within the last decade, largely qualitative, and mainly examined parents and CCS together. Parents most frequently mentioned relationships with their practitioner and CCS as contributing to HCT readiness, while abstract factors, such as goal-setting and expectations around HCT, were not mentioned. Our results are limited by the dearth of research on this topic, the homogeneity of samples, and joint presentation of CCS and parent data. Nonetheless, our results indicate that parents do not weigh all aspects of SEM equally, with macrolevel barriers, such as sociodemographic factors being viewed as less salient for HCT readiness. Parents mostly focused on interpersonal factors, such as their relationships with practitioners and CCS, indicating that practitioners should emphasize these in preparing parents for HCT.

54. **TRANSITIONING TO ADULT CARE - A NEW PROJECT FOR YOUNG ADULTS WITH DUCHENNE MUSCULAR DYSTROPHY.****Longford, E., Smith, L., Curtis, A. & Guerrero, J.**

BMJ Supportive and Palliative Care 12, A26 (2022) doi:10.1136/spcare-2022-HUNC.64

Over the past three years Wirral Hospice St John's and Claire House Children's Hospice have collaborated on projects aiming to provide continuing care for young adults transitioning from paediatric to adult services.

The success of this project has been previously presented; the feedback has been overwhelming positive. This initial cohort was comprised of patients with severe learning difficulties and support for parents was a significant focus. We now recognise the need to extend this offer to other young adults entering the transition process. The next phase aims to engage with young adults with Duchenne Muscular Dystrophy (DMD). DMD is a genetic disorder characterised by progressive muscle degeneration typically presenting in childhood. Until recently survival beyond teenage years was unusual, thanks to advances in respiratory care, life expectancy now stretches into the third decade. Our aim was to engage young adults with DMD in adult palliative care services. We provide physical and psychological support for young adults and their families, as well as offer engagement in advance care planning. We recognise the shift for families, as care becomes more patient rather than family focused and aim to support young adults as the expectation moves to them taking responsibility for their own care. This project is ongoing. Four young adults with DMD are engaged in adult palliative care services. These patients have seen consultants initially then linked into dietician, counselling and physiotherapy support as appropriate. Connections made with adult specialist services and when admission to hospital has been required, specialist palliative care has supported. Support has been offered to parents. This has presented challenges for adult services in terms of equipment/services offered; we continue to adjust to the requirements of younger patients. There is significant unmet need for young adults facing the daunting prospect of leaving paediatric services, this project has shown that palliative care services can work together to improve this transition.

55. **TRANSITION READINESS IN KIDNEY DISEASE.**

Lopez, I., Coufal, S. K., Shappell, T. & Ku, E.

Journal of the American Society of Nephrology 33, 962–963 (2022)

Background: To mitigate the challenges faced by patients transferring into adult care, we established a Transition Clinic to support adolescents with kidney disease during the transition to adult care. The clinic focused on improving self-efficacy including educating patients about their baseline kidney function, laboratory values, and concrete health care management skills necessary for post-kidney transplant care. The clinic also performed assessments of mental health. Methods: 40 participants >18 years of age were asked to complete a survey on their transition experience, quality of health (using the PROMIS survey), and transition readiness. Subjects were asked to self-report hospitalizations and emergency room visits over the prior 12 months. Chi square tests were used to relate knowledge about kidney disease and quality of mental health with use of emergency room or hospitalizations. Results: The mean age of participants was 23 and 52% had a functional kidney transplant. Overall, knowledge regarding kidney disease (Figure 1) and participants' self-reported mental health varied (Figure 2). We found that 60% of patients who did not know their baseline serum creatinine had at least 1 emergency room visit in the past year. Additionally, 66% of patients who rated their mental health "very good" had no hospital overnight stays in the past year, versus 65% of patients who rated their mental health poor had at least 1 overnight stay. Conclusions: We found that individuals who did not know their baseline serum creatinine were more likely to have emergency room visits and subjects who reported poor mental health tended to be admitted to the hospital. Addressing specific knowledge gaps and recognizing individuals with poor mental health may improve outcomes in this vulnerable population. (Figure Presented).

56. **TRANSITION READINESS BEFORE VERSUS AFTER ADOLESCENTS WITH RHEUMATIC DISEASE TRANSITION TO ADULT CARE.**

Ma, C. et al.

Arthritis and Rheumatology 74, 3822–3823 (2022) doi:10.1002/art.42355

Background/Purpose: The transition from pediatric to adult rheumatology care is associated with increased disease activity and morbidity for patients with rheumatic disease. Consequently, there has been increasing focus on transitional programs involving multidisciplinary teams to improve self-management skills and other transition-related outcomes. Unfortunately, there is a lack of research surrounding the final stage of transition that occurs immediately after patients transition to adult care. Thus, our study aimed to characterize healthcare self-management skills and assess how transition readiness may compare pre-transfer to adult care to post-transfer in a cohort of youth who were seen in a multidisciplinary rheumatology transition program. Methods: Youth aged 17-18 years old with JIA or jSLE were recruited in our

multidisciplinary pediatric rheumatology transition clinic and followed after they transitioned to adult care at age 18. Upon transfer to adult care, patients are seen by an adult rheumatologist and an Advanced Clinical Practitioner in Arthritis Care (ACPAC) physiotherapist who sets goals and coaches patients on self-management skills and strategies. Prior to and after the transfer to adult care, all patients completed the TRANSITION-Q, a 14-item, validated, self-administered questionnaire assessing healthcare self-management skills where higher scores (max. 100) indicate greater transition readiness. Total scores and frequencies of responses to each question (“never”, “sometimes” or “always”) were recorded, and a paired t-test determined compared the pre-to post-transfer scores. Results: Of 33 patients (n=27 female, n=25 JIA), the means (SD) and ranges of TRANSITION-Q scores prior to compared to post-transfer to adult care were 68.0 (13.4, range 38-92) versus 83.5 (15.6, range 48-100) ($p < 0.01$). Total TRANSITION-Q scores increased in 31 (94%) patients. Domains where the greatest number of patients improved pertained to traveling to doctors appointments on their own, contacting the doctor when they need to, booking their own doctor’s appointments, and seeing the doctor on their own. Conclusion: Youth in our transition clinic show improved self-management skills after transitioning to adult care as shown by increases in TRANSITION-Q scores. Notably, TRANSITION-Q scores prior to transfer reveal that patients generally have considerable room for improvement in self-management skills suggesting that they can benefit from support even after transfer. While reasons for improvement are likely multifactorial and related to our transition program and patient maturation, the involvement of the ACPAC physiotherapist who works individually with each patient after transfer to adult care to set goals for improvement likely plays a key role. Future work will involve increasing our sample size and comparing with patients who did not have access to an ACPAC after transfer.

57. **INSIGHTS ON TRANSITION OF CARE-RELATED DEATHS OF YOUNG ADULTS WHO WERE RECIPIENTS OF PEDIATRIC LIVER TRANSPLANTATION.**

Mandato, C. & Vajro, P.

Journal of Pediatric Gastroenterology and Nutrition 75, 551–552 (2022)
doi:10.1097/MPG.0000000000003591

Commentary on “Education and Psychosocial Factors Predict Odds of Death After Transfer to Adult health Care in Pediatric Liver Transplant Patients” by Stevens et al., 2022

58. **TRAJECTORIES OF PSYCHIATRIC CARE IN AN INNOVATIVE OUTPATIENT PROGRAM DESIGNED FOR TRANSITIONAL AGE YOUTH (16 TO 24 YEARS OLD) IN FRENCH-SPEAKING BELGIUM: RESULTS OF A RETROSPECTIVE STUDY.**

Marchini, S., Reis, J., Hussein, I. & Delvenne, V.

European Psychiatry 65, S100–S101 (2022) doi:10.1192/j.eurpsy.2022.288

Introduction: Transitional age youth (TAY), from 16 to 24 years old, are a particularly at-risk population in mental health. They have specific needs, not currently covered between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS), mainly because of existing barriers. Objectives: This retrospective study was carried out to describe sociodemographic and clinical characteristics of 243 patients who attended a new TAY-tailored outpatient psychiatric program. Methods: Outcomes related to trajectories of psychiatric care were analysed, such as leading symptom, consultation’s referral and requester, and final orientation. Results: The sample was mainly composed by female; the average age was 18.7 (± 2.0) years. Leading symptoms were divided into three dimensions: internalizing (67.5%), externalizing (21.8%) and psychotic (10.7%). Leading symptom differed according to sex ($p < 0.001$), with internalizing symptoms more frequent in women, externalizing and psychotic symptoms more frequent in men. Patients presenting psychotic symptoms were significantly older than both those with internalizing ($p=0.016$) and externalizing symptoms ($p=0.008$). After first assessment, 81.5% of youth were followed-up in our specific outpatient program, without any difference according to sex ($p=0.081$) or leading symptom ($p= 0.092$). Overall and final psychiatric orientation are showed in the flowchart. Conclusions: This TAY-tailored psychiatric outpatient program represents an innovative contribution to reinforce CAMHS-AMHS interface in French-speaking Belgium. This study enlightens the importance to enhance clinical expertise in youth mental health. Classical boundaries, determined by artificial variables such as age or type of psychopathology, do not seem to be efficient criteria to achieve a good quality psychiatric evaluation

and continuity of care in TAY. (Figure Presented).

59. **TRANSITION TO ADULT CARE IN FINNISH ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS.**

Mikola, K. et al.

Scandinavian Journal of Rheumatology 51, 490–494 (2022) doi:10.1080/03009742.2022.2040117

Objective: The symptoms of juvenile idiopathic arthritis (JIA) and the necessity for continuous treatment may persist in adulthood. Therefore, patients with JIA need to be appropriately transferred to adult care. We aimed to analyse the timing of the patients' transition to adult care, and patients' self-management skills with the process and the quality of the transition. Method: This study included 161 Finnish participants of the population-based Nordic JIA cohort who attended a 17 year follow-up appointment. Special attention was paid to the three groups: those referred by the paediatric rheumatology outpatient clinic to primary healthcare (PHC), those who were directly transferred to adult rheumatology care, and those who were later referred. Results: A total of 136 patients (84%) were eligible to participate in the study, and 40% of them were directly transferred to an adult rheumatology clinic. Of the patients, 72% eventually ended up being referred to an adult rheumatology outpatient clinic. However, 16% of the patients in the PHC group had active disease during the study appointment and were referred to adult services after the study visit. Conclusion: This study reveals the need to improve the transition process from paediatric care to adult care and to find the variables that can indicate the need for immediate transition. Although challenging, it is important to avoid treatment delay in adult patients with JIA who may have active disease but who do not have appropriate access to an adult rheumatological outpatient clinic.

60. **[TRANSITION FROM PEDIATRIC TO ADULT CARE IN CHRONIC RESPIRATORY DISEASES: THE CYSTIC FIBROSIS MODEL].**

Mittaine, M., Roditis, L. & Dupuis, M.

Medecine sciences : M/S 39, 58–63 (2023) doi:10.1051/medsci/2022200

Increased life expectancy in cystic fibrosis has made transition from pediatric to adult cystic fibrosis centers a crucial step for patients, their families and caregivers. This transition must be gradual and carefully prepared. A formalized process, early discussion with patients and families about transition, patient's empowerment prior to transfer, and close links between pediatric and adult teams are key points to succeed. Therapeutic education, validated questionnaires, personalized action plans or connected tools can help. Transfer will take place at the appropriate time for each patient, ideally during a period of disease stability, in a progressive manner, with joint or alternating consultations between pediatric and adult cystic fibrosis center teams. Other chronic respiratory diseases with pediatric onset may benefit from similar transition processes.

61. **[THE TRANSITION OF CHILDREN WITH RARE DISEASES FROM PEDIATRIC TO ADULT CARE].**

Molnár, M. J., Cs Sági, J., Szabó, L. & Grosz, Z.

Orvosi hetilap 163, 2021–2026 (2022) doi:10.1556/650.2022.32660

Diagnostics for rare diseases have advanced as a result of technological advancement. Innovative treatments have also made it possible for children with rare disorders to survive into adulthood. Growing up is crucial for someone who has a chronic childhood illness since the change from pediatric to adult treatment comes with new difficulties that might feel like an extra burden from the condition. Transition in rare diseases poses more challenges than in common diseases, because not all health care providers in adult care may have the expertise needed to provide optimal patient care. In addition, longer illness courses and the requirement for adult care in diseases for which there is no prior experience will result from the increasing number of better therapies. Occasionally, new clinical symptoms may appear that are unknown to clinicians. Despite the importance they should have, the majority of rare diseases do not currently have standardized recommendations and standards for the transition phase. Every transfer to adult care should be unique and stick to a predetermined plan. A transition coordinator should ideally work with the pediatrician, the adult specialist, the patient, and parents to support patients during this transition. The needs analysis of caregivers is an essential part in the transition process, too. The parties need to be

educated, a protocol outlining the process needs to be developed, and the necessary infrastructure must be in place to support an optimal transition. *Orv Hetil.* 2022; 163(51): 2021-2026.

62. **EFFECTIVE TRANSITION OF YOUNG PEOPLE WITH LONG-TERM CONDITIONS INTO ADULT SERVICES.**

Morgan, S., Gibson, F., Aldiss, S. & Porter, L.

Nursing children and young people 35, 34–42 (2023) doi:10.7748/ncyp.2022.e1439

Healthcare transition involves the purposeful and planned process of preparing, empowering and supporting young people with long-term conditions and their families when they are moving from child to adult services. Transition is a series of events that provides the young person with the knowledge and skills they require to be able to function in adult services. Until recently little has been done to address the perceived barriers and challenges involved in transition. In this article, the authors discuss the challenges associated with effective transition and describe their experience of implementing a healthcare transition pathway using a quality improvement model.

63. **TRANSITIONING FROM PAEDIATRIC TO ADULT RHEUMATOLOGICAL HEALTHCARE: ENGLISH SUMMARY OF THE JAPANESE TRANSITION SUPPORT GUIDE.**

Mori, M. et al.

Modern Rheumatology 32, 248–255 (2022) doi:10.1093/mr/roab071

Issues related to transitioning from paediatric to adult healthcare are currently receiving international attention. In Japan, 1000 patients with childhood-onset chronic rheumatological diseases reach adulthood every year and require transition from care by paediatric to care by adult rheumatologists. Here, we propose a guide for the latter, wherein the adult caregiver poses the clinical questions about transitional support that they need to have answered, and the paediatric caregiver mainly compiles the plans for the transition. To formulate the guide, we sought comments from both the Japan College of Rheumatology and the Pediatric Rheumatology Association of Japan and obtained their approval. Here, we present the outcome of this consultation in the form of a Guide for Supporting Transitional Care, aiming to provide essential knowledge to physicians in the fields of adult internal medicine and orthopaedics who may be involved in treating patients with rheumatic disease during the transition from paediatric to adult care. The features of transitional support that are common for patients with various different rheumatic diseases are presented in this guide, with the aim of informing policy and strategies to deliver optimal outcomes in transitional care by non-paediatric rheumatologists.

64. **GASTROINTESTINAL DISORDERS IN ADOLESCENTS AND YOUNG ADULTS: PREPARING FOR A SMOOTH TRANSITION TO ADULT-CENTERED CARE.**

Nabbijohn, A. N. & Ahola Kohut, S.

Gastroenterology clinics of North America 51, 849–865 (2022) doi:10.1016/j.gtc.2022.07.008

Chronic gastrointestinal disorders are prevalent in youth worldwide. The chronicity of these conditions often results in their persistence into adulthood. Challenges typically faced by young people transitioning to adulthood are often exacerbated in those with chronic gastrointestinal disease. Increased awareness of these challenges among health care professionals and appropriate policies and procedures for health care transition are critical. This article summarizes research on the challenges faced by emerging adults with the gastrointestinal disease during the transition to adult care. Barriers to optimal transitional care and current guidelines are discussed and used to offer practical recommendations for health care professionals working with this population.

65. **EFFECT OF TRANSITION CARE ON CLINICAL OUTCOMES AND TREATMENT ADHERENCE IN PATIENTS WITH INFLAMMATORY BOWEL DISEASE: AN OBSERVATIONAL PROSPECTIVE STUDY.**

Nardone, O. M. et al.

United European Gastroenterology Journal 10, 648–649 (2022) doi:10.1002/ueg2.12290

Introduction: Inflammatory bowel diseases (IBD) are chronic diseases with an increasing incidence in the

paediatric population. Given the lifelong impact of these diseases, the transition from paediatric to adult healthcare in patients with IBD is essential to ensure the continuity of care. Aims & Methods: We aimed to evaluate the impact of structured transition from pediatric to adult IBD services on objective patient outcomes including disease flares, admission rates, hospitalization and surgery. We further assessed the rate of medication adherence and the quality of life pre-and post-transition. An observational, prospective study was conducted in a tertiary IBD centre and included adolescent/young adult (aged ≥ 17 years) with a confirmed diagnosis of IBD before 16 yo and in clinical remission who underwent structured transition (joint transition care). We collected demographics and clinical data in the previous 12 months before the transition and 12 months after. Patients completed the following questionnaires at recruitment: the Morisky Medication Adherence Scale and the short form health survey (SF36) Questionnaire. Results: We recruited 41 patients (aged 18-20) in clinical remission based on Crohn's Disease Activity Index [CDAI] score 117 ± 145 for Crohn's Disease [CD] and pMayo $2,7 \pm 1,4$ for ulcerative colitis [UC] who had recently transitioned to adult care and completed 12 months follow-up. Demographic details were summarized in Table 1. There was a significant reduction in the number of outpatient visits and in the rate of flares in the 12 months post-transition (outpatient visits pretransition 2.3 ± 0.7 , post-transition 1.8 ± 0.8 , $p=0.005$) (exacerbations pretransition: 1.2 ± 0.9 , post-transition 0.6 ± 0.7 , $p=0.005$) (flares pre-transition 1.2 ± 0.9 , post transition 0.6 ± 0.7 , $p= 0.001$). While, there was no statistically significant difference between patients' Body Mass Index (BMI) before (22.8 ± 3.4) and after transition (23 ± 3.5 ; $p=0.72$). Similarly, no significant difference was observed in terms of hospitalization (hospitalization pre-transition 0.2 ± 0.5 , post-transition 0.2 ± 0.4 , $p=0.6$); surgery (surgery pre-transition 0.02 ± 0.15 , post-transition 0.10 ± 0.3 , $p=0.17$); medication adherence (adherence pre-transition 1.6 ± 0.5 , post-transition 1.6 ± 0.5 , $p=0.7$); quality of life (SF-36 pre-transition 100 ± 6 , post-transition 101 ± 5 , $p=0.2$). Conclusion: Attendance at dedicated transition clinics can contribute to the achievement of the continuity of care. Transition patients have similar BMI, rate of hospitalization, surgery, adherence to medications and quality of life pre and 12 months post-transition clinic. Whilst there was a significant reduction in the rate of flares and thereby in the number of outpatient visits in the 12 months post-transition since most patients were in clinical remission. (Table Presented).

66. **FACTORS AND OUTCOMES ASSOCIATED WITH VIRAL SUPPRESSION TRAJECTORY GROUP MEMBERSHIP AMONG YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HIV CARE.**

Nassau, T. *et al.*

Journal of Adolescent Health 71, 737–743 (2022) doi:10.1016/j.jadohealth.2022.07.009

Purpose: Youth experiencing healthcare transition (HCT) from pediatric to adult HIV care are at risk for poor viral suppression (VS). We have a limited understanding of VS trajectory groups (VSTGs) pre- and post-HCT and factors associated with these trajectories. Methods: We analyzed Philadelphia HIV surveillance data of youth diagnosed with HIV at least 2 years pre-HCT. We used group-based trajectory analysis to characterize VS trends pre- and post-HCT. We compared baseline sociodemographic characteristics across the different VSTGs and care continuum outcomes in the year post-HCT. Generalized estimating equations evaluated the association between VSTG and HIV care continuum outcomes measured 2 years post-HCT. Results: Between 2012 and 2019, 232 eligible youth underwent HCT: 69.4% were aged 24–25, 75.4% male, and 76.7% non-Hispanic Black. Three VSTGs were identified: low (30.6%), increasing (26.7%), and high probability (42.7%) for VS. Younger age was associated with high-probability VSTG membership: 59.2% of those aged 18–23 versus 35.4% of those aged 24–25 were in the high-probability VSTG ($p < .001$). Demographics found to be associated with linkage to care post-HCT included younger age ($p = .018$), female sex at birth ($p = .038$), and perinatal acquisition ($p = .012$). Perinatal acquisition was also associated with retention in care in the year post-HCT ($p = .029$). For those transitioning between 2012 and 2018, those in the high-probability VSTG had greater odds of being retained (adjusted odds ratio 1.68, 95% confidence interval 1.03–2.71) and VS (adjusted odds ratio 6.95, interval 3.74–12.95) 2 years post-HCT, compared to those in the low VSTG. Discussion: We identified distinct VSTGs that informed long-term trends post-HCT. VSTG membership may allow for tailoring of appropriate HCT support.

67. **IT'S NEVER THE RIGHT TIME TO SAY GOODBYE...UNTIL IT IS: TRANSITIONING FROM PEDIATRIC TO ADULT PRIMARY CARE.**

Nguyen, A. T., Lewis, C. & Geary, M.

Rhode Island medical journal (2013) 105, 74–75 (2022)

68. **TRANSITION TO INDEPENDENT CARE FOR YOUTH LIVING WITH HIV: A CLUSTER RANDOMISED CLINICAL TRIAL.**

Njuguna, I. N. et al.

The Lancet HIV 9, e828–e837 (2022) doi:10.1016/S2352-3018(22)00244-2

Background: Transitioning youth living with HIV to adult care is a crucial step in the HIV care continuum; however, tools to support transition in sub-Saharan Africa are insufficient. We assessed the effectiveness of an adolescent transition package (ATP) to improve youth readiness for transition to independent HIV care. Methods: In this hybrid type 1, multicentre, cluster randomised clinical trial, we assessed the effectiveness of an ATP (administered by routine clinic staff, which included standardised assessments and chapter books to guide discussions at scheduled clinic visits) in four counties in Kenya, with HIV clinics randomly assigned 1:1 to ATP or control (standard-of-care practice). Clinics were eligible to participate if they had at least 50 youth (aged 10–24 years) living with HIV enrolled in care. We used restricted randomisation to achieve cluster balance and an independent biostatistician used computer-generated random numbers to assign clinics. We excluded very large clinics with more than 1000 youth, clinics with fewer than 50 youth, paediatric-only clinics, clinics with logistical challenges, and the smallest clinics in Homa Bay county. Youth were eligible for the transition intervention if they were enrolled in participating clinics, were aged 15–24 years, and were aware of their positive HIV diagnosis. Study staff assessed transition readiness scores overall and by four domains (HIV literacy, self-management, communication, and support) in youth with HIV, which were then compared between groups by use of mixed-effects linear regression models. Analysis was by intention-to-treat and was adjusted for multiple comparisons. This trial is registered with ClinicalTrials.gov, NCT03574129. Findings: We identified 35 clinics in four counties; of these, ten were assigned to the intervention group and ten to the control group. Of 1066 youth with HIV enrolled between Nov 1, 2019, and March 18, 2020, 578 (54%) were in intervention and 488 (46%) in control sites. Mean baseline transition readiness score was 12.1 (SD 3.4) in ATP sites and 11.4 (3.7) in control sites. At 1 year, adjusting for baseline scores, age, and months since HIV disclosure, participants in the ATP group had significantly higher overall transition readiness scores (adjusted mean difference 1.7, 95% CI 0.3–3.1, $p=0.024$), and higher scores in HIV literacy domain (adjusted mean difference 1.0, 0.2–1.7, $p=0.011$). At 12 months, 15 serious adverse events were recorded, none of which were thought to be related to study participation. Interpretation: Integrating ATP approaches could enhance long-term HIV care in youth with HIV as they age into adulthood. Funding: US National Institutes of Health.

69. **THE INPATIENT EXPERIENCE OF EMERGING ADULTS IN THE UNITED STATES.**

Oakman, N., Driver, D., Berlacher, M., Warsi, M. & Chu, E. S.

Hospital practice (1995) 50, 400–406 (2022) doi:10.1080/21548331.2022.2129176

OBJECTIVES: Emerging adults transitioning from pediatric to adult care experience worse outcomes including increased mortality. Improved patient experience (PEX) correlates with decreased inpatient mortality and better adherence to quality guidelines. We aimed to evaluate trends in the PEX of inpatients aged 14–29 years in the United States (US). METHODS: We performed a retrospective cohort study using a national, de-identified PEX survey obtained from hospitalized patients aged 14–29 years between 2017 and 2019. We described and compared survey responses across 10 domains. Composite mean scores for each health facility were converted to percentile rankings, which were then compared by age group to determine differences in percentile ranking (Δ PR). RESULTS: We evaluated the results of 174,174 PEX surveys across a national sample of 1519 US hospitals. The PEX percentile rankings for ages 18–21 were lower than ages 14–17 in almost every domain including experience with nurses (Δ PR = 43.4, $p < 0.001$), physicians (Δ PR = 31.1, $p < 0.001$), treatment (Δ PR = 12.3, $p < 0.001$), and overall experience (Δ PR = 26.5, $p < 0.001$). Similarly, 22–25-year-olds reported a worse PEX across nearly all domains when compared to 26–29-year-olds. CONCLUSION: In a national sample of PEX surveys, hospitalized emerging adults aged 18–25 reported worse PEX when compared to both older children and established adults. These lower ratings were most strongly attributed to people, processes, and relationships as opposed to differences in the hospital environment. By ages 26–29, PEX returned to levels similar to those reported by ages 14–17. These results suggest that further investigation to elucidate the unique needs of hospitalized emerging adults may be warranted.

70. TRANSITION FROM PAEDIATRIC TO ADULT CARE IN CYSTIC FIBROSIS.**Office, D. & Heeres, I.***Breathe* 18, (2022) doi:10.1183/20734735.0157-2021

In the decades since cystic fibrosis (CF) was first clinically defined in the 1930s, there have been many advancements in the treatment and management of this disease. Initially it was considered a disease of childhood where the majority of those affected died before reaching adolescence. Now, through advancements in management and treatment, the vast majority of those affected will live into adulthood. Therefore, paediatric and adult CF services must collaborate to ensure that young people and their families experience a positive and supportive transition into adult services. Key aspects of transition will be discussed, including when to begin the transition process, who should coordinate this and how the transition process should be structured. Challenges of the transition process and potential pitfalls when transition does not run smoothly will also be discussed, as well as tools that may be used to support a positive transition for young people and their families.

71. SICKLE CELL TREVOR THOMPSON TRANSITION PROJECT (ST3P-UP) PROTOCOL FOR MANAGING CARE TRANSITIONS: METHODS AND RATIONALE.**Osunkwo, I. et al.***Contemporary clinical trials* 126, 107089 (2023) doi:10.1016/j.cct.2023.107089

BACKGROUND: Emerging adults with sickle cell disease (EASCD) experience significant challenges transitioning from pediatric to adult care. Acute care utilization increases, quality of life (QOL) declines, with an increased risk of mortality. Currently, there are no practice standards to guide emerging adults through the transition process. We are creating a structured transition education (STE) based program for EASCD by customizing the Six Core Elements (6 CE) of Health Care Transition model and are evaluating the effectiveness of adding peer mentoring (PM). **METHODS:** The Sickle Cell Trevor Thompson Transition Project (ST3P-UP) is an ongoing multi-site, cluster randomized clinical trial with a target enrollment of 537 EASCD aged 16 to 25 years in pediatric care. Each site (n = 14) comprises a pediatric clinic, adult clinic, and a sickle cell disease (SCD) community-based organization (CBO). Sites are randomized 1:1 to either STE or STE + PM. EASCDs are followed prospectively for 24 months. Rapid cycle plan-do-study-act quality improvement (QI) methods are used to implement the STE. The primary objective is to compare the effectiveness of STE + PM versus STE only at decreasing the number of acute care visits per year over 24 months. The secondary objectives are to compare overall healthcare utilization and patient-reported QOL outcomes at 24 months. **CONCLUSION:** We aim to demonstrate the feasibility of using a QI approach to implement 6 CE-based practice standards at 14 disparate SCD clinical programs to guide EASCD through the transition process. We hypothesize that adding PM to the STE program will improve acute care reliance, QOL, and satisfaction with transition outcomes.

72. PATIENT AND PARENT PERCEPTIONS OF AN ESTABLISHED RHEUMATOLOGY TRANSITION CLINIC FOR ADOLESCENTS AND YOUNG ADULTS.**Overbury, R. et al.***Arthritis and Rheumatology* 74, 3809–3812 (2022) doi:10.1002/art.42355

Background/Purpose: The Adult Center for Childhood Onset Rheumatic Disease (ACCORD) is a clinical and research center for the health care transition (HCT) of adolescent and young adult (AYA) patients with rheumatic disease. It serves to improve the experience and health outcomes for these patients as they transition from a pediatric-centered to an adult-centered clinical home. Here we present the perceptions of our patients and their parents regarding what factors are important in a transition clinic and how well this clinic currently performs these factors. **Methods:** Patients and their parents were recruited if they were cared for in the ACCORD clinic and had a rheumatic disease diagnosis. Patients and their parents were asked to complete a Mind the Gap survey via email. This previously validated survey has 44 questions, using 7-point Likert scales to rate 1) the importance of 22 factors in a transition clinic and 2) how well the transition clinic currently performs these 22 factors. Patients and parents completed this survey independently. Survey responses are presented as averages. Discordance between patient and parent responses are provided.

Discordance between how well the clinic is performing those factors are provided. Table 3. Non-Rheumatic Diagnoses Results: 49 patients completed the survey (Table 1). 35 parents completed the survey. Both identify as valuable factors: knowledgeable staff, honest explanations of disease and therapy options, and autonomy of the patient to decide who is in the exam room and in medical decision making (Fig. 1). Patients identify wasted time in clinic and convenience of clinic times as the most valuable factors with the greatest room for improvement (Fig. 1). Parents identify organizational support and communication inside medical teams as the most valuable factors with the greatest room for improvement (Fig. 1). The greatest discordance in valuable factors between patients and parents are the patient having the opportunity to be seen alone (more important to patients) and having staff who know how to talk to teenagers (more important to parents) (Fig. 3). Compared to patients, parents place less cumulative importance on these 22 factors while also reporting that these factors are currently less well implemented in the clinic (Fig. 1). Conclusion: We show that patient autonomy, knowledgeable providers, and honest explanations of diagnoses and therapy are important themes for both patients and their parents. Perhaps unsurprisingly, patients value more of these factors than do their parents. However, patients are also more likely to report that the clinic is successfully implementing these factors. This could reflect more familiarity with the clinic (many of these patients attend their visits alone) or a shifting relationship from the parent-provider dyad of a pediatric-centered clinic to a patient-provider dyad of an adult-centered clinic. Interestingly, it is parents who most value a clinic that generally caters to teenagers, while patients most value a clinic that allows for their autonomy and individualism. These findings are valuable qualitative insights for transition clinics caring for AYA patients and should be considered in the customization of HCT for patients and their parents.

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

Perales, C. P. et al.

Arthritis and Rheumatology 74, 1606–1608 (2022) doi:10.1002/art.42355

Background/Purpose: Juvenile Idiopathic Arthritis (JIA) is the leading cause of chronic inflammatory rheumatic disease in children. It's classified into subtypes with different relative prevalences depending on geographical area (Oligoarticular 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. 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 first visit to the transitional care unit. Results: 72 patients were included (46 women), mean age at diagnosis of 9.5 ± 4.6 y and a mean of 11.3 ± 4.36 y from diagnosis to first visit at the transitional care unit. 27.7% were diagnosed with oligoarticular JIA, 20.8% with arthritis-enthesitis JIA, 19.4% with Rheumatoid Factor negative (RF-) polyarticular JIA, 11.1% with systemic JIA, 9.7% with undifferentiated JIA, 5.5% with Rheumatoid Factor positive (RF+) polyarticular JIA and 5.5% of psoriatic arthritis. The mean age at the first visit to the transitional care unit was 20.81 ± 2.96 y (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 antinuclear antibodies (ANA) titers $>1/160$ at some point in course of the disease. 43% were treated with methotrexate, 38% with biological therapies, 11.% with glucocorticoids (GC) and 22.% had no treatment (Table). Conclusion: The oligoarticular form was the most prevalent subtype of JIA, similar to previously published series from Western Europe. The first visit at the transition care unit occurred significantly 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.

74. **THE TRANSITION FROM PEDIATRIC TO ADULT CARE IN INDIVIDUALS WITH PRADER-WILLI SYNDROME.**

Poitou, C. et al.

Endocrine connections 12, (2023) doi:10.1530/EC-22-0373

Prader-Willi syndrome (PWS), the most common form of syndromic obesity, is a complex neurodevelopmental genetic disorder including obesity with hyperphagia, endocrine and metabolic disorders and also psychiatric disorders. The most frequent endocrine disturbances include hypogonadism and growth hormone (GH) deficiency. Hypothyroidism and central adrenal insufficiency can also be observed but are less frequent. The transition of individuals with PWS from adolescence to adult life is challenging because of multiple comorbidities and complex disabilities. Individuals and caregivers face psychological, medical and social issues. This period of profound changes is thus prone to disruptions, and the main risks being the worsening of the medical situation and loss to follow-up of the individuals. Medical care may be poorly adapted to the needs of individuals because of a lack of knowledge concerning the syndrome and also lack of the necessary specific skills. A multidisciplinary panel composed of several experts in PWS met in November 2021 during an European Reference Network on Rare Endocrine Conditions (Endo-ERN) webinar. They presented complementary aspects of PWS from the perspective of the transition including psychiatric, pediatric and adult endocrinological and parent's and patient's points of view and shed light on the best way to approach this pivotal period.

75. **BARRIERS, GOALS, AND ENABLERS OF TRANSITION OF CARE IN PEDIATRIC DERMATOLOGY.****Pope, E. I. & Joseph, M.**

Pediatric Dermatology (2022) doi:10.1111/pde.15191

Adolescent patients with complex skin disorders may require ongoing care for their conditions as they “age out” of the pediatric setting into adult care. Yet despite consensus from the Canadian Paediatric Society and American Academy of Pediatrics on the importance of dedicated transition programs for these patients, there is a scarcity of such programs worldwide, and no formal programs in Canada. This paper explores several barriers, goals, and potential enablers of transition programs in this discipline and proposes principles of transition versus transfer in the context of pediatric dermatology.

76. **KNOWLEDGE, ATTITUDES, AND PRACTICES OF ALLERGISTS/IMMUNOLOGISTS REGARDING TRANSITION OF CARE FOR PRIMARY IMMUNODEFICIENCY PATIENTS.****Rai, S., Treyster, Z. & Jongco, A. M.**

Journal of Clinical Immunology 43, 595–603 (2023) doi:10.1007/s10875-022-01415-1

Purpose: Only some allergists/immunologists provide care throughout the lifespan despite their training. Although transition of care (TOC) guidelines exist, research on provider perspectives on TOC for pediatric primary immunodeficiency (PID) patients is lacking. We aimed to characterize knowledge, attitudes, and practices and establish clinician needs using a needs assessment survey. Methods: The 15-min online survey was adapted from an existing rheumatology TOC survey and was emailed to the American Academy of Allergy Asthma and Immunology (AAAAI) and Clinical Immunology Society (CIS) members. Our primary hypothesis was that both AAAAI and CIS providers report being underprepared for TOC and would express interest in TOC resources and consensus. Results: Forty-nine of 1250 eligible AAAAI and 67 of 698 eligible CIS participants completed the survey (4.8% vs 11.3% participation rate). Many (53.1% vs 59.7%) respondents transition their own patients but also retain adult patients (59.2% vs 52.2%). Many accepted transition patients (85.7% vs 92.5%). In total, 24.1% of respondents did not have a TOC policy while 18.9% have an informal policy. Only 25.0% were satisfied with their current practices while 43.9% agreed that a consensus statement would be useful. Conclusion: Despite a small sample size and high rate of unanswered questions, our findings show that TOC remains overlooked in our specialty and that providers want and need additional training and resources. There is a clear need to develop and evaluate the effectiveness of evidence-based TOC guidelines, resources, and best practices for PID patients.

77. **LONGITUDINAL ASSESSMENT OF PREPARATION FOR CARE TRANSITION AMONG ADOLESCENTS AND YOUNG ADULTS WITH RHEUMATOLOGIC DISEASE: A SINGLE-CENTER PILOT STUDY.****Roberts, J. E. et al.**

Pediatric Rheumatology 20, (2022) doi:10.1186/s12969-022-00751-1

Adolescents and young adults (AYA) with rheumatologic diseases are at high risk for poor outcomes and gaps in care when transitioning from pediatric to adult care. However, tools for evaluating transition readiness and assessing the impact of transition interventions are limited. We implemented a written transition policy at our pediatric rheumatology center and evaluated preparation for transition among AYA 16 and older before and after distribution. 31 of 77 patients completed the follow-up survey (response rate 40%). Patient report of transition counseling increased following written transition policy implementation, though these results were not statistically significant in our small cohort. Most follow-up respondents (n = 19, 61%) had not yet completed care transfer; 4 (13%) had arranged a visit with an adult rheumatologist and 8 (26%) had fully transitioned to adult care. Those who successfully completed care transfer were older, had completed higher levels of education, and had significantly higher baseline transition preparation scores compared to those with no transfer arranged or planned visit only. Our single-center pilot study demonstrated that longitudinal assessment of transition preparation is feasible and that scores are significantly associated with care transfer outcomes. Tracking transition preparation over time may provide practices with information on areas of highest need for transition guidance and predict successful transfer among AYA with rheumatologic disease.

78. BENEFITS OF PAEDIATRIC TO ADULT TRANSITION PROGRAM IN INFLAMMATORY BOWEL DISEASE: THE BUTTERFLY STUDY OF GETECCU.

Rubín de Célix, C. et al.

United European Gastroenterology Journal 10, 124–125 (2022) doi:10.1002/ueg2.12293

Introduction: It has been suggested that the transition of patients from paediatric to adult care units may be key in the outcomes of inflammatory bowel disease (IBD). However, the impact of transition in real clinical practice has been barely studied. Aims & Methods: Aims: Principal: To evaluate the impact of transition on clinical outcomes in IBD. Secondary: To describe the prevalence of transition programs in Spain; to identify predictive factors of poor clinical outcomes; and to evaluate the percentage of patients with loss to follow-up. Methods: Multicenter, retrospective, and observational study of IBD patients transferred between 2017-2020. Two groups (transition/no-transition) were compared retrospectively. Transition was defined as a structured process with at least 1 joint visit involving the gastroenterologist, paediatrician, and a program coordinator, as well as the parents and the patient. Outcomes within the first 12 months after transfer were analysed. The main variable was the presence of poor clinical outcome defined as the occurrence of at least one of the following events: IBD flare, hospitalisation, surgery or any change of the treatment due to an IBD flare. Predictive factors of poor clinical outcome (including the presence of a transition program) were identified in multivariate analysis. Results: A total of 278 patients from 34 Spanish hospitals were included: 185 patients (67%) from 21 hospitals (62%) performed a structured transition. In hospitals without transition, 91% of the patients were transferred to an IBD-specialist. In 66% of the patients in the transition group, 1 joint visit was performed. The median age of transfer was 16 years [interquartile range (IQR)=12-20]. Baseline characteristics of both groups are detailed in Table 1. At 1-year after transfer, hospitalisations and corticosteroid treatment were more frequent in the no-transition group (10 vs. 3%; p=0.025; 16 vs. 5%; p=0.002). At 1-year after transfer, 89 patients (27% transition vs. 43% notransition; p=0.005) had poor clinical outcome [median time: 9.3 months; 95% confidence interval (CI)=8.4-10.1 in no-transition; 10.4 months (95%CI 9.9-10.9) in the transition group]. In the multivariate analysis, the lack of structured transition [Hazard Ratio (HR)=2.1; 95%CI=1.4-3.3], IBD activity at transfer (HR=4.9; 95%CI=3.1-7.9), BMI <18.5 (HR=1.9; 95%CI=1.1-3.2) and corticosteroid treatment at transfer (HR=4.8; 95%CI=2.1-10.9) were associated with a poor clinical outcome. Twelve patients (4%) were lost to follow-up [1.1% in the no-transition vs. 5.9% in the transition group (p=0.06)]. Conclusion: In the present study, to our knowledge the largest performed so far, the benefit of paediatric to adult transition program on patients' outcomes has been demonstrated. The importance of achieving remission before transfer has also been highlighted.

79. THE OUTCOMES OF TRANSITION FROM PEDIATRICS TO ADULT CARE AMONG ADOLESCENTS AND YOUNG ADULTS WITH HIV AT A TERTIARY CARE CENTER IN BANGKOK.

Rungmaitree, S. et al.

Journal of the International Association of Providers of AIDS Care 21, (2022)

doi:10.1177/23259582221143673

Background: Adolescents and young adults with HIV (AYHIV) are at high-risk of loss to follow up and virologic failure, particularly during transition from pediatric to adult clinics. **Methods:** We reviewed the medical records of AYHIV to characterize retention and virologic suppression following their transition. **Results:** 101 AYHIV, 97% perinatally infected, were transferred at the median age of 20 (IQR: 19-21) years. At 1-year post-transition, 92.1% were retained in care and 73.3% had viral suppression and at 2-years the retention and viral suppression were 87.1% and 76.7%, respectively. Factors associated with viral suppression were transition at ≥ 20 years of age (aOR 4.38, 95% CI 1.41-13.65) and receiving first-line ART regimen, compared to second- or third-line regimens, at transition (aOR 6.05, 95% CI 1.55-23.58). **Conclusion:** Transition outcomes of AYHIV in our setting were suboptimal. There is a need for interventions to support AYHIV transition during this vulnerable period.

80. **TRANSITION TO ADULT SERVICES EXPERIENCED BY YOUNG PEOPLE WITH CEREBRAL PALSY: A CROSS-SECTIONAL STUDY.**

Ryan, J. M. et al.

Developmental Medicine and Child Neurology 65, 285–293 (2023) doi:10.1111/dmcn.15317

Aim: To assess if young people with cerebral palsy experience and health professionals provide practices that may improve transition from child to adult health services. **Method:** Seventy-five young people (31 females, 44 males; mean age 18 years 5 months [standard deviation 2 years 2 months]) and/or parents and 108 health professionals completed a questionnaire describing their experience or the provision of nine transition practices. **Results:** The percentage of young people reporting each practice was: appropriate parent involvement (90%); promotion of health self-efficacy (37%); named worker who supports the transition process (36%); self-management support for physical health (36%); self-management support for mental health (17%); information about the transition process (24%); meeting the adult team (16%); and life skills training (16%). Post-discharge, 10% of young people reported that their general practitioner (GP) received a discharge letter. The percentage of health professionals reporting each practice was: promotion of health self-efficacy (73.2%); self-management support (73.2%); information (69%); consulting the parent and young person about parent involvement (63% and 66%); discharge letter to a GP (55%); life skills training (36%); named worker (35%); meeting the adult team (30%); and senior manager (20%). **Interpretation:** Many young people did not experience practices that may improve the experience and outcomes of transition. Young people should be involved in the development and delivery of transition to ensure it meets their needs. **What this paper adds:** Many young people with cerebral palsy (CP) do not receive support that may improve the experience of transition. Appropriate protocols and training for health professionals may improve the provision of transition and reduce inconsistency in care between and within organizations. Young people and their families should be involved in service design, delivery, and evaluation related to the transition to ensure it meets their needs.

81. **NURSING STAFF COMMUNICATION WITH PEDIATRIC PATIENTS AND FAMILIES IN A PEDIATRIC TRANSITIONAL CARE UNIT: A BEST PRACTICE IMPLEMENTATION PROJECT.**

Sandridge, S., Palokas, M. & Odom, A.

JBI evidence implementation (2022) doi:10.1097/XEB.0000000000000363

OBJECTIVES: The objective of this project was to promote evidence-based practices regarding nursing communication with pediatric patients/families. **INTRODUCTION:** Effective communication between healthcare providers and patients/families is an essential component of patient care and plays a vital role in patient outcomes. Ineffective communication among the healthcare team and patient families has been described as a significant factor contributing to adverse events and poor health outcomes. **METHODS:** The project used JBI's Practical Application of Clinical Evidence System and Getting Research into Practice audit tool for encouraging evidence-based practices. A baseline audit was conducted, followed by the implementation of targeted strategies. The project was completed with a follow-up audit to determine change in practice. **RESULTS:** Three evidence-based practices were utilized as audit criteria for the project. The baseline audit on the three audit criteria revealed an average compliance of 30%. After providing communication skills training to nursing staff and education and visual aids to patients/families and nursing staff regarding the use of white boards, follow-up audits revealed an average compliance of 62%, an

increase of 32%. CONCLUSIONS: These implementation strategies will continue to be utilized on the unit and will be implemented in other areas of the hospital to further improve communication between patients/families and their healthcare team.

82. **CHARACTERISTICS OF TRANSITIONING JIA PATIENTS: WHO IS ARRIVING ON THE ADULT RHEUMATOLOGISTS' DOORSTEPS?**

Semalulu, T., Beattie, K., Berard, R., Guzman, J. & Batthish, M.

Arthritis and Rheumatology 74, 1698–1699 (2022) doi:10.1002/art.42355

Background/Purpose: Patients with JIA are at an increased risk of loss to follow-up, morbidity and mortality as they transition from pediatric to adult care. Thus, adult rheumatologists must understand the disease-related characteristics of their incoming JIA patients to provide appropriate care and support. Initiated in 2017, the Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI) JIA registry prospectively collects disease-related outcomes among newly (< 3 months) diagnosed JIA patients. We aimed to characterize disease activity and disease-related outcomes of adolescents with JIA, prior to their transfer to adult care. Methods: We obtained data from patients in the CAPRI registry whose 17-year-old data collection was complete by December 2021. These include newly diagnosed patients with JIA and data from established patients from two additional Canadian JIA cohorts (Linking Exercise, Activity and Pathophysiology in Childhood Arthritis [LEAP] and Research in Arthritis in Canadian Children emphasizing Outcomes [ReACCh-Out]). At each clinic visit, the most responsible physician (MRP) completed a questionnaire on disease activity, treatment and adverse events. The MRP completed an additional questionnaire once the patient reached age 17 to characterize disease-related damage. Patient-reported outcomes (as measure on a 21-point Likert scale, 0-10) included pain scores, patient global assessment of disease activity and Quality of My Life. Descriptive statistics were used to characterize patients' disease activity, disease-related outcomes and medication use at age 17 and changes that occurred in the year prior to transfer to adult care. Table 1: 17-year-old Patient Characteristics (n=131) Results: One hundred and thirty-one 17-year-olds (63% female, mean (SD) age at diagnosis 10.3 (4.7) years), were included (Table 1). Most patients (n=129) were taking medications prior to transfer, including NSAIDs (n=45), methotrexate (n=45), biologic agents (n=44), oral (n=5) or ocular steroids (n=1). Mean (SD) scores for patient pain, patient global assessment of disease activity, and Quality of My Life scores were 3.7 (2.7), 3.3 (2.8), and 7.7 (2.6), respectively. Changes in disease course one year prior to transition are shown in Table 2. Among 80 (59.7%) patients whose data were available for the 17-year-old questionnaire, half (n=41, 51.3%) were in remission (Table 3). Clinically detectable joint damage was present in 21 (26%) patients, while 25 (31%) had radiographic damage. The TMJ, wrists and hips were most commonly affected. Few patients were ever hospitalized (n=6) or experienced serious adverse events (n=5). Conclusion: Among this Canadian cohort of JIA patients, one third had active disease and almost all were taking medications prior to transfer to adult care. One third had radiographic joint damage while one quarter had clinically detectable joint damage, with the TMJ being the most commonly affected joint. Patient reported outcomes were generally favourable. This study highlights the disease burden transitioning patients carry at the vulnerable time of transfer to adult care. These results will help adult rheumatologists anticipate the medical needs of newly transitioned patients given the degree of active disease and extent of medication use.

83. **ASSESSING BARRIERS AND FACILITATORS TO TRANSITION IN SICKLE CELL DISEASE CARE PRIOR TO IMPLEMENTATION OF A FORMALIZED PROGRAM.**

Sheppard, S., Hellemann, G., Lebensburger, J. & Kanter, J.

Pediatric blood & cancer 70, e30160 (2023) doi:10.1002/pbc.30160

Over 95% of children with sickle cell disease (SCD) survive into adulthood in the United States. However, early mortality remains a problem, especially in persons between the ages of 18 and 35. One possible explanation for the increased mortality rate in young adults is difficulties in engaging in care during the transition from a heavily contiguous pediatric healthcare model to a more self-reliant adult healthcare model. The goal of this study was to identify potential facilitators and barriers to a successful transfer in care from the pediatric to adult SCD program before the formation of a formal transition program. This is a retrospective cohort study of transition outcomes for 472 individuals with SCD (all genotypes) treated at the University of Alabama at Birmingham (UAB) sickle cell clinic (aged 18-24). The primary outcome was

whether the patient continued care in (any) adult SCD program (defined as being seen at least once in an adult hematology/SCD clinic). One hundred eighty-eight (45%) transition age patients successfully transferred to adult care. Facilitators to successful transfer in care included being treated at the same hospital for both pediatric and adult programs, having the genotype HbSS, and/or receiving an SCD-modifying therapy at the time of transition (hydroxyurea and/or red cell transfusion therapy). Of primary interest, many of the patients who failed to transition to an adult clinic were lost to follow-up prior to 15 years of age. Importantly, these patients who had previously been labeled as 'transition failures,' were lost to follow-up long before the transition age. Early engagement is needed for this population.

84. **MAPPING OF THE CURRENT TRANSITION OF CARE PRACTICE FOR PATIENTS WITH PITUITARY DISEASE AT ENDO-ERN REFERENCE CENTERS.**

Shishkov, S. et al.

Hormone Research in Paediatrics 95, 433 (2022) doi:10.1159/000525606

Rare endocrine conditions present specific diagnostic and management challenges to healthcare providers, especially regarding transition. Despite the need for practical guidance on this subject, consensus on structured approaches to transition are lacking. The aim was to map the current clinical practice, and identify the unmet needs regarding transition of care for patients with pituitary disease in the reference centers (RCs) of the European Reference Network on Rare Endocrine Conditions (Endo-ERN). A survey-based, cross-sectional study using the EU Survey tool was performed, and completed by 46 physicians (n) from 30 RCs (N). The respondents were pediatric and adult endocrinologists, representatives for Main thematic group 6 (MTG6) for their respective centers. The survey demonstrated that transition is a common practice among Endo-ERN centers (n=44/46), usually accomplished by a multidisciplinary team meeting (N=20/30). Criteria for start and end of transition were defined in half of the RCs (N=15/30), with 20% (N=5/30) of centers providing conflicting answers. Another aspect - the transition readiness was assessed in more than 75% of the RCs (N=26/30). That was done primarily by unvalidated tools such as subjective opinions and informal consultations. Pituitary-specific transition assessment tool was applied in one center only. Transition protocol was present in 9% of RC. Decisions about transition management were taken at combined meetings, or based on clinicians' personal judgment in 91% RCs. A minority of physicians evaluated the effectiveness of transition-related interventions (n=11/46), or medical outcomes (n=8/46). Patient-reported outcome measures were least often used (n=4/46). Unmet needs included development of guidelines (n=5/46), and EU-wide approach (n=2/46). This study exemplifies the unmet needs for a structured approach to transition of patients with rare hypothalamic and pituitary conditions from healthcare providers and patients' perspective. It also demonstrates the need for further research on the definitions of successful transition of care and factors facilitating the successful transition.

85. **TRANSITIONAL CARE AND CLINICAL MANAGEMENT OF ADOLESCENTS, YOUNG ADULTS, AND SUSPECTED NEW ADULT PATIENTS WITH CONGENITAL CENTRAL HYPOVENTILATION SYNDROME.**

Slattery, S. M. et al.

Clinical Autonomic Research (2022) doi:10.1007/s10286-022-00908-8

Purpose: With contemporaneous advances in congenital central hypoventilation syndrome (CCHS), recognition, confirmatory diagnostics with PHOX2B genetic testing, and conservative management to reduce the risk of early morbidity and mortality, the prevalence of identified adolescents and young adults with CCHS and later-onset (LO-) CCHS has increased. Accordingly, there is heightened awareness and need for transitional care of these patients from pediatric medicine into a multidisciplinary adult medical team. Hence, this review summarizes key clinical and management considerations for patients with CCHS and LO-CCHS and emphasizes topics of particular importance for this demographic. Methods: We performed a systematic review of literature on diagnostics, pathophysiology, and clinical management in CCHS and LO-CCHS, and supplemented the review with anecdotal but extensive experiences from large academic pediatric centers with expertise in CCHS. Results: We summarized our findings topically for an overview of the medical care in CCHS and LO-CCHS specifically applicable to adolescents and adults. Care topics include genetic and embryologic basis of the disease, clinical presentation, management, variability in autonomic nervous system dysfunction, and clarity regarding transitional care with unique

considerations such as living independently, family planning, exposure to anesthesia, and alcohol and drug use. Conclusions: While a lack of experience and evidence exists in the care of adults with CCHS and LO-CCHS, a review of the relevant literature and expert consensus provides guidance for transitional care areas.

86. **RELIABLE TRANSITION POLICY DISTRIBUTION AND TRANSITION READINESS ASSESSMENT QUESTIONNAIRE COMPLETION USING A DIGITAL INTERVENTION IN A PEDIATRIC RHEUMATOLOGY CLINIC.**

Smitherman, E. et al.

Arthritis and Rheumatology 74, 2563–2565 (2022) doi:10.1002/art.42355

Background/Purpose: The process of transition from pediatric-to adult-based care should be well-timed, coordinated, and planned to educate and encourage the adolescent towards an adult role and healthcare independence. While national practice guidelines for structured transition processes are published, significant variation exists in how these guidelines are implemented into routine practice. Our objective was to use a digital intervention to improve transition policy distribution and collection of the Transition Readiness Assessment Questionnaire (TRAQ). Methods: The intervention took place from August 2021 through April 2022 at a tertiary care pediatric rheumatology clinic. Eligible visits for patients at least 16 years-old with at least one prior ambulatory pediatric rheumatology visit were identified using the electronic health record (EHR). Improvement science methodology was applied including process maps, key driver diagrams, and failure modes effect analysis (FMEA) (Figure 1). Baseline performance was calculated. Using Plan-Do-Study-Act cycles, we implemented a process using tablets during the clinic visit to distribute the transition policy and collect the TRAQ digitally via REDCap software. Primary outcome measures included percentage of eligible patients each week who acknowledged policy distribution, who completed the TRAQ digitally, and with recorded TRAQ score in the EHR as a proxy for discussion with care team. Performance on these measures was monitored over time using run chart software. Results: Prior to the intervention, our clinic had a written transition policy, but no system to monitor distribution to patients. We also collected the TRAQ manually with results scanned as a document into the EHR after the clinic visit. This process made it difficult to quickly calculate a score and monitor completion and change in scores over time. Our intervention began by benchmarking 2 months of baseline data. In October 2021, we received tablet equipment and began testing our digital transition policy distribution and TRAQ collection process in a limited number of clinics. In December 2021, we spread the process to all non-satellite pediatric rheumatology clinics at our center. A total of 475 visits were evaluated during the baseline and intervention periods. We improved our performance on transition policy distribution from 0% to 84% of eligible visits (Figure 2). We improved our performance on TRAQ score completion from 17% to 84% of eligible visits. We improved our performance on TRAQ score entered in the EHR from 17% to 50% of eligible visits (Figure 3). Failure modes effect analysis for the pediatric rheumatology digital transition policy and transition readiness assessment questionnaire (TRAQ) intervention. Run chart for the percentage of eligible return visits for patients ≥ 16 years with a transition policy reviewed from August 2021 through April 2022. Conclusion: By implementing a digital intervention, we improved reliable performance of recommended structured health care transition processes, including transition policy distribution and TRAQ completion, for adolescent age pediatric rheumatology patients. We are currently pursuing additional interventions to improve reliability of entering the digitally collected TRAQ score into the EHR. By concurrently implementing a structured pediatric to adult health care transfer program, we will be able to evaluate pre-transfer TRAQ scores with transfer outcomes in the future.

87. **TRANSITIONING FROM PEDIATRIC TO ADULT HEALTHCARE: EXPLORING THE PRACTICES AND EXPERIENCES OF CARE PROVIDERS.**

Splane, J., Doucet, S. & Luke, A.

Annals of family medicine (2022) doi:10.1370/afm.20.s1.2974

Context: Youth with complex care needs (CCN) experience complex health conditions, many of which were once seen as fatal and are now increasingly associated with survival into adulthood. As a result, more youth are transitioning from pediatric to adult healthcare as they approach adulthood. Current transition practices, when present, are disorganized, resulting in health status deterioration and complications due to unmet

needs. Objective: The purpose of this study is to develop a broader understanding of the current transition practices and experiences, as well as recommendations of care providers in the support of youth with CCN as they transition from pediatric to adult healthcare. Study Design: This study uses a qualitative descriptive design. The data collected was analyzed using inductive thematic analysis following the six phases outlined by Braun and Clarke (2006). Population Studied: A purposeful sample of 15 primary care providers (PCP), specialists, and subspecialists who support youth in the transition from pediatric to adult healthcare were interviewed using a semi-structured interview guide. Setting: The study spanned the province of New Brunswick and included pediatric providers from the IWK Health Centre in Nova Scotia. Results: The findings from this research demonstrate a shortage of care providers and lack of community services available for youth with CCN who move into adult healthcare services. Specifically, due to the significant amount of primary care pediatricians provide youth during childhood, improved access to PCPs was a recommendation. Moreover, participants indicated that a designated transition coordinator can enhance the transition process for the youth and stakeholders involved in their care. Conclusion: The results of this study can potentially improve transition practices and policies for primary care practice, and guide future research in this area.

88. **A TRANSITION PROGRAM AND NOVEL JOINT PEDIATRIC-ADULT CLINIC MODEL DECREASES ADULT MORTALITY IN PEDIATRIC LIVER TRANSPLANT RECIPIENTS.**

Stevens, J. et al.

Hepatology 76, S1546 (2022) doi:10.1002/hep.32697

Background: Pediatric liver transplant recipients have a high risk of complications following transfer of care to an adult provider. Our center's previously published data showed 28% mortality in young adults, with death disproportionately affecting Black patients. In 2015 we implemented formal transition processes, including a teen clinic with one physician providing continuity of care and a joint pediatric-adult clinic. Our study aims to analyze outcomes since the formation of this program. Methods: Single-center, retrospective study describing demographics, pediatric characteristics, and adult outcomes from a university health system with affiliated pediatric and adult liver transplant programs. Pediatric transplant recipients who completed the transition program and were seen in the joint pediatric-adult clinic from March 2015-2020 were included. Results: Fifty nine patients completed transition. The cohort was 64% female, 59% White and 32% Black. Median age at first transplant was 6.9years, median age at transfer 20.7years. Thirty five children (59%) had a major co-morbidity. Comparing transition cohort (T) to a prior non-transition cohort (NT, n=64), prevalence of pediatric complications was similar including acute cellular rejection (ACR, 61% vs. 64% T vs NT respectively, p=0.85) and re-transplant (15% vs 20%, p=0.49). Medication level variability index (MLVI) was <2 (reflecting adherence) in 55% of T patients vs. 20% NT (p<0.01). T children had less hypertension (19% vs. 38%, p=0.03) and diabetes mellitus (DM, 12% vs. 38%, p<0.01). There was no difference in psychiatric illness (53% vs 39%, p=0.15), or high school (HS) graduation (71% vs 77%, p=0.67). Adult transition outcomes show a decrease in mortality since program initiation (from 28% to 3%, n=2, p<0.01). Both deaths were in Black females with immune-mediated liver diseases. Compared to other races, Black adults had higher prevalence of ACR (67% vs 20%, p=0.02) and re-transplantation (26% vs 2.5%, p=0.01). Substance use was higher overall in adulthood than childhood (37% vs 10%, p<0.01) though DM, hypertension, and obesity did not change. Adults continued to graduate HS (increasing from 71% to 89%). Conclusion: Following implementation of a transition program and joint pediatric-adult clinic model adult mortality decreased and adolescent MLVI improved compared to patients not receiving formal transition. Further work is needed to address ongoing racial disparities, adult mental health and substance use.

89. **EDUCATION AND PSYCHOSOCIAL FACTORS PREDICT ODDS OF DEATH AFTER TRANSFER TO ADULT HEALTH CARE IN PEDIATRIC LIVER TRANSPLANT PATIENTS.**

Stevens, J. P. et al.

Journal of Pediatric Gastroenterology and Nutrition 75, 623–628 (2022)
doi:10.1097/MPG.0000000000003549

Objectives: To analyze demographic, psychosocial, and clinical factors in pediatric liver transplant recipients for their association with death or loss to follow up in adulthood. We aimed to better understand known

health disparities in transplant outcomes and identify potentially modifiable risk factors prior to transfer. Methods: A retrospective cohort study of children who underwent liver transplantation at a large tertiary transplant center and were transferred to adult care between 2000 and 2015. Results: During the study period, 101 qualifying patients were transferred. Ninety-Three individuals followed with an adult provider, while 8 were lost to follow up. In total 23 of 93 patients died after transfer (24.7%). Several childhood factors were associated with adult death: Black race [odds ratio (OR) 6.59, $P < 0.001$]; psychiatric illness or substance use (OR 2.81, $P = 0.04$); failure to graduate high school before transfer (OR 9.59, $P < 0.001$); posttransplant tacrolimus medication-level variability index >2.5 (OR 5.36, $P = 0.04$); provider documentation of medication nonadherence (OR 4.72, $P = 0.02$); acute cellular rejection (OR 4.44, $P = 0.03$); the presence of diabetes mellitus (OR 5.71, $P = 0.001$), and chronic kidney disease (OR 2.82, $P = 0.04$). Failure to graduate HS was associated with loss to follow up ($P < 0.001$). On multivariate analysis, Black race, substance use, diabetes, and failure to graduate HS retained association with adult death (each $P < 0.05$). Conclusions: Complex, intertwined patient characteristics are associated with increased odds of death in pediatric liver transplant recipients transferred to adult care. Early recognition of high-risk patients and intervention for modifiable factors, such as improved HS graduation and substance use prevention, may improve long-Term outcomes.

90. **CURRENT STATUS OF TRANSITION MEDICINE FOR 21-HYDROXYLASE DEFICIENCY IN JAPAN: FROM THE PERSPECTIVE OF PEDIATRIC ENDOCRINOLOGISTS.**

Takasawa, K. et al.

Endocrine Journal 69, 75–83 (2022) doi:10.1507/endocrj.EJ21-0292

To manage of 21-hydroxylase deficiency (21-OHD), transition medicine from pediatric to adult health care is an important process and requires individually optimized approaches. We sent cross-sectional questionnaire surveys on the current status of transition from pediatric to adult health care in 21-OHD patients to all councillors of the Japanese Society for Pediatric Endocrinology. Many pediatric departments (42.2%) experienced adult 21-OHD patients, and 115 patients (53 males, mean age of 26) in 46 institutions were identified. Whereas almost two-thirds of pediatric endocrinologists regarded the problems of counterparts and cooperation as hindrance of transition medicine, the major reason for continuing to be treated in pediatrics was the patient's own request. The prevalence of long-term complications including obesity, osteoporosis, infertility, menstrual disorder, gender dysphoria, and testicular adrenal rest tumor were 27.5%, 8.8%, 11.1%, 26.3%, 7.1%, 12.5%, respectively, which is comparable to those of other cohorts previously reported. However, several items, especially infertility and osteoporosis were not checked well enough in adult 21-OHD patients treated in pediatrics. Though 44 of 62 female patients had genital reconstructive surgery, more than half of them were not followed up by gynecologists or pediatric urologists. Quite a few adult 21-OHD patients had been followed up in pediatrics even after coming of age; however, surveillance by pediatric endocrinologists of gynecological, reproductive, and mental problems may be insufficient. Therefore, multidisciplinary approaches should be required in transition medicine for 21-OHD and prerequisite for graduation of pediatrics. Pediatric endocrinologists will need to play a leading role in the development of transition systems.

91. **STRATEGIES AND TOOLS TO AID THE TRANSITION BETWEEN PAEDIATRIC AND ADULT HEALTH SERVICES FOR YOUNG ADULTS WITH NEURODEVELOPMENTAL DISORDERS: A SCOPING REVIEW PROTOCOL.**

Thanalingam, Y. et al.

BMJ Open 12, (2022) doi:10.1136/bmjopen-2022-065138

Introduction The transition from paediatric to adult healthcare comes with risk and vulnerability for young adults with neurodevelopmental disorders and their carers. Deficits in health, social and disability systems and the fragmentation of services exacerbate problems during the transition period, leaving young people and their carers feeling disconnected with existing services. With advances in healthcare, the number of young adults with neurodevelopmental disorders requiring transition services is increasing. This scoping review aims to summarise the strategies and tools that help ease the transition to adult services for young adults with neurodevelopmental disorders. Methods and analysis Systematic searches of MEDLINE, EMBASE and PsychInfo on the OVID platform were performed on 28/05/2022. Studies that describe tools

or strategies designed to ease the transition from child-centred to adult-orientated healthcare for young adults with neurodevelopmental disorders will be included. Two authors will independently review titles, abstracts and full-text articles against the inclusion criteria to determine eligibility. Data will be extracted and synthesised using descriptive stats and thematic analysis. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews guidelines will be followed. Conclusion This scoping review will synthesise the published literature describing strategies and tools to improve the transition of young adults with neurodevelopmental disorders to adult services. The findings of the review may inform areas of future research to improve care for all involved in the transition process. Ethics and dissemination This review will include published data; as such, ethics approval is not required. We will publish our findings in an open-access, peer-reviewed journal and summarise the results for dissemination to the wider community of clinicians, allied healthcare professionals, teaching professionals, policymakers, non-governmental organisations, impacted youth and parents.

92. **A COMPREHENSIVE TRANSFER PROGRAM FROM PEDIATRICS TO ADULT CARE FOR PARENTS OF ADOLESCENTS WITH CHRONIC ILLNESS (PARTNERSTEPS): STUDY PROTOCOL FOR A RANDOMIZED CONTROLLED TRIAL.**

Thomsen, E. L. *et al.*

Trials 23, (2022) doi:10.1186/s13063-022-06997-0

Background: Previous research shows that adolescents with a chronic illness have more successful transfers to adult care if their parents are involved during the transition. However, there is a lack of structured and evaluated transfer programs for parents. Our aim will be to test a comprehensive transfer program for parents of adolescents with chronic illness during the transfer from pediatric to adult care and to evaluate the program's effectiveness, acceptability, and costs. Methods: The overall design for this protocol will be a randomized controlled trial. A total of 62 dyads consisting of an adolescent (age 16.5–17.5) and at least one parent will be recruited from one of four pediatric outpatient clinics (nephrology, hepatology, neurology, or rheumatology) at Copenhagen University Hospital - Rigshospitalet, Denmark. The dyads will be randomized to receive the transfer program in addition to usual care or to receive usual care only. The program includes an informative website, bi-annual online educational events, and transfer consultations across pediatric and adult care. Outcome measures will include transition readiness, allocation of responsibility, parental uncertainty level, and transfer satisfaction. Data will be collected from participants at baseline, every 6 months until transfer, at transfer, and 3 months after transfer. The parents' acceptance of and satisfaction with the program will be explored through semi-structured interviews. Cost, barriers, and facilitators affecting future implementation will be identified in interviews with health care professionals, using the Normalization Process Theory as a framework for the process analysis. Discussion: To our knowledge, this transfer program is one of the first interventions for parents of adolescents with a chronic illness during their child's transfer to adult care. Our trial will include parental and adolescent measures allowing us to examine whether a transfer program for parents will improve transfer to adult care for both parents and adolescents. We believe that results from our trial will be helpful in forming recommendations to ensure better involvement of parents in transitional care. Trial registration: ClinicalTrials.gov NCT04969328. Retrospectively registered on 20 July 2021.

93. **A CALL FOR ACTION: RECOMMENDATIONS TO IMPROVE TRANSITION TO ADULT CARE FOR YOUTH WITH COMPLEX HEALTH CARE NEEDS.**

Toulany, A., Gorter, J. W. & Harrison, M.

Paediatrics and Child Health (Canada) 27, 297–302 (2022) doi:10.1093/pch/pxac047

Youth with complex health care needs, defined as those requiring specialized health care and services for physical, developmental, and/or mental health conditions, are often cared for by paediatricians and paediatric specialists. In Canada, the age at which provincial/territorial funders mandate the transfer of paediatric care to adult services varies, ranging between 16 and 19 years. The current configuration of distinct paediatric and adult care service boundaries is fragmentary, raising barriers to continuity of care during an already vulnerable developmental period. For youth, the lack of care integration across sectors can negatively impact health engagement and jeopardize health outcomes into adulthood. To address these barriers and improve transition outcomes, paediatric and adult care providers, as well as family

physicians and other community partners, must collaborate in meaningful ways to develop system-based strategies that streamline and safeguard care for youth transitioning to adult services across tertiary, community, and primary care settings. Flexible age cut-offs for transfer to adult care are recommended, along with considering each youth's developmental stage and capacity as well as patient and family needs and circumstances. Specialized training and education in transitional care issues are needed to build capacity and ensure that health care providers across diverse disciplines and settings are better equipped to accept and care for young people with complex health care needs.

94. **[THE TRANSITION OF PSYCHIATRIC ILL ADOLESCENTS FROM CHILD AND ADOLESCENT PSYCHIATRIC CARE TO ADULT PSYCHIATRIC CARE].**

Trabi, T., Purtscher-Penz, K. & Plener, P.

Neuropsychiatrie : Klinik, Diagnostik, Therapie und Rehabilitation : Organ der Gesellschaft Osterreichischer Nervenarzte und Psychiater 37, 26–32 (2023) doi:10.1007/s40211-022-00441-0

Transition in psychiatry describes the transition from child psychiatric to adult psychiatric care. This transition is not purely medical, it takes place on many levels of care. Transition in the narrow sense describes the targeted and planned process of making this change ideal for patients and medical treaters. Due to the legally fixed border to be an adult at the age of 18 years and different financing systems for children and adults, there is often a break in care of psychiatric ill adolescents. The few available studies show that only about a quarter of patients are satisfied with the process of transition and 90% of employees in the healthcare system also experience this phase as deficient. So far there are no general concepts for an orderly transition in Austria, different individual solutions are available regionally. It is necessary to include all professional groups involved, but due to the regionally very heterogeneous supply, adapted concepts are necessary. It is aimed to include a meeting of all involved professionals, the establishment of good communication and flexibility regarding to the age of transition. Concerning the need for specialized transition facilities, there is currently a lack of solid data in Austria, these data should be collected. Likewise, legal framework conditions would have to be specified and then outpatient, day clinic and inpatient settings would have to be created under child psychiatric and adult psychiatric co-management in order to support the process of transition as best as possible.

95. **ASSESSMENT OF THE TRANSITION OF CARE FROM PEDIATRIC TO ADULT RHEUMATOLOGY IN A TERTIARY CENTER.**

Ugurlu, S. et al.

Arthritis and Rheumatology 74, 2565–2567 (2022) doi:10.1002/art.42355

Background/Purpose: Taking the responsibility for their own health should be an important goal for the patients in the health care transition process. The Transition Readiness Assessment Questionnaire (TRAQ) is an effective tool to assess the competencies of the patients in five domains, which is usually administered before transitioning to adult care. For the first time, we aimed to measure the self-management skills of the patients with rheumatologic diseases who had already transitioned to adult rheumatology by using the TRAQ. **Methods:** 310 patients who had transitioned from pediatric to adult rheumatology between June 2020-June 2021 were interviewed. The TRAQ was administered to the patients by the physicians in our clinic. The patients were divided into groups according to their diagnoses. The patients with two rheumatologic diagnoses in different categories were included in both groups. The data evaluated included sex, age at diagnosis, age at transition to adult care, age at TRAQ administration, and diagnoses of the patients. **Results:** There were 184 female (59.4%) and 126 male (40.6%) patients. The mean age at diagnosis, the mean transition age and the mean age when the TRAQ was administered were 10.7 ± 4.29 , 21.1 ± 1.69 and 24.0 ± 2.26 years, respectively. The minimum and maximum ages of transition were 16 and 26, respectively (IQR:20-22). 22 patients were in the 16-18 age group, 170 patients were in the 19-21 age group, and 118 patients were in the 22+ age group according to the transition age. The patients consisted of four groups: FMF (n=203), arthritis (JIA and juvenile SpA, n=81), connective tissue disorders (SLE, scleroderma, polymyositis, dermatomyositis and Sjögren's syndrome, n=29) and others (Behçet syndrome, Henoch-Schönlein purpura, polyarteritis nodosa, Raynaud phenomenon, acute rheumatic fever, and cryoglobulinemic vasculitis, n=23). The TRAQ results according to the diseases are given in Table 1. The results according to sex are given in Figure 1. Females had higher scores than males in tracking health

issues (2.65 ± 1.02 vs. 2.31 ± 1.11 , $p=0.005$) and overall TRAQ score (4.31 ± 0.326 vs. 4.22 ± 0.360 , $p=0.02$). The TRAQ results according to the transition age and age at TRAQ administration are given in Table 2. Conclusion: Tracking health issues was the weakest domain in our cohort irrespective of other factors. Females performed better than males in overall TRAQ score. The transition age, the age at TRAQ administration or the diagnosis didn't affect the overall TRAQ score. Thus, initiating the transition period earlier can be recommended due to the fact that a later transition did not necessarily lead to better outcomes in self-management. Assessing the abilities after the transition in addition to pretransition period can be a good first step to address the needs of the patients with rheumatologic diseases.

96. **EXPERIENCE WITH THE TRANSITION PROCESS OF ADOLESCENTS WITH CHRONIC DISEASES FROM PEDIATRIC TO ADULT CARE IN A GENERAL HOSPITAL.**

Vainman, S. et al.

Archivos Argentinos de Pediatría 120, 398–404 (2022) doi:10.5546/aap.2022.eng.398

Introduction. The continuity of care from pediatrics to adult medicine is key to optimal health care. Objective. To describe the experience of the transition process of adolescent patients with chronic diseases from pediatric to adult care in a general hospital. Population and methods. Cross-sectional study of patients aged 16–24 years with a history of liver transplantation, kidney transplantation, endocrine, metabolic, rheumatic diseases, and myelomeningocele seen at a tertiary care teaching general hospital between 2015 and 2019 during the transition process. The process of health care and transition success were assessed. The Transition Readiness Assessment Questionnaire (TRAQ) was used. Results. A total of 372 patients were included. The myelomeningocele clinic, the kidney transplant and the liver transplant teams were the most common specialties. Thirty-seven percent of participants were involved in the transition process. The mean duration of follow-up by pediatrics until transition initiation was 9 years. The mean age at the beginning of transition was 19 years, and the mean age at the end, 21 years. The joint clinic transition strategy was the most frequent, used in 96% of cases. The median value of the ordinal TRAQ was 4; of these, 32% had already seen adult care physicians. A successful transition was achieved by 32.7%. Conclusions. The continuity of care during transition is a process that took almost 2 years; more than one third of the patients had a successful transition.

97. **FACILITATING THE TRANSITION FROM PAEDIATRIC TO ADULT CARE IN ENDOCRINOLOGY: A FOCUS ON GROWTH DISORDERS.**

Vakharia, J. D. & Stanley, T. L.

Current Opinion in Endocrinology, Diabetes and Obesity 30, 32–43 (2023) doi:10.1097/MED.0000000000000785

Purpose of review. Many childhood-onset growth disorders (COGDs) require continued care into adulthood, and the time of transition between paediatric and adult providers carries a high risk for interruptions in medical care and consequent worsening of disease management.

Recent findings. Research into best practices for healthcare transition (HCT) describes three distinct stages. Stage 1, transition planning and preparation, begins in the paediatric setting during early adolescence and ensures that the patient has adequate medical knowledge, self-management skills, and readiness for transition. Stage 2, transfer to adult care, occurs with variable timing depending on transition readiness and is best facilitated by warm hand-offs and, when possible, joint visits with the paediatric and adult provider(s) and/or involvement of a care coordinator. Stage 3, intake and integration into adult care, entails retaining the patient in the adult setting, ideally through the involvement of a multidisciplinary approach.

Summary. This review covers general principles for ensuring smooth transition of adolescents and young adults (AYA) with COGD, disease-specific medical considerations for paediatric and adult endocrinologists during the transition process, and general and disease-specific resources to assess transition readiness and facilitate transition.

98. **THE IMPORTANCE OF CLINICIANS' AND PARENTS' AWARENESS OF SUICIDAL BEHAVIOUR IN ADOLESCENTS REACHING THE UPPER AGE LIMIT OF THEIR MENTAL HEALTH SERVICES IN**

EUROPE.**van Bodegom, L. S. et al.***Journal of Affective Disorders* 325, 360–368 (2023) doi:10.1016/j.jad.2022.12.164

Background: To study clinicians' and parents' awareness of suicidal behaviour in adolescents reaching the upper age limit of their Child and Adolescent Mental Health Service (CAMHS) and its association with mental health indicators, transition recommendations and mental health service (MHS) use. Methods: 763 CAMHS users from eight European countries were assessed using multi-informant and standardised assessment tools at baseline and nine months follow-up. Separate ANCOVA's and pairwise comparisons were conducted to assess whether clinicians' and parents' awareness of young people's suicidal behaviour were associated with mental health indicators, clinician's recommendations to continue treatment and MHS use at nine months follow-up. Results: 53.5 % of clinicians and 56.9 % of parents were unaware of young people's self-reported suicidal behaviour at baseline. Compared to those whose clinicians/parents were aware, unawareness was associated with a 72–80 % lower proportion of being recommended to continue treatment. Self-reported mental health problems at baseline were comparable for young people whose clinicians and parents were aware and unaware of suicidal behaviour. Clinicians' and parents' unawareness were not associated with MHS use at follow-up. Limitations: Aspects of suicidal behaviour, such as suicide ideation, -plans and -attempts, could not be distinguished. Few young people transitioned to Adult Mental Health Services (AMHS), therefore power to study factors associated with AMHS use was limited. Conclusion: Clinicians and parents are often unaware of suicidal behaviour, which decreases the likelihood of a recommendation to continue treatment, but does not seem to affect young people's MHS use or their mental health problems.

99. **COMMUNITY-BASED ACCOMPANIMENT FOR ADOLESCENTS TRANSITIONING TO ADULT HIV CARE IN URBAN PERU: A PILOT STUDY.**

Vargas, V. et al.*AIDS and behavior* 26, 3991–4003 (2022) doi:10.1007/s10461-022-03725-2

We piloted a community-based intervention to improve outcomes among adolescents living with HIV who were transitioning to adult-oriented care in Lima, Peru. We assessed feasibility and potential effectiveness, including within-person changes in self-reported adherence, psychosocial metrics (NIH Toolbox), and transition readiness ('Am I on TRAC' questionnaire, 'Got Transition' checklist). From October 2019 to January 2020, we enrolled 30 adolescents (15-21 years). The nine-month intervention consisted of logistical, adherence and social support delivered by entry-level health workers and group sessions to improve health-related knowledge and skills and social support. In transition readiness, we observed within-person improvements relative to baseline. We also observed strong evidence of improvements in adherence, social support, self-efficacy, and stress, which were generally sustained three months post-intervention. All participants remained in treatment after 12 months. The intervention was feasible and potentially effective for bridging the transition to adult HIV care. A large-scale evaluation, including biological endpoints, is warranted.

100. **HEALTHCARE TRANSITION OF TRANSGENDER AND GENDER DIVERSE YOUTH FROM PEDIATRIC TO ADULT CARE SETTINGS: NEEDS ASSESSMENT FROM A QUALITY IMPROVEMENT PROJECT.**

Walch, A., Pennella, S., Russell, M. & Lee, J. Y.*Hormone Research in Paediatrics* 95, 249–250 (2022) doi:10.1159/000525242

Objectives Scant evidence-based resources for transitioning transgender and gender diverse (TGD) youth from pediatric to adult care models exist. To address this deficit, a multidisciplinary pediatric gender-affirming endocrine clinic initiated a quality improvement (QI) project to build an equitable healthcare transition (HCT) program adapted to the unique medical and social needs of TGD youth. Methods Needs assessments included stakeholders using a mixed-methods approach. An informal needs assessment was conducted through interviews with seven clinic staff and 13 TGD youth (\pm legal guardians if <18 years old) who met inclusion criteria: 1. \geq 16 years old, 2. established care \geq 2 years ago, 3. on a stable medication regimen. Interviews facilitated by a non-clinician focused on topics including HCT awareness, emotions, skills, resources, policy, readiness, and program implementation and sustainability. To further explore HCT-related needs, findings from interviews directed the development of a formal needs assessment survey

administered via REDCap to 150 patients who met above inclusion criteria. Results Forty-one (27%) individuals completed the formal needs assessment. Respondents identified needing the most support with these HCT-related skills: managing and refilling prescriptions (71%), finding medical providers for adult gender care (83%), and navigating health insurance/paying for gender-affirming care (83%) [Figure]. They also expressed preferences in learning about the HCT program after establishing a relationship with their provider, and in starting the program at age ≥ 16 years old and once on a stable hormone regimen. Conclusions Our findings indicate that TGD youth have needs that require a specialized approach to HCT the current HCT programs and toolkits do not incorporate. As the population of transition age TGD youth grows, this work addresses the highly relevant and pressing demands for a generalizable HCT approach for TGD youth. Our findings highlight gaps suitable for interventions at the clinical level which pediatric clinics may use to develop their own HCT programs. Based on responses, we developed and disseminated clinic policies specifying age criteria for new and established patients and facilitation of the transition process to address HCT program needs. This QI project is ongoing and learnings from future Plan-Do-Study-Act cycles will be shared. .

101. **HEALTH CARE TRANSITION IN SCHOOL-BASED HEALTH CENTERS: A PILOT STUDY.**

White, P. H., Ilango, S. M., Caskin, A. M., la Guardia, M. G. A. & McManus, M. A.

The Journal of school nursing : the official publication of the National Association of School Nurses 38, 526–532 (2022) doi:10.1177/1059840520975745

Nationally, there are low rates of high school-age youth receiving health care transition (HCT) preparation from health care providers. This pilot study implemented and assessed the use of a structured HCT process, the Six Core Elements of HCT, in two school-based health centers (SBHCs) in Washington, DC. The pilot study examined the feasibility of incorporating the Six Core Elements into routine care and identified self-care skill gaps among students. Quality improvement methods were used to customize, implement, and measure the Six Core Elements and HCT supports. After the pilot, both SBHCs demonstrated improvement in their implementation of the structured HCT process. More than half of the pilot participants reported not knowing how to find their doctor's phone number and not knowing what a referral is. These findings indicate the need for incorporating HCT supports into SBHCs to help students build self-care skills necessary for adulthood.

102. **REVAMPING THE TRANSITION TO ADULT CARE IN A PEDIATRIC CENTER: IMPLEMENTATION OF A ONE-ON-ONE MEETING PROCESS.**

Williams, K. et al.

Journal of Cystic Fibrosis 21, S144–S146 (2022) doi:10.1016/S1569-1993(22)00933-X

Background: Most teens with special health care needs (SHCN) and their families do not receive adequate support in the transition from pediatric to adult health care. The 2016 National Survey of Children's Health indicated that 83% of teens with SHCN did not meet the national health care transition performance measure standards, including time to speak alone with their health care providers [1]. Meeting one on one with providers can help establish this practice as part of routine care and allows for regular opportunities to discuss concerns in an open manner [2], but studies have shown that as few as 38% of teens aged 15 to 17 have met alone with a provider during routine clinic visits [3]. The current quality improvement project seeks to implement systematic one-on-one visits as part of the pediatric clinic's transition to adult care process. We aimed to have 60% of eligible teens provided education on the one-on-one process and have a one-on-one visit with a provider by the end of 2021. Methods: A transition registry was created and maintained for all individuals aged 17 to 22 with cystic fibrosis (CF) beginning the transition process. Individuals aged 17 to 22 participated in our clinic's transition process between January 1, 2021, and December 31, 2021. The psychosocial team and clinical educator identified individuals eligible for one-on-one visits during weekly patient review. Participants were educated on one-on-one visits using materials adapted from GOT Transition and Centers for Disease Control and Prevention guidelines (Figure 1). Individuals with one-on-one visits were indicated on the CF clinic track board and marked on Figure 1: One-on-One Time with Your Health Care Team. (Figure Presented) their patient visit sheet for provider identification. Survey data were collected electronically at the end of the visit from May through December 2021. Surveys asked about the feasibility and acceptability of one-on-one visits for providers and teens. Surveys were discontinued when

data saturation was reached. Results: Of 49 individuals aged 17 to 22 were eligible to participate in the one-on-one transition process, 67% received one-on-one education, and 57% met one-on-one with a provider. Three refused to meet one-on-one. We met our goal of educating 60% but did not meet our goal of 60% of participants meeting one-on-one during 2021. All of the 22 individuals who participated in one-on-one visits in 2021 and were surveyed and their providers found the one-on-one visits helpful and productive; 96% of teens felt comfortable meeting alone with providers. Conclusions: One-on-one visits are a useful tool in preparing teens and young adults for transition to adult care. Providers and young people with CF expressed favorability for one-on-one visits and were able to discuss important health-related concerns collaboratively. Barriers to the one-on-one visits included parent or teen refusal, missed appointments, and family preference for inclusion of parents during visits addressing admissions or pulmonary exacerbations. Next steps include participation in one-on-one visits with ancillary team members such as social work, psychology, and nursing

103. **TRANSITION OF ADULT PATIENTS WITH PEDIATRIC ORTHOSTATIC INTOLERANCE FROM CHILD-CENTERED CARE TO ADULT-CENTERED CARE.**

Yanagimoto, Y.

Frontiers in Pediatrics 10, (2022) doi:10.3389/fped.2022.946306

104. **STUDY PROTOCOL: A PRAGMATIC TRIAL REVIEWING THE EFFECTIVENESS OF THE TRANSITIONMATE MOBILE APPLICATION IN SUPPORTING SELF-MANAGEMENT AND TRANSITION TO ADULT HEALTHCARE SERVICES FOR YOUNG PEOPLE WITH CHRONIC ILLNESSES.**

Yeung, J. et al.

BMC health services research 22, 1443 (2022) doi:10.1186/s12913-022-08536-8

BACKGROUND: Transition from paediatric to adult health care services is a challenging time for many adolescents with chronic illnesses and may include deterioration in illness control as a consequence of inadequate self-management skills, poor understanding of their chronic illness and failure to engage with adult services. Successful transfer of health care requires the development of self-management skills and increased autonomy. Mobile technology has been proposed as a modality to assist in this process. Evidence is limited and generally restricted to illness specific applications. The TransitionMate app (TMApp) is a generic (non-illness specific) mobile application designed to support young people with chronic illness in their transition from paediatric to adult health care services. The overall aim of the study is to assess the effectiveness of TMApp in improving engagement and retention of adolescents with chronic illness within adult healthcare services, as well as preventing the deterioration in illness control and unplanned hospitalisations. **METHODS:** The TransitionMate trial is a dual centre, pragmatic, single arm, mixed methods cohort study conducted within two university teaching tertiary paediatric hospitals in Australia. Data collection points are planned at 0, 6, 12 and 18 months. Outcome indicators include: usage of TransitionMate, engagement with adult services, quantitative markers of illness control, and unplanned hospital admissions. Data are collected through telephone interviews with the participants, their primary healthcare providers, electronic medical records and de-identified mobile application analytics. The development of the application involved co-design with recently transitioned young people with a number of chronic illnesses as well as online user experience in younger adolescents. **DISCUSSION:** The TransitionMate study is the first identified trial of a generic mobile application designed to support adolescents with chronic illnesses during the transition process. Results are expected to provide novel insights into the value of technological tools in the transition space, especially their effectiveness in improving both the transition process and clinical outcomes of adolescents with chronic illnesses. Furthermore, the approach of a pragmatic study design may help identify research methods better designed to overcome inherent challenges in research involving adolescents, transition of care and use of mobile application technology. **TRIAL REGISTRATION:** Registered retrospectively as of 30/1/2020 with Australian New Zealand Clinical Trials Registry: ACTRN1262000074998 .

EPILESSIA

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

Kwack, D. W., Lee, H., Lee, R., & Kim, D. W.

Seizure (2022) <https://doi.org/10.1016/j.seizure.2022.01.015>

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

2. PATIENT AND PROVIDER PERSPECTIVES ON TRANSITION OF CARE FOR PATIENTS WITH EPILEPSY. NASCIMENTO, F. A., MELENDEZ

Zaidi, A., Swoyer, B., & Thiele, E. A.

Epileptic Disorders (2022) <https://doi.org/10.1684/epd.2022.1465>

DIABETE

1. DEVELOPMENT AND IMPLEMENTATION OF A PILOT TRANSITION PREPARATION INTERVENTION FOR YOUNG ADULTS WITH TYPE 1 DIABETES IN AN INTEGRATED HEALTHCARE SETTING.

Caccavale, L. J., LaRose, J. G., Mazzeo, S. E. & Bean, M. K.

Journal of pediatric psychology (2022) doi:10.1093/jpepsy/jsac084

OBJECTIVE: To evaluate the feasibility, acceptability, and preliminary efficacy of a multisystem transition preparation intervention, SHIFT, for young adults (YAs) with type 1 diabetes (T1D). METHODS: A single-arm, clinic-based pilot was conducted with 25 YAs with T1D (M age = 18.9 ± 1.0 years; 80% female), their parents ($n = 25$), and their providers ($n = 10$). Young adults and parents participated in a 6-month intervention designed to enhance transition readiness and independent diabetes management. Providers viewed a video module highlighting their role preparing YAs for transition and received individualized reports of YA's goals and transition readiness. Intervention feasibility (i.e., recruitment, retention, and engagement) and acceptability (e.g., program satisfaction) were assessed. Assessments of transition readiness, diabetes engagement, hemoglobin A1c (HbA1c), and related psychosocial variables were conducted at baseline, post-intervention (6 m), and follow-up (9 m). Paired t-tests examined 0-6 m and 0-9 m changes in study constructs. RESULTS: SHIFT was feasible, evidenced by recruitment (100% of sample recruited in 4 m), retention (100% at 6 m), and YA session attendance (100%). Program satisfaction was high for YAs, parents, and providers (9.12 ± 1.40 , 8.79 ± 1.56 , 8.20 ± 1.30 , respectively, [out of 10]). Significant improvements (with effect sizes ranging from small to medium) were observed in parent and YA-reported transition readiness at 6 and 9 m ($ps < .05$) and diabetes engagement at 9 m ($ps < .05$). Although based on limited data due to COVID-19-related disruptions, a potential reduction in HbA1c was also

observed. CONCLUSION: Findings support the feasibility, acceptability, and preliminary efficacy of SHIFT (although limited by the single arm design and homogeneous sample), and suggest a larger randomized controlled trial is warranted.

2. **TRANSITION FROM PEDIATRIC TO ADULT CARE FOR INDIVIDUALS WITH TYPE 1 DIABETES: OPPORTUNITIES AND CHALLENGES.**

D'Amico, R. P., Pian, T. M. & Buschur, E. O.

Endocrine Practice (2023) doi:10.1016/j.eprac.2022.12.006

Objectives: Type 1 diabetes (T1D) is a chronic disease with patients across the age spectrum that has high potential for morbidity and mortality. Unfortunately, patients transitioning from pediatric to adult care continue to demonstrate worsened glycemic control in part due to lack of understanding of transition of care best practices. Methods: This review highlights the impact of existing transition of care interventions, assessment tools, and other recently published strategies for providers to consider to improve care of adolescent and young adult (AYA) patients with T1D in both hospital- and clinic-based settings. Results: Many barriers impact patients with T1D during the transition period and disparities by race, sex, insurance status, and comorbid illness persist. As diabetic care continues to evolve and the prevalence of adolescents and young adults living with T1D increases, an intentional approach to transition of care is more pressing than ever. While current literature on transition of care models is limited, many show promise in improving clinic attendance and decreasing hospitalization. There are critical discussions that providers should lead with AYA patients to improve their outcomes and increase diabetes self-management, such as re-addressing carbohydrate counseling, sleep hygiene, and reproductive planning. Conclusion: While further research on transition of care is needed, many care models offer the promise of improved T1D outcomes, enhancements in our approach to care, and increased value for our health care system at large.

3. **DIAGNOSIS, THERAPY AND FOLLOW-UP OF DIABETES MELLITUS IN CHILDREN AND ADOLESCENTS.**

Holder, M. et al.

Experimental and Clinical Endocrinology and Diabetes 130, S49–S79 (2022) doi:10.1055/a-1624-3388

4. **TRANSITION FROM PAEDIATRIC TO ADULT CARE IN YOUNG PEOPLE WITH DIABETES; A STRUCTURED PROGRAMME FROM A REGIONAL DIABETES SERVICE, AUCKLAND, NEW ZEALAND.**

Hornung, R. J. et al.

Diabetic medicine : a journal of the British Diabetic Association 40, e15011 (2023) doi:10.1111/dme.15011

AIM: To assess participation with a structured transition programme for adolescents with diabetes. METHODS: Data from a regional cohort aged less than 16 years of age with type 1 (T1) and type 2 diabetes (T2D) in Auckland, New Zealand (2006-2016). Participation was defined as opting into a structured transition programme. RESULTS: Five hundred and twelve adolescents who were to be transferred to adult care (476 type 1 (T1D) and 36 type 2 (T2D)), overall participation rate of 83%, 86% (408/476) with T1D compared to 47% (17/36) with T2D. Within the cohort of T1D, participation rates for Māori and Pacific were lower (74% and 77%, respectively) than New Zealand Europeans (88%, $p = 0.020$ and $p = 0.039$, respectively). Lower socio-economic status was associated with reduced participation (77%) compared to higher socio-economic status (90%, $p = 0.002$). Of the 476 T1D who participated, 408 (96%) subsequently attended at least one adult service clinic ('capture'). 42% attended an adult clinic within the planned 3 months, 87% at 6 months and retention in adult clinics over 5 years of follow-up was 78%. By contrast, the 68 young people with T1D who did not participate in the structured transition had a capture rate of 78% ($p < 0.001$) and retention of 63% ($p = 0.036$). CONCLUSIONS: In adolescents with diabetes, a formal transition from a paediatric service was associated with high rates of adult capture and subsequent retention in adult care over a 5-year follow-up period. Low socio-economic status, Māori or Pacific ethnicity and T2D were associated with reduced participation in the structured transition programme.

5. **THE ASSOCIATION BETWEEN PEDIATRIC MENTAL HEALTH DISORDERS AND TYPE 1 DIABETES-**

RELATED OUTCOMES.**Hu, T. Y., Price, J., Pierce, J. S. & Gannon, A. W.***Pediatric Diabetes* 23, 507–515 (2022) doi:10.1111/pedi.13330

Objective: Transition from pediatric to adult healthcare systems is a difficult process for young adults with Type 1 Diabetes (T1D) and most patients experience a deterioration in disease control. Mental health (MH) disorders are common in individuals with T1D and are believed to play a role in disease control and transition of care. We evaluated the association between the presence of pediatric MH disorder and measures of success in diabetes care in young adults who recently transitioned to adult care. Research Design and Methods: Retrospective cohort study of young adults in a large adult endocrinology system who transitioned from a pediatric hospital system after 2009. MH disorders were diagnosed by clinical pediatric psychologists during routine care at the pediatric hospital. Measurements of Hemoglobin A1c, diabetes-related emergencies, clinic attendance and intervals in transition were assessed and compared between the pediatric and adult hospital systems. Results: 237 young adults were identified and 100 (42%) of these were diagnosed with a MH disorder during pediatric care. Presence of a MH disorder was associated with higher Hemoglobin A1c levels prior to transition and increased rates of diabetes-related hospitalizations during the transition interval. Patients with a MH disorder were less likely to establish a pattern of consistent follow up after transition ($p = 0.021$). Conclusions: MH disorders are common and predict greater challenges with diabetes management and less effective transition into the adult endocrinology system. Early recognition of MH disorders may allow for allocation of more proactive and intensive support for affected patients.

6. **ADULT HEALTHCARE IS ASSOCIATED WITH MORE EMERGENCY HEALTHCARE FOR YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS.**

Jarvis, S., Flemming, K., Richardson, G. & Fraser, L.*Pediatric Research* 92, 1458–1469 (2022) doi:10.1038/s41390-022-01975-3

Background: Children with life-limiting conditions receive specialist paediatric care in childhood, but the transition to adult care during adolescence. There are concerns about transition, including a lack of continuity in care and that it may lead to increases in emergency hospital visits. Methods: A retrospective cohort was constructed from routinely collected primary and hospital care records for young people aged 12–23 years in England with (i) life-limiting conditions, (ii) diabetes or (iii) no long-term conditions. Transition point was estimated from the data and emergency inpatient admissions and Emergency Department visits per person-year compared for paediatric and adult care using random intercept Poisson regressions. Results: Young people with life-limiting conditions had 29% (95% CI: 14–46%) more emergency inpatient admissions and 24% (95% CI: 12–38%) more Emergency Department visits in adult care than in paediatric care. There were no significant differences associated with the transition for young people in the diabetes or no long-term conditions groups. Conclusions: The transition from paediatric to adult healthcare is associated with an increase in emergency hospital visits for young people with life-limiting conditions, but not for young people with diabetes or no long-term conditions. There may be scope to improve the transition for young people with life-limiting conditions. Impact: There is evidence for increases in emergency hospital visits when young people with life-limiting conditions transition to adult healthcare. These changes are not observed for comparator groups - young people with diabetes and young people with no known long-term conditions, suggesting they are not due to other transitions happening at similar ages. Greater sensitivity to changes at transition is achieved through estimation of the transition point from the data, reducing misclassification bias.

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

Kamoun, C., Khoury, J. C., Beal, S. J., Crimmins, N. & Corathers, S. D.*Diabetes Spectrum* 35, 57–65 (2022) doi:10.2337/ds20-0104

There is an ongoing need to determine best practices for effective transition from pediatric to adult care for adolescents and emerging adults (EAs) with type 1 diabetes given the potential for poor health outcomes post-transfer. This study evaluated self-reported confidence ratings as measured by the Readiness of Emerging Adults with Diabetes Diagnosed in Youth (READDY) tool among adolescents and EAs with type 1

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

8. A STUDY ABOUT THE PARENTAL INVOLVEMENT FOR THE TRANSITION FROM FAMILY MANAGEMENT TO SELF-CARE IN CHILDHOOD TYPE 1 DIABETES.

Ogura, A. et al.

Pediatric Diabetes 23, 104 (2022) doi:10.1111/pedi.13400

Introduction: Type 1 diabetes children have to get the knowledge and skills about their disease for acquiring self-care independently before adulthood. In this study, we focused on the parental involvement for the transition from family management to self-care of them. Objectives: To clarify parental involvement of school-aged type 1 diabetic patients who are going to acquire self-care skills. Methods: We conducted semi-structured interviews with the parents of school age or over children whose onset were below 9 of age, among outpatients of Hospital A. Interview data were analyzed qualitative inductive content analysis. Results: There were 10 study participants, all of whom were mothers. As a result of the analysis, 6 categories, a total of 24 subcategories, were extracted. The 6 categories were: Complementing diabetes management that is difficult for the child to carry out by themselves, Manage with the child, To promote diabetes management by the child under the supervision of parents, Collaborate with school staff to management diabetes in school, Establish a safe and secure environment for children, and Devise ways to encourage the child's independence. Conclusions: This study revealed that the parents were trying to shift diabetes management to self-care at the child's pace. In addition, parents worked to create an environment in which children can safely and reliably manage diabetes even when parents cannot be on their side. It is thought that the parental actions that respects the child's intentions and wishes will lead to the child taking the initiative in managing type 1 diabetes and living with diabetes. It is important for medical staff to understand the implications of parental involvement and supporting children with type 1 diabetes and their parents.

9. TRANSITION FROM PEDIATRIC TO ADULT CARE IN TYPE 1 DIABETES MELLITUS: A LONGITUDINAL ANALYSIS OF AGE AT TRANSFER AND GAP IN CARE.

Soliman, D. et al.

BMJ Open Diabetes Research and Care 10, (2022) doi:10.1136/bmjdr-2022-002937

Introduction Adolescents and young adults (AYAs) with type 1 diabetes (T1D) are at risk of suboptimal glycemic control and high acute care utilization. Little is known about the optimal age to transfer people with T1D to adult care, or time gap between completing pediatric care and beginning adult endocrinology care. Research design and methods This retrospective, longitudinal study examined the transition of AYAs with T1D who received endocrinology care within Duke University Health System. We used linear multivariable or Poisson regression modeling to assess the association of (1) sociodemographic and clinical factors associated with gap in care and age at transfer among AYAs and (2) the impact of gap in care and age at transfer on subsequent glycemic control and acute care utilization. Results There were 214 subjects included in the analysis (54.2% female, 72.8% white). The median time to transition and age at transition were 8.0 months and 21.5 years old, respectively. The median gap in care was extended by a factor of 3.39 (95% CI=1.25 to 9.22, p=0.02) for those who did not see a mental health provider pre-transfer. Individuals

who did not see a diabetes educator in pediatrics had an increase in mean age at transition of 2.62 years (95% CI=0.93 to 4.32, $p<0.01$). The post-transfer emergency department visit rate was increased for every month increase in gap in care by a relative factor of 1.07 (95% CI=1.03 to 1.11, $p<0.01$). For every year increase in age at transition, post-transfer hospitalization rate was associated with a reduction of a relative factor of 0.62 (95% CI=0.45 to 0.85, $p<0.01$) and emergency department visit rate by 0.58 (95% CI=0.45 to 0.76, $p<0.01$). Conclusions Most AYAs with T1D have a prolonged gap in care. When designing interventions to improve health outcomes for AYAs transitioning from pediatric to adult-based care, we should aim to minimize gaps in care.

10. **HEALTH CARE EXPERIENCES AND ASPECTS OF DIABETES MANAGEMENT IN THE TRANSITION TO ADULTHOOD IN EMERGING ADULTS WITH TYPE 1 DIABETES.**

Sparud-Lundin, C. et al.

Pediatric Diabetes 23, 21 (2022) doi:10.1111/pedi.13399

Introduction: Emerging adults with type 1 diabetes (T1D) comprise an explicitly vulnerable group, which has received growing attention. Yet, research and guidelines remain incoherent regarding their needs and experiences, and effective transitional care practices. Objectives: The aim was to map emerging adults' experiences of transitional care from pediatric to adult diabetes care settings and to explore potential correlates of these experiences, as well as of glycemic control. Methods: A cross-sectional study including 122 emerging adults (43% response rate) with T1D, in median 20.0 years (min 19- max 21), who had been transferred from pediatric to adult diabetes clinics in six centers in Sweden (and had at least two visits in adult care). Outcome measures were transitional care experiences, health care climate in adult care, empowerment, and self-efficacy. Diabetes related data and time between last visit in pediatric care and first in adult care were also included. Associations were evaluated by using Spearman's correlation test. Results: Time to follow up in adult care after last visit in pediatric care was in median 65 days (min 0-max 253). Women showed a tendency to rate a lower degree of satisfaction with transitional care than men ($p = 0.056$). In the total group, more positive transitional experiences were associated with higher degree of satisfaction with the health care climate in adult care ($\rho = 0.43$, $p < 0.001$), empowerment ($\rho = 0.46$, $p < 0.001$) and self-efficacy ($\rho = 0.42$, $p < 0.001$). Low levels of HbA1c were weakly associated with higher total score of health care climate in adult care, empowerment, and self-efficacy. Conclusions: Outcomes of different transitional care models are widely debated, mainly focusing on loss to follow-up and glycemic control. The association between more positive health care experiences and higher degree of empowerment and self-efficacy in young people with T1D during transition to adulthood indicates that these aspects are essential to consider when planning for transitional care.

11. **TRANSITIONING CARE IN YOUTH-ONSET TYPE 1 AND TYPE 2 DIABETES: A SCOPING REVIEW PROTOCOL USING THE SOCIO-ECOLOGICAL MODEL FRAMEWORK.**

Ude, A. O. et al.

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Introduction The transition from paediatric to adult diabetes care in youth-onset diabetes (type 1 diabetes mellitus, Y-T1DM and type 2 diabetes mellitus, Y-T2DM) is associated with worsening glycaemic control, missed clinical visits, decreased medication adherence and the emergence of cardiometabolic complications. The socio-ecological challenges that influence transitioning to adult diabetes care may be distinct between Y-T1DM and Y-T2DM. The goal of this scoping review is to map the state of the literature on transitioning care in Y-T2DM compared with Y-T1DM and to identify the main sources and types of evidence available. The objectives are: (1) to identify the factors within the socio-ecological framework (individual, relationship, community, societal) associated with transitioning to adult care in Y-T2DM compared with Y-T1DM, and (2) to identify knowledge gaps related to transitioning to adult care. Methods The scoping review protocol and reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for scoping reviews guidelines. A systematic search of scientific databases (PubMed, Embase, Cumulative Index to Nursing and Allied Health, Scopus and APA PsycNet will be undertaken for articles between 1 January 1990 and 30 September 2022. Study designs will include peer-reviewed experimental and quasi-experimental published studies without language or country-specific restrictions. We will exclude articles on other diabetes subtypes and will exclude non-peer reviewed articles such as

opinion papers, anecdotal reports or supplementary commentaries. Analysis References will be collated, sorted and extracted using Covidence. Factors associated with transition from paediatric to adult diabetes care in Y-T1DM and Y-T2DM will be identified using the socio-ecological framework and results will be presented in narrative format, tables, and summary graphs. Ethics and dissemination Ethical approval will not be applicable for this review. Trial registration number <https://osf.io/k2pwc>.

12. OUTCOMES OF A MULTIDISCIPLINARY TRANSITION CLINIC FOR YOUTH WITH TYPE 1 DIABETES.

Wongyai, W. et al.

Pediatrics International 64, (2022) doi:10.1111/ped.15356

Background: Emerging adults with type 1 diabetes (T1D) have several challenges regarding diabetes management and care transition from pediatric to adult services. In this study we aimed to assess the effectiveness of the newly established transition clinic for emerging adults with T1D. Methods: We conducted an observational study of emerging adults with T1D treated in a transition clinic jointly operated by a pediatric and adult multidisciplinary care team during 2019–2021. A retrospective chart review of hemoglobin A1c (HbA1c), frequency of clinic attendance, acute diabetes-related complications, assessment of gaps in knowledge and behavior, and psychosocial outcomes was analyzed. Results: A total of 21 patients with T1D were included. Median age at the transfer to the transition clinic was 24 years (range 21–34). Fifteen patients (71%) were successfully transferred to adult services; mean duration of follow-up at the transition clinic was 9.2 months (SD 3.9). None of the patients was lost to follow-up or experienced serious diabetes related complications. Mean (95% confidence interval) HbA1c levels decreased from 8.97% (7.87–10.07) at baseline to 8.25% (7.45–9.05) at the most recent visit ($p = 0.01$). A proportion of patients achieving the glycemic target (HbA1c < 7.5%) was increased from 24% at the first visit to 38% at the most recent visits. Patients' HbA1c levels at the adult clinic continued a favorable trend. Seven patients (33%) were identified as having symptoms of depression. Knowledge and behavioral gaps were identified and counselled by clinical care team. Conclusion: The multidisciplinary transition clinic has shown to be beneficial in terms of improving glycemic control, maintaining continuity of care and clinic attendance.

ADHD

1. PARENTING ROLES FOR YOUNG PEOPLE WITH ATTENTION-DEFICIT/HYPERACTIVITY DISORDER TRANSITIONING TO ADULT SERVICES.

Janssens, A., Blake, S., Eke, H., Price, A. & Ford, T.

Developmental Medicine and Child Neurology 65, 136–144 (2023) doi:10.1111/dmcn.15320

Aim: To inform transitions from child to adult health services, we explored the work and roles parents take in the care of young people with attention-deficit/hyperactivity disorder (ADHD) aged 14 to 25 years old. Method: Using framework thematic analysis, we analysed data collected from 28 semi-structured interviews with parents of young people with ADHD to generate a typology and triangulated it against findings from 64 interviews with young people with ADHD. The interviews were carried out as part of a three-strand, interactive mixed-method study. Results: An entourage typology of three parent roles was identified. Parents moved between 'manager' and 'roadie' roles as their child gradually matured. A 'superfan' role was identified which supported young people's positive self-image but may impede withdrawal from the 'manager' role. Continued parental involvement into adulthood reflected a need to maintain the balance of resources required to maintain quality of life for the whole family. Interpretation: This is the first study to explore parental roles in the health care of young people with ADHD. Parents will vary in their capacity to fulfil the identified roles and step back their care as their children reach adulthood. The findings can inform intervention development to support families and transition between services. What this paper adds: Parents move from a 'manager' to 'roadie' role as young people mature. A 'superfan' role supports positive self-image and directed health care work. Continued involvement reflects parental responsibility to juggle wider family needs and resources. Parents differ in capacity to fulfil and move between these roles.