



INDICE:

Dalle banche dati bibliografiche

GENERALE

pag. 2

EPILESSIA

pag. 8

DIABETE

pag. 9

ADHD

pag. 10

Nr. 4 anno II – Feb/Apr2023

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. ASSESSMENT OF AN ELECTRONIC HEALTHCARE TRANSITION TOOLKIT TO IMPROVE SUCCESSFUL PATIENT CARE TRANSITION.

Beddows, K., Hudgins, K., Makinde, A., Rodriguez, W. & Hsu, D.

Journal of Heart and Lung Transplantation 42, S484–S485 (2023) doi:10.1016/j.healun.2023.02.1340

Purpose: The effectiveness of a Healthcare Transition (HCT) toolkit embedded in the Electronic Medical Record (EMR) to improve provider workflow and provide resources and tools to facilitate HCT discussions in adolescents following heart transplant (HT) was assessed. We hypothesized that an EMR-based electronic HCT toolkit would improve Anticipatory Guidance (AG) and transition readiness in HT patients (pts). Methods: A retrospective cohort study was conducted through review of all HT visits in pts > 12 years who received care from 1/1/22-9/1/22. On 5/3/22, a customized electronic HCT toolkit was implemented into the EMR which included: a Best Practice Advisory Alert (BPA) tool reminding providers to address HCT, enabling electronic documentation of AG based on stages in healthcare independence, Transition Assessment Readiness Questionnaire (TRAQ) in the EMR visit navigator, and providing resources for patient portal access and HCT website education by adding two QR codes to the after-visit summary. Data was collected pre- and post- toolkit implementation and included age at visit and frequency of HCT AG and TRAQ administration. The occurrence of documented AG and TRAQ administration pre- and post- toolkit implementation was compared using chi-square analysis. Results: Pre-toolkit, 63 visits were performed: 5% (3/63) had HCT AG documented and 11% (7/63) of patients had a paper TRAQ completed. Post-toolkit, 55 visits were performed: 47% (26/55) had HCT AG documented, and 47% (26/55) of patients had TRAQ documented electronically. TRAQ administration ($p<0.01$) and AG documentation were significantly higher post-toolkit implementation ($p<0.01$), Figure 1. Conclusion: This study demonstrates that implementation of an EMR-based electronic HCT toolkit significantly increased assessment of HCT readiness and provision of HCT AG. EMR access to a standardized HCT toolkit has the potential to improve compliance with best practices and facilitate important HCT discussions among providers and patients.

2. VALIDATION OF THE TRANSITION READINESS ASSESSMENT QUESTIONNAIRE (TRAQ) 5.0 FOR USE AMONG YOUTH IN MENTAL HEALTH SERVICES.

Cleverley, K., Davies, J., Allemang, B. & Brennenstuhl, S.

Child: care, health and development 49, 248–257 (2023) doi:10.1111/cch.13035

BACKGROUND: Among youth with psychiatric disorders, the transition from child to adult mental health services is a period of vulnerability to discontinuous care and service disengagement. Regular assessment of transition readiness has been identified as a core component of transition planning, contributing to successful care transitions. The Transition Readiness Assessment Questionnaire (TRAQ) 5.0 is a 20-item questionnaire that measures transition readiness in youth preparing to transition to adult care. Although the TRAQ has been validated and used across many health settings, it has not been validated in youth with primarily mental health concerns. The objective of this study was to validate the TRAQ for use among youth accessing mental health services. METHODS: This study used the Longitudinal Youth in Transition Study baseline cohort, which consists of 237 clinically referred youth (aged 16-18 years) receiving outpatient mental health treatment. Psychometric evaluation of the TRAQ 5.0 included confirmatory factor analysis (CFA), assessment of internal consistency, testing convergent validity using the Dimensions of Emerging Adulthood (IDEAS) and Difficulty in Emotional Regulation (DERS) scales, criterion validity using a question on whether the participant had talked about transition with their clinician and known-group testing based on age. RESULTS: The CFA indicated adequate fit of the five-factor TRAQ structure. The overall scale ($=.86$) and three of the subscales demonstrated adequate internal consistency. As hypothesized, overall TRAQ scores were higher for youth who had discussed transition and those aged 18. Small correlations were found between the overall TRAQ score and measures of developmental maturity (IDEAS) and emotional awareness (DERS); however, certain

subscales did not demonstrate correlation with these constructs. **CONCLUSIONS:** The TRAQ 5.0 appears to be valid tool to assess the transition readiness of youth in outpatient mental health services. Additional work needs determine whether findings are similar among specific mental health conditions, including substance use disorders and psychotic disorders.

3. **FEASIBILITY, ACCEPTABILITY AND PRELIMINARY IMPLEMENTATION OF THE CORNERSTONE PROGRAM FOR TRANSITION-AGE YOUTH WITH MENTAL HEALTH CONDITIONS: A MIXED METHODS STUDY.**

Cole, A. R. *et al.*

Administration and policy in mental health (2023) doi:10.1007/s10488-023-01254-1

Transition-age youth with mental health conditions from low socio-economic backgrounds often drop out of mental health services and, as such, do not receive therapeutic doses of treatment. Cornerstone is an innovative team-based, multi-component intervention designed to address the clinical needs of this understudied population through coordination and extensive provision of services in vivo (in the community). The present study used a convergent parallel mixed-methods design. Researchers collected quantitative and qualitative data during a small developmental trial, analyzing the two data types independently and then exploring them side-by-side to evaluate feasibility, acceptability, and preliminary implementation. Semi-structured interviews and quantitative surveys were conducted with transition-age youth, clinic staff, and policy makers. Qualitative interview guides were developed using the Consolidated Framework for Implementation Research to build understanding on implementation determinants alongside feasibility and acceptability. A two-group preliminary randomized trial was conducted to assess feasibility outcomes, such as recruitment, randomization, measurement performance, and trends in pre- to post- outcomes. Using grounded theory coding techniques, transcripts were coded by multiple coders, and themes were identified on acceptability and implementation. The team recruited fifty-six transition-age youth. Randomization was used in the study and the intervention was provided without incident. Results suggest individual components with both the social worker and mentor were more acceptable to participants than group-based approaches. Thematic analyses revealed themes associated with the inner, outer, and policy contexts describing a range of critical implementation determinants. Findings suggest that Cornerstone is feasible, acceptable, and promising for transition-age youth. It represents an innovative multi-component intervention worth exploring for transition-age youth with mental health conditions in a larger efficacy trial. Trial registration: The trial was registered at ClinicalTrials.gov (NCT02696109) on 22 April 16, Protocol Record R34-MH102525-01A1, New York University, Cornerstone program for transition-age youth with serious mental illness: study protocol for a randomized controlled trial.

4. **CARER PERSPECTIVES OF A TRANSITION TO ADULT CARE MODEL FOR ADOLESCENTS WITH AN INTELLECTUAL DISABILITY AND/OR AUTISM SPECTRUM DISORDER WITH MENTAL HEALTH COMORBIDITIES.**

Culnane, E. *et al.*

Child: care, health and development 49, 281–291 (2023) doi:10.1111/cch.13040

BACKGROUND: Transition to adult care for adolescents with an intellectual disability and/or autism spectrum disorder with coexisting mental health disorders, often termed ‘dual disability’, is complex. It requires a family-centred approach, with collaboration among health, disability and social services and early planning. **AIM:** To describe carer perspectives of transition to adult care and the outcomes of a transition support intervention, Fearless, Tearless Transition, for adolescents with dual disabilities piloted at a tertiary children’s hospital.

METHODS: Carers of adolescents with a dual disability were invited to complete a survey at the commencement of their participation in the Fearless, Tearless Transition model, and again at the conclusion of the project. Within this intervention, carers and adolescents were encouraged to attend dedicated transition clinics and participate in a shared care general practitioner (GP) and paediatrician process. **RESULTS:** One hundred and fifty-one carers of adolescents with dual disabilities were included in Fearless, Tearless Transition. Of this cohort, 138 adolescents and their carers received support in a dedicated transition clinic with 99 carers completing the initial survey at the commencement of the model. Eighty-two per cent of carers reported moderate to high levels of anxiety about transitioning from paediatric to adult care with 39% feeling

‘unprepared’ about transition. Eighty-one per cent reported having inadequate access to respite care with 47% reporting a lack of access to services in the community and 56% expressing dissatisfaction with their GPs. One hundred and two families participated in the shared care process with 80 GPs and 33 paediatricians. Twenty-two carers completed the second survey reporting a modest but significant improvement in preparedness for transition to adult care. **CONCLUSION:** This study highlights the potential to improve transition outcomes for adolescents with dual disabilities and their carers through early, centralized transition planning, consistent methods of assessing adolescent and carer needs and shared care.

5. **CROSSED PERSPECTIVES ON PEDIATRICS TO ADULT HEALTH CARE TRANSITION IN BELGIUM.**

Devaux, F., Fonteyne, C., Deriez, M. & Lambotte, I.

Medicine sciences : M/S 39, 137–144 (2023) doi:10.1051/medsci/2023017

In Belgium, there is not yet a standardized procedure for supporting the transition of patients with chronic diseases from pediatrics to adult health care. However, the field increasingly calls for the development of multidisciplinary landmarks. By crossing perspectives of a pediatrician, two psychologists and an ethicist, we propose the key elements of a successful transition: 1. Start preparing for the transition early; 2. Promote the patient’s knowledge, know-how and interpersonal skills; 3. Improve continuity of care and collaboration between patient, family, healthcare teams, patient associations and families; 4. Support parents; 5. Improve the skills of healthcare teams in the specificities of adolescent medicine; 6. Individualize the transition, respecting each person’s pace and uniqueness; 7. Develop an interdisciplinary approach of the transition; 8. Develop collaboration with public authorities, national and international experts; 9. Develop research on this emerging field of study.

6. **BARRIERS TO EFFECTIVE TRANSITIONS OF CARE FROM ADOLESCENT TO ADULT MEDICINE.**

Eniola, K.

Southern medical journal 116, 296–297 (2023) doi:10.14423/SMJ.0000000000001518

7. **USE OF TELEMEDICINE HEALTHCARE SYSTEMS IN CHILDREN AND ADOLESCENTS WITH CHRONIC DISEASE OR IN TRANSITION STAGES OF LIFE: CONSENSUS DOCUMENT OF THE ITALIAN SOCIETY OF TELEMEDICINE (SIT), OF THE ITALIAN SOCIETY OF PREVENTIVE AND SOCIAL PEDIATRICS (SIPPS), OF THE ITALIAN SOCIETY OF PEDIATRIC PRIMARY CARE (SICUPP), OF THE ITALIAN FEDERATION OF PEDIATRIC DOCTORS (FIMP) AND OF THE SYNDICATE OF FAMILY PEDIATRICIAN DOCTORS (SIMPEF).**

Esposito, S. *et al.*

Journal of personalized medicine 13, (2023) doi:10.3390/jpm13020235

Telemedicine is considered an excellent tool to support the daily and traditional practice of the health profession, especially when referring to the care and management of chronic patients. In a panorama in which chronic pathologies with childhood onset are constantly increasing and the improvement of treatments has allowed survival for them into adulthood, telemedicine and remote assistance are today considered effective and convenient solutions both for the chronic patient, who thus receives personalized and timely assistance, and for the doctors, who reduce the need for direct intervention, hospitalizations and consequent management costs. This Consensus document, written by the main Italian Scientific Societies involved in the use of telemedicine in pediatrics, has the objectives to propose an organizational model based on the relationships between the actors who participate in the provision of a telemedicine service aimed at minors with chronic pathologies, identifying specific project links between the areas of telemedicine in the developmental age from the first 1000 days of life to the age adult. The future scenario will have to be able to integrate digital innovation in order to offer the best care to patients and citizens. It will have to be able to provide the involvement of patients from the very beginning of the design of any care pathway, increasing where possible the proximity of the health service to citizens.

8. **STAKEHOLDERS’ PERSPECTIVES ON CAREGIVER OUTCOMES FOR HEALTH CARE TRANSITION FOR ADOLESCENTS AND YOUNG ADULTS WITH SPECIAL HEALTH CARE NEEDS: A QUALITATIVE STUDY.**

Fair, C. D. V. *et al.*

Child: care, health and development (2023) doi:10.1111/cch.13114

BACKGROUND: Previous literature has explored parent/caregiver perspectives and satisfaction with the health care transition (HCT) process for their adolescents and young adults with special health care needs (AYASHCN). Limited research has explored the opinion of health care providers and researchers on parent/caregiver outcomes associated with a successful HCT for AYASHCN. **METHODS:** A web-based survey was distributed through the international and interdisciplinary Health Care Transition Research Consortium listserv, which at the time of the survey was composed of 148 providers dedicated to optimizing the HCT of AYASHCN. Participants responded to the open-ended question, 'What parent/caregiver-related outcome(s) would represent a successful healthcare transition?' Respondents included 109 providers (52 health care professionals, 38 social service professionals and 19 other). Responses were coded for emergent themes, and research suggestions were identified. **RESULTS:** Qualitative analyses identified two major themes: emotion- and behaviour-based outcomes. Emotion-based subthemes included relinquishing control of child's health management (n = 50, 45.9%) as well as parental satisfaction and confidence in their child's care and HCT (n = 42, 38.5%). Respondents also noted that parents/caregivers should experience an improved sense of well-being and decreased stress (n = 9, 8.2%) due to a successful HCT. Behaviour-based outcomes included early preparation and planning for HCT (n = 12, 11.0%) and parental instruction on the knowledge and skills necessary for their adolescent to independently manage their health (n = 10, 9.1%). **CONCLUSIONS:** Health care providers can assist parents/caregivers in learning strategies for instructing their AYASHCN about condition-related knowledge and skills as well as provide support for 'letting go' of the caregiver role during the HCT to adult-focused health services and adulthood. Communication between the AYASHCN, their parents/caregivers and paediatric- and adult-focused providers needs to be consistent and comprehensive to ensure continuity of care and a successful HCT. We also offered strategies to address the outcomes suggested by the participants of this study.

9. **ADDRESSING EDUCATION AND EMPLOYMENT OUTCOMES IN THE PROVISION OF HEALTHCARE FOR YOUNG PEOPLE WITH PHYSICAL LONG-TERM CONDITIONS: A SYSTEMATIC REVIEW AND MIXED METHODS SYNTHESIS.**

Farre, A., Lunt, L., Lee, R., Verstappen, S. & McDonagh, J. E.

Patient Education and Counseling 112, (2023) doi:10.1016/j.pec.2023.107765

Objective: To identify and synthesise the experiences and benefits of addressing vocational issues in the provision of healthcare for young people (YP) with long-term conditions (LTCs). **Methods:** We searched 10 bibliographic databases. Restrictions were applied on publication date (1996–2020) and language (English). Two reviewers independently screened records against eligibility criteria. Articles reporting relevant qualitative and/or quantitative research were included. Quality appraisal was undertaken following study selection. Qualitative data were synthesised thematically, and quantitative data narratively. A cross-study synthesis integrated qualitative and quantitative findings. **Results:** 43 articles were included. Thematic synthesis of qualitative studies (n = 23) resulted in seven recommendations for intervention (psychological support; information/signposting; skills training; career advice; healthcare-school/workplace collaboration; social support; flexible/responsive care). The narrative synthesis summarised results of 17 interventions (n = 20 quantitative studies). The cross-study synthesis mapped interventions against recommendations. Transitional care was the intervention type that most comprehensively met our proposed recommendations. **Conclusions:** Evidence from YP perspectives highlights that vocational development is an important area to address in healthcare provision. Robust intervention studies in this area are lacking. **Practice implications:** Our evidence-based recommendations for intervention can support health professionals to better address vocational issues/outcomes. With minimal adaptations, transitional care interventions would be particularly well suited to deliver this.

10. **IMPROVING THE USE OF TRANSITION READINESS MEASURES IN RESEARCH AND CLINICAL CARE.**

Hart, L. C. & Chisolm, D.

Pediatric research (2023) doi:10.1038/s41390-023-02596-0

Measurement of transition readiness is considered a crucial component of effective transition. It is included as one of the Six Core Elements of Transition in national transitional care guidelines. However, the current measures of transition readiness have not been found to correlate with either current or future health outcomes for youth. In addition, there are challenges in measuring transition readiness in youth with intellectual and developmental disabilities, who may not be expected to achieve skills and knowledge that are considered essential for transition in typically developing youth. These concerns make it difficult to know

how best to use transition readiness measures in research and clinical care. This article highlights the appeal of measuring transition readiness in clinical and research contexts, the current barriers that prevent us from fully achieving those benefits, and potential strategies for bridging the gap. IMPACT: Transition readiness measures were developed as an attempt to identify those patients who were ready to successfully navigate the transition from pediatric to adult health care. Thus far, the measures that have been developed do not appear to be related to health outcomes such as disease control or timely attendance of the first adult appointment in adult care. We provide suggestions for how to address the current concerns with the available transition readiness measures.

11. **THE DEVELOPMENT OF A TRANSITION MEDICAL HOME UTILIZING THE INDIVIDUALIZED TRANSITION PLAN (ITP) MODEL FOR PATIENTS WITH COMPLEX DISEASES OF CHILDHOOD.**

Hopson, B. *et al.*

Disability and Health Journal 16, (2023) doi:10.1016/j.dhjo.2022.101427

Background: Advances in medicine and technology, have enabled greater numbers of children with complex illness to survive into adulthood. Adolescents with these conditions are at high risk for adverse outcomes when transitioning to adult health care. The “Staging Transition for Every Patient” (STEP) Program was developed to systematically improve the transition from pediatric to adult healthcare. Objective: This article details the development of the STEP program and the novel use of “Individualized Transition Plans” (ITP) in the clinic setting. Methods: A provider needs’ assessment of the existing transition services among youth with specific diagnoses was performed, a steering committee was developed that created a transition policy, and a medical home within the adult system was established with an interdisciplinary approach. The ITP focuses on 5 individualized goals, it was developed and tested with the first-year cohort of patients. Results: In the initial needs assessment, 7 of 35 diagnoses were found to have an effective transition plan. The STEP program partnered with departments across the adult facility to conduct 267 interdisciplinary patient visits. In the first year, 169 new patients were seen in the clinic. The average age was 23.0 ± 4.1 years old. The ITP goals included referrals to adult specialists, advanced care planning, career and education, transition readiness, caregiver burden, and an emergency sick plan. Conclusion: There is a need for organized transition care for medically complex youth. The STEP program answers that need by addressing the unique needs of each patient. Individualized transition planning builds trust and addresses multiple domains of health.

12. **EDITORIAL: ADVANCES OF HEALTH CARE TRANSITION FOR PATIENTS WITH CHILDHOOD-ONSET CHRONIC DISEASES: INTERNATIONAL PERSPECTIVES, VOLUME II.**

Ishizaki, Y., Ochiai, R. & Maru, M.

Frontiers in pediatrics 11, 1147397 (2023) doi:10.3389/fped.2023.1147397

13. **TRANSITIONAL CARE FOR A PEDIATRICS CLINIC AND ITS PATIENTS: A QUALITY IMPROVEMENT STORY.**

Joshi, A., Blair, S., Hundman, C., Lee, A. & Yaun, J.

American Journal of the Medical Sciences 365, S362–S363 (2023) doi:10.1016/S0002-9629(23)00668-7

Purpose of Study: In the last twenty years, the American Academy of Pediatrics, with endorsements from the American Academy of Family Physicians and the American College of Physicians, has emphasized the importance of standardized transitional care for adolescent patients from pediatric to adult providers. The purpose of this quality improvement (QI) project is to develop and implement a standardized transitional care policy for adolescent patients at the UTHSC pediatric clinic in Memphis, Tennessee with a goal of 80% adherence to transitional care discussion and documentation at the 15-, 16-, and 17-year-old well child checks (WCC) within three years of policy implementation. Methods Used: The study design is based on a traditional plan/do/study/act (PDSA) cycle. Initial chart review included all 15- to 17-year-old WCC that occurred at the UTHSC pediatric clinic from January to June 2021. A transitional care handout, including the clinic policy and a list of local primary care providers, was created for distribution at all 15- to 17-year-old WCC and implemented on October 20, 2021. Education was provided to clinical staff regarding project goals and implementation. Further chart review was done on a quarterly basis following intervention implementation to determine adherence to the new transitional care policy. Summary of Results: Initial chart review showed significant room for improvement in adolescent transitional care planning. Baseline data analysis showed that transitional care was discussed and documented in only 20% of the 15- to 17-year-old WCC. Age stratification revealed increasing discussion with age, with discussion documented in 1.4%, 11.8%, and

51.6% at the 15-, 16-, and 17-year-old WCC, respectively. Analysis after implementation of the transitional care handout showed improvement to 35% of documentation of transitional care discussion at the 15- to 17-year-old WCC. Further chart review will be aimed at analysis of data after continued education of clinical staff and other future interventions to improve adherence to the standardized transitional care policy. [Table presented] Conclusions: The goal of this QI project is to develop and implement a standardized transitional care policy at an academic pediatric center. Initial data showed significant room for improvement regarding transitional care discussion and documentation. Implementation of a standardized transitional care policy at this primary care clinic showed an increase in transitional care discussion and documentation during adolescent WCC; however, room for improvement remains. Further analysis regarding the impact of physician education on adherence to the transitional care policy is ongoing.

14. **QUALITY MEASUREMENT GAPS IN PEDIATRIC-TO-ADULT HEALTH CARE TRANSITION IN THE UNITED STATES: A FRAMEWORK TO GUIDE DEVELOPMENT OF NEW MEASURES.**

McManus, M., Schmidt, A., Ilango, S. & White, P.

The Journal of adolescent health : official publication of the Society for Adolescent Medicine 72, 779–787 (2023) doi:10.1016/j.jadohealth.2022.12.025

PURPOSE: Pediatric-to-adult health care transition (HCT) is a critical component of care for youth and young adults (Y/YA), especially those with chronic conditions. Positive outcomes in population health, patient experience, and utilization of care for Y/YA with chronic conditions have been associated with a structured HCT approach. Despite these outcomes and professional recommendations, few Y/YA receive HCT guidance from providers. Compounding this problem is the lack of attention to HCT quality measurement to stimulate and evaluate practice improvements and ensure accountability in pediatric and adult care. **METHODS:** A multistep process was undertaken to develop a new HCT quality measurement framework and identify existing HCT measures from national databases. Based on an environmental scan, the framework was created, measure gaps identified, and measure concepts proposed to fill these gaps. A multistakeholder advisory committee provided guidance throughout this initiative. **RESULTS:** The HCT measurement framework has 11 domains: one structure domain (health organization characteristics), three process domains (clinician HCT activities, Y/YA/F activities, continuity of care), four outcome domains (population health, utilization/cost/value of care, patient experience, and clinician experience), and three mediator domains (Y/YA/F-centered care, care coordination, and Y/YA/F characteristics). The search yielded 49 potentially relevant measures but only four qualified as directly relevant to HCT. Fifty four HCT measure concepts were proposed to address these shortcomings. **DISCUSSION:** Pediatric-to-adult HCT quality measurement is largely absent in nationally recognized databases. This article provides a comprehensive HCT quality measurement framework, which was used to identify gaps and propose measure concepts as a roadmap for future HCT quality measurement improvements.

15. **HEALTH CARE TRANSITIONS FOR ADOLESCENTS.**

Meyers, M. J. & Irwin, C. E.

Pediatrics 151, e2022057267L (2023) doi:10.1542/peds.2022-057267L

The transition from pediatric to adult models of care poses many challenges to adolescent and young adult (AYA) patients. Several academic societies have established clinical reports to help providers prepare patients for this transition, facilitate the transfer of care between providers, and integrate patients into adult models of care. Furthermore, several novel care delivery models have been developed to expand health care transition (HCT) services. Despite this, a minority of patients receive transition services meeting the goals of these clinical reports and few data exist on their effectiveness. Given this, ongoing research and clinical innovation in the field are imperative. This article aims to summarize the current landscape of HCT for AYAs, outline the contemporary imperative for its integration into preventive health care given the unique challenges of the COVID-19 pandemic, and expand the current literature by providing a summary of novel emerging strategies being used to meet the health care transition (HCT) needs of adolescent and young adult (AYA) patients.

16. **CURRENT PRACTICES OF TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE FOR PATIENTS WITH NEUROLOGICAL DISEASE: PROMOTE THE COOPERATION BETWEEN CHILD AND ADULT NEUROLOGISTS.**

Mochizuki, Y. *et al.*

Rinsho shinkeigaku = Clinical neurology 63, 67–72 (2023) doi:10.5692/clinicalneurolog.cn-001815

The Special Committee for Measures Against Transition from Pediatric to Adult Health Care of the Japanese Society of Neurology, which consists of child and adult neurologists, started to tackle the issues of pediatric to adult health care transition for patients with neurological disease in July 2020. The Committee held a workshop with a theme of ‘cooperation between child and adult neurologists,’ which is a critical issue in the pediatric to adult health care transition. To solve the many problems in the pediatric to adult health care transition, it is crucial that child and adult neurologists and primary care physicians cooperate on the following issues: preparing child neurologists for the transition, encouraging adult neurologists to study child neurology, promoting the formation of multidisciplinary teams, improving the medical system and medical fees, appealing to governmental agencies for issues of community health care and welfare services.

17. **BENEFITS AND CHALLENGES OF PEDIATRIC-TO-ADULT HEALTH CARE TRANSITION IN CHILDHOOD-ONSET NEUROLOGIC CONDITIONS.**

Osako, M., Yamaoka, Y., Takeuchi, C., Fujiwara, T. & Mochizuki, Y.

Neurology. Clinical practice 13, e200130 (2023) doi:10.1212/CPJ.0000000000200130

BACKGROUND AND OBJECTIVES: Although the importance of pediatric-to-adult health care transition (HCT) has been recognized, individuals with childhood-onset neurologic conditions often encounter challenges during pediatric-to-adult HCT, and HCT benefits for this population remain elusive. We assessed the current HCT situation in individuals with childhood-onset neurologic conditions to develop an improved transition system that incorporates patient perspectives. **METHODS:** This cross-sectional study was conducted at the Tokyo Metropolitan Kita Medical and Rehabilitation Center for the Disabled from November 2020 to December 2020. We targeted adults with childhood-onset neurologic conditions who visited the Department of Internal Medicine and their families. Questionnaires provided to 127 patients asked them about their experiences with pediatric-to-adult HCT (i.e., educational opportunities regarding HCT during pediatric visits, difficulties in transition, and the merits/demerits of adult practice) and their families’ perspectives regarding pediatric-to-adult HCT. We also reviewed the patients’ medical records to examine the severity of their disabilities. **RESULTS:** Responses were collected from 111 patients (response rate: 87%). Most patients had both severe physical and intellectual disabilities, and approximately half had a physical disability level of Gross Motor Function Classification System V and a profound intellectual disability. Half of the respondents were not transitioned through pediatric-to-adult HCT by their pediatricians, and they visited adult departments by themselves without a formal referral process. They experienced difficulties during HCT, such as a lack of knowledge regarding adult health care providers and consultants. However, those who underwent HCT benefited from it in terms of their health, experience, and service use, such as age- and condition-appropriate care, seeing adult specialists, and the introduction of adult services. They also addressed challenges in managing appointments and having adult doctors understand their medical history. Nonetheless, they were not informed about diseases and medical and welfare resources for adulthood during pediatric visits and desired to discuss future plans with pediatricians. **DISCUSSION:** Systems that provide sufficient pediatric-to-adult HCT for individuals with childhood-onset neurologic conditions are required. Lifelong education for patients and families, training for pediatricians on HCT and neurologists on childhood-onset conditions and disabilities, and clinical practice and human resources that support patients and families are warranted.

EPILESSIA

1. **OUTCOMES FOLLOWING A MULTI-DISCIPLINARY PEDIATRIC-TO-ADULT TRANSITION AND TRANSFER CLINIC AT A LEVEL FOUR EPILEPSY CENTER.**

Vickery, S. S., Maturu, S., Khandker, N., Eisner, M. & Twanow, J.-D. E.

Epileptic disorders : international epilepsy journal with videotape (2023) doi:10.1002/epd2.20027

OBJECTIVE: Transition and transfer from the pediatric to adult care model is crucial to the continued long-term health and well-being of patients impacted by life-long diseases. This project explores the impact of a novel epilepsy transition collaboration between Nationwide Children’s Hospital (NCH) and Ohio State University (OSU) Wexner Medical Center. **METHODS:** We retrospectively analyzed the characteristics and outcomes of 56 consecutive patients transferred to an adult health care system. These patients were divided

into two groups. A cohort of 23 patients transferred in 2019 prior to clinic implementation were compared to a cohort of 33 consecutive patients transferred in 2019 and early 2020 using the epilepsy transition and transfer clinic model. Data points of interest included demographic information, age at transfer, epilepsy diagnosis, pharmaco-resistance of epilepsy, surgical history and compliance with follow-up. RESULTS: Patients transferred to OSU through the transition clinic were statistically more likely to be followed at OSU ($p=0.037$) within 6 months ($p=0.013$). Additionally, there was improved patient retention at OSU following transition clinic implementation ($p=0.037$). SIGNIFICANCE: Data demonstrating statistically significant improvement in care has not been reported for an epilepsy transition clinic model. This study establishes that our clinic model improves continuity of care in this at-risk population. Our clinic model also successfully transitioned and transferred patients with pharmaco-resistant and/or genetically mediated epilepsy, often cited as having barriers to successful transfer. This work also suggests that this clinic structure has potential to foster the growth of associated adult epilepsy subspecialty practices. These findings are encouraging as they offer potential for improved health care in the youth and young adult epilepsy population

DIABETE

1. **DEVELOPING THE ‘HEALTHCARE CEO APP’ FOR PATIENTS WITH TYPE 1 DIABETES TRANSITIONING FROM ADOLESCENCE TO YOUNG ADULTHOOD: A MIXED-METHODS STUDY.**

Chiang, Y.-T. *et al.*

Nursing open 10, 1755–1766 (2023) doi:10.1002/nop2.1432

AIM: To develop and test a mobile application that supports the disease self-management of adolescents with type 1 diabetes during their transition to early adulthood. DESIGN: A sequential mixed-methods design was employed. METHODS: The application content was designed according to previously identified care needs and expectations, followed by application development on the Android operating system. From the outpatient clinic of the Department of Paediatric Endocrinology and Metabolism at a medical centre in northern Taiwan, 35 individuals aged between 16-25 years participated in application testing. RESULTS: The overall median score of the QUIS was 4-5, most of the 25% quartile was 4-5, and all of the 75% quartile was 5, indicating adequate user interaction satisfaction.

2. **DO ADOLESCENTS AND EMERGING ADULTS RECEIVE THE DIABETES CARE THEY TRULY NEED? A NATIONWIDE STUDY OF THE QUALITY OF DIABETES HEALTH CARE DURING THE TRANSITION FROM PAEDIATRIC TO ADULT CARE.**

Hodnekvam, K., Iversen, H. H., Gani, O., Brunborg, C. & Skriverhaug, T.

Diabetic medicine : a journal of the British Diabetic Association e15091 (2023) doi:10.1111/dme.15091

AIMS: The aim of this study was to assess the paediatric and adult diabetes care provided to adolescents and young adults with childhood-onset type 1 diabetes during the transition. METHODS: This nationwide population-based cohort study included 776 individuals with type 1 diabetes who were last registered in the Norwegian Childhood Diabetes Registry (NCDR) between 2009 and 2012 and had received adult health care for at least 2 years. The patients' experiences were reported in a validated questionnaire. Clinical data from the annual registrations in the NCDR were coupled with data from the medical records in adult diabetes care. The longitudinal measures of glycaemic control were analysed using a growth mixture model. RESULTS: A total of 321 young people answered the questionnaire and provided written informed consent for the collection of their data from their medical records. The mean age at transfer was 18.0 years (range = 15.0-23.5 years), and the mean age at participation was 22.7 years (range = 20.9-26.7 years). Significant differences ($p < 0.001$) in patient experiences were found between paediatric and adult diabetes care in several areas: contact with health-care personnel, continuity of care, interval between consultations and overall satisfaction. Registry and medical records data confirmed the patient-reported experiences. The longitudinal analyses identified two groups with distinctly different trajectories of glycaemic outcome over time. Patient-provider continuity and perceived preparedness for transfer were the most influential predictors. CONCLUSIONS: This study highlights several areas to be addressed for improving health care and the transition to adult diabetes care in adolescents and young adults with type 1 diabetes, including provider continuity, individualised care and involvement of multidisciplinary teams.

ADHD

1. **TRANSITION CARE FOR ADOLESCENTS AND YOUNG ADULTS WITH ATTENTION-DEFICIT HYPERACTIVITY DISORDER (ADHD): A DESCRIPTIVE SUMMARY OF QUALITATIVE EVIDENCE.**

Scarpellini, F. & Bonati, M.

Child: care, health and development 49, 431–443 (2023) doi:10.1111/cch.13070

The review presents a summary of available evidence about transition care of ADHD patients from all service users' perspectives. Common barriers, and suggestions for improvement ADHD of transition care, were extrapolated from qualitative research, including case notes studies, and were exposed. A comprehensive search of the PubMed, Embase, PsychInfo and Web of Science databases for articles published up to October 2021 was conducted to summarize recent evidence on the experiences of all stakeholders involved in the transition process. Reviews, other chronic conditions and different meaning of transition were excluded. Authors extracted data and assessed study quality independently. Findings were discussed taking into consideration barriers and suggestions from all service users' perspectives. Findings from 23 studies with different context and methods were collected and summarized. Most of the studies were conducted in UK, using interviews and questionnaires, and addressed to the physicians. The lack of information about ADHD as a condition and about transition process were the barriers most reported, while joint working and sharing transition protocols were the suggestions pointed out by all stakeholders. Despite different perspectives, all stakeholders exposed similar needs. The review reveals an evident need for defining and evaluating the effectiveness of transition programmes from child to adult ADHD services.

2. **TRANSITION-ORIENTED PATIENT EDUCATION PROGRAM FOR ADOLESCENTS AND YOUNG ADULTS WITH ADHD.**

Schmidt, H. *et al.*

Zeitschrift für Kinder- und Jugendpsychiatrie und Psychotherapie 51, 28–40 (2023) doi:10.1024/1422-4917/a000871

Background: The transition from child- to adult-centered treatment includes numerous challenges in the treatment of chronic disorders. This process can be further complicated by disease-specific characteristics of attention-deficit/hyperactivity disorders (ADHD). This secondary analysis evaluated a transition workshop in individuals with ADHD. Methods: In total, 56 adolescents and young adults with ADHD (age M = 17.3 years, SD = 1.1; 17.9 % female) and their parents were quasi-randomly assigned to a control group (CG, n = 28) or an intervention group (IG, n = 28). The CG received regular medical care, whereas the IG additionally participated in a one-and-a-half-day transition workshop (ModuS-T). Before and 4 weeks after the intervention, transition competence was assessed with the Transition Competence Scale (TKS), patient activation with the Patient Activation Measure 13 for Adolescents (PAM® 13), and satisfaction with care with the Patient Satisfaction Questionnaire (ZUF-8). Results: The IG showed significantly improved transition competence ($p \leq .001$) compared to the CG. There was no significant intervention effect in terms of patient activation ($p = .194$). Overall, the IG was highly satisfied with the workshop. Discussion: To date, transition workshops have been evaluated predominantly in individuals with chronic somatic disorders. This secondary analysis indicates that a generic workshop is also associated with improved transition competence and high satisfaction in individuals with chronic mental disorders. The integration of such approaches into routine care needs to be discussed.

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