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Nr. 6 anno III –
Febbraio / Maggio 2024

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.

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GENERALE

1. YOUNG ADULTS' PERCEPTION OF TRANSITION FROM PAEDIATRIC TO ADULT CARE.

Forsberg, J., Lööf, G. & Burström, Å.

Acta Paediatrica 113, 1612–1620 (2024) doi:[10.1111/apa.17231](https://doi.org/10.1111/apa.17231)

Abstract: Aim Medical advancements will lead to more children with long-term illnesses and/or disabilities undergoing the transition to adult care. Previous studies show that many young adults are unprepared for this transition, and might suffer from loss of follow-up. This study aimed to investigate the post-transfer experiences of the transition among young adults with long-term illnesses and/or disabilities. Methods: A qualitative descriptive design was used. Three semi-structured focus group interviews were conducted with 15 participants (18–25 years of age) recruited via patient organisations focusing on children and young adults with disabilities and/or long-term illnesses. The interviews were analysed with conventional content analysis. Results: One theme emerged: limbo, defined as an indefinite experience without knowing when or even if something would happen, or whether they would be overlooked. The theme rested on four categories: transition experiences, organisational aspects, influence on daily life, and self-management. Conclusion: Areas for improvement were identified across the entire transition that is, in the preparation, transfer, and post-transfer stages. Our findings indicate a limited understanding among healthcare providers (HCPs) that the transition continues until the young adult **has been fully integrated into adult care.**

2. THE EFFECT OF TRANSITION TO ADULTHOOD TRAINING PROGRAM FOR MOTHERS OF YOUNG ADULTS WITH INTELLECTUAL DISABILITY ON FAMILY QUALITY OF LIFE AND PERCEIVED STRESS LEVEL: A PILOT RANDOMIZED CONTROLLED STUDY.

Savaş, E. H., Aydin, A. & Bertan, İ.

Journal of intellectual disabilities : JOID 17446295241259100 (2024) doi:[10.1177/17446295241259100](https://doi.org/10.1177/17446295241259100)

Families cannot easily identify and cope with the changing health problems and needs of children transitioning into adulthood. This pilot randomized controlled study aims to improve the family's quality of life and reduce mothers' perceived stress levels by implementing an educational program (Transition to Adulthood Training Program - TATP). A total of 33 mothers of children with intellectual disabilities were randomly assigned to the groups. Data were collected using the Personal Information Form, Beach Center Family Quality of Life (BCFQOL), and Perceived Stress Scale. The intervention group showed a significant increase in the BCFQOL mean score rather than the control group ($p < .001$). There was a significant decrease in the perceived stress scores of the mothers in the intervention group after the TATP training sessions ($p < .05$). The TATP intervention not only increased the quality of family life for these mothers but also led to a reduction in their perceived stress levels.

3. A TRANSITION MODEL TO ADULT CARE FOR SPECIAL HEALTHCARE ADOLESCENTS AND YOUNG ADULTS.

Prussein, K. V.

Pediatric dentistry 46, 167 (2024)

4. THE INDIAN ACADEMY OF PEDIATRICS AND DIRECTORATE GENERAL OF HEALTH SERVICES, GOVERNMENT OF INDIA WHITE PAPER ON TRANSITION OF CARE FOR YOUTH WITH SPECIAL HEALTH CARE NEEDS.

Chandra, J. *et al.*

Indian pediatrics 61, 475–481 (2024)

Over the years, survival of children with chronic diseases has significantly improved and a large proportion of them now are entering into adulthood. Transition of Care (ToC) of such patients with having childhood onset of chronic diseases to the adult health care system is well organized in developed countries, although it is an emerging concept in India. In situations where the systems for ToC are not in place, such cases are fraught with unsatisfactory health outcomes. With proper ToC in place, these patients are likely to receive uninterrupted care by the adult care physicians and hence reach their full potential. This document highlights the need, rationale and way forward for ToC of youth with special health care needs (YSHCN) across the country. It also describes the standard operating procedures to develop the ToC at a hospital level for clinicians and administrators.

5. MATURING INTO ADULTHOOD: TRANSITION READINESS OVER TIME IN PRIMARY CARE.

Woods, J. *et al.*

Journal of Adolescent Health 74, S83–S84 (2024) doi:[10.1016/j.jadohealth.2023.11.355](https://doi.org/10.1016/j.jadohealth.2023.11.355)

Purpose: Healthcare transition is a crucial aspect of adolescent development and adulthood, yet there is limited research on transition readiness within primary care settings. Adolescents and young adults (AYA) typically have irregular healthcare visits in their medical homes, emphasizing the importance of ongoing readiness assessment. Our objective was to evaluate transition readiness across various health domains and its evolution over time as patients prepare to transition into the adult healthcare system. Methods: A retrospective cohort study of an adolescent primary care clinic (July 2021-June 2023) assessed patient responses over time for the validated 20-item Transition Readiness Assessment Questionnaire (TRAQ) in the domains of managing medications, keeping appointments, managing health issues, and communicating with providers ('no' for don't know how/want to learn/am learning to do; 'yes' for have started/always do). Patients (14-25 years) completed the assessment every six months during preventive and follow-up visits corresponding with the transition program implementation of age-specific packets and short interventions with a program manager. For patients with more than two TRAQ assessments, investigators selected results closest to one year apart. Nonparametric median tests (for continuous variables) and chi-squared tests (for categorical variables) assessed for differences by age (14-15, 16-17, 18-25), gender, and insurance. The study received exempt approval from the hospital institutional review board. Results: Patients (N=329; median=17.3 years; 74% female; 49% Hispanic) had repeated TRAQ assessments. Responses in the medication domain improved for all ages ($p<0.001$) while communication improved for only 16-17-year-old patients ($p=0.02$). Keeping an appointment calendar ($p=0.03$), speaking to a pharmacist ($p=0.04$), and filling and reordering prescriptions ($p<0.001$) improved for >25% 14-15-year-old patients; attending visit by self, making appointment changes and reordering prescriptions (all $p<0.001$), contacting with concern ($p=0.01$), and speaking with a pharmacist ($p=0.04$) increased for >25% 16-17-year-old patients. Filling and reordering prescriptions increased for >25% 18 years and older ($p<0.001$). Managing medications increased for female ($p<0.001$) and male patients ($p=0.02$); keeping appointments increased for females ($p=0.02$). Male patients increased transition readiness with >25% moving to 'yes' answers for reporting medication reaction ($p<0.001$), explaining medications ($p=0.01$), keeping appointment calendar ($p<0.001$), speaking to a pharmacist ($p=0.005$), and calling about health changes ($p=0.02$). Females improved readiness with >25% moving to 'yes' answers for reporting medication reaction ($p<0.001$), filling ($p<0.001$) and reordering ($p=0.003$) prescriptions and speaking to a pharmacist ($p=0.005$). For making appointments and speaking with pharmacist, 20% of males moved down in transition readiness ($p=0.01$; $p=0.005$). Patients with all insurance types improved for the medication domain ($p<0.001$); the health domain improved for patients with public insurance ($p=0.04$). Dealing with medication reactions improved for >30% of patients with both insurance types ($p=0.03$). Conclusions: Transition readiness improves over time with AYA, but changes vary by age, gender and insurance. Focused transition work can assist in the process by including age- and gender-specific interventions with considerations of social determinants of health. Awareness of how adolescent development may affect the transition process should be incorporated into transition readiness and interventions. Sources of Support: Upper Payment Limit Medicaid Dollars, University of Colorado.

6. **A PEDIATRICIAN'S PRACTICAL GUIDE FOR NAVIGATING TRANSITION TO ADULTHOOD WITH AUTISTIC YOUTH AND THEIR CAREGIVERS.**

Sohl, K., Oberweiser, C., Ranum, E., Oberweiser, C. & Cornell, W.

Pediatric Clinics of North America 71, 315–326 (2024) doi:[10.1016/j.pcl.2024.01.007](https://doi.org/10.1016/j.pcl.2024.01.007)

7. **CONTINUATION OF PEDIATRIC CARE AFTER TRANSFER TO ADULT CARE AMONG AUTISTIC YOUTH OVERLAP OF PEDIATRIC AND ADULT CARE.**

Sirrianni, J., Hanks, C., Rust, S. & Hart, L. C.

Journal of Autism and Developmental Disorders (2024) doi:[10.1007/s10803-024-06314-5](https://doi.org/10.1007/s10803-024-06314-5)

The transition from pediatric to adult health care is a vulnerable time period for autistic adolescents and young adults (AYA) and for some autistic AYA may include a period of receiving care in both the pediatric and adult health systems. We sought to assess the proportion of autistic AYA who continued to use pediatric health services after their first adult primary care appointment and to identify factors associated with continued pediatric contact. We analyzed electronic medical record (EMR) data from a cohort of autistic AYA seen in a primary-care-based program for autistic people. Using logistic and linear regression, we assessed the relationship between eight patient characteristics and (1) the odds of a patient having ANY pediatric visits after their first adult appointment and (2) the number of pediatric visits among those with at least one pediatric visit. The cohort included 230 autistic AYA, who were mostly white (68%), mostly male (82%), with a mean age of 19.4 years at the time of their last pediatric visit before entering adult care. The majority (n = 149; 65%) had pediatric contact after the first adult visit. Younger age at the time of the first adult visit and more pediatric visits prior to the first adult visit were associated with continued pediatric contact. In this cohort of autistic AYA, most patients had contact with the pediatric system after their first adult primary care appointment.

8. **WCN24-2133 STARX HEALTHCARE TRANSITION READINESS SCORES AMONG ARABIC-SPEAKING CAREGIVERS OF YOUTH WITH CHRONIC CONDITIONS.**

Said, P., Abumohsen, Y., El Adl, A., Filler, G. & Diaz-Gonzalez de Ferris, M.

Kidney International Reports 9, S287–S288 (2024) doi:[10.1016/j.ekir.2024.02.590](https://doi.org/10.1016/j.ekir.2024.02.590)

Introduction: Without healthcare transition (HCT) preparation from pediatric to adult-centered care, the outcomes of youth with chronic conditions can be unfavorable. In a USA cohort, we have demonstrated that youth prefer to learn about their health condition from their caregivers. Assessments of HCT readiness guide customized interventions based of skill achievements. The youth and caregiver versions of the STARx Questionnaire (as well as other tools) measures HCT readiness, however, studies among Arabic-speaking dyads are elusive. We hypothesized that the HCT readiness scores by youth with chronic conditions would be different. Methods: The clinical version of the 18-item self-administered STARx Questionnaire (max score 90), has been translated into 8 languages and is utilized in 15 countries. After translation/back translation into Arabic and ethics approval from the University of North Carolina at Chapel Hill and Zagazig University hospital in Zagazig, Egypt, dyads of youths with chronic conditions and their caregivers joined our study the summer of 2022. Results: We enrolled 107 youth/caregiver dyads. Youths' characteristics were: 64 (60%) males; mean age 13.3±1.2 years (range 10-16) and their diagnoses were 26 (24%) renal failure, 35 (33%) thalassemia, and 46 (43%) diabetes mellitus. The median number of medications was 2 (range 0-4) and DM patients received 21 insulin injections/week. Female caregivers were 93 (87%) and all had attended public school. Total Caregiver STARx Questionnaire scores correlated positively and significantly with the youth's age (Pearson $r=0.31$, Figure 1). While caregivers' and youths' total STARx Questionnaire scores correlated significantly (Pearson $r=0.18$, Figure 1), caregivers' scores were significantly lower (51±5) than their youths' scores of 54±5 ($p=1.34772E-07$, paired t-test). Lower caregiver score percentages of the maximum possible score in each domain were noted for the domains of disease knowledge, followed by selfmanagement. By contrast, in the domain of provider communication, the caregivers scored the skills better than the youths (Table 1). The percentages of points in each 3 domains were 50±8 versus 75±6% for disease knowledge, 53±8 versus 61±7% for self-management, and 75±8 versus 62±10% for provider communication, respectively. [Formula presented] Conclusions: In this Arabic-speaking cohort, caregivers had lower HCT readiness scores compared to their youth's based on total, disease knowledge and self-management subdomains of the STARx Questionnaire, whereas the youth scored themselves lower than their caregivers for healthcare communication. It is unclear if the youth overestimate their skills in the disease

knowledge and self-management domains. The significant difference between the caregiver and youth assessment in the domain of provider communication requires further studies and needs to aim at improving the skills and perceptions of the youths.

9. DIFFERENCES IN HEALTH CARE TRANSITION KNOWLEDGE, ATTITUDES, AND BEHAVIORS AMONG GRADUATE MEDICAL TRAINEES FROM PEDIATRICS- AND ADULT-FOCUSED PROGRAMS: RESULTS FROM A CROSS-SECTIONAL SURVEY.

Patel, J. *et al.*

Journal of General Internal Medicine (2024) doi:[10.1007/s11606-024-08679-w](https://doi.org/10.1007/s11606-024-08679-w)

10. HEALTH CARE TRANSITION KNOWLEDGE, ATTITUDES AND BASELINE READINESS SCORES OF ADOLESCENTS WITH CHRONIC HEALTH CONDITIONS AT THE EAST AVENUE MEDICAL CENTER.

Montemayor Quirona, F. L. & Noblejas Mangubat, M. A.

Journal of Adolescent Health 74, S22–S23 (2024) doi:[10.1016/j.jadohealth.2023.11.237](https://doi.org/10.1016/j.jadohealth.2023.11.237)

Purpose: Health Care Transition improves quality of life, maximizes independence and minimizes interruption in patient care. Adequate knowledge and careful preparation of the adolescent is essential for a successful health care transition process. The aim of this study is to determine the health care transition knowledge, attitudes and baseline readiness scores of adolescents with chronic health conditions at the East Avenue Medical Center. Methods: This study utilized a prospective cross-sectional analytic research design. Data was analyzed using the Statistical Package for Social Sciences (SPSS) version 20. Descriptive statistics (mean, standard deviation, frequency and percentage) were used to describe the clinico-demographic profile of the adolescents with chronic health conditions. Pearson correlation and independent T-test were used to determine the correlation and association of the adolescents' UNC TRxANSITION Scale Scores with the type of chronic health condition and stage of adolescence. Results: Fifty (50) adolescents ages 15-18 years old and diagnosed with chronic health conditions for at least 3 months were included. Only 20% of the adolescents were familiar with the concept of health care transition and 16% learned about this from their physicians. Majority of the participants (88%, n=44) agreed that a health care transition program would prepare them for transfer to adult health care providers and would help them learn self-management. Almost all the adolescents (94%, n=47) agreed to consult a new doctor when they turned 19 years old. Majority (74%, n=37) also wanted to enroll in the program. The total UNC TRxANSITION Scale scores of the participants ranged from 2.21 to 8.01, with a mean score of 5.14 (SD 1.24). The highest mean scores obtained were in the ongoing support (0.81; SD 0.32) and adherence (0.78; SD 0.24) subscales. The lowest mean scores documented were in the subscales of health insurance (0.22; SD 0.21) and new health care providers (0.27; SD 0.29). The five (5) adolescents with chronic renal disease had the lowest baseline transition readiness scores while the two (2) adolescents with diabetes mellitus scored the highest. A negative moderate correlation was noted between the ongoing support subscale and the stage of adolescence ($r = -0.342$, $p\text{-value} = 0.015$). The mean score of middle adolescents in this subscale was 0.95 (SD= 0.16) while late adolescents had a mean score of 0.73 (SD 0.36). Conclusions: Health Care transition is an essential process in the management of adolescents with chronic health conditions. Raising awareness on the value of a health care transition program is vital. Adequate knowledge and guidance are needed to ensure readiness of chronically ill adolescents for transition to adult health care services.

11. BARRIERS TO MENTAL HEALTH CARE TRANSITION FOR YOUTH AND YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND CO-OCCURRING MENTAL HEALTH CONDITIONS: STAKEHOLDERS' PERSPECTIVES.

Mirzaian, C. B., Deavenport-Saman, A., Hudson, S. M. & Betz, C. L.

Community mental health journal (2024) doi:[10.1007/s10597-024-01262-x](https://doi.org/10.1007/s10597-024-01262-x)

Youth and young adults (YYA) with intellectual and developmental disabilities (IDD) have high rates of co-occurring mental health (MH) conditions. The time during transition from pediatric to adult health and mental health care can be a very challenging, with risk of loss of services leading to poor outcomes. This study aimed to explore barriers to transition from pediatric to adult health and mental health care and services for individuals with IDD and co-occurring MH conditions, by eliciting the view of stakeholders, including disability advocates. Qualitative analysis was conducted using grounded theory, and themes were coded based upon the social-

ecological model (SEM). We generated themes into multiple levels: the individual level, the family level, the provider level, the systems of care level, and the societal level. Stakeholders expressed a critical need to improve coordination between systems, and to increase provider availability to care for YYA with IDD and co-occurring MH conditions.

12. **BARRIERS AND FACILITATORS TO TRANSITION FROM PEDIATRIC TO ADULT HEALTHCARE FOR IMMIGRANT YOUTH WITH CHRONIC HEALTH CONDITIONS.**

Mackie, A. S. *et al.*

Journal of pediatric nursing (2024) doi:[10.1016/j.pedn.2024.05.014](https://doi.org/10.1016/j.pedn.2024.05.014)

PURPOSE: The objective of this study was to investigate the experience of first- and second- generation immigrant youth living with chronic health conditions in Canada, their parents or caregivers, and healthcare and service providers who care for immigrant youth, regarding the transition from pediatric to adult healthcare. **DESIGN AND METHODS:** We conducted semi-structured individual interviews and focus groups. Youth were 1st or 2nd generation immigrants, aged 16-25, with pediatric-onset chronic health conditions. Parents or caregivers had raised youth children as described. Providers delivered healthcare or other services to immigrant populations. Thematic analysis was conducted of all transcripts. **RESULTS:** Twenty youth, 14 parents/caregivers and five service providers participated. Most participants described healthcare transition as very difficult to navigate. Two major themes emerged across participant narratives: 1. Barriers to transition: lack of family experience in Canada, language, discrimination, financial strain, stigma, and long wait times. Some of these barriers are specific to newcomer families, but others are generalizable to the Canadian population. 2. Facilitators of transition: youth independence, youth acting as cultural bridges within their families, and cross-sector support between healthcare, education, social work and settlement services. **CONCLUSIONS:** Immigrant youth and their families face a broad range of barriers to healthcare transition. The collaborative nature of cross-sector support effectively addressed some of the barriers faced by newcomer families. **PRACTICE IMPLICATIONS:** Clinicians should provide immigrant youth and their families with accessible information about the health condition and how to navigate the adult healthcare system prior to transition, particularly when language barriers exist.

13. **CRAFTING A 'TRANSITIONOMETER': A PROPOSED FRAMEWORK FOR DEVELOPING AND HONING CAPABILITIES OF YOUNG PEOPLE TRANSITIONING TO ADULT HEALTHCARE SERVICES.**

Levy, S., Wynd, A. H. D. & Motee, A.

Comprehensive child and adolescent nursing 1–12 (2024) doi:[10.1080/24694193.2024.2348830](https://doi.org/10.1080/24694193.2024.2348830)

This paper focuses on an innovative approach to preparing children and young people, with Spina Bifida, to move from child-centered to adult-oriented healthcare systems. Reflecting on our role in delivering a national nurse led service, we set to identify and critique international transition tools in use for this population. Specifically, we aimed to identify the core capabilities and indicators of progression to successful transition, so that holistic interventions could be planned to match the needs of individuals and their carers. There were two phases to the study, initially focusing on a systematic literature review on transition tools and the specific items that these tools captured, including skills, abilities and behaviors. Phase two culminated in the articulation of a segmented and incremental 'road map', aligned with facets deemed essential for a successful healthcare transition. The reporting of the literature review (phase one) followed the PRISMA guidelines and shaped the qualitative element of the study (phase two) through the use of semi-structured interviews and thematic analysis. The search strategy yielded 11 studies, which were then manually searched for other relevant literature, adding a further 14 articles. The review analyzed 7 specific tools for spina bifida and 8 generic tools, which were deemed appropriate for this group of patients. A comprehensive list of core capabilities was then articulated and framed to fit a progression timeline. Specific interventions were formulated to explore ways to co-produce resources that could enhance and support a planned transition to adult-focused services. Our proposed mapping of capabilities and progression could shape other transition programs, where nurses work collaboratively with young people, carers and other members of a team. More work is needed to further explore and embed the framework that, as we did, could be digitized and shared with all stakeholders involved in the transition process.

14. CHANGES IN HEALTH-RELATED QUALITY OF LIFE DURING TRANSITION TO ADULT HEALTHCARE: AN INTERNATIONAL PROSPECTIVE COHORT STUDY.

Kallio, M. M. *et al.*

Archives of Disease in Childhood (2024) doi:[10.1136/archdischild-2024-327017](https://doi.org/10.1136/archdischild-2024-327017)

Objective: To study changes in health-related quality of life (HRQoL) in adolescents and young adults (AYAs) with chronic medical conditions across the transfer to adult healthcare and associations of HRQoL with transition readiness and experience of care. Methods: Participants in this international (Finland, Australia) prospective cohort study were recruited in the year prior to transfer to adult health services and studied 12 months later. In addition to two HRQoL scales (Pediatric Quality of Life inventory (PedsQL), 16D), the Am I ON TRAC for Adult Care Questionnaire and Adolescent Friendly Hospital Survey measured transition readiness and experience of care and categorised by quartile. Data were compared before and after transfer to adult healthcare. Results: In total, 512 AYAs completed the first survey (0-12 months before transfer of care) and 336 AYAs completed it 1 year later (retention rate 66%, mean ages 17.8 and 18.9 years, respectively). Mean total PedsQL scores (76.5 vs 78.3) showed no significant change, although the social and educational subdomains improved after transfer of care. The mean single-index 16D score remained the same, but in Finland, distress increased and the ability to interact with friends decreased after transfer. AYAs within the best quartiles of experience of care and transition readiness had better HRQoL than AYAs within the worst quartiles. Conclusions: Overall HRQoL of AYAs remained unchanged across the transfer to adult healthcare. Recognising and supporting AYAs with unsatisfactory experience of care and poor transition readiness could improve overall HRQoL during the transition process. Trial registration number: NCT04631965.

15. COCCOS STUDY: DEVELOPING A TRANSITION PROGRAM FOR ADOLESCENTS WITH CHRONIC CONDITIONS USING EXPERIENCE-BASED CO-DESIGN. A STUDY PROTOCOL.

Janssens, N. *et al.*

PLoS ONE 19, (2024) doi:[10.1371/journal.pone.0298571](https://doi.org/10.1371/journal.pone.0298571)

Background During adolescence, adolescents and young adults (AYAs) are expected to transfer their care from the pediatric environment towards an adult-focused setting. To prevent an abrupt transfer of care, it is recommended to provide AYAs with chronic conditions an adequate transition program. The aim of this paper is to describe the study protocol for the development of a transition program for AYAs with common chronic conditions (COCCOS study), using the Experience-Based Co-Design (EBCD) methodology. Methods and analysis A qualitative, participatory study is conducted in Flanders (Belgium). Study participants are AYAs (n≥15, 14–25 years old, diagnosed with type 1 diabetes, asthma, or obesity), their families, and healthcare providers (n≥15). The study is composed of eight EBCD stages: clinical site observations, in-depth interviews, trigger film, healthcare providers' feedback event, AYAs' feedback event, joint event, co-design workshops, and a celebration event. Photovoice will take place as a starting point of EBCD. Data will be analyzed using thematic analysis. Results Data collection has started in January 2023 and is expected to be completed in May 2024. As of August 2023, over 15 clinical site observations have been conducted. A total of 18 AYAs, two parents, six healthcare providers have been enrolled and a total of 20 interviews have been conducted. Conclusion Advancing transitional care is essential for tackling negative health outcomes. Applying the innovative participatory EBCD methodology will reveal key elements of transitional care for AYAs with common chronic conditions in the development of a person-centered transition program. Practice implications Study findings will apply key elements of transitional care of AYAs with chronic conditions in the development of an adequate transition program.

16. THE CURRENT STATE OF PEDIATRIC TO ADULT TRANSITION OF CARE: A ROUND TABLE DISCUSSION WITH KEY STAKEHOLDER GROUPS.

Hu, M., Gakhal, N., Kabakulak, C., LoMonaco, J. & Bollegala, N.

Journal of the Canadian Association of Gastroenterology 7, 65–66 (2024) doi:[10.1093/jcag/gwad061.092](https://doi.org/10.1093/jcag/gwad061.092)

Background: There is a severe paucity in available resources to facilitate a safe and effective pediatric to adult health care transition for patients with chronic disease. Aims: This study aims to better understand the experiences of key stakeholder groups involved in pediatric to adult transition of care across various chronic disease specialties within a tertiary care urban environment. Methods: A focus group was conducted on July 12th, 2018 at Women's College Hospital with key stakeholder groups. Questions focused on the top issues

related to pediatric to adult transition of care and an ideal transition model for their respective patient populations. The second part of this study included individual interviews with patients and carepartners. Focus group meetings and individual interviews were both audio-recorded and transcribed for qualitative thematic analysis. Results: Seventeen pediatric and adult care physicians representing ten chronic disease specialties were represented. Seven patients and care partners were interviewed. Major focus group themes included: disproportionate access to resources between and within specialties (n=10), lack of mental health support in the adult setting (n=8), fragmentation of care due to multiple providers as a result of patients leaving for employment or education (n=6), patients feeling alienated due to decrease in allied health support or due to shorter appointment times (n=8), and difficulty retaining consistent care due to missed appointments as a result of inconsistent communications or change in location for education or employment (n=7). Ideal care models were suggested to include: centralized intake procedure to identify patients who may require extra support (n=9), education for scheduling administrators about second chances after a no-show (n=5), implementation of joint clinics with pediatric and adult care teams or back-and-forth clinic sessions to ensure bidirectional provider comfort before discharge to adult care system (n=4), and implementation of a dedicated transitions navigator or point of contact for patients (n=10). The individual patient and carepartner interviews emphasized the need for: centralized and comprehensive online resource (n=7), simple and clear educational content introducing the adult healthcare system (n=7), opportunities to meet and share information with other individuals in a similar position (n=3), and availability of a transitions navigator (n=4). Conclusions: Current pediatric to adult transition of care resources are fragmented, allocated inefficiently, difficult to ascertain and often constrained to a specific condition or location. Future efforts should focus on improving the care transition process for high-risk patient populations by taking a comprehensive approach utilizing innovative, and multidisciplinary solutions.

17. FACTORS ASSOCIATED WITH HEALTHCARE TRANSITION READINESS FOR ADOLESCENTS WITH CHRONIC CONDITIONS: A CROSS-SECTIONAL STUDY.

Hong, H. S. & Im, Y.

Journal of Child Health Care (2024) doi:[10.1177/13674935241248859](https://doi.org/10.1177/13674935241248859)

Healthcare transition readiness (HCTR) plays a vital role by fostering autonomy, self-management skills, and active involvement in healthcare, leading to positive health outcomes. This study aimed to examine the factors associated with HCTR in adolescents with chronic conditions (ACCs) including adolescents' autonomy, parental overprotection, and autonomy support from healthcare providers (HCPs). This descriptive study included 107 adolescents aged 14–19 years (median age: 17 years, IQR = 1), recruited from online communities and support groups in South Korea. Data were analyzed using hierarchical linear regression. Our research has shown that HCTR is linked to a lower level of parental overprotection ($\beta = -0.46$, 95% CI [-0.59, -0.33]) and higher levels of autonomy support from HCPs ($\beta = 0.46$, 95% CI [0.36, 0.56]). Among general characteristics, we also found that having a transfer plan to adult care ($\beta = 0.24$, 95% CI [0.04, 0.44]) is significantly associated with HCTR. This study contributes to a broader understanding of HCTR by examining its associated factors in ACC. The results emphasize the pivotal roles of parental involvement, healthcare provider support, and structured transition to adult care in enhancing HCTR. These findings underscore the need for comprehensive assistance to ensure successful healthcare transitions.

18. HOW TRANSITION FROM CHILD TO ADULT SERVICES FOR YOUNG PEOPLE WITH DISABILITIES IS AFFECTED BY LIMITED PERSPECTIVES: A PARENT'S VIEW.

Fox, C.

Developmental Medicine and Child Neurology 66, 555–556 (2024) doi:[10.1111/dmcn.15843](https://doi.org/10.1111/dmcn.15843)

19. TRANSITION READINESS ASSESSMENT QUESTIONNAIRE: SKILL GAPS AND PSYCHOSOCIAL PREDICTORS OF TRANSITION READINESS AMONG ADOLESCENTS AND YOUNG ADULTS WITH CHRONIC MEDICAL CONDITIONS.

Chapados, P. *et al.*

Child: care, health and development 50, e13156 (2024) doi:[10.1111/cch.13156](https://doi.org/10.1111/cch.13156)

BACKGROUND: Transferring from paediatric to adult care can be challenging. Adolescents and young adults (AYAs) with chronic health conditions need to develop a specific set of skills to ensure lifelong medical follow-up

due to the chronicity of their condition. The Transition Readiness Assessment Questionnaire-French version (TRAQ-FR) is a 19-item questionnaire measuring such skills. The aims of the study were to (1) describe participant characteristics and (2) identify constructs related to, and predictors of, having learned domain-specific transition readiness skills. METHODS: Participants included 216 AYAs aged 14-20 years (M = 15.93; SD = 1.35; 54.1% male) recruited from five outpatient clinics in a Canadian tertiary hospital. AYAs completed the TRAQ-FR, the Pediatric Quality of Life Inventory 4.0 (PedsQL) and a sociodemographic questionnaire. Descriptive, bivariate and binary logistic regression analyses were conducted. RESULTS: Overall, participants reported significantly higher scores on the Talking with Providers, Managing Daily Activities and Managing Medications subscales than on the Appointment Keeping and Tracking Health Issues subscales ($F[4,1075] = 168.970, p < .001$). At the item level, median scores (on a 5-point Likert scale) suggest that AYAs had begun practising five of the 19 skills (median scores ≥ 4 ; 'Yes, I have started doing this'), while a median score of 1 ('No, I don't know how') was found for one item ("Do you get financial help with school or work?"). At the subscale level, TRAQ-FR skills and skill gaps were related to AYAs' age, sex and PedsQL scores ($ps < .05$). CONCLUSION: Older and female AYAs were more likely to have begun practising specific TRAQ-FR subscale skills. Better psychosocial functioning was also related to having learned specific transition readiness skills. AYAs show several gaps in transition readiness. Targeted intervention in transition readiness skill development could take into account AYAs' age, sex and psychosocial functioning for a successful transfer to adult care.

20. CLIFF OR BRIDGE: BREAKING UP WITH THE PAEDIATRIC HEALTHCARE SYSTEM.

Baumbusch, J.

Paediatrics and Child Health (Canada) 29, 84–86 (2024) doi:[10.1093/pch/pxad061](https://doi.org/10.1093/pch/pxad061)

Transition from paediatric to adult healthcare is a normal part of the care trajectory, yet the process often leaves much to be desired. In this commentary, I share my family's journey of this care transition, particularly the handover aspect, by providing examples of different ways that relationships were ended by paediatric healthcare professionals. The ending of these relationships often felt like 'breaking up'. I also share an example of a supported handover, which bridged the transition from paediatric to adult care. To improve transitions, we need genuine acknowledgement of the paediatric medical trauma stress (PMTS) experienced by families such as mine following years of interactions in the healthcare system. Along with following transition checklists, patients and families need authentic and meaningful closure to longitudinal relationships and trauma-informed care practices as we move forward into the adult care system.

21. A QUALITY IMPROVEMENT INITIATIVE TO IMPROVE HEALTH CARE TRANSITION PLANNING AT ADOLESCENT WELL VISITS.

Arons, A. *et al.*

Academic Pediatrics (2024) doi:[10.1016/j.acap.2024.03.013](https://doi.org/10.1016/j.acap.2024.03.013)

Objective: Health care transition (HCT) planning supports adolescents as they move from pediatric to adult health care and is recommended for all youth. HCT planning uptake remains low, with little known about HCT in the adolescent well child check (WCC) setting. We sought to increase rates of HCT planning at WCCs by adapting best practices for HCT from specialty and chronic care. Methods: This quality improvement initiative at 12 to 17-year-old WCCs at four Internal Medicine-Pediatrics primary care clinics, was based on the first three of the "Six Core Elements" of HCT framework and integrated into the electronic health record. Two uptake measures were assessed via chart review after three plan-do-study-act (PDSA) cycles, with two provider surveys and an implementation science analysis further informing interpretation. Results: By the final PDSA cycle, the percentage of 14 to 17-year-old WCCs at which HCT planning was discussed and a screening tool completed increased from 5% to 31%, and the percentage of 12 to 13-year-old WCCs at which the HCT policy was discussed increased from 6% to 47%. Provider survey results revealed endorsement of HCT goals, but time and technological barriers, which were further elucidated in the implementation science analysis. Conclusions: This quality improvement initiative increased rates of HCT planning during adolescent WCCs. While limited to three Core Elements and Internal Medicine-Pediatrics clinics, strengths include measures capturing all WCCs, contextualized by provider surveys and an implementation science framework. Lessons from this effort can inform future tailored HCT initiatives at adolescent WCCs.

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EPILESSIA

1. BEING AN ADOLESCENT WITH EPILEPSY DURING THE TRANSITION FROM PEDIATRIC TO ADULT HOSPITAL CARE: A QUALITATIVE DESCRIPTIVE STUDY.

Abildgaard Hansen, O. *et al.*

Epilepsy and Behavior 155, (2024) doi:[10.1016/j.yebeh.2024.109780](https://doi.org/10.1016/j.yebeh.2024.109780)

Background: The transition from pediatric to adult care is challenging for adolescent patients despite numerous recommendations in recent decades. However, the perspective of the patients is sparsely investigated. Aim: To explore the experiences and needs of adolescents with epilepsy (AWE) during the transition from pediatric to adult hospital care. Methods: We conducted 15 semi-structured interviews with AWEs aged 13–20 years and 10 h of field observations of consultations. Interviews were audio-recorded, transcribed, anonymized, and entered into NVivo (version 12, QSR International) with the transcribed field notes. Data were analyzed using systematic text condensation. Results: Three themes were identified: (1) Navigating epilepsy in everyday life; (2) The difficult balance between concealment and openness about epilepsy; and (3) Being seen as an individual and not an illness. AWEs' needs in transition are closely associated with their experiences and perceptions of illness, treatment, consultations, and seizures. Notably, AWEs reveal a significant concern about being overlooked beyond their medical condition in appointments. Conclusions: This study highlights the vulnerability and challenges of AWEs transitioning to adult care. Overall, AWEs seek understanding, acceptance, and autonomy in managing their epilepsy and transitioning to adult care. Their experiences underscore the importance of holistic support and communication in healthcare settings. A concerted effort from healthcare professionals (HCP) is necessary to foster the recognition of AWEs as individuals with distinct personalities, needs, and capabilities.

2. TRANSITIONING FROM PAEDIATRIC TO ADULT CARE IN EPILEPSY: A QUALITATIVE STUDY OF ADOLESCENT EXPERIENCES.

Goselink, R. J. *et al.*

Seizure 119, 92–97 (2024) doi:[10.1016/j.seizure.2024.05.011](https://doi.org/10.1016/j.seizure.2024.05.011)

OBJECTIVE: Transition into adulthood and adult medical care is an important step in the life of young people with epilepsy. We aimed to gain a better insight into the lived experience of the transition to adulthood and adult medical care in epilepsy in Sweden, to improve future transitional care. METHODS: A cross-sectional observational study with digital focus-group meetings and interviews with young people with epilepsy (16-22 years, n = 37) prior to, or after the transfer to adult care, or their primary caregivers if they had intellectual disability. We used reflexive thematic analysis to analyse the experiences and expectations on the transition to adulthood and adult medical care. RESULTS: The results of the thematic analysis included four key areas during transition to adulthood and adult care for young persons with epilepsy: (I) worries on coming changes and future, (II) transfers are not smooth and adult care is less integrated, (III) epilepsy is part of a bigger picture, and (IV) parental roles change. In those with intellectual disability, parents experienced a stressful process and had to increase their efforts to coordinate all care contacts in adult care. Here, epilepsy was often experienced as a minor part of a more complex disease picture, where neurodevelopmental issues were often the primary concern. SIGNIFICANCE: Transition in epilepsy is often complex due to the large burden of co-occurring disease, specifically intellectual disability and neuropsychiatric diagnoses. Transfer to adult care is experienced as unplanned and participants experience uncertainty, indicating a need for an improved transition process. As effective interventions are known in other chronic diseases, future studies should focus on the evaluation of how these approaches can be feasible and effective in young people with epilepsy.

3. EPITRANS. QUALITY ASSESSMENT OF THE EPILEPSY TRANSITION PROCESS.

Ortiz de Zarate, Z. *et al.*

European Journal of Paediatric Neurology 48, 121–128 (2024) doi:[10.1016/j.ejpn.2024.01.004](https://doi.org/10.1016/j.ejpn.2024.01.004)

Objective: To analyze the differences in clinical management during the epilepsy transition process from pediatric to adult care and to determine the quality of life and degree of satisfaction of patients and caregivers during the transition. Methods: This is a longitudinal study including patients with epilepsy transferred from pediatric to adult epilepsy care between 2013 and 2017. Patients had a minimum follow-up of 3 years before the transition visit and at least 3 years consulting in the adults section. Clinical characteristics were retrieved from the medical chart. Quality of life and satisfaction questionnaires were administered by online access to patients and caregivers at the end of the adult follow-up period. Results: 99 patients (50.5 % women, mean transition age 16.5 ± 1 years old) were included. Before the transition visit, 90 % of patients received a transition discussion and 88 % had a formal clinical report. In the pediatric period, patients were visited more frequently, had more EEGs and genetic studies, and were seen by the same neuropaediatrician ($P < 0.05$). In the adult period, patients underwent a larger number of prolonged video EEGs and were prescribed polytherapy more often ($P < 0.05$). Quality of life remained steady during the entire transition, but satisfaction with the care received was significantly higher during the pediatric period. Conclusions: Significant differences were seen in epilepsy care during transition from pediatric to adult management, and this had an impact on the degree of satisfaction reported by patients and caregivers. Our results provide evidence of the potential value of development and early implementation of a protocolled transition program.

4. DELPHI CONSENSUS ON THE TRANSITION FROM PAEDIATRIC TO ADULT EPILEPSY CARE.

Toledo, M. *et al.*

Neurology Perspectives 4, (2024) doi:[10.1016/j.neurop.2024.100155](https://doi.org/10.1016/j.neurop.2024.100155)

Introduction: The transition from paediatric to adult neurology consultations in patients with epilepsy must be understood as a process in which the patient acquires independence in the management of their disease and faces new issues related to adulthood. The aim of this study is to gather the opinion of experts in epilepsy on this transition in order to issue recommendations. Methods: Using a Delphi consensus process, 54 paediatric and adult neurologists with expertise in epilepsy expressed their degree of agreement on 38 statements on about the transition from paediatric to adult consultations, grouped into the following sections: (1) preparation and moments prior to transition; (2) transition process; and (3) moments after the transition and follow-up. Results: After 2 rounds, consensus was reached for 33 statements (86.8%). For the remaining 5 statements (13.2%), there was neither agreement nor disagreement. Among the subjects for which consensus was strongest was the involvement of the patient and family, who must be provided sufficient information to resolve their doubts and concerns. Before referral, the clinical report must be reviewed to ensure that it contains all relevant information on the disease. During the first follow-up visits after the transition, the patient's knowledge should be brought up to date in order to promote their autonomy. Conclusion: The clinical report, early preparation, and complete case review are considered fundamental in the process of transition from paediatric to adult neurology care.

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DIABETE

1. AN ASSESSMENT OF ADAPTATION AND FIDELITY IN THE IMPLEMENTATION OF AN AUDIT AND FEEDBACK-BASED INTERVENTION TO IMPROVE TRANSITION TO ADULT TYPE 1 DIABETES CARE IN ONTARIO, CANADA.

Ahmad, S. Z. *et al.*

Implementation science communications 5, 25 (2024) doi:[10.1186/s43058-024-00563-2](https://doi.org/10.1186/s43058-024-00563-2)

BACKGROUND: The fit between an intervention and its local context may affect its implementation and effectiveness. Researchers have stated that both fidelity (the degree to which an intervention is delivered, enacted, and received as intended) and adaptation to the local context are necessary for high-quality implementation. This study describes the implementation of an audit and feedback (AF)-based intervention to improve transition to type 1 diabetes adult care, at five sites, in terms of adaptation and fidelity.

METHODS: An audit and feedback (AF)-based intervention for healthcare teams to improve transition to adult care for patients with type 1 diabetes was studied at five pediatric sites. The Framework for Reporting Adaptations and Modifications to Evidence-based Implementation Strategies (FRAME-IS) was used to document the adaptations made during the study. Fidelity was determined on three different levels: delivery, enactment, and receipt. **RESULTS:** Fidelity of delivery, receipt, and enactment were preserved during the implementation of the intervention. Of the five sites, three changed their chosen quality improvement initiative, however, within the parameters of the study protocol; therefore, fidelity was preserved while still enabling participants to adapt accordingly. **CONCLUSIONS:** We describe implementing a multi-center AF-based intervention across five sites in Ontario to improve the transition from pediatric to adult diabetes care for youth with type 1 diabetes. This intervention adopted a balanced approach considering both adaptation and fidelity to foster a community of practice to facilitate implementing quality improvement initiatives for improving transition to adult diabetes care. This approach may be adapted for improving transition care for youth with other chronic conditions and to other complex AF-based interventions. **TRIAL REGISTRATION:** ClinicalTrials.gov NCT03781973. Registered 13 December 2018. Date of enrolment of the first participant to the trial: June 1, 2019.

2. **ASSESSING THE READINESS TO TRANSITION TO ADULT CARE, PERCEIVED MEDICATION BARRIERS, AND GLYCEMIC CONTROL AMONG TEENS WITH TYPE 1 DIABETES.**

Alhamed, A.

Applied nursing research : ANR 75, 151772 (2024) doi:[10.1016/j.apnr.2024.151772](https://doi.org/10.1016/j.apnr.2024.151772)

AIM: This study assessed the readiness to transition (RT) from pediatric to adult care, perceived medication barriers (PMB), and glycemic control in teens with type one diabetes (T1D). **BACKGROUND:** During the transition from pediatric to adult care, teens with T1D are at risk of long-term complications related to impaired adherence. With the increasing prevalence of T1D in Saudi Arabia, research is required to identify the challenges facing teens with T1D during their transition. **METHODS:** This was a cross-sectional study with a convenient sample of 83 adolescents (12-17 years old) diagnosed with T1D for ≥ 6 months, their parents, and their pediatric endocrinologists from the pediatric endocrinology clinic in a tertiary hospital in Riyadh. The RT Questionnaire was used to measure RT, and the Medication Barriers Scale was used to measure PMB. Glycemic control was measured using hemoglobin A1c (HbA1c). **RESULTS:** About 96 % of teens had HbA1c > 7 %. Male teens had higher HbA1c than female teens. Teens and their parents reported high PMB and low RT. PMB (teens), disease duration, family history of diabetes mellitus, and comorbidity were significant predictors of RT (parents). PMB (teens), teens' age, and having a family history of diabetes mellitus were significant predictors of RT (providers). RT (parents) and RT (providers) were the only significant predictors of HbA1c, with RT (providers) being the strongest predictors of HbA1c. **CONCLUSIONS:** Health policy reform is required to develop national RT programs to prepare teens with T1D to take full responsibility for managing their medical conditions while ensuring adherence.

3. **EMERGING ADULTS WITH TYPE 2 DIABETES: UNDERSTANDING ILLNESS EXPERIENCE AND TRANSITION TO ADULT CARE.**

Edmondson, E. K. *et al.*

The Journal of adolescent health : official publication of the Society for Adolescent Medicine 75, 107–114 (2024) doi:[10.1016/j.jadohealth.2024.02.021](https://doi.org/10.1016/j.jadohealth.2024.02.021)

PURPOSE: Youth-onset type 2 diabetes (T2D) is increasingly common and is often diagnosed shortly before transition from pediatric to adult care. Little is known about the experience of emerging adults (EAs) with T2D and the readiness, barriers, and facilitators to transition. This study sought to describe the illness experience of EAs with T2D and perceptions about transition, and explore themes by 'transition readiness,' measured by the Transition Readiness Assessment Questionnaire (TRAQ). **METHODS:** In this mixed-methods study, we conducted semi-structured interviews with EAs with T2D using a guide grounded in the health belief model, administered the TRAQ, and collected disease metrics from the electronic medical record. We developed a coding scheme using a directed content-analysis approach and triangulated qualitative and quantitative data to compare themes stratified by mean TRAQ score. **RESULTS:** Participants described modifying factors like adjusting to life with a chronic illness and coping with mental health issues as critical elements of the illness experience that influence transition. Individual beliefs emerged including the perceived risk of disease complications being informed by experience of family members, self-efficacy in diabetes care hinging on the ability to be highly organized, and transition as a daunting obstacle with numerous emotional and logistical

barriers. Participants emphasized the need for support from caregivers and providers throughout transition. Themes did not vary significantly by TRAQ score. DISCUSSION: Experiences of EAs with T2D suggest more assistance is needed in the transition period to address factors such as mental health, organizational skills, and identifying support people to facilitate care.

4. FROM PEDIATRIC TO ADULT CARE: A SURVEY ON THE TRANSITION PROCESS IN TYPE 1 DIABETES MELLITUS AND THE DIABETES SERVICES IN ITALY.

Graziani, V., Suprani, T., Di Bartolo, P. & Marchetti, F.

Acta Diabetologica (2024) doi:[10.1007/s00592-024-02268-3](https://doi.org/10.1007/s00592-024-02268-3)

Aims: The present study assessed the transitioning process of young adults with type 1 diabetes mellitus (T1D) in Italy. **Materials and methods:** We asked Pediatric Diabetes Centers (PDC) and Adult Diabetes Centers (CAD) to fill in a web-based survey on the current state of services, the number of transitioning adolescents with T1D within the last year, observations on limitations, and future directions. **Results:** 93 centers (46 PDCs, 47 CADs) joined the study. The total number of subjects with T1D being followed by a PDC was 16,261 (13,779 minors and 2483 young adults), while CADs had 25,500 patients. The survey showed an uneven situation. Only some services had a dedicated diabetes team (78% of PDCs, 64% of CADs). 72% of PDCs and 58% of CADs reported a protocol dedicated to transition. The median age for transition was 19 (range 16–25 years); the time required for preparing transition, indicated by both PDCs and CADs, was 5.5 months. A high percentage of CADs (80%) confirmed receiving sufficient clinical information, mainly through paper or computerized reports. The transition process is hampered by a lack of resources, logistical facilities, and communication between services. While some services have a protocol, monitoring of results is only carried out in a few cases. Most specialists expressed the need to enhance integration and continuity of treatment. **Conclusions:** The current situation could be improved. Applying standard guidelines, taking into consideration both clinicians' and patients' necessities, would lead to a more successful transition process.

5. PSYCHOLOGICAL SEPARATION, HEALTH LOCUS OF CONTROL, AND TRANSITION READINESS IN ADOLESCENTS AND YOUNG ADULTS WITH TYPE I DIABETES.

Kang, N. & Lee, S.

Journal of pediatric nursing 76, 38–44 (2024) doi:[10.1016/j.pedn.2024.01.033](https://doi.org/10.1016/j.pedn.2024.01.033)

PURPOSE: The purpose of this study was to examine the effects of psychological separation and health locus of control on the health care transition readiness of adolescents and young adults (AYAs) with type 1 diabetes. **METHODS:** Data were collected between December 2020 and October 2021. One hundred twelve AYAs with type 1 diabetes treated at a tertiary hospital and under follow-up observation as well as AYAs with type 1 diabetes nationwide who were part of the type 1 diabetes internet community were enrolled. The Psychological Separation Inventory, the Multidimensional Health Locus of Control scale from C, and the Self-management and Transition to Adulthood with Therapeutics = Rx Questionnaire were used. **RESULTS:** Multiple regression analysis indicated that age ($\beta = 0.302$, $p = .001$), hemoglobin A1c (HbA1c) ($\beta = -0.174$, $p = .040$), conflictual separation ($\beta = 0.242$, $p = .005$), functional separation ($\beta = 0.200$, $p = .045$) and attitudinal separation ($\beta = -0.240$, $p = .015$) were significantly associated with health management transition readiness; these predictors explained 27.6% of health care transition readiness ($F = 8.062$, $p = .000$). **CONCLUSIONS:** AYAs with type 1 diabetes can enhance readiness for health care transition by fostering psychological separation from parents, effectively managing blood glucose levels, and taking into account age-related factors during the preparation process. At this point, it is essential for healthcare professionals to guide parents in recognizing adolescents' psychological independence and facilitating their supportive role through the process of redefining their roles. **PRACTICE IMPLICATIONS:** Health care providers should promote psychological separation in AYAs. Additionally, taking into account the developmental characteristics of adolescence can facilitate a successful health care transition.

6. TRANSITION COMPETENCE AS AN INDICATOR OF HEALTH OUTCOMES RELATED TO TRANSITION.

Markwart, H., Schmidt, S., Thyen, U., Ernst, G. & Muehlan, H.

Child: care, health and development 50, e13142 (2024) doi:[10.1111/cch.13142](https://doi.org/10.1111/cch.13142)

BACKGROUND: Adolescents and young adults (AYAs) with chronic conditions face a transfer, defined as an actual shift from paediatric to adult-oriented health care. Transition competence as the self-perceived

knowledge, skills and abilities regarding the transition process was considered extremely useful. AIM: This study was designed to investigate the impact of transition competence before and after the transfer on disease-specific quality of life (QoL) and health care satisfaction of AYAs with diabetes. RESULTS: In total, a sample of N = 90 AYAs with diabetes self-reported their transition competence, diabetes-specific QoL and satisfaction with care. Multiple linear regressions were used to analyse the impact of transition competence on satisfaction with care and QoL. Transition competence positively influenced the outcomes of satisfaction with care and QoL. CONCLUSION: Young adults with diabetes showed higher transition competence scores than adolescents with diabetes.

7. SERVICE USE AND GLYCAEMIC CONTROL OF YOUNG PEOPLE WITH TYPE 1 DIABETES TRANSITIONING FROM PAEDIATRIC TO ADULT CARE: A 5-YEAR STUDY.

Perry, L. *et al.*

Internal Medicine Journal (2024) doi:[10.1111/imj.16387](https://doi.org/10.1111/imj.16387)

Background: Regular contact with specialist care has been linked to better diabetes outcomes for young people with type 1 diabetes (YPwT1D), but evidence is limited to population-based service usage and outcomes. Aims: This observational 5-year study sought to capture YPwT1D living in the study catchment area (covering metropolitan, regional and rural Australia) as they transitioned to adult-based diabetes healthcare services and to describe their glycaemic control and complication rates, service usage and associated factors. Methods: Records between 2010 and 2014 in a public healthcare specialist diabetes database were extracted, care processes and outcomes were described, and associations were sought between episodes of care (EOC) and potentially predictive variables. Results: Annual cohort numbers increased yearly, but without significant differences in demographic characteristics. Each year around 40% had no reported planned specialist care, and the average number of planned EOC decreased significantly year on year. Overall, mean HbA1c levels also reduced significantly, but with higher values recorded for those living in non-metropolitan than metropolitan areas (achieving significance in 3 out of 5 years). Diabetes complication assessments were only reported in 37–46%, indicating one in five with retinopathy and hypertension affecting one in three to five young people. Conclusions: Findings highlight the importance of investment to address the specific needs of adolescents and young adults and demonstrate the need for better support during these vulnerable early years, particularly for non-metropolitan residents. This will entail changes to funding mechanisms, the health workforce and infrastructure, and new models of care to provide equity of access and quality of specialist care.

8. PREFERENCES FOR HEALTH CARE PROFESSIONAL INTERACTIONS AMONG ADOLESCENTS AND YOUNG ADULTS WITH TYPE 1 DIABETES.

Wang, C. H., Bryant, B. L., Cogen, F. R., Marks, B. E. & Monaghan, M.

Clinical Pediatrics 63, 620–624 (2024) doi:[10.1177/00099228231189649](https://doi.org/10.1177/00099228231189649)

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ADHD

1. PERSPECTIVES ON PARENTAL SUPPORT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER SELF-MANAGEMENT AT THE TRANSITION TO ADULTHOOD.

Bui, H. N. T., Marsh, N. P. & Chronis-Tuscano, A.

Nature Mental Health 2, 489–495 (2024) doi:[10.1038/s44220-024-00234-0](https://doi.org/10.1038/s44220-024-00234-0)

2. HEALTH AND WELL-BEING AT THE TRANSITION TO ADULTHOOD AMONG INDIVIDUALS WITH DISABILITIES: AN ANALYSIS OF THE PANEL STUDY OF INCOME DYNAMICS.

Hotez, E. *et al.*

Journal of Adolescent Health 74, 964–970 (2024) doi:[10.1016/j.jadohealth.2023.12.011](https://doi.org/10.1016/j.jadohealth.2023.12.011)

3. **“A BIT LOST”—LIVING WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER IN THE TRANSITION BETWEEN ADOLESCENCE AND ADULTHOOD: AN EXPLORATORY QUALITATIVE STUDY.**

Rasmussen, I. L., Schei, J. & Ørjasæter, K. B.

BMC Psychology 12, 20 (2024) doi:[10.1186/s40359-024-01522-1](https://doi.org/10.1186/s40359-024-01522-1)

Abstract Background Attention deficit hyperactivity disorder (ADHD) begins in childhood and in many cases persists into adulthood. The transition from adolescence to adulthood for young people with ADHD is a vulnerable time and can be associated with comorbid conditions and unfavorable outcomes. Thus, further studies are needed to explore the characteristics of the transition period in emerging adulthood. The overall aim of this study was to gain increased knowledge of emerging adults' experience of living with ADHD in the transition from adolescence to adulthood. This is a follow-up from a previous qualitative study that examined how young people experience receiving and living with a diagnosis of ADHD. **Method** The study has a qualitative retrospective design. Seven participants were included in this study using a purposive sampling method. We re-invited the same participants who were interviewed in 2015–2016 and conducted in-depth interviews. The data were subjected to Malterud's systematic text condensation (STC). **Results** Four crosscutting themes were identified from our analysis: (1) low level of knowledge about ADHD and treatment options; (2) barriers to seeking and accessing help; (3) developing self-help strategies; and (4) a preference to discontinued medication use. **Conclusion** The participants emphasized a need for more information about ADHD in transition phases and support, both from professionals and peers, about finding ways to live meaningful lives. The treatment they had been offered was particularly linked to symptom reduction and medication use. A more appropriate focus would have been linked to how they, as citizens, could gain knowledge and skills to live meaningful lives with ADHD.

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Il Progetto è realizzato con il contributo, del Ministero della Salute, Direzione
Generale della Ricerca Sanitaria e Biomedica e della Vigilanza sugli Enti
nell'ambito del Bando Ricerca Finalizzata 2019 esercizio finanziario anni 2018-
2019

