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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. **A COMMENTARY ON THE HEALTHCARE TRANSITION POLICY LANDSCAPE FOR YOUTH WITH DISABILITIES OR CHRONIC HEALTH CONDITIONS, THE NEED FOR AN INCLUSIVE AND EQUITABLE APPROACH, AND RECOMMENDATIONS FOR CHANGE IN CANADA.**

Nguyen, L. *et al.*

Frontiers in rehabilitation sciences 4, 1305084 (2023) doi:[10.3389/freesc.2023.1305084](https://doi.org/10.3389/freesc.2023.1305084)

There is a growing number of youth with healthcare needs such as disabilities or chronic health conditions who require lifelong care. In Canada, transfer to the adult healthcare system typically occurs at age 18 and is set by policy regardless of whether youth and their families are ready. When the transition to adult services is suboptimal, youth may experience detrimental gaps in healthcare resulting in increased visits to the emergency department and poor healthcare outcomes. Despite the critical need to support youth with disabilities and their families to transition to the adult healthcare system, there is limited legislation to ensure a successful transfer or to mandate transition preparation in Canada. This advocacy and policy planning work was conducted in partnership with the Patient and Family Advisory Council (PFAC) within the CHILD-BRIGHT READYorNot™ Brain-Based Disabilities (BBD) Project and the CHILD-BRIGHT Policy Hub. Together, we identified the need to synthesize and better understand existing policies about transition from pediatric to adult healthcare, and to recommend solutions to improve healthcare access and equity as Canadian youth with disabilities become adults. In this perspective paper, we will report on a dialogue with key informants and make recommendations for change in healthcare transition policies at the healthcare/community, provincial and/or territorial, and/or national levels.

2. **A WEB-BASED PEER-PATIENT NAVIGATION PROGRAM (COMPASSIONATE ONLINE NAVIGATION TO ENHANCE CARE TRANSITIONS) FOR YOUTH LIVING WITH CHILDHOOD-ACQUIRED DISABILITIES TRANSITIONING FROM PEDIATRIC TO ADULT CARE: QUALITATIVE DESCRIPTIVE STUDY.**

Kokorelias, K. M. *et al.*

JMIR pediatrics and parenting 7, e47545 (2024) doi:[10.2196/47545](https://doi.org/10.2196/47545)

BACKGROUND: Studies have highlighted significant challenges associated with the transition from pediatric to adult health and social care services for youth living with childhood-acquired disabilities and their caregivers. Patient navigation has been proposed as an effective transitional care intervention. Better understanding of how patient navigation may support youth and their families during pediatric to adult care transitions is warranted. **OBJECTIVE:** This study aims to describe the preferred adaptations of an existing web-based platform from the perspectives of youth with childhood-onset disabilities and their family caregivers to develop a web-based peer-patient navigation program, Compassionate Online Navigation to Enhance Care Transitions (CONNECT). **METHODS:** A qualitative descriptive design was used. Participants included youth living with childhood-acquired disabilities (16/23, 70%) and their caregivers (7/23, 30%). Semistructured interviews and focus groups were conducted, digitally recorded, and transcribed. Thematic analysis was used to analyze the data and was facilitated through NVivo software (Lumivero). **RESULTS:** Participants desired a program that incorporated (1) self-directed learning, (2) a library of reliable health and community resources, and (3) emotional and social supports. On the basis of participants' feedback, CONNECT was deemed satisfactory, as it was believed that the program would help support appropriate transition care through the provision of trusted health-related information. Participants highlighted the need

for options to optimize confidentiality in their health and social care and the choice to remain anonymous to other participants. **CONCLUSIONS:** Web-based patient navigation programs such as CONNECT may deliver peer support that can improve the quality and experience of care for youth, and their caregivers, transitioning from pediatric to adult care through personalized support, health care monitoring, and health and social care resources. Future studies are needed to test the feasibility, acceptability, usability, use, and effectiveness of CONNECT among youth with childhood-onset disabilities.

3. **BEHAVIORAL HEALTH STRATIFIED TREATMENT (B.E.S.T.) TO OPTIMIZE TRANSITION TO ADULTHOOD FOR YOUTH WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES.**

Berg, K. L. *et al.*

Contemporary Clinical Trials 136, (2024) doi:[10.1016/j.cct.2023.107374](https://doi.org/10.1016/j.cct.2023.107374)

Youth with intellectual and/or developmental disabilities (IDD) often struggle with depression and anxiety, which adversely impacts transition to adulthood. Integrated behavioral health care coordination, wherein care coordinators and behavioral health specialists collaborate to provide systematic, cost-effective, patient-centered care, is a promising strategy to improve access to behavioral health services and address factors that impact transition to adulthood, including depression/anxiety symptoms. Current care coordination models (e.g., Title V Maternal and Child Health Bureau [MCHB]) do not include behavioral health services. The CHECK (Coordinated HealthCarE for Complex Kids) mental health model, hereby refined and renamed BEhavioral Health Stratified Treatment (B.E.S.T.), is a behavioral health intervention delivery program designed for integration into care coordination programs. This study aims to determine whether an integrated behavioral health care coordination strategy (i.e., MCHB care coordination plus B.E.S.T.) would be more acceptable and lead to better youth health and transition outcomes, relative to standard care coordination (i.e., MCHB care coordination alone). Results would guide future investment in improving outcomes for youth with IDD. This study is a two-arm randomized clinical trial of 780 transition-aged youth with IDD (13–20 years) to evaluate the comparable efficacy of MCHB Care Coordination alone vs. MCHB Care Coordination plus B.E.S.T. on the following outcomes: 1) decreased symptoms and episodes of depression and anxiety over time; 2) improved health behaviors, adaptive functioning and health related quality of life; 3) increased health care transition (HCT) readiness; and 4) improved engagement and satisfaction with care coordination among stakeholders.

4. **CLINICS DEDICATED TO TRANSITION PREPARATION FOR ADOLESCENTS AND YOUNG ADULTS WITH CHRONIC CONDITIONS: FACTORS INFLUENCING THEIR USE.**

Le Roux, E. *et al.*

Archives de Pediatrie 30, 617–619 (2023) doi:[10.1016/j.arcped.2023.08.004](https://doi.org/10.1016/j.arcped.2023.08.004)

To pool resources and reduce inequalities in access to transition preparation for patients, transition clinics were created in France. They are places in hospitals, independent of the usual care departments, offering multiple resources and services for adolescents and their parents. Of the 24 physicians from care departments who were surveyed, half of them do not use transition clinics. The implementation of transition clinics in hospitals did not lead to their adoption by the care departments that needed the most support for transition preparation of their patients. A strategy improving adoption is needed to allow transition clinics to reduce inequalities.

5. **EVALUATING THE IMPLEMENTATION OF A PERSON-CENTRED TRANSITION PROGRAMME FOR ADOLESCENTS AND YOUNG ADULTS WITH LONG-TERM CONDITIONS: THE ROLE OF CONTEXT AND ORGANISATIONAL BEHAVIOUR.**

Feather, J., Kaehne, A. & Kiernan, J.

Journal of health organization and management ahead-of-print, (2023) doi:[10.1108/JHOM-03-2023-0095](https://doi.org/10.1108/JHOM-03-2023-0095)

PURPOSE: Drawing on the experiences of healthcare professionals in one paediatric hospital, this paper explores the influence of context and organisational behaviour on the implementation of a person-centred transition programme for adolescents and young adults (AYA) with long-term conditions. **DESIGN/METHODOLOGY/APPROACH:** A single embedded qualitative case study design informed by a realist evaluation framework, was used. Participants who had experience of implementing the transition

programme were recruited from across seven individual services within the healthcare organisation. The data were gathered through semi-structured interviews (n = 20) and analysed using thematic analysis. FINDINGS: Implementation of the transition programme was influenced by the complex interaction of macro, meso and micro processes and contexts. Features of organisational behaviour including routines and habits, culture, organisational readiness for change and professional relationships shaped professional decision-making around programme implementation. ORIGINALITY/VALUE: There exists a significant body of research relating to the role of context and its influence on the successful implementation of complex healthcare interventions. However, within the area of healthcare transition there is little published evidence on the role that organisational behaviour and contextual factors play in influencing transition programme implementation. This paper provides an in-depth understanding of how organisational behaviour and contextual factors affect transition programme implementation.

6. **FACT-FINDING SURVEY OF DOCTORS AT THE DEPARTMENTS OF PEDIATRICS AND PEDIATRIC SURGERY ON THE TRANSITION OF PATIENTS WITH CHILDHOOD-ONSET CHRONIC DISEASE FROM PEDIATRIC TO ADULT HEALTHCARE.**

Kikuchi, R. *et al.*

PloS one 18, e0289927 (2023) doi:[10.1371/journal.pone.0289927](https://doi.org/10.1371/journal.pone.0289927)

BACKGROUND: The number of adult patients with childhood-onset chronic diseases is increasing. However, the process of transitioning these patients from child- to adult-centered medical services faces many difficulties. Despite the key role that doctors in the pediatric field are considered to play in transition, few fact-finding surveys about transition have been conducted among these doctors. OBJECTIVE: The aim of this study was to demonstrate the current status and challenges in the transition of patients with childhood-onset chronic diseases by a fact-finding survey of pediatricians and pediatric surgeons at a university hospital. METHODS: A cross-sectional survey was performed using an anonymous self-administered questionnaire. Seventy-six doctors of pediatrics and pediatric surgery (excluding junior residents) in a university hospital were asked to answer an anonymous self-report questionnaire. A multidisciplinary research team selected items related to the transitional process. RESULTS: Sixty (79%) doctors participated, of whom 52 (87%) showed awareness of transition. No doctor answered that 'Transition is conducted smoothly.' Doctors with shorter pediatric department experience had lower awareness and poorer experience with transition. In contrast to pediatric surgeons, pediatricians explained 'job-seeking activities' and 'contraceptive methods' to the patient, and reported a higher patient age at which to initiate explanation of transition to the patient and his/her family. Among factors inhibiting transition, 39 (65%) respondents selected 'The patient's family members do not desire transition' and 34 (57%) selected 'Although a relevant adult healthcare department is available, it will not accept the patient.' The medical providers most frequently considered to have responsibility for playing a central role in the transition process were 'pediatrician/pediatric surgeon,' 'medical social worker,' and 'regional medical liaison office.' DISCUSSION: To promote transition, pediatric and adult healthcare departments should share concerns about and cooperate in the establishment of more effective methods of transition, and provide multidisciplinary collaboration to support patients and their families.

7. **GROWING UP CAN BE HARD TO DO: REIMAGINING 1 STRUCTURALLY SUPPORTIVE PEDIATRIC-TO-ADULT TRANSITIONS OF CARE FROM A RIGHTS-BASED PERSPECTIVE.**

Munyikwa, M., Hammond, C. K., Langmaid, L. & Ratner, L.

Health and human rights 25, 51–65 (2023)

Extended life expectancies and shifting dynamics in chronic disease have changed the landscape of public health interventions worldwide, with an increasing emphasis on chronic care. As a result, transition from pediatric to adult care for medically complex adolescents and young adults is a growing area of intervention. Transition medicine is a nascent field whose current emphasis is on middle- and high-income countries, and thus far its methods and discourse have reflected those origins. Through several case-based examples, this paper aims to highlight the possibilities of an analytic approach grounded in structural competency for transforming transition medicine through a human rights-based framework, with an emphasis on imagining a more global framework for transition medicine. Our cases highlight the disparities between patients navigating pediatric to adult-based care, illuminating social stigma, stratification between public and private insurances, engagement in risk-taking behaviors, family conflict, and challenges with transition readiness. To

reimagine transition medicine so that it is based on human rights, we must prioritize structural solutions that embrace multisectoral integration and holistic mental health support rather than oppress and marginalize these critical systemic adaptations. We aim to reconfigure this scaffolding to center structures that integrate holistic well-being and imagine alternate realities to healing. Our work contributes to the literature bringing structural competency to new spaces of clinical practice, contextualizing new frontiers for the exploration of chronic diseases across diverse clinical contexts worldwide.

8. **HEALTH CARE TRANSITION PLANNING FOR ADOLESCENTS AND EMERGING ADULTS WITH INTELLECTUAL DISABILITIES AND DEVELOPMENTAL DISABILITIES: DISTINCTIONS AND CHALLENGES.**

Betz, C. L.

Journal for specialists in pediatric nursing : JSPN 28, e12415 (2023) doi:[10.1111/jspn.12415](https://doi.org/10.1111/jspn.12415)

PURPOSE: The purpose of this article is to provide the reader with insight and enhanced understanding of the health care transition planning process for adolescents and emerging adults with intellectual disabilities and developmental disabilities. There are distinctly different programmatic considerations that need to be addressed in advancing their transfer of care to adult providers and promoting their transition to adulthood. These differences are due in part to the federal and state legislative initiatives that were established in the education, rehabilitation, employment, and developmental disabilities service systems. In contrast, no comparable federal and state mandates exist in the system of health care. The legislative mandates in education, rehabilitation, and employment are presented and discussed as well as the federal legislation on rights and protections for individuals with intellectual disabilities and developmental disabilities. Consequently, health care transition (HCT) planning involves application of a framework of care that is characteristically different than the planning efforts undertaken for adolescents and emerging adults (AEA) with special health care needs (SHCN)/disabilities and for typically developing AEA. The best practice HCT recommendations are discussed in the context of this intellectual disabilities and developmental disabilities framework of care. **CONCLUSIONS:** Health care transition planning for adolescents and emerging adults with intellectual disabilities and developmental disabilities involves additional and distinctly clinical and programmatic models of care. **PRACTICE IMPLICATIONS:** Health care transition planning guidance for adolescents and emerging adults with intellectual disabilities and developmental disabilities are provided based upon best practice recommendations.

9. **HEALTH CARE TRANSITION: THE STRUGGLE TO DEFINE ITSELF.**

Betz, C. L., Coyne, I. & Hudson, S. M.

Comprehensive child and adolescent nursing 46, 162–176 (2023) doi:[10.1080/24694193.2021.1933264](https://doi.org/10.1080/24694193.2021.1933264)

Health care transition is an expanding field of health care practice and research focused on facilitating adolescents and emerging adults with long-term conditions to transfer uninterruptedly from pediatric to adult health care services and to transition successfully into adulthood and beyond. There is a widespread need to develop and implement service models as approximately one million adolescents and emerging adults with long-term conditions transfer their care into the adult system and enter adulthood. The purpose of this article is to explore major issues associated with the current state of health care transition practice, research and ultimately policymaking and systems change. The prominent issues addressed in this article include the following. Defining clearly what constitutes models of health care transition practice as ambiguity exists with terminology used with concepts integral to health care transition. The indistinct meanings of health care transition terminology commonly used, such as transition, transfer, readiness, and preparation, need to be operationalized for widespread application. Furthermore, questions remain as to what goal-directed outcomes are expected within this field of practice and science.

10. **HEALTHCARE COSTS FOR YOUNG PEOPLE TRANSITIONING THE BOUNDARY BETWEEN CHILD/ADOLESCENT AND ADULT MENTAL HEALTH SERVICES IN SEVEN EUROPEAN COUNTRIES: RESULTS FROM THE MILESTONE STUDY.**

Canaway, A. *et al.*

BJPsych open 9, e175 (2023) doi:[10.1192/bjo.2023.559](https://doi.org/10.1192/bjo.2023.559)

BACKGROUND: The boundary between services for children and adolescents and adults has been identified as problematic for young people with mental health problems. **AIMS:** To examine the use and cost of healthcare for young people engaged in mental healthcare before and after the child/adolescent and adult service boundary. **METHOD:** Data from 772 young people in seven European countries participating in the MILESTONE trial were analysed. We analysed and costed healthcare resources used in the 6-month period before and after the service boundary. **RESULTS:** The proportion of young people engaging with healthcare services fell substantially after crossing the service boundary (associated costs €7761 pre-boundary v. €3376 post-boundary). Pre-boundary, the main cost driver was in-patient care (approximately 50%), whereas post-boundary costs were more evenly spread between services; cost reductions were correlated with pre-boundary in-patient care. Severity was associated with substantially higher costs pre- and post-boundary, and those who were engaged specifically with mental health services after the service boundary accrued the greatest healthcare costs post-service boundary. **CONCLUSIONS:** Costs of healthcare are large in this population, but fall considerably after transition, particularly for those who were most severely ill. In part, this is likely to reflect improvement in the mental health of young people. However, qualitative evidence from the MILESTONE study suggests that lack of capacity in adult services and young people's disengagement with formal mental health services post-transition are contributing factors. Long-term data are needed to assess the adverse long-term effects on costs and health of this unmet need and disengagement.

11. **'I CAN'T POSE A WHOLE HEAP OF QUESTIONS THAT I KNOW I DON'T HAVE TIME TO FOLLOW UP'- EXPLORING PERCEPTIONS OF AN ADOLESCENT TRANSITION PROGRAM.**

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

PloS one 18, e0293947 (2023) doi:[10.1371/journal.pone.0293947](https://doi.org/10.1371/journal.pone.0293947)

BACKGROUND: Adolescent transition programs are patient education programs. They are geared towards enabling adolescents with chronic or long-term illnesses to become active partners in their health care and manage their own health. Although there is agreement about their importance, there is not an agreement on content or how they should be delivered. The study reported here was part of the first steps of an action research project. **AIM:** Our aim was to explore how health professionals understand the program at our hospital, and their opinions of its implementation. This would advance our knowledge of the practice of the program to support its development. **METHODS:** We conducted semi-structured individual interviews with 18 physicians and nurses. Data were analysed using qualitative content analysis. In our discussion of the generated data, we use the theory of practice architectures as a lens. **RESULTS AND DISCUSSION:** We generated four themes through the analysis, namely 'We are (back) at scratch', 'Time is always an issue', 'Getting them ready for what is to come-transition as a synonym to transfer' and 'Raising topics that go beyond medical issues'. Changes to a practice requires changes to the practice architectures. Practice architectures can both enable and constrain a practice. Our analysis suggests a need for a more unified perception of the program goals, the cultural-discursive arrangements. Health professionals see time as a significant barrier to implementation and changes to the material-economic arrangements are particularly called for, i.e., more time, space and staff to practice the program. These also tie into the social-political arrangements of the program. **CONCLUSION:** There are arrangements in the practice architecture that currently seem to constrain the practice of the program. The practice is currently fragmented both within and across subspecialties. Efforts should be made to establish a more shared understanding of the program among health professionals. Furthermore, we should investigate how the practice of the program can be better supported.

12. **IMPLEMENTATION OF PROGRAMMES FOR THE TRANSITION OF ADOLESCENTS TO ADULT CARE.**

Moreno-Galdó, A. *et al.*

Anales de pediatria 99, 422–430 (2023) doi:[10.1016/j.anpede.2023.09.014](https://doi.org/10.1016/j.anpede.2023.09.014)

Up to 15-20% of adolescents have a chronic health problem. Adolescence is a period of particular risk for the development or progression of chronic diseases for both individuals with more prevalent conditions and those affected by rare diseases. The transition from paediatric to adult care begins with preparing and training the paediatric patient, accustomed to supervised care, to assume responsibility for their self-care in an adult care setting. The transition takes place when the young person is transferred to adult care and discharged from paediatric care services. It is only complete when the youth is integrated and functioning competently within

the adult care system. Adult care providers play a crucial role in welcoming and integrating young adults. A care transition programme can involve transitions of varying complexity, ranging from those required for common and known diseases such as asthma, whose management is more straightforward, to rare complex disorders requiring highly specialized personnel. The transition requires teamwork with the participation of numerous professionals: paediatricians and adult care physicians, nurses, clinical psychologists, health social workers, the pharmacy team and administrative staff. It is essential to involve adolescents in decision-making and for parents to let them take over gradually. A well-structured transition programme can improve health outcomes, patient experience, the use of health care resources and health care costs.

13. **JUST TRAC IT! TRANSITIONING RESPONSIBLY TO ADULT CARE USING SMART PHONE TECHNOLOGY.**

Han, A. *et al.*

The Journal of adolescent health : official publication of the Society for Adolescent Medicine 73, 561–566 (2023) doi:[10.1016/j.jadohealth.2023.04.023](https://doi.org/10.1016/j.jadohealth.2023.04.023)

PURPOSE: There is little evidence on whether smartphone technology influences transition readiness among adolescents with heart disease. Just TRAC it! is a method of using existing smartphone features (Notes, Calendar, Contacts, Camera) to manage personal health. We evaluated the impact of Just TRAC it! on self-management skills. **METHODS:** Randomized clinical trial of 16-18 year-olds with heart disease. Participants were randomly allocated 1:1 to either usual care (education session) or intervention (education session including Just TRAC it!). The primary outcome was change in TRANSITION-Q score between baseline, 3 and 6 months. Secondary outcomes were frequency of use and perceived usefulness of Just TRAC it! Analysis was intention-to-treat. **RESULTS:** We enrolled 68 patients (41% female, mean age 17.3 years), 68% having previous cardiac surgery and 26% had cardiac catheterization. TRANSITION-Q scores were similar at baseline and increased over time in both groups but were not significantly different between groups. Each additional point at the baseline score brought, on average, a 0.7-point increase in TRANSITION-Q score (95% CI 0.5-0.9) at each of 3 and 6 months. The Camera, Calendar and Notes apps were reported as most useful. All intervention participants would recommend Just TRAC it! to others. **DISCUSSION:** A nurse-led transition teaching with versus without Just TRAC it! improved transition readiness, with no significant difference between groups. Higher baseline TRANSITION-Q scores were associated with greater increase in scores over time. Participants had a positive reception to Just TRAC it! and would recommend it to others. Smartphone technology may be useful in transition education.

14. **MULTIDISCIPLINARY COLLABORATION FOR TRANSITION READINESS AND PLANNING.**

Williams, K., Alba, J., Greenland, D., Gallegos, S. & Attel, S.

Journal of Cystic Fibrosis 22, S212 (2023) doi:[10.1016/S1569-1993\(23\)01336-X](https://doi.org/10.1016/S1569-1993(23)01336-X)

Background: There is an increasing need for health care transition programs in pediatric centers that promote readiness and optimize health and social outcomes throughout the lifespan [1]. Established transition guidelines emphasize transition readiness assessments, youth specific goals, medical education, psychosocial education, and preparing youth and families for legal aspects of transition [2]. The current quality improvement project is designed to improve our current transition process using a multidisciplinary care approach. The project emphasizes collaboration between medical providers, psychosocial providers, nurses, and parent and family partners to create a more systematic process for transition to adult care and improve transition readiness. We aimed to complete monthly planning meetings with the core pediatric transition team and continue quarterly meetings with our adult care partners. Improvement in transition readiness will be demonstrated by the number of teens completing the established transition planning elements and patient feedback surveys. **Methods:** In the fall of 2020, the clinic social workers, psychologist, nurse, and parent partner implemented monthly meetings to create and monitor transition planning interventions. Core transition team members provided updates and received feedback from additional pediatric and adult team members during quarterly joint pediatric and adult transition meetings. Interventions created and implemented through the workgroup included creation of a transition planning checklist (Figure 1), transition letter, transition journey map, implementation of a transition readiness assessment (TRAQ), creation of a one-to-one visit process, implementation of medical summaries, CF-specific education, education related to social issues (e.g., insurance, co-pay assistance), protected health information

education, and better patient feedback surveys. Results: 13 patients transitioned from our pediatric clinic to an adult clinic in 2022 and four in 2023. Nine transitions are planned by the end of 2023. 80% of transitioned patients felt ready to transition to an adult clinic at their last pediatric visit, and 20% felt somewhat ready. 92% of teens reported a successful transition once at the adult clinic. More data will follow. Conclusions: Using a multidisciplinary team approach to transition planning increases patient readiness and comfort with the transition to adult care. The feasibility of maintaining a comprehensive transition process is bolstered by collaboration and responsibility sharing among core team members. Teens expressed greater readiness and favorability to transition after participation in the program. Barriers to transition planning include missed patient visits, clinic workflow, additional team member responsibilities, and parent and patient willingness to engage in the transition process. Our next steps include transition-related interventions for younger patients to continue expanding transition education and readiness. [Figure presented]

15. **NAVIGATING LIMINAL SPACES TOGETHER: A QUALITATIVE METASYNTHESIS OF YOUTH AND PARENT EXPERIENCES OF HEALTHCARE TRANSITION.**

South, K., Deforge, C., Celona, C. A., Smaldone, A. & George, M.
Journal of Transition Medicine 5, (2023) doi:[10.1515/jtm-2022-0004](https://doi.org/10.1515/jtm-2022-0004)

Transition from pediatric to adult care for adolescents and young adults (AYAs) with chronic illness affects the entire family. However, little research has compared AYA and parent experiences of transition. Using Sandelowski and Barroso's method, the aim of this metasynthesis was to summarize findings of qualitative studies focusing on the transition experiences of AYAs and their parents across different chronic physical illnesses. PubMed, EMBASE and CINAHL were searched followed by forward and backward citation searching. Two authors completed a two-step screening process. Quality was appraised using Guba's criteria for qualitative rigor. Study characteristics and second order constructs were extracted by two authors and an iterative codebook guided coding and data synthesis. Of 1,644 records identified, 63 studies met inclusion criteria and reflect data from 1,106 AYAs and 397 parents across 18 diagnoses. Three themes were synthesized: transition is dynamic and experienced differently (differing perceptions of role change and growth during emerging adulthood), need for a supported and gradual transition (transition preparation and the factors which influence it) and liminal space (feeling stuck between pediatric and adult care). While AYAs and parents experience some aspects of transition differently, themes were similar across chronic illnesses which supports the development of disease agnostic transition preparation interventions. Transition preparation should support shifting family roles and responsibilities and offer interventions which align with AYA and family preferences.

16. **PARENTAL INVOLVEMENT IN THE TRANSITION FROM PAEDIATRIC TO ADULT CARE FOR YOUTH WITH CHRONIC ILLNESS: A SCOPING REVIEW OF THE NORTH AMERICAN LITERATURE.**

Badour, B., Bull, A., Gupta, A. A., Mirza, R. M. & Klinger, C. A.
International journal of pediatrics 2023, 9392040 (2023) doi:[10.1155/2023/9392040](https://doi.org/10.1155/2023/9392040)

With medical advancements and improvements in medical technology, an increasing number of children with chronic conditions survive into adulthood. There is accordant growing interest toward supporting adolescents throughout the transition from paediatric to adult care. However, there is currently a paucity of research focusing on the role that these patients' parents should play during and after the transition to adult care and if maintained parental involvement is beneficial during this transition within a North American context. Accordingly, this scoping review utilized Arksey and O'Malley's five-step framework to consider parental roles during chronically ill children's transition to adult care. APA PsycInfo, CINAHL, EMBASE, MEDLINE, ProQuest, and Scopus were searched alongside advanced Google searches. Thematic content analysis was conducted on 30 articles meeting the following inclusion criteria: (1) published in English between 2010 and 2022, (2) conducted in Canada or the United States, (3) considered adolescents with chronic conditions transitioning to adult care, (4) family being noted in the title or abstract, and (5) patient populations of study not being defined by delays in cognitive development, nor mental illness. Three themes emerged from the literature: the impacts of maintaining parental involvement during transition to adult care for patients, parents experiencing feeling loss of stability and support surrounding the transition of their child's care, and significant nonmedical life events occurring for youths at the time of transition of care. Parents assuming supportive roles which change alongside their maturing child's needs were reported as being beneficial to young

peoples' transition processes, while parents who hover over or micromanage their children during this time were found to hinder successful transitions. Ultimately, the majority of reviewed articles emphasized maintained parental involvement as having a net positive impact on adolescents' transitions to adult care. As such, practice and policies should be structured to engage parents throughout the transition process to best support their chronically ill children during this time of change.

17. **PARENTS' VIEWS ON AND NEED FOR AN INTERVENTION DURING THEIR CHRONICALLY ILL CHILD'S TRANSFER TO ADULT CARE.**

Thomsen, E. L., Hanghøj, S., Esbensen, B. A., Hansson, H. & Boisen, K. A.

Journal of child health care : for professionals working with children in the hospital and community 27, 680–692 (2023) doi:[10.1177/13674935221082421](https://doi.org/10.1177/13674935221082421)

Parents of chronically ill adolescents play a significant role during their child's transition and transfer to adult care. Parents seek help and support, but appropriate initiatives are still lacking. Thus, there is an urgent call for knowledge regarding parents' needs and views on such support. The aim of this study was to examine, in relation to parents of chronically ill adolescents: 1) views and experiences regarding their child's transfer from paediatric to adult care, and 2) which initiatives parents preferred in relation to the transfer. The study was based on the interpretive description method, and data were collected through face-to-face or telephone interviews with parents of chronically ill adolescents aged 16-19 (n = 11). We found three overall findings: 'Feeling acknowledged vs. feeling excluded', 'Perceived differences between paediatric and adult care' and 'Feeling safe vs. entering the unknown', together with three preferred initiatives: 1) Joint consultations, 2) Educational events and 3) Online support/website. In general, we found that some parents were extremely worried about the transfer, while others were not. Our results suggest that transfer initiatives targeting parents should focus on knowledge, expectations, relationships and goals in accordance with the social-ecological model of adolescent and young adult readiness to transition (SMART).

18. **PILOTING A TRANSITION OF CARE CURRICULUM AT TWO BI-COASTAL MEDICINE-PEDIATRICS RESIDENCY PROGRAMS.**

Kim, S., Mennito, S. & Wan, L.

Cureus 15, e46418 (2023) doi:[10.7759/cureus.46418](https://doi.org/10.7759/cureus.46418)

BACKGROUND: Lack of consistency in primary care residency training exists in transitions of care (TOC) of adolescents from pediatric to adult medicine, which can lead to conflicting or incomplete training. To fill this gap, we developed a curriculum based on the Got Transition Six Core Elements and piloted it at two bicoastal, academic Medicine-Pediatrics (Med-Peds) residency programs. **OBJECTIVES:** The goals of this project are to increase resident TOC knowledge, increase transition discussion comfort and skills, and obtain feedback for curriculum improvement. **METHODS:** Two educational sessions were held at both institutions between 2020-2021. Of 32 potential resident participants, 26 participated in session one and 22 participated in session two. Sessions included a didactic presentation, small group activities, and a guest speaker discussing transitional experience. Electronic pre-session, post-session, and retention surveys evaluated resident knowledge, comfort, and self-reported skills of TOC. A Hybrid Type II design was used with mixed methods to evaluate curriculum effectiveness and implementation. **RESULTS:** The first and second sessions had 81% and 68% attendance, respectively. Eighty-four percent completed the pre-session survey, 65% completed the post-session survey, and 68% completed the retention survey. TOC knowledge increased by 19% overall (p<0.001). First-year residents gained the most knowledge and implementation skills. Residents participating in alternating medicine and pediatric clinics gained more knowledge than those in a combined Med-Peds clinic (p=0.001). Comfort increased for both initiating and continuing TOC discussions after the first session. Knowledge retention was not statistically significant. **CONCLUSION:** A standardized TOC curriculum can improve resident knowledge and is easily implemented at multiple institutions. Early-in-training residents and those in alternating medicine and pediatric clinics particularly benefit.

19. **PREDICTORS OF TRANSITIONING TO ADULT MENTAL HEALTH SERVICES AND ASSOCIATED COSTS: A CROSS-COUNTRY COMPARISON.**

Appleton, R. *et al.*

BMJ mental health 26, (2023) doi:[10.1136/bmjment-2023-300814](https://doi.org/10.1136/bmjment-2023-300814)

BACKGROUND: Young people are at risk of falling through the care gap after leaving child and adolescent mental health services (CAMHS) despite an ongoing need for mental health support. Currently, little is known about the predictors of transitioning to adult mental health services (AMHS), and associated healthcare and societal costs as young people cross the transition boundary. **OBJECTIVE:** To conduct a secondary data analysis exploring predictors of transitioning or falling through the gap and associated costs. **METHODS:** Data were used from a longitudinal study, which followed young people from seven European countries for 2 years after reaching their CAMHS boundary. Predictors of transitioning (including sociodemographic and clinical variables) and longitudinal resource use were compared for 488 young people who transitioned to AMHS versus those who fell through the gap. **FINDINGS:** Young people were more likely to transition to AMHS if they were severely ill. Those from Italy, the Netherlands and the UK were more likely to fall through the gap than transition to AMHS. Healthcare costs fell for all young people over the study, with a sharper decrease for those who fell through the gap. **CONCLUSIONS:** Total healthcare costs fell for all participants, indicating that the intensity of mental health support reduces for all young people as they cross the CAMHS boundary, regardless of clinical need. **CLINICAL IMPLICATIONS:** It is important that alternative forms of mental health support are available for young people who do not meet the AMHS care threshold but still have mental health needs after leaving CAMHS.

20. **SOCIAL AND STRUCTURAL DRIVERS OF HEALTH AND TRANSITION TO ADULT CARE.**

Bailey, K. *et al.*

Pediatrics 153, e2023062275 (2024) doi:[10.1542/peds.2023-062275](https://doi.org/10.1542/peds.2023-062275)

CONTEXT: Youth with chronic health conditions experience challenges during their transition to adult care. Those with marginalized identities likely experience further disparities in care as they navigate structural barriers throughout transition. **OBJECTIVES:** This scoping review aims to identify the social and structural drivers of health (SSDOH) associated with outcomes for youth transitioning to adult care, particularly those who experience structural marginalization, including Black, Indigenous, and 2-spirit, lesbian, gay, bisexual, transgender, queer or questioning, and others youth. **DATA SOURCES:** Medline, Embase, CINAHL, and PsycINFO were searched from earliest available date to May 2022. **STUDY SELECTION:** Two reviewers screened titles and abstracts, followed by full-text. Disagreements were resolved by a third reviewer. Primary research studying the association between SSDOH and transition outcomes were included. **DATA EXTRACTION:** SSDOH were subcategorized as social drivers, structural drivers, and demographic characteristics. Transition outcomes were classified into themes. Associations between SSDOH and outcomes were assessed according to their statistical significance and were categorized into significant ($P < .05$), nonsignificant ($P > .05$), and unclear significance. **RESULTS:** 101 studies were included, identifying 12 social drivers (childhood environment, income, education, employment, health literacy, insurance, geographic location, language, immigration, food security, psychosocial stressors, and stigma) and 5 demographic characteristics (race and ethnicity, gender, illness type, illness severity, and comorbidity). No structural drivers were studied. Gender was significantly associated with communication, quality of life, transfer satisfaction, transfer completion, and transfer timing, and race and ethnicity with appointment keeping and transfer completion. **LIMITATIONS:** Studies were heterogeneous and a meta-analysis was not possible. **CONCLUSIONS:** Gender and race and ethnicity are associated with inequities in transition outcomes. Understanding these associations is crucial in informing transition interventions and mitigating health inequities.

21. **STREAMLINING THE PROCESS OF TRANSITION OF CARE FROM PEDIATRIC NEUROLOGY TO ADULT NEUROLOGY PROVIDERS.**

Acharya, V. & Acharya, J.

Journal of the Neurological Sciences 455, (2023) doi:[10.1016/j.jns.2023.121249](https://doi.org/10.1016/j.jns.2023.121249)

Background and aims: Advances in medical science in the past few decades have allowed an increasing number of children with medically complex conditions and transition to adult age group. The mindset of training of pediatric and adult providers is often different. Smooth transition of care is important to maintain the quality of life. **Aim:** To create a system that will help the continuation of comprehensive care of pediatric patients to adult providers. **Methods:** We identified the stakeholders for this project as leadership for clinical

affairs from pediatric and adult neurology, office managers, nursing staff patients, families, scheduling staff and the advocacy group members. We identified a lead person for pediatric and adult teams. The leads made sure there was an appropriate hand off from the pediatric to adult providers and the nursing staff and coordinatoes from both sides were involved. Results: There was improvement in the quality of care and safety. Patient's medications were better managed. There was increased patient satisfaction. Patients, families, adult and pediatric providers became more accountable. Conclusions: A successful transition of care empowers patients and their families to understand and take responsibilities in managing their condition, foster independcent functioning to the extent that is possible, integrate educational, legal and community resources in the care plan and identify appropriate healthcare providers at the time of transfe. This is a need for today's changing health system. This will lead to enhanced patient safety and quality of care, This will lead to decreased emergency room visits and hospitalizations and reduced burden on healthcare,

22. **THE BLACK HOLE OF THE TRANSITION PROCESS: DROPOUT OF CARE BEFORE TRANSITION AGE IN ADOLESCENTS.**

Reneses, B. *et al.*

European child & adolescent psychiatry 32, 1285–1295 (2023) doi:[10.1007/s00787-021-01939-8](https://doi.org/10.1007/s00787-021-01939-8)

Recent evidence confirms the risks of discontinuity of care when young people make a transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS), although robust data are still sparse. We aimed to identify when and how patients get lost to care during transition by tracking care pathways and identifying factors which influence dropping out of care during transition. This is a retrospective observational study of 760 patients who reached the transition age boundary within 12 months before transition time and being treated at CAMHS for at least during preceding 18 months. Data were collected at two time points: last visit to CAHMS and first visit to AHMS. Socio-demographic, clinical and service utilization variables on CAMHS treatment were collected. In the 12 months leading up to the transition boundary, 46.8% of subjects (n = 356) withdrew from CAHMS without further contact with AHMS, 9.3% withdrew from CAHMS but were referred to AHMS by other services, 29% were transferred from CAHMS to AHMS, 10% remained at CAHMS and 5% patients were transferred to alternative services. Fifty-six percent of subjects experience cessation of care before the transition age. The risk of dropout increases with shorter contact time in CAMHS, is greater in subjects without pharmacological treatment, and decreases in subjects with psychosis, bipolar disorder, eating disorders, mental retardation, and neurodevelopmental disorders. This study confirms that a large number of people drop out of care as they approach the CAMHS transition and experience discontinuity of care during this critical period.

23. **THE HEALTH CARE TRANSITION NEEDS OF ADOLESCENTS AND EMERGING ADULTS WITH CHRONIC PAIN: A NARRATIVE REVIEW.**

Lynch Milder, M. K. *et al.*

Journal of clinical psychology in medical settings (2023) doi:[10.1007/s10880-023-09966-0](https://doi.org/10.1007/s10880-023-09966-0)

The aim of this narrative review was to provide an overview of what is known about the health care transition process in pediatric chronic pain, barriers to successful transition of care, and the roles that pediatric psychologists and other health care providers can play in the transition process. Searches were run in in Ovid, PsycINFO, Academic Search Complete, and PubMed. Eight relevant articles were identified. There are no published protocols, guidelines, or assessment measures specific to the health care transition in pediatric chronic pain. Patients report many barriers to the transition process, including difficulty attaining reliable medical information, establishing care with new providers, financial concerns, and adapting to the increased personal responsibility for their medical care. Additional research is needed to develop and test protocols to facilitate transition of care. Protocols should emphasize structured, face-to-face interactions and include high levels of coordination between pediatric and adult care teams.

24. **THE ROLE AND THE COMPOSITION OF A LIAISON TEAM TO FACILITATE THE TRANSITION OF ADOLESCENTS AND YOUNG ADULTS: AN UMBRELLA REVIEW.**

Wyngaert, K. V. *et al.*

European Journal of Pediatrics 182, 1483–1494 (2023) doi:[10.1007/s00431-023-04835-2](https://doi.org/10.1007/s00431-023-04835-2)

Adolescents and young adults (AYAs) benefit from healthcare transition (HCT) programs. Despite the well-established literature reviewing HCT, a considerable heterogeneity exists on the involved healthcare professionals. This review aims to explore systematic reviews on the practices and recommendations on which disciplines of professionals should be involved in HCT. An umbrella review was performed using the MEDLINE, EMBASE, and Web of Science databases. To be eligible, systematic reviews had to report on the composition and/or the rationale of members of a transition team. Seventeen reviews were included in this systematic review. A healthcare professional that coordinates HCT was identified as a key caregiver in all reviews. Other reported members of a HCT team were nurses (75% of the reviews), social workers (44%), and peers/mentors (35%). The reported key responsibilities of a HCT team were to (i) manage communication, (ii) ensure continuity of care, and (iii) maintain contact with community services. Conclusions: A team responsible for HCT should be active on the organizational, medical, and social levels. Key members of a HCT team vary little between diseases and included a coordinator, social worker, and nurse. A coordinating physician could facilitate transition in complex conditions. At all times, the condition and needs of the AYA should determine who should be involved as caregiver. What is Known: • The psychosocial needs of adolescents and young adults during healthcare transition are largely similar between chronic diseases. What is New: • Coordinators, nurses and social workers were the most involved, independent of the condition. • A liaison team should be active on organizational-, medical- and social-levels.

25. **THE STEPSTONES-CHD STUDY: A MODEL FOR CONDUCTING LONGITUDINAL, INTERVENTIONAL HEALTH CARE TRANSITION RESEARCH FOR ADOLESCENTS AND YOUNG ADULTS WITH CHRONIC ILLNESS.**

Wiemann, C. M. & Hergenroeder, A. C.

The Journal of adolescent health : official publication of the Society for Adolescent Medicine 73, 618–619 (2023) doi:[10.1016/j.jadohealth.2023.06.031](https://doi.org/10.1016/j.jadohealth.2023.06.031)

In this issue of the *Journal*, Bratt and colleagues report the results of their STEPSTONES-CHD (Swedish Transition Effects Project Supporting Teenagers with chrONic mEdical conditions-Congenital Heart Disease) trial with a primary aim of investigating the effectiveness of a structured, multicomponent, person-centered transition program for adolescents with CHD on patient empowerment (primary outcome) [1]. Empowerment was defined as “an enabling process or outcome arising from communication with the healthcare professional and a mutual sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities, and ability to achieve change over their condition” [2]. The study was conducted in seven centers in Sweden and used a hybrid randomized controlled trial embedded in a longitudinal observational study design. A total of 139 16-year-old patients were randomized to intervention or control groups and another 69 were enrolled as a contamination check control. Outcome measures were assessed at baseline (16 years of age), first follow-up (17 years), and second follow-up (18.5 years). Parents of the included adolescents were asked but not required to participate. Secondary adolescent and parent-reported outcomes were also assessed. Intervention participants demonstrated greater change in empowerment, perceived parental involvement, disease-related knowledge, and satisfaction with physical appearance. The STEPSTONES project is an important model of a carefully planned and executed longitudinal evaluation research project. While the paper in the *Journal* focused on the randomized controlled trial outcomes, the authors cite numerous of their prior studies that round out our understanding of the project's true potential impact.

26. **TRANSITION IN ADOLESCENTS WITH CHRONIC DISEASE. IT IS AN INTEGRAL CARE.**

Anta, M. Á. Z.

Anales de pediatria 99, 373–375 (2023) doi:[10.1016/j.anpede.2023.11.010](https://doi.org/10.1016/j.anpede.2023.11.010)

27. **TRANSITION OF CARE IN ADOLESCENTS WITH CHRONIC DISEASE: A CONCEPT ANALYSIS.**

Seydel, A.

Journal for specialists in pediatric nursing : JSPN 28, e12414 (2023) doi:[10.1111/jspn.12414](https://doi.org/10.1111/jspn.12414)

PURPOSE: The aim of this concept analysis was to define the concept of transitional care as it applied to adolescents with chronic health conditions as they transfer from pediatric to adult care. DESIGN AND

METHODS: Walker and Avant's eight step method was used to guide this concept analysis. An electronic search of the literature using CINAHL, PubMed, and MEDLINE was conducted in March of 2022. Articles were included if they were peer-reviewed articles published in English between 2016 and 2022 and aided in the development of the concept. **RESULTS:** A total of 14 articles met inclusion criteria within the search. These articles were used to identify the defining attributes of transitional care as it applied to adolescents with chronic disease. These attributes were empowerment, a comprehensive process, and transfer completion. The antecedents identified were aging, readiness, and support. For an individual to begin the transition process all of these must be present. Consequences include growth, independence, and improved quality of life and health outcomes. Model, borderline, related, and contrary cases were presented to exemplify the concept. **PRACTICE IMPLICATIONS:** Adolescents and young adults with chronic disease require unique care as they transition to adulthood. Defining the concept of transitional care as it relates to this population provided a foundation of knowledge that has implications for nursing practice. This conceptual structure provided a foundation of knowledge for theory development and encouraged widespread use of transition programs. Future research should explore the long-term outcomes of specific interventions used during transitional care.

28. **TRANSITION READINESS AND ANXIETY AMONG ADOLESCENTS WITH A CHRONIC CONDITION AND THEIR PARENTS: A CROSS-SECTIONAL INTERNATIONAL STUDY.**

Tornivuori, A. *et al.*

Journal of advanced nursing 80, 756–764 (2024) doi:[10.1111/jan.15860](https://doi.org/10.1111/jan.15860)

AIMS: To evaluate associations of age, transition readiness and anxiety in adolescents with chronic conditions and to compare perceptions of adolescents and their parents regarding health self-management and transition readiness. **DESIGN:** Cross-sectional international study, reported following STROBE guidelines. **METHODS:** Adolescents and young adults (N = 512, mean age 17.7) with a chronic medical condition and their parents (N = 322) from Finland and Australia. Data were collected through surveys (between September 2017 and December 2020). Adolescents reported the duration of their condition. Age at survey was defined by the response date of the questionnaires. Validated questionnaires were used to measure transition readiness (Am I ON TRAC? for Adult Care) and anxiety related to transition of care (State-Trait Anxiety Inventory short form). Perceptions of health self-management and transition readiness were compared in adolescent/parent dyads. Associations were explored using Spearman's correlation. **RESULTS:** Duration of condition and age at survey correlated weakly with transition readiness knowledge and behaviour. Higher transition readiness knowledge scores correlated with higher behaviour scores. Higher transition readiness behaviour scores were associated with lower levels of anxiety. Adolescents were less anxious than their parents and adolescents and parents mostly agreed about health self-management and transition readiness. **CONCLUSION:** Transition readiness should be determined by an assessment of knowledge, self-management and psychosocial skills instead of age alone. Further research should address how well transition readiness predicts positive health outcomes after the transfer of care. **IMPLICATIONS FOR PATIENT CARE:** Transition readiness and self-management skills should be formally assessed because positive feedback may decrease the anxiety of both adolescents and their parents regarding the transfer of care. **REPORTING METHOD:** We have adhered to the STROBE statement, using STROBE checklist for cross-sectional studies. **PATIENT OR PUBLIC INVOLVEMENT STATEMENT:** No patient or public involvement. **TRIAL AND PROTOCOL REGISTRATION:** ClinicalTrials.org NCT04631965.

29. **TRANSITION READINESS OF ADOLESCENTS TO ADULT HEALTH CARE.**

Lara-Macaraeg, B. R., Cardinal, A. & Bermejo, B. G.

Frontiers in pediatrics 11, 1204019 (2023) doi:[10.3389/fped.2023.1204019](https://doi.org/10.3389/fped.2023.1204019)

BACKGROUND: Transition in health care is a process wherein adolescents gradually prepare for and shift towards care in the adult system. An initial assessment of the readiness of these adolescents is fundamental in providing appropriate health services for them. This paper aims to determine the readiness of adolescent patients towards transitioning to adult care. **METHODS:** This is a prospective cross-sectional study utilizing an interviewer-guided modified Transition Readiness Assessment Questionnaire (TRAQ). Sixty-three adolescents ages 15 to 18 years seen in the Pediatric Outpatient Department (OPD) of a tertiary hospital in Baguio City from July 1 to October 31, 2020 were enrolled. Frequency and percentages were used to

describe the demographic data; while mean score and standard deviation determined readiness based on a Likert scale. One-way ANOVA was utilized to determine association between factors and readiness to transition. RESULTS: For all domains of TRAQ, the mean score was 3.64, implying that they are not yet ready to transition. 49.2% belong to General Pediatrics. 44.4% belong to the Igorot ethnic groups. Most are still in High school, and majority of their parents finished High School level. Furthermore, the P-values were more than 0.05 for all variables suggesting no association between readiness to transition and the identified factors in this study. DISCUSSION: This study showed that adolescents who had both acute and chronic illnesses, were not yet ready to transition. Provision of a platform for assisting the adolescents in their assumption of bigger roles/responsibilities for their own health care is necessary to ensure proper transitioning to adult health care.

30. **TRANSITION READINESS OF YOUTH WITH CO-OCCURRING CHRONIC HEALTH AND MENTAL HEALTH CONDITIONS: A MIXED METHODS STUDY.**

Allemang, B. *et al.*

Health expectations : an international journal of public participation in health care and health policy 26, 2228–2244 (2023) doi:[10.1111/hex.13821](https://doi.org/10.1111/hex.13821)

BACKGROUND: A large proportion of youth with chronic conditions have mental health comorbidities. However, the effect of these comorbidities on paediatric-adult transition readiness, and the relevance of widely used tools for measuring transition readiness, are unknown. OBJECTIVE: The objectives of this study were to describe and explore the transition readiness of youth with co-occurring chronic health and mental health conditions using a combination of quantitative data obtained from participants completing the Transition Readiness Assessment Questionnaire (TRAQ) and qualitative data. DESIGN AND PARTICIPANTS: A three-phase sequential explanatory mixed methods design was employed, with the qualitative strand taking priority. First, the TRAQ scores (range 1-5) of youth with co-occurring conditions (n = 61) enrolled in a multisite randomized controlled trial were measured, followed by qualitative interviews with a sample of youth (n = 9) to explain the quantitative results. Results from both strands were then integrated, yielding comprehensive insights. RESULTS: Median TRAQ scores ranged from 2.86 on the appointment keeping subscale to 5.00 on the talking with providers subscale. The qualitative results uncovered the complexities faced by this group concerning the impact of a mental health comorbidity on transition readiness and self-management skills across TRAQ domains. The integrated findings identified a diverse and highly individualized set of strengths and challenges amongst this group that did not align with overarching patterns as measured by the TRAQ. CONCLUSIONS: This mixed methods study generated novel understandings about how youth with co-occurring conditions develop competencies related to self-care, self-advocacy and self-management in preparation for paediatric-adult service transitions. Results demonstrated the assessment of transition readiness using a generic scale does not address the nuanced and complex needs of youth with co-occurring chronic health and mental health conditions. Our findings suggest tailoring transition readiness practices for this group based on youths' own goals, symptoms, coping mechanisms and resources. PATIENT OR PUBLIC INVOLVEMENT: This study was conducted in collaboration with five young adult research partners (YARP) with lived experience transitioning from paediatric to adult health/mental health services. The YARP's contributions across study phases ensured the perspectives of young people were centred throughout data collection, analysis, interpretation and presentation of findings. All five YARP co-authored this manuscript.

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

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

Journal of child health care : for professionals working with children in the hospital and community 13674935231202870 (2023) doi:[10.1177/13674935231202870](https://doi.org/10.1177/13674935231202870)

Complex paediatric health conditions are increasingly associated with survival into adulthood resulting in more youth with complex care needs (CCN) transitioning from paediatric to adult healthcare. Current transition practices, when present, are disorganized, resulting in health status deterioration and complications due to unmet needs. The aim of this qualitative descriptive study is to develop a broader understanding of the current transition practices and experiences, as well as recommendations of care providers who support

youth with CCN in the transition from paediatric to adult healthcare. Fifteen care providers from two Eastern Canadian provinces were interviewed using a semi-structured interview guide. The data collected were analyzed using inductive thematic analysis following the six phases outlined by Braun and Clarke (2006). The findings from this research demonstrate (1) a shortage of care providers, (2) inconsistent timing for transition initiation, and (3) lack of available community resources and services. Participant recommendations include (1) a designated transition coordinator; (2) transition policy implementation; (3) improved collaboration between and across care teams; and (4) the integration of virtual care to facilitate the transition process. The results of this study can potentially improve transition practices and policies and guide future research in this area.

32. **TRANVIA: A PROGRAM FOR CONTINUUM MENTAL HEALTH ASSISTANCE IN TRANSITION PERIOD.**

Pérez Gómez, L. *et al.*

European Psychiatry 66, S728 (2023) doi:[10.1192/j.eurpsy.2023.1526](https://doi.org/10.1192/j.eurpsy.2023.1526)

Introduction: Transition between adolescence and adulthood represents the most important challenge for personal development and involves several transformations: physical, psychological and social. It is a complex age bracket, concurring the transition from youth psychiatric units to adult ones, with an increased risk for the appearance of mental disorders and risky behaviours. TRANVIA program, developed in Avilés, provides psychiatric assistance to patients between 15 and 25 years old, diagnosed with a severe psychiatric disorder or with an increased risk of having one. Objectives: Our objectives are: ensuring clinical continuity assistance, promoting communication among professionals and the empowerment of our patients to improve their functionality and quality of life. Methods: Descriptive study including patients involved in TRAN-VIA program from November 2019 to November 2021. Results: During this two-years period there have been 44 referrals to the program, 11 of them were rejected for failure to comply with diagnostic criteria. In November 2021 there were 33 patients included in the TRANVIA program with an average age of 17 years old (range: 15-22). 70% of them were men and 30% women. All of them had psychiatric assistance from different sources: youth mental health units, neuropsychiatry. About 75% of the patients were diagnosed with autistic spectrum disorder and approximately three-quarters of the sample needed pharmacological treatment. Risperidone was the most prescribed drug. We have also developed other assistance alternatives as home-based care, relaxation sessions, social worker interventions and coordination with schools. Conclusions: TRANVIA program has allowed us to provide continual attention to vulnerable patients that shift from youth psychiatric units to adult ones. Patients that meet inclusion criteria were enrolled independently the type of assistance they have previously received. Accessibility and flexibility were our priority. During the described period there was only one dropout, three patients required psychiatric hospitalization and two others visited the emergency department. There have been no cases of completed suicide.

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EPILESSIA

1. **ACHIEVING NICE TRANSITION-RELATED STANDARDS OF CARE FOR YOUNG PEOPLE WITH EPILEPSY - A QUALITY IMPROVEMENT PROJECT.**

Barrow, S. & Devereux, E.

Archives of Disease in Childhood 108, A411–A412 (2023) doi:[10.1136/archdischild-2023-rcpch.644](https://doi.org/10.1136/archdischild-2023-rcpch.644)

Objectives Moving from paediatric to adult services is a worrying and challenging time for young people with long-term conditions such as epilepsy. Evidence suggests that effective transition between services can improve long-term outcomes,¹ yet national data highlights that transition is often overlooked with little recognition as an area of importance within healthcare. ² However, there has recently been a drive to refine and improve the transition process through the NHS long term plan. This quality improvement project aimed to achieve the NICE quality transition standards³ of care for epilepsy across a nine-month period in one paediatric department. Methods An initial transition gap analysis was undertaken using 11 NICE quality

transition-focused standards of care to demonstrate current performance of services for epilepsy. Diagnostic tools including a process map, fishbone diagram, and RAG rating were completed to help define the problem further. Some of the factors highlighted included lack of engagement from adult services, increased workload for the paediatric team and lack of dedicated transition clinics. Following this, several change ideas were generated and PDSA cycles were undertaken. Some of the change ideas included regular transition progress meetings, along with implementation of time-bound action points, using the Ready, Steady, Go paperwork and setting-up joint transition clinics between paediatric and adult epilepsy services. Results Baseline measurement showed that 8 out of 11 transition-related standards of care were unmet for epilepsy, with only one standard being fully met. Following the implementation of several change ideas, the measurement for partially meeting and meeting standards increased to 45%, and 27%, respectively, with improvement seen across several standards of care. Conclusion The focus of this QI project has enabled us to better achieve transition-related standards of care for young people with epilepsy. Particular highlights and achievements included setting-up joint transition clinics between paediatric and adult epilepsy services, which created engagement at a Trust level along with successfully obtaining funding for a new epilepsy transition specialist nurse through Roald Dahl's Marvellous Children's Charity. Measurable progress has been made in implementing transition-related standards of care, however; further work is needed to ensure young people and their families are actively involved in the design, delivery, and evaluation of transition services.

2. **CLINICAL, SOCIODEMOGRAPHIC, AND PSYCHOLOGICAL FACTORS ASSOCIATED WITH TRANSITION READINESS IN PATIENTS WITH EPILEPSY.**

Vacca, M. *et al.*

Brain Sciences 14, (2024) doi:[10.3390/brainsci14010021](https://doi.org/10.3390/brainsci14010021)

Background: The transition to adult care for patients with epilepsy is a complicated clinical issue associated with adverse outcomes, including non-adherence to treatment, dropout of medical care, and worse prognosis. Moreover, youngsters with epilepsy are notably prone to emotional, psychological, and social difficulties during the transition to adulthood. Transition needs depend on the type of epilepsy and the epileptic syndrome, as well as on the presence of co-morbidities. Having a structured transition program in place is essential to reduce poor health consequences. A key strategy to optimize outcomes involves the use of transition readiness and associated factors assessment to implement the recognition of vulnerability and protective aspects, knowledge, and skills of these patients and their parents. Therefore, this study aims to provide a comprehensive framework of clinical and psychosocial aspects associated with the transition from pediatric to adult medical care of patients with epilepsy. Methods: Measures examining different aspects of transition readiness and associated clinical, socio-demographic, psychological, and emotional factors were administered to 13 patients with epilepsy (Mage = 22.92, SD = 6.56) with (n = 6) or without (n = 7) rare diseases, and a respective parent (Mage = 56.63, SD = 7.36). Results: patients showed fewer problems in tracking health issues, appointment keeping, and pharmacological adherence as well as low mood symptoms and moderate resiliency. Moreover, they referred to a low quality of sleep. Notably, parents of patients with rare diseases reported a lower quality of sleep as compared to the other group of parents. Conclusions: Increasing awareness around transition readiness is essential to promote self-management skills of patients with epilepsy and their parents. Anticipating the period of transition could be beneficial, especially to prevent problematic sleep patterns and promote independence in health care management. Parents of patients with epilepsy and rare diseases should be monitored for their mental status which can affect patients' well-being.

3. **TRANSITION OF CARE IN ADOLESCENTS WITH EPILEPSY: PERSPECTIVE OF PEDIATRIC NEUROLOGISTS IN INDIA.**

Kanhere, S. & Joshi, S. M.

Indian journal of pediatrics 90, 1149–1151 (2023) doi:[10.1007/s12098-023-04579-9](https://doi.org/10.1007/s12098-023-04579-9)

This cross-sectional study was designed to determine the current status of transition of care for adolescents with epilepsy to adult neurological services in India and to understand pediatric neurologists' perspectives. After approval from the appropriate Ethics Committee, a pre-designed questionnaire was distributed electronically. Twenty-seven pediatric neurologists from 11 cities across India responded. Pediatric care ended under 15 y for 55.4% responders and at 18 y in another 40.7%. Eighty nine percent introduced the concept of transition or had transition discussions with their patients and parents. Majority of providers did not

have a formal plan for transferring the children with epilepsy to an adult neurologist, and very few had transition clinics. Communication with adult neurologists was also variable. Several pediatric neurologists followed patients after transfer for varying periods of time. This study demonstrates increasing awareness regarding the importance of transition of care in this population.

4. **TRANSITION OF CARE IN EPILEPSY.**

Kanhere, S. & Joshi, S. M.

Indian journal of pediatrics 90, 1127–1133 (2023) doi:[10.1007/s12098-023-04658-x](https://doi.org/10.1007/s12098-023-04658-x)

Transition of care is the planned, coordinated movement from a child and family environment of pediatrics to a patient centered adult care setting. Epilepsy is a common neurological condition. While seizures remit in a proportion of children, in around 50% of children seizures persist into adulthood. Also, with advances in diagnostics and therapeutics, more children with epilepsy survive into adulthood, and need services of adult neurologists. Clinical guidelines from the American Academy of Pediatrics, American College of Family Physicians and American College of Physicians called for ‘supporting the healthcare transition from adolescence to adulthood’, but this occurs in a minority of patients. There are several challenges to implementing transition of care at the level of the patient and family, pediatric and adult neurologist and with systems of care. Transition needs vary based on the type of epilepsy and epilepsy syndrome and presence of co-morbidities. Transition clinics are essential to effective transfer of care, but implementation remains extremely variable, with a variety of clinics or program structures in countries around the world. There is a need to develop multidisciplinary transition clinics, enhance physician education and establish national guidelines for this important process to be put into practice. Further studies are also needed to develop best practices and assess outcomes of well executed transition programs on epilepsy.

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DIABETE

1. **A NOVEL RECEIVERSHIP MODEL FOR TRANSITION OF YOUNG ADULTS WITH DIABETES: EXPERIENCE FROM A SINGLE-CENTER ACADEMIC TRANSITION PROGRAM.**

Iyengar, J. J. *et al.*

Endocrine practice : official journal of the American College of Endocrinology and the American Association of Clinical Endocrinologists 30, 113–121 (2024) doi:[10.1016/j.eprac.2023.11.008](https://doi.org/10.1016/j.eprac.2023.11.008)

OBJECTIVE: The transition from pediatric to adult care for young adults with diabetes represents an important but often challenging time characterized by a shift from a family-centered care model of pediatrics to a patient-centered care model of adult medicine. We developed a structured transition program based on an adult receivership model at a large academic medical center to improve care coordination and patient satisfaction with the transition process. **METHODS:** From 2016 to 2020, we implemented a series of quality improvement efforts for young adults aged 18 to 23 years with diabetes by incorporating best practices from the American Diabetes Association guidelines on care for emerging adults. We measured transition orientation attendance, patient satisfaction, hemoglobin A1c (HbA1c) pre- and post-transfer, and care gaps to determine the impact of the program. **RESULTS:** In this study, 307 individuals with type 1 diabetes and 16 individuals with type 2 diabetes were taken care of by the adult endocrinology department at the University of Michigan between January 1, 2016 and October 31, 2020. We observed high attendance rates (86% among internal transfers) and favorable patient satisfaction scores for the transition orientation session. Despite the glycemic challenges posed during the transition, HbA1c modestly yet significantly improved 1-year after transfer (-0.4%, $P < .01$). **CONCLUSION:** We successfully established and maintained a young adult diabetes transition program using a quality improvement approach. Future work will focus on reducing care gaps at the time of transfer, assessing long-term retention rates, and enhancing care coordination for patients referred from outside the health network.

2. **ADAPTATION OF AN ADULT WEB APPLICATION FOR TYPE 1 DIABETES SELF-MANAGEMENT TO YOUTH USING THE BEHAVIOR CHANGE WHEEL TO TAILOR THE NEEDS OF HEALTH CARE TRANSITION: QUALITATIVE INTERVIEW STUDY.**

Xie, L. F. *et al.*

JMIR diabetes 8, e42564 (2023) doi:[10.2196/42564](https://doi.org/10.2196/42564)

BACKGROUND: Youth (aged 14-24 years) living with type 1 diabetes (T1D) encounter increased challenges in their diabetes self-management (DSM), especially during the transition to adult care. Although DSM education and support are imperative, there is insufficient information on how web-based digital tools tailored to their demands can be developed. **OBJECTIVE:** On the basis of the Behavior Change Wheel, this study aims to identify, among youth living with T1D, the needs and factors influencing their DSM in the context of health care transition and to inform the adaptation (content and features) of an adult self-guided web application (Support). **METHODS:** Internet-based semistructured individual interviews based on a phenomenological study design were conducted with 21 youths, and transcripts were analyzed using an inductive approach with concept mapping. **RESULTS:** Factors influencing T1D self-management were categorized into barriers and facilitators and then as external or internal. Features influencing the accessibility to information, increasing the sense of support, and use of the tool were positively accepted. Features unrelated to their expectations of digital tool use or difficulty navigating were viewed negatively. Participants expressed an interest in reliable, practical, and novel educational content. Although youth considered the information provided by medical professionals to be important, peer exchange was deemed necessary to obtain a practical perspective and real-life examples. **CONCLUSIONS:** Compared with the adult population, in addition to tailored content and a simplified information search process, when building a DSM education and support digital tool for youth, features should be selected to encourage supervised peer exchange.

3. **ADHERENCE TO TYPE 1 DIABETES CARE VISITS AFTER TRANSFER FROM PEDIATRIC TO ADULT CARE: A PROSPECTIVE COHORT STUDY.**

Lafontaine, S. *et al.*

Canadian Journal of Cardiology 39, S122 (2023) doi:[10.1016/j.cjca.2023.06.192](https://doi.org/10.1016/j.cjca.2023.06.192)

BACKGROUND: Adolescents with type 1 diabetes (T1D) are at risk of disengaging from regular care, particularly during the transition to adult care. In emerging adults with T1D, our objectives were to 1) describe health-care utilization after transfer to adult care, and 2) determine predictors of gaps in diabetes care visits after transfer from pediatric to adult care. **METHODS AND RESULTS:** This was a prospective cohort study of adolescents with T1D followed for 18 months after their last pediatric diabetes care visit, from 2017 to 2021. We assessed health-care utilization during follow-up using health administrative data. Primary exposure: delay in establishing adult diabetes care, defined as a gap in care ≥ 6 months after the last pediatric visit. Our secondary exposures were self-reported self-efficacy, transition readiness, and diabetes distress before transfer to adult care. Primary outcome: gap in adult diabetes care visits after transfer, defined as having a gap ≥ 6 months after the first adult visit or after the end of the 6-month transfer washout period if no adult visits occurred. Our secondary outcomes were: ≥ 1 diabetes-related emergency department (ED) visits and ≥ 1 diabetes-related hospitalizations. We used multivariable logistic regression to examine associations of delay in establishing adult diabetes care and psychosocial factors before transfer with gaps in diabetes care visits within the adult health-care setting. We adjusted for sex, socioeconomic status, diabetes duration, insulin pump use, diagnosed mental health comorbidities, use of a glucose monitoring system, and mean A1C prior to transfer to adult care. Results: We included 74 adolescents with T1D. While fifteen (20%) had a delay in establishing adult diabetes care, twenty (27%) had a gap in adult diabetes care visits after transfer. Six participants (8.1%) had at least 1 ED visit and 1 participant (1.4%) was hospitalized. We found a direct association between delay in establishing adult diabetes care and subsequent gaps in adult diabetes care visits after transfer (adjusted odds ratio: 29.9; 95% confidence interval, 5.3–169.9). We did not find evidence of an association between psychosocial measures before transfer and gaps in adult diabetes care visits after transfer. **CONCLUSION:** Health-care utilization after transfer is suboptimal in emerging adults with T1D. Delayed transfer of care may place emerging adults at risk of disengaging from adult diabetes care. Further studies should monitor gaps in adult diabetes care on a population level and over longer follow-up periods.

4. **AGE AT LAST PEDIATRIC TYPE 1 DIABETES VISIT PREDICTS A SUCCESSFUL TRANSITION TO ADULT DIABETES CARE.**

Leung, J. M. W. S. *et al.*

Journal of the Endocrine Society 7, A736–A737 (2023) doi:[10.1210/jendso/bvad114.1381](https://doi.org/10.1210/jendso/bvad114.1381)

Introduction: Adolescents with type 1 diabetes are known to experience a substantial gap when transitioning from pediatric to adult care.¹ We have previously validated a pediatric diabetes case definition and differentiating algorithm to create an administrative cohort of individuals diagnosed with type 1 diabetes using linked provincial administrative health data (physician billing, hospital discharge abstracts, and pharmacy dispensations) from British Columbia, Canada. ² The objective of this study was to identify predictors of successful transition from pediatric to adult diabetes care within this cohort. Methods: Using our administrative cohort, we isolated adolescents who were diagnosed with type 1 diabetes between the ages of 0.5 to 18 years in 1992-2020. We excluded individuals whose last healthcare encounter was at age <14 years (i.e. individuals who had not yet reached adolescence) at the time of data acquisition (2020). Last pediatric visit before transition (LPVBT) was defined as the date of last billing by a pediatrician. First adult visit after transition (FAVAT) was defined as the date of first billing by an adult medicine specialist. We determined age at LPVBT and we calculated duration between LPVBT and FAVAT. ‘Successful transition’ was defined as ≤1 year between LPVBT and FAVAT. We fit logistic regression models to determine predictors of successful transition. Results: We identified 3660 adolescents who were diagnosed with type 1 diabetes in pediatric care. 1615 (44.1%) did not have any adult diabetes visits, while 2045 (55.9%) had one or more adult diabetes visits. Of these, 1405 (38.4%) had FAVAT >1 year after LPVBT and only 640 (17.5%) had a duration between LPVBT and FAVAT of ≤1 year (i.e. successful transition). The mean duration between LPVBT and FAVAT was 3.70 years (median 2.46, IQR = 0.68-5.45). For every 1-year increase in the age at LPVBT, there was an increased odds of successful transition in both the unadjusted analysis (OR 1.809, 95% confidence interval (CI) 1.704-1.925, p<0.001) and when adjusted for sex, age at diagnosis, and urban-rural residency (OR 1.816, 95% CI 1.709-1.933, p<0.001). Those who successfully transitioned were older at their LPVBT (17.74 years, 95% CI 17.62-17.85) compared to those who did not successfully transition (15.10 years, 95% CI 14.99-15.21). Conclusion: Adolescents with type 1 diabetes who remain in pediatric care until at least age 17 are more likely to transition successfully to adult care. Conversely, those who leave pediatric care prematurely are less likely to experience a successful transition. These findings suggest that a key area of focus to improve the transition from pediatric to adult diabetes care is ensuring that youth remain engaged in pediatric care as close to the age of transition as possible.

5. **ANALYSIS ON THE STATUS AND INFLUENCING FACTORS OF HEALTH CARE INTENTION IN TRANSITIONAL CHILDREN AND ADOLESCENTS WITH DIABETES.**

Wang, Y. *et al.*

Chinese Journal of Practical Nursing 39, 1554–1561 (2023) doi:[10.3760/cma.j.cn211501-20220517-01533](https://doi.org/10.3760/cma.j.cn211501-20220517-01533)

Objective To investigate the intention to participate in health care in transitional children and adolescents with diabetes and analyze its influencing factors. Methods This was a cross-sectional survey study. From March to October 2021, 185 children and adolescents with diabetes were selected as research subjects by convenience sampling method from People’s Hospital Affiliated to Jiangsu University. General data questionnaire, Participation in Health Care Intention Questionnaire, Health Literacy Scale and Diabetes Self-management Scale were used to investigate, and multiple linear regression was used to analyze the influencing factors of the population’s intention to participate in health care. Results The transitional children and adolescents with diabetes participation in health care intention total score was (124.87 ± 16.31) points, the health literacy total score was (33.70 ± 4.38) points, diabetes self-management total score was (35.11 ± 5.19) points. The regression analysis found that age, course of the disease, diabetes type, family structure modes, health literacy, and self-management ability were the main factors influencing adolescents involved in health care intention (t values were -1.99-2.66, all P<0.05), including health literacy ability and disease management ability was positively correlated with the disease (r = 0.250, 0.232, both P<0.01). Conclusions The transitional children and adolescents with diabetes have a medium level of intention to participate in health care. The transitional children and adolescents with older age, longer disease course and nuclear family structure had higher levels of health care intention. The higher the level of health literacy and self-management, the higher the level of intention to participate in health care, medical staff should take targeted measures to improve the intention to participate in health care, promote this group to improve disease

management ability and quality of life.

6. **ASSOCIATION OF STIGMA, DIABETES DISTRESS AND SELF-EFFICACY WITH QUALITY OF LIFE IN ADOLESCENTS WITH TYPE 1 DIABETES PREPARING TO TRANSITION TO ADULT CARE.**

Soufi, A. *et al.*

Diabetic Medicine 41, (2024) doi:[10.1111/dme.15159](https://doi.org/10.1111/dme.15159)

Aims: In type 1 diabetes (T1D), psychosocial factors may impact quality of life (QOL) and clinical outcomes, but remain understudied, particularly during late adolescence. Our aim was to determine whether stigma, diabetes distress and self-efficacy are associated with QOL in adolescents with T1D as they are preparing to transition to adult care. Methods: We conducted a cross-sectional study of adolescents (ages 16–17 years) with T1D participating in the Group Education Trial to Improve Transition (GET-IT) in Montreal, Canada. Participants completed validated questionnaires on stigma using the Barriers to Diabetes Adherence (BDA) stigma subscale, self-efficacy (Self-Efficacy for Diabetes Self-Management Measure [SEDM], score 1–10), diabetes distress (Diabetes Distress Scale for Adults with type 1 diabetes) and QOL (Pediatric Quality of Life Inventory [PedsQL] 4.0 Generic Core Scale and PedsQL 3.2 Diabetes Module). We examined associations of stigma, diabetes distress and self-efficacy with QOL using multivariate linear regression models adjusted for sex, diabetes duration, socioeconomic status and HbA1c. Results: Of 128 adolescents with T1D, 76 (59%) self-reported having the diabetes-related stigma and 29 (22.7%) reported experiencing diabetes distress. Those with stigma had lower diabetes-specific and general QOL scores compared with those without stigma, and stigma and diabetes distress were both associated with lower diabetes-specific QOL and lower general QOL. Self-efficacy was associated with higher diabetes-specific and general QOL. Conclusions: Stigma and diabetes distress are associated with lower QOL, whereas self-efficacy is associated with higher QOL in adolescents with T1D preparing to transfer to adult care.

7. **ASSOCIATIONS OF DIABETES-RELATED AND HEALTH-RELATED QUALITY OF LIFE WITH GLYCEMIC LEVELS IN ADOLESCENTS WITH TYPE 1 DIABETES PREPARING TO TRANSITION TO ADULT CARE.**

Lafontaine, S. *et al.*

Canadian Journal of Diabetes 47, 525–531 (2023) doi:[10.1016/j.jcjd.2023.05.002](https://doi.org/10.1016/j.jcjd.2023.05.002)

Objectives: As adolescents with type 1 diabetes (T1D) progress to adulthood, they assume responsibility for diabetes self-management while dealing with competing life demands, decreasing parental support, and the transfer to adult care. Lower perceived quality of life (QOL) may hamper diabetes management, which is associated with suboptimal glycemic levels. Our objective was to determine associations of diabetes- and health-related QOL with glycemic management (glycated hemoglobin [A1C]) in adolescents with T1D before their transfer to adult care. Methods: We conducted a cross-sectional analysis of baseline data from the Group Education Trial to Improve Transition (GET-IT- T1D) in adolescents with T1D (16 to 17 years of age). Participants completed validated questionnaires measuring diabetes-related QOL (PedsQL 3.2 Diabetes Module) and health-related QOL (PedsQL 4.0 Generic Core Scales). Associations of QOL Total and subscale scores with A1C were assessed using linear regression models adjusted for sex, diabetes duration, socioeconomic status, insulin pump use, and mental health comorbidity. Results: One hundred fifty-three adolescents with T1D were included (mean age, 16.5 [standard deviation, 0.3] years). Diabetes-related QOL Total scores (adjusted $\beta=-0.04$; 95% confidence interval [CI], -0.05 to -0.02) as well as subscale scores for Diabetes Symptoms (adjusted $\beta=-0.02$; 95% CI, -0.04 to -0.00) and Diabetes Management (adjusted $\beta=-0.04$; 95% CI, -0.05 to -0.02) were inversely associated with A1C. Health-related QOL Total scores were not associated with A1C, but Psychosocial Health subscale scores were (adjusted $\beta=-0.01$; 95% CI, -0.03 to -0.00). Conclusion: Our results suggest that strategies focussing on diabetes-related QOL and psychosocial health may help prepare adolescents for the increasing responsibility of diabetes self-care.

8. **BARRIERS TO TRANSITION FROM PEDIATRIC TO ADULT CARE: A QUALITATIVE STUDY OF TYPE 1 DIABETES PROVIDERS IN BOTSWANA.**

Craven, M. *et al.*

Hormone Research in Paediatrics 96, 393–396 (2023) doi:[10.1159/000531602](https://doi.org/10.1159/000531602)

Objectives In Botswana, improvements in care of children with type 1 diabetes (T1D) has led to increasing numbers of adolescents with T1D aging into adulthood. Transitions from pediatric to adult care are associated with increased loss to follow-up and higher HbA1c worldwide. Yet, Botswana does not have standard guidelines for transitioning T1D care. There is now a need to understand factors associated with successful healthcare transition of adolescents with T1D to optimize outcomes in this and similar settings. Methods In-depth interviews with Botswana providers and other key stakeholders were conducted and analyzed using the Consolidated Framework for Implementation Research. The interviews discussed readiness for transition, linkage to and retention in adult care, long-term health maintenance, and the acceptability and feasibility of specific transition support strategies. Transcribed interviews were coded independently by two investigators and discrepancies were refereed by a senior investigator. Results Thirteen interviews were conducted, including both early career and more established stakeholders (range of 1-22 years working with T1D). Most participants were physicians (61%), but stakeholders also included three diabetes youth leaders, a public health resident working for the Ministry of Health, and a diabetes nurse educator. All but three worked in the capital city of Gaborone. Interviews lasted an average of 46 minutes (range 31-63). Results underscore the need for formalized transition planning. While the foundations for a transition program exists, there is not currently a formal process for transfer of care. Implementation barriers include patient's denial of their care needs and desire to be more like their healthy peers, lack of family support, lack of education on adolescent topics, poor access to mental health services, competing commitments, and a lack of familiarity with the adult clinic. Facilitators include a diabetes nurse who covers both clinics in the capital city, multidisciplinary care and flexible scheduling at adult clinics, and support of the Botswana Diabetes Association. Conclusions With improvement in early T1D care, providers in Botswana need policies and implementation tools for safe transition of patients to adult care. Our study addresses barriers that exist in creating successful transition to adult care and gives guidance to possible implementation of low-cost transition programs.

9. **CHARACTERISTICS OF YOUNG ADULTS WITH TYPE 1 DIABETES (T1D) ATTENDING A VIRTUAL YOUNG ADULT DIABETES CLINIC (YADC) AS A COMPONENT OF TRANSITION FROM PEDIATRIC TO ADULT DIABETES CARE.**

Joarder, F. *et al.*

Diabetes 72, (2023) doi:[10.2337/db23-692-P](https://doi.org/10.2337/db23-692-P)

Objectives: Young adults (18-25) living with T1D are at high risk of acute and chronic complications and poor glycemic control in part because of difficulties seen in transitioning from pediatric to adult care. In 2017 an in-person YADC was created to help engage and support new patients transitioning from pediatric to adult care. In 2021, in response to the COVID-19 pandemic, the YADC was adapted to a virtual model. This study characterizes the participants of the virtual YADC. Methods: The YADC is a comprehensive virtual clinic that includes a group welcome, orientation to adult diabetes care, peer-to-peer interaction, group discussion about pediatric-to-adult transition of care (facilitated by a behavioral health clinician), a diabetes education visit and a medical provider visit. Young adult attendees were self-select; those who were referred to an adult endocrinologist were given the option to join the YADC. Descriptive statistics were utilized to summarize the characteristics of patients attending the virtual YADC. Results: Of 89 patients scheduled, 61 patients attended the virtual YADC between January 2021 and December 2022. Attendees ranged in age from 18 to 25, with a mean age of 21. Forty-one attendees (67%) had private insurance and 20 had state insurance. The mean HbA1c of virtual YADC participants was 8.61%. In comparison, the mean HbA1c of those who did not attend was 9.84%. Among young adult patients who did not attend, 19 (67%) attendees had state insurance, whereas 9 attendees had private insurance. Conclusions: Characterization of virtual YADC attendees reveals a higher proportion with private insurance vs state insurance. This finding implies potential differences in access to care. Future studies will focus on understanding the differences between those who do and do not attend virtual YADC and how to increase patient engagement.

10. **DIABETES DISTRESS AND TRANSITION READINESS IN YOUTHS WITH TYPE 1 DIABETES TRANSITIONING FROM PEDIATRIC TO ADULT CARE.**

Leung, J. M. W. S. *et al.*

Pediatric Diabetes 2023, (2023) doi:[10.1155/2023/5580180](https://doi.org/10.1155/2023/5580180)

Background. Youths with type 1 diabetes transitioning from pediatric to adult care are known to experience significant glycemic excursions and medical complications. Diabetes distress and transition readiness are two potentially related constructs involved in this transition process, but the relationship between them has not been extensively studied. Hypothesis. Lower diabetes distress is associated with increased transition readiness among youths with type 1 diabetes transitioning to adult care. Subjects. One hundred one adolescents and emerging adults with type 1 diabetes transitioning to adult care complete data in 63 study participants. Methods. In this cross-sectional study, we collected diabetes distress scale scores (via T1-DDS) and transition readiness scores (via Am I ON TRAC) at the last pediatric diabetes visit. We fitted regression models to estimate the relationship between T1-DDS scores and ON TRAC scores. Results. The total mean T1-DDS score was associated with ON TRAC knowledge score ($\beta = -2.73$, 95% CI -4.41,-1.06, $p=0.002$), behavior score ($\beta = -2.61$, 95% CI -4.39,-0.84, $p=0.005$), and transition readiness indicator ($\beta = -0.18$, -0.34,-0.01, $p=0.03$). Multiple T1-DDS subscales were associated with ON TRAC knowledge score: powerlessness, management distress, negative social perceptions, eating distress, physician distress, and family/friend distress. Multiple T1-DDS subscales were also associated with ON TRAC behavior score: management distress, negative social perceptions, eating distress, and family/friend distress. Conclusions. Diabetes distress and transition readiness have an inversely proportional relationship in youths with type 1 diabetes transitioning to adult care. Targeting diabetes distress may also improve transition readiness (and vice versa) in this population.

11. **ENGAGEMENT OF YOUNG ADULTS WITH TYPE 1 DIABETES (T1D) IN A VIRTUAL YOUNG ADULT DIABETES CLINIC AS A COMPONENT OF TRANSITION FROM PEDIATRIC TO ADULT DIABETES CARE.**

Pandharipurkar, T. H. *et al.*

Diabetes 72, (2023) doi:[10.2337/db23-643-P](https://doi.org/10.2337/db23-643-P)

Objectives: Young adults with Type 1 Diabetes (T1D) face unique challenges with engaging in care as they transition from the pediatric to the adult setting. The Young Adult Diabetes Clinic (YADC) is a multidisciplinary clinic that includes a group clinic, combining endocrinology, diabetes education, and behavioral health. Due to the COVID-19 pandemic, the need for a virtual YADC group clinic arose. We sought to understand how this virtual setting could impact engagement as compared with the in-person model. Methods: We conducted a retrospective cohort study comparing in-person to virtual engagement, characterized by three central measures: rates of scheduled group visits after referral, rates of attended group visits after scheduling, and rates of follow-up after attending a group visit. A z-test was used to compare proportions of no-shows and lost-to-follow-ups between the in-person and virtual attendees. Results: Two hundred and seventy-one patients were referred to the YADC between December 2017 and December 2022. Out of those, 149 (54%) scheduled a group visit. Subsequently, 112 scheduled patients attended a group visit. Sixty-one (54%) attended a virtual group visit, compared to 51 (46%) in-person. Out of these attendees, 45 (62%) in-person attendees followed-up subsequently with a member of the care team, and 28 (38%) virtual attendees. No-show rates were significantly higher in the virtual population at 35% vs. 4% in-person ($P=.002$). Lost-to-follow-up rate was 27% in the virtual population and 12% in-person, ($P=.07$). Conclusions: Young adults with T1D face significant barriers to engagement that virtual medicine may help overcome. This data illustrates the continued challenges with engaging young adults in the virtual setting, and need for further understanding of what other factors may influence follow-up in this patient population.

12. **EXPERIENCES OF TRANSITION TO ADULTHOOD AND TRANSFER TO ADULT CARE IN YOUNG ADULTS WITH TYPE 1 DIABETES: A QUALITATIVE STUDY.**

Olsson, S., Otten, J., Blusi, M., Lundberg, E. & Hörnsten, Å.

Journal of advanced nursing 79, 4621–4634 (2023) doi:[10.1111/jan.15740](https://doi.org/10.1111/jan.15740)

AIM: To explore young adults' experiences of living with type 1 diabetes in the transition to adulthood, including experiences of the transfer from paediatric to adult care. DESIGN: A qualitative approach was used. METHOD: Ten young adults, six women and four men, aged 19-29 years, participated. Participants were recruited at their regular diabetes clinic from spring 2021 to spring 2022. Semi-structured interviews were transcribed and analysed using qualitative content analysis. FINDINGS: Dreaming of being nurtured towards self-reliance was the overarching theme. Personal experiences of the transition to adulthood, including the

transfer from paediatric to adult care, were described in terms of struggling to find balance in daily life, dealing with feelings of being different, being gradually supported to achieve independence, and wishing to be approached as a unique person in healthcare. **CONCLUSION:** In healthcare, it is important to emphasize not only diabetes-related factors but also emotional and psychosocial aspects of life connected to the transition to adulthood, including the transfer to adult care. The young adults wished to be seen as unique persons in healthcare during their emerging adulthood and should therefore be supported to achieve self-reliance through personal preparations for new challenges and for the consequences of transitioning to adulthood. Specialist nurses can provide appropriate knowledge and leadership. **IMPLICATIONS FOR THE PROFESSION:** These findings can guide nurse specialists in support for emerging adults to achieve self-reliance and indicate the importance of person-centred care when experiencing transition and transfer. **REPORTING METHOD:** The study adhered to EQUATOR guidelines, and the COREQ checklist for qualitative studies was used as the reporting method.

13. **EXPERIENCES OF YOUNG PEOPLE LIVING WITH TYPE 1 DIABETES IN TRANSITION TO ADULTHOOD: THE IMPORTANCE OF CARE PROVIDER FAMILIARITY AND SUPPORT.**

Laursen, M. G., Rahbaek, M. Ø., Jensen, S. D. & Praetorius, T.

Scandinavian journal of caring sciences 38, 126–135 (2024) doi:[10.1111/scs.13214](https://doi.org/10.1111/scs.13214)

BACKGROUND: During the developmental transition from childhood to adulthood, young people living with type 1 diabetes (T1D) are more likely to take less care of their chronic disease. Alongside the developmental transition, young people with T1D also experience an organisational transition in which the care responsibility changes from a family-based approach in paediatric care to an individualised approach in adult care. Little is known from the perspective of the young people about what their interactions with the healthcare providers mean during these transitions. **AIM:** The aim of this study is to explore how young people living with T1D experience interactions with their care providers, and what it means for their developmental transition. **METHOD:** Semi-structured interviews with 10 respondents aged 18-20 living with T1D who were recruited from a youth outpatient diabetes clinic in Denmark. Recorded audio data were transcribed and analysed using an interpretative phenomenological analysis approach. **RESULTS:** Young people experience continuity in the relationship with the diabetes nurse from the paediatric clinic and a personal patient-provider relationship with their well-known and new care providers. This creates a feeling of familiarity and contributes to a seamless transition. The young people express that becoming more involved in diabetes treatment increases their willingness to take more responsibility for their own health. They also express that care providers should support them in managing their diabetes and talk about sensitive topics. **CONCLUSION:** Continuity in the relationship with the diabetes nurse makes the transition from paediatric to adult care more satisfying and seamless. To support the developmental transition, care providers should gradually involve young people more in diabetes management and be supportive as they become more independent during the developmental transition.

14. **EXPLORING THE ATTITUDES AND EXPERIENCES OF ADOLESCENTS WITH TYPE 1 DIABETES TOWARDS TRANSITION OF CARE.**

D'Sa, S. *et al.*

Journal of Public Health (Germany) 31, 1151–1156 (2023) doi:[10.1007/s10389-021-01628-5](https://doi.org/10.1007/s10389-021-01628-5)

Introduction: Transition from adolescence to adult care is very challenging for most patients. Without appropriate appointments and education, adolescents can get lost to follow up within one-year of transitioning to adult care (Mistry *et al.* *Diabet Med* 32(7):881–885, 2015). Loss to follow-up can increase risks of adverse short and long term diabetes-related complications, with healthcare contacts mainly limited to crisis-based management (Iversen *et al.* *Scand J Caring Sci* 33(3):723–730, 2019). **Aims:** The purpose of this study was to evaluate the patient's perspective of the process of transition from paediatric to adult-based diabetes services in the Mid-West Region of Ireland. **Methods:** We implemented a new transition clinic at University Hospital Limerick with the collaboration of paediatric and adult endocrinology teams. Eighteen patients opted to attend the clinic, but only 17 patients consented to participate in a qualitative assessment study and completed questionnaires before and after the transition clinic. **Results and conclusion:** In terms of medical management, patients had a good understanding of hypoglycaemia and insulin dose adjustment principles, but were least comfortable with carbohydrate counting. Patients self-ranked their knowledge on driving and

sexual health with a diagnosis of diabetes as poor, in comparison to understanding effects of alcohol and smoking on diabetes. Overall, a majority of the respondents felt more confident in moving to adult-care after attending the transition clinic.

15. **FACTORS ASSOCIATED WITH COMPLETION OF A DIABETES TRANSITION PROGRAM (DTP) IN YOUTH WITH DIABETES MELLITUS.**

Alnayem, W., Krall, J. S., Siminerio, L. M. & Libman, I.

Diabetes 72, (2023) doi:[10.2337/db23-1825-PUB](https://doi.org/10.2337/db23-1825-PUB)

Adolescence and young adulthood are periods of transition when youth with DM typically experience poor outcomes. Programs that equip youth with confidence, support, and knowledge to foster successful lifelong DM management are needed. The DTP was developed to provide care and guided peer-discussions on pertinent topics with a multidisciplinary team over 4 clinic visits annually. To identify predictors for program completion, characteristics of patients who completed the program versus those who did not were examined. A total of 152 subjects were referred (prior to Covid) (53% male, 91% white, mean age at 1st visit 18.8±1.4 years, age at diagnosis 9.8±4.8 years, body mass index (BMI) %ile 74.6±20.6, HbA1c 8.9±2%, 54% on insulin pumps, 17% on continuous glucose monitors (CGM). Half (n=76) completed the program. Characteristics are presented below. There were no differences between those that completed the program vs those that did not in depression score (measured by (PHQ-9)) (8.8±0.5 vs 8.8±0.4, p=0.87), history of visits to ED (3 vs 7%, p=0.44) or admissions (4.5 vs 7%, p=0.72) in the year prior to referral. Patients referred to the DTP appear to be a high-risk population which may explain why completion of the program was 50%. Moreover, identifying as non-white appears to be associated with non-completion of the program, emphasizing the need for different approaches to reach emerging adults.

16. **FROM PAEDIATRIC TO ADULT DIABETES CARE: LOST IN TRANSITION.**

de Beaufort, C., Gomber, A., Sap, S. & Laffel, L.

The lancet. Diabetes & endocrinology 11, 446–448 (2023) doi:[10.1016/S2213-8587\(23\)00091-8](https://doi.org/10.1016/S2213-8587(23)00091-8)

17. **HEALTH CARE TRANSITION TO ADULT CARE IN TYPE 1 DIABETES: ASSOCIATIONS WITH STUDENT AND EMPLOYMENT STATUS-THE SEARCH FOR DIABETES IN YOUTH STUDY.**

Majidi, S. *et al.*

Clinical diabetes : a publication of the American Diabetes Association 41, 510–517 (2023) doi:[10.2337/cd22-0122](https://doi.org/10.2337/cd22-0122)

Successful transition from a pediatric to adult diabetes care provider is associated with reduced ambulatory diabetes care visits and increased acute complications. This study aimed to determine whether the degree of independence in diabetes care and the rate of acute complications after transition to adult diabetes care were associated with individuals' student or employment status. Nonstudents were found to be less likely than students to be independent with diabetes care, and employed nonstudents were at lower risk of diabetic ketoacidosis than unemployed nonstudents. Additional support may be needed for young adults who are not students or are unemployed to improve independence and reduce the risk for acute complications.

18. **IMPROVING PLANNING FOR TRANSITION TO ADULT CARE IN A PEDIATRIC DIABETES CLINIC.**

Wee, E. *et al.*

Clinical diabetes : a publication of the American Diabetes Association 42, 156–160 (2024) doi:[10.2337/cd23-0018](https://doi.org/10.2337/cd23-0018)

Quality Improvement Success Stories are published by the American Diabetes Association in collaboration with the American College of Physicians and the National Diabetes Education Program. This series is intended to highlight best practices and strategies from programs and clinics that have successfully improved the quality of care for people with diabetes or related conditions. Each article in the series is reviewed and follows a standard format developed by the editors of Clinical Diabetes. The following article describes efforts at a large midwestern pediatric health system to improve planning for patients' transition from pediatric to adult diabetes care settings.

19. **INCORPORATING THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION IN TYPE 1 DIABETES CARE FOR EMERGING ADULTS.**
Malik, F. S., Weaver, K. W., Corathers, S. D. & White, P. H.
Endocrinology and metabolism clinics of North America 53, 53–65 (2024) doi:[10.1016/j.ecl.2023.09.003](https://doi.org/10.1016/j.ecl.2023.09.003)
A growing body of literature finds persistent problems in the provision of recommended health care transition services, as well as adverse outcomes associated with the lack of these services in emerging adults with type 1 diabetes. The Six Core Elements of Health Care Transition offers a structured approach to the phases of health care transition support for both pediatric and adult diabetes practices. This article reviews strategies to incorporate the Six Core Elements into ambulatory diabetes care to support successful health care transition for emerging adults with type 1 diabetes.
20. **INDICATORS OF HEALTHCARE TRANSITION PROGRESS AMONG COLLEGE YOUTH WITH TYPE 1 DIABETES.**
Tsevat, R. K., Weitzman, E. R. & Wisk, L. E.
Academic pediatrics 23, 737–746 (2023) doi:[10.1016/j.acap.2022.08.012](https://doi.org/10.1016/j.acap.2022.08.012)
OBJECTIVE: Adolescents with chronic diseases must navigate changing healthcare needs in college and beyond. This study examined the ability of college youth with type 1 diabetes (T1D) to achieve transition milestones and ascertained sociodemographic predictors of a successful healthcare transition (HCT). METHODS: College youth with T1D were recruited via social media and direct outreach to participate in a web-based study, during which they answered questions about the HCT process. Descriptive statistics and multivariable regression were used to evaluate HCT measures as a function of sociodemographic variables. RESULTS: Nearly two-thirds of participants (N = 138) had discussions with their providers about changing healthcare needs (65.9%) and transferring care to adult physicians (64.5%); less than one-third (27.9%) discussed obtaining health insurance as an adult. Females were more likely than males to discuss transitioning to adult providers (70.3% vs 40.7%, $P < .01$). Those covered on a parent's insurance (vs other) plan were more likely to receive help with finding adult providers (79.3% vs 44.4%, $P = .04$) but less likely to discuss how to obtain health insurance (25.0% vs 61.1%, $P < .01$). These differences persisted after adjustment. CONCLUSIONS: Improvement is needed with regard to college youth with T1D becoming autonomous managers of their own care. Gaps were found in their experiences of discussing changing healthcare needs, locating adult providers, and obtaining health insurance-especially among those who were younger, male, and not covered under parental insurance. Efforts to improve the HCT process should focus particularly on these subgroups to advance healthcare delivery in this population.
21. **ONLINE EDUCATIONAL RESOURCES FOR YOUTH LIVING WITH TYPE 1 DIABETES TRANSITIONING TO ADULT CARE: AN ENVIRONMENTAL SCAN OF CANADIAN CONTENT.**
Housni, A. *et al.*
Canadian journal of diabetes S1499-2671(23)00727-X (2024) doi:[10.1016/j.jcid.2023.12.008](https://doi.org/10.1016/j.jcid.2023.12.008)
OBJECTIVES: There are many educational resources for adolescents and young adults living with type 1 diabetes; however, it is unknown whether they address the breadth of topics related to transition to adult care. Our aim in this study was to collect educational resources relevant to Canadian youth and assess their quality and comprehensiveness in addressing the knowledge necessary for youth to prepare for interdependent management of their diabetes. METHODS: We conducted an environmental scan, a systematic assessment and analysis, of online education resources in English and French relevant to Canadian youth living with type 1 diabetes. Resources were screened using an open education resource evaluation grid and relevant resources were mapped to the Readiness for Emerging Adults with Diabetes Diagnosed in Youth, a validated diabetes transition readiness assessment tool. RESULTS: From 44 different sources, 1,245 resources were identified and, of these, 760 were retained for analysis. The majority were webpages (50.1%) and downloadable PDFs (42.4%), and 12.1% were interactive. Most resources covered Diabetes Knowledge (46.0%), Health Behaviour (23.8%), Insulin and Insulin Pump Management (11.8% and 8.6%, respectively), and Health System Navigation (9.7%). Topic areas with the fewest resources were disability accommodations (n=5), sexual health/function (n=4), and locating trustworthy diabetes resources

(n=3). CONCLUSIONS: There are many resources available for those living with type 1 diabetes preparing to transition to adult care, with the majority pertaining to diabetes knowledge and the least for navigation of the health system. Few resources were available on the topics of substance use, sexual health, and reproductive health. An interactive presentation of these resources, as well as a central repository to house these resources, would improve access for youth and diabetes care providers during transition preparation.

22. **PRELIMINARY OUTCOMES OF A TRANSITION INTERVENTION WITH ADOLESCENTS AND YOUNG ADULTS (AYAS) WITH TYPE 1 DIABETES (T1D).**

Monaghan, M., Bryant, B. L., Wang, C. H., Bost, J. E. & Streisand, R.

Diabetes 72, (2023) doi:[10.2337/db23-649-P](https://doi.org/10.2337/db23-649-P)

Introduction: The transition from pediatric to adult diabetes care is particularly risky for AYAs with T1D. We evaluate preliminary outcomes of a behavioral intervention targeting AYA health communication, T1D self-care, and transition readiness. Methods: 52 AYAs (48.1% male; 48.1% non-Hispanic White; M age=20.63±1.10 yrs) enrolled in Planning, Reflecting, and Engaging with Providers for Diabetes Care (PREP-DC) and were randomized to intervention (Int; n=26) or standard care (SC; n=26) groups. AYAs reported on communication, T1D self-care, and transition readiness at baseline and 4 mos (1 mo postintervention); A1c was taken from medical records. AYAs rated satisfaction with PREP-DC participation (1-5; 5=extremely satisfied). T-tests examined change from baseline to follow-up and by group. Results: At follow-up, 51 AYAs (98%) completed questionnaires and 37 (71%) had A1c data. AYAs reported improvements in communication, T1D self-care, and transition readiness (Table 1), with few group differences. Both groups reported high satisfaction with participation (Int M=4.41±.59; SC M=4.45±.60). Discussion: AYAs were engaged in a behavioral trial promoting health communication; the Int group did not demonstrate significant improvements as compared to SC. Future analyses will evaluate final follow-up outcomes (8 mos post-intervention), including transfer to adult care.

23. **PSYCHOLOGICAL RESOURCES OF YOUNG ADULTS WITH TYPE 1 DIABETES MELLITUS DURING TRANSITION FROM A PEDIATRIC TO ADULT DIABETES CLINIC-A MULTICENTER CROSS-SECTIONAL STUDY.**

Matejko, B. *et al.*

Diabetes 72, (2023) doi:[10.2337/db23-701-P](https://doi.org/10.2337/db23-701-P)

Introduction: The period of transition of patients with type 1 diabetes from pediatric to adult-oriented health care is very vulnerable time, as it is associated with poorer glycemic control and less frequent clinic attendance. Aim: The purpose of this study was to evaluate psychological parameters of transitioning young patients with type 1 diabetes during the 1st visit in adult outpatient clinic. Methods: We examined 50 consecutive patients (56% females) transitioning from 03.2021 - 11.2022 into adult care (3 diabetes centers from 3 regions in southern Poland (A=16; B=21; C= 13)) and their basic demographic information. All patients fulfilled the following psychological questionnaires: STAI, GSES, PSS-10, SWLS, AIS, MHLC and CECS. Furthermore, we made comparison of data obtained in the study with data for general healthy population and general population with persons with diabetes. Results: During the first adult outpatients visit patients mean age was 19.2±1.4 yrs. with 9.8±4.3 yrs. of diabetes duration and BMI 23.5±3.1 kg/m². Considering the therapy type: 67% of patients were treated with insulin pump therapy while 33% with multiple daily injections. There was no difference regarding the level of life satisfaction, perceived level of stress and state anxiety between studied population and general/diabetes population. Studied patients had similar locus of health control and negative emotions control in comparison to general population of diabetes. Patients had higher level of suppression of negative emotions: anger, depression, and anxiety than age matched general population. In addition, our population was characterized by higher acceptance of illness and higher level of self-efficacy compared to general/diabetes population. Conclusions: This study indicated good psychological resources and coping mechanisms of young patients transitioning to adult outpatient clinic.

24. **QUALITATIVE STUDY EXPLORING THE PERSPECTIVES OF EMERGING ADULTS WITH TYPE 1 DIABETES AFTER TRANSFER TO ADULT CARE FROM A PAEDIATRIC DIABETES CENTRE IN MONTREAL, CANADA.**

Vaillancourt, M. *et al.*

BMJ open 13, e076524 (2023) doi:[10.1136/bmjopen-2023-076524](https://doi.org/10.1136/bmjopen-2023-076524)

INTRODUCTION: Among youth living with type 1 diabetes (T1D), the increasing demands to diabetes self-care and medical follow-up during the transition from paediatric to adult care has been associated with greater morbidity and mortality. Inadequate healthcare support for youth during the transition care period could exacerbate psychosocial risks and difficulties that are common during emerging adulthood. The current investigation sought to explore the post-transfer perceptions of emerging adults living with T1D relating to their transition to adult care. **RESEARCH DESIGN AND METHODS:** Thirty-three emerging adults living with T1D were recruited during paediatric care and contacted for a semistructured interview post-transfer to adult care (16.2±4.2 months post-transfer) in Montreal, Canada. We analysed data using thematic analysis. **RESULTS:** We identified four key themes: (1) varied perceptions of the transition process from being quick and abrupt with minimal advice or information from paediatric healthcare providers (HCP) to more positive including a greater motivation for self-management and the transition being concurrent with the developmental period; (2) facilitators to the transition process included informational and tangible social support from HCPs and family or friends, a positive relationship with adult HCP and a greater ease in communicating with the adult care clinic or adult HCP; (3) barriers to adequate transition included lack of advice or information from paediatric HCPs, loss of support from HCPs and friends or family, the separation of healthcare services and greater difficulty in making appointments with adult clinic or HCP and (4) participants recommendations for improving the transition included increasing the length and frequency of appointments in adult care, having access to educational information, and better transition preparation from paediatric HCPs. **CONCLUSIONS:** The experiences and perceptions of emerging adults are invaluable to guide the ongoing development and improvement of transition programmes for childhood-onset chronic illnesses.

25. **RESULTS OF A NEW TRANSITION OF CARE PROCESS FROM PEDIATRIC TO ADULT DIABETES SERVICES.**

Cooper, F. I., Vyas, N., Pierce, J. & Kulasingham, A. Y.

Journal of the Endocrine Society 7, A800–A801 (2023) doi:[10.1210/jendso/bvad114.1501](https://doi.org/10.1210/jendso/bvad114.1501)

Adolescence is a challenging time in a child's life and can be even more stressful for those living with diabetes. It has been shown that glycemic levels worsen in young adulthood due to factors such as increasing insulin resistance and gaps in care during the transitioning from pediatric to adult diabetes care. Data suggest that beginning transition preparation in early adolescence is associated with better outcomes. Our aim was to create a transition of care program for youth in our diabetes clinic following the Got Transition Core Elements and assess its effectiveness. First, we established a clinic transition policy and corresponding informational letter, which we distributed to youth ages 12-16. Then, we adopted a Diabetes Summary Form to track and monitor transition progress. Next, we implemented transition readiness screening to youth ages 14-16 using the Readiness Assessment of Emerging Adults with Diabetes Diagnosed in Youth (READDY) tool. Last, we distributed GotTransition.org surveys to youth and their caregivers to assess satisfaction with our clinic's transition process and perceived readiness to move to an adult provider. The transition letter distribution rate had a mean of 56% and the READDY completion rate had a mean of 40%. Although we did not achieve our distribution target goal of 80%, 90% of those who did complete the READDY indicated they were somewhat or very ready to transition to adult care. The satisfaction survey revealed that many youths still need assistance with insurance (32%) and finding an adult provider (45%). Overall, our initial efforts to establish a healthcare transition program were successful. We will continue our work on 1) improving letter distribution and readiness screening rates, 2) designing a curriculum centered around adolescent-specific issues, including insurance needs and 3) increasing our connections with adult endocrinologists to facilitate seamless transitions. We hope other pediatric diabetes clinics can learn from our experience, as well expanding to other subspecialty clinics in our children's hospital.

26. **SUPPORTIVE USE OF DIGITAL TECHNOLOGIES DURING TRANSITION TO ADULT HEALTHCARE FOR YOUNG PEOPLE WITH LONG-TERM CONDITIONS, FOCUSING ON TYPE 1 DIABETES MELLITUS: A SCOPING REVIEW.**

Orpin, J. *et al.*

Journal of child health care: for professionals working with children in the hospital and community 13674935231184920 (2023) doi:[10.1177/13674935231184919](https://doi.org/10.1177/13674935231184919)

Type 1 diabetes mellitus (T1DM) is the second most common chronic or long-term condition (LTC) affecting young people (YP); when transitioning from paediatric to adult healthcare, young people with LTCs such as T1DM are expected to self-manage medication, diet and clinical appointments. This scoping review aimed to analyse research examining ways digital health technologies were used to support YP with LTCs during transition from paediatric to adult healthcare and to establish YP's needs, experiences and challenges when transitioning. We aimed to identify knowledge gaps and inform development of a novel chatbot with components such as avatars and linked videos to help YP with T1DM gain self-management confidence and competence during transition. Nineteen studies identified through searching five electronic databases were included in this review. A combination of digital health technologies was used to support transition of YP with LTCs to adult healthcare. Barriers to successful transition were reported and YP described the importance of social relationships and transition readiness and expressed the need for individualised interventions that acknowledge social factors such as work and college. No supportive chatbots with components to help YP with T1DM were identified. This contribution will inform future development and evaluation of such a chatbot.

27. **TEXT MESSAGE-BASED INTERVENTION, KEEPING IN TOUCH (KIT), TO SUPPORT YOUTH AS THEY TRANSITION TO ADULT TYPE 1 DIABETES CARE: A PROTOCOL FOR A MULTISITE RANDOMISED CONTROLLED SUPERIORITY TRIAL.**

Sanmugalingham, G. *et al.*

BMJ open 13, e071396 (2023) doi:[10.1136/bmjopen-2022-071396](https://doi.org/10.1136/bmjopen-2022-071396)

INTRODUCTION: Transition from paediatric to adult care can be challenging for youth living with type 1 diabetes (T1D), as many youth feel unprepared to transfer to adult care and are at high risk for deterioration of glycaemic management and acute complications. Existing strategies to improve transition experience and outcomes are limited by cost, scalability, generalisability and youth engagement. Text messaging is an acceptable, accessible and cost-effective way of engaging youth. Together with adolescents and emerging adults and paediatric and adult T1D providers, we co-designed a text message-based intervention, Keeping in Touch (KiT), to deliver tailored transition support. Our primary objective is to test the effectiveness of KiT on diabetes self-efficacy in a randomised controlled trial. **METHODS AND ANALYSIS:** We will randomise 183 adolescents with T1D aged 17-18 years within 4 months of their final paediatric diabetes visit to the intervention or usual care. KiT will deliver tailored T1D transition support via text messages over 12 months based on a transition readiness assessment. The primary outcome, self-efficacy for diabetes self-management, will be measured 12 months after enrolment. Secondary outcomes, measured at 6 and 12 months, include transition readiness, perceived T1D-related stigma, time between final paediatric and first adult diabetes visits, haemoglobin A1c, and other glycaemia measures (for continuous glucose monitor users), diabetes-related hospitalisations and emergency department visits and the cost of implementing the intervention. The analysis will be intention-to-treat comparing diabetes self-efficacy at 12 months between groups. A process evaluation will be conducted to identify elements of the intervention and individual-level factors influencing implementation and outcomes. **ETHICS AND DISSEMINATION:** The study protocol version 7 July 2022 and accompanying documents were approved by Clinical Trials Ontario (Project ID: 3986) and the McGill University Health Centre (MP-37-2023-8823). Study findings will be presented at scientific conferences and in peer-reviewed publications. **TRIAL REGISTRATION NUMBER:** NCT05434754.

28. **TRANSITION FROM CHILDHOOD TO ADULT CARE IN PATIENTS WITH TYPE 1 DIABETES: 20 YEARS OF EXPERIENCE FROM THE TÜBINGER TRANSITION STUDY.**

Schweizer, R. *et al.*

Experimental and clinical endocrinology & diabetes : official journal, German Society of Endocrinology [and] German Diabetes Association 131, 532–538 (2023) doi:[10.1055/a-2132-9585](https://doi.org/10.1055/a-2132-9585)

AIMS: Transition from pediatric to adult care is difficult for patients with chronic diseases. In this study, factors associated with metabolic control in childhood-onset type 1 diabetes (T1D) after transfer to adult care were analyzed. **METHODS:** Overall, 224 persons with T1D were contacted yearly from 1998 to 2019. They voluntarily answered a questionnaire about their current hemoglobin A1c (HbA1c) levels, diabetes-associated complications, kind of care, living conditions, and family situation. Then, mixed longitudinal-cross-sectional

analyses were carried out. RESULTS: Overall, 190 patients answered at least once (mean age: 26.6 years). Diabetes complications were mentioned by 10 patients (5 microalbuminuria, 5 retinopathy). Most patients (92.6%) were in diabetes-specific care during the first year after transfer, with a trend to leave diabetes-specific care during the observation period. Patients in diabetes-specific care displayed lower HbA1c levels (%/mmol/mol) (7.1/54 vs. 7.5/58). An important predictor for HbA1c after transfer was HbA1c during the year before transfer ($r=0.67$, $p < 0.001$). Patients living alone showed no difference in HbA1c levels from those living with their parents. Married patients had lower HbA1c levels (7.0/53 vs. 7.3/56, $p < 0.05$) than unmarried ones. Patients with children (15.8%) presented lower HbA1c levels (6.9/52 vs. 7.3/56, $p < 0.01$) than those without. CONCLUSIONS: Good metabolic results are favored in patients followed-up in specialized care, are married, and are parents. We recommend transfer to a diabetologist with experience in T1D at an individual age.

29. **TRANSITION MODELS OF CARE FOR TYPE 1 DIABETES: A SYSTEMATIC REVIEW.**

Zurynski, Y. *et al.*

BMC health services research 23, 779 (2023) doi:[10.1186/s12913-023-09644-9](https://doi.org/10.1186/s12913-023-09644-9)

BACKGROUND: Managing the care regimen for Type 1 Diabetes is challenging for emerging adults, as they take on greater responsibility for self-management. A diverse range of models of care have been implemented to improve safety and quality of care during transition between paediatric and adult services. However, evidence about acceptability and effectiveness of these is limited. Our aim was to synthesise the evidence for transition models and their components, examine the health related and psychosocial outcomes, and to identify determinants associated with the implementation of person-centred models of transition care. METHOD: We searched Medline, CINAHL, EMBASE and Scopus. Peer reviewed empirical studies that focused on T1D models of care published from 2010 to 2021 in English, reporting experimental, qualitative, mixed methods, and observational studies were included. RESULTS: Fourteen studies reported on health and psychosocial outcomes, and engagement with healthcare. Three key models of care emerged: structured transition education programs (6 studies), multidisciplinary team transition support (5 studies) and telehealth/virtual care (3 studies). Compared with usual practice, three of the six structured transition education programs led to improvements in maintenance of glycaemic control, psychological well-being, and engagement with health services. Four MDT transition care models reported improved health outcomes, and improved engagement with health services, however, three studies reported no benefit. Reduced diabetes related stress and increased patient satisfaction were reported by two studies, but three reported no benefit. Telehealth and virtual group appointments improved adherence to self-management and reduced diabetes distress but did not change health outcomes. CONCLUSIONS: Although some health and psychosocial benefits are reported, the results were mixed. No studies reported on T1D transition model implementation outcomes such as acceptability, adoption, and appropriateness among clinicians or managers implementing these models. This gap needs to be addressed to support future adoption of successful models.

30. **TRANSITION OF CARE OF PEDIATRIC PATIENTS WITH SPECIAL NEEDS TO ADULT CARE SETTINGS: CHILDREN WITH DIABETES MELLITUS AND OTHER ENDOCRINE DISORDERS.**

Singh, P. & Seth, A.

Indian journal of pediatrics 90, 1134–1141 (2023) doi:[10.1007/s12098-023-04780-w](https://doi.org/10.1007/s12098-023-04780-w)

Childhood onset endocrine disorders need long-term medical, psychological and social management. Over time, many illnesses evolve, while others may witness onset of new complications. Thus, the components of the care change as the child grows into adolescence and then adulthood. The transition of children and adolescents with chronic endocrine disorders to adult care continues to be a major challenge. Pediatric and adult healthcare teams should together design a transitional care plan that is developmentally appropriate and responsive to the needs of young adults. The preparation for transition to adult care should begin early in adolescence and involve both the adolescent and his parents. A structured and planned transitional care bridges the gap between pediatric and adult care teams, promote ongoing engagement and build trust with the new healthcare teams. Combined pediatric-adult care transition model for endocrine conditions has yielded high adherence rates and patient satisfaction.

31. **UNDERSTANDING WHETHER AND HOW A DIGITAL HEALTH INTERVENTION IMPROVES TRANSITION CARE FOR EMERGING ADULTS LIVING WITH TYPE 1 DIABETES: PROTOCOL FOR A MIXED METHODS REALIST EVALUATION.**

Wang, R. *et al.*

JMIR research protocols 12, e46115 (2023) doi:[10.2196/46115](https://doi.org/10.2196/46115)

BACKGROUND: Emerging adults living with type 1 diabetes (T1D) face a series of challenges with self-management and decreased health system engagement, leading to an increased risk of acute complications and hospital admissions. Effective and scalable strategies are needed to support this population to transfer seamlessly from pediatric to adult care with sufficient self-management capability. While digital health interventions for T1D self-management are a promising strategy, it remains unclear which elements work, how, and for which groups of individuals. **OBJECTIVE:** This study aims to evaluate the design and implementation of a multicomponent SMS text message-based digital health intervention to support emerging adults living with T1D in real-world settings. The objectives are to identify the intervention components and associated mechanisms that support user engagement and T1D health care transition experiences and determine the individual characteristics that influence the implementation process. **METHODS:** We used a realist evaluation embedded alongside a randomized controlled trial, which uses a sequential mixed methods design to analyze data from multiple sources, including intervention usage data, patient-reported outcomes, and realist interviews. In step 1, we conducted a document analysis to develop a program theory that outlines the hypothesized relationships among ‘individual-level contextual factors, intervention components and features, mechanisms, and outcomes,’ with special attention paid to user engagement. Among them, intervention components and features depict 10 core characteristics such as transition support information, problem-solving information, and real-time interactivity. The proximal outcomes of interest include user engagement, self-efficacy, and negative emotions, whereas the distal outcomes of interest include transition readiness, self-blood glucose monitoring behaviors, and blood glucose. In step 2, we plan to conduct semistructured realist interviews with the randomized controlled trial’s intervention-arm participants to test the hypothesized ‘context-intervention-mechanism-outcome’ configurations. In step 3, we plan to triangulate all sources of data using a coincidence analysis to identify the necessary combinations of factors that determine whether and how the desired outcomes are achieved and use these insights to consolidate the program theory. **RESULTS:** For step 1 analysis, we have developed the initial program theory and the corresponding data collection plan. For step 2 analysis, participant enrollment for the randomized controlled trial started in January 2023. Participant enrollment for this realist evaluation was anticipated to start in July 2023 and continue until we reached thematic saturation or achieved informational power. **CONCLUSIONS:** Beyond contributing to knowledge on the multiple pathways that lead to successful engagement with a digital health intervention as well as target outcomes in T1D care transitions, embedding the realist evaluation alongside the trial may inform real-time intervention refinement to improve user engagement and transition experiences. The knowledge gained from this study may inform the design, implementation, and evaluation of future digital health interventions that aim to improve transition experiences.

[torna all'indice](#)

ADHD

1. **TRANSITIONING TO ADULT MENTAL HEALTH SERVICES FOR YOUNG PEOPLE WITH ADHD: AN ITALIAN-BASED SURVEY ON PRACTICES FOR PEDIATRIC AND ADULT SERVICES.**

Roberti, E. *et al.*

Child and Adolescent Psychiatry and Mental Health 17, (2023) doi:[10.1186/s13034-023-00678-9](https://doi.org/10.1186/s13034-023-00678-9)

Background: Supporting young ADHD patients in transition to adult services is essential. Yet, the low percentages of successful referrals and the issues reported by patients and clinicians stress the need for further attention to transitioning practices. The present study assessed the transitioning process of Attention-Deficit/Hyperactivity Disorder (ADHD) patients in Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) in the Italian territory. We asked child and adult psychiatrists to report the current state of services and their observations on limitations and possible future matters that must be

addressed. Method: Seventy-seven centers (42 CAMHS, 35 AMHS) filled in a web-based survey in which they reported the number of ADHD patients, how many transitioning patients they had within the past year, and how they structured transition. Results: A fragmented picture emerged from the survey. Lack of resources, training, and communication between services hinder the transition process, and many adult patients remain under CAMHS' care. While some services have a protocol, there is no structured guidance that can help improve integration and continuity of treatment. Conclusion: The observed situation reflects a need for improvement and standard guidelines to enable a successful transition process, considering clinicians' and patients' necessities.

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