



Comparative Effectiveness Review
Number 255

Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs



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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of healthcare in the United States.

This report from the EPC Program at AHRQ is one of several efforts underway across the U.S. Department of Health and Human Services to implement provisions of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act of 2018 (Public Law No: 115-180). The National Cancer Institute of the National Institutes of Health funded this report from the EPC Program at AHRQ.

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To bring the broadest range of experts into the development of evidence reports and health technology assessments, AHRQ encourages the EPCs to form partnerships and enter into collaborations with other medical and research organizations. The EPCs work with these partner organizations to ensure that the evidence reports and technology assessments they produce will become building blocks for healthcare quality improvement projects throughout the Nation. The reports undergo peer review and public comment prior to their release as a final report

AHRQ expects that the EPC evidence reports and technology assessments, when appropriate, will inform individual health plans, providers, and purchasers as well as the healthcare system as a whole by providing important information to help improve healthcare quality.

If you have comments on this evidence report, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857, or by email to epc@ahrq.hhs.gov.

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Technical Expert Panel

In designing the study questions and methodology at the outset of this report, the EPC consulted several technical and content experts. Broad expertise and perspectives were sought. Divergent and conflicting opinions are common and perceived as healthy scientific discourse that results in a thoughtful, relevant systematic review. Therefore, in the end, study questions, design, methodologic approaches, and/or conclusions do not necessarily represent the views of individual technical and content experts.

Technical Experts must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential conflicts of interest identified.

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Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs

Structured Abstract

Objective. To understand the evidence base for care interventions, implementation strategies, and between-provider communication tools among children with special healthcare needs (CSHCN) transitioning from pediatric to adult medical care services.

Data sources. We searched Ovid MEDLINE[®], Ovid Embase[®], the Cochrane Central trials (CENTRAL) registry, and CINAHL[®] to identify studies through September 10, 2021. We conducted grey literature searches to identify additional resources relevant to contextual questions.

Review methods. Using a mixed-studies review approach, we searched for interventions or implementation strategies for transitioning CSHCN from pediatric to adult services. Two investigators screened abstracts and full-text articles of identified references for eligibility. Eligible studies included randomized controlled trials, quasi-experimental observational studies, and mixed-method studies of CSHCN, their families, caregivers, or healthcare providers. We extracted basic study information from all eligible studies and grouped interventions into categories based on disease conditions. We summarized basic study characteristics for included studies and outcomes for studies assessed as low to medium risk of bias using RoB-2.

Results. We identified 9,549 unique references, 440 of which represented empirical research; of these, 154 (16 major disease categories) described or examined a care transition intervention with enough detail to potentially be eligible for inclusion in any of the Key Questions. Of these, 96 studies met comparator criteria to undergo risk of bias assessment; however only 9 studies were assessed as low or medium risk of bias and included in our analytic set. Low-strength evidence shows transition clinics may not improve hemoglobin A1C levels either at 12 or 24 months in youth with type 1 diabetes mellitus compared with youth who received usual care. For all other interventions and outcomes, the evidence was insufficient to draw meaningful conclusions because the uncertainty of evidence was too high. Some approaches to addressing barriers include dedicating time and resources to support transition planning, developing a workforce trained to care for the needs of this population, and creating structured processes and tools to facilitate the transition process.

No globally accepted definition for effective transition of care from pediatric to adult services for CSHCN exists; definitions are often drawn from principles for transitions, encompassing a broad set of clinical aspects and other factors that influence care outcomes or promote continuity of care. There is also no single measure or set of measures consistently used to evaluate effectiveness of transitions of care. The literature identifies a limited number of available training and other implementation strategies focused on specific clinical specialties in targeted settings. No eligible studies measured the effectiveness of providing linguistically and culturally competent healthcare for CSHCN. Identified transition care training, and care interventions to

prepare pediatric patients and their families for transitioning from CSHCN to adult care, varied considerably.

Conclusions. Little rigorous evidence exists to inform care interventions and implementation strategies. Significant barriers impede implementation of interventions, tools, and trainings to transition CSHCN, which may be reduced in future intervention development. This review highlights the need for more rigorous studies across the diverse populations of CSHCN in order to provide clearer answers for CSHCN, their families, caregivers, providers, funders, and policymakers.

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Executive Summary

Main Points

- With only a single exception that showed no benefit, we found that for all outcomes and interventions the evidence was insufficient to draw conclusions because the uncertainty of evidence was too high. Insufficient evidence does not mean that the intervention is of no value to children with special healthcare needs (CSHCN).
- Transition clinics may not improve hemoglobin A1C levels at 12 or 24 months in youth with type 1 diabetes mellitus compared with youth who received usual care (low-strength evidence).
- While significant barriers impede implementation of interventions, some approaches to reduce these barriers in future interventions include dedicating time and resources to support transition planning, developing a workforce trained to care for the needs of this population, and creating structured processes and tools to facilitate the transition process.
- No globally accepted definition exists for effective transition of care from pediatric to adult services for CSHCN, nor is a single measure or set of measures consistently used to evaluate effectiveness of transitions of care.
- The literature identifies only a limited number of available trainings or other implementation strategies, generally focused on specific clinical specialties in targeted settings.
- No included studies measured the effectiveness of providing linguistically and culturally competent healthcare for CSHCN.
- Trainings and interventions to prepare pediatric patients and their families for transitioning CSHCN to adult care vary considerably in their components, structures, and processes.

Background and Purpose

In the United States, nearly 20 percent of children under age 18 have special healthcare needs,¹ defined as having or being at increased risk for chronic physical, developmental, behavioral, or emotional conditions—and this population is growing.² Often, these children will require lifelong health-related services. Between 2011 and 2017, approximately 4.5 million CSHCN ages 12–18 transitioned from pediatric to adult healthcare providers.³ Such transitions are often difficult and can lead to gaps in care, adverse health outcomes, and frustration for patients and families.³⁻⁵

This review sought to evaluate the effectiveness and harms of (1) healthcare interventions targeted toward CSHCN and their families/caregivers, (2) strategies to implement interventions for healthcare transitions including provider-related training, and (3) tools to facilitate communication between pediatric and adult providers. Further, this review discusses definitions and measures for effective healthcare transition for CSHCN, training and implementation strategies available to prepare pediatric patients, families, and healthcare providers for transitioning to adult medical care (including culturally competent approaches), and strategies to increase the availability of adult care providers in the transition process. The target audience for this review includes not only CSHCN, their families, caregivers, and providers, but also policymakers, all of whom rely upon current evidence for interventions to support healthcare

transitions for CSHCN. The National Cancer Institute will use our findings to help develop its own independent recommendations regarding future research and funding.

Methods

The methods for this systematic review follow the Agency for Healthcare Research and Quality Methods Guide for Effectiveness and Comparative Effectiveness Reviews. See the review protocol (<https://effectivehealthcare.ahrq.gov/products/transitions-care-pediatric-adult/protocol>) and the full report of the review for additional details. We searched Ovid MEDLINE®, Ovid Embase®, the Cochrane Central trials (CENTRAL) registry, and CINAHL® to identify randomized controlled trials and quasi-experimental designs published and indexed in bibliographic databases through September 2021.

Results

We identified 9,549 unique references of which 440 represented empirical research using quantitative or qualitative method; of these, we categorized 154 as describing or examining a care transition intervention with enough detail to be potentially eligible for inclusion in any of the Key Questions. Of the 154 potentially eligible studies, which comprised 16 major disease categories, 96 met comparator criteria to undergo risk of bias assessment; however, only nine were assessed as low or medium risk of bias and included in our analytic set. We did not combine data quantitatively due to variability of interventions, comparison groups, outcomes measured, and study timing.

Populations in the studies included those diagnosed with conditions common among CSHCN such as diabetes mellitus, cystic fibrosis, congenital heart disease, inflammatory heart disease, juvenile idiopathic arthritis, cancer, and others. Interventions were implemented across the age range eligible for transition, with some studies conducted in early adolescence (e.g., 14–15) and others in young adult populations (e.g., 19–23). Care interventions ranged widely, from transition programs and clinics to educational workbooks and care coordinators. Intervention approaches varied both within and across disease conditions. Transition outcomes from these studies included measures ranging from transition readiness to ongoing care. Studies also used a diverse set of outcome measures to evaluate intervention effects. Most interventions were conducted within specialty settings, transition clinics, and integrated health systems, with a notable lack of studies in primary care settings.

Low-strength evidence showed transition clinics may not improve hemoglobin A1C levels at 12 or 24 months in youth with type 1 diabetes mellitus compared with usual care.^{6,7} For all other interventions and outcomes, we found the evidence insufficient to draw conclusions. Insufficient evidence does not mean that the intervention is of no value to CSHCN. Rather, it means that, due to the uncertainty of the evidence, we cannot draw meaningful conclusions at this time.

Significant barriers impede the implementation of interventions, tools, and trainings for transitioning CSHCN from pediatric to adult services. Examples of barriers include challenges with the adaptability of interventions, complex social challenges for patients (e.g., insurance, employment), lack of dedicated resources to support transitions, lack of care team training, and lack of a structured transition processes. The interventions and trainings identified by this literature set vary considerably in their components, structure, and processes. Additionally, no globally accepted definition exists for effective care transitions for CSHCN; instead, current definitions encompass a broad range of clinical and patient-centered factors. Similarly, no single measure or set of measures is used in this body of research. Even within a single domain, such as

transition readiness or quality of life, multiple measures are used. Further, the literature has identified only a limited number of available trainings and other implementation strategies, generally focused on specific clinical specialties in targeted settings, and none of the included studies measured the effectiveness of providing linguistically and culturally competent healthcare care for CSHCN who are transitioning from pediatric to adult services. CSHCN, their caregivers, providers, and other stakeholders may initially draw from evidence and best practices outside of this population by using a few systematic reviews and organizational trainings that inform culturally and linguistically competent healthcare in general populations and settings, but these are not specific to CSHCN.

Limitations

We applied a broad definition of care interventions, implementation strategies, and trainings in order to enlarge the scope of studies and thus better understand the range of interventions used in this population. However, we did not include care interventions for transitioning CSHCN to non-healthcare adult services. Educational and vocational interventions may contribute meaningfully to successful transitions for CSHCN, but were beyond the scope of our review.

Implications and Conclusions

Despite identifying a diverse range of intervention components and implementation strategies, our review was unable to provide a synthesized robust evidence base for which interventions work for effectively transitioning CSHCN from pediatric to adult medical care. The lack of sufficient evidence provides no clear answers for CSHCN, their families, caregivers and providers, or for funders and policymakers. Healthcare transitions are complex and multi-dimensional; however, stakeholders rely on institutional policies and professional organization position statements to determine whether to disseminate or implement specific interventions in their populations or care settings as the field continues to emerge.⁸

Many aspects of interventions for CSHCN need more thorough evaluation. Importantly, we found that study designs used in this literature lacked the necessary rigor to provide a solid evidence base. Future research for this population is crucial to generate quality evidence—not only to understand the most effective interventions, but also to understand how these interventions support adaptability across diverse disease conditions and sub-populations (e.g., race/ethnicity, sex/sexual orientation, socioeconomic status, and care setting).

References

1. HRSA Maternal and Child Health. Children and Youth with Special Health Care Needs. <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs#ref1>. Accessed on April 30, 2021.
2. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998 Jul;102(1 Pt 1):137-40. doi: 10.1542/peds.102.1.137. PMID: 9714637.
3. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013 Jun;131(6):1090-7. doi: 10.1542/peds.2012-3050. PMID: 23669518.
4. Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatric Blood and Cancer*. 2013;60(8):1365-8. doi: 10.1002/pbc.24494. PMID: 369155822.

5. Bloom SR, Kuhlthau K, Van Cleave J, et al. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012 Sep;51(3):213-9. doi: 10.1016/j.jadohealth.2012.01.007. PMID: 22921130.
6. Spaic T, Robinson T, Goldbloom E, et al. Closing the gap: Results of the multicenter Canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. *Diabetes Care*. 2019;42(6):1018-26. doi: 10.2337/dc18-2187. PMID: 2002045490.
7. White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *The Lancet Child & Adolescent Health*. 2017. doi: 10.1016/s2352-4642(17)30089-5. PMID: 30169183.
8. Quinn S, Chung R, Kuo A, Maslow G, et al. Transition to adulthood for youth with chronic conditions and special health care needs. *J Adolesc Health*. 2020: 631-634. doi.org/10.1016/j.jadohealth.2020.02.006

Chapter 1. Introduction

Background and Objective for Systematic Review

In the United States, nearly 20 percent of children under age 18 have special healthcare needs,¹ defined as having or being at increased risk for chronic physical, developmental, behavioral, or emotional conditions—and this population is growing.² Often, these children will require lifelong health-related services. Between 2011 and 2017, an estimated 4.5 million children with special healthcare needs (CSHCN) ages 12–18 transitioned or prepared to transition from pediatric to adult healthcare providers.³ Such transitions are often difficult and can lead to gaps in care, adverse health outcomes, and frustration for patients and families.³⁻⁵ Therefore, identifying the most effective interventions to improve healthcare transitions and outcomes for CSHCN is critical. This need is further underscored by prioritization of healthcare transitions as a Healthy People 2030 research objective⁶ and inclusion as a performance measure in state and federal programs.⁷

Previous reviews of literature on interventions for healthcare transition in CSHCN have called for new research to rigorously examine the effectiveness of programs or services, while noting that the few existing studies mostly fail to use rigorous study designs, leading to a weak evidence base.^{5, 8} Some of the difficulty stems from lack of clarity around managing transitions, particularly as no globally accepted definition exists for effective transition from pediatric to adult medical care. In 2011, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians sought to address this issue by publishing a framework for implementing care transitions for youth (starting in early adolescence) to aid clinicians in transition within their medical home.⁹ In this report, they define the goal of healthcare transition as “maximizing lifelong functioning and well-being...[thereby] ensuring that high-quality, developmentally appropriate healthcare services are available in an uninterrupted manner as the person moves from adolescence to adulthood.”⁹ Subsequently, Got Transitions[®] (a federally funded national resource center on healthcare transitions) developed a structured clinical quality improvement approach for transitioning patients from pediatric to adult medical care. One of several models for managing transitions, Got Transitions approach is called “Six Core Elements of Health Care Transition.” This approach is customizable across many transition care models^{10, 11} and includes transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer completion.¹²

Healthcare providers have integrated the Six Core Elements into practice in various ways, including direct interventions for healthcare transitions with children and their caregivers, implementation strategies such as provider training, and tools to facilitate communication between pediatric and adult providers. However, the broad spectrum of included components targeted within the Six Core Elements has raised questions about the best transition intervention designs, implementation tools, and strategies to address these complex transitions. Questions persist around whether/how intervention and participant characteristics affect outcomes of specific approaches, and whether/how those approaches could be improved. Characteristics that might affect transition outcomes include patient demographics (e.g., age, ethnicity, immigration status), capacity for self-management (e.g., health literacy, prior healthcare attendance), condition type and severity, provider/hospital features (e.g., access to specialty services, specialty training) and care setting (e.g., specialty center, telemedicine).¹³⁻¹⁵

While CSHCN often experience significant barriers to effectively transitioning from pediatric to adult medical care,^{4, 14, 16, 17} the lack of rigorous evaluation of interventions and strategies to

reduce these barriers may hinder widespread development and dissemination of policies and programs for this population, as has been highlighted in previous evidence reviews.^{18, 19} Further, interventions vary widely in their components, structure, and processes,³ and might also lack effective tools or engagement to address the needs of culturally diverse populations. Measures of successful transition also vary widely across study populations and interventions, raising questions about how best to assess transition interventions. Finally, providers who care for CSHCN face persistent uncertainty about effective programs and practices, as well uncertainty or inconsistency about incentives to engage in transition care (e.g., reimbursement, capacity, training) across settings and specialties (e.g., primary care).²⁰ Identifying and understanding intervention characteristics that lead to more successful transitions will help patients, caregivers, and providers make more informed decisions about which interventions (or components) might work for whom and under what circumstances.

Purpose and Scope

The National Cancer Institute (NCI) requested this review as part of a series of projects for The Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act, which is devoted to advancing the state of science and improving the healthcare and quality of life for children and adolescent cancer survivors. Because NCI anticipated limited research on healthcare transitions specific to pediatric cancer, our review examined transitions to adult healthcare for all CSHCN. The target audience for this review includes not only CSHCN, their families, caregivers, and providers, but also policymakers, all of whom rely upon current evidence for interventions to support healthcare transitions for CSHCN. The key decisional dilemmas addressed by the review include the effectiveness and harms of 1) healthcare interventions targeted toward CSHCN and their families/caregivers, 2) strategies to implement interventions for healthcare transitions including provider-related training, and 3) tools to facilitate communication between pediatric and adult providers. Further, this review discusses definitions and measures for effective healthcare transition for CSHCN, training and implementation strategies available to prepare pediatric patients, their families, and healthcare providers for transitioning to adult medical care (including culturally competent strategies), and strategies to increase the availability of adult care providers in the transition process.

The Research Questions

This review addressed three Key Questions (KQs) to evaluate the effects of interventions for transition from pediatric to adult services for **children with special healthcare needs**. Healthcare transition interventions can be complex or multicomponent, including behavior changes on the part of patients and care providers. Therefore, the review included a question to help understand barriers and facilitators for such interventions. We also included a set of Contextual Questions (CQs) to provide information on the context within which care transitions happen. KQs and CQs were developed based on National Cancer Institute priorities and input from technical experts, with further feedback and refinement received during a public comment period.

Key Questions for Systematic Review

- **KQ1:** What are the effectiveness, comparative effectiveness, harms, and costs of **care interventions for transition** from pediatric to adult

medical care services, including primary care, for children with special healthcare needs and their families/caregivers?

- **KQ1a:** How do outcomes vary by intervention characteristics or components?
- **KQ1b:** How do outcomes vary by patient/caregiver or provider characteristics or setting?
- **KQ1c:** What are the barriers and facilitators to effective transitions?
- **KQ1d:** What are the gaps in evidence for the effectiveness of the interventions?
- **KQ2:** What are the effectiveness, comparative effectiveness, harms, and costs of **implementation strategies for care interventions for transition**, including provider-related training?
 - **KQ2a:** How do outcomes vary by intervention characteristics or components?
 - **KQ2b:** How do outcomes vary by patient/caregiver or provider characteristics or setting?
 - **KQ2c:** What are the barriers and facilitators to effective implementation?
 - **KQ2d:** What are the gaps in evidence for the effectiveness of the interventions?
- **KQ3:** What are the effectiveness, comparative effectiveness, harms, and costs of **tools to facilitate communication between pediatric and adult providers** for care transitions from pediatric to adult medical care for children with special healthcare needs and their families/caregivers?
 - **KQ3a:** How do outcomes vary by intervention characteristics or components?
 - **KQ3b:** How do outcomes vary by patient/caregiver or provider characteristics or setting?
 - **KQ3c:** What are the barriers and facilitators to effective tools to facilitate communication?
 - **KQ3d:** What are the gaps in evidence for the effectiveness of the interventions?

Contextual Questions

1. How is effectiveness defined and measured for transitions of care from pediatric to adult services for children with special healthcare needs?

2. What transition care training and other implementation strategies are available to prepare pediatric medical providers (e.g., pediatricians and other specialists) and adult medical providers (e.g., primary care providers, nurse practitioners, physician assistants) for transitioning children with special healthcare needs to adult care?
3. What training is available for linguistically and culturally competent care?
4. What transition care training and other implementation strategies are available to prepare pediatric patients and their families for transitioning children with special healthcare needs to adult care?
5. What care interventions including primary care have been used for transition from pediatric to adult medical care for children with special healthcare needs?
6. What strategies have been proposed to increase availability of adult care providers for people transitioning from pediatric to adult care?

Population, Intervention, Comparator, Outcome, Timing and Setting

Table 1.1 provides detailed information on the populations, interventions, comparators, outcomes, timing, and settings (PICOTS), and include criteria used for inclusion of studies in the review based on Key Questions.

Table 1.1. Population, intervention, comparator, outcome, timing, and setting (PICOTS)

| Element | KQ1: Benefits and Harms of Care Intervention | KQ2: Implementation Strategies | KQ3: Communication Tools |
|-------------------|--|--|--|
| Population | Adolescents and young adults (diagnosed with cancer or other special healthcare condition before 21 years old) with a chronic physical or mental illness or physical, intellectual, or developmental disability, their parents and/or care givers. Patient subgroups: disease condition (including cancer), age of diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, adverse childhood events Provider subgroups: age, sex, race/ethnicity, education, socioeconomic status, specialty, care setting | Multi-disciplinary care providers (defined in Table 1.2, e.g. primary care/ family medicine physicians, specialty care physicians, nurse practitioners, physician assistant, etc.) caring for adolescents and young adults with a special healthcare need Patient subgroups: disease condition (including cancer), age of diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, adverse childhood events Provider subgroups: age, sex, race/ethnicity, education, socioeconomic status, specialty, care setting | Multi-disciplinary care providers (e.g. primary care/family medicine physicians, specialty care physicians, nurse practitioners, physician assistant, etc.) providers caring for adolescents and young adults with a special need Patient subgroups: disease condition (including cancer), age of diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, adverse childhood events Provider subgroups: age, sex, race/ethnicity, education, socioeconomic status, specialty, care setting |

| Element | KQ1: Benefits and Harms of Care Intervention | KQ2: Implementation Strategies | KQ3: Communication Tools |
|---------------------|---|--|---|
| Intervention | Intervention related to the care transition from pediatric to adult medical care (e.g., any single- or multi-component intervention that addresses the Six Core Elements of healthcare transition such as educational materials, patient care documents, processes, etc. There are not widely established neat packages of intervention components; interventions vary widely in their components, structure, and processes.) No healthcare transition intervention is explicitly excluded. However, transition interventions that address the full spectrum of transition to adult life, such as transition to independent living from foster care or among people with developmental disabilities, will be excluded. | Implementation strategies, including training (e.g., any single- or multi-component intervention that addresses implementing the Six Core Elements of healthcare transition such as trainings) | Tools for provider communication (e.g., any single- or multi-component intervention that addresses communication that supports the Six Core Elements of healthcare transition such as patient care documents) |
| Comparators | Comparator required, but no exclusion based on comparator type | Comparator required, but no exclusion based on comparator type | Comparator required, but no exclusion based on comparator type |
| Outcomes | <p>Transition readiness (e.g., patient, family, provider, and system level)</p> <p>Quality of life</p> <p>Mortality</p> <p>Morbidity</p> <p>Disease-specific clinical outcomes</p> <p>Wellness visits/screenings (e.g., screening for depression, anxiety, STIs, other risk and resiliency factors such as alcohol use, substance abuse, violence)</p> <p>Treatment or care adherence</p> <p>Engagement in care (e.g., no shows, time between providers, satisfaction, loss to follow-up, time between leaving pediatric setting to going to adult)</p> <p>Satisfaction (patient and family)</p> <p>Family caregiver outcomes</p> <p>Harms</p> <p>Unintended consequences (e.g., ethics of transition)</p> <p>Psychosocial (e.g., social-emotional, mental health, etc.)</p> <p>Insurance</p> <p>Cost</p> <p>Resource utilization (ER visit, hospitalization, length of stay)</p> | <p>Intervention, Adoption, Fidelity, Sustainability, Feasibility, Acceptability and/or Satisfaction (e.g., physician and other formal caregiver satisfaction)</p> <p>Quality of life</p> <p>Mortality</p> <p>Morbidity</p> <p>Disease-specific clinical outcomes</p> <p>Family caregiver outcomes</p> <p>Harms</p> <p>Unintended consequences (e.g., ethics of transition, provider burden)</p> <p>Cost of implementation</p> <p>Insurance</p> | <p>Transition readiness</p> <p>Quality of life</p> <p>Mortality</p> <p>Morbidity</p> <p>Disease-specific clinical outcomes</p> <p>Treatment or care adherence</p> <p>Engagement in care (e.g., no shows, time between providers, satisfaction, loss to follow-up, time between leaving pediatric setting to going to adult)</p> <p>Satisfaction (patient and family)</p> <p>Family Caregiver outcomes</p> <p>Harms</p> <p>Unintended consequences (e.g., ethics of transition)</p> <p>Insurance</p> <p>Cost</p> <p>Resource utilization (ER visit, hospitalization, length of stay)</p> |
| Timing | At least 6 months post transition for tests of interventions. No exclusions for qualitative or mixed methods studies for barriers and facilitators subquestion. | At least 6 months for tests of interventions. No exclusions for qualitative or mixed methods studies for barriers and facilitators subquestion. | At least 6 months for tests of interventions. No exclusions for qualitative or mixed methods studies for barriers and facilitators subquestion. |

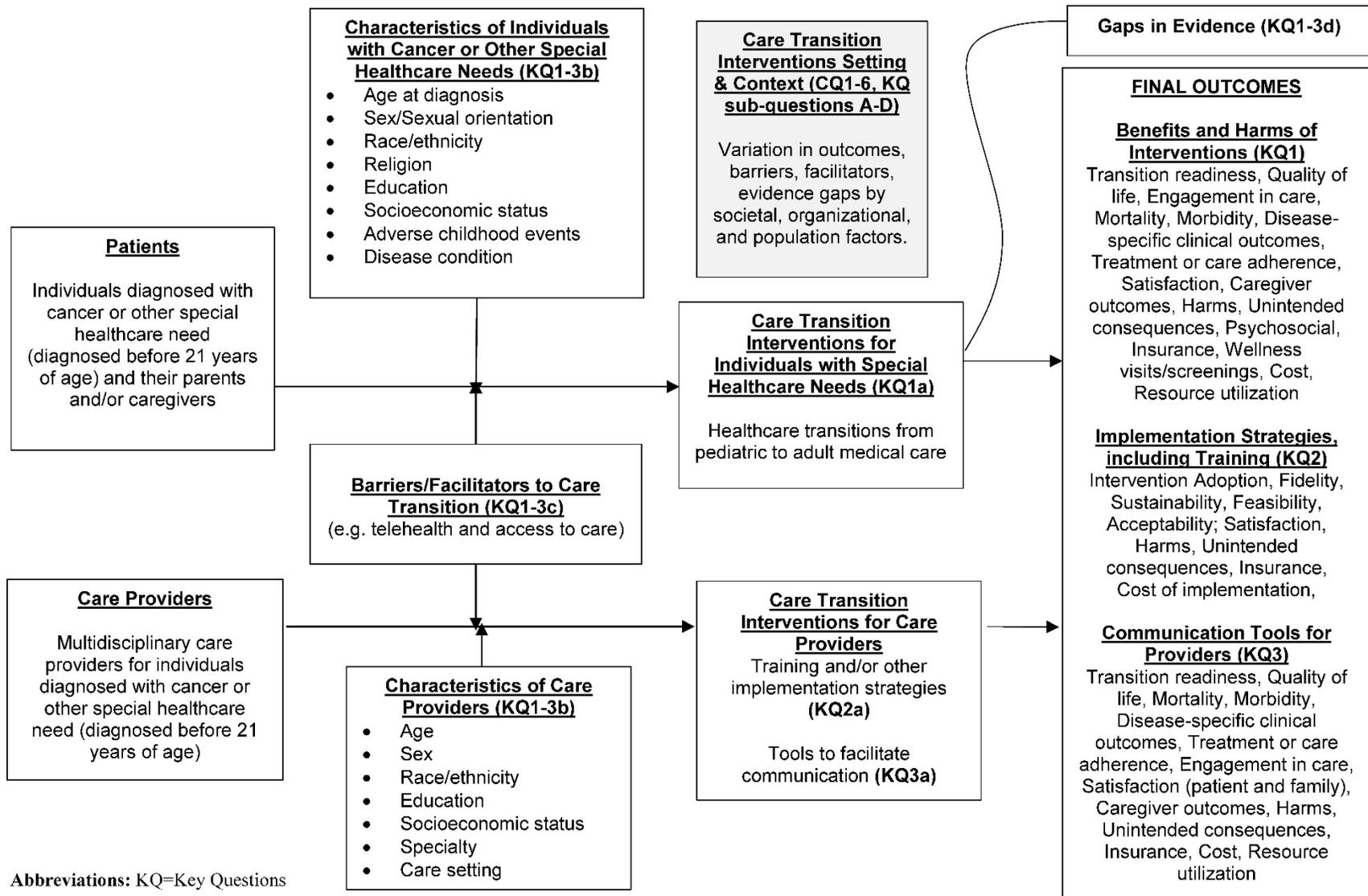
| Element | KQ1: Benefits and Harms of Care Intervention | KQ2: Implementation Strategies | KQ3: Communication Tools |
|---------|--|--|--|
| Setting | All settings (e.g., primary care, specialty care, schools, rural, resource limited settings, and telehealth) | All settings (e.g., primary care, specialty care, schools, rural, resource limited settings, and telehealth) | All settings (e.g., primary care, specialty care, schools, rural, resource limited settings, and telehealth) |

Abbreviations: ER=Emergency room visit; PICOTS=population, intervention, comparator, outcome, timing, setting

Analytic Framework

Figure 1.1 shows a visual representation of the analytic framework for the Key Questions, illustrating the relationship of interventions and outcomes.

Figure 1.1. Analytic framework



Report Organization

Chapter 2 outlines the methods used to conduct this systematic review. Chapter 3 presents the overall results of the search for the review’s eligible studies. Beginning in Chapter 4, we present results for KQ 1 (overall and by condition group), followed by outcome findings. Chapter 5 presents aggregated results for KQs 2 and 3. Chapter 6 presents a summary of overall barriers and facilitators to interventions. Chapters 7–11 present results from each of the Contextual Questions, with results for CQs 4 and 5 grouped in Chapter 10. Following this is the discussion including research gaps and future research considerations in Chapter 12. A glossary of terms for the report is provided in Table 1.2.

Table 1.2. Glossary of terms

| Term | Description |
|---|--|
| Analytic set | For the purposes of this review, the analytic set is the set of studies that underwent synthesis. It consists of the studies not judged to be pilots or have a high potential for bias that might have interfered with the ability of the study to answer its research question. |
| Care intervention for transition | Care intervention for transition relates to the care transition from pediatric to adult medical care (e.g., any single- or multi-component intervention) that addresses the Six Core Elements of healthcare transition such as educational materials, patient care documents, processes, etc. There are not widely established neat packages of intervention components; interventions vary widely in their components, structure, and processes. |
| Caregiver | For the purposes of this review caregivers are parents, spouses, family, friends and volunteers providing care to CSHCN. |
| Children with special healthcare needs (CSHCN) | For the purpose of this review CSHCN are adolescents and young adults diagnosed with cancer or other special healthcare condition before 21 years old (i.e., ages 10-21) with a chronic physical or mental illness or physical, intellectual, or developmental disability. |
| Eligible study | An eligible study is one that meets the initial study criteria that were defined in advance regarding the type of study that would be included in the systematic or comparative effectiveness review. |
| Got Transitions® Six Core Elements | Six Core Elements is a structured clinical approach for transitioning patients from pediatric to adult medical care developed by Got Transitions® (a federally funded national resource center on healthcare transitions). This approach includes: transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care and transfer completion. |
| Healthcare transition | Healthcare transition, or HCT, is the process of moving from a child/family-centered model of healthcare to an adult/patient-centered model of healthcare, with or without transferring to a new clinician. ¹² |
| Multidisciplinary care providers | For the purpose of this review multi-disciplinary care providers are primary care/ family medicine physicians, specialty care physicians, nurse practitioners, physician assistants, social workers, nurse navigators, community health workers, psychologists, etc. who are caring for adolescents and young adults with a special healthcare need. |
| Risk of bias | Risk of bias is the extent to which the design and conduct of a study are likely to have prevented bias in the results. |

Chapter 2. Methods

Review Approach

The methods for this systematic review followed the Agency for Healthcare Research and Quality (AHRQ) Methods Guide for Effectiveness and Comparative Effectiveness Reviews (available at <https://effectivehealthcare.ahrq.gov/topics/ceer-methods-guide/overview>), modified slightly to support a mixed-studies approach. This systematic review also reports in accordance with the Preferred Items for Reporting in Systematic Reviews and Meta-Analyses (PRISMA).²¹ The final protocol was posted online November 19, 2020 (<https://effectivehealthcare.ahrq.gov/products/transitions-care-pediatric-adult/protocol>).

Search Strategy and Study Selection

We selected studies based on the populations, interventions, comparators, outcomes, timing, and settings (PICOTS) framework outlined in Table 1.1 if they were published in English in a peer-reviewed journal in both U.S. and non-U.S. settings. Any quantitative or qualitative study design examining transition to adult healthcare that enrolled children or youth with special healthcare needs (CSHCN) up to age 21, their parents or informal caregivers, or providers, were evaluated for fit to either Key Questions (KQs) or Contextual Questions (CQs). Studies that described or examined a care transition intervention, implementation strategy, or tool were considered specifically eligible for KQs. As this review focused on healthcare transitions, studies evaluating transitions to school or work were beyond the scope of this review. All literature identified as potentially eligible for the review were potentially eligible for the CQs as well.

We conducted a comprehensive literature search in September 2020 (updated September 2021) searching Ovid MEDLINE[®], Ovid Embase[®], the Cochrane Central Register of Controlled Trials, and CINAHL[®] databases that included literature published prior to September 2021. See Appendix A for full details. We supplemented our search strategies with backward and forward citation searches of recent relevant systematic reviews.

Search results were downloaded and screened in PICO Portal,²² a systematic review platform. Two independent investigators reviewed titles and abstracts using predefined criteria, then conducted full-text screening to determine if inclusion criteria were met. Differences in screening decisions were resolved by consultation between investigators, and, if necessary, with a third investigator. Throughout the screening process, members of the review team met regularly to discuss training material and any issues that arose to ensure that inclusion criteria were applied consistently.

We conducted additional grey literature searches using the Google search engine to identify relevant completed and ongoing studies, outcomes, and analyses not reported in the published literature, to assess publication and reporting bias, and inform future research needs. We also conducted targeted searches for grey literature sources for additional material to address the CQs. (See Appendix A.)

Assessing Methodological Risk of Bias of Individual Studies

For risk of bias assessments, we focused on studies with the least potential for bias and the fewest limitations. Included studies were not formally assessed for risk of bias if they did not meet threshold criteria of comparing outcomes with different groups or time points, referred to in this report as “meeting comparator criteria.” Included studies using randomized and non-

randomized controlled trials, cohort studies with comparator arms, and single arm pre/post design were subjected to risk of bias assessment. Based on AHRQ guidance,²³ two independent reviewers assessed risk of bias and consulted to reconcile discrepancies in overall risk of bias using RoB-2. (See Appendix A for decision rules.) Overall risk of bias assessments for each study were classified as low, moderate, or high based on the collective risk of bias inherent in each domain and confidence that the results were believable given the study's limitations.

Data Abstraction and Data Management

Studies with comparator arms or single arm pre/post design were included in the basic characteristics table and underwent risk of bias assessment. Studies with low or medium risk of bias were evaluated as part of the analytic set. Studies that did not meet comparator criteria were not assessed for risk of bias, but are briefly described in brief evidence maps in the appendix materials. For all study designs, data fields included author, year of publication, study design, population, intervention, study follow-up, and setting.

For the KQs, additional information pertaining to risk of bias, intervention duration, comparison, outcomes cited, barriers, facilitators, and cited gaps were abstracted. These fields included subject inclusion and exclusion criteria, intervention and comparison characteristics, study funding source and special subpopulations (e.g., sex/sexual identity, race/ethnicity, socioeconomic status), if reported. In the report, we use the term sex/sexual identity as a broader umbrella to encompass an individual's sexual or gender identity which may include sexual orientation, gender identity, or expression.²⁴ Intervention characteristics included components and activities, timing, frequency, duration, use of technology, training, delivery approach (prescriptive or manualized vs tailored), other delivery modalities, and use of cultural adaptations or modifications. We noted the age, developmental stage, or cognitive ability for which the intervention is intended. For CQs, we abstracted additional information pertaining to the definition and measurement of effectiveness, implementation strategies (including training available to providers, patients, and families), care intervention, and strategies for increasing provider availability. One reviewer extracted relevant data to evidence and outcomes tables, while a second reviewer verified for accuracy.

To examine KQ1-3c (barriers and facilitators to implementation), we abstracted examples from articles included in KQ1-3 as well as additional articles identified through our primary search strategy that specifically examined barriers and facilitators to successful transitions until themes were saturated. We also assessed these articles for further usefulness for addressing the CQs. If studies seemed useful, we abstracted data into tables. Quantitative or qualitative studies identified with the search algorithm that did not directly address any KQ, or did not provide useful information for the CQs, are provided as a reference list by disease category in appendix materials.

Data Synthesis

We categorized studies using the National Institutes of Health Stage Model for Behavioral Interventions.²⁵ This model provides a conceptual framework of intervention research development, ranging from basic science research (Stage 0) to new intervention creation (Stage I), research-setting efficacy (Stage II), "real-world" community-clinic efficacy (Stage III), broad community-based effectiveness (Stage IV), to eventually dissemination and implementation research (Stage V). This model not only describes the stages of behavioral intervention development, but also supports eventual implementation. While the stages do not directly assess

study designs, the model suggests that interventions at Stage 0 to II create a basic understanding of a potential intervention. Conversely, a quality improvement project, regardless of study design or rigor, can be viewed as Stage V, or a direct attempt at dissemination or implementation.

We summarized results in evidence tables and synthesized evidence for each unique population, comparison, outcome, or harm. The evidence tables were organized by intervention targets, interventions, comparators, and patient populations/disease condition, care provider, or other system-level outcomes. Considering the complexity and variety of CSHCN identified during a scoping of the literature, we categorized patients by condition/disease type. We did this both to ensure that pediatric oncology populations were presented as specific groupings, and to make it easier for readers to locate specific CSHCN populations.

Because we were not able to identify any consistent taxonomy of interventions, we categorized empirically by intervention and comparator pairs using the Six Core Elements as a framework. For studies that addressed barriers and facilitators for the KQs, we abstracted themes until saturation, at which point no additional themes were found from reviewing successive studies. We grouped barriers and facilitators by each of the five domains from the Consolidated Framework for Implementation Research (CFIR), a conceptual framework developed to guide systematic assessment of multilevel implementation contexts to identify factors that might influence intervention implementation and effectiveness.²⁶ For the CQs, we focused on the included studies used to address the KQs, supplemented with material identified through grey literature searches. Where literature was scarce, we present all identified material; where literature was more abundant, we sampled and abstracted themes until saturation.

Grading Strength of Evidence

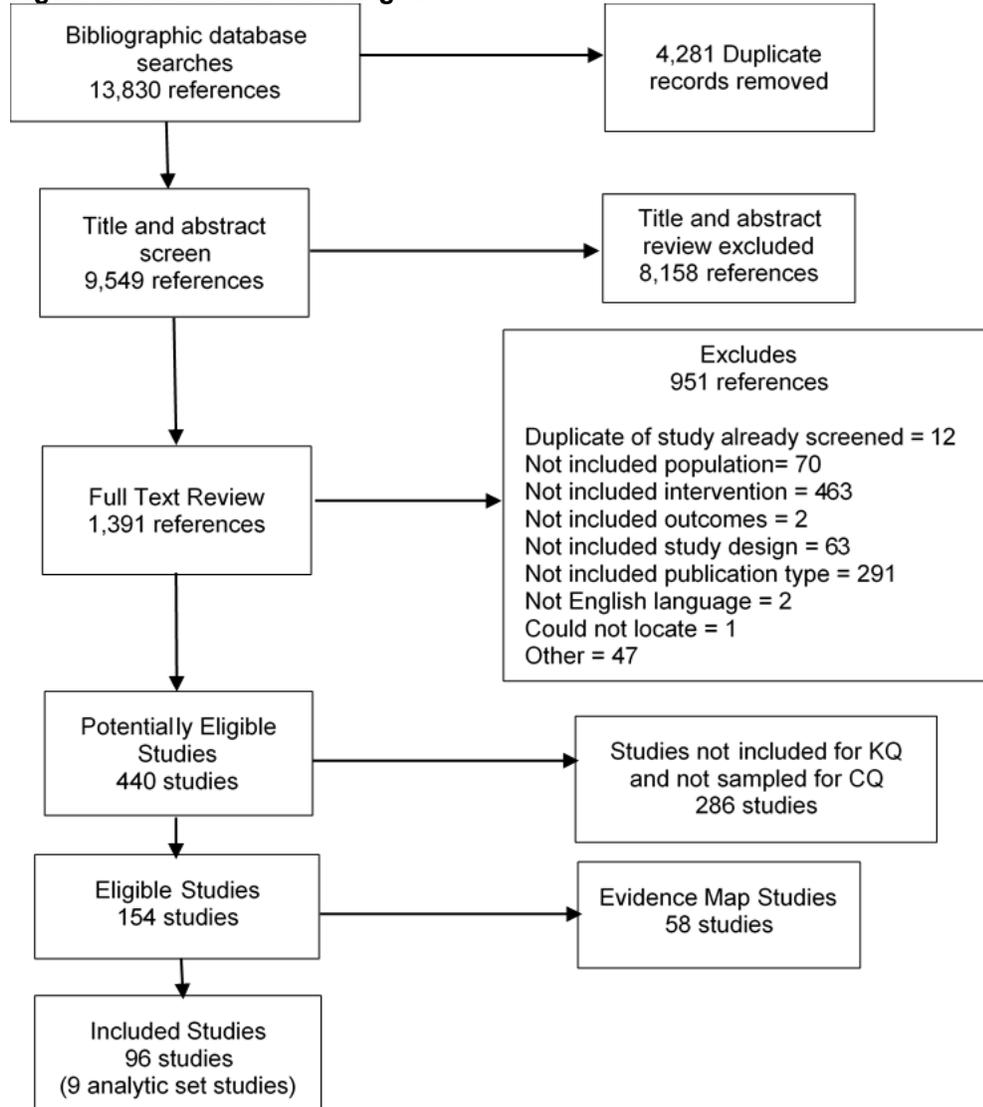
We evaluated overall strength of evidence for select quantitative outcomes for KQs within each comparison based on five required domains: (1) study strengths and limitations (risk of bias); (2) directness (single, direct link between intervention and outcome); (3) consistency (similarity of effect direction and size); (4) precision (degree of certainty around an estimate); and (5) reporting bias.²⁷ Based on these domains, the overall strength of evidence for each outcome was rated as:

- **High:** Very confident that estimate of effect lies close to true effect. Few or no deficiencies in body of evidence, findings believed to be stable.
- **Moderate:** Moderately confident that estimate of effect lies close to true effect. Some deficiencies in body of evidence; findings likely to be stable, but some doubt.
- **Low:** Limited confidence that estimate of effect lies close to true effect; major or numerous deficiencies in body of evidence. Additional evidence necessary before concluding that findings are stable or that estimate of effect is close to true effect.
- **Insufficient:** No evidence, unable to estimate an effect, or no confidence in estimate of effect. No evidence is available, or the body of evidence precludes judgment.

Chapter 3. Search Results

We list all studies excluded at full text screening, by exclusion category, in Appendix B. Studies identified as potentially eligible but not sampled or used for the Contextual Questions are reported in Appendix C. See Figure 3.1 for details of the screening process.

Figure 3.1. Literature flow diagram



Abbreviations: CQ=Contextual Question; KQ=Key Question

Of the 440 identified studies of empirical research using quantitative or qualitative methods, representing 55 disease conditions, we categorized 154 as describing or examining a care transition intervention with enough detail to be eligible for potential inclusion in any of the Key Questions. The 286 studies on transitioning children with special healthcare needs (CSHCN) that did not explicitly describe or examine care transition interventions (e.g., studies that described the characteristics of CSHCN transitioning, or identified challenges with transition, but did not propose an intervention) are listed in Appendix C. A further 58 studies failed the threshold

criteria of comparing outcomes with different groups or time points; some of these studies supported a contextual question. The remaining 96 studies that did meet the threshold criteria were assessed for risk of bias; only nine studies were assessed as low to medium risk of bias and included in the analytic set. Table 3.1 provides an overview of the eligible literature set.

We categorized studies based on primary diagnoses. The chronic conditions category included interventions generally designed for any condition, although most aimed toward more complex patients. We present conditions for which we found few studies together as Other Conditions (e.g., hemophilia, endocrine conditions). Medical conditions were the most commonly represented conditions. Solid organ transplant, sickle cell, and cystic fibrosis were the most commonly studied. Many important sub-populations (e.g., race, socio-economic status, sex/sexual identify) reported in these studies were either not included as subjects of study or results were not separately reported the context of these interventions. Developmental or physical disabilities, or mental health, were more likely to have used qualitative or cross-sectional methods (Appendix C).

Table 3.1. Identified unique eligible studies by condition category, by results chapter

| Location | Condition | Total Eligible (Included + Brief Evidence Map) | Included | Analytic Set (Subset of Included) | Brief Evidence Map |
|-------------------------------------|-------------------------------|--|-----------|---|--------------------------|
| Chapter 4 (KQ1) | Cancer | 8 | 2 | 0 | 6 |
| | Chronic conditions | 11 | 5 | 2 | 6 |
| | Congenital heart disease | 9 | 6 | 1 | 3 |
| | Cystic fibrosis | 12 | 6 | 0 | 6 |
| | Diabetes Mellitus | 15 | 11 | 2 | 4 |
| | HIV | 4 | 2 | 0 | 2 |
| | Inflammatory bowel disease | 12 | 9 | 0 | 3 |
| | Juvenile idiopathic arthritis | 7 | 5 | 1 | 2 |
| | Kidney disease | 3 | 2 | 0 | 1 |
| | Neurological conditions | 3 | 3 | 0 | 0 |
| | Rheumatic conditions | 4 | 1 | 0 | 3 |
| | Sickle cell disease | 17 | 9 | 0 | 8 |
| | Solid organ transplant | 17 | 15 | 1 | 2 |
| | Spina bifida | 7 | 3 | 1 | 4 |
| | Urological conditions | 2 | 0 | 0 | 2 |
| | Other conditions | 16 | 10 | 1 | 6 |
| | Chapter 4 TOTAL | 147 | 89 | 9 | 58 |
| Chapter 5 (KQ 2 & 3) | All conditions | 9* | 9* | 0 | 0 |
| | Chapter 5 TOTAL | 9 | 9 | 0 | 0 |

*Note: Two studies are used in both Chapter 4 and Chapter 5, for a total of 154 (147+9-2) unique studies and 96 (89+9-2) that were assessed for risk of bias.

Abbreviations: KQ=Key Question

Chapter 4. Care Interventions for Transition

Key Points

- With only a single exception that showed no benefit, we found that for all outcomes and interventions the evidence was insufficient to draw conclusions because the uncertainty of evidence was too high.
- Transition clinics may not improve hemoglobin A1C levels at 12 to 24 months in youth with type 1 diabetes mellitus compared with usual care (low-strength evidence).

Introduction

This chapter addresses Key Question (KQ) 1 and includes care interventions for transition from pediatric to adult medical services among children with special healthcare needs (CSHCN). We first present interventions in aggregate across all disease conditions (e.g., cancer, autism). When low- to medium-risk-of-bias studies were available for interventions, we present a summary of outcome findings by patient outcomes when available. We report conditions separately to allow for more detailed evaluation of evidence by underlying disease. For each disease condition, we present three summary sections: Key Points, Eligible Studies, and Intervention Research Context (a brief discussion of what has been examined in the included literature). We could not combine outcomes for statistical meta-analysis due to differences in outcome measures and intervention complexity; therefore, we present summary findings as brief statements of how many studies reported statistically significant beneficial results for the intervention or no statistically significant difference between the intervention and the comparator. Appendix D presents all studies included as part of the brief evidence map (with studies grouped by disease condition) along with evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Intervention Description

Care interventions for transition from pediatric to adult medical services may include a wide range of components, structures, and processes. We included studies related to the medical care transition from pediatric to adult services that evaluated any single or multicomponent intervention addressing at least one of the Six Core Elements of healthcare transition, such as educational materials or patient care documents, by measuring outcomes at more than one time point.

All Eligible Studies

We identified 147 unique transition interventions describing or examining care interventions for transition from pediatric to adult medical services among CSHCN. Eighty-nine studies met comparator criteria and were eligible for risk of bias assessment. Studies not eligible for risk of bias assessment are included in brief evidence maps in Appendix D. Table 4.1 summarizes the characteristics of the included studies addressing KQ1. One study was assessed as low risk of bias, eight studies as medium risk of bias, and the remaining studies as high risk of bias. Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes by disease condition.

Table 4.1. Basic characteristics of KQ1 literature set: all included studies

| Characteristic | Information |
|---|--|
| Total Studies | 89 Total studies |
| Study Design | 12 Randomized controlled trials 2 Other controlled trials 67 Observational studies 8 Mixed methods studies |
| NIH Stage Model | 1 Stage 0 67 Stage I 15 Stage II 2 Stage III 4 Stage IV |
| Study Risk of Bias | 80 High risk of bias 8 Medium risk of bias 1 Low risk of bias |
| Included Disease Condition Studies | 16 Disease condition groups included the following number of studies: 2 Cancer 5 Chronic Conditions (generalized or nonspecific) 6 Congenital Heart Disease 6 Cystic Fibrosis 11 Diabetes Mellitus 2 HIV 9 Inflammatory Bowel Disease 5 Juvenile Idiopathic Arthritis 2 Kidney Disease 3 Neurological Conditions 1 Rheumatic Conditions 9 Sickle Cell Disease 15 Solid Organ Transplant 3 Spina Bifida 10 Other Conditions (e.g., hemophilia, endocrine conditions) |
| Setting | 36 Tertiary centers or clinics, unknown pediatric or adult 35 Pediatric tertiary centers, clinics or hospitals 6 Pediatric and adult tertiary centers and clinics 6 Adult tertiary centers 1 Summer program 1 Music program 1 School-based health center 3 Not reported |
| Intervention Type | 72 Transition program or clinic 10 Transition skill-based training or education 3 Transition workbook or toolkit 2 Electronic medical record transition tool 1 Summer program 1 Music therapy program |
| Mode of Delivery | 79 In-person 6 Online 4 In-person and online |
| Analytic Set Studies | 9 Studies from the following disease condition groups: 2 Chronic Conditions 1 Congenital Heart Disease 2 Diabetes Mellitus 1 Juvenile Idiopathic Arthritis 1 Solid Organ Transplant 1 Spina Bifida 1 Other Conditions (e.g., hemophilia, endocrine conditions) |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the 89 included studies, most used observational designs, with only 12 randomized controlled trials, four other controlled trials and six mixed methods studies. Most studies focused on Stage I of the NIH Model. The number of studies varied by disease condition, with solid organ transplant, inflammatory bowel disease, and diabetes mellitus comprising the largest number. Several disease conditions contributed fewer than three studies; these included cancer, HIV, kidney disease, and rheumatic conditions. Studies were conducted across a variety of settings but focused primarily on either adult or pediatric tertiary centers, clinics, or hospitals. Interventions included a range of approaches including evaluation of transition programs and clinics, workbooks or toolkits, and skill-based training or education for transition, and more. Most interventions were delivered in person. Studies also included a range of population development stages, outcomes, and maximum follow up time.

CSHCN Outcomes Across All Disease Conditions

Only nine of the 89 included studies were assessed as medium or low risk of bias and included in the analytic set. These nine studies examined congenital heart disease, diabetes mellitus, juvenile idiopathic arthritis, solid organ transplant, spina bifida, chronic conditions, and other miscellaneous conditions. Two studies demonstrated low-strength evidence for improved outcomes for diabetes mellitus from transition care interventions. The analytic set did not report outcomes related to caregivers or providers. Table 4.2 summarizes the outcome findings. All but the one finding for HbA1C were rated as insufficient; so, while we report the outcome, the level of uncertainty regarding the evidence too high to draw conclusions.

Table 4.2. Summary of KQ1 outcome findings for all disease conditions

| Outcomes | Chronic Conditions | Congenital Heart Disease | Diabetes Mellitus | Solid Organ Transplant | Spina Bifida | Misc. Conditions (Hemophilia) |
|----------------------------------|-------------------------------|-------------------------------|-----------------------------------|-------------------------------|--------------|-------------------------------|
| Transition Readiness (Full TRAQ) | ↑ K=1, M=1 Insufficient | ↑ K=1, M=1 Insufficient | NA | NA | NA | NA |
| QoL | ↔ K=1, M=1 Insufficient | NA | NA | NA | NA | NA |
| Care Quality | ↑ K=1, M=2 Insufficient | NA | NA | NA | NA | NA |
| Disease Status | ↔ K=1, M=2 Insufficient | NA | ↔ K=2, M=1 Low-strength | NA | NA | NA |
| Engagement in care | ↑ K=1, M=2 Insufficient | ↑ K=1, M=1 Insufficient | Mixed K=2, M=2 Insufficient | NA | NA | NA |
| Self Efficacy | NA | NA | NA | ↔ K=1, M=5 Insufficient | NA | ↔ K=1, M=1 Insufficient |

| Outcomes | Chronic Conditions | Congenital Heart Disease | Diabetes Mellitus | Solid Organ Transplant | Spina Bifida | Misc. Conditions (Hemophilia) |
|-----------------|--------------------|-------------------------------|-------------------|-------------------------------|-------------------------------|-------------------------------|
| Self-management | NA | NA | NA | ↔ K=1, M=1 Insufficient | ↔ K=1, M=1 Insufficient | ↔ K=1, M=1 Insufficient |
| Knowledge | NA | ↑ K=1, M=1 Insufficient | NA | ↔ K=1, M=1 Insufficient | NA | ↑ K=1, M=1 Insufficient |
| Adherence | NA | NA | NA | ↓ K=1, M=1 Insufficient | NA | NA |
| Satisfaction | NA | NA | NA | NA | NA | ↑ K=1, M=1 Insufficient |
| Social Support | NA | NA | NA | ↔ K=1, M=1 Insufficient | NA | NA |
| Retention | NA | NA | NA | ↓ K=1, M=1 Insufficient | NA | ↔ K=1, M=1 Insufficient |

Note: Up arrows signify results favor the intervention; down arrows signify results favor usual care; horizontal double-headed arrows signify no difference between groups.

Abbreviations: K=number of studies; M=number of measures; NA=not applicable; QoL=quality of life; TRAQ=transition readiness assessment questionnaire

Care Interventions by Disease Condition

Cancer

Key Points

- No transition interventions for CSHCN with a history of cancer advanced to the analytic set for further analysis.

Eligible Studies

Eight publications described or examined care interventions for transition from pediatric to adult care among individuals with a history of cancer.²⁸⁻³⁵ Six did not meet comparator criteria and were not eligible for risk of bias assessment;³⁰⁻³⁵ we report these in the brief evidence map in Appendix D. Table 4.3 summarizes the characteristics of the KQ literature set. Two remaining studies were assessed as high risk of bias^{28, 29} and no studies were included in the analytic set. Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.3 Basic characteristics of KQ1 literature set: cancer

| Characteristic | Information |
|-------------------------------|------------------------------------|
| Total Included Studies | 2 Studies |
| Study Design | 1 Observational 1 Mixed methods |
| NIH Stage Model | 2 Stage I |
| Study Risk of Bias | 2 High risk of bias |
| Included Disease Stages/Types | 2 All cancer types and stages |

| Characteristic | Information |
|--|--|
| Population Development Stage | 1 <18 years old 1 Not reported |
| Setting | 2 Pediatric tertiary centers, clinics or hospitals |
| Intervention Type | 1 Transition workbook or toolkit 1 Patient navigator program |
| Mode of Delivery | 2 In-person |
| Outcomes Evaluated | 2 Transition readiness (1 general transition readiness, 1 worry) 3 Engagement in care (1 staff time required for the intervention, 1 total number of patients and families who met with patient navigator, 1 total number of patient navigator visit approvals) |
| Maximum Intervention Follow-up Time | 1 6 months |
| Got Transitions ® Six Core Elements Targeted | 1 Transition Readiness |
| Analytic Set Studies | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

One study was conducted in a large pediatric tertiary center in North America with a predominately female cohort of unknown race/ethnicity,²⁹ while the other took place in a large children’s research hospital.²⁸ One intervention implemented the transition readiness component of the Six Core Elements by examining the role of an interactive transition workbook on transition outcomes. The most recent intervention (2021) implemented a patient navigator program.²⁸ Outcomes focused mainly on participant worry (general and about leaving pediatrics) and transition readiness. No outcomes were collected for patient caregivers or providers.

Chronic Conditions

Key Points

- Evidence was insufficient to draw conclusions about the effect of transition interventions on CSHCN with chronic conditions.

Eligible Studies

Eleven unique transition interventions from 12 publications described or examined care interventions for transition from pediatric to adult medical services among CSHCN with broadly defined chronic conditions.³⁶⁻⁴⁸ Six studies did not meet comparator criteria, were not eligible for risk of bias assessment, and thus excluded from the analytic set.^{36 28-30, 34, 36} The brief evidence map of these studies can be found in Appendix D. Table 4.4 summarizes the characteristics of the KQ literature set. Of the five studies that used comparators, three (from four publications) were assessed as high risk of bias.^{37, 41, 45, 47} Two were assessed as medium risk of bias and included in the analytic set.^{42, 43} Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.4. Basic characteristics of KQ1 literature set: chronic conditions

| Characteristic | Information |
|------------------------|--|
| Total Included Studies | 5 Studies |
| Study Design | 2 Randomized controlled trials 2 Observational study 1 Mixed methods study |
| NIH Stage Model | 4 Stage II 1 Stage III |

| Characteristic | Information |
|---|---|
| Study Risk of Bias | 3 High risk of bias 2 Medium risk of bias |
| Included Disease Stages/Types | 3 Nonspecific chronic conditions 1 Nonspecific chronic conditions, intellectual disabilities/ medically complex patients 1 Chronic conditions without cognitive impairment, represented by inflammatory bowel disease, cystic fibrosis, and type 1 diabetes mellitus |
| Population Development Stage | 1 12-22 years old 2 16-22 years old 1 18+ years 1 Average age 20 years old (range 17 - 43) |
| Setting | 4 Pediatric tertiary centers, clinics or hospitals 1 School-based health center |
| Intervention Type | 2 Transition program or clinic 2 Transition workbook or toolkit 1 Structured transition service |
| Mode of Delivery | 3 In-person 2 Online |
| Outcomes Evaluated | 3 Transition Readiness (1 Transition Readiness Assessment Questionnaire, 1 self-care skills); 1 Patient Activation Measure (self-efficacy) 1 Quality of Life (1 Pediatric Quality of Life Scale) 2 Clinical Outcomes (1 disease specific index1 Karnofsky Performance Scale) 1 Engagement in Care(1 patient-initiated communications) 2 Satisfaction or Experience with Care (1 Patient Assessment of Chronic Illness Care (quality of care); 1 Client Perceptions of Coordination Questionnaire (care coordination)) 1 Resource Utilization (1 inpatient admission days and outpatient clinic visits) 1 Treatment or care adherence (frequency of intervention use) 2 Satisfaction with care (1 intervention helpfulness; 1 Goal Achievement) |
| Maximum Intervention Follow-up Time | 1 8 months 2 12 months 1 12-47 months 1 Unclear (2 year pilot) |
| Got Transitions ® Six Core Elements Targeted | 2 Transition Readiness 2 Transition Planning 3 All Six Core Elements |
| Analytic Set Studies | 2 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

All five studies examined interventions conducted at urban tertiary pediatric academic health centers in North America; three in the United States, one in Canada. One was conducted in a high-school-based health center. The U.S.-enrolled populations were majority nonwhite. Three interventions implemented the Six Core Elements using care coordination frameworks. Another intervention evaluated the effects of a Web- and text-messaging tool (with a healthcare team communication portal) for disease management and decision support. The Canadian intervention used a toolkit and online mentor to promote organizational skills, goal setting, and self-management. Outcomes did not focus on health status/disease outcomes, and no outcomes were collected for patient caregivers or providers.

CSHCN Outcomes

Evidence was insufficient to draw conclusions about the effects of interventions for care transitions for CSHCN. Two studies reported a range of outcomes. Table 4.5 provides a summary of findings.

One study enrolled 209 CSHCN; virtually all were African American. The study reported higher scores for patient assessment of quality of care for the healthcare transition care coordination group compared with the control group (3.6 versus 3.3) at 12 months. The intervention group was also more likely to report higher perceptions of care coordination.

One study enrolled 81 CSHCN, 67 percent nonwhite, in MD2Me, a Web- and text-based disease management and skill-training intervention. The intervention group reported improvements in disease management tasks, as measured by the Transition Readiness Assessment Questionnaire, self-efficacy, and patient-initiated communication compared with the control group at 8 months. However, no differences in health outcomes were reported.

Table 4.5. Summary of findings for outcomes: chronic conditions

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|--|--|--|-----------------|---------------------------|
| Total Patient Assessment of Chronic Illness Care (PACIC) HCT vs enhanced care | 1 RCT ⁴³ (n=209) 12 months | Individuals recruited age 16-22 years with chronic conditions in US | 1 found benefit | Insufficient |
| Client Perceptions of Coordination Questionnaire (CPCQ) HCT vs enhanced care | 1 RCT ⁴³ (n=209) 12 months | Individuals recruited age 16-22 years with chronic conditions in US | 1 found benefit | Insufficient |
| Transition Readiness Assessment Questionnaire (TRAQ) MD2Me vs attention control | 1 RCT ⁴² (n=81) 8 months | Individuals recruited age 12-22 years with chronic conditions; IBD, CF, and T1 diabetes mellitus, without cognitive impairment in US | 1 found benefit | Insufficient |
| Patient Activation Measure (PAM) MD2Me vs attention control | 1 RCT ⁴² (n=81) 8 months | Individuals recruited age 12-22 years with chronic conditions; IBD, CF, and T1 diabetes mellitus, without cognitive impairment in US | 1 found benefit | Insufficient |
| Patient-Initiated Communications MD2Me vs attention control | 1 RCT ⁴² (n=81) 8 months | Individuals recruited age 12-22 years with chronic conditions; IBD, CF, and T1 diabetes mellitus, without cognitive impairment in US | 1 found benefit | Insufficient |

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|--|--|--|-----------------------|---------------------------|
| Health outcomes: disease status, functional performance, quality of life MD2Me vs attention control | 1 RCT ⁴² (n=81) 8 months | Individuals recruited age 12-22 years with chronic conditions; IBD, CF, and T1 diabetes mellitus, without cognitive impairment in US | 1 found no difference | Insufficient |

Note: *Insufficient ratings due to few studies and imprecision in findings. No difference based on statistical significance.
Abbreviations: CF=cystic fibrosis; HCT=healthcare transition; n=number; IBD=inflammatory bowel disease; RCT=randomized controlled trial

Congenital Heart Disease (CHD)

Key Points

- Evidence was insufficient to draw conclusions about the effect of transition interventions on CSHCN with CHD.

Eligible Studies

Nine eligible studies examined care interventions for transition from pediatric to adult medical services among CSHCN with CHD.⁴⁹⁻⁵⁷ Three studies did not meet comparator criteria, were not eligible for risk of bias assessment, and excluded from the analytic set.^{53, 54, 57} The brief evidence map of these studies can be found in Appendix D. Six studies met comparator criteria and examined the effect of transition program on time to transition, transition readiness, health knowledge, quality of life, satisfaction, and various clinical outcomes (Table 4.6).^{49-52, 55, 56} Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.6. Basic characteristics of KQ1 literature set: congenital heart disease

| Characteristics | Information |
|-------------------------------|---|
| Total Included Studies | 6 Studies |
| Study Design | 1 Randomized controlled trial 1 Nonrandomized controlled trial 4 Observational studies |
| NIH Stage Model | 4 Stage I 2 Stage II |
| Study risk of bias | 5 High risk of bias 1 Medium risk of bias |
| Included Disease Stages/Types | All CHD types and stages |
| Population Development Stage | 1 11-18 years old 2 15-17 years old 1 16+ years 1 19-23 years old 1 Not reported |
| Setting | 5 Tertiary centers or clinics, unknown pediatric or adult setting 1 Children's hospital |
| Intervention Type | 3 Education interventions 1 Transition program or clinic 1 Electronic medical record healthcare transition tool |
| Mode | 6 In-person clinic based |

| Characteristics | Information |
|---|---|
| Outcomes Evaluated | 7 Transition Readiness (2 general transition readiness, 2 health knowledge, 1 self-management knowledge, 1 emotional regulation; 1 transfer) 2 Engagement in care (2 time to transition) 1 Quality of life (1 quality of life) 2 Clinical outcomes (2 clinical outcomes) 1 Satisfaction or experience with care (1 satisfaction) 1 Resource utilization (1 unplanned cardiac hospitalizations) |
| Maximum Intervention Follow-up Time | 1 4 months 1 6 months 2 12 months 1 18 months 1 26 months |
| Got Transitions® Six Core Elements Targeted | 3 Transition Readiness 3 Transition Planning |
| Analytic Set Studies | 1 Study |

Abbreviations: CHD=congenital heart disease; KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the six included studies, three provided educational interventions aimed at transition readiness, two in Canada and one in Malaysia. One Italian transition clinic used a multidisciplinary approach for standardized educational and support interventions. Outcomes included health perceptions, knowledge, and quality of life. One U.S.-based transition program included coordination between pediatric and adult nurses, physicians, and social workers to improve clinical outcomes and hospitalizations. Another U.S.-based study used a transition planning tool embedded in electronic medical records to improve clinical outcomes.

CSHCN Outcomes

We found insufficient evidence to draw conclusions about the effects of interventions for care transitions for CSHCN with CHD. Table 4.7 provides a summary of findings. At 12 months, authors reported improvement in all outcomes (disease knowledge, transition readiness, and excessive time to transition) in the educational intervention group compared with the control (usual care).⁵⁶ Excess time to transition was reduced in 68 percent of the intervention group vs. 51 percent of the control (p=0.059). Disease knowledge (p<0.001) and transition readiness (p=0.032) were also better in the intervention group than the control, but exact values were not reported. We did not assess outcomes at 18 months due to high risk of attrition bias.

Table 4.7. Summary of findings for outcomes: congenital heart disease

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|--|--|--|--|---------------------------|
| Excess time to adult CHD care, CHD knowledge (MyHeart CHD knowledge survey), and Transition readiness (TRAQ) Nurse-led transition education intervention vs. Usual care | 1 RCT ⁵⁶ (n=121) 12 months | Individuals recruited age 15-17 years with congenital heart disease severities in Canada | 1 found benefit across all outcome measures. | Insufficient |

Note: *Insufficient ratings due to few studies and imprecision in findings. No difference based on statistical significance.
Abbreviations: CHD=congenital heart disease; n=number; RCT=randomized controlled trial

Cystic Fibrosis

Key Points

- No transition interventions for CSHCN with cystic fibrosis advanced to the analytic set for further analysis.

Eligible Studies

Twelve unique transition interventions described or examined care interventions for transition from pediatric to adult care among CSHCN with cystic fibrosis.⁵⁸⁻⁶⁹ Six studies did not meet comparator criteria and were not eligible for risk of bias assessment.^{58-60, 62, 63, 69} The brief evidence map of these studies can be found in Appendix D. Table 4.8 summarizes the characteristics of the KQ literature set. The six remaining studies were assessed as high risk of bias and were excluded from the analytic set.^{61, 64-68} Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.8. Basic characteristics of KQ1 literature set: cystic fibrosis

| Characteristics | Information |
|--|---|
| Total Included Studies | 6 Studies |
| Study Design | 6 Observational studies |
| NIH Stage Model | 6 Stage I |
| Study risk of bias | 6 High risk of bias |
| Included Disease Stages/Types | General |
| Population Development Stage | 1 Families of patients aged 8 and older, and patients aged 16 and older 1 Average age 22 1 12-18 years old 1 16-18 years old 1 17-20 years old 1 17-22 years old |
| Setting | 3 Pediatric and adult tertiary centers 2 Tertiary centers, unknown pediatric/adult setting 1 Pediatric tertiary center |
| Intervention Type | 4 Transition program or clinic 1 Transition program (notebook & guide) 1 Structured individualized transition process |
| Mode | 6 In-person |
| Outcomes Evaluated | 9 Transition readiness (2 general transition readiness transition, 4 self-management, 1 independence during consultations, 1 self-efficacy, 1 transition concerns) 2 Quality of life 4 Clinical outcomes (3 general disease-specific clinical outcomes, 1 disease severity) 1 Treatment or care adherence (1 treatment adherence) 3 Engagement in care (1 general engagement in care, 1 percent split consultations, 1 participation in transition) 3 Satisfaction or experience with care (1 transition perceptions, 2 satisfaction) 4 Resource utilization (2outpatient visitsand2 hospitalization, 1 other resource utilization) |
| Maximum Intervention Followup Time | 1 12 months 1 18 months 3 24 months 1 Not applicable |
| Got Transitions® Six Core Elements Targeted | 1 Transition and Care Policy/Guide 5 Transition Readiness 3 Transition Planning 1 Transfer of Care |

| Characteristics | Information |
|----------------------|-------------|
| Analytic Set Studies | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the six included studies, five examined interventions conducted at cystic fibrosis centers located in the United States,⁶⁴ Australia,⁶⁷ France,⁶⁸ the Netherlands,⁶⁵ and Denmark.⁶⁶ The sixth study was conducted at a children’s hospital in Australia.⁶¹ Two studies implemented a transition guide and notebook and assessed transition readiness and healthcare use.^{64, 65} One study examined the implementation of a transition clinic that employed a transition coordinator, evaluating its effects on healthcare use, clinical outcomes, and self-management related skills.⁶⁵ One study implemented staff training, a parents’ evening, and youth-friendly environment and consultations.⁶⁶ Two studies conducted a preliminary evaluation of a transition program, and examined patient or parent concerns.^{61, 67} The interventions assessed were primarily focused on transition readiness, self-management skills, and clinical outcomes. The studies included several of the Six Core Elements.

Diabetes Mellitus

Key Points

- Compared with usual care, transition clinics may not improve hemoglobin A1C levels at 12 to 24 months in youth with type 1 diabetes mellitus (low-strength evidence).
- Evidence was insufficient to draw conclusions about the effect of transition interventions on clinic attendance in youth with diabetes mellitus.

Eligible Studies

Fifteen eligible studies examined care interventions for transition from pediatric to adult medical services among individuals with diabetes mellitus.⁷⁰⁻⁸³ Four studies did not meet comparator criteria and were not eligible for risk of bias assessment.^{72-74, 81, 84-87} The brief evidence map of these studies can be found in Appendix D. Table 4.9 summarizes the characteristics of the KQ literature set. Nine studies were assessed as high risk of bias,^{70-75, 77, 78, 80, 88} and two were assessed as medium risk of bias and included in the analytic set.^{76, 79} Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.9. Basic characteristics of KQ1 literature set: diabetes mellitus

| Characteristics | Information |
|-------------------------------|--|
| Total Included Studies | 11 studies |
| Study Design | 4 Randomized controlled trials 1 Nonrandomized controlled trials 6 Observational studies |
| NIH Stage Model | 1 Stage 0 3 Stage I 1 Stage II 1 Stage III 5 Stage IV |
| Study risk of bias | 9 High risk of bias 2 Medium risk of bias |
| Included Disease Stages/Types | 11 Type 1 diabetes mellitus |

| Characteristics | Information |
|---|---|
| Population Development Stage | 1 Average 18 years old (range 19-25) 1 Average 18 years old (range 17-18) 2 Average 19 years old (recruited 18-25) 1 Average 19 years old 1 17-19 years old 1 17-20 years old 1 18-20 years old 1 Average 21 years old (range 20 - 23) 2 Not reported |
| Setting | 11 Pediatric tertiary diabetes centers, clinics, or hospitals 3 Adult tertiary center, adult diabetes clinic 1 Tertiary centers or clinics, unknown pediatric or adult |
| Intervention Type | 11 Transition program or clinic |
| Mode | 9 In-person 2 Mixed in person and on-line or text-based |
| Outcomes Evaluated | 3 Quality of Life (3 life satisfaction/quality of life) 11 Clinical Outcomes (7 HbA1C levels, 4 other clinical outcomes) 12 Engagement in Care (9 attendance, 3 disengagement/loss to follow-up) 3 Resource Utilization (2 utilization) 3 Satisfaction or Experience with Care (3 satisfaction) |
| Maximum Intervention Followup Time | 1 12 weeks 1 3 months 2 1 year 2 2 years 3 2.5 years 1 4 years 1 6 years |
| Got Transitions ® Six Core Elements Targeted | 11 Transition Planning 11 Transfer of Care |
| Analytic Set | 2 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Eleven studies described or examined interventions for healthcare transition from pediatric to adult healthcare for diabetes mellitus. These interventions were conducted at urban tertiary pediatric academic health centers in North America or Australia; four in the United States, one in Canada, and one in Australia. Outcomes included clinic attendance, loss to followup, disengagement, utilization, satisfaction, quality of life, and clinical outcomes.

Diabetes Mellitus Outcomes

Evidence was insufficient to draw conclusions about the effects of interventions for care transitions for diabetes mellitus for clinic attendance. Low-strength evidence showed no effect of interventions on HbA1C. Table 4.10 provides a summary of findings.

One Canadian study enrolled 205 CSHCN; 85 percent of participants of whom were white.⁷⁶ This study reported improved clinic attendance for the intervention group during the 12-month intervention, but no difference at 12 months postintervention. An Australian study reported no difference in clinic attendance for the healthcare transition intervention group during the intervention period, but improved attendance for the intervention group during a 12-month post-intervention followup period.⁸⁹ These studies reported no difference in HbA1C for intervention groups. One study reported no differences between intervention and control groups at study completion for satisfaction, disease-related distress, or quality of life.

Table 4.10. Summary of findings for outcomes: diabetes mellitus

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|--|---|--|------------------------------------|---------------------------|
| Clinic Attendance/Appointment keeping Transition clinic vs usual care | 2 RCT ^{76, 79} (n=309) 0-12 months, 0-18 months | Individuals recruited age 17-20 years with type 1 diabetes mellitus in non-US settings | 1 found benefit 1 no difference | Insufficient |
| Clinic Attendance/Appointment keeping Transition clinic vs usual care | 2 RCT ^{76, 79} (n=274) 24-36 months | Individuals recruited age 17-20 years with type 1 diabetes mellitus in non-US settings | 1 found benefit 1 no difference | Insufficient |
| HbA1C Transition clinic vs usual care | 2 RCTs ^{76, 79} (n=309) 12-18 months | Individuals recruited age 17-20 years with type 1 diabetes mellitus in non-US settings | 2 no difference | Low |
| HbA1C Transition clinic vs usual care | 2 RCTs ^{76, 79} (n=274) 24-36 months | Individuals recruited age 17-20 years with type 1 diabetes mellitus in non-US settings | 2 no difference | Low |
| Satisfaction, disease-related distress, quality of life Transition clinic vs usual care | 1 RCT ^{76, 79} (n=205) 18 months | Individuals recruited age 17-19 years with type 1 diabetes mellitus in Canada | No difference on any measure | Insufficient |

Note: *Insufficient ratings due to few studies and imprecision in findings. No difference based on statistical significance.

Abbreviations: n=number; RCT=randomized controlled trial

Human Immunodeficiency Virus (HIV)

Key Points

- No transition interventions for CSHCN with HIV advanced to the analytic set for further analysis.

Eligible Studies

Four eligible studies examined care interventions for transition from pediatric to adult medical services among CSHCN with HIV.⁹⁰⁻⁹³ Two studies did not meet comparator criteria, were not eligible for risk of bias assessment, and were excluded from the analytic set.^{91, 92} The brief evidence map of these studies can be found in Appendix D. Two studies met comparator criteria and were assessed as high risk of bias and excluded from the analytic set (Table 4.11).^{90, 93} Appendix D provides evidence tables, and summary risk of bias assessments.

Table 4.11. Basic characteristics of KQ1 literature set: HIV

| Characteristics | Information |
|------------------------|-------------------------|
| Total Included Studies | 2 Studies |
| Study Design | 2 Observational |
| NIH Stage Model | 1 Stage I 1 Stage II |
| Study risk of bias | 2 High risk of bias |

| Characteristics | Information |
|--|---|
| Included Disease Stages/Types | All HIV types and stages |
| Population Development Stage | 1 13-20 years old 1 18+ years |
| Setting | 1 Adult and pediatric tertiary clinic 1 Tertiary centers or clinics, unknown pediatric or adult |
| Intervention Type | 2 Transition program or clinic |
| Mode | 2 In-person clinic based |
| Outcomes Evaluated | 1 Transition Readiness (1 disease knowledge) 1 Clinical Outcomes (1 viro-immunological parameters, 1 clinical outcomes) 2 Health behavior and wellness screening (1 psychological well-being, 1 self-esteem) 2 Engagement in care (1 successful transition, 1 retention) |
| Maximum Intervention Follow-up Time | 1 18 months |
| Got Transitions @ Six Core Elements Targeted | None |
| Analytic Set Studies | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the two included studies, one was conducted in Italy at a tertiary HIV center and examined a bundle of initiatives run by a multidisciplinary team,⁹⁰ while one U.S. study took place in a university pediatric/adult HIV clinic; most participants were Black. Neither study targeted any core elements. Outcomes focused on disease knowledge, self-esteem, and general health. Neither study collected outcomes for patient caregivers or providers.

Inflammatory Bowel Disease (IBD)

Key Points

- No transition interventions for CSHCN with IBD advanced to the analytic set for further analysis.

Eligible Studies

Twelve eligible studies described or examined care interventions for transition from pediatric to adult medical services for CSHCN with IBD.⁹⁴⁻¹⁰⁵ Three did not meet comparator criteria and were not eligible for risk of bias assessment.^{94, 98, 105} The brief evidence map of these studies can be found in Appendix D. Nine studies met comparator criteria but were assessed as high risk of bias and excluded from the analytic set.^{95-97, 99-104} Table 4.12 summarizes the characteristics of the KQ literature set. Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.12. Basic characteristics of KQ1 literature set: inflammatory bowel disease

| Characteristics | Information |
|-------------------------------|---|
| Total Included Studies | 9 Studies |
| Study Design | 8 Observational studies 1 Mixed methods study |
| NIH Stage Model | 9 Stage I |
| Study risk of bias | 9 High risk of bias |
| Included Disease Stages/Types | 7 Crohn's disease and ulcerative colitis 2 Unclassified IBD 2 Indeterminate colitis |

| Characteristics | Information |
|--|--|
| Population Development Stage | 1 >14 years 1 15-16 years old 2 16-18 years old 1 16-25 years old 1 17-18 years old 1 18 years old 1 18-25 years old 1 < 18 years |
| Setting | 6 Pediatric tertiary centers, clinics, or hospitals 1 Adult and pediatric tertiary clinic 1 Tertiary outpatient clinic unknown pediatric and adult setting 1 Tertiary pediatric and adult outpatient 1 Adult tertiary outpatient department |
| Intervention Type | 6 Transition program or clinic 2 Joint transition consultations 1 Transition coordinator |
| Mode | 9 In-person |
| Outcomes Evaluated | 8 Transition readiness (1 general transition, 2 self-management, 1 independence in consultations, 2 disease-specific knowledge, 2 self-efficacy) 3 Quality of life 10 Clinical outcomes (4 disease-specific clinical outcomes, 3 disease activity, 1 BMI, 1 clinical activity of disease, 1 current state of patient health) 4 Health behaviors and wellness screenings (1 smoker status, 1 nicotine consumption, 1 depression & anxiety, 1 resilience) 5 Treatment or care adherence (1 treatment adherence, 3 medication adherence, 1 pharmacological therapy) 2 Engagement in care (1 percent of patients who bounced back to pediatrics, 1 attitudes and beliefs about medical therapy) 4 Satisfaction or experience with care (1 transfer experiences, 1 transition satisfaction, 1 perceived patient-centeredness, 1 quality of transition) 10 Resource utilization (3 resource utilization, 1 clinic attendance, 1 surgery, 1 hospitalization 1 time to adult visits, 1 non-attendance rates, 1 surgical intervention, 1 cost) 1 Other (1 socioeconomic parameters) |
| Maximum Intervention Follow-up Time | 5 12 months 4 24 months |
| Got Transitions® Six Core Elements Targeted | 4 Transition Readiness 4 Transition Planning 1 Transfer of Care |
| Analytic Set | 0 Studies |

Abbreviations: IBD=inflammatory bowel disease; KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

All nine included studies examined interventions at tertiary IBD care clinics or centers, and all but one were conducted outside of the United States. The interventions primarily targeted one or more components of the Six Core Elements which included of transition readiness, planning, and transfer of care. Outcomes primarily focused on disease-related clinical outcomes healthcare use, and self-management.

Juvenile Idiopathic Arthritis

Key Points

- No transition interventions for CSHCN with juvenile idiopathic arthritis advanced to the analytic set for further analysis.

Eligible Studies

Seven studies examined transition interventions for CSHCN with individuals with juvenile idiopathic arthritis.¹⁰⁶⁻¹¹² Two studies did not meet comparator criteria and were not eligible for risk of bias assessment.^{106, 111} The brief evidence map of these studies can be found in Appendix D. Table 4.13 summarizes the characteristics of the KQ literature set. Four studies were assessed as high risk of bias.¹⁰⁸⁻¹¹⁰ One study was assessed as medium risk of bias.¹⁰⁷ Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.13. Basic characteristics of KQ1 literature set: juvenile idiopathic arthritis

| Characteristics | Information |
|--|---|
| Total Included Studies | 5 Studies |
| Study Design | 1 Randomized controlled trials 3 Observational studies 1 Mixed methods study |
| NIH Stage Model | 3 Stage I 2 Stage II |
| Study risk of bias | 4 High risk of bias 1 Medium risk of bias |
| Included Disease Stages/Types | 5 All juvenile idiopathic types and stages |
| Population Development Stage | 2 11-17 years old 1 12-20 years old 1 14-16 years old 1 16-20 years old |
| Setting | 4 Pediatric tertiary centers, clinics or hospitals 1 Tertiary centers or clinics, unknown pediatric or adult setting |
| Intervention Type | 5 Transition program or clinic |
| Mode | 5 In-person |
| Outcomes Evaluated | 8 Transition Readiness (1 illness-related knowledge, 2 arthritis-related knowledge, 1 parenting dimension/promotion of independence, 1 support of autonomy, 1 independent health behaviors, 1 behavioral control, 1 psychological control) 5 Quality of Life (1 perceived health status, 1 global quality of life, 3 health related quality of life) 6 Clinical Outcomes (1 fatigue, 1 absence of disease activity, 1 functional status, 1 clinical remission, 1 disease outcome, 1 disease activity) 1 Treatment or Care Adherence (1 medication adherence) 4 Satisfaction or Experience with Care (2 satisfaction, 1 acceptability, 1 retention) 1 Resource use (1 usability) 1 Other (1 pre-vocational experience) |
| Maximum Intervention Follow-up Time | 2 12 months 1 9 months 2 Not reported |
| Got Transitions® Six Core Elements Targeted | 2 Transition and Care Policy/Guide 5 Transition Readiness 1 Transition Planning 1 Transition of Care |
| Analytic Set Studies | 1 Study |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the five included studies, three examined transition program interventions while two looked at transition clinics between 2007 and 2019. All studies were conducted outside of the United States (Belgium, United Kingdom, Denmark, and Finland). Interventions were conducted in various settings including outpatient and rheumatology clinics. All interventions included

transition readiness of the Six Core Elements while two also incorporated transition and care policy/guide, and one incorporated both transition planning and transition of care. Selected outcomes primarily focused on perceived health status, medication adherence, illness-related knowledge, quality of life, clinical remission, and satisfaction.

CSHCN Outcomes

No usable outcomes were available from the medium risk of bias study conducted in Denmark.¹⁰⁷

Kidney Disease

Key Points

- No transition interventions for CSHCN with kidney disease advanced to the analytic set for further analysis.

Eligible Studies

Three studies examined care interventions for transition from pediatric to adult medical services among CSHCN with kidney disease.¹¹³⁻¹¹⁵ One study did not meet comparator criteria and was not eligible for risk of bias assessment.¹¹⁴ The brief evidence map of this study can be found in Appendix D. Table 4.14 summarizes the characteristics of the literature set. Two studies were assessed as high risk of bias and excluded from the analytic set. Appendix D provides evidence tables, summary of risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.14. Basic characteristics of KQ1 literature set: kidney disease

| Characteristics | Information |
|---|---|
| Total Included Studies | 2 Studies |
| Study Design | 1 Observational cohort 1 Mixed methods |
| NIH Stage Model | 2 Stage I |
| Study risk of bias | 2 High risk of bias |
| Included Disease Stages/Types | 2 All kidney disease types and stages |
| Population Development Stage | 1 15-27 years old 1 19-26 years old |
| Setting | 1 Pediatric tertiary centers, clinics or hospitals 1 Tertiary centers or clinics, unknown pediatric or adult setting |
| Intervention Type | 1 Young adult clinic 1 Transition model |
| Mode | 2 In-person |
| Outcomes Evaluated | 1 Transition Readiness (1 self-management) 1 Quality of Life (disease-specific quality of life) 2 Clinical Outcomes (1 type of illness, 1 nutrition, 3 Treatment or Care Adherence (1 medications, 2 adherence) 4 Engagement in Care (1 time trade-off, 1 new health provider, 1 insurance issues, 1 informed reproduction) 1 Satisfaction or Experience with Care (1 ongoing support) |
| Maximum Intervention Follow-up Time | 2 6 months |
| Got Transitions © Six Core Elements Targeted | 2 Transition Readiness 1 Transition Planning |
| Analytic Set Studies | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the two included studies, one examined a young adult clinic while the other examined a transition model. Both were conducted between 2015 and 2019 in renal clinics, one in the United States and the other in Australia. Both interventions included components of the Six Core Elements which include transition readiness, while one study also incorporated transition planning. Outcomes primarily focused on quality of life, medication adherence, and self-management.

Neurologic Disorders

Key Points

- No transition interventions for CSHCN with neurologic disorders advanced to the analytic set for further analysis.

Eligible Studies

Three eligible studies examined care interventions for CSHCN with neurological disorders including epilepsy.¹¹⁶⁻¹¹⁸ All studies were assessed as high risk of bias and excluded from the analytic set. Table 4.15 summarizes the characteristics of the KQ literature set. Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.15. Basic characteristics of KQ1 literature set: neurologic disorders

| Characteristics | Information |
|--|--|
| Total Included Studies | 3 Studies |
| Study Design | 2 Observational studies 1 Mixed methods |
| NIH Stage Model | 2 Stage I 1 Stage II |
| Study risk of bias | 3 High risk of bias |
| Included Disease Stages/Types | 2 Adolescents with Epilepsy 1 Children and adolescents recruited from neuropsychiatry clinic with diagnosed chronic condition |
| Population Development Stage | 1 9-15 years old (12.1 years old average) 1 12-20 years old 1 15-25 years old |
| Setting | 1 Tertiary centers or clinics, unknown pediatric or adult setting 1 Pediatric tertiary centers, clinics, or hospitals 1 Summer program |
| Intervention Type | 1 Epilepsy Transition Clinic 1 Cognitive remediation summer program 1 Electronic medical record transition flow sheet |
| Mode | 3 In-person |
| Outcomes Evaluated | 5 Transition Readiness (1 adaptive behavior, 1 executive control, 1 executive function, 1 problem-solving, 1 transition health knowledge) 2 Clinical Outcomes (1 Remission, 1 Diagnosis Change) 3 Treatment or Care Adherence (1 referral, 1 prescription, 1 consultation) |
| Maximum Intervention Followup Time | 1 2.5 years 1 4 years 1 Not reported |
| Got Transitions® Six Core Elements Targeted | 2 Transition Readiness 1 Transition Planning 1 Transfer of Care |
| Analytic Set | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the three included studies, two examined transition interventions for CSHCN with neurological disorders, and one used a longitudinal design to examine a pilot pediatric cognitive remediation summer program to prepare for transition of care. This study reported CSHCN neuropsychological outcomes, and perception and behaviors among parents of CSHCN. One study examined an epilepsy transition clinic staffed with a multidisciplinary team. This study reported CSHCN outcomes of diagnosis, treatment and therapeutic consequences, and seizure remission.

Rheumatic Conditions

Key Points

- No transition interventions for CSHCN with rheumatic conditions advanced to the analytic set for further analysis.

Eligible Studies

Four studies examined transition interventions for CSHCN with rheumatic diseases.¹¹⁹⁻¹²² Three studies did not meet comparator criteria and were not eligible for risk of bias assessment.¹²⁰⁻¹²² The brief evidence map of these studies can be found in Appendix D. Table 4.16 summarizes the characteristics of the literature set.¹¹⁹ One study was assessed as high risk of bias and excluded from the analytic set. Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.16. Basic characteristics of KQ1 literature set: rheumatic conditions

| Characteristics | Information |
|---|--|
| Total Included Studies | 1 Study |
| Study Design | 1 Observational study |
| NIH Stage Model | 1 Stage I |
| Study risk of bias | 1 High risk of bias |
| Included Disease Stages/Types | 1 Broad category of rheumatic conditions |
| Population Development Stage | 1 16+ years |
| Setting | 1 Pediatric tertiary centers, clinics, or hospitals |
| Intervention Type | 1 Transition program or clinic |
| Mode | 1 In-person |
| Outcomes Evaluated | 1 Satisfaction or Experience with Care (1 satisfaction) |
| Maximum Intervention Follow-up Time | 1 6-8 months |
| Got Transitions® Six Core Elements Targeted | 1 Transition Readiness 1 Transition Planning 1 Transfer Completion |
| Analytic Set Studies | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

This 2015 study examined a transition program¹¹⁹ in a U.S. rheumatology clinic. The intervention included components of the Six Core Elements which include transition readiness, transition planning, and transfer completion. The study focused on patient satisfaction as the outcome.

Sickle Cell Disease

Key Points

- No transition interventions for CSHCN with sickle cell disease advanced to the analytic set for further analysis.

Eligible Studies

Seventeen studies examined transition interventions for CSHCN with sickle cell disease.¹²³⁻¹³⁹ Eight studies did not meet comparator criteria and were not eligible for risk of bias assessment,^{124, 126-129, 131, 134, 135} the brief evidence map of these studies can be found in Appendix D. Table 4.17 summarizes the characteristics of the KQ literature set. Nine studies were assessed as high risk of bias and were excluded from the analytic set.^{123, 125, 130, 132, 133, 136-139} Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.17. Basic characteristics of KQ1 literature set: sickle cell disease

| Characteristics | Information |
|--------------------------------------|--|
| Total Included Studies | 9 Studies |
| Study Design | 9 Observational studies |
| NIH Stage Model | 9 Stage I |
| Included Disease Stages/Types | 9 All sickle cell disease types and stages |
| Study risk of bias | 9 High risk of bias |
| Population Development Stage | 1 12-25 years old 1 13-21 years old 1 15-18 years old 1 16-17 years old 1 17-20 years old 1 18-23 years old 1 18-25 years old 2 18+ years |
| Setting | 6 Pediatric tertiary centers, clinics or hospitals 2 Adult tertiary centers or clinics 1 Tertiary centers or clinics, unknown pediatric or adult setting |
| Intervention Type | 6 Transition program or clinic 1 Adolescent autonomy checklist 1 Music therapy intervention 1 Educational videos |
| Mode | 8 In-person 1 Online |
| Outcomes Evaluated | 16 Transition Readiness (4 general transition readiness, 3 self-management, 3 disease-specific knowledge, 1 health literacy 1 transition concerns, 1 emotion, 2 self-efficacy, 1 trust) 1 Quality of life (1 health-related quality of life) 4 Treatment or Care Adherence (1 adherence, 2 medication adherence, 1 barrier to adherence) 9 Engagement in Care (1 pediatric abandonment, 2 matriculation to adult care, 1 adult care abandonment, 1 loss to follow-up, 1 appointment attendance, 1 reason for refusal, 1 engagement with intervention, 1 reason for drop-out) 2 Satisfaction or Experience with Care (1 satisfaction) 3 Resource utilization (1 hospitalizations, 1 enrollment rates, 1 retention rates) |

| Characteristics | Information |
|--|---|
| Maximum Intervention Follow-up Time | 1 8 weeks 1 6 months 3 12 months 2 years 1 161-882 days 2 Not reported |
| Got Transitions ® Six Core Elements Targeted | 2 Transition and Care Policy/Guide 2 Tracking and Monitoring 8 Transition Readiness 4 Transition Planning 4 Transfer of Care 3 Transition Completion |
| Analytic Set Studies | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the nine included studies, three examined transition programs, two looked at a transition program with a transition navigator, one examined a music therapy intervention, one used an adolescent autonomy checklist between 2011 and 2019, one used educational videos, and one used a student mentorship approach. Eight studies were conducted in the United States and one in Canada. Interventions took place in various settings (hematology clinic, sickle cell disease clinics, medical home and hemoglobinopathy care center). All interventions included components of the Six Core Elements (mainly including transition readiness). One study incorporated all Six Core Elements of healthcare transition in the intervention. Outcomes primarily focused on transition readiness, knowledge, self-efficacy, loss to followup, hospitalizations, and medication adherence.

Solid Organ Transplant

Key Points

- Evidence was insufficient to draw conclusions about the effect of transition interventions on CSHCN with a solid organ transplant.

Eligible Studies

Seventeen studies examined care interventions for transition from pediatric to adult medical services among individuals with a solid organ transplant.¹⁴⁰⁻¹⁵⁶ Two studies did not meet comparator criteria and were not eligible for risk of bias assessment.^{141, 148} The brief evidence map of these studies can be found in Appendix D. Table 4.18 summarizes the characteristics of the literature set. Fourteen studies were assessed as high risk of bias; just one was low risk of bias and included in the analytic set.¹⁴⁶ Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.18. Basic characteristics of KQ1 literature set: solid organ transplant

| Characteristics | Information |
|------------------------|---|
| Total Included Studies | 15 Studies |
| Study Design | 1 Randomized controlled trial 13 Observational cohort 1 Mixed methods study |
| NIH Stage Model | 14 Stage I 1 Stage II |

| Characteristics | Information |
|--|--|
| Study risk of bias | 14 High risk of bias 1 Low risk of bias |
| Included Disease Stages/Types | 10 Kidney transplant 3 Liver transplant 2 Heart transplant |
| Population Development Stage | 1 11+ years 2 13+ years 1 14+ years 1 16 to 18 years old 1 16 to 22 years old 1 16+ years 1 <18 years of age 2 18 years old 1 18 to 21 years old 1 18 to 35 years old 1 18+ years 1 21 years old 1 Not reported |
| Setting | 6 Tertiary centers or clinics, unknown pediatric or adult setting 3 Pediatric tertiary centers, clinics or hospitals 3 Adult tertiary centers, clinics or hospitals 1 Pediatric and adult tertiary centers and clinics 2 Not Reported |
| Intervention Type | 9 Transition program or clinic 2 Transition model 2 Transition coordinator 1 Young adult clinic 1 Transfer clinic |
| Mode | 14 In-person 1 In-person and online |
| Outcomes Evaluated | 13 Transition readiness (3 general transition readiness, 1 Autonomous or controlled motivation, 1 Self-reported confidence, 3 Medical knowledge, 1 Perceived competence, 1 Efficacy, 1 Perceived autonomy support, 1 Social support, 1 Developmentally Based Skills) 2 Quality of life (2 general quality of life) 13 Clinical outcomes (7 general clinical outcomes, 1 Clinicians subjective assessment of overall graft stability, 2 Episodes of rejection, 1 Graft loss, 1 Loss of kidney transplant, 1 health status) 15 Treatment or care adherence (6 unspecified adherence, 3 clinic attendance, 2 medication adherences, 1 continuity of care, 2 retention, 1 bounce backs) 2 Satisfaction or Experience with Care (2 Satisfaction) 2 Resource Utilization (1 hospitalizations related to graft issues, 1 Cost) |
| Maximum Intervention Follow-up Time | 6 12 months 2 6 months 1 60 months 1 24 months 1 5 years 1 36 months 3 Not reported |
| Got Transitions® Six Core Elements Targeted | 15 Transition Readiness 12 Transition Planning 4 Transfer of Care 4 Transfer Completion |
| Analytic Set Studies | 1 Study |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

Of the 15 included studies, six examined transition program interventions, three looked at transition clinics, two looked at transition models, two looked at a transition coordinator, and the final two looked at a young adult clinic and a transfer clinic. All studies were conducted between 2006 and 2019, with six taking place in the United States and the other nine in Finland, Germany, Canada, United Kingdom, and Switzerland. Interventions were conducted in a transition outpatient clinic, hospital clinic, outpatient clinic, heart transplant center and renal outpatient clinic. All interventions included components of the Six Core Elements which include transition readiness while three studies incorporated elements of transition planning, transfer of care, and transfer completion. Only one study used all Six Core Elements in the development of their program. Outcomes primarily focused on transition readiness, quality of life, clinical outcomes, knowledge, medication adherence, and satisfaction.

CSHCN Outcomes

Evidence was insufficient to draw conclusions about the effects of interventions for care transitions for CSHCN with heart transplants. One U.S. study reported on heart-transplant-related knowledge, transition readiness (self-advocacy), transition readiness (self-management), social support, adherence to medical regimen, retention, and efficacy for heart transplant recipients, of whom more than 75 percent were white.¹⁴⁶ Table 4.19 provides a summary of findings. The study reported increased transition readiness (self-management) in the control group compared to the intervention (p=0.007) over time. No difference was found in all other outcomes. The study reported patient retention of 86 percent in the intervention group and 91 percent in the control group.

Table 4.19. Summary of findings for outcomes: solid organ transplant

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|--|--|--|---------------------------|---------------------------|
| Heart transplant related knowledge Transitioning to Adult Care (TRANSIT) program vs usual care | 1 RCT ¹⁴⁶ (n=37 intervention; n=41 control) 6 months | Individuals recruited age 18 years or older with a heart transplant in the US. | 1 found no difference | Insufficient |
| Transition readiness (TRAQ)-Self-advocacy Transitioning to Adult Care (TRANSIT) program vs usual care | 1 RCT ¹⁴⁶ (n=37 intervention; n=41 control) 6 months | Individuals recruited age 18 years or older with a heart transplant in the US. | 1 found no difference | Insufficient |
| Transition readiness (TRAQ)-Self-management Transitioning to Adult Care (TRANSIT) program vs usual care | 1 RCT ¹⁴⁶ (n=37 intervention; n=41 control) 6 months | Individuals recruited age 18 years or older with a heart transplant in the US. | 1 found favors usual care | Insufficient |
| Social support (SSI) Transitioning to Adult Care (TRANSIT) program vs usual care | 1 RCT ¹⁴⁶ (n=37 intervention; n=41 control) 6 months | Individuals recruited age 18 years or older with a heart transplant in the US. | 1 found no difference | Insufficient |

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|---|--|--|--|---------------------------|
| Adherence to medical regimen Transitioning to Adult Care (TRANSIT) program vs usual care | 1 RCT ¹⁴⁶ (n=37 intervention; n=41 control) 6 months | Individuals recruited age 18 years or older with a heart transplant in the US. | 1 found favors usual care | Insufficient |
| Retention Transitioning to Adult Care (TRANSIT) program vs usual care | 1 RCT ¹⁴⁶ (n=37 intervention; n=41 control) 6 months | Individuals recruited age 18 years or older with a heart transplant in the US. | 86% retention intervention 91% retention comparator | Insufficient |
| Efficacy Transitioning to Adult Care (TRANSIT) program vs usual care | 1 RCT ¹⁴⁶ (n=37 intervention; n=41 control) 6 months | Individuals recruited age 18 years or older with a heart transplant in the US. | Not statistically significant different on 5 out of 5 | Insufficient |

*Insufficient ratings due to few studies and imprecision in findings.

Abbreviations: N=number; RCT=randomized controlled trial

Spina Bifida

Key Points

- No transition interventions for CSHCN with spina bifida advanced to the analytic set for further analysis.

Eligible Studies

Seven studies examined transition interventions for CSHCN with spina bifida.^{146, 157-163} Four did not meet comparator criteria and were not eligible for risk of bias assessment.^{157, 159-161} The brief evidence map of these studies can be found in Appendix D. Table 4.20 summarizes the characteristics of the KQ literature set. Two studies were assessed as high risk of bias.^{162, 163} One study was assessed as medium risk of bias and included in the analytic set.¹⁵⁸ Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.20. Basic characteristics of KQ1 literature set: spina bifida

| Characteristics | Information |
|-------------------------------|---|
| Total Included Studies | 3 Studies |
| Study Design | 1 Randomized controlled trial 1 Observational study 1 Mixed methods study |
| NIH Stage Model | 2 Stage I 1 Stage II |
| Study risk of bias | 2 High risk of bias 1 Medium risk of bias |
| Included Disease Stages/Types | All spina bifida types and stages |
| Population Development Stage | 1 11-17 years old 1 14-18 years old 1 Not reported |
| Setting | 2 Tertiary centers or clinics, unknown pediatric or adult setting 1 Pediatric tertiary centers, clinics or hospitals |

| Characteristics | Information |
|--|--|
| Intervention Type | 1 Transition care coordination program 1 Spina bifida transition program 1 Transition preparation training |
| Mode | 3 In-person |
| Outcomes Evaluated | 3 Transition readiness (1 TRAQ, 1 role mastery, 1 self-care practice) 1 Satisfaction or Experience with Care (1 barriers) 1 Psychosocial Health (1 well-being) |
| Maximum Intervention Follow-up Time | 1 4-6 months 1 12 months 1 4 months |
| Got Transitions® Six Core Elements Targeted | 2 Transition Readiness 1 Transfer of Care |
| Analytic Set Studies | 1 Study |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health; TRAQ=Transition readiness assessment questionnaire

Intervention Research Context

Of the three included studies, one examined a transition care coordination program, one examined a transition program, and the third looked at a training program for transition preparation. All were conducted between 2010 and 2017 in the United States, two in an outpatient clinic and one in a spina bifida clinic. Of note, participants in one study were almost 90 percent Latinx. All interventions included components of the Six Core Elements which include transition readiness and transfer of care. Outcomes primarily included transition readiness, role mastery, well-being, and self-care.

CSHCN Outcomes

Evidence was insufficient to draw conclusions about the effects of interventions for care transitions for CSHCN with spina bifida. One study reported on subjective well-being, role mastery, and self-care. Table 4.21 provides a summary of findings.¹⁵⁸ No benefit was found across all outcome measures.

Table 4.21. Summary of findings for outcomes: spina bifida

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|---|--|---|-----------------------|---------------------------|
| Subjective well-being (PARS III) Transition Program Training (TPT) intervention in combination management vs only management | 1 RCT ¹⁵⁸ (n=31 intervention; n=34 control) 4 months | Individuals recruited age 14-18 years with all spina bifida severities in the U.S. and their caregivers | 1 found no difference | Insufficient |
| Role mastery (CLSS) Transition Program Training (TPT) intervention in combination with management vs only management | 1 RCT ¹⁵⁸ (n=31 intervention; n=34 control) 4 months | Individuals recruited age 14-18 years with all spina bifida severities in the U.S. and their caregivers | 1 found no difference | Insufficient |
| Self-care practice (DSCPI-90) Transition Program Training (TPT) intervention in combination with management vs only management | 1 RCT ¹⁵⁸ (n=31 intervention; n=34 control) 4 months | Individuals recruited age 14-18 years with all spina bifida severities in the U.S. and their caregivers | 1 found no difference | Insufficient |

*Insufficient ratings due to few studies and imprecision in findings.

Abbreviations: PARS III=Personal Adjustment and Role Skills Scale; CLSS=Community Life Skills Scale; DSCPI-90=Denyes Self-Care Practice Instrument; RCT=randomized controlled trial

Urological Conditions

Key Points

- No transition interventions for CSHCN with urological conditions advanced to the analytic set for further analysis.

Eligible Studies

Two unique publications described a transition intervention.^{164, 165} These studies did not meet comparator criteria; we report these in the brief evidence map in Appendix D.

Other Conditions

Key Points

- Evidence was insufficient to draw conclusions about the effect of transition interventions on CSHCN with various conditions.
- No other conditions (such as asthma, cerebral palsy, or muscular dystrophy) advanced to the analytic set for further analysis.

Eligible Studies

Sixteen studies examined transition interventions for CSHCN with various conditions.^{84-87, 166-177} Six studies did not meet comparator criteria and were not eligible for risk of bias assessment.^{84-87, 176, 177} The brief evidence map of these studies can be found in Appendix D. Table 4.22 summarizes the characteristics of the KQ literature set. Nine studies were assessed as high risk of bias and excluded from the analytic set.¹⁶⁷⁻¹⁷⁵ One study was assessed as medium risk of bias and included in the analytic set.¹³² Appendix D provides evidence tables, summary risk of bias assessments, and strength of evidence for key comparisons and outcomes.

Table 4.22. Basic characteristics of KQ1 literature set: other conditions

| Characteristics | Information |
|--------------------------------------|--|
| Total Included Studies | 10 Studies |
| Study Design | 2 Randomized controlled trials 8 Observational studies |
| NIH Stage Model | 8 Stage I 2 Stage II |
| Risk of Bias | 9 High risk of bias 1 Medium risk of bias |
| Included Disease Stages/Types | 2 Hemophilia 1 Hirschsprung disease and anorectal malformations 1 Asthma 1 Type 1 diabetes mellitus, cystic fibrosis, or inflammatory disease 1 Esophageal atresia 1 Genetic disorder, muscular dystrophy, spinal muscular atrophy, cerebral palsy, wildervanck syndrome, VACTERL 1 Endocrine conditions 1 IBD + Diabetes mellitus 1 Phenylketonuria |

| Characteristics | Information |
|---|--|
| Population Development Stage | 1 12-18 years old 1 13-18 years old 1 14-20 years old 1 14-21 years old 1 15+ years 1 16-25 years old 1 16+ years 1 18+ years 2 Not reported |
| Setting | 5 Pediatric tertiary centers, clinics or hospitals 2 Pediatric and adult tertiary centers and clinics 1 Adult tertiary centers or clinics 1 Tertiary centers or clinics, unknown pediatric or adult setting 1 Not Reported |
| Intervention Type | 2 Transition program or clinic 1 Web-based interactive application 1 HEMO-milestones tool 1 Transition workshops 1 Young person's clinic 1 Patient education program with Web-based component 1 Online self-management program 1 Transition-oriented patient education program |
| Mode | 7 In-person 2 Online 1 In-person & online |
| Outcomes Evaluated | 10 Transition readiness (1 general transition readiness, 1 transition Competence, 2 general self-efficacy, 2 self-management, 1 asthma related knowledge, 1 Disease-specific knowledge, 1 patient competency, 1 patient engagement) 4 Quality of life (1 general QoL, 3 health-related QoL) 1 Clinical outcomes (1 metabolic control, 1 disease-specific symptoms, 1 disease-specific functioning) 5 Treatment or Care Adherence (1 medication adherence, 1 Clinic attendance, 1 documentation of patient completion of skill plan, 1 documentation of patient completion of competency assessment, adherence) 1 Engagement in care (1 loss of follow-up) 3 Satisfaction or experience with care 1 Retention |
| Maximum Intervention Follow-up Time | 1 4 weeks 1 3 months 2 6 months 3 12 months 1 24 months 2 Not reported |
| Got Transitions ® Six Core Elements Targeted | 10 Transition Readiness 3 Transition Planning |
| Analytic Set Studies | 1 Study |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health; IBD=inflammatory bowel disease; QoL=quality of life; VACTERL=vertebral defects, anal atresia, cardiac defects, tracheo-esophageal fistula, renal anomalies, and limb abnormalities

Intervention Research Context

The included studies examined various interventions including a transition outpatient clinic, Web-based interactive application, HEMO-milestones tool, transition workshops, transition program, young persons' clinic, educational program, and online self-management program. All studies were conducted between 2013 and 2021, with two taking place in the United States and the rest in the Netherlands, Germany, Canada, United Kingdom, Portugal, and Germany. Settings included outpatient clinics, immunology clinic, hemophilia clinic, long-term ventilation clinic, and hospital. All interventions included transition readiness from the Six Core Elements; two

studies also incorporated transition planning. Outcomes primarily focused on transition readiness, transition competence, knowledge, quality of life, self-efficacy, and satisfaction.

CSHCN Outcomes

Evidence was insufficient to draw conclusions about the effects of interventions for care transitions for CSHCN with hemophilia. One Canadian study reported on disease-specific knowledge, self-efficacy, self-management, satisfaction, and retention.¹⁶⁶ Table 4.23 provides a summary of findings. The study reported increased disease-specific knowledge in the intervention group compared to control (p=0.01). No difference was found in self-efficacy, self-management, or retention across groups; 91 percent of participants reported satisfaction with the program. No description of the participants was provided beyond whether they spoke English or French.

Table 4.23. Summary of findings for outcomes: other conditions

| Outcome Comparisons | #Studies/Design (n Analyzed) Timing | Population | Findings | Strength of the Evidence* |
|--|---|--|-----------------------|---------------------------|
| Disease-specific knowledge Online self-management program vs no intervention | 1 RCT (pilot) ¹⁶⁶ (n=16 intervention; n=13 control) Timing NR | Individuals recruited age 12-18 with hemophilia in Canada. | 1 found benefit | Insufficient |
| Self-efficacy (GSE-S 12) Online self-management program vs no intervention | 1 RCT (pilot) ¹⁶⁶ (n=16 intervention; n=13 control) Timing NR | Individuals recruited age 12-18 with hemophilia in Canada. | 1 found no difference | Insufficient |
| Self-management (Self-Management Skills Assessment Guide) Online self-management program vs no intervention | 1 RCT (pilot) ¹⁶⁶ (n=16 intervention; n=13 control) Timing NR | Individuals recruited age 12-18 with hemophilia in Canada. | 1 found no difference | Insufficient |
| Satisfaction Online self-management program vs no intervention | 1 RCT (pilot) ¹⁶⁶ (n=16 intervention; n=13 control) Timing NR | Individuals recruited age 12-18 with hemophilia in Canada. | 91% satisfied | Insufficient |
| Retention Online self-management program vs no intervention | 1 RCT (pilot) ¹⁶⁶ (n=16 intervention; n=13 control) Timing NR | Individuals recruited age 12-18 with hemophilia in Canada. | 1 found no difference | Insufficient |

*Insufficient ratings due to few studies and imprecision in findings.

Abbreviations: NR=not reported; NA=not applicable; GSE-S 12=Generalized Self-Efficacy-Sherer Scale; RCT=randomized controlled trial

Chapter 5. Implementation Strategies and Communication Tools

Key Question (KQ) 2, Implementation Strategies

Key Points

- No implementation strategies for transition interventions advanced to the analytic set for further analysis.

Eligible Studies

Nine unique studies described or examined training or quality improvement implementation interventions for transition from pediatric to adult medical services for children with special healthcare needs (CSHCN).^{48, 64, 178-184} Diseases and conditions included childhood cancer survivors, epilepsy, cystic fibrosis, and chronic conditions. Table 5.1 summarizes the characteristics of the KQ2 literature set. All studies were assessed as high risk of bias. Appendix E provides evidence tables.

Table 5.1. Basic characteristics of KQ literature set: KQ2, all populations

| Characteristic | Information |
|---|---|
| Total Studies | 9 Studies |
| Study Design | 9 Observational studies |
| NIH Stage Model | 4 Stage I 3 Stage II 2 Stage V |
| Study Risk of Bias | 9 High risk of bias |
| Included Disease Stages/Types | 1 Childhood cancer survivors 4 Chronic conditions 2 Neurologic conditions/Epilepsy 1 Cystic fibrosis 1 Attention deficit/hyperactivity disorder (ADHD) |
| Population | 4 Providers 4 Patients 2 Parents/Caregivers |
| Setting | 5 Pediatric tertiary centers, clinics or hospitals 2 Pediatric and adult tertiary centers and clinics 1 Adult tertiary centers or clinics 1 Family medical center |
| Intervention Type/ Implementation Strategy | 5 Transition program or clinic 3 Training 1 Training program and network linkage |
| Mode of Delivery | 9 In-person |
| Outcomes Evaluated | 4 Provider Knowledge 4 Provider Confidence/comfort 2 Provider Experience related to transition before and after 1 Provider satisfaction 2 Implementation of six core elements 1 Provider Care provision 2 Patient acceptability 1 Patient confidence 2 Parent/caregiver acceptability 1 Waiting time 1 Referral rate 1 Handover/transition |

| Characteristic | Information |
|--|--|
| Maximum Intervention Follow-up Time | 1 8 months 2 11-12 months 2 18 months 2 24 months 1 Unclear 1 Not applicable |
| Got Transitions ® Six Core Elements Targeted | 4 Transition and Care Policy/Guide 4 Transition Readiness 2 Transition Planning 1 Transfer of Care 2 All Six Core Elements |
| Analytic Set Studies | 0 Studies |

Abbreviations: KQ=Key Question; NIH=National Institutes of Health; CSHCN=children with special healthcare need; NA=not applicable

Intervention Research Context

One study was conducted in Australia, one in the United Kingdom, and the remaining seven in the United States. The studies generally fell into two groups, training programs or multicomponent transition programs.

One training program addressed childhood cancer survivor care.¹⁸² This study described the development of a network to increase awareness and provide ongoing education to providers at university health centers on survivor care for incoming students. Provider education included surveillance for the specific late effects for which the survivor is at risk based on their cancer treatment, and to ensure provider access to their student survivors' survivor healthcare plans through an internet-based patient-controlled communication tool. Another U.S. study examined a nurse-led 60-minute education session in an outpatient rehabilitation department for CSHCN.¹⁸⁴ One Australian study paired training for providers with patient education for young patients with epilepsy.¹⁸⁰ All training program studies were Stage I or II.

Transition programs were described and examined in one U.K. study and four U.S. studies. Comprehensive healthcare transition programs based on the Six Core Elements were examined in a pilot study of three pediatric primary care clinics for CSHCN eligible for Supplemental Security Insurance. This pilot was later expanded upon in a large-scale quality improvement learning network of seven learning health systems¹⁷⁹ that were geographically located to provide a national representation. Implementation of all Six Core Elements was the primary study outcome. A third study looked at a multicomponent transition program for young people with cystic fibrosis, focusing on developing a program guide and notebook, along with joint staff meetings between adult and pediatric clinics.⁶⁴ A fourth study sought to improve communication through electronic medical record tracking and best practice advisory, and to increase structured patient education for young people with epilepsy.¹⁷⁸ A fifth used a quality improvement approach and plan-do-study-act cycles to improve CSHCN engagement.⁴⁸ The remaining study enrolled adolescents with attention deficit/hyperactivity disorder (ADHD) of unknown demographic composition (e.g., sex, race).¹⁸³ The intervention implemented a joint transition clinic as a collaborative effort between children's and adult mental health services and focused on the transition planning and transfer of care.

KQ3, Communication Tools

Key Point

- No communication tools for transition interventions advanced to the analytic set for further analysis.

Eligible Studies

Two unique studies described or examined tools to facilitate communication between pediatric and adult providers for care transitions.^{52, 54} Both enrolled CSHCN with congenital heart disease (CHD). One did not meet comparator criteria and was not eligible for risk of bias assessment.⁵⁴ The brief evidence map of this study can be found in Appendix E. Table 5.2 summarizes the characteristics of the remaining high risk of bias study.⁵² Appendix E provides evidence tables.

Table 5.2. Basic characteristics of KQ literature set: KQ3, all populations

| Characteristics | Information |
|--|-----------------------------|
| Total Studies | 1 Study |
| Study Design | 1 Observational |
| NIH Stage Model | 1 Stage I |
| Study risk of bias | 1 High risk of bias |
| Included Disease Stages/Types | 1 Congenital heart disease |
| Population | 1 Patients |
| Setting | 1 Children's hospital |
| Intervention Type | 1 EMR-based transition tool |
| Mode | 1 In-person |
| Outcomes Evaluated | 1 Heart failure |
| Maximum Intervention Follow-up Time | 1 ~26 months |
| Got Transitions @ Six Core Elements Targeted | None |
| Analytic Set Studies | 0 Studies |

Abbreviations: CSHCN=children with special healthcare need; EMR=electronic medical record; KQ=Key Question; NIH=National Institutes of Health

Intervention Research Context

One study was conducted in the United States.^{52, 185} The intervention was an electronic medical record-based transition planning tool used by both pediatric and adult CHD care providers. The tool was created by one of the study authors, and documentation in the tool was completed by two research nurses. Unfortunately, the study reported no further detail on the tool itself.

Chapter 6. Barriers and Facilitators for Implementing Interventions and Tools

Key Points

- Significant barriers impede implementing interventions, tools, and trainings for transitioning children with special healthcare needs from pediatric to adult services.
- Examples of barriers include challenges with the adaptability of interventions, complex social challenges for patients (e.g., insurance, employment), and a lack of dedicated resources to support transitions, care team training, or structured transition process.
- Some approaches to address these barriers include dedicating time and resources to support transition planning, developing a workforce trained to care for the needs of this population, and creating structured processes and tools to facilitate the transition process.

Introduction

This chapter includes Key Questions 1-3 subquestion c, which address barriers and facilitators to implementing interventions and tools for transitioning children with special healthcare needs (CSHCN) from pediatric to adult services. We identified barriers and facilitators from included studies (k=154) that evaluated 1) care interventions for transitioning CSHCN and their families/caregivers, 2) implementation strategies for care interventions for transition, and 3) tools to facilitate communication between pediatric and adult providers. These 154 studies were supplemented by literature (identified from our broader search strategy) that specifically examined barriers and facilitators to successful transitions, but not in the context of an intervention. Themes were abstracted until saturation, at which point no additional themes were found from reviewing successive studies. We grouped barriers and facilitators using the five domains from the Consolidated Framework for Implementation Research (CFIR).²⁶ CFIR is a conceptual framework developed to guide systematic assessment of multilevel implementation contexts in order to identify factors that might influence intervention implementation and effectiveness. CFIR domains include: intervention characteristics (e.g., adaptability, complexity), outer setting (e.g., patient needs, external policy), inner setting (e.g., networks, culture, available resources), characteristics of individuals (e.g., self-efficacy, knowledge and beliefs about the intervention), and process (e.g., champions, implementation leaders). Figure 6.1 includes a summary of example barriers and facilitators for implementing transition interventions and tools across each of the CFIR domains. Detailed data sources for the following discussion can be found in Appendix F.

Intervention Characteristics

When organizations/settings attempt to implement interventions, individuals affected by the intervention sometimes hesitate. Therefore, interventions may need to be adapted for their intended structures and systems.²⁶ Within the context of transitions for CSHCN, studies noted several barriers related to the characteristics of the intervention—the first being a perception that the optimal model and configuration for care transitions for CSHCN likely depends on needs and demographics of the local population.^{20, 183} This barrier is compounded by the fact that no consistent group of services or interventions for healthcare transition are consistently or widely used in pediatrics.¹⁸⁶ Such wide variation in models and processes for care transitions can

negatively affect how stakeholders view and/or accept the quality and validity of newly introduced interventions. Additionally, several studies have noted that physicians and other providers lack time and resources to meaningfully participate in intervention implementation.^{65, 187} Finally, studies note concerns that single component or brief interventions may not provide the depth of training necessary to address a range of common medical, mental health, social, and transition-related needs.^{29, 187}

To address these intervention-related barriers, studies suggest several tactics. First, stakeholders need to perceive that implementing the intervention is better than the status quo (i.e., the intervention provides a relative advantage). This may be achieved by bringing clinicians and managers together to map the current state and create a shared vision for the future that includes new models or interventions.¹⁸³ Additionally, interventions and tools should equip providers, particularly primary care providers, with additional support and resources for best practice care.⁴ To accomplish this, interventions should be implemented alongside the streamlining of systems, processes, and people to effectively implement transition practices and programs.^{183, 188} Finally, studies have noted that intervention processes and programs must be adaptable for diverse patient populations and settings, while also offering approaches for addressing unintended consequences of adaptations (i.e., appointment reminders to address changes to the volume and complexity of new healthcare appointments, or changing days/times of transition clinics and programs to accommodate patient preferences and needs).⁴

Outer Setting

An intervention's implementation can be greatly influenced by its outer setting—i.e., an organization's economic, political, and social context.²⁶ Patient needs and resources present a large and varied set of barriers to effective implementation of interventions for transition for CSHCN. Specifically, as patients reach eligibility for transition, they experience a number of complex social and medical challenges, including employment and income issues, insurance education, comorbid disease, and higher risk for mental health challenges (e.g., anxiety, depression) and substance abuse compared with children without special healthcare needs.^{126, 162, 183, 189} Of note, supports provided by many community, social, and health systems become unavailable to CSHCN when they age out of the child and adolescent services system.^{162, 186, 187} Therefore, CSHCN face decreased availability of and eligibility for resources and supportive services to facilitate their care transition.^{20, 190} Unfortunately, many CSHCN are reluctant to disclose their need for support,²⁹ and report feelings of disruption and abandonment around the transition from pediatric to adult services due to the strong patient-pediatric provider relationship.^{64, 115} This, in turn, can result in additional barriers as pediatric providers become reluctant or unwilling to “let go” of CSHCN.^{20, 154} Importantly, these patient and provider level barriers are compounded by inadequate external policies and incentives to encourage comprehensive transition services and interventions for CSHCN, including the lack of reimbursement and resources for transition services.^{20, 47, 132, 191}

Studies have noted strategies for making outer settings more conducive to effective transitions for CSHCN. Especially crucial would be to develop and implement initiatives to increase awareness of the importance of readily available social and medical services to support CSHCN across the lifespan.^{66, 186} Also critical is the need to create a comprehensive set of programs and supports that address the wide range of social and emotional needs of CSHCN.⁴ Studies have noted the importance of ongoing support and guidance from parents and pediatric healthcare professionals, both to reduce feelings of abandonment and to ensure that CSHCN are

connected to the specialists and resources necessary for a successful care transition.^{66, 148, 183} Strategies may include the incorporation of nurse coordinators to serve as transition navigators into the care process.¹⁹² Finally, in light of the time and resources required for management of this population of CSHCN, new strategies should aim toward creating adequate reimbursement and administrative models to support these tasks.²⁰

Inner Setting

An intervention's inner setting of implementation can also greatly influence the success of the program or tool. The inner setting typically includes structural, political and social contexts (e.g., an organization, clinical practice).²⁶ Several studies noted overall lack of communication between pediatric and adult providers at the beginning of the transition process.¹⁸³ An array of complex reasons underlie this lack of communication, including inadequate internal resources to manage and coordinate transitions, inadequate time to coordinate care for transitions, and lack of administrative support.^{108, 168, 186} Once the transition is initiated, studies note both a dearth of available adult providers with expertise in caring for CSHCN as well as a lack of post-referral followup from adult providers.^{20, 165, 183, 187} Both of these factors increase patient anxiety at the time of transition.¹⁴⁸ In addition to reducing patient confidence in the care transition, these barriers also reduce trust among pediatric providers, who are then less likely to make referrals.¹⁶⁸ Once a transition to adult services has occurred, adult providers note a lack of educational and training content focused on the healthcare needs of CSHCN.^{4, 189} This results in adult models of care that cannot effectively accommodate CSHCN transitioning from pediatric services,^{130, 132} which can then even further exacerbate the pediatric team's reluctance to let go of their patients. Finally, studies note a lack of sensitivity about special healthcare needs (e.g., autism) among adult providers, which reduces trust among CSHCN in the ability of adult providers to meet their needs.^{64, 186}

Strategies to address these barriers include good communication and enhancement of the workforce across disciplines of care provision for CSHCN. Specifically, studies note the importance of building a workforce of practitioners (e.g., family medicine nurse practitioners, Med-Peds trained providers and shared adult and pediatric support staff) specifically trained to provide healthcare across the lifespan.¹⁸⁹ This requires integration of content on caring for CSHCN within health profession training and continued professional education.¹⁸⁹ Toward this end, studies note the importance of reducing stigma by sensitizing clinicians to the medical needs of CSHCN transitioning to adult care.¹⁸⁶ Additional strategies may include increasing patient comfort by creating a welcoming and inclusive space within the clinical setting.^{4, 66} Finally, communication is critical, not only between patients and providers, but also between providers themselves. Clear communication about patient needs and preferences during the care transition is necessary to enhance patient comfort with the process, setting, and tools of adult healthcare (e.g. electronic medical records or other technologies).^{148, 168} Finally, the need is great for processes and incentives to improve information transfer between pediatric and adult teams as well as between specialists. Improved information transfer will improve patient and provider confidence in an effective transition process.^{162, 168, 183}

Characteristics of the Individuals

Individuals—patients, providers, and caregivers—play important and consequential roles when using or implementing an intervention. Individuals wield power and influence over others through the choices they make around facilitating and/or developing barriers to effective

implementation of transition interventions.²⁶ Both patients and caregivers note challenges with self-efficacy to engage in the transition process.^{64, 135, 162} Notably, patients and caregivers feel uncertain about where to find appropriate medical care, overwhelmed by the steps to seek services, and frustrated by the lack of comprehensive information about the healthcare transition process and fear/anxiety of the unknown. Providers note similar barriers including the lack of knowledge about available community and healthcare resources to support transitions for CSHCN.^{193, 194} Additionally, clinicians note a lack of training and education about the medical needs of CSHCN transitioning to adult care, when and how to refer to specialists, and available resources to support referrals. These barriers hinder providers' self-efficacy to care for this population.¹⁸⁶ Finally, adult providers feel ill-prepared to manage the transition from pediatric to adult services due to a lack of clear processes and an incomplete transfer of information regarding past treatments in the pediatric setting and future risks of the condition.¹⁹⁵

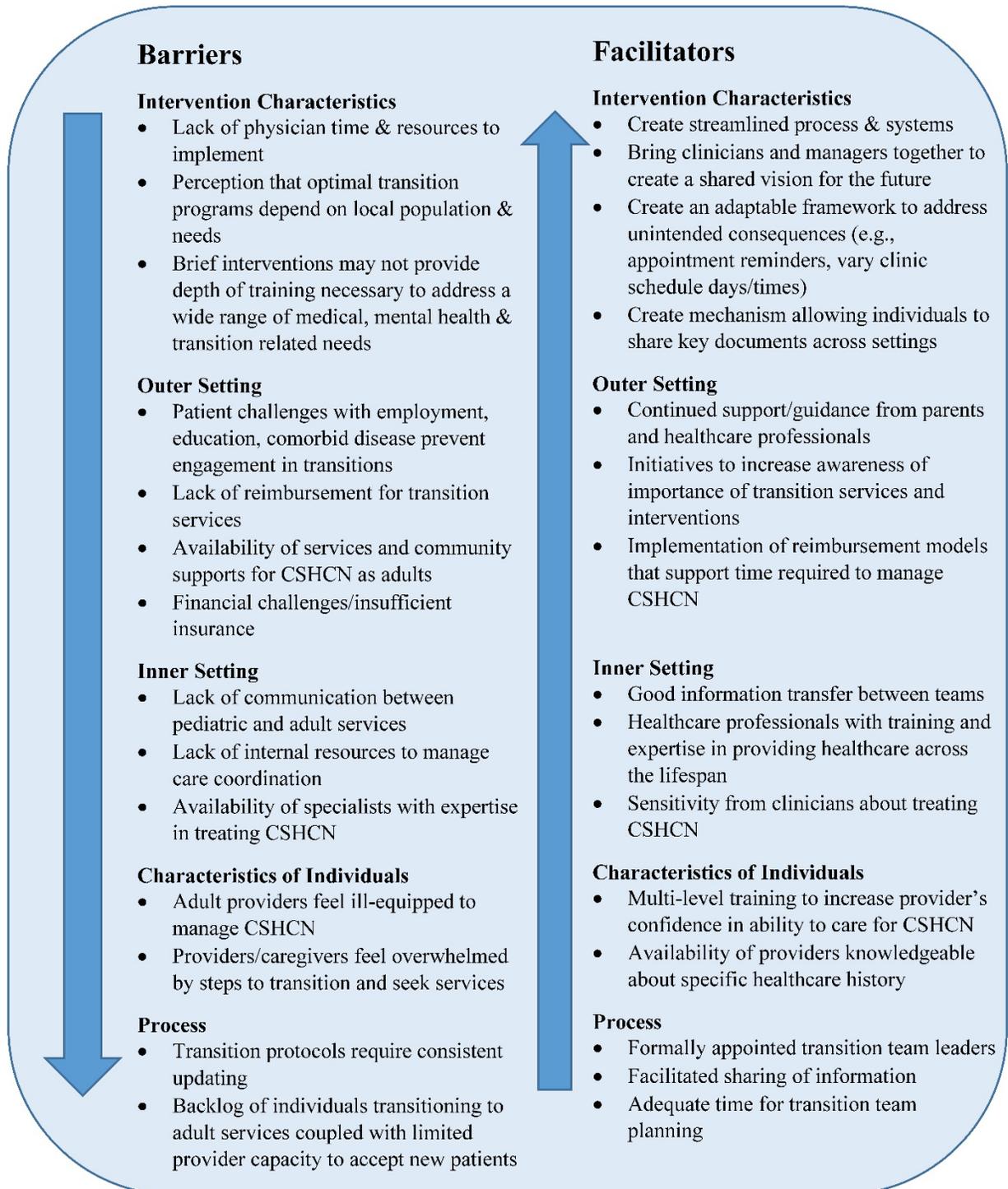
Strategies to enhance self-efficacy of patients, caregivers, and providers in effectively managing the transition to adult services for CSHCN focus on training. Specifically, providers need to create opportunities for dedicated pre-transition training that includes discussion of medical histories, navigating adult-oriented clinics, and choosing community providers and services.²⁰ For providers, implementing training around the unique needs and preferences of CSHCN can improve self-efficacy and improve confidence, which in turn creates a workforce more knowledgeable about the healthcare needs of this population.^{148, 151} However, in order to usefully engage providers on top of their existing workload, such trainings and tools for improving self-efficacy must seek to avoid exacerbating the reality of provider burnout.

Process

Successful intervention implementation typically requires making changes to existing processes.²⁶ Process-related barriers to implementation include a lack of clear, detailed protocols for transitioning from pediatric to adult services. Additionally, as providers and organizations adapt and change due to other external and internal factors, processes may become outdated.^{153, 183} In cases where effective protocols are lacking, studies have noted challenges with missing or inadequate information for patients and providers to successfully transition from pediatric services (e.g., incomplete treatment history or transition planning documents).¹⁸³ These challenges are exacerbated by transition delays stemming from limited capacity among adult providers.^{20, 123, 183}

To address process-related barriers, studies have proposed a number of approaches. These include appointing formal internal implementation leaders to answer questions, ensure protocols are implemented correctly, and provide support or encouragement to those considering implementing the intervention.⁶⁴ Other strategies include ensuring that the providers to care for CSHCN transitioning to adult care will have ready access to transition protocols and medical and social documents (with considerations for technology or tools that can cross health systems and electronic medical records).¹⁸³ One example consistently cited in the literature is the adoption of toolkits such as Got Transitions[®] to facilitate use of transition protocols.¹² Finally, the process for transition must ensure adequate time for facilitated preparation and planning between providers and patients.^{20, 29, 183}

Figure 6.1. Example barriers and facilitators for implementing effective interventions and tools for transition services



Abbreviations: CSHCN=children with special healthcare needs

Chapter 7. Definitions and Measures for Transitions of Care

Key Point

- No globally accepted definition has been established for effective transition of care from pediatric to adult services for children with special healthcare needs. Current definitions encompass a broad range of clinical and patient-centered factors. Similarly, no single measure or set of measures is consistently used to evaluate effectiveness of transitions of care from pediatric to adult services for children with special healthcare needs. Even within a domain, such as transition readiness or quality of life, multiple measures are used to evaluate effectiveness.

Introduction

This chapter addresses Contextual Question 1 and describes how effectiveness is defined and measured for transitions of care from pediatric to adult services for children with special healthcare needs (CSHCN). We used reported definitions and primary quantitative outcome measures (if definitions were provided) from eligible studies addressing Key Questions 1–3. This review of definitions of healthcare transition intervention outcomes is not meant to be exhaustive, but provide context for how studies evaluate the impact of their interventions across diverse populations. We recognize that other definitions outside of this literature set exist (e.g., performance measures from state and federal programs and national surveys) and may be included as measures of healthcare transition effectiveness in future studies. As definitions of effectiveness were rarely reported in the Key Questions, we supplemented these definitions with a grey literature search. (See Appendix A for search strategy.)

Definition of Effective Transition of Care

No globally accepted definition exists for effective transition of care from pediatric to adult services for children with special healthcare needs. Often, effectiveness is framed as a goal, intent or set of principles for a transition, which encompasses a broad set of clinical aspects and other factors that influence care outcomes or promote continuity of care such as the experiences and needs of the patient and their family. Example definitions of effective transitions of care include:

- The goal of a planned healthcare transition is “to maximize lifelong functioning and well-being...[thereby] ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood.” —*American Academy of Pediatrics, 2011*⁹
- Effective transition from pediatric to adult health care is intended to ensure continuity of developmental and age-appropriate care for all patients, including children with special health care needs. ~*Technical Brief, Agency for Healthcare Research and Quality, 2014*⁸
- [Healthcare Transition] is the process of moving from a child to an adult model of health care with or without a transfer to a new clinician...[and is informed by] the following overarching principles:
 - Importance of youth- and/or young adult–centered, strength-based focus;

- Emphasis on self-determination, self-management, and family and/or caregiver engagement;
- Acknowledgment of individual differences and complexities;
- Recognition of vulnerabilities and need for a distinct population health approach for youth and young adults;
- Need for early and ongoing preparation, including the integration into an adult model of care;
- Importance of shared accountability, effective communication, and care coordination between pediatric and adult clinicians and systems of care;
- Recognition of the influences of cultural beliefs and attitudes as well as socioeconomic status;
- Emphasis on achieving health equity and elimination of disparities; and
- Need for parents and caregivers to support youth and young adults in building knowledge regarding their own health and skills in making health decisions and using health care.

~Transitions Clinical Report, American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians, 2018¹⁹⁶

- “An effective transition process can provide appropriate, high-quality, and uninterrupted medical care services for the patient, as well as a communication platform for the main participants in the patient’s treatment, including the patient, family members, paediatricians, nurses, adult-healthcare providers, and other healthcare professionals, to enhance the patient’s health, life outcomes, self-management and autonomy.” *~ BMC Pediatric, 2016¹⁹⁷*
- *The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child- centered to adult-oriented healthcare systems. ~ Society for Adolescent Medicine, 1993¹⁹⁸*

Measures of Effective Transitions of Care

Studies that evaluate the effectiveness of transitions from pediatric to adult medical care for CSHCN use a wide variety of measures. Measures span a range of domains such as transition readiness, quality of life, clinical outcomes, treatment adherence and healthcare use. Studies evaluating the effectiveness of care transitions do not use consistent measures within or across domains. For example, some focus solely on transition readiness domains while others evaluate effectiveness across multiple domains ranging from transition readiness to engagement in care. Within domains, multiple measures are used across studies. For example, many measures are used to evaluate quality of life in CSHCN transitioning from pediatric to adult services. Such measures include a combination of disease specific measures (e.g., autism) as well as more general measures of effectiveness such as healthcare use. Many of the measures focus on a single Got Transition[®] element. No comprehensive measure was identified to examine effectiveness of transitions across domains and Six Core Elements.

Table 7.1 provides examples of measures used to examine effectiveness to demonstrate the breadth of topics and measures across domains. A full list of quantitative outcome measures used to evaluate effectiveness from studies included in Key Questions 1–3 are included in Appendix G (when definitions were provided).

Table 7.1. Example measures used to evaluate the effectiveness of transitions of care

| Measure | Measure Description | Disease Specific Vs. General Transition Measure | Validated Measure | Got Transitions® Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|---|---|---|-------------------|------------------------------------|---|---|
| Transition Readiness Assessment Questionnaire (TRAQ) | Measure of readiness for transition and assesses performance of chronic disease self-management skills using a Likert scale | General | Yes | Transition readiness | Patient | Huang 2014 ⁴² Mackie 2014 ⁵⁵ Mackie 2018 ⁵⁶ Okumura 2014 ⁶⁴ Gray 2019 ⁹⁷ Seeley 2017 ¹⁶³ Saulsberry 2019 ¹³² Anton 2019 ¹⁴³ Grady 2018 ¹⁹⁹ |
| On Your Own Feet Self-Efficacy Scale (YOOF-SES) | Assesses disease-related self-efficacy on four domains: (1) knowledge about the condition, (2) coping, (3) competencies during consultations, and (4) medication | General | Yes | Transition Readiness/ Ongoing care | Patient | Peeters 2019 ⁶⁵ Sattoe 2020 ¹⁰⁰ |
| EQ-5D Health Questionnaire | Designed to elucidate patient's quality of life according to the following domains: mobility, self-care, daily activities, pain/discomfort and anxiety/ depression | General | Yes | All | Patient | Flocco 2019 ⁵¹ |
| Pediatric Quality of Life Inventory (PedsQL) | 23-item scale to assess Health-related quality of life on four domains: (1) physical, (2) emotional, (3) social, and (4) school/work Note: different modules used across studies | General | Yes | All | Patient | Flocco 2019 ⁵¹ Sattoe 2020 ¹⁰⁰ Hilderson 2016 ¹⁰⁸ |

| Measure | Measure Description | Disease Specific Vs. General Transition Measure | Validated Measure | Got Transitions® Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--|--|---|-------------------|-------------------------------|---|--|
| Juvenile Arthritis Quality of Life Questionnaire (JAQQ) | 74 item assessment of quality of life across four dimensions: gross motor function, psychosocial function, fine motor function and systematic symptoms | Disease specific- Juvenile Idiopathic Arthritis | Yes | All | Patient | McDonagh 2007 ¹⁰⁹ Shaw 2007 ¹¹² |
| Mortality | Death, measured at various time-points relative to transition | General | Unknown | All | Patient | Kosola 2019 ¹⁴⁹ Fredericks 2015 ¹⁴⁵ |
| Visual Analog Scale (VAS)-general health | Self-reported health on a vertical visual analog scale during the last day | General | Yes | All | Patient | Flocco 2019 ⁵¹ Scaldeferri 2020 ¹⁰¹ Tong 2015 ¹¹⁵ |
| Body Mass Index (BMI) | Differences in body mass index across time | General | Unknown | Transfer of Care/Ongoing Care | Patient | Okumura 2014 ⁶⁴ Peeters 2019 ⁶⁵ Levy-Shraga 2016 ⁷³ Skov 2018 ⁶⁶ Craig 2007 ⁶¹ Testa 2019 ¹⁰³ Schultz 2019 |
| Childhood Health Assessment Questionnaire (CHAQ) | Assesses functional status from good to poor | General | Yes | Transfer of Care/Ongoing Care | Patient | Hilderson 2016 ¹⁰⁸ Shaw 2007 ¹¹² |
| Medication Adherence Rating Scale (MARS-5) | 5-item scale to assess self-reported adherence to medical treatment | General | Yes | Transfer of Care/Ongoing Care | Patient | Peeters 2019 ⁶⁵ Sattoe 2020 ¹⁰⁰ |

| Measure | Measure Description | Disease Specific Vs. General Transition Measure | Validated Measure | Got Transitions® Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|---|--|---|-------------------|-------------------------------|---|---|
| Excess time between pediatric and adult care | Time interval (in months) between the final pediatric visit and the first adult visit, minus the recommended time interval. Recommended time interval was defined as the interval suggested by the specialist at the final pediatric visit | General | Unknown | Transfer of Care | Patient | Mackie 2018 ⁵⁶ |
| Visit Attendance | Attending a threshold of disease specific visits per year | General | Unknown | Transfer of Care/Ongoing Care | Patient | Levy-Shraga 2016 ⁷³ Cole 2015 ⁹⁵ Fredericks 2015 ¹⁴⁵ |
| Mind the Gap | Measures the difference or 'gap' between a young person's ideal service and the service they have received (with subdomains for management of the environment, provider characteristics and process issues) | General | Yes | All | Patient | Colver 2018 ²⁰⁰ Sattoe 2020 ¹⁰⁰ Shaw 2007 ¹¹² |
| On Your Own Feet Transfer Experiences Scale (OYOF-TES) | Examines experiences across two domains: 1) organization of healthcare related to transition and 2) satisfaction with preparation to transfer | General | Yes | Transfer of Care | Patient | Peeters 2019 ⁶⁵ Sattoe 2020 ¹⁰⁰ |
| Satisfaction with Life Scale | 5-item global life satisfaction measure | General | Yes | All | Patient | Weigensberg 2018 ⁷⁸ Pyatak, 2017 ²⁰¹ |

| Measure | Measure Description | Disease Specific Vs. General Transition Measure | Validated Measure | Got Transitions® Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--|--|---|-------------------|--------------------------|---|--|
| Psychological General Well-Being (PGWB) Index | 22-item instrument to assess general well-being across six domains: anxiety, depressed mood, positive well-being, self-control, general health and vitality | General | Yes | All | Patient | Continisio 2020 ⁹⁰ |
| Hospitalization | Hospitalizations one year after transfer to adult center (Okumura, 2014); Hospitalizations in the three year period before and after the 18th birthday (Williams 2020) plus other timeframes | General | Unknown | Ongoing Care | Patient | Okumura 2014 ⁶⁴ Williams 2020 ⁸⁰ Sequeira 2015 ⁷⁵ Pyatak 2017 ²⁰¹ Testa 2019 ¹⁰³ Cole 2015 ⁹⁵ Fredericks 2015 ¹⁴⁵ |
| Emergency Department Visits | Number of emergency department visits | General | Unknown | Ongoing Care | Patient | Sequeira 2015 ⁷⁵ Pyatak 2017 ²⁰¹ Van Wallegghem 2008 ⁸³ |

Chapter 8. Training and Implementation Strategies To Prepare Pediatric and Adult Medical Providers

Key Point

- This literature set identifies only a limited number of available trainings and other implementation strategies, generally focused on specific clinical specialties in targeted settings.

Introduction

This chapter addresses Contextual Question 2 on providing examples of training and other implementation strategies available to prepare pediatric (e.g., pediatricians and other specialists) and adult (e.g., primary care providers, nurse practitioners, physician assistants, etc.) providers for transitioning children with special healthcare needs to adult care (CSHCN). To assess available trainings and implementation strategies, we used studies included as part of Key Question 2. Table 8.1 provides an overview of all the identified training and other implementation strategies. Because many trainings and implementation strategies have not been evaluated in the published literature, we also conducted a grey literature search, Table 8.2.

Included Literature Set Results

Seven training and other implementation strategies were identified in the literature. The majority of trainings addressed a specific disease. Only two studies implemented a structured healthcare transition process based on the Got Transitions[®] program. One implemented the Six Core Elements within several health systems while another incorporated the Six Core Elements into a Medicaid managed care plan.^{179, 181} Other trainings included educational sessions and lectures.^{180, 182, 184} One study used joint pediatric adult meetings in order to facilitate communication.⁶⁴ The implementation of a Best Practice Advisory guideline tool in the electronic medical record was also seen.¹⁷⁸ A summary transition letter template in the electronic medical record populated specific fields from patients' health records to increase communication between providers. Overall, these trainings targeted providers of various clinical backgrounds, often relative to the setting in which they practiced.

Table 8.1. Available training and implementation strategies identified in literature set

| Training/ Strategy | Training/Strategy Description Developer/Source of Training | Disease Specific Vs. General Transition? | Training Population Target | Duration/ Delivery Method/ Availability |
|--|--|--|---|---|
| <p>Health care Got Transitions® program based on the Six Core Elements</p> <p>Jones 2019¹⁷⁹</p> | <p>Structured HCT process implementation using the Six Core Elements within several health systems: six integrated healthcare delivery systems (four ACOs, a federally qualified health center, and a military health facility) and one free-standing children's hospital.</p> <p>The National Alliance to Advance Adolescent Health's Got Transitions®</p> | <p>General transition</p> | <p>Various clinical backgrounds (e.g., physician's, nurse practitioners, social workers, etc.)</p> | <p>Got Transition's co-director facilitated conversation with the LN health system leaders on monthly one-hour phone calls.</p> |
| <p>Education session</p> <p>Le Marne 2019¹⁸⁰</p> | <p>Group epilepsy education sessions. Education components include: current evidence regarding teratogenicity and driving regulations; mental health supports; and the transition process.</p> <p>Children's hospital</p> | <p>Disease specific</p> | <p>Epilepsy clinical nurse consultant, epilepsy coordinator, neurology fellow, and transition staff</p> | <p>80 min face-to-face</p> |
| <p>Nurse-led 60-minute education session</p> <p>Phillips 2018¹⁸⁴</p> | <p>The following education topics were included: Review purpose and goals of the AYAHT program. Consensus statement by the AAP, ANFP, and AACP. Departmental transition statement. Identification of barriers to transition. Review of the TRAQ Community transition resources. Obtaining guardianship for AYA who are not independent in selfcare. Obtaining up to date medical summary. Adult approach to care. Transferring to adult providers. Documentation of the transition plan.</p> <p>Teaching and research hospital</p> | <p>Disease specific</p> | <p>Pediatric rehabilitation providers</p> | <p>Nurse-led 60-minute education session</p> |

| Training/ Strategy | Training/Strategy Description Developer/Source of Training | Disease Specific Vs. General Transition? | Training Population Target | Duration/ Delivery Method/ Availability |
|---|--|--|--|---|
| Implementation of guideline tool Disabato 2015¹⁷⁸ | Implementation of a Best Practice Advisory guideline tool in the EMR increase communication between providers and social workers in planning and providing resources for transition. Plus, educational module. Academic medical center neurology clinic | Disease specific | Epilepsy provider team (e.g., physicians, nurse practitioners, and physician assistants) | Epilepsy Transition Summary Letter template in the EMR that populated specific fields from the patient's health record and included the key disease specific information requested by the adult team. 10-slide teaching modules were on the topics of Medication Management and Managing Appointments in Adult Care. |
| Insurance transition plan McManus 2015¹⁸¹ | Health care Got Transition program based on the 6 Core Elements incorporated into a Medicaid managed care plan, Health Services for Children with Special Needs (HSCSN) The National Alliance to Advance Adolescent Health's Got Transitions® | General transition | NA | 18-month process, with the first 9 months focused on customizing Six Core Elements with plan officials. Final 9 months were devoted to piloting the new transition process and tools. |
| Lecture Meacham 2014¹⁸² | Lectures were given to each UHC's medical staff, with the following concepts presented: description of type and frequency of late effects seen after pediatric cancer treatment, the use of a SHP to direct long-term follow-up, and the use of SurvivorLink as a communication tool that enables survivors to share key health documents with their provider. University health center | Disease specific | General healthcare providers | Medical directors at six UHCs were contacted and offered a lecture for their healthcare providers on survivor care. |

| Training/ Strategy | Training/Strategy Description Developer/Source of Training | Disease Specific Vs. General Transition? | Training Population Target | Duration/ Delivery Method/ Availability |
|---|--|--|---|---|
| Joint pediatric adult meetings Okumura 2014⁶⁴ | Facilitate communication between pediatric and adult centers. Academic center | Disease specific | Center’s clinical providers (e.g., respiratory therapists, social workers, pharmacists, dieticians, etc.) | Joint 3-hour meetings were held every 2 months. |

Abbreviations: ACO=accountable care organization; AAP=American Academy of Pediatrics; AFNP=Association for Nutrition & Foodservice Professionals; AACP=American Association of Colleges of Pharmacy; AYA=adolescents and young adults; AYAHT=adolescents and young adult health transitions; EMR=electronic medical records; HCT=healthcare transition; LN=learning network; TRAQ UHC

Additional Example Trainings and Implementation Strategies From the Grey Literature

The majority of example available trainings identified through the grey literature search were developed by professional medical organizations such as the American Academy of Pediatrics (AAP); American College of Physicians (ACP); Society for Adolescent Health and Medicine (SAHM); Endocrine Society, Children’s Oncology Group, etc. A number of organizations provide educational material to train residents in pediatric and adult medicine in transitioning patients from pediatric to adult care. ACP provides disease-specific transition toolkits that consist of information adapted from the Six Core Elements for adult care physicians. The Health Services for Children with Special Needs also educates providers of various clinical backgrounds (e.g., pediatric, adult, specialty, nurses, etc.) on strategies related to infrastructure, education and training, payment, and research. Overall, the majority of identified training through the grey literature search focused on educational materials, toolkits, and strategies to transfer pediatric patients to adult care. Many were focused on disease-specific transitions from the pediatric or adolescent provider perspective (Table 8.2). This review of trainings and implementation strategies is not meant to be exhaustive, but provide context for resources stakeholders can examine for use in future research and practice implementation.

Table 8.2. Examples of additional available training and implementation strategies identified from grey literature

| Training/ Strategy | Training/Strategy Description Developer/Source of Training | Disease Specific Vs. General Transition? | Training Population Target | Duration/Delivery Method/Availability |
|---|--|--|------------------------------|--|
| Module 4: Facilitating the Transition from Pediatric to Adult Care | A series of five case-based, educational modules on key medical home principles for pediatric residency programs. Each module, both as a full set and individually, is designed to be incorporated into existing curriculum. American Academy of Pediatrics | Disease specific (CSHCN) | Pediatric residency programs | Modules available to download online https://www.aap.org/en-us/professional-resources/practice-transformation/medicalhome/Pages/Modules.aspx |

| Training/Strategy | Training/Strategy Description Developer/Source of Training | Disease Specific Vs. General Transition? | Training Population Target | Duration/Delivery Method/Availability |
|---|--|---|--|---|
| Transition to adult care module | Readings and videos, materials to develop educational sessions. Part of the Adolescent Medicine Resident Curriculum. Society for Adolescent Health and Medicine | Disease specific (chronic illness) | Residents in Adolescent Medicine | Materials available online at https://www.adolescenthealth.org/Training-and-CME/Adolescent-Medicine-Resident-Curriculum/Adolescent-Medicine-Resident-Curriculum-(9).aspx |
| ACP Pediatric to Adult Care Transitions Toolkit | Sets of disease-specific tools that consist of information adapted from the Got Transition Six Core Elements of Health Care Transition that are customized to assist with and improve the transition experience for young adults with specific diseases and/or chronic conditions. American College of Physicians | General and disease specific | Adult care physicians | Educational materials available to download online at https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative |
| Health Care Transition for Adolescents and Young Adults | Program educates participants on strategies related to infrastructure, education and training, payment and research. Health Services for Children with Special Needs, Inc. (HSCSN), The National Alliance to Advance Adolescent Health/Got Transition, and DC Health | Disease specific (CSHCN) | Pediatric and adult primary and specialty physicians, nurses, and social workers | Online course available at https://www.hscsnlearning.org/transition/ |
| Young people living with chronic conditions (Module B5). | Training on developing and implementing a management plan including transitional care. European Training in Effective Adolescent Care and Health (EuTEACH) | Disease specific (adolescent chronic conditions) | Adolescent health professionals | Modules available online at https://www.unil.ch/euteach/home/menuinst/what-to-teach/euteach-modules-1.html |
| Transition toolkits | Toolkits Include a clinical summary template, recommended strategies for pediatric practices in planning the transition process, and strategies for adult providers in receiving a new patient. Endocrine Society | Disease specific (Type 1 diabetes mellitus, Growth Hormone Deficiency, and Turner Syndrome) | Care teams | Toolkit available online https://www.endocrine.org/improving-practice/transitions |
| A Health Care Provider's Guide to Helping Youth Transition from Pediatric to Adult Health Care | Strategies and tools to educate staff and facilitate transition services in medical practice. CME credit available for practice improvement activities. Carolina Health and Transition Program (CHAT) | Disease specific (YSHCN) | Healthcare providers | Educational materials available for download at https://mahec.net/innovation-and-research/special-initiatives/chat-project |

| Training/Strategy | Training/Strategy Description Developer/Source of Training | Disease Specific Vs. General Transition? | Training Population Target | Duration/Delivery Method/Availability |
|---|---|--|--|--|
| Chronic Conditions in Young Adults: Transitioning from Pediatric to Adult Care | Provides strategies to transfer and accept patients with chronic conditions. https://www.mycme.com/courses/chronic-conditions-in-young-adults-transitioning-from-pediatric-to-adult-care-6132 Jointly Provided by Harvard Medical School and Brigham and Women's Hospital | Disease specific (chronic childhood conditions in adolescent and adult patients) | Physicians in Pediatrics, Internal Medicine, Family Medicine, Psychologists, Social Workers, Counselors. | Case-based lectures, online video, CME 26.75 credits |
| Optimizing Transition and Transfer from Pediatric to Adult Healthcare | Provides state-of-the-art strategies to optimize clinical practices, effectively transition patients to adult care, and help patients elevate their quality of life in the pediatric, family medicine, Med-Ped, Internal medicine, Ped. & adult subspecialty practices. https://transition.hmscme.com/course-overview Faculty from Harvard Medical School and the Boston Children's Hospital BRIDGES Young Adult Transition Program | Disease specific (common chronic conditions) | Pediatric, Family Medicine, Internal Medicine, and Subspecialty Practices | Live streaming sessions, course materials and presentations available online for course registrants; CME credits available |
| Ready Steady Go (RSG) | A generic program for young people with a long-term condition aged 11+ years. Used across all subspecialties as a structured but adaptable transition program. A key principle throughout Ready Steady Go is 'empowering' youth to take control of their lives and equipping them with the necessary skills and knowledge to manage their own healthcare confidently and successfully in both pediatric and adult services. National Health Service Teaching Hospital | General transition | Pediatric | Transition policies, RSG tools and implementation guide available freely online at: http://www.uhs.nhs.uk/readysteadygo |

| Training/Strategy | Training/Strategy Description Developer/Source of Training | Disease Specific Vs. General Transition? | Training Population Target | Duration/Delivery Method/Availability |
|---|--|--|--|--|
| Six Core Elements Implementation Guides and Quality Improvement Primer | <p>These Implementation Guides are intended to help clinicians/practices/systems carry out and support healthcare transition (HCT) improvements using the Six Core Elements of HCT 3.0 for their patients transitioning to adult-centered care with or without changing their clinician. Each guide below contains practical guidance, resources, and examples for conducting HCT quality improvement (QI) in a range of healthcare settings, using the Model for Improvement as its framework. Each guide contains specific QI considerations, tools, and measures for each core element.</p> <p>Got Transition</p> | General transition | Pediatric, Family Medicine, Internal Medicine, and Subspecialty Practices | <p>Implementation guides and quality improvement primers available at: https://www.gottransition.org/six-core-elements/implementation.cfm</p> |
| Passport for Care | <p>Allows pediatric oncology caregivers to enter details about the specific types and scope of cancer treatments that the survivor received into a secure database.</p> <p>A guideline-based algorithm generates specific risks for late effects from childhood cancer and recommendations for screening, as well as follow-up to manage risks.</p> <p>This information can be shared with other care providers, including primary and specialty care providers.</p> <p>Children's Oncology Group</p> | Disease specific | Pediatric and adult subspecialty practices, Family Medicine, Internal Medicine | <p>Treatment database, algorithms for determining late effects</p> <p>Available at: https://www.passportforcare.org/en/</p> |
| Cancer SurvivorLink | <p>Allows healthcare providers to access records about their patient's (cancer survivor's) ongoing medical needs and find evidence-based recommendations for long-term follow-up. Cancer survivors can share documents with primary and specialty healthcare providers.</p> <p>Aflac Cancer and Blood Disorders Center at Children's Healthcare of Atlanta/Emory University</p> | Disease specific | Pediatric and adult subspecialty practices, Family Medicine, Internal Medicine | <p>Treatment database, evidence based recommendations for cancer survivor ongoing medical needs, document sharing</p> <p>Available at: https://www.cancersurvivorlink.org/</p> |

Abbreviations: ACP=American College of Physicians; CME=continuing medical education; CSHCN=children with special healthcare needs; HCT=healthcare transition; QI=quality improvement; YSHCN=youth with special healthcare need

Chapter 9. Training Available for Linguistically and Culturally Competent Care

Key Point

- None of the studies included in Key Questions 1–3 measured the effectiveness of providing linguistically and culturally competent healthcare care for children with special healthcare needs (CSHCN) transitioning from pediatric to adult services. A few systematic reviews and organizational trainings exist to inform and support culturally and linguistically competent healthcare more broadly, but these are not specific to CSHCN.

Introduction

This chapter addresses Contextual Question 3 on available training for linguistically and culturally competent care training for children with special healthcare needs transitioning from pediatric to adult services. We examined studies included in Key Questions 1–3, and, due to the lack of culturally and linguistically competent training specific to CSHCN, supplemented this literature with a grey literature search in Google Scholar and a scan of organizational websites for information about linguistically and cultural competency training and guidance. See Appendix A for a complete search strategy.

Included Literature Set Results

Culturally competent pediatric healthcare is defined as the delivery of care within the context of appropriate physician knowledge, understanding, and appreciation of all cultural distinctions leading to optimal health outcomes.²⁰² Linguistically competent healthcare is defined as providing readily available, culturally appropriate oral and written language services to limited English proficiency (LEP) members through such means as bilingual/bicultural staff, trained medical interpreters, and qualified translators.²⁰³ Both culturally and linguistically competent healthcare are critical to the effective delivery of medical care—and this is especially true for CSHCN. Prior research has demonstrated that diverse belief systems exist across cultures related to health, healing and wellness such as the perception of illness and their causes.²⁰⁴ Additionally, culture influences help-seeking behaviors and attitudes toward providers.²⁰⁴ Differences in underlying beliefs and approaches across cultures are coupled with the underrepresentation of culturally and linguistically diverse groups in the current healthcare delivery system.²⁰⁴ Each of these factors can influence appropriate access to and use of medical care for transition age CSHCN.

No studies included in Key Questions 1 – 3 specifically examined the effectiveness of providing linguistically and culturally competent healthcare care for CSHCN transitioning from pediatric to adult services. Some studies were provided in the context of more racially and ethnically diverse populations (e.g., Huang 2014, Rodgers-Melnick 2019, Annunziato 2013); however, in many cases, the studies did not report the racial, cultural and linguistically composition of participants (Appendix D-E).

Outside of these eligible studies, our grey literature search identified a scarcity of resources for providing culturally and linguistically competent care for CSHCN. Little evidence examines effectiveness of existing training. One case study described how creative art was incorporated into a community-based mental health counseling services as part of program for Asian

American youth over a period of 6 months.²⁰⁵ Additionally, one pilot test in CSHCN of transition age who had type 1 diabetes mellitus included a 12-week holistic, multimodality facilitated group intervention consisting of “council” process based on indigenous community practices, stress-reduction guided imagery, narrative medicine modalities, simple ritual, and other integrative modalities.⁷⁸

A number of systematic reviews have been published in the past 20 years on interventions to improve cultural competence in healthcare, but not specifically for CSHCN transition care outcomes.^{193, 206-213} Other reviews have examined the effectiveness of patient-centered care models that incorporate a cultural competence component.²¹² Several organizations also provide linguistically and cultural competence training; however, these trainings are not specific to transition age CSHCN (Table 9.1).

Overall, scarce evidence exists for the effectiveness of training for linguistically and culturally competent care for healthcare providers of CSHCN. Currently, patients, caregivers, providers and other stakeholders must currently rely on evidence and best practices outside of this population.

Table 9.1. Examples of culturally and linguistically competent training resources

| Resource | Provider | Targets Transitional Care | Audience | Brief Description |
|--|--|---------------------------|--|--|
| Culturally Effective Care Toolkit ²¹⁴ | American Academy of Pediatrics | No | Pediatricians | A nine chapter, practical, hands-on resource to help practicing pediatricians and their office staff provide culturally effective care to their patients and families. https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/effective-care.aspx |
| Think Cultural Health ²¹⁵ | Department of HHS Office of Minority Health | No | Healthcare providers | Free, continuing education e-learning programs, designed to provide culturally and linguistically appropriate services (CLAS). https://thinkculturalhealth.hhs.gov/education |
| National CLAS Standards ²¹⁶ | HHS Office of Minority Health | No | Health organizations (ambulatory care, hospital, public health) | Toolkit to guide healthcare organizations' in evaluating their implementation of the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care. PDF available at https://minorityhealth.hhs.gov/assets/PDF/Evaluation_of_the_Natn_CLAS_Standards_Toolkit_PR3599_final.508Compliant.pdf |
| National Center for Cultural Competence (NCCC) ²¹⁷ | Georgetown University Center for Child & Human Development | Yes | Health centers, healthcare systems, professional organization | Online curricula, learning tools, and self-assessments, publications and research available at https://nccc.georgetown.edu/ Organization also provides a cultural and linguistic competence checklist for medical home teams that reflects the Six Core Elements of Health Care Transition 2.0 |
| Cultural competence: essential ingredient for successful transitions of care ²¹⁸ | National Transitions of Care Coalition (NTOCC) | Yes | Patients and caregivers, policy makers, Healthcare professionals | Information about culture and cultural competence, as well as strategies and resources to enhance professionals' capacity to deliver culturally competent services during transitions of care (Cultural Competence: Essential Ingredient for Successful Transitions of Care white paper at: https://www.ntocc.org/s/CulturalCompetence.pdf |

| Resource | Provider | Targets Transitional Care | Audience | Brief Description |
|--|---|---------------------------|---------------------|--|
| Culturally competent care for practices²¹⁹ | National Resource Center for Patient/Family Centered Medical Home | Yes | Pediatric practices | Resources for pediatric practices interested in pediatric medical homes to help with implementation and enhancement of culturally competent care. https://medicalhomeinfo.aap.org/tools-resources/ |

Abbreviations: HHS= Health and Human Services

Chapter 10. Training, Implementation Strategies, and Interventions To Prepare Pediatric Patients and Families

Key Point

- Transition care trainings vary considerably, as do care interventions to prepare pediatric patients and their families for transitioning children with special healthcare needs (CSHCN) to adult care.

Introduction

This chapter addresses Contextual Questions 4 and 5 on providing examples of transition care training, implementation strategies, and care interventions to prepare pediatric patients and their families for transitioning CSHCN to adult care. To assess available transition care training, implementation strategies and care interventions, we used the Key Question 1 eligible literature set. Table 10.1 provides an overview of the types of interventions that were identified in Key Question 1. The full list of interventions can be found in Appendix D and Appendix E.

Included Literature Set Results

Transition care trainings vary considerably, as do care interventions to prepare pediatric patients and their families for transitioning CSHCN to adult care. A limited number of programs were well-defined and structured (e.g., Let’s Empower and Prepare, or LEAP).^{75, 201} A number of studies also developed targeted clinics in various modes such as multidisciplinary transition clinics, young adult clinics, and half-day transfer clinic.^{80, 151, 153} Program designs often incorporated the use of transition navigators and transition coordinators.^{123, 142} Educational interventions in the form of transition workbooks, educational sessions, and workshops to prepare pediatric patients were also common.^{29, 55, 158} Recently published studies have examined interventions that incorporate technology to promote patient autonomy (such as appointment management systems and online self-management programs).^{79, 166} Rarely did studies examine implementation strategies.

Table 10.1. Available training, implementation strategies, and care interventions

| Study (PMID) | Training/Strategy/Care Intervention | Developer/US-Based Vs. Non-US-Based | Disease-Specific Vs. General Transition | Duration/Delivery Method/Setting |
|---------------------------------------|-------------------------------------|--|---|---|
| Bashore 2016 ²⁹ (26206471) | Transition work book | Pediatric tertiary care center US-based | Disease-specific (cancer) | Transition workbook Includes information about medical information, educational/vocational goals, staying healthy and life skills Intervention duration: 5-6 months Pediatric tertiary care center |

| Study (PMID) | Training/ Strategy/ Care Intervention | Developer/ US-Based Vs. Non-US-Based | Disease-Specific Vs. General Transition | Duration/Delivery Method/Setting |
|---|---|---|---|--|
| Sequeira 2015 ⁷⁵ (25906787) Pyatak 2017 ²⁰¹ (27889401) | Let's Empower and Prepare (LEAP) | Hospital-system US-based | Disease-specific (diabetes mellitus) | Five major components included: diabetes mellitus education tailored to patients developmental stage at each quarterly visit; case managers facilitated program delivery, coordinated transfer from pediatric clinic to adult clinic and encouraged adherence to scheduled clinic visits; participants had option to transfer to a newly formed young adult clinic; participants had access to carbohydrate counting classes; and invited to join a private social networking website. Hospital |
| White 2017 ⁷⁹ (30169183) | Appointment management (TrACeD) | Children's hospital Non-US-based | Disease-specific (diabetes mellitus) | Provided personalized pre-appointment telephone and short message service (SMS) reminders with automatic rebooking of missed appointments. Outpatient hospital clinic |
| Van Wallegheem 2011 ²²⁰ (18458141) | Systems navigator model (The Maestro Project) | Not Reported Non-US-based | Disease-specific (diabetes mellitus) | Uses several methods of service delivery including a comprehensive website (www.maestroproject.com), a bimonthly newsletter, a monthly, casual evening drop-in group, and educational events. These events are designed to encourage socialization with peers and to facilitate relationships with diabetes educators, endocrinologist, researchers, and other service providers. Setting Not Reported |
| Grady 2019 ¹⁴⁶ (31276804) | Transitioning to Adult Care (TRANSIT) program | Academic institution US-based | Disease-specific (solid organ transplant) | Phase 1: Four computer-based educational modules, followed by a discussion with pediatric Health Transition coordinator. Phase 2: Assessment, reinforcement, and tailoring of the module content by the adult HT coordinator at the first clinic visit. This discussion was followed by three telephone calls from the adult Health Transition nurse coordinator, 6, 8, and 10 weeks after the 1st visit, to further assess and tailor discussions. Heart transplant center |

| Study (PMID) | Training/Strategy/Care Intervention | Developer/US-Based Vs. Non-US-Based | Disease-Specific Vs. General Transition | Duration/Delivery Method/Setting |
|--|---|---|---|---|
| Betz 2010 ¹⁵⁸ (22229060) | Transition Preparation Training in combination with Spina Bifida management | Childrens Hospital US-based | Disease-specific (spina bifida) | The Transition Preparation Training Program (TPT) was a three-module, eight session program offered in a 2-day workshop format (Day 1: 5 hours; Day 2: 4.5 hours) that involved the development of an adolescent-centered transition plan (Transition Roadmap to the Future) based on comprehensive assessment of the adolescent's goals for the future. Spina Bifida clinic |
| Allemang 2019 ¹²³ (31045326) | Transition program with transition navigator | Pediatric and an adult hemoglobinopathy clinic Non-US-based (Canada) | Disease-specific (sickle cell disease) | Patients begin receiving transition support at the age of 12 from the transition navigator, whose role expands across the pediatric and adult hemoglobinopathy clinics. The pediatric and adult teams collaborate to operate monthly transfer clinics for patients preparing to move from pediatric to adult care. The transition navigator continues to meet with patients at hemoglobinopathy clinic appointments in adult care until age 20. Hemoglobinopathy care center |
| Annunziato 2015 ¹⁴² (26308783) | Transition coordinator | Hospital US-based | Disease-specific (solid organ transplant-heart) | Transition coordinator meets with patients at least twice before transfer to discuss and review this process. Setting Not Reported |
| Prestidge 2012 ¹⁵³ (21823039) | Multidisciplinary transition clinic | Tertiary Children's Hospital Non-US-based | Disease-specific (solid organ transplant-renal) | Patients are seen at 4- and 6-month intervals. During each individual TC (which can be up to 3-h duration), the youth are seen in their own clinic room by some or all of the multidisciplinary team members, depending on whether it is their first or subsequent visits and on what components of care are deemed a priority for that specific young person. Renal outpatient clinic |
| Mackie 2014 ⁵⁵ (24842870) | Educational session | Tertiary Children's Hospital Non-US-based | Disease-specific (CHD) | One-hour nurse-led teaching session Cardiac hospital unit |

| Study (PMID) | Training/Strategy/Care Intervention | Developer/US-Based Vs. Non-US-Based | Disease-Specific Vs. General Transition | Duration/Delivery Method/Setting |
|---|-------------------------------------|---|---|---|
| Breakey 2014 ¹⁶⁶ (25311370) | Online self-management program | Children's hospital Non-US-based | Disease-specific (hemophilia) | Eight module program that consists of hemophilia-specific information, self-management strategies and social support. The modules are based on the following topics: basics of hemophilia, hemophilia management, managing bleeds, complications of hemophilia, mind and body (relaxation, distraction, managing stress and lifestyle), transition of care and looking ahead (education, vocation). Children's hospital |
| Williams 2020 ⁸⁰ (32518677) | Half-day transfer clinic | Children's health and rehabilitation center | Disease-specific (diabetes mellitus) | Transfer clinic was intended to replace the patients' final pediatric clinic visit and was designed to be completed in approximately 2 hours. During the transfer clinic, young adults met individually with a pediatric endocrinologist, a diabetes nurse, a dietician, and took part in a group session with a social worker. Each healthcare professional was given specific topics related to transition to discuss with the patients. |
| Michaud 2019 ¹⁵¹ (31062926) | Young adult clinic | Hospital | Disease-specific (kidney transplant) | YAC is held once a month. Intervention components include: frequent reminders about appointments, blood tests, and medication; individual transition plan established by both the pediatric and the adult care teams; discussion around self-management and what can facilitate it; young patients seen independently by the nurse and nephrologists during consultations; therapeutic education; assessment of family and social support; referral to other professionals if needed. Transplant outpatient clinic |

Abbreviations: CSHCN=children with special healthcare need; CHD=congenital heart disease; YAC=young adult clinic

Chapter 11. Strategies To Increase Availability of Adult Providers

Key Point

- A limited number of strategies aimed to increase the number of adult providers available to care for children with special healthcare needs (CSHCN) transitioning to adult care. Strategies include developing value-based models of care that support needed services for this population such as accountable care organizations or including specific contract provisions in payer contract arrangements. These strategies address previously identified barriers that impede effective care for CSHCN, and they should be rigorously evaluated in future studies.

Introduction

This chapter addresses Contextual Question 6 and identifies strategies for increasing the availability of adult care providers for CSHCN transitioning from pediatric to adult care. No studies included in Key Questions 1–3 specifically evaluated such strategies. Several barriers were noted in Chapter 6 that may hinder the availability of adult care providers for CSHCN including 1) lack of available training and educational content focused on the healthcare needs of this population, 2) uncertainty about available community and healthcare resources to support transitions, 3) uncertainty and incomplete information about effectively conducting transitions and 4) limited resources and reimbursement for coordinating and conducting care to transition CSHCN.^{16, 20, 47, 187, 189, 221} These barriers can lead to adult models of care that can neither accommodate the influx of CSHCN transitioning to adult services nor effectively support their care once transitioned.²²²

Included Literature Set Results

We supplemented evidence from the Key Questions with a grey literature search (see Appendix A for a complete search strategy). Overall, we found a limited number of strategies for increasing the number of adult providers available to care for CSHCN transitioning to adult services. Lack of adult providers for CSHCN has been recognized for some time. In a 2008 paper, Okumura et al. found that the majority of general internists feel uncomfortable providing primary care for young adults with chronic illness. This study highlighted the need for expanded efforts to strengthen adult training in childhood-onset conditions.²²³ Some organizations focus on increasing the availability of adult providers for this population. The National Alliance to Advance Adolescent Health, in collaboration with other organizations, works to expand the availability of adolescent-centered care, access to mental health services, and improvement in health insurance coverage for adolescents and young adults. The National Alliance has proposed a number of contract provisions that state Medicaid agencies and managed care organizations can use or adapt to improve the availability of pediatric-to-adult healthcare transition services for their enrollee populations.²²⁴ One example they provide includes conducting regular surveys of adult provider networks to assess availability for special populations of transition-aged youth and young adults, including those with medical complexity, intellectual and developmental disabilities, and chronic mental/behavioral health conditions. This work also specifies that efforts to expand adult provider capacity among contracting agencies should be described, including

new partnerships with medical school training programs, expanded infrastructure support (e.g., care coordination), pediatric consultation arrangements, and financial incentives.

Some organizations have proposed value-based strategies to improve the financing of care for CSHCN, because financial factors are a significant barrier to increasing the number adult providers for this population. The Catalyst Center published a primer on providing value-based strategies for improving the financing of care for CSHCN.²²⁵ They propose focusing on opportunities to incorporate alternative payment mechanisms and delivery innovations to address the needs of this population (e.g., through accountable care organizations). They argue that these organizations can provide needed care to this population because they 1) have expertise in the specific system of care elements needed by CSHCN, 2) provide access to a medical/health home model of primary care, 3) provide a robust specialty care network, and 4) include protections and incentives for providers/organizations that have high/intense patient acuity. Other organizations support evaluating these innovative payment models and suggest additional mechanisms such as 1) leveraging the Centers for Medicare & Medicaid Services State Innovation Model Initiative awards or state-specific options such as the “STAR Kids” managed care program for Medicaid eligible children and young adults with disabilities,²²⁶ and 2) expanding or making permanent telehealth policies implemented due to the COVID-19 pandemic.²²⁷ Initiatives are needed to determine the scope of the work involved in transition care planning and implementation and develop aligned reimbursement policies to provide such services.

Ultimately, evidence remains scarce on how best to increase the number of adult providers available to care for CSHCN. However, researchers and policymakers have proposed strategies to address identified barriers to caring for this population. These strategies should be rigorously evaluated in future studies.

Chapter 12. Discussion

Overview

This systematic review sought to assess the evidence base for care interventions and implementation strategies among children with special healthcare needs (CSHCN) transitioning from pediatric to adult medical care. Our findings aim to help identify programs, trainings, tools, other implementation strategies, and the barriers and facilitators that impede or support implementing transition interventions, as well as opportunities for further development in future research.

The review covered a diverse set of interventions implemented across a wide range of disease conditions. The Got Transitions® Six Core Elements were well-represented in most of the included studies. Most interventions were conducted within specialty settings, transition clinics, and integrated health systems, with a notable lack of studies in primary care settings. Far fewer studies evaluated implementation strategies, trainings, and tools for facilitating communication between pediatric and adult providers, and represented a limited set of interventions across a range of disease conditions. Transition outcomes in these studies were focused primarily on the transition readiness and care policy elements of the six core elements framework. Evidence was insufficient to address the effects of any care intervention. Only one low-strength finding noted no statistical benefit from transition clinics for hemoglobin A1C levels in adolescents with type 1 diabetes mellitus. However, this does not mean that none of the individual interventions and implementation strategies described are useful. Rather, it means that current available evidence cannot yet provide clear answers about which interventions and implementation strategies offer consistent benefits.

This is equally true at the universal level, both for drawing broader guidance and for disease-specific transitions. Even within a specific disease condition, important variations in a patient's journey may arise because of characteristics such as severity, involvement of cognitive impairment, multisystem/multi-organ complexity, or the availability of knowledge as more people survive into adulthood with disease conditions previously known only in pediatric care facilities. We had hoped the review process would allow us to draw broad strokes across disease conditions, consolidating information and lessons learned into phenotypes or archetypes that could breach more siloed approaches. Ideally, the combination of generalized and specific transition research would have allowed individual decision makers to import, out of the wide range of disease conditions and individual and system-level characteristics, what would help address their specific decisional dilemma relevant to their local concern.

Broader Context of Available Interventions and Strategies

The contextual questions addressed in the review may provide some further information to help decision makers address their specific question for their specific patient population more fully. Training and implementation strategies to prepare pediatric and adult medical providers to transition CSHCN included approaches such as online training modules, workshops, and toolkits. While some trainings and implementation strategies are published in peer-reviewed literature, a large number are not, and instead can be accessed through the developer for download or enrollment in their educational content. Training focused specifically on providing linguistically and culturally competent care to CSHCN was notably absent from the literature, with most available resources focusing cultural and linguistic competence in general medical care.

Strategies to increase the number of adult providers available to care for CSHCN, which has been noted as a significant barrier to effectively transitioning CSHCN, are also limited. Approaches have included development of value-based models of care that support needed services for this population (e.g., accountable care organizations) or including specific contract provisions in payer contract arrangements to support resources needed to manage the transition.

Interventions available to prepare patients and their families/caregivers also ranged widely but most commonly included transition programs or skills-based training or education. Lack of a globally accepted definition for effectiveness in CSHCN transitions to adult care makes it challenging to evaluate the effectiveness of these programs. Current definitions encompass a broad range of clinical and patient-centered factors, and reflect the disparate practices in transition. Similarly, no single measure or set of measures is consistently used to evaluate effectiveness of these care transitions.

Among the studies included in our review, the lack of sufficient evidence to support widespread dissemination of interventions and implementation strategies for effective transitions for CSHCN analyzed in this review provides no clear answers for CSHCN, for their families, caregivers, and providers, or for funders and policymakers. Healthcare transitions are complex and multi-dimensional; however, stakeholders must, as the field continues to emerge, rely on institutional policies and professional organization position statements to determine whether to disseminate or implement these interventions in their populations or care settings.

Future Research

The question of which interventions (or components) work best and under what circumstances is of vital importance. The numbers of CSHCN reaching adulthood continues to grow along with advances in treatment and supportive care. This trend of more CSHCN reaching adulthood leads, in turn, to greater diversity in the patient populations who need effective interventions to support their transition to adult medical services.^{1, 228} Despite identifying a wide range of intervention and implementation strategies, only nine studies met criteria for inclusion in our analytic set to conduct outcome evaluations across our three Key Questions. Importantly, many of the barriers identified in the Agency for Healthcare Research and Quality-funded 2014 Technical Brief on this topic persist,⁸ as outlined in Chapter 6. While our review provides no strong evidence for which interventions (or components) work best, our findings provide valuable insights for the further development and improvement of intervention and implementation science for CSHCN. Below, we outline several areas of opportunity for developing rigorous and robust future interventions and implementation strategies in this population.

Methodological Rigor

Most studies in this literature set included only a post-transition assessment of outcomes. Few studies included, at a minimum, pre- and post-assessments of outcomes, and fewer still included comparison groups of individuals who did not participate in the intervention or implementation strategy. Even among those studies that did use comparison groups, transitions or transition interventions often took place at different times. This is primarily because many transition interventions are conducted at the clinic or system level. Therefore, studies rely on information from individuals who have previously transitioned and are now receiving adult medical care, despite that systems or contextual factors may have evolved. Of note, included studies with a low to medium risk of bias were mainly published within the past 5 years,

indicating a potential trend toward more rigorous evaluation of these interventions. Still, we found insufficient evidence overall to conclude that interventions were effective or not.

In addition to problems with study design, the majority of included studies are in Stage I of the National Institutes of Health (NIH) Stage Model.²⁵ Stage I encompasses the generation of new behavioral interventions as well as feasibility and pilot test of these interventions. Few studies evaluated interventions focused on later stages of the model such as efficacy (Stages II and III), effectiveness (Stage IV), or implementation and dissemination of interventions in community settings (Stage V).

Finally, most interventions and implementation strategies focused on a single component for intervention (e.g., transition workbooks, transition clinics) rather than a comprehensive, multi-component intervention addressing the spectrum of Six Core Elements. These intervention designs do not allow for the optimization of the most important elements or components of an intervention that in turn produce the most benefits.

In order for stakeholders and funders to implement effective interventions and implementation strategies for transitioning CSHCN to adult care, studies must use rigorous evaluations. Research must also expand to later NIH Stages to fully examine the efficacy and effectiveness of research implemented across care settings. Strategies may include the adoption of more rigorous study designs in early-stage feasibility and pilot tests of new interventions. Many such feasibility and pilot tests could be built into current clinical work and care pathways through the further development of research networks and infrastructure dedicated to this population (e.g., Got Transitions). Other approaches may include the optimization of intervention components through frameworks such as the Multiphase Optimization Strategy (MOST) that allow for optimizing and rigorously evaluating multi-component interventions as well as hybrid effectiveness-implementation designs that blend design components of clinical effectiveness and implementation research.^{229, 230}

Populations

During topic refinement, we received many requests to include specific subgroups of CSHCN in the review. Stakeholders were eager to understand the available literature within specific disease conditions among CSHCN (e.g., cancer, diabetes mellitus, autism, congenital heart disease, and others). Additionally, stakeholders noted the importance of understanding the variation in effectiveness of interventions across characteristics of CSHCN (e.g., age at diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, immigration status, adverse childhood events such as trauma, and care setting). While the included literature may have enrolled individuals from these important subpopulations, studies rarely reported results according to these characteristics. Similarly, important clinical conditions relevant to CSHCN were also limited and varied across conditions. For example, we included only one study addressing Key Question 1 within the population of cancer survivors. Additionally, as noted in Contextual Question 3, scarce literature addressed intervention components focused on linguistically or culturally competent care (and the research on this topic has generally focused on culturally competent approaches to medical care more broadly). Finally, we found few interventions in diverse treatment settings. Notably, interventions focused on populations seen in specialty clinics and tertiary care settings, but rarely did research examine the effects of interventions in resource-limited, rural, primary care, and telehealth delivery. Interventions need to be adaptable to provide personalized support to the needs of individual survivors. The risk of lifelong infections in sickle cell patients differs from the longitudinal risk of infection in a patient

with cystic fibrosis. This example illustrates how the same risk can vary greatly in medical approach, and thus represent very different populations. Future research should examine the effects of interventions and implementation strategies across these important subpopulations and settings as well as disease agnostic approaches that focus on important categories of needed care (e.g., healthcare literacy, care coordination).

Intervention

Overall, we note significant diversity in the target interventions and implementation strategies to effectively transition CSHCN from pediatric to adult medical services. Patient-focused interventions included predominately transition clinics and educational workbooks, while provider-focused implementation and training focused on program development and individual-level provider workshops and other training methods. Several challenges related to the interventions themselves limit their potential for broad implementation. First, although the Six Core Elements framework is the most widely used model for understanding approaches and best practices for transitioning CSHCN, studies rarely reported results in a way that allowed for direct linkage back to specific principles from this framework. This made it difficult to appropriately classify interventions and implementation strategies by their *a priori* target.

Ideally, providers would develop and disseminate interventions broadly applicable all CSHCN. But specific implementation of interventions must reflect the substantial heterogeneity of the population, which includes diverse social, behavioral and medical needs. For example, children with cancer who underwent surgery and cardio-toxic chemotherapy may warrant a different clinical approach to transition than an individual with a surgically managed congenital heart condition as an infant. Additionally, some CSHCN require behaviorally and intellectually complex care. And yet another example encompasses the subtle yet critical difference between supporting the transition of a child that has lived with developmental delays their entire life versus one who acquired a development delay after treatment for a central nervous system (e.g. brain) tumor. Across the spectrum of CSHCN, some care may be appropriately provided in the context of adult primary care while other conditions may require care in specialized centers. To further complicate this issue, the intervention must have the flexibility to cross between multiple types of healthcare systems such as academic health centers, free standing children's hospitals, and adult-only private practices.

To address these gaps, the field needs a consistent terminology that incorporates Got Transitions® or other consistent framework. A consistent terminology would not only help improve evaluation of the literature, but would also make it easier to identify applicable interventions targeted at specific components of the transition process. More adaptability would also help—that is, studies could improve their adaptability across populations of CSHCN by including elements of transition care that are common across different populations and conditions.

Outcomes

Outcomes across the included studies included a range of measures across the Six Core Elements (e.g., transition readiness, transition planning). Several challenges remain to effectively measure the impact of the transition interventions on clinically meaningful social, psychological, and health outcomes. Namely, the literature lacks a clear, consistent definition of an effective transition. Definitions vary widely across included concepts (e.g., communication, management, functioning) and applicability to all populations of CSHCN and participants in the transition

process (e.g., patients, caregivers, healthcare professionals). Specific definitions have been advocated within specialty groups, individual research teams, and funding agencies, but these groups have yet to endorse and support common definitions.

Outcomes included in the evaluation of transition interventions also vary widely by disease condition, population, and intervention type. Included domains (e.g., transition readiness, quality of life, clinical measures) and measures of effectiveness varied considerably. Measures included a range of psychosocial, clinical, and quality of life measures across the Six Core Elements. Within each domain, such as transition readiness, researchers adopted variable approaches to evaluating outcomes that often included under-described or unvalidated measures of effectiveness. Even among those studies that did use validated measures, such as quality of life, many adopted disease specific measures of quality of life (e.g., diabetes mellitus, cystic fibrosis) or did not select consistent measures across studies (e.g., Pediatric Quality of Life Inventory (PedsQL), EQ-5D Health Questionnaire). Certain outcomes not evaluated in the context of this review might provide additional insights into the impact of interventions (e.g., Got Transitions Current Assessment of Healthcare Transitions Activities) and may eventually be included in future studies in this population.¹² This variability in measures of effectiveness presents a number of challenges. Not only does the variability make it difficult to compare populations and outcomes across interventions, but it also leaves the field with no standard set of measures when developing a transition intervention.

Some variance in effectiveness measures may be necessary due to the complexities of conditions among CSHCN; however, this field would benefit from a consistent definition of healthcare transition supported or endorsed across the diverse patient populations, specialty societies, and federal agencies that develop and support research in transitions for CSHCN. Also helpful would be consolidated measures of transition effectiveness focused on key social, psychological, and health outcomes broadly applicable to the diverse population of CSHCN such as incorporating recommended measures from the National Institutes of Health PhenX (<https://www.phenxtoolkit.org/>) or PROMIS[®] (<https://commonfund.nih.gov/promis/index>) into a consolidated measure set. Consolidated measures would make it easier to measure outcomes and pool data across in future systematic reviews, increasing the likelihood of a broader evidence base for transition interventions.

Implementation and Systems Complexity

Overall, the literature lacks evidence on the appropriate dissemination and implementation of care interventions, trainings, and tools for effectively transitioning CSHCN to adult care. CSHCN often require multidisciplinary care that spans medical, behavioral, and social support. Therefore, to expedite the timeline from intervention development to dissemination and implementation, this research needs to incorporate measures of successful implementation (e.g., acceptability, feasibility, and cost) alongside other clinically relevant outcomes. Other challenges to implementation include complexity and diversity of care settings for CSCHCN, the lack of adult providers for this population and the ongoing challenges with insurance coverage for healthcare transitions and underinsurance in this population. These challenges, highlighted in the barriers of Chapter 6, compound the ongoing challenges faced by CSHCN as they age out of pediatric care (e.g., availability of social support programs, infrastructure support). We additionally note the diverse geographic settings where interventions were implemented (e.g., U.S. vs. non-U.S. settings), which vary significantly in healthcare financing and infrastructure. Several approaches have been proposed to facilitate the additional resources and administrative

support required to integrate transition programs, trainings, or other interventions into complex care systems, including value-based care models or medical homes that support innovative approaches to addressing barriers faced by lack of funding and dedicated resources to support these efforts. Quality improvement methodologies presented a key component of many research designs for understanding best approaches to transitions from pediatric to adult care for CSHCN. While an important contribution to the literature to understand feasibility and key components of potential transition interventions, these approaches require more rigorous research designs in future research to ensure evidence-based implementation.

Strengths and Limitations of the Review

We determined methods for this review to assess the effects of available interventions, implementation strategies, and trainings to transition CSHCN from pediatric to adult medical care. We broadly defined care interventions, implementation strategies, and trainings to enlarge the scope of studies and thus better understand the range of relevant interventions. However, we focused on health services and did not include interventions used to support CSHCN transitioning to adulthood more broadly (e.g., school or work transitions). Resultingly, we excluded the majority of the literature addressing autism and other intellectual and physical disabilities, because most of these studies evaluated transitions in other contexts (e.g., work, school) and therefore failed to meet our inclusion criteria. Educational or vocational interventions were beyond the scope of our review, they may provide an important component of successful transition for CSHCN and could be examined in future studies as a component of integrated developmental transitions among CSHCN. Also beyond the scope of our review were studies that focused exclusively on self-management of conditions among CSHCN in the absence of a healthcare transition interventions. As with work and school transition interventions, future evaluation of this literature may provide important insights for components of a broader healthcare transition intervention.

Due to the heterogeneity of populations, intervention approaches, and the largely observational literature set, our approach to risk of bias assessment was generous compared with how risk of bias is assessed in more targeted systematic review topics. We based this decision on the varied studies included in this review as well as the complexity of care approaches for CSHCN.

Conclusion

Many aspects of interventions for CSHCN need more thorough evaluation in future research. Importantly, study designs in this literature set lack the necessary rigor to provide evidence on the best interventions (or components) that most effectively support care transitions for CSHCN. Ideally the current set of evidence could provide a foundation for proposing specific components that should be included in future interventions and a defined set of outcome measures to evaluate effectiveness. However, currently the lack of sufficient evidence provides no clear answers for CSHCN, their families, caregivers and providers, or for funders and policymakers. Future work in this population is crucial to the high-quality evidence needed for understanding not only the most effective interventions but how these interventions support adaptability across diverse disease conditions and sub-populations (such as race/ethnicity, sex/sexual orientation, socioeconomic status, and care setting).

References

1. HRSA Maternal and Child Health. Children and Youth with Special Health Care Needs. <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs#ref1>. Accessed on April 30, 2021.
2. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998 Jul;102(1 Pt 1):137-40. doi: 10.1542/peds.102.1.137. PMID: 9714637.
3. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013 Jun;131(6):1090-7. doi: 10.1542/peds.2012-3050. PMID: 23669518.
4. Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatric Blood and Cancer*. 2013;60(8):1365-8. doi: 10.1002/pbc.24494. PMID: 369155822.
5. Bloom SR, Kuhlthau K, Van Cleave J, et al. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012 Sep;51(3):213-9. doi: 10.1016/j.jadohealth.2012.01.007. PMID: 22921130.
6. Increase the proportion of adolescents who get support for their transition to adult health care — AH-R01. Office of Disease Prevention and Health Promotion; 2021. <https://health.gov/healthypeople/objectives-and-data/browse-objectives/adolescents/increase-proportion-adolescents-who-get-support-their-transition-adult-health-care-ah-r01>. Accessed on November 29 2021.
7. National performance measures. U.S. Department of Health and Human Services; 2021. <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures>. Accessed on November 29 2021.
8. McPheeters M, Davis AM, Taylor JL, et al. Transition Care for Children With Special Health Needs [Internet]. In Technical Brief, No 15. Rockville, MD: Agency for Healthcare Research and Quality (US). 2014. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK222123/>.
9. American Academy of P, American Academy of Family P, American College of P, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011 Jul;128(1):182-200. doi: 10.1542/peds.2011-0969. PMID: 21708806.
10. Betz CL, Ferris ME, Woodward JF, et al. The health care transition research consortium health care transition model: a framework for research and practice. *J Pediatr Rehabil Med*. 2014;7(1):3-15.
11. Wang G, McGrath BB, Watts C. Health care transitions among youth with disabilities or special health care needs: an ecological approach. *J Pediatr Nurs*. 2010;25(6):505-50.
12. Got Transition: Six Core Elements of health care transition™. <https://www.gottransition.org/six-core-elements/>. Accessed on April 30, 2021.
13. Gray WN, Resmini AR, Baker KD, et al. Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflamm Bowel Dis*. 2015;21(7):1641-51. doi: 10.1097/mib.0000000000000419. PMID: 604980805.
14. Gray WN, Schaefer MR, Resmini-Rawlinson A, et al. Barriers to Transition From Pediatric to Adult Care: A Systematic Review. *J Pediatr Psychol*. 2018;43(5):488-502. doi: 10.1093/jpepsy/jsx142. PMID: 29190360.
15. Schmidt A, Ilango SM, McManus MA, et al. Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *J Pediatr Nurs*. 2020;51:92-107.
16. Eshelman-Kent D, Kinahan KE, Hobbie W, et al. Cancer survivorship practices, services, and delivery: A report from the Children's Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. *J Cancer Surviv*. 2011;5(4):345-57. doi: 10.1007/s11764-011-0192-8. PMID: 51606103.
17. Goralski JL, Nasr SZ, Uluer A. Overcoming barriers to a successful transition from pediatric to adult care. *Pediatr Pulmonol*. 2017;52(S):S52-S60. doi: 10.1002/ppul.23778. PMID: 619170392.

18. Otth M, Denzler S, Koenig C, et al. Transition from pediatric to adult follow-up care in childhood cancer survivors—a systematic review. *J Cancer Surviv.* 2021;15(1):151-62.
19. Le L, Wasman W, Sun B, et al. NPM 12 MCH Evidence Health Care Transitions. Georgetown University; 2020.
20. Mouw MS, Wertman EA, Barrington C, et al. Care Transitions in Childhood Cancer Survivorship: Providers' Perspectives. *J Adolesc Young Adult Oncol.* 2017;6(1):111-9. doi: 10.1089/jayao.2016.0035. PMID: 614848099.
21. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med.* 2009 Jul 21;6(7):e1000097. doi: 10.1371/journal.pmed.1000097. PMID: 19621072.
22. PICO Portal. picoportal.org; 2020.
23. Viswanathan M, Ansari MT, Berkman ND, et al. Assessing the Risk of Bias of Individual Studies in Systematic Reviews of Health Care Interventions. March 8, 2012. In *Methods Guide for Effectiveness and Comparative Effectiveness Reviews* [Internet]. Rockville, MD: Agency for Healthcare Research and Quality (US). 2008. Available from: <https://pubmed.ncbi.nlm.nih.gov/22479713/>.
24. *Methods and measurement in sexual & gender minority health research.* Bethesda, MD: National Institutes of Health; 2021. <https://dpcpsi.nih.gov/sgmro/measurement>. Accessed on November 29 2021.
25. Onken L, Carroll K, Shoham V, et al. Reenvisioning clinical science: Unifying the discipline to improve the public health. *Clinical Psychological Science.* 2014. doi: 10.1177/2167702613497932. PMID: 25821658.
26. Damschroder LJ, Aron DC, Keith RE, et al. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci.* 2009 Aug 7;4:50. doi: 10.1186/1748-5908-4-50. PMID: 19664226.
27. Berkman ND, Lohr KN, Ansari M, et al. Grading the Strength of a Body of Evidence When Assessing Health Care Interventions for the Effective Health Care Program of the Agency for Healthcare Research and Quality: An Update. November 18, 2013. In *Methods Guide for Effectiveness and Comparative Effectiveness Reviews* [Internet]. Rockville, MD: Agency for Healthcare Research and Quality (US). 2008-. Available from: <https://pubmed.ncbi.nlm.nih.gov/24404627/>.
28. Cox KH, Morgan J, Russo C. Using a Nonclinical Patient Navigator Program in a Pediatric Oncology Network. *Journal of Oncology Navigation & Survivorship.* 2021;12(3):77-81.
29. Bashore L, Bender J. Evaluation of the Utility of a Transition Workbook in Preparing Adolescent and Young Adult Cancer Survivors for Transition to Adult Services: A Pilot Study. *J Pediatr Oncol Nurs.* 2016;33(2):111-8. doi: 10.1177/1043454215590102. PMID: 615601995.
30. Glaser A, Levitt G, Morris P, et al. Enhanced quality and productivity of long-term aftercare of cancer in young people. *Arch Dis Child.* 2013;98(1):818-24. doi: 10.1136/archdischild-2013-304348. PMID: 23966026.
31. Granek L, Nathan PC, Rosenberg-Yunger ZRS, et al. Psychological factors impacting transition from paediatric to adult care by childhood cancer survivors. *J Cancer Surviv.* 2012;6(3):260-9. doi: 10.1007/s11764-012-0223-0. PMID: 51997440.
32. Linendoll N, Murphy-Banks R, Barthel E, et al. The Creation of a Comprehensive Adolescent and Young Adult Cancer Survivorship Program: "Lost in Transition" No More. *J Adolesc Young Adult Oncol.* 2020. doi: 10.1089/jayao.2020.0024. PMID: 632310062.
33. Ryan D, Moorehead P, Chafe R. Evaluating a Transition Workbook for Childhood Cancer Survivors: a Pilot Study. *Journal of cancer education : the official journal of the American Association for Cancer Education.* 2020. doi: 10.1007/s13187-020-01850-x. PMID: 632704280.

34. Van Laar M, Glaser A, Phillips RS, et al. The impact of a managed transition of care upon psychosocial characteristics and patient satisfaction in a cohort of adult survivors of childhood cancer. *Psychooncology*. 2013;22(9):2039-45. doi: 10.1002/pon.3248. PMID: 52443591.
35. Vollmer Dahlke D, Fair K, Hong YA, et al. Adolescent and Young Adult Cancer Survivorship Educational Programming: A Qualitative Evaluation. *JMIR Cancer*. 2017. doi: 10.2196/cancer.5821. PMID: 28410172.
36. Teed M, Bekx A, Paul M, et al. Health Care Transition for Children with Medical Complexity: Challenges and Lessons Learned. *J Pediatr Nurs*. 2021 Nov-Dec;61:275-9. doi: <https://dx.doi.org/10.1016/j.pedn.2021.07.022>. PMID: 34365163.
37. White PH, Ilango SM, Caskin AM, et al. Health Care Transition in School-Based Health Centers: A Pilot Study. *The Journal of school nursing : the official publication of the National Association of School Nurses*. 2020 08 Dec;1059840520975745. doi: <http://dx.doi.org/10.1177/1059840520975745>. PMID: 633651124.
38. Morton B, Damato EG, Ciccarelli MR, et al. Care coordination for children with special healthcare needs anticipating transition: A program evaluation. *J Pediatr Nurs*. 2021 09 Mar;61:7-14. doi: <http://dx.doi.org/10.1016/j.pedn.2021.02.024>. PMID: 634560877.
39. Bert F, Camussi E, Gili R, et al. Transitional care: A new model of care from young age to adulthood. *Health Policy*. 2020. doi: 10.1016/j.healthpol.2020.08.002. PMID: 2007560821.
40. Cadogan K, Waldrop J, Maslow G, et al. S.M.A.R.T. Transitions: A Program Evaluation. *J Pediatr Health Care*. 2018;32(4):e81-e90. doi: 10.1016/j.pedhc.2018.02.008. PMID: 628699056.
41. Gorter JW, Stewart D, Cohen E, et al. Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: a mixed-methods longitudinal prospective cohort study. *BMJ open*. 2015;5(5):e007553. doi: 10.1136/bmjopen-2014-007553. PMID: 25948409.
42. Huang JS, Terrones L, Tompane T, et al. Preparing adolescents with chronic disease for transition to adult care: A technology program. *Pediatrics*. 2014;133(6):e1639-e46. doi: 10.1542/peds.2013-2830. PMID: 373234573.
43. Lemke M, Kappel R, McCarter R, et al. Perceptions of health care transition care coordination in patients with chronic illness. *Pediatrics*. 2018;141(5):e20173168. doi: 10.1542/peds.2017-3168. PMID: 622038911.
44. Nagra A, McGinnity PM, Davis N, et al. Implementing transition: Ready Steady Go. *Arch Dis Child Educ Pract Ed*. 2015;100(6):313-20. doi: 10.1136/archdischild-2014-307423. PMID: 604925567.
45. Razon AN, Greenberg A, Trachtenberg S, et al. A Multidisciplinary Transition Consult Service: Patient Referral Characteristics. *J Pediatr Nurs*. 2019;47:136-41. doi: 10.1016/j.pedn.2019.04.021. PMID: 31129412.
46. Stinson JN, Lalloo C, Harris L, et al. ICANcope with Pain™: User-centred design of a web- and mobile-based self-management program for youth with chronic pain based on identified health care needs. *Pain Research and Management*. 2014;19(5):257-65. doi: 10.1155/2014/935278. PMID: 600143275.
47. Szalda D, Steinway C, Greenberg A, et al. Developing a Hospital-Wide Transition Program for Young Adults With Medical Complexity. *J Adolesc Health*. 2019;65(4):476-82. doi: 10.1016/j.jadohealth.2019.04.008. PMID: 2002205287.
48. Lestishock L, Nova S, Disabato J. Improving Adolescent and Young Adult Engagement in the Process of Transitioning to Adult Care. *J Adolesc Health*. 2021 Mar 21;21:21. doi: <https://dx.doi.org/10.1016/j.jadohealth.2021.01.026>. PMID: 33762131.
49. Bushee C, Ginde S, Earing MG, et al. Changes in care patterns associated with a transition program in adolescents with congenital heart disease: A single center study. *Prog Pediatr Cardiol*. 2021;article in press. doi: <http://dx.doi.org/10.1016/j.ppedcard.2021.101343>. PMID: 2011122778.

50. Tye SK, Wan Ahmadul Badwi SA, Alwi A, et al. The development and evaluation of a "heartBEAT" Adolescent Transition Psychoeducational Program for adolescents with congenital heart defects: A preliminary study. *Cardiol Young*. 2021;31(1):166-73. doi: <http://dx.doi.org/10.1017/S1047951120004722>. PMID: 633929076.
51. Flocco SF, Dellafiore F, Caruso R, et al. Improving health perception through a transition care model for adolescents with congenital heart disease. *J Cardiovasc Med*. 2019;20(4):253-60. doi: 10.2459/jcm.0000000000000770. PMID: 627001851.
52. Hergenroeder AC, Moodie DS, Penny DJ, et al. Functional classification of heart failure before and after implementing a healthcare transition program for youth and young adults transferring from a pediatric to an adult congenital heart disease clinics. *Congenit Heart Dis*. 2018;13(4):548-53. doi: 10.1111/chd.12604. PMID: 623614407.
53. Ladouceur M, Calderon J, Traore M, et al. Educational needs of adolescents with congenital heart disease: Impact of a transition intervention programme. *Arch Cardiovasc Dis*. 2017;110(5):317-24. doi: 10.1016/j.acvd.2017.02.001. PMID: 614976186.
54. Lopez KN, O'Connor M, King J, et al. Improving Transitions of Care for Young Adults With Congenital Heart Disease: Mobile App Development Using Formative Research. *JMIR Formative Research*. 2018. doi: 10.2196/formative.9963. PMID: 30574573.
55. Mackie AS, Islam S, Magill-Evans J, et al. Healthcare transition for youth with heart disease: a clinical trial. *Heart (British Cardiac Society)*. 2014;100(1):1113-8. doi: 10.1136/heartjnl-2014-305748. PMID: 24842870.
56. Mackie AS, Rempel GR, Kovacs AH, et al. Transition Intervention for Adolescents With Congenital Heart Disease. *J Am Coll Cardiol*. 2018;71(1):1768-77. doi: 10.1016/j.jacc.2018.02.043. PMID: 29673467.
57. Werner O, Abassi H, Lavastre K, et al. Factors influencing the participation of adolescents and young adults with a congenital heart disease in a transition education program: A prospective multicentre controlled study. *Patient Educ Couns*. 2019;102(1):2223-30. doi: 10.1016/j.pec.2019.06.023. PMID: 2002189786.
58. Askew K, Bamford J, Hudson N, et al. Current characteristics, challenges and coping strategies of young people with cystic fibrosis as they transition to adulthood. *Clin Med*. 2017;17(2):121-5. doi: 10.7861/clinmedicine.17-2-121. PMID: 28365620.
59. Baker AM, Riekert KA, Sawicki GS, et al. CF RISE: Implementing a Clinic-Based Transition Program. *Pediatric, Allergy, Immunology, and Pulmonology*. 2015;28(4):250-4. doi: 10.1089/ped.2015.0594. PMID: 607440735.
60. Chaudhry SR, Keaton M, Nasr SZ. Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatr Pulmonol*. 2013;48(7):658-65. doi: 10.1002/ppul.22647. PMID: 52156322.
61. Craig SL, Towns S, Bibby H. Moving on from paediatric to adult health care: An initial evaluation of a transition program for young people with cystic fibrosis. *Int J Adolesc Med Health*. 2007;19(3):333-43. doi: 10.1515/ijamh.2007.19.3.333. PMID: 350186415.
62. Gerardin M, Pesle A, Pougheon-Bertrand D, et al. A quality improvement program for adolescents with cystic fibrosis: Focus on psychosocial skills. *Orphanet J Rare Dis*. 2018;13(S):7. doi: 10.1186/s13023-017-0747-5. PMID: 620583638.
63. Gravelle AM, Paone M, Davidson AG, et al. Evaluation of a multidimensional cystic fibrosis transition program: a quality improvement initiative. *J Pediatr Nurs*. 2015;30(1):236-43. doi: 10.1016/j.pedn.2014.06.011. PMID: 615282450.
64. Okumura MJ, Ong T, Dawson D, et al. Improving transition from paediatric to adult cystic fibrosis care: programme implementation and evaluation. *BMJ quality & safety*. 2014;23:i64-i72. doi: 10.1136/bmjqs-2013-002364. PMID: 24415776.
65. Peeters MAC, Sattoe JNT, van Staa A, et al. Controlled evaluation of a transition clinic for Dutch young people with cystic fibrosis. *Pediatr Pulmonol*. 2019;54(1):1811-20. doi: 10.1002/ppul.24476. PMID: 2002601462.
66. Skov M, Teilmann G, Damgaard IN, et al. Initiating transitional care for adolescents with cystic fibrosis at the age of 12 is both feasible and promising. *Acta Paediatrica, International Journal of Paediatrics*. 2018;107(1):1977-82. doi: 10.1111/apa.14388. PMID: 622389368.

67. Collins R, Singh B, Payne DN, et al. Effect of transfer from a pediatric to adult cystic fibrosis center on clinical status and hospital attendance. *Pediatr Pulmonol.* 2021;56(7):2029-35. doi: <http://dx.doi.org/10.1002/ppul.25398>. PMID: 2011197779.
68. Bourgeois G, Magne F, Nove Josserand R, et al. A formalized transition program for cystic fibrosis: A 10-year retrospective analysis of 97 patients in Lyon. *Pediatr Pulmonol.* 2021 Mar 10;10:10. doi: <https://dx.doi.org/10.1002/ppul.25364>. PMID: 33751837.
69. Genovese VV, Perceval M, Buscarlet-Jardine L, et al. Smoothing the transition of adolescents with CF from pediatric to adult care: Pre-transfer needs. *Arch Pediatr.* 2021 May;28(4):257-63. doi: <https://dx.doi.org/10.1016/j.arcped.2021.03.008>. PMID: 33863608.
70. Butalia S, Crawford SG, McGuire KA, et al. Improved transition to adult care in youth with type 1 diabetes: a pragmatic clinical trial. *Diabetologia.* 2021. doi: 10.1007/s00125-020-05368-1. PMID: 33439284.
71. Cadario F, Prodam F, Bellone S, et al. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: A hospital-based approach. *Clin Endocrinol (Oxf).* 2009;71(3):346-50. doi: 10.1111/j.1365-2265.2008.03467.x. PMID: 355131215.
72. Holmes-Walker DJ, Llewellyn AC, Farrell K. A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with type 1 diabetes aged 15-25 years. *Diabet Med.* 2007;24(7):764-9. doi: 10.1111/j.1464-5491.2007.02152.x. PMID: 47012129.
73. Levy-Shraga Y, Elisha N, Ben-Ami M, et al. Glycemic control and clinic attendance of emerging adults with type 1 diabetes at a transition care clinic. *Acta Diabetol.* 2016;53(1):27-33. doi: 10.1007/s00592-015-0734-z. PMID: 603274719.
74. Logan J, Peralta E, Brown K, et al. Smoothing the transition from paediatric to adult services in type 1 diabetes. *Journal of Diabetes Nursing.* 2008;12(9):12p-p. PMID: 104982498.
75. Sequeira PA, Pyatak EA, Weigensberg MJ, et al. Let's empower and prepare (LEAP): Evaluation of a structured transition program for young adults with type 1 diabetes. *Diabetes Care.* 2015;38(8):1412-9. doi: 10.2337/dc14-2577. PMID: 609627328.
76. Spaic T, Robinson T, Goldbloom E, et al. Closing the gap: Results of the multicenter Canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. *Diabetes Care.* 2019;42(6):1018-26. doi: 10.2337/dc18-2187. PMID: 2002045490.
77. Vanelli M, Caronna S, Adinolfi B, et al. Effectiveness of an uninterrupted procedure to transfer adolescents with Type 1 diabetes from the Paediatric to the Adult Clinic held in the same hospital: Eight-year experience with the Parma protocol. *Diabetes, Nutrition and Metabolism - Clinical and Experimental.* 2004;17(5):304-8. PMID: 40124181.
78. Weigensberg MJ, Vigen C, Sequeira P, et al. Diabetes Empowerment Council: Integrative Pilot Intervention for Transitioning Young Adults With Type 1 Diabetes. *Global advances in health and medicine.* 2018;7:2164956118761808. doi: 10.1177/2164956118761808. PMID: 29552422.
79. White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *The Lancet Child and Adolescent Health.* 2017;1(4):274-83. doi: 10.1016/s2352-4642%2817%2930089-5. PMID: 619313830.
80. Williams S, Newhook LAA, Power H, et al. Improving the transitioning of pediatric patients with type 1 diabetes into adult care by initiating a dedicated single session transfer clinic. *Clinical Diabetes and Endocrinology.* 2020;6(1):11. doi: 10.1186/s40842-020-00099-z. PMID: 632001083.
81. Gerber BS, Solomon MC, Shaffer TL, et al. Evaluation of an internet diabetes self-management training program for adolescents and young adults. *Diabetes Technology and Therapeutics.* 2007;9(1):60-7. doi: 10.1089/dia.2006.0058. PMID: 46309708.

82. Pyatak EA, Sequeira PA, Whittemore R, et al. Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with Type 1 diabetes. *Diabet Med*. 2014;31(1):1615-24. doi: 10.1111/dme.12485. PMID: 600477213.
83. Van Walleggem N, MacDonald CA, Dean HJ. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. *Diabetes Care*. 2008;31(8):1529-30. doi: 10.2337/dc07-2247. PMID: 354454701.
84. Twito O, Shatzman-Steuerman R, Dror N, et al. The "combined team" transition clinic model in endocrinology results in high adherence rates and patient satisfaction. *J Pediatr Endocrinol Metab*. 2019;32(5):505-11. doi: 10.1515/jpem-2019-0056. PMID: 627601276.
85. Dogba MJ, Rauch F, Wong T, et al. From pediatric to adult care: strategic evaluation of a transition program for patients with osteogenesis imperfecta. *BMC Health Serv Res*. 2014;14:489. doi: 10.1186/s12913-014-0489-1. PMID: 609517779.
86. Downing J, Gleeson H, Clayton PE, et al. Communication with young people in paediatric and adult endocrine consultations: An intervention development and feasibility study. *BMC Endocr Disord*. 2017;17(1):33. doi: 10.1186/s12902-017-0182-6. PMID: 617794651.
87. Zahra B, Lyall H, Sastry A, et al. Evaluating transition in Turner syndrome in the West of Scotland. *J Pediatr Endocrinol Metab*. 2021 Apr 27;34(4):473-7. doi: <https://dx.doi.org/10.1515/jpem-2020-0242>. PMID: 33647195.
88. Bindiganavle A, Manion A. Creating a sustainable pediatric diabetes transition program. *J Pediatr Nurs*. 2021 Jun 07;07:07. doi: <https://dx.doi.org/10.1016/j.pedn.2021.05.010>. PMID: 34112532.
89. White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *The Lancet Child & Adolescent Health*. 2017. doi: 10.1016/s2352-4642(17)30089-5. PMID: 30169183.
90. Continisio GI, Lo Vecchio A, Basile FW, et al. The Transition of Care From Pediatric to Adult Health-Care Services of Vertically HIV-Infected Adolescents: A Pilot Study. *Frontiers in Pediatrics*. 2020;8:322. doi: 10.3389/fped.2020.00322. PMID: 632397640.
91. Righetti A, Prinapori R, Nulvesu L, et al. Transitioning HIV-infected children and adolescents into adult care: an Italian real-life experience. *J Assoc Nurses AIDS Care*. 2015. doi: 10.1016/j.jana.2015.05.003. PMID: 26116060.
92. Campbell T, Beer H, Wilkins R, et al. "I look forward. I feel insecure but I am ok with it". The experience of young HIV+ people attending transition preparation events: a qualitative investigation. *AIDS Care*. 2010;22(2):263-9. doi: 10.1080/09540120903111460. PMID: 20390505.
93. Ryscavage P, Herbert L, Roberts B, et al. Stepping up: retention in HIV care within an integrated health care transition program. *AIDS Care*. 2021 Apr 09:1-5. doi: <https://dx.doi.org/10.1080/09540121.2021.1909696>. PMID: 33832366.
94. Waschmann M, Lin HC, Stellway JE. 'Adulthood' with IBD: Efficacy of a Novel Virtual Transition Workshop for Pediatric Inflammatory Bowel Disease. *J Pediatr Nurs*. 2021 Sep-Oct;60:223-9. doi: <https://dx.doi.org/10.1016/j.pedn.2021.07.002>. PMID: 34280734.
95. Cole R, Ashok D, Razack A, et al. Evaluation of Outcomes in Adolescent Inflammatory Bowel Disease Patients Following Transfer from Pediatric to Adult Health Care Services: Case for Transition. *J Adolesc Health*. 2015;57(2):212-7. doi: 10.1016/j.jadohealth.2015.04.012. PMID: 605294019.
96. Fu N, Jacobson K, Round A, et al. Transition clinic attendance is associated with improved beliefs and attitudes toward medicine in patients with inflammatory bowel disease. *World J Gastroenterol*. 2017;23(2):5405-11. doi: 10.3748/wjg.v23.i29.5405. PMID: 28839441.
97. Gray WN, Holbrook E, Dykes D, et al. Improving IBD Transition, Self-management, and Disease Outcomes With an In-clinic Transition Coordinator. *J Pediatr Gastroenterol Nutr*. 2019;69(2):194-9. doi: 10.1097/mpg.0000000000002350. PMID: 627316402.

98. Greveson K, Morgan N, Furman M, et al. Attitudes and experiences of adolescents in an innovative IBD transition service. *Gastrointestinal Nursing*. 2011;9(1):35-40. doi: 10.12968/gasn.2011.9.1.35. PMID: 104842956.
99. Otto C, Tarnok A, Eros A, et al. Planned Transition of Adolescent Patients with Inflammatory Bowel Disease Results in Higher Remission Rates. *J Pediatr Nurs*. 2019;45:62-6. doi: 10.1016/j.pedn.2019.02.003. PMID: 627027990.
100. Sattoe JNT, Peeters MAC, Haitsma J, et al. Value of an outpatient transition clinic for young people with inflammatory bowel disease: A mixed-methods evaluation. *BMJ Open*. 2020;10(1):e033535. doi: 10.1136/bmjopen-2019-033535. PMID: 630526377.
101. Scaldaferrri F, Angelino G, Romeo EF, et al. A transition clinic model for inflammatory bowel disease between two tertiary care centers: outcomes and predictive factors. *Eur Rev Med Pharmacol Sci*. 2020 Aug;24(16):8469-76. doi: 10.26355/eurrev_202008_22644. PMID: 32894553.
102. Schutz L, Radke M, Menzel S, et al. Long-term implications of structured transition of adolescents with inflammatory bowel disease into adult health care: A retrospective study. *BMC Gastroenterol*. 2019;19(1):128. doi: 10.1186/s12876-019-1046-5. PMID: 628577774.
103. Testa A, Giannetti E, Rispo A, et al. Successful outcome of the transitional process of inflammatory bowel disease from pediatric to adult age: A five years experience. *Dig Liver Dis*. 2019. doi: 10.1016/j.dld.2018.11.034. PMID: 30704905.
104. van den Brink G, van Gaalen MAC, Zijlstra M, et al. Self-efficacy did not predict the outcome of the transition to adult care in adolescents with inflammatory bowel disease. *Acta Paediatrica, International Journal of Paediatrics*. 2019;108(2):333-8. doi: 10.1111/apa.14471. PMID: 623220494.
105. Corsello A, Pugliese D, Bracci F, et al. Transition of inflammatory bowel disease patients from pediatric to adult care: an observational study on a joint-visits approach. *Ital J Pediatr*. 2021 Jan 28;47(1):18. doi: 10.1186/s13052-021-00977-x. PMID: 33509223.
106. Grande SW, Longacre MR, Palmblad K, et al. Empowering Young People Living With Juvenile Idiopathic Arthritis to Better Communicate With Families and Care Teams: Content Analysis of Semistructured Interviews. *JMIR mhealth uhealth*. 2019;7(2):e10401. doi: 10.2196/10401. PMID: 30794202.
107. Hanghoj S, Boisen KA, Schmiegelow K, et al. Feasibility of a transition intervention aimed at adolescents with chronic illness. *Int J Adolesc Med Health*. 2018;30(3):20160047. doi: 10.1515/ijamh-2016-0047. PMID: 622761138.
108. Hilderson D, Moons P, Van der Elst K, et al. The clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: Results of the DON'T RETARD project. *Rheumatology (United Kingdom)*. 2016;55(1):133-42. doi: 10.1093/rheumatology/kev284. PMID: 608878427.
109. McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology*. 2007;46(1):161-8. doi: 10.1093/rheumatology/kel198. PMID: 44932806.
110. Relas H, Kosola S. Acceptable quality of life and low disease activity achievable among transition phase patients with rheumatic disease. *Clin Rheumatol*. 2019. doi: 10.1007/s10067-018-4351-4. PMID: 30374749.
111. Relas H, Luosujarvi R, Kosola S. Outcome of transition phase patients with juvenile idiopathic arthritis. *Mod Rheumatol*. 2018. doi: 10.1080/14397595.2017.1416890. PMID: 29251024.
112. Shaw KL, Southwood TR, McDonagh JE. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child Care Health Dev*. 2007;33(4):368-79. doi: 10.1111/j.1365-2214.2006.00698.x. PMID: 46909322.
113. Hill T, Haut C. Adolescents with Chronic Kidney Disease: A Model for Transition to Adult Care. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*. 2019. PMID: 31566348.

114. Joslin B, Langman C, Nishi L, et al. Assessing success in transitioning of young adults from pediatric to adult kidney practice. *BMC Nephrol.* 2020;21(1):8. doi: 10.1186/s12882-019-1665-7. PMID: 630610227.
115. Tong A, Gow K, Wong G, et al. Patient perspectives of a young adult renal clinic: A mixed-methods evaluation. *Nephrology.* 2015;20(5):352-9. doi: 10.1111/nep.12396. PMID: 603785181.
116. Geerlings RPJ, Aldenkamp AP, Gottmer-Welschen LMC, et al. Long-term effects of a multidisciplinary transition intervention from paediatric to adult care in patients with epilepsy. *Seizure.* 2016;38:46-53. doi: 10.1016/j.seizure.2016.04.004. PMID: 27131211.
117. Murdaugh DL, King TZ, O'toole K. The efficacy of a pilot pediatric cognitive remediation summer program to prepare for transition of care. *Child Neuropsychol.* 2019;25(2):131-51. doi: 10.1080/09297049.2017.1391949. PMID: 618941363.
118. Andreoli A, Klingbeil C. Implementing Pediatric Transition Education Initiative During Inpatient Admissions in the Epilepsy Monitoring Unit. *J Pediatr Nurs.* 2021 Mar-Apr;57:50-5. doi: 10.1016/j.pedn.2020.10.010. PMID: 33242830.
119. Jensen PT, Karnes J, Jones K, et al. Quantitative evaluation of a pediatric rheumatology transition program. *Pediatric Rheumatology.* 2015;13(1):17. doi: 10.1186/s12969-015-0013-0. PMID: 604640538.
120. Rettig P, Athreya BH. Adolescents with chronic disease: Transition to adult health care. *Arthritis Care Res.* 1991;4(4):174-80. doi: 10.1002/art.1790040407. PMID: 22079468.
121. Stringer E, Scott R, Mosher D, et al. Evaluation of a rheumatology transition clinic. *Pediatric Rheumatology.* 2015;13(1):22. doi: 10.1186/s12969-015-0016-x. PMID: 604889697.
122. Tattersall RS, McMahon A-M. The MAGICC and practical approach to rheumatology transition. *British Journal of Hospital Medicine (17508460).* 2012;73(1):552-7. doi: 10.12968/hmed.2012.73.10.552. PMID: 86880648.
123. Allemang B, Allan K, Johnson C, et al. Impact of a transition program with navigator on loss to follow-up, medication adherence, and appointment attendance in hemoglobinopathies. *Pediatric Blood and Cancer.* 2019;66(8):e27781. doi: 10.1002/pbc.27781. PMID: 627600170.
124. Andemariam B, Owarish-Gross J, Grady J, et al. Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care. *Pediatr Blood Cancer.* 2014. doi: 10.1002/pbc.24870. PMID: 24347402.
125. Calhoun CL, Abel RA, Pham HA, et al. Implementation of an educational intervention to optimize self-management and transition readiness in young adults with sickle cell disease. *Pediatric Blood and Cancer.* 2019;66(7):e27722. doi: 10.1002/pbc.27722. PMID: 626912966.
126. Darbari I, Jacobs E, Gordon O, et al. Correlates of successful transition in young adults with sickle cell disease. *Pediatr Blood Cancer.* 2019. doi: 10.1002/pbc.27939. PMID: 31429531.
127. Hankins JS, Osarogiagbon R, Adams-Graves P, et al. A Transition Pilot Program for Adolescents With Sickle Cell Disease. *J Pediatr Health Care.* 2012;26(6):e45-e9. doi: 10.1016/j.pedhc.2012.06.004. PMID: 52120555.
128. Latzman RD, Majumdar S, Bigelow C, et al. Transitioning to adult care among adolescents with sickle cell disease: a transitioning clinic based on patient and caregiver concerns and needs. *Int J Child Adolesc health.* 2010;3(4):537-45. PMID: 104987757.
129. Porter JS, Carroll YM, Anderson S, et al. Transition readiness assessment for sickle cell patients: A quality improvement project. *J Clin Outcomes Manag.* 2014;21(6):263-9. PMID: 373595094.
130. Rodgers-Melnick SN, Pell TJG, Lane D, et al. The effects of music therapy on transition outcomes in adolescents and young adults with sickle cell disease. *Int J Adolesc Med Health.* 2019;31(3):20170004. doi: 10.1515/ijamh-2017-0004. PMID: 619716532.
131. Saulsberry AC, Hodges JR, Cole A, et al. Web-Based Technology to Improve Disease Knowledge Among Adolescents With Sickle Cell Disease: Pilot Study. *JMIR Pediatrics and Parenting.* 2020. doi: 10.2196/15093. PMID: 31909718.

132. Saulsberry AC, Porter JS, Hankins JS. A program of transition to adult care for sickle cell disease. *Hematology (United States)*. 2019;2019(1):496-504. doi: 10.1182/hematology.2019000054. PMID: 2004196131.
133. Smith GM, Lewis VR, Whitworth E, et al. Growing up with sickle cell disease: A pilot study of a transition program for adolescents with sickle cell disease. *J Pediatr Hematol Oncol*. 2011;33(5):379-82. doi: 10.1097/MPH.0b013e318211bb2e. PMID: 51435181.
134. Smith WR, Sisler IY, Johnson S, et al. Lessons Learned from Building a Pediatric-to-Adult Sickle Cell Transition Program. *South Med J*. 2019;112(3):190-7. doi: 10.14423/smj.0000000000000950. PMID: 626607940.
135. Sobota A, Akinlonu A, Champigny M, et al. Self-reported transition readiness among young adults with sickle cell disease. *J Pediatr Hematol Oncol*. 2014;36(5):389-94. doi: 10.1097/mph.000000000000110. PMID: 53002390.
136. Viola AS, Drachtman R, Kaveney A, et al. Feasibility of Medical Student Mentors to Improve Transition in Sickle Cell Disease. *J Pediatr Psychol*. 2021;article in press. doi: <https://dx.doi.org/10.1093/jpepsy/jsab031>. PMID: 33779756.
137. Johnson R, Edwards R, Rivers A, et al. Evaluating literacy levels of patient education materials for a sickle cell transition group education programme. *Health Educ J*. 2020;79(3):253-65. doi: 10.1177/0017896919876668. PMID: 2003468366.
138. Howell KE, Saulsberry-Abate AC, Mathias JG, et al. Transition care continuity promotes long-term retention in adult care among young adults with sickle cell disease. *Pediatr Blood Cancer*. 2021 Oct;68(10):e29209. doi: <https://dx.doi.org/10.1002/pbc.29209>. PMID: 34286896.
139. Manwani D, Doyle M, Davidson L, et al. Transition Navigator Intervention improves transition readiness to adult care for youth with Sickle Cell Disease. *Acad Pediatr*. 2021 Aug 10;10:10. doi: <https://dx.doi.org/10.1016/j.acap.2021.08.005>. PMID: 34389516.
140. Annunziato RA, Baisley MC, Arrato N, et al. Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. *The Journal of pediatrics*. 2013;163(6):1628-33. doi: 10.1016/j.jpeds.2013.07.031. PMID: 23993138.
141. Annunziato RA, Emre S, Shneider BL, et al. Transitioning health care responsibility from caregivers to patient: a pilot study aiming to facilitate medication adherence during this process. *Pediatr Transplant*. 2008. doi: 10.1111/j.1399-3046.2007.00789.x. PMID: 18435606.
142. Annunziato RA, Parbhakar M, Kapoor K, et al. Can transition to adult care for transplant recipients be improved by intensified services while patients are still in pediatrics? Progress in transplantation (Aliso Viejo, Calif). 2015;25(3):236-42. doi: 10.7182/pit2015599. PMID: 621750556.
143. Anton CM, Anton K, Butts RJ. Preparing for transition: The effects of a structured transition program on adolescent heart transplant patients' adherence and transplant knowledge. *Pediatr Transplant*. 2019;23(7):e13544. doi: 10.1111/ptr.13544. PMID: 628839471.
144. Belair C, Gilleland J, Amaral S. Assessing the Satisfaction of Teens with Kidney Transplants who have Attended an Adolescent Transition Clinic. *Int J Child Adolesc health*. 2011;4(3):257-63. PMID: 108207347.
145. Fredericks EM, Magee JC, Eder SJ, et al. Quality Improvement Targeting Adherence During the Transition from a Pediatric to Adult Liver Transplant Clinic. *J Clin Psychol Med Settings*. 2015;22(2):150-9. doi: 10.1007/s10880-015-9427-6. PMID: 605500773.
146. Grady KL, Andrei A-C, Shankel T, et al. Pediatric Heart Transplantation: Transitioning to Adult Care (TRANSIT): Feasibility of a Pilot Randomized Controlled Trial. *J Card Fail*. 2019;25(1):948-58. doi: 10.1016/j.cardfail.2019.06.011. PMID: 2002367508.
147. Harden PN, Walsh G, Bandler N, et al. Bridging the gap: An integrated paediatric to adult clinical service for young adults with kidney failure. *BMJ (Online)*. 2012;344(7):e3718. doi: 10.1136/bmj.e3718. PMID: 365023203.

148. Hubbard, Rhona. Evaluation of liver transition services for young people at a UK paediatric hospital. *Gastrointestinal Nursing*. 2016;14(s):S16-S23. doi: 10.12968/gasn.2016.14.Sup10.S16. PMID: 120270005.
149. Kosola S, Ylinen E, Finne P, et al. Implementation of a transition model to adult care may not be enough to improve results: National study of kidney transplant recipients. *Clin Transplant*. 2019;33(1):e13449. doi: 10.1111/ctr.13449. PMID: 625447115.
150. McQuillan RF, Toulany A, Kaufman M, et al. Benefits of a transfer clinic in adolescent and young adult kidney transplant patients. *Canadian Journal of Kidney Health and Disease*. 2015;2(1):45. doi: 10.1186/s40697-015-0081-6. PMID: 613401208.
151. Michaud V, Achille M, Chainey F, et al. Mixed-methods evaluation of a transition and young adult clinic for kidney transplant recipients. *Pediatr Transplant*. 2019;23(4):e13450. doi: 10.1111/petr.13450. PMID: 31062926.
152. Pape L, Lammermuhle J, Oldhafer M, et al. Different models of transition to adult care after pediatric kidney transplantation: a comparative study. *Pediatr Transplant*. 2013. doi: 10.1111/petr.12102. PMID: 23730905.
153. Prestidge C, Romann A, Djurdjev O, et al. Utility and cost of a renal transplant transition clinic. *Pediatr Nephrol*. 2012;27(2):295-302. doi: 10.1007/s00467-011-1980-0. PMID: 21823039.
154. Remorino R, Taylor J. Smoothing things over: the transition from pediatric to adult care for kidney transplant recipients. *Progress in transplantation (Aliso Viejo, Calif)*. 2006;16(4):303-8. PMID: 17183936.
155. Weitz M, Heeringa S, Neuhaus TJ, et al. Standardized multilevel transition program: Does it affect renal transplant outcome? *Pediatr Transplant*. 2015;19(7):691-7. doi: 10.1111/petr.12570. PMID: 610736550.
156. Jordan M S, Ryan H, Saira K, et al. A multidisciplinary approach to improving transition readiness in pediatric liver transplant recipients. *Pediatr Transplant*. 2020:e13839. doi: 10.1111/petr.13839. PMID: 32997866.
157. Aguilera AM, Wood DL, Keeley C, et al. Young adults with spina bifida transitioned to a medical home: A survey of medical care in Jacksonville, Florida. *J Neurosurg Pediatr*. 2016;17(2):203-7. doi: 10.3171/2015.7.Peds14694. PMID: 610580671.
158. Betz CL, Smith K, Macias K. Testing the transition preparation training program: A randomized controlled trial. *Int J Child Adolesc health*. 2010;3(4):595-607. PMID: 22229060.
159. Betz CL, Smith K, Van Speybroeck A, et al. Descriptive Analysis and Profile of Health Care Transition Services Provided to Adolescents and Emerging Adults in the Movin' On Up Health Care Transition Program. *J Pediatr Health Care*. 2018;32(3):273-84. doi: 10.1016/j.pedhc.2017.11.006. PMID: 628698167.
160. Hopson B, MSHA, Alford EN, et al. Development of an evidence-based individualized transition plan for spina bifida. *Neurosurg Focus*. 2019;47(4):E17. doi: 10.3171/2019.7.Focus19425. PMID: 31574471.
161. Roth JD, Szymanski KM, Ferguson EJ, et al. Transitioning young adults with neurogenic bladder-Are providers asking too much? *J Pediatr Urol*. 2019;15(4):384. doi: 10.1016/j.jpuro.2019.04.013. PMID: 2001979011.
162. Sawin KJ, Rauen K, Bartelt T, et al. Transitioning adolescents and young adults with spina bifida to adult healthcare: initial findings from a model program. *Rehabilitation nursing : the official journal of the Association of Rehabilitation Nurses*. 2015;40(1):3-11. doi: 10.1002/rnj.140. PMID: 603209921.
163. Seeley A, Lindeke L. Developing a Transition Care Coordination Program for Youth With Spina Bifida. *J Pediatr Health Care*. 2017;31(6):627-33. doi: 10.1016/j.pedhc.2017.04.015. PMID: 622863603.
164. Harhuis A, Cobussen-Boekhorst H, Feitz W, et al. 5 years after introduction of a transition protocol: An evaluation of transition care for patients with chronic bladder conditions. *J Pediatr Urol*. 2018;14(2):150. doi: 10.1016/j.jpuro.2017.09.023. PMID: 619361647.

165. Shalaby MS, Gibson A, Granitsiotis P, et al. Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. *J Pediatr Urol.* 2015;11(2):89. doi: 10.1016/j.jpuro.2014.11.024. PMID: 603089843.
166. Breakey VR, Ignas DM, Warias AV, et al. A pilot randomized control trial to evaluate the feasibility of an Internet-based self-management and transitional care program for youth with haemophilia. *Haemophilia.* 2014;20(6):784-93. doi: 10.1111/hae.12488. PMID: 606154213.
167. Croteau SE, Padula M, Quint K, et al. Center-Based Quality Initiative Targets Youth Preparedness for Medical Independence: HEMO-Milestones Tool in a Comprehensive Hemophilia Clinic Setting. *Pediatr Blood Cancer.* 2016. doi: 10.1002/pbc.25807. PMID: 26496140.
168. Dale CM, Carbone S, Amin R, et al. A transition program to adult health services for teenagers receiving long-term home mechanical ventilation: A longitudinal qualitative study. *Pediatr Pulmonol.* 2020;55(3):771-9. doi: 10.1002/ppul.24657. PMID: 2004169204.
169. Dingemann J, Szczepanski R, Ernst G, et al. Transition of Patients with Esophageal Atresia to Adult Care: Results of a Transition-Specific Education Program. *Eur J Pediatr Surg.* 2017;27(1):61-7. doi: 10.1055/s-0036-1587334. PMID: 611707854.
170. Downing J, Gleeson HK, Clayton PE, et al. Transition in endocrinology: the challenge of maintaining continuity. *Clin Endocrinol (Oxf).* 2013. doi: 10.1111/j.1365-2265.2012.04473.x. PMID: 22734661.
171. Nair AS, DeMuth K, Chih-Wen C, et al. Asthma Academy: Developing educational technology to improve Asthma medication adherence and intervention efficiency. Conference proceedings : Annual International Conference of the IEEE Engineering in Medicine and Biology Society IEEE Engineering in Medicine and Biology Society Annual Conference. 2017;2017:1364-7. doi: 10.1109/embc.2017.8037086. PMID: 625115830.
172. Schmidt S, Herrmann-Garitz C, Bomba F, et al. A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults. *Patient Educ Couns.* 2016;99(3):421-8. doi: 10.1016/j.pec.2015.10.024. PMID: 608678062.
173. Silke S, Henriette M, Franziska B, et al. Differential effect of a patient-education transition intervention in adolescents with IBD vs. diabetes. *Eur J Pediatr* 2018;177(4):497-505. doi: 10.1007/s00431-017-3080-z. PMID: 29340756.
174. Witvliet MJ, Petersen N, Ekkerman E, et al. Transitional health care for patients with Hirschsprung disease and anorectal malformations. *Tech Coloproctol.* 2017;21(7):547-54. doi: 10.1007/s10151-017-1656-2. PMID: 617172381.
175. Peres M, Almeida MF, Pinto EJ, et al. Implementing a Transition Program from Paediatric to Adult Services in Phenylketonuria: Results After Two Years of Follow-Up with an Adult Team. *Nutrients.* 2021 Feb 28;13(3):28. doi: <https://dx.doi.org/10.3390/nu13030799>. PMID: 33671057.
176. Pedersen M, Hoybye C. An Adapted Model for Transition to Adult Care in Young Adults with Prader-Willi Syndrome. *Journal of Clinical Medicine.* 2021 May 06;10(9):06. doi: <https://dx.doi.org/10.3390/jcm10091991>. PMID: 34066432.
177. Hart LC, Saha H, Lawrence S, et al. Implementation and Evolution of a Primary Care-Based Program for Adolescents and Young Adults on the Autism Spectrum. *J Autism Dev Disord.* 2021 Jul 02;02:02. doi: <https://dx.doi.org/10.1007/s10803-021-05171-w>. PMID: 34215949.
178. Disabato JA, Cook PF, Hutton L, et al. Transition from Pediatric to Adult Specialty Care for Adolescents and Young Adults with Refractory Epilepsy: A Quality Improvement Approach. *J Pediatr Nurs.* 2015;30(5):e37-e45. doi: 10.1016/j.pedn.2015.06.014. PMID: 616617788.

179. Jones MR, Hooper TJ, Cuomo C, et al. Evaluation of a Health Care Transition Improvement Process in Seven Large Health Care Systems. *J Pediatr Nurs*. 2019;47:44-50. doi: 10.1016/j.pedn.2019.04.007. PMID: 31029928.
180. Le Marne FA, Towns SJ, Gaskin C, et al. Implementing a new adolescent epilepsy service: Improving patient experience and readiness for transition. *J Paediatr Child Health*. 2019;55(7):819-25. doi: 10.1111/jpc.14301. PMID: 625142053.
181. McManus M, White P, Pirtle R, et al. Incorporating the Six Core Elements of Health Care Transition Into a Medicaid Managed Care Plan: Lessons Learned From a Pilot Project. *J Pediatr Nurs*. 2015;30(5):700-13. doi: 10.1016/j.pedn.2015.05.029. PMID: 616617102.
182. Meacham LR, Williamson RS, Forehand RL, et al. University health centers and young adult survivors of pediatric cancer: Changes in providers' familiarity with and practice of survivor care. *J Adolesc Young Adult Oncol*. 2014;3(1):12-9. doi: 10.1089/jayao.2013.0029. PMID: 372628683.
183. Moosa F, Sandhu T. Transition from children's to adult services for patients with ADHD: A model of care. *Adolesc Psychiatry*. 2015;5(1):22-30. PMID: 604494967.
184. Phillips, Leslie. Development and Evaluation of a Training Program for Adolescents With Special Healthcare Needs. *Pediatr Nurs*. 2018;44(2):89-94. PMID: 129092695.
185. Wiemann CM, Hergenroeder AC, Bartley KA, et al. Integrating an EMR-based Transition Planning Tool for CYSHCN at a Children's Hospital: A Quality Improvement Project to Increase Provider Use and Satisfaction. *J Pediatr Nurs*. 2015. doi: 10.1016/j.pedn.2015.05.024. PMID: 26209173.
186. Rast JE, Shattuck PT, Roux AM, et al. The Medical Home and Health Care Transition for Youth With Autism. *Pediatrics*. 2018 Apr;141(Suppl 4):S328-S34. doi: 10.1542/peds.2016-4300J. PMID: 29610414.
187. Mazurek MO, Stobbe G, Loftin R, et al. ECHO Autism Transition: Enhancing healthcare for adolescents and young adults with autism spectrum disorder. *Autism*. 2020;24(3):633-44. doi: 10.1177/1362361319879616. PMID: 2003478413.
188. Philbin MM, Tanner AE, Chambers BD, et al. Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: using adolescent and adult providers' insights to create multi-level solutions to address transition barriers. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*. 2017;29(1):1227-34. doi: 10.1080/09540121.2017.1338655. PMID: 616783735.
189. Iannuzzi D, Rissmiller P, Duty SM, et al. Addressing a Gap in Healthcare Access for Transition-Age Youth with Autism: A Pilot Educational Intervention for Family Nurse Practitioner Students. *J Autism Dev Disord*. 2019;49(4):1493-504. doi: 10.1007/s10803-018-3846-9. PMID: 135779446.
190. Hess JS, Straub DM, Mateus JS, et al. Preparing for Transition from Pediatric to Adult Care: Evaluation of a Physician Training Program. *Adv Pediatr*. 2015;62(1):137-64. doi: 10.1016/j.yapd.2015.04.003. PMID: 610715912.
191. Belling R, McLaren S, Paul M, et al. The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. *J Health Serv Res Policy*. 2014;19(3):169-76. doi: 10.1177/1355819614527439. PMID: 103966098.
192. Sadak KT, Neglia JP, Freyer DR, et al. Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative study of survivorship providers. *Pediatr Blood Cancer*. 2017. doi: 10.1002/pbc.26587. PMID: 28557375.
193. Henderson S, Kendall E, See L. The effectiveness of culturally appropriate interventions to manage or prevent chronic disease in culturally and linguistically diverse communities: a systematic literature review. *Health Soc Care Community*. 2011 May;19(3):225-49. doi: 10.1111/j.1365-2524.2010.00972.x. PMID: 21208326.
194. Seybolt L. Transition of care for HIV-infected youth can be challenging for both provider and patient. *HIV Clin*. 2014. PMID: 26685340.

195. Hill T, Haut C. Adolescents with Chronic Kidney Disease: A Model for Transition to Adult Care. *Nephrology nursing journal : journal of the American Nephrology Nurses' Association*. 2019;46(5):533-41. PMID: 629460180.
196. White PH, Cooley WC, Transitions Clinical Report Authoring G, et al. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2018 Nov;142(5). doi: 10.1542/peds.2018-2587. PMID: 30348754.
197. Jin YT, Chen CM, Chien WC. Factors influencing transitional care from adolescents to young adults with cancer in Taiwan: A population-based study. *BMC Pediatr*. 2016 Aug 2;16:122. doi: 10.1186/s12887-016-0657-z. PMID: 27484184.
198. Blum, R W. Transition to adult health care: setting the stage. *J Adolesc Health*. 1995;17(1):3-5. PMID: 7578159.
199. Grady KL, Hof KV, Andrei A-C, et al. Pediatric Heart Transplantation: Transitioning to Adult Care (TRANSIT): Baseline Findings. *Pediatr Cardiol*. 2018;39(2):354-64. doi: 10.1007/s00246-017-1763-x. PMID: 619137474.
200. Colver A, McConachie H, Le Couteur A, et al. A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Med*. 2018;16(1):111. doi: 10.1186/s12916-018-1102-y. PMID: 623119427.
201. Pyatak EA, Sequeira PA, Vigen CLP, et al. Clinical and Psychosocial Outcomes of a Structured Transition Program Among Young Adults With Type 1 Diabetes. *J Adolesc Health*. 2017;60(2):212-8. doi: 10.1016/j.jadohealth.2016.09.004. PMID: 613872919.
202. Britton CV, American Academy of Pediatrics Committee on Pediatric W. Ensuring culturally effective pediatric care: implications for education and health policy. *Pediatrics*. 2004 Dec;114(6):1677-85. doi: 10.1542/peds.2004-2091. PMID: 15574635.
203. Agency for Healthcare Research and Quality. What Is Cultural and Linguistic Competence. Rockville, MD. <https://www.ahrq.gov/ncepcr/tools/cultural-competence/definition.html>. Accessed on April 30, 2021.
204. Goode T, Dunne C. Rationale for Cultural Competence in Primary Care National Center for Cultural Competence,, Georgetown University Center for Child and Human Development. Policy Brief 1. Washington, DC: 2003. http://nccc.georgetown.edu/documents/Policy_Brief_1_2003.pdf
205. Shik, Angela WY. Integrating creative art into a community-based mental health program for Asian American transition age youth. *Child Youth Serv Rev*. 2013;35(3):377-83. doi: 10.1016/j.chilyouth.2012.12.002. PMID: 104241126.
206. Anderson LM, Scrimshaw SC, Fullilove MT, et al. Culturally competent healthcare systems. *Am J Prev Med*. 2003;24(3):68-79. doi: 10.1016/s0749-3797(02)00657-8.
207. Clifford A, McCalman J, Bainbridge R, et al. Interventions to improve cultural competency in health care for Indigenous peoples of Australia, New Zealand, Canada and the USA: a systematic review. *Int J Qual Health Care*. 2015 Apr;27(2):89-98. doi: 10.1093/intqhc/mzv010. PMID: 25758442.
208. Gallagher RW, Polanin JR. A meta-analysis of educational interventions designed to enhance cultural competence in professional nurses and nursing students. *Nurse Educ Today*. 2015 Feb;35(2):333-40. doi: 10.1016/j.nedt.2014.10.021. PMID: 25466790.
209. Govere L, Govere EM. How Effective is Cultural Competence Training of Healthcare Providers on Improving Patient Satisfaction of Minority Groups? A Systematic Review of Literature. *Worldviews Evid Based Nurs*. 2016 Dec;13(6):402-10. doi: 10.1111/wvn.12176. PMID: 27779817.
210. Horvat L, Horey D, Romios P, et al. Cultural competence education for health professionals. *Cochrane Database Syst Rev*. 2014 May 5(5):CD009405. doi: 10.1002/14651858.CD009405.pub2. PMID: 24793445.

211. Truong M, Paradies Y, Priest N. Interventions to improve cultural competency in healthcare: a systematic review of reviews. *BMC Health Serv Res.* 2014 Mar 3;14:99. doi: 10.1186/1472-6963-14-99. PMID: 24589335.
212. Renzaho AM, Romios P, Crock C, et al. The effectiveness of cultural competence programs in ethnic minority patient-centered health care--a systematic review of the literature. *Int J Qual Health Care.* 2013 Jul;25(3):261-9. doi: 10.1093/intqhc/mzt006. PMID: 23343990.
213. Butler M, McCreedy E, Schwer N, et al. Improving cultural competence to reduce health disparities [Internet]. 2016.
214. Cora-Bramble D. Culturally Effective Care Toolkit. <https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/effective-care.aspx>.
215. Office of Minority Health, U.S. Department of Health and Human Services. Think Cultural Health Education. <https://thinkculturalhealth.hhs.gov/education>. Accessed on May 1, 2021.
216. Williams MV, Martin LT, Davis LM, et al. Evaluation of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care: Tips and Resources. U.S. Department of Health and Human Services, OPHS Office of Minority Health. 2018. https://minorityhealth.hhs.gov/assets/PDF/Evaluation_of_the_Natn_CLAS_Standards_Toolkit_PR3599_final.508Compliant.pdf
217. Goode TD, Jones W. Transition: Cultural and Linguistic Competence Checklist for Medical Home Teams. National Center for Cultural Competence, Georgetown University Center for Child and Human Development. Washington, DC: 2015. https://nccc.georgetown.edu/documents/NCCC_Transition_Checklist.pdf
218. National Transitions of Care Coalition. Cultural Competence: Essential Ingredient for Successful Transitions of Care . <https://www.ntocc.org/s/CulturalCompetence.pdf>
219. National Resource Center for Patient/Family-Centered Medical Home. Culturally Competent Care Resources for Practices. <https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Practices.aspx>. Accessed on May 1, 2021.
220. Van Walleghe N, MacDonald CA, Dean HJ. The Maestro Project: A Patient Navigator for the Transition of Care for Youth With Type 1 Diabetes. *Diabetes Spectr.* 2011;24(1):9-13. doi: 10.2337/diaspect.24.1.9. PMID: 104869299.
221. Achola EO, Greene G. Person-family centered transition planning: Improving post-school outcomes to culturally diverse youth and families. *Journal of Vocational Rehabilitation.* 2016;45(2):173-83. doi: 10.3233/jvr-160821. PMID: 611932114.
222. Sadak KT, Szalda D, Lindgren BR, et al. Transitional care practices, services, and delivery in childhood cancer survivor programs: A survey study of U.S. survivorship providers. *Pediatric Blood and Cancer.* 2019;66(8):e27793. doi: 10.1002/pbc.27793. PMID: 627808808.
223. Okumura MJ, Heisler M, Davis MM, et al. Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. *J Gen Intern Med.* 2008 Oct;23(10):1621-7. doi: 10.1007/s11606-008-0716-8. PMID: 18661191.
224. McManus M, Schmidt A, White P. Medicaid Managed Care Contract Language to Expand the Availability of Pediatric-to-Adult Transitional Care. The National Alliance to Advance Adolescent Health/Got Transition. Washington, DC: September 2020. <https://www.thenationalalliance.org/s/Medicaid-Managed-Care-Contract-Language-to-Expand-the-Availability-of-Pediatric-to-Adult-Transitiona.pdf>
225. Special CCIFoCfCaYw, Health Care Needs. A Primer on Value-based Strategies for Improving Financing of Care for Children and Youth with Special Health CareNeeds. 2017 June.
226. Johnson T. Improving Systems of Care for Children with Special Health Needs Resources and Policy Options. September 2017. <https://www.ncsl.org/documents/health/ChildrenSpecialNeeds17.pdf>

227. Honsberger K, VanLandeghem K, Girmash E. Supporting States To Improve Care For Children With Special Health Care Needs During COVID-19. Health Affairs; 2021.
228. Genetic Alliance, Family Voices. Chapter 1, Children and Youth with Special Healthcare Needs, Then and Now. In Children and Youth with Special Healthcare Needs in Healthy People 2020 A Consumer Perspective. Washington DC: Genetic Alliance Feb 2013
229. Curran GM, Bauer M, Mittman B, et al. Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. Med Care. 2012;50(3):217.
230. Collins LM. Optimization of behavioral, biobehavioral, and biomedical interventions : the Multiphase Optimization Strategy (MOST). Cham, Switzerland: Cham, Switzerland : Springer; 2018.

Available from:

<https://www.ncbi.nlm.nih.gov/books/NBK132160/>.

Abbreviations and Acronyms

| | |
|--------|---|
| AAP | American Academy of Pediatrics |
| ACP | American College of Physicians |
| ADHD | attention deficit hyperactivity disorder |
| AHRQ | Agency for Healthcare Research and Quality |
| CFIR | Consolidated Framework for Implementation Research |
| CHD | congenital heart disease |
| CSHCN | Children with special healthcare needs |
| CQ | Contextual Question |
| EPC | Evidence-based Practice Center |
| HIV | human immunodeficiency virus |
| IBD | inflammatory bowel disease |
| KQ | Key Question |
| LTV | long term ventilation |
| MOST | multiphase optimization strategy |
| NCI | National Cancer Institute |
| NIH | National Institutes of Health |
| PedsQL | Pediatric Quality of Life Inventory |
| PICOTS | population, intervention, comparator, outcome, timing and setting |
| PRISMA | Preferred Items for Reporting in Systematic Reviews and Meta-Analyses |
| PROMIS | Patient-Reported Outcomes Measurement Information System |
| RCT | randomized controlled trial |
| SAHM | Society for Adolescent Health and Medicine |
| STAR | Childhood Cancer Survivorship, Treatment, Access, and Research Act |

Appendixes

Appendix A. Methods

Search Strategy

Risk of Bias

Appendix B. Excluded Studies at Full Text

Appendix C. Expanded Eligible Studies Bibliography

Appendix D. Evidence Tables and Evidence Maps for Care Interventions for Transition from Pediatric to Adult Medical Services (Chapter 4)

Appendix E. Evidence Tables and Evidence Maps for Implementation Strategies and Communication Tools for Care Interventions for Transition, Including Provider-Related Training (Chapter 5)

Appendix F. Sources for Barriers and Facilitators for Implementing Effective Interventions and Tools for Transition From Pediatric to Adult Medical Services

Appendix G. Measures Used To Evaluate the Effectiveness of Transitions of Care from Pediatric to Adult Services

Appendix H. References for Evidence Tables

Appendix A. Methods

Search Strategy

Search Details and data sources:

The search strategy was designed and conducted by an experienced systematic review librarian with input from investigators. We applied the following limits or filters to the database searches:

- Date. We did not limit the search by date.
- Language. Limited to English language. Publications were excluded if they were written in a language other than English. This was due to resource constraints.
- Publication Status. We search for published studies.
- Human or organism. The search was not restricted by human or organism.
- Study design. The search was not restricted by study design.
- Filters. For our Embase search we used the conference abstract status publication type limit to exclude conference abstracts. For our CINAHL search we used the exclude Medline records filter.

We conducted a comprehensive literature search in September 2020 (updated May 2021). We searched the following databases:

- Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) Date searched: May 13, 2021
- CINAHL PLUS with Full Text (EBSCOhost) Date searched: May 13, 2021
- Embase Classic+Embase 1947 to 2021 May 12 (Ovid) Date searched: May 13, 2021
- Cochrane Central Register of Controlled Trials (Wiley) (issue 4, April 2021) Date Searched: May 13, 2021

Database search strategies:

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to 1 May 2021

.mp. = multi-purpose, will search several fields at once (title, abstract, subject heading)

1. (adolescen* or child* or emerg* adult* or p?ediatr* or teen* or young adult* or youth).mp.
2. (transition* adj5 (care or plan* or process* or program* or service*)).mp.
3. limit to english language

CINAHL Plus with Full Text

Search Screen - Advanced Search

Expanders - Apply equivalent subjects

Search modes - Boolean/Phrase

Default-(no field codes selected) searches Title/Abstract/Subject Headings

((adolescen* or child* or emerg* adult* or p?ediatr* or teen* or young adult* or youth)) AND (transition* N5 care OR transition* N5 plan* OR transition* N5 process* OR transition* N5 program* OR transition* N5 service*)

Embase Classic+Embase 1947 to 2021 May 12

1. (transition* adj5 (care or plan* or process* or program* or service*)).ti,ab.
2. (adolescen* or emerg* adult* or p?ediatr* or teen* or young adult* or young adult* or youth).ti,ab.
3. Limit to english language
4. Limit 4 to Conference Abstract Status records
5. 3 not 4 (excludes conference abstracts from results)

Cochrane Central Register of Controlled Trials

ID Search Hits

- #1 ((adolescen* or child* or emerg* next adult* or p?ediatric? or teen* or young next adult* or youth))
- #2 (transition* near/5 (care or plan* or process* or program* or service*))
- #3 #1 and #2

We conducted a grey literature search in April 2021 that included the following resources: We search engines/specific web sites. We searched for grey literature using Google, Google Scholar, Got Transition Webpage for relevant government, organization and society websites. Combinations of relevant terms and synonyms were used.

CQ1 Definitions of “Transition Effectiveness”:

Search Terms: (goals and definitions and principles and effective and transitions of care and children with special healthcare needs)

CQ2 Transition Care Training and Other Implementation Strategies:

Search Terms: transitional care training, health care providers, adolescents, chronic illness

CQ3 Linguistic and Culturally Competent Care:

Search Terms: cultural competency training, health care providers, transitional care, chronic illness and adolescents

CQ6 Strategies to Increase Availability of Adult Care Providers:

Search Terms: health care providers, availability, transitional care, adolescents, chronic illness, financial incentives to increase the number of providers carrying for youth with special healthcare needs

Risk of Bias Assessment Guide

INSTRUCTIONS: Review the methods of each trial and assess each risk of bias component as described in these instructions. You may need to have separate assessments for different outcomes (i.e., different measures; different time points may have different attrition rates).

Table A.1. Selection bias

| Description/Guiding Questions | Notes |
|---|--|
| <p>Systematic differences between baseline characteristics of the groups that arise from self-selection of treatments, physician-directed selection of treatments, or association of treatment assignments with demographic, clinical, or social characteristics.</p> <ul style="list-style-type: none">• Did method of randomization create biased allocation to interventions (inadequate randomization)? | <ul style="list-style-type: none">• “Good” Randomization: Detailed methodology would include providing method of randomization such as use of a random numbers table, or computer random number generator. Limited methodology would be the study saying simply saying they randomized in the methods or provided limited detail such as randomizing by a 2:1 ratio.• “Poor”/No Randomization: Randomized based on week of the month of birthday or a non-randomized clinical trial, observational study. |

Figure A.1. Selection bias assessment guidance

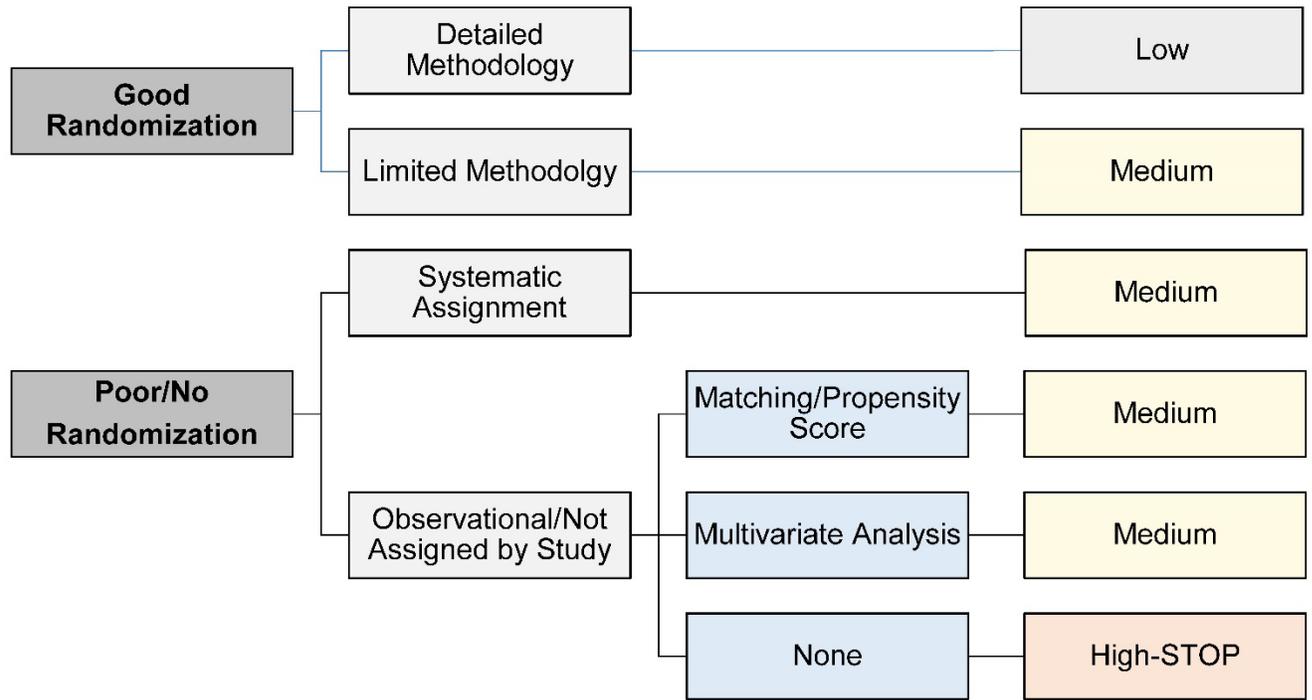


Table A.2. Detection bias

| Description/Guiding Questions | Notes |
|--|--|
| <p><i>Systematic differences in outcomes assessment among groups being compared, including systematic misclassification of the exposure or intervention, covariates, or outcomes because of variable definitions and timings, diagnostic thresholds, recall from memory, inadequate assessor blinding, and faulty measurement techniques. Erroneous statistical analysis might also affect the validity of effect estimates.</i></p> <ul style="list-style-type: none"> • Were the outcome assessors blinded to the intervention (“outcome assessor blinded”)? • Was the timing of the outcome assessment similar in all groups (“comparable timing outcomes assessment”)? • Was the scale used to measure outcomes validated, reliable? • Were outcomes measured in clinically meaningful ways? | <ul style="list-style-type: none"> • [No notes] |

Figure A.2. Detection bias assessment guidance

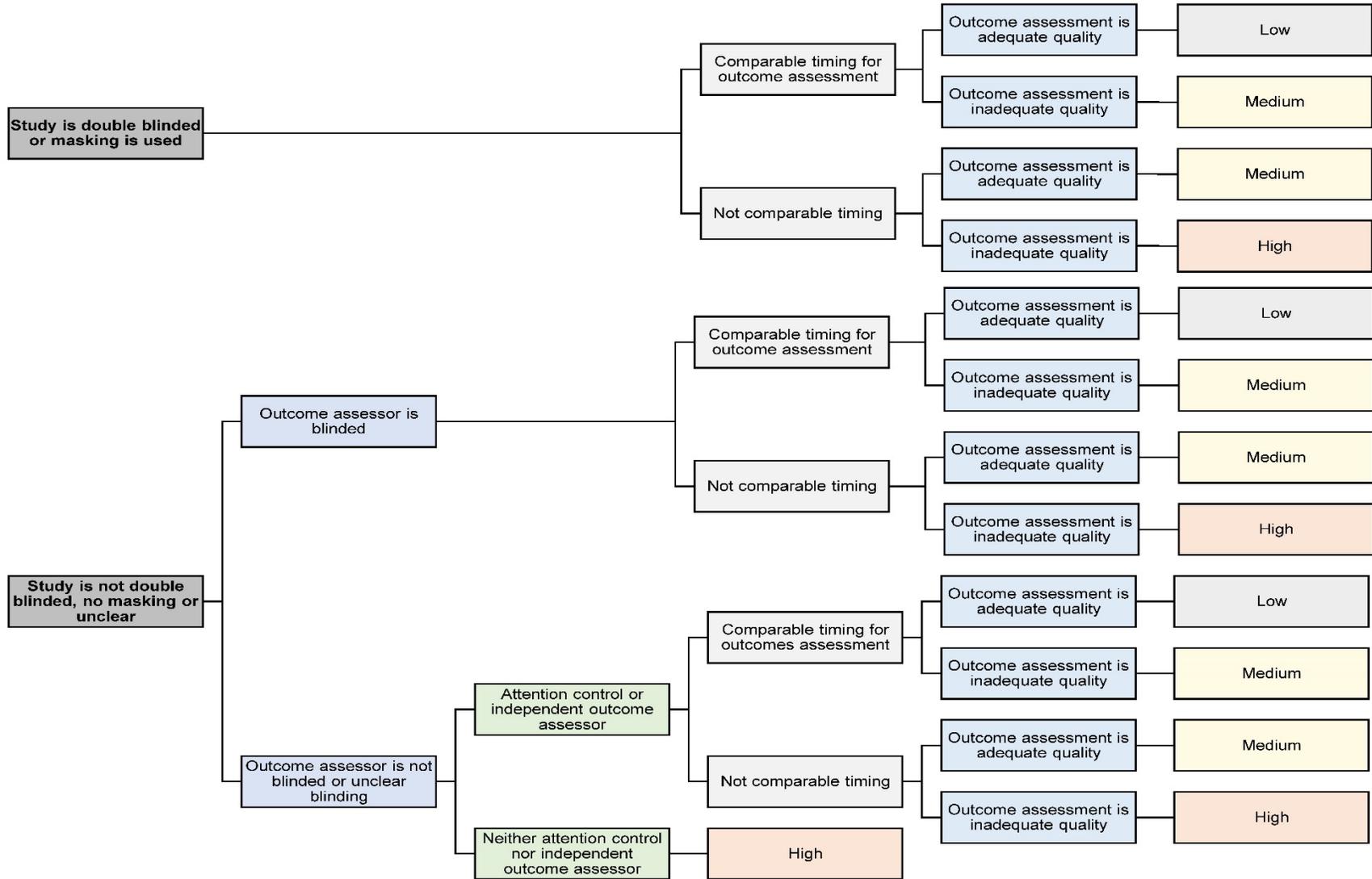
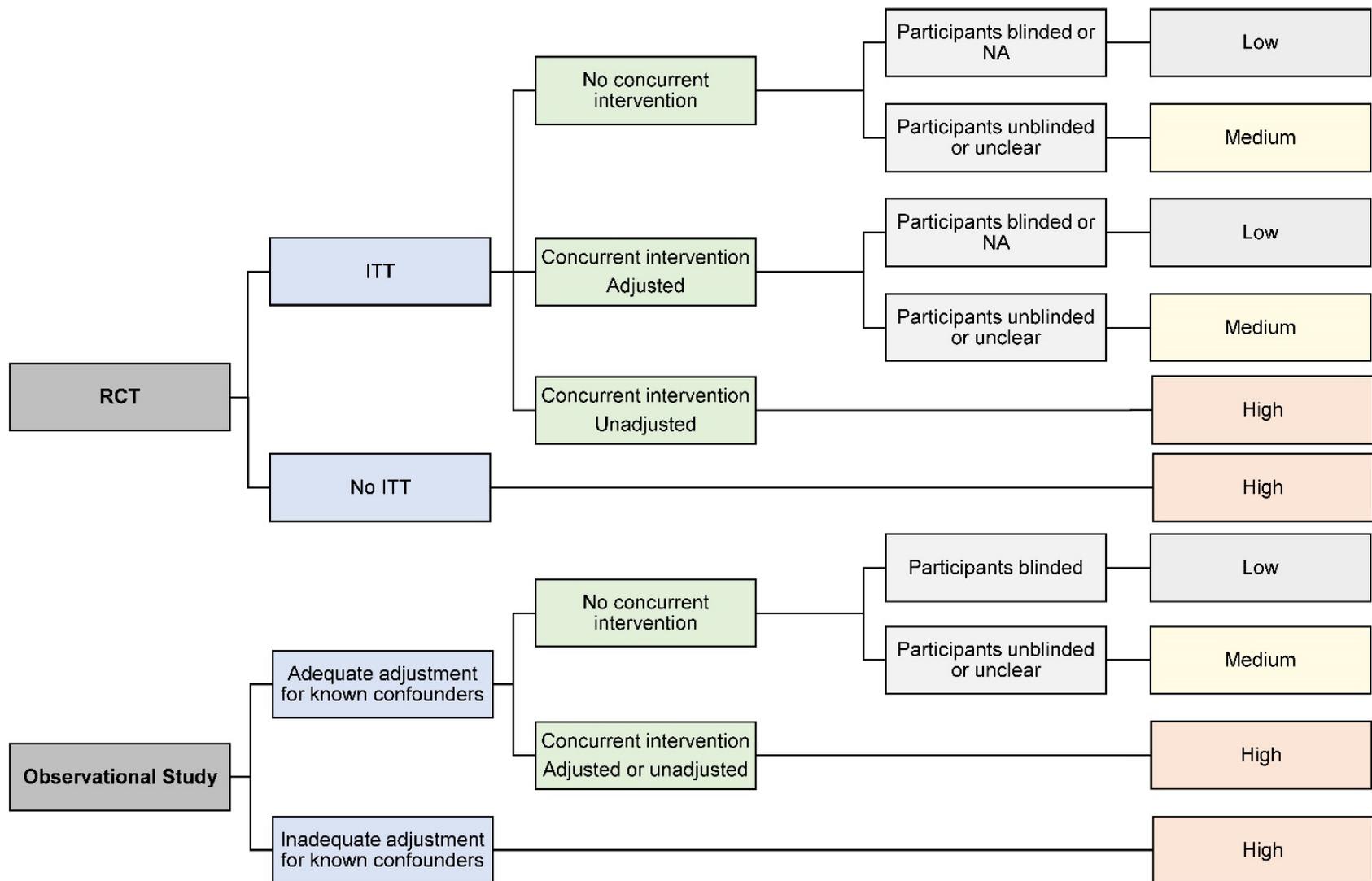


Table A.3. Performance bias

| Description/Guiding Questions | Notes |
|---|--|
| Systematic differences in the care provided to participants and protocol deviation. Examples include contamination of the control group with the exposure or intervention, problems with fidelity to the intervention, unbalanced provision of additional interventions or co-interventions, difference in co-interventions, and inadequate blinding of providers and participants. | <ul style="list-style-type: none">• Intention-to-Treat (ITT): Includes every subject according to randomized treatment assignment. Ignores noncompliance, protocol deviations, withdrawal, and anything that happens after randomization.• Concurrent Intervention: Study participants are receiving another intervention (i.e., treatment) that is not part of the intervention being tested. Example: Participants are randomized to a physical activity intervention (or no intervention), but are also dieting. |

Figure A.3. Performance bias assessment guidance



Abbreviations: ITT= intent to treat; NA=not applicable; RCT=randomized controlled trial

Table A.4. Fidelity to intervention

| Description/Guiding Questions | Notes |
|---|---|
| <p>We anticipate that care delivery studies will generally fall in the range of NIH Stage 3 to 4, with the possibility that one or a few may be carried out as quality improvement and thus Stage 5. Since the Stage Model is explicitly designed to balance, or trade off, internal and external validity, we will approach risk of bias assessment as a threshold requirement rather than a continuum.</p> <ul style="list-style-type: none"> • Look for reporting on intervention compliance, any data reported on consistency of intervention use, or any mechanisms used to ensure compliance (e.g., reminders, guides, manuals). | <ul style="list-style-type: none"> • Information may appear in methods, results, or discussion sections. |

Table A.5. Fidelity to intervention assessment guidance

| Domain | Options | Rating |
|--------------------------|------------------------------------|--------|
| Fidelity to intervention | Yes (at least 70%) | Low |
| | Yes-adaptation planned/ replicable | Medium |
| | No-adaptation not planned | High |
| | Unclear/Not Reported | Medium |

Table A.6. Reporting bias

| Description/Guiding Questions | Notes |
|---|--|
| <p>Systematic differences between reported and unreported findings (e.g., differential reporting of outcomes or harms, incomplete reporting of study findings, potential for bias in reporting through source of funding).</p> <ul style="list-style-type: none"> Was a select group of outcomes reported? | <ul style="list-style-type: none"> Compare results to methods section and/ or protocol. Check if some results are reported in a different publication. |

Table A.7. Reporting bias assessment guidance

| Domain | Options | Rating |
|-----------------------|--------------|--------|
| All outcomes reported | Yes | Low |
| | No | Medium |
| | Not Reported | Medium |

Table A.8. Attrition bias

| Description/Guiding Questions | Notes |
|--|--|
| <p>Systematic differences in the loss of participants from the study and how they were accounted for in the results (e.g., incomplete follow-up, differential attrition). Those who drop out of the study or who are lost to follow-up may be systematically different from those who remain in the study. Attrition bias can potentially change the collective (group) characteristics of the relevant groups and their observed outcomes in ways that affect study results by confounding and spurious associations.</p> <ul style="list-style-type: none">• Reasons for incomplete/missing data adequately explained?• Do the author's attempt to address attrition in the analysis? | <ul style="list-style-type: none">• Attrition assessment is dependent on overall study duration (see flowchart)• Report attrition rate in spreadsheet.• If a study reports outcomes at multiple intervals (e.g., 6 months, 12 months, 18 months) assess attrition at the first relevant time point and the last time-point separately, you do not need to do every time point.• Analysis should be done with appropriate method (i.e. sensitivity analysis with various scenarios); last value forward would only be appropriate for interventions that are supposed to improve the outcomes (i.e. memory training that intends to improve memory). |

Figure A.4. Attrition bias assessment guidance

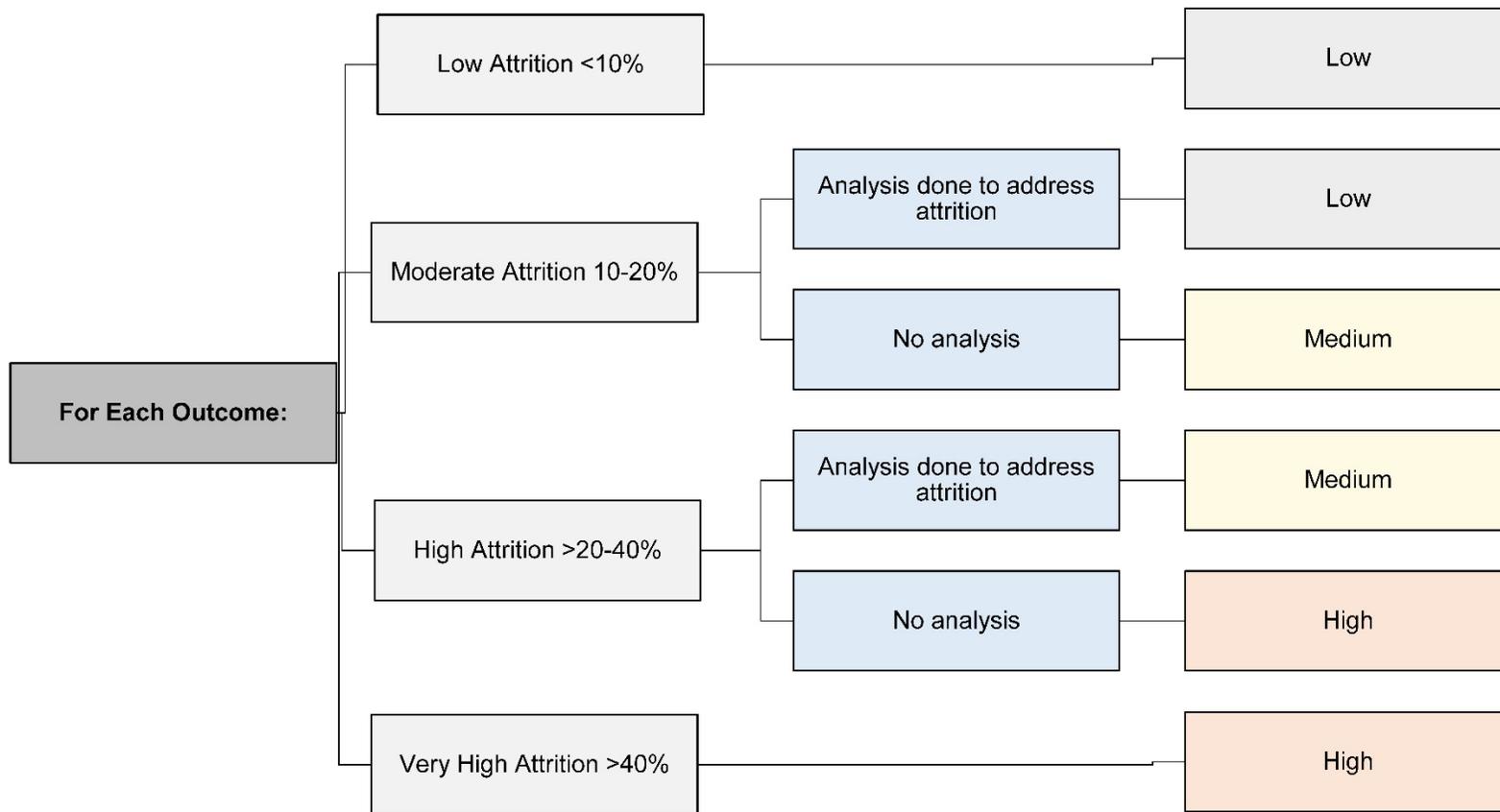
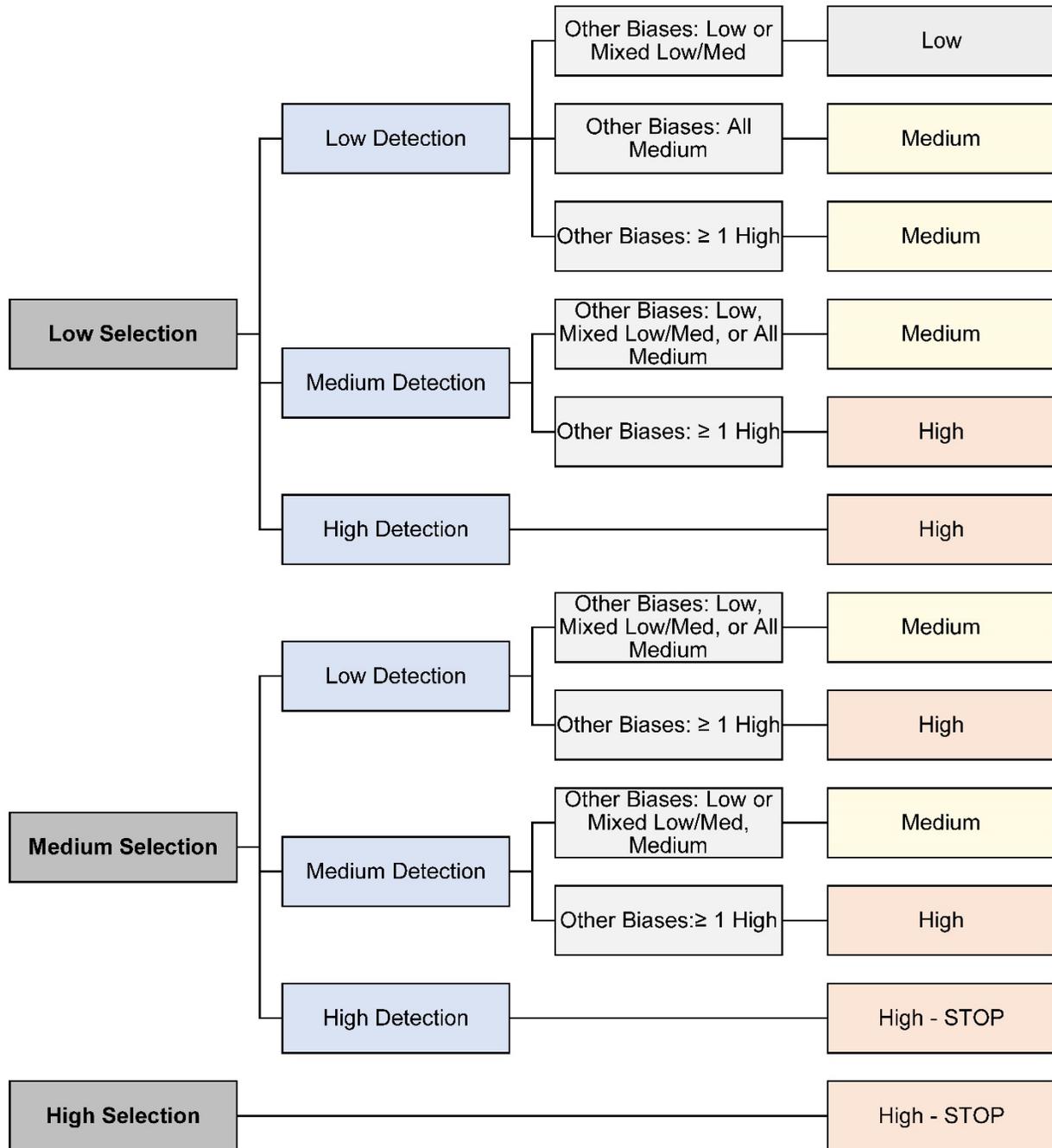


Figure A.5. Overall risk of bias assessment guidance



Appendix B. Excluded Studies at Full Text

Intervention Abel RA, Cho E, Chadwick-Mansker KR, et al. Transition Needs of Adolescents With Sickle Cell Disease. *Am J Occup Ther.* 2015 Mar-Apr;69(2):6902350030p1-5. doi: 10.5014/ajot.2015.013730. PMID: 26122692.

Achola EO, Greene G. Person-family centered transition planning: Improving post-school outcomes to culturally diverse youth and families. *Journal of Vocational Rehabilitation.* 2016;45(2):173-83. doi: 10.3233/jvr-160821. PMID: 611932114.

Agarwal A, Willis D, Tang X, et al. Transition of respiratory technology dependent patients from pediatric to adult pulmonology care. *Pediatr Pulmonol.* 2015 Dec;50(12):1294-300. doi: 10.1002/ppul.23155. PMID: 25652000.

Agrawal S, Slocombe K, Wilson T, et al. Urologic provider experiences in transitioning spina bifida patients from pediatric to adult care. *World J Urol.* 2019 Apr;37(4):607-11. doi: 10.1007/s00345-019-02635-8. PMID: 30649590.

Al-Gamal E, Long T. Health-related quality of life and its association with self-esteem and fatigue among children diagnosed with cancer. *J Clin Nurs.* 2016 Nov;25(21-22):3391-9. doi: 10.1111/jocn.13467. PMID: 27378717.

Al-Maliky MA, Frentzen M, Meister J. Laser-assisted prevention of enamel caries: a 10-year review of the literature. *Lasers Med Sci.* 2020 Feb;35(1):13-30. doi: 10.1007/s10103-019-02859-5. PMID: 31399861.

Aldiss S, Rose L, McCutcheon D, et al. Gathering expert opinion to inform benchmarks to support transitional care. *J Child Health Care.* 2019 Mar;23(1):131-46. doi: 10.1177/1367493518780486. PMID: 29911431.

Alimi A, Weeth-Feinstein LA, Stettner A, et al. Overlap of Juvenile polyposis syndrome and Cowden syndrome due to de novo chromosome 10 deletion involving BMPR1A and PTEN: implications for treatment and surveillance. *Am J Med Genet A.* 2015 Jun;167(6):1305-8. doi: 10.1002/ajmg.a.36876. PMID: 25846706.

Allen D, Gregory J. The transition from children's to adult diabetes services: understanding the 'problem'. *Diabet Med.* 2009 Feb;26(2):162-6. doi: 10.1111/j.1464-5491.2008.02647.x. PMID: 19236619.

Altiok H, Flanagan A, Krzak JJ, et al. Quality of life, satisfaction with life, and functional mobility of young adults with arthrogyrosis after leaving pediatric care. *Am J Med Genet C Semin Med Genet.* 2019 Sep;181(3):461-8. doi: 10.1002/ajmg.c.31717. PMID: 31260186.

Ames JL, Massolo ML, Davignon MN, et al. Transitioning youth with autism spectrum disorders and other special health care needs into adult primary care: A provider survey. *Autism.* 2021 Apr;25(3):731-43. doi: 10.1177/1362361320926318. PMID: 32551940.

Anderson DL, Flume PA, Hardy KK, et al. Transition programs in cystic fibrosis centers: perceptions of patients. *Pediatr Pulmonol.* 2002 May;33(5):327-31. doi: 10.1002/ppul.10083. PMID: 11948976.

Anelli CG, Amorim ALM, Osaku FM, et al. Challenges in transitioning adolescents and young adults with rheumatologic diseases to adult Care in a Developing Country - the Brazilian experience. *Pediatr Rheumatol Online J.* 2017 May 30;15(1):47. doi: 10.1186/s12969-017-0176-y. PMID: 28558790.

Ankeny EM, Lehmann JP. Journey Toward Self-Determination. *Remedial and Special Education.* 2010;32(4):279-89. doi: 10.1177/0741932510362215. PMID: 104652097.

Annunziato RA, Emre S, Shneider B, et al. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatr Transplant.* 2007 Sep;11(6):608-14. doi: 10.1111/j.1399-3046.2007.00689.x. PMID: 17663682.

Applebaum MA, Lawson EF, von Scheven E. Perception of transition readiness and preferences for use of technology in transition programs: teens' ideas for the future. *Int J Adolesc Med Health.* 2013;25(2):119-25. doi: 10.1515/ijamh-2013-0019. PMID: 23740658.

Appleton R, Elahi F, Tuomainen H, et al. "I'm just a long history of people rejecting referrals" experiences of young people who fell through the gap between child and adult mental health services. *Eur Child Adolesc Psychiatry.* 2021 Mar;30(3):401-13. doi: 10.1007/s00787-020-01526-3. PMID: 32274589.

Asp A, Bratt EL, Bramhagen AC. Transfer to Adult Care--Experiences of Young Adults with Congenital Heart Disease. *J Pediatr Nurs.* 2015 Sep-Oct;30(5):e3-10. doi: 10.1016/j.pedn.2015.05.025. PMID: 26199097.

- Ayuk AC, Onukwuli VO, Obumneme-Anyim IN, et al. Pre-Transition Readiness in Adolescents and Young Adults with Four Chronic Medical Conditions in South East Nigeria - An African Perspective to Adolescent Transition. *Adolesc Health Med Ther*. 2020;11:29-38. doi: 10.2147/AHMT.S238603. PMID: 32210656.
- Babler E, Strickland CJ. Moving the Journey Towards Independence: Adolescents Transitioning to Successful Diabetes Self-Management. *J Pediatr Nurs*. 2015 Sep-Oct;30(5):648-60. doi: 10.1016/j.pedn.2015.06.005. PMID: 26190456.
- Badejo OA, Menson WNA, Sam-Agudu NA, et al. Pediatric to adult healthcare transitioning for adolescents living with HIV in Nigeria: A national survey. *PLoS One*. 2018;13(6):e0198802. doi: 10.1371/journal.pone.0198802. PMID: 29894519.
- Bar C, Ghobeira R, Azzi R, et al. Experience of follow-up, quality of life, and transition from pediatric to adult healthcare of patients with tuberous sclerosis complex. *Epilepsy Behav*. 2019 Jul;96:23-7. doi: 10.1016/j.yebeh.2019.04.027. PMID: 31077938.
- Barendse RM, Asn de Kerk DJ, Kindermann A, et al. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of Dutch adult gastroenterologists' perspectives. *International Journal of Child & Adolescent Health*. 2010;3(4):609-16. PMID: 104987763.
- Barger J, Contri D, Gibbons LJ, et al. Transition Planning for Youth With Special Health Care Needs (YSHCN) in Illinois Schools. *J Sch Nurs*. 2015 Aug;31(4):253-60. doi: 10.1177/1059840514542130. PMID: 25061092.
- Bau V, Rose K, Pollack K, et al. [Effectivity of an occlusion-supporting PC-based visual training programme by horizontal drifting sinus gratings in children with amblyopia]. *Klin Monbl Augenheilkd*. 2012 Oct;229(10):979-86. doi: 10.1055/s-0032-1315308. PMID: 23096142.
- Beal SJ, Riddle IK, Kichler JC, et al. The Associations of Chronic Condition Type and Individual Characteristics With Transition Readiness. *Acad Pediatr*. 2016 Sep-Oct;16(7):660-7. doi: 10.1016/j.acap.2016.06.007. PMID: 27345693.
- Begley T. Transition to adult care for young people with long-term conditions. *Br J Nurs*. 2013 May 9-22;22(9):506, 8-11. doi: 10.12968/bjon.2013.22.9.506. PMID: 23752622.
- Bensen R, McKenzie RB, Fernandes SM, et al. Transitions in Pediatric Gastroenterology: Results of a National Provider Survey. *J Pediatr Gastroenterol Nutr*. 2016 Nov;63(5):488-93. doi: 10.1097/MPG.0000000000001199. PMID: 27027904.
- Benson ND, Cunningham C, Braun L, et al. Transitioning Pediatric Patients to Adult Health Care: A Quality Improvement Needs Assessment. *J Pediatr Health Care*. 2018 May - Jun;32(3):216-22. doi: 10.1016/j.pedhc.2017.09.014. PMID: 29398164.
- Berg C, Stratton E, Esiashvili N, et al. Providers' Perspectives of Survivorship Care for Young Adult Survivors of Childhood Cancer. *J Cancer Educ*. 2016 Mar;31(1):31-8. doi: 10.1007/s13187-015-0848-6. PMID: 25943901.
- Berg CA, Wiebe DJ, Suchy Y, et al. Executive Function Predicting Longitudinal Change in Type 1 Diabetes Management During the Transition to Emerging Adulthood. *Diabetes Care*. 2018 Nov;41(11):2281-8. doi: 10.2337/dc18-0351. PMID: 30131398.
- Berg CJ, Stratton E, Esiashvili N, et al. Young Adult Cancer Survivors' Experience with Cancer Treatment and Follow-Up Care and Perceptions of Barriers to Engaging in Recommended Care. *J Cancer Educ*. 2016 Sep;31(3):430-42. doi: 10.1007/s13187-015-0853-9. PMID: 25948413.
- Betz CL, Ferris ME, Woodward JF, et al. The health care transition research consortium health care transition model: a framework for research and practice. *J Pediatr Rehabil Med*. 2014;7(1):3-15. doi: 10.3233/PRM-140277. PMID: 24919934.
- Bjorquist E, Nordmark E, Hallstrom I. Parents' Experiences of Health and Needs When Supporting Their Adolescents With Cerebral Palsy During Transition to Adulthood. *Phys Occup Ther Pediatr*. 2016;36(2):204-16. doi: 10.3109/01942638.2015.1101041. PMID: 26642865.
- Bono-Neri F, Romano C, Isedeh A. Cystic Fibrosis: Advancing Along the Continuum. *J Pediatr Health Care*. 2019 May - Jun;33(3):242-54. doi: 10.1016/j.pedhc.2018.08.008. PMID: 30529125.
- Borromeo GL, Bramante G, Betar D, et al. Transitioning of special needs paediatric patients to adult special needs dental services. *Aust Dent J*. 2014 Sep;59(3):360-5. doi: 10.1111/adj.12197. PMID: 24889651.

- Both P, Ten Holt L, Mous S, et al. Tuberos sclerosis complex: Concerns and needs of patients and parents from the transitional period to adulthood. *Epilepsy Behav.* 2018 Jun;83:13-21. doi: 10.1016/j.yebeh.2018.03.012. PMID: 29631156.
- Bratt EL, Burstrom A, Hanses K, et al. Do not forget the parents-Parents' concerns during transition to adult care for adolescents with congenital heart disease. *Child Care Health Dev.* 2018 Mar;44(2):278-84. doi: 10.1111/cch.12529. PMID: 28980341.
- Bratt EL, Luyckx K, Goossens E, et al. Patient-Reported Health in Young People With Congenital Heart Disease Transitioning to Adulthood. *J Adolesc Health.* 2015 Dec;57(6):658-65. doi: 10.1016/j.jadohealth.2015.07.021. PMID: 26444322.
- Brooks F, Bloomfield L, Offredy M, et al. Evaluation of services for children with complex needs: mapping service provision in one NHS Trust. *Prim Health Care Res Dev.* 2013 Jan;14(1):52-62. doi: 10.1017/S1463423612000217. PMID: 22784821.
- Brown M, Higgins A, MacArthur J. Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities. *J Clin Nurs.* 2020 Jan;29(1-2):195-207. doi: 10.1111/jocn.15077. PMID: 31610045.
- Brown P, Nourse S. Moving from school to adult life: transition services for students with disabilities. *Phys Med Rehabil Clin N Am.* 1997;8(2):359-70. PMID: 107347395.
- Brumfield K, Lansbury G. Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disabil Rehabil.* 2004 Feb 18;26(4):223-34. doi: 10.1080/09638280310001644924. PMID: 15164956.
- Bryant R, Young A, Cesario S, et al. Transition of chronically ill youth to adult health care: experience of youth with hemoglobinopathy. *J Pediatr Health Care.* 2011 Sep-Oct;25(5):275-83. doi: 10.1016/j.pedhc.2010.02.006. PMID: 21867855.
- Buford T. Transfer of responsibility for asthma self-management from parents to their school-age children. *Transfer of Responsibility for Asthma Self-management From Parents to Their School-age Children.* 2001:121 p- p. PMID: 109876412.
- Burke R, Spoerri M, Cardosi A, et al. Survey of primary care pediatricians on the transition and transfer of adolescents to adult healthcare. *Dev Med Child Neurol.* 2006;48:37-8. PMID: 106252116.
- Burke R, Spoerri M, Price A, et al. Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. *Clin Pediatr (Phila).* 2008 May;47(4):347-54. doi: 10.1177/0009922807310938. PMID: 18180341.
- Burstrom A, Bratt EL, Frenckner B, et al. Adolescents with congenital heart disease: their opinions about the preparation for transfer to adult care. *Eur J Pediatr.* 2017 Jul;176(7):881-9. doi: 10.1007/s00431-017-2917-9. PMID: 28508990.
- Caldwell EP. Health literacy in adolescents with sickle cell disease: The influence of caregiver health literacy. *J Spec Pediatr Nurs.* 2020 Apr;25(2):e12284. doi: 10.1111/jspn.12284. PMID: 31825171.
- Camacho CB, Hemmeter J. Linking youth transition support services: results from two demonstration projects. *Soc Secur Bull.* 2013;73(1):59-71. PMID: 23687742.
- Camfield PR, Gibson PA, Douglass LM. Strategies for transitioning to adult care for youth with Lennox-Gastaut syndrome and related disorders. *Epilepsia.* 2011 Aug;52 Suppl 5(S):21-7. doi: 10.1111/j.1528-1167.2011.03179.x. PMID: 21790562.
- Cappelli M, MacDonald NE, McGrath PJ. Assessment of readiness to transfer to adult care for adolescents with cystic fibrosis. *Child Health Care.* 1989 Fall;18(4):218-24. doi: 10.1207/s15326888chc1804_4. PMID: 10296097.
- Cardell B, Clark L, Pett MA. Measurement considerations for achieving equity in research inclusion for transition-aged youth with disabilities. *J Pediatr Nurs.* 2015 Jan-Feb;30(1):36-44. doi: 10.1016/j.pedn.2014.10.019. PMID: 25448476.
- Carrizosa J, An I, Appleton R, et al. Models for transition clinics. *Epilepsia.* 2014 Aug;55 Suppl 3(s):46-51. doi: 10.1111/epi.12716. PMID: 25209087.
- Carroll, Ellen M. The lived experiences of transition to adult healthcare in young adults with cerebral palsy. *Lived Experiences of Transition to Adult Healthcare in Young Adults With Cerebral Palsy.* 2013:132 p- p. PMID: 109863983.
- Carroll EM. Health Care Transition Experiences of Young Adults With Cerebral Palsy. *J Pediatr Nurs.* 2015 Sep-Oct;30(5):e157-64. doi: 10.1016/j.pedn.2015.05.018. PMID: 26142160.
- Chaplin S. The impact of transition on NHS diabetes service delivery: key audit results spanning 2003-2014. *Practical Diabetes.* 2017;34(7):254-7. doi: 10.1002/pdi.2131. PMID: 125084552.

- Chauveau S, Jeny F, Montagne ME, et al. Child-Adult Transition in Sarcoidosis: A Series of 52 Patients. *J Clin Med*. 2020 Jul 3;9(7). doi: 10.3390/jcm9072097. PMID: 32635292.
- Cheak-Zamora NC, Farmer JE, Mayfield WA, et al. Health care transition services for youth with autism spectrum disorders. *Rehabil Psychol*. 2014 Aug;59(3):340-8. doi: 10.1037/a0036725. PMID: 25019309.
- Cheak-Zamora NC, Teti M. "You think it's hard now ... It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services. *Autism*. 2015 Nov;19(8):992-1001. doi: 10.1177/1362361314558279. PMID: 25504639.
- Cheak-Zamora NC, Yang X, Farmer JE, et al. Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics*. 2013 Mar;131(3):447-54. doi: 10.1542/peds.2012-1572. PMID: 23400613.
- Chen CW, Su WJ, Chiang YT, et al. Healthcare needs of adolescents with congenital heart disease transitioning into adulthood: a Delphi survey of patients, parents, and healthcare providers. *Eur J Cardiovasc Nurs*. 2017 Feb;16(2):125-35. doi: 10.1177/1474515116643622. PMID: 27045011.
- Chilton R, Pires-Yfantouda R. Understanding adolescent type 1 diabetes self-management as an adaptive process: A grounded theory approach. *Psychol Health*. 2015;30(12):1486-504. doi: 10.1080/08870446.2015.1062482. PMID: 26084198.
- Clarizia NA, Chahal N, Manlhiot C, et al. Transition to adult health care for adolescents and young adults with congenital heart disease: perspectives of the patient, parent and health care provider. *Can J Cardiol*. 2009 Sep;25(9):e317-22. doi: 10.1016/s0828-282x(09)70145-x. PMID: 19746251.
- Clayton-Jones D, Matthie N, Treadwell M, et al. Social and Psychological Factors Associated With Health Care Transition for Young Adults Living With Sickle Cell Disease. *J Transcult Nurs*. 2021 Jan;32(1):21-9. doi: 10.1177/1043659619896837. PMID: 31889479.
- Clegg J, Murphy E, Almack K, et al. Tensions around inclusion: reframing the moral horizon. *Journal of Applied Research in Intellectual Disabilities*. 2008;21(1):81-94. PMID: 105652326.
- Cleverley K, Gore D, Nasir S, et al. Facilitating Effective Transitions from Hospital to Community for Children and Adolescent Mental Health Services: Overview of the Transition Support Worker Role and Function. *J Can Acad Child Adolesc Psychiatry*. 2018 Nov;27(4):228-35. PMID: 30487938.
- Cleverley K, Lenters L, McCann E. "Objectively terrifying": a qualitative study of youth's experiences of transitions out of child and adolescent mental health services at age 18. *BMC Psychiatry*. 2020 Apr 3;20(1):147. doi: 10.1186/s12888-020-02516-0. PMID: 32245439.
- Cohen E, Gandhi S, Toulany A, et al. Health Care Use During Transfer to Adult Care Among Youth With Chronic Conditions. *Pediatrics*. 2016 Mar;137(3):e20152734. doi: 10.1542/peds.2015-2734. PMID: 26933203.
- Condren M, Lubsch L, Vats TS. Long-term follow-up of survivors of childhood cancer. *Indian J Pediatr*. 2005 Jan;72(1):39-43. doi: 10.1007/BF02760579. PMID: 15684447.
- Court JM. Outpatient-based transition services for youth. *Pediatrician*. 1991;18(2):150-6. PMID: 1886837.
- Court JM. Issues of transition to adult care. *J Paediatr Child Health*. 1993;29 Suppl 1:S53-5. doi: 10.1111/j.1440-1754.1993.tb02263.x. PMID: 8268025.
- Cox A, Breau L, Connor L, et al. Transition of care to an adult spina bifida clinic: patient perspectives and medical outcomes. *J Urol*. 2011 Oct;186(4 Suppl):1590-4. doi: 10.1016/j.juro.2011.04.011. PMID: 21855907.
- Coyne I, Malone H, Chubb E, et al. Transition from paediatric to adult healthcare for young people with cystic fibrosis: Parents' information needs. *J Child Health Care*. 2018 Dec;22(4):646-57. doi: 10.1177/1367493518768448. PMID: 29618237.
- Coyne I, Sheehan A, Heery E, et al. Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences. *J Clin Nurs*. 2019 Nov;28(21-22):4062-76. doi: 10.1111/jocn.15006. PMID: 31327174.
- Crowley SL, Byrne S, McNulty S, et al. The Temple Star Transitional Model of Care for epilepsy; the outcome of a quality improvement project. *Epilepsy Behav*. 2018 Feb;79:4-8. doi: 10.1016/j.yebeh.2017.10.043. PMID: 29223006.

- Dale CM, King J, Amin R, et al. Health transition experiences of Canadian ventilator-assisted adolescents and their family caregivers: A qualitative interview study. *Paediatr Child Health*. 2017 Aug;22(5):277-81. doi: 10.1093/pch/pxx079. PMID: 29479234.
- Danielson J, Karlbom U, Graf W, et al. Outcome in adults with anorectal malformations in relation to modern classification - Which patients do we need to follow beyond childhood? *J Pediatr Surg*. 2017 Mar;52(3):463-8. doi: 10.1016/j.jpedsurg.2016.10.051. PMID: 27894765.
- Darrah J, Wiart L, Magill-Evans J, et al. Are family-centred principles, functional goal setting and transition planning evident in therapy services for children with cerebral palsy? *Child Care Health Dev*. 2012 Jan;38(1):41-7. doi: 10.1111/j.1365-2214.2010.01160.x. PMID: 21083684.
- Das J, Ghosh J, Manna P, et al. Protective role of taurine against arsenic-induced mitochondria-dependent hepatic apoptosis via the inhibition of PKCdelta-JNK pathway. *PLoS One*. 2010 Sep 7;5(9):e12602. doi: 10.1371/journal.pone.0012602. PMID: 20830294.
- Davidson LF, Chhabra R, Cohen HW, et al. Pediatricians Transitioning Practices, Youth With Special Health Care Needs in New York State. *Clin Pediatr (Phila)*. 2015 Oct;54(11):1051-8. doi: 10.1177/0009922815573940. PMID: 25724992.
- Davidson LF, Doyle M, Silver EJ. Discussing Future Goals and Legal Aspects of Health Care: Essential Steps in Transitioning Youth to Adult-Oriented Care. *Clin Pediatr (Phila)*. 2017 Sep;56(10):902-8. doi: 10.1177/0009922817706142. PMID: 28466656.
- Davies H, Rennick J, Majnemer A. Transition from pediatric to adult health care for young adults with neurological disorders: parental perspectives. *Can J Neurosci Nurs*. 2011;33(2):32-9. PMID: 21977770.
- de Beaufort C, Jarosz-Chobot P, Frank M, et al. Transition from pediatric to adult diabetes care: smooth or slippery? *Pediatr Diabetes*. 2010 Feb;11(1):24-7. doi: 10.1111/j.1399-5448.2009.00524.x. PMID: 20015124.
- de Luna KS, Mercado-Asis LB. Pediatric endocrinology transition clinic profile at the university of Santo Tomas hospital outpatient department - clinical division (USTH OPD-CD). *Phillippine Journal of Internal Medicine*. 2017;55(2). PMID: 617660230.
- De Vere Hunt I, Chapman K, Wali G, et al. Establishing and developing a Teenage and Young Adult dermatology clinic with embedded specialist psychological support. *Clin Exp Dermatol*. 2019 Dec;44(8):893-6. doi: 10.1111/ced.13950. PMID: 30784103.
- Dellon ES, Jones PD, Martin NB, et al. Health-care transition from pediatric to adult-focused gastroenterology in patients with eosinophilic esophagitis. *Dis Esophagus*. 2013 Jan;26(1):7-13. doi: 10.1111/j.1442-2050.2011.01315.x. PMID: 22309247.
- Deng LX, Gleason LP, Awh K, et al. Too little too late? Communication with patients with congenital heart disease about challenges of adult life. *Congenit Heart Dis*. 2019 Jul;14(4):534-40. doi: 10.1111/chd.12778. PMID: 31054179.
- Diaz-Gonzalez de Ferris ME, Del Villar-Vilchis M, Guerrero R, et al. Self-Management and Health Care Transition Among Adolescents and Young Adults With Chronic Kidney Disease: Medical and Psychosocial Considerations. *Adv Chronic Kidney Dis*. 2017 Nov;24(6):405-9. doi: 10.1053/j.ackd.2017.09.010. PMID: 29229172.
- DiFazio RL, Harris M, Vessey JA, et al. Opportunities lost and found: experiences of patients with cerebral palsy and their parents transitioning from pediatric to adult healthcare. *J Pediatr Rehabil Med*. 2014;7(1):17-31. doi: 10.3233/PRM-140276. PMID: 24919935.
- Dimitropoulos G, Herschman J, Toulany A, et al. A qualitative study on the challenges associated with accepting familial support from the perspective of transition-age youth with eating disorders. *Eat Disord*. 2016 May-Jun;24(3):255-70. doi: 10.1080/10640266.2015.1064276. PMID: 26212112.
- Dimitropoulos G, Toulany A, Herschman J, et al. A qualitative study on the experiences of young adults with eating disorders transferring from pediatric to adult care. *Eat Disord*. 2015;23(2):144-62. doi: 10.1080/10640266.2014.976106. PMID: 25402167.
- Dimitropoulos G, Tran AF, Agarwal P, et al. Navigating the transition from pediatric to adult eating disorder programs: perspectives of service providers. *Int J Eat Disord*. 2012 Sep;45(6):759-67. doi: 10.1002/eat.22017. PMID: 22431280.
- Disabato JA, Mannino JE, Betz CL. Pediatric Nurses' Role in Health Care Transition Planning: National Survey Findings and Practice Implications. *J Pediatr Nurs*. 2019 Nov - Dec;49:60-6. doi: 10.1016/j.pedn.2019.08.003. PMID: 31494347.

- Dore A, de Guise P, Mercier LA. Transition of care to adult congenital heart centres: what do patients know about their heart condition? *Can J Cardiol*. 2002 Feb;18(2):141-6. PMID: 11875583.
- Doshi K, Kazak AE, Hocking MC, et al. Why mothers accompany adolescent and young adult childhood cancer survivors to follow-up clinic visits. *J Pediatr Oncol Nurs*. 2014 Jan-Feb;31(1):51-7. doi: 10.1177/1043454213518111. PMID: 24451909.
- Downing KF, Oster ME, Farr SL. Preparing adolescents with heart problems for transition to adult care, 2009-2010 National Survey of Children with Special Health Care Needs. *Congenit Heart Dis*. 2017 Jul;12(4):497-506. doi: 10.1111/chd.12476. PMID: 28523852.
- Doyle M, Werner-Lin A. That eagle covering me: transitioning and connected autonomy for emerging adults with cystinosis. *Pediatr Nephrol*. 2015 Feb;30(2):281-91. doi: 10.1007/s00467-014-2921-5. PMID: 25159720.
- du Plessis K, Peters R, Culnane E, et al. Traversing the liminal: what can Fontan adults' transition experiences and perspectives teach us about optimizing healthcare? *Int J Adolesc Med Health*. 2018 Sep 26;32(6). doi: 10.1515/ijamh-2018-0020. PMID: 30256759.
- Dudman L, Rapley P, Wilson S. Development of a transition readiness scale for young adults with cystic fibrosis: face and content validity. *Neonatal, Paediatric & Child Health Nursing*. 2011;14(2):9-13. PMID: 104670618.
- Duke DC, Raymond JK, Shimomaeda L, et al. Recommendations for transition from pediatric to adult diabetes care: patients' perspectives. *Diabetes Management*. 2013;3(4):297-304. doi: 10.2217/dmt.13.26. PMID: 369178345.
- Dupuis F, Duhamel F, Gendron S. Transitioning care of an adolescent with cystic fibrosis: development of systemic hypothesis between parents, adolescents, and health care professionals. *J Fam Nurs*. 2011 Aug;17(3):291-311. doi: 10.1177/1074840711414907. PMID: 21813812.
- Durkin ET, Zurakowski D, Rangel SJ, et al. Passing the baton: The pediatric surgical perspective on transition. *J Pediatr Surg*. 2015 Jul;50(7):1196-200. doi: 10.1016/j.jpedsurg.2014.10.050. PMID: 25783307.
- Dwyer-Matzky K, Blatt A, Asselin BL, et al. Lack of Preparedness for Pediatric to Adult-Oriented Health Care Transition in Hospitalized Adolescents and Young Adults. *Acad Pediatr*. 2018 Jan - Feb;18(1):102-10. doi: 10.1016/j.acap.2017.07.008. PMID: 28778828.
- Eiser C, Flynn M, Green E, et al. Coming of age with diabetes: patients' views of a clinic for under-25 year olds. *Diabet Med*. 1993 Apr;10(3):285-9. doi: 10.1111/j.1464-5491.1993.tb00061.x. PMID: 8485964.
- Eke H, Janssens A, Downs J, et al. How to measure the need for transition to adult services among young people with Attention Deficit Hyperactivity Disorder (ADHD): a comparison of surveillance versus case note review methods. *BMC Med Res Methodol*. 2019 Aug 20;19(1):179. doi: 10.1186/s12874-019-0820-y. PMID: 31429715.
- Eklund H, Cadman T, Findon J, et al. Clinical service use as people with Attention Deficit Hyperactivity Disorder transition into adolescence and adulthood: a prospective longitudinal study. *BMC Health Serv Res*. 2016 Jul 11;16:248. doi: 10.1186/s12913-016-1509-0. PMID: 27400778.
- Eluri S, Book WM, Kodroff E, et al. Lack of Knowledge and Low Readiness for Health Care Transition in Eosinophilic Esophagitis and Eosinophilic Gastroenteritis. *J Pediatr Gastroenterol Nutr*. 2017 Jul;65(1):53-7. doi: 10.1097/MPG.0000000000001415. PMID: 28644350.
- Eros A, Veres G, Tarnok A, et al. A Cross-Sectional Survey on the Transitional Care of Adolescents with Inflammatory Bowel Disease in Hungary. *J Pediatr Nurs*. 2020 Nov - Dec;55:e279-e85. doi: 10.1016/j.pedn.2020.06.002. PMID: 32624314.
- Ersig AL. An Exploratory Study: Transition to Adulthood for College Students with Type 1 Diabetes and Their Parents. *J Pediatr Nurs*. 2019 May - Jun;46:12-7. doi: 10.1016/j.pedn.2019.01.008. PMID: 30811974.
- Espeleta HC, Bakula DM, Delozier AM, et al. Transition readiness: The linkage between adverse childhood experiences (ACEs) and health-related quality of life. *Transl Behav Med*. 2019 May 16;9(3):533-40. doi: 10.1093/tbm/iby130. PMID: 30566673.

- Fair CD, Goldstein B, Dizney R. Congruence of Transition Perspectives Between Adolescents With Perinatally-Acquired HIV and Their Guardians: An Exploratory Qualitative Study. *J Pediatr Nurs*. 2015 Sep-Oct;30(5):684-90. doi: 10.1016/j.pedn.2015.06.001. PMID: 26117807.
- Fair CD, Sullivan K, Gatto A. Best practices in transitioning youth with HIV: perspectives of pediatric and adult infectious disease care providers. *Psychol Health Med*. 2010 Oct;15(5):515-27. doi: 10.1080/13548506.2010.493944. PMID: 20835962.
- Faleiros F, Warschausky S, Kappler C, et al. Bladder Self-management in the Transition to Adulthood With Spina Bifida in 3 Countries: A Comparative Study. *J Wound Ostomy Continence Nurs*. 2019 Jul/Aug;46(4):321-6. doi: 10.1097/WON.0000000000000545. PMID: 31274863.
- Fernandes SM, Khairy P, Fishman L, et al. Referral patterns and perceived barriers to adult congenital heart disease care: results of a survey of U.S. pediatric cardiologists. *J Am Coll Cardiol*. 2012 Dec 11;60(23):2411-8. doi: 10.1016/j.jacc.2012.09.015. PMID: 23141490.
- Fernandes SM, O'Sullivan-Oliveira J, Landzberg MJ, et al. Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective. *J Pediatr Rehabil Med*. 2014;7(1):43-51. doi: 10.3233/PRM-140269. PMID: 24919937.
- Fernet M, Lapointe N, Lévy JJ, et al. The Importance of Meanings of Antiretroviral Treatment and Care Providers for Adherence and Transitioning to Adult Services Among Youth With Perinatally Acquired HIV Infection. *J HIV AIDS Soc Serv*. 2015;14(3):257-76. doi: 10.1080/15381501.2014.912172. PMID: 109078463.
- Ferris ME, Cuttance JR, Javalkar K, et al. Self-management and transition among adolescents/young adults with chronic or end-stage kidney disease. *Blood Purif*. 2015;39(1-3):99-104. doi: 10.1159/000368978. PMID: 25662749.
- Fiorantino L, Phillips D, Walker A, et al. Leaving paediatrics: the experience of service transition for young disabled people and their family carers. *Health Soc Care Community*. 1998 Jul;6(4):260-70. doi: 10.1046/j.1365-2524.1998.00124.x. PMID: 11560598.
- Fisher E, Lazar L, Shalitin S, et al. Association between Glycemic Control and Clinic Attendance in Emerging Adults with Type 1 Diabetes: A Tertiary Center Experience. *J Diabetes Res*. 2018;2018:9572817. doi: 10.1155/2018/9572817. PMID: 30116747.
- Fishman LN, DiFazio R, Miller P, et al. Pediatric Orthopaedic Providers' Views on Transition From Pediatric to Adult Care. *J Pediatr Orthop*. 2016 Sep;36(6):e75-80. doi: 10.1097/BPO.0000000000000629. PMID: 26296228.
- Franklin MS, Beyer LN, Brotkin SM, et al. Health Care Transition for Adolescent and Young Adults with Intellectual Disability: Views from the Parents. *J Pediatr Nurs*. 2019 Jul - Aug;47:148-58. doi: 10.1016/j.pedn.2019.05.008. PMID: 31152999.
- Frederick NN, Bober SL, Berwick L, et al. Preparing childhood cancer survivors for transition to adult care: The young adult perspective. *Pediatr Blood Cancer*. 2017 Oct;64(10):e26544. doi: 10.1002/pbc.26544. PMID: 28383822.
- Gabay Gillie G, Tarabeih M. "A Bridge Over Troubled Water": Nurses' Leadership in Establishing Young Adults' Trust Upon the Transition to Adult Renal-Care - A Dual-Perspective Qualitative Study. *J Pediatr Nurs*. 2020 Jul - Aug;53:e41-e8. doi: 10.1016/j.pedn.2020.02.004. PMID: 32139233.
- Garvey KC, Beste MG, Luff D, et al. Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study. *Adolesc Health Med Ther*. 2014;5:191-8. doi: 10.2147/AHMT.S67943. PMID: 25349485.
- Garvey KC, Telo GH, Needleman JS, et al. Health Care Transition in Young Adults With Type 1 Diabetes: Perspectives of Adult Endocrinologists in the U.S. *Diabetes Care*. 2016 Feb;39(2):190-7. doi: 10.2337/dc15-1775. PMID: 26681724.
- Garvey KC, Telo GH, Needleman JS, et al. Health Care Transition in Young Adults With Type 1 Diabetes: Perspectives of Adult Endocrinologists in the U.S. *Diabetes Care*. 2016 Feb;39(2):190-7. doi: 10.2337/dc15-1775. PMID: 26681724.
- Garvey KC, Wolpert HA, Rhodes ET, et al. Health care transition in patients with type 1 diabetes: young adult experiences and relationship to glycemic control. *Diabetes Care*. 2012 Aug;35(8):1716-22. doi: 10.2337/dc11-2434. PMID: 22699289.

- Gauthier-Boudreault C, Gallagher F, Couture M. Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing? *Res Dev Disabil.* 2017 Jul;66:16-26. doi: 10.1016/j.ridd.2017.05.001. PMID: 28577424.
- Gawlik A, Kaczor B, Kaminska H, et al. Quality of medical follow-up of young women with Turner syndrome treated in one clinical center. *Horm Res Paediatr.* 2012;77(4):222-8. doi: 10.1159/000337780. PMID: 22538845.
- Geerlings RP, Aldenkamp AP, Gottmer-Welschen LM, et al. Developing from child to adult: Risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy. *Epilepsy Behav.* 2015 Oct;51:182-90. doi: 10.1016/j.yebeh.2015.07.035. PMID: 26291772.
- Gentles, Marilyn E. School Nursing Health Care Transition Policies and Practices for Serving Youth with Disabilities and Special Health Care Needs. *School Nursing Health Care Transition Policies & Practices for Serving Youth With Disabilities & Special Health Care Needs.* 2013:369 p- p. PMID: 109859787.
- Gerardin J, Raskind-Hood C, Rodriguez FH, 3rd, et al. Lost in the system? Transfer to adult congenital heart disease care-Challenges and solutions. *Congenit Heart Dis.* 2019 Jul;14(4):541-8. doi: 10.1111/chd.12780. PMID: 31066199.
- Gerritsen SE, Dieleman GC, Beltman MAC, et al. Transitional psychiatry in the Netherlands: Experiences and views of mental health professionals. *Early Interv Psychiatry.* 2020 Dec;14(6):684-90. doi: 10.1111/eip.12890. PMID: 31747718.
- Ghattas M, El-Shaarawy F, Mesbah N, et al. DNA methylation status of the methylenetetrahydrofolate reductase gene promoter in peripheral blood of end-stage renal disease patients. *Mol Biol Rep.* 2014 Feb;41(2):683-8. doi: 10.1007/s11033-013-2906-7. PMID: 24363223.
- Ghotme KA, Alvarado-Gomez F, Lampe C, et al. Spinal cord issues in adult patients with MPS: transition of care survey. *Childs Nerv Syst.* 2018 Sep;34(9):1759-65. doi: 10.1007/s00381-018-3834-6. PMID: 29804213.
- Giarelli E, Bernhardt BA, Mack R, et al. Adolescents' transition to self-management of a chronic genetic disorder. *Qual Health Res.* 2008 Apr;18(4):441-57. doi: 10.1177/1049732308314853. PMID: 18354044.
- Gibson-Scipio W, Gourdin D, Krouse HJ. Asthma Self-Management Goals, Beliefs and Behaviors of Urban African American Adolescents Prior to Transitioning to Adult Health Care. *J Pediatr Nurs.* 2015 Nov-Dec;30(6):e53-61. doi: 10.1016/j.pedn.2015.06.012. PMID: 26169338.
- Gitahi N, Camlin C, Mwanja V, et al. Psychosocial needs among older perinatally infected adolescents living with HIV and transitioning to adult care in Kenya. *PLoS One.* 2020;15(7):e0233451. doi: 10.1371/journal.pone.0233451. PMID: 32726306.
- Godbout A, Tejedor I, Malivoir S, et al. Transition from pediatric to adult healthcare: assessment of specific needs of patients with chronic endocrine conditions. *Horm Res Paediatr.* 2012;78(4):247-55. doi: 10.1159/000343818. PMID: 23128858.
- Gooding HC, Rodday AM, Wong JB, et al. Application of Pediatric and Adult Guidelines for Treatment of Lipid Levels Among US Adolescents Transitioning to Young Adulthood. *JAMA Pediatr.* 2015 Jun;169(6):569-74. doi: 10.1001/jamapediatrics.2015.0168. PMID: 25845026.
- Gravelle A, Davidson G, Chilvers M. Cystic fibrosis adolescent transition care in Canada: A snapshot of current practice. *Paediatr Child Health.* 2012 Dec;17(10):553-6. doi: 10.1093/pch/17.10.553. PMID: 24294062.
- Gray V, Palmer L, Whelby K, et al. Exploring the role of knowledge of condition and psycho-social profiles of young people with epilepsy during transition. *Epilepsy Behav.* 2017 Aug;73:156-60. doi: 10.1016/j.yebeh.2017.05.003. PMID: 28641167.
- Gray WN, Maddux MH. Current Transition Practices in Pediatric IBD: Findings from a National Survey of Pediatric Providers. *Inflamm Bowel Dis.* 2016 Feb;22(2):372-9. doi: 10.1097/MIB.0000000000000642. PMID: 26752464.
- Gray WN, Monaghan MC, Gilleland Marchak J, et al. Psychologists and the Transition From Pediatrics to Adult Health Care. *J Adolesc Health.* 2015 Nov;57(5):468-74. doi: 10.1016/j.jadohealth.2015.07.011. PMID: 26499856.
- Gray WN, Reed-Knight B, Morgan PJ, et al. Multi-Site Comparison of Patient, Parent, and Pediatric Provider Perspectives on Transition to Adult Care in IBD. *J Pediatr Nurs.* 2018 Mar - Apr;39:49-54. doi: 10.1016/j.pedn.2018.01.008. PMID: 29525216.

- Grimsby GM, Burgess R, Culver S, et al. Barriers to transition in young adults with neurogenic bladder. *J Pediatr Urol*. 2016 Aug;12(4):258 e1-5. doi: 10.1016/j.jpuro.2016.04.015. PMID: 27270070.
- Grivetta SA, Gilot CB, Coggiola M, et al. HIV positive youth's healthcare transition from pediatric to adult service: nursing implications. *Children's Nurses: Italian Journal of Pediatric Nursing Science / Infermieri dei Bambini: Giornale Italiano di Scienze Infermieristiche Pediatriche*. 2012;4(3):98-101. PMID: 83753110.
- Gumidyala AP, Greenley RN, Plevinsky JM, et al. Moving On: Transition Readiness in Adolescents and Young Adults With IBD. *Inflamm Bowel Dis*. 2018 Feb 15;24(3):482-9. doi: 10.1093/ibd/izx051. PMID: 29462383.
- Gutierrez-Colina AM, Reed-Knight B, Eaton C, et al. Transition readiness, adolescent responsibility, and executive functioning among pediatric transplant recipients: Caregivers' perspectives. *Pediatr Transplant*. 2017 May;21(3). doi: 10.1111/petr.12898. PMID: 28239931.
- Haarbauer-Krupa J, Alexander NM, Mee L, et al. Readiness for transition and health-care satisfaction in adolescents with complex medical conditions. *Child Care Health Dev*. 2019 May;45(3):463-71. doi: 10.1111/cch.12656. PMID: 30836446.
- Haghighat R, Toska E, Cluver L, et al. Transition Pathways Out of Pediatric Care and Associated HIV Outcomes for Adolescents Living With HIV in South Africa. *J Acquir Immune Defic Syndr*. 2019 Oct 1;82(2):166-74. doi: 10.1097/QAI.0000000000002125. PMID: 31335586.
- Hait EJ, Barendse RM, Arnold JH, et al. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. *J Pediatr Gastroenterol Nutr*. 2009 Jan;48(1):61-5. doi: 10.1097/MPG.0b013e31816d71d8. PMID: 19172125.
- Hald M, Carlsen K, Nordgaard-Lassen I, et al. Challenges and obstacles in the transition process through the eyes of the gastroenterologist. *Eur J Gastroenterol Hepatol*. 2019 Apr;31(4):486-93. doi: 10.1097/MEG.0000000000001359. PMID: 30688664.
- Han AX, Whitehouse SR, Tsai S, et al. Perceptions of the family physician from adolescents and their caregivers preparing to transition to adult care. *BMC Fam Pract*. 2018 Aug 23;19(1):140. doi: 10.1186/s12875-018-0830-6. PMID: 30134842.
- Hart LC, Deusen RV, Gonzaga AM. Pediatric residents' attitudes and practice patterns regarding transition to adult-oriented care. *J Commun Healthc*. 2017;10(2):149-55. doi: 10.1080/17538068.2017.1313479. PMID: 30197665.
- Hart LC, Mouw MS, Teal R, et al. What Care Models Have Generalists Implemented to Address Transition from Pediatric to Adult Care?: a Qualitative Study. *J Gen Intern Med*. 2019 Oct;34(10):2083-90. doi: 10.1007/s11606-019-05226-w. PMID: 31410810.
- Hart LC, Pollock M, Hill S, et al. Association of Transition Readiness to Intentional Self-Regulation and Hopeful Future Expectations in Youth With Illness. *Acad Pediatr*. 2017 May - Jun;17(4):450-5. doi: 10.1016/j.acap.2016.12.004. PMID: 27979748.
- Hart LC, van Tilburg MAL, Campbell R, Jr., et al. Association of youth health care transition readiness to role overload among parents of children with chronic illness. *Child Care Health Dev*. 2019 Jul;45(4):577-84. doi: 10.1111/cch.12683. PMID: 31049987.
- Hasan R, Maloney L, Solondz K, et al. Transition Task Force: Early efforts towards comprehensive pediatric to adult transition services in an academic medical center. *Journal of Transition Medicine*. 2020;2(1). doi: 10.1515/jtm-2020-0006. PMID: 2006858170.
- Hashmi SK, Lee SJ, Savani BN, et al. ASBMT Practice Guidelines Committee Survey on Long-Term Follow-Up Clinics for Hematopoietic Cell Transplant Survivors. *Biol Blood Marrow Transplant*. 2018 Jun;24(6):1119-24. doi: 10.1016/j.bbmt.2018.03.023. PMID: 29608957.
- Heldman MR, Sohn MW, Gordon EJ, et al. National survey of adult transplant hepatologists on the pediatric-to-adult care transition after liver transplantation. *Liver Transpl*. 2015 Feb;21(2):213-23. doi: 10.1002/lt.24044. PMID: 25378291.
- Henderson JL, Chaim G, Luca S, et al. Program manager perspectives on the service system to meet the needs of youth with concurrent disorders: findings from a Canadian national survey. *BMC Health Serv Res*. 2015 Sep 18;15:393. doi: 10.1186/s12913-015-1060-4. PMID: 26384786.
- Heron LM, Agarwal R, Greenup J, et al. Disparities in healthcare transition support received by adolescents with special healthcare needs. *J Appl Res Intellect Disabil*. 2020 Mar;33(2):180-92. doi: 10.1111/jar.12658. PMID: 31694076.

- Hettel D, Tran C, Szymanski K, et al. Lost in transition: Patient-identified barriers to adult urological spina bifida care. *J Pediatr Urol*. 2018 Dec;14(6):535 e1- e4. doi: 10.1016/j.jpurol.2018.06.009. PMID: 30061086.
- Hilderson D, Eyckmans L, Van der Elst K, et al. Transfer from paediatric rheumatology to the adult rheumatology setting: experiences and expectations of young adults with juvenile idiopathic arthritis. *Clin Rheumatol*. 2013 May;32(5):575-83. doi: 10.1007/s10067-012-2135-9. PMID: 23238606.
- Hilderson D, Moons P, Westhovens R, et al. Attitudes of rheumatology practitioners toward transition and transfer from pediatric to adult healthcare. *Rheumatol Int*. 2012 Dec;32(12):3887-96. doi: 10.1007/s00296-011-2273-4. PMID: 22193217.
- Hilderson D, Saidi AS, Van Deyk K, et al. Attitude toward and current practice of transfer and transition of adolescents with congenital heart disease in the United States of America and Europe. *Pediatr Cardiol*. 2009 Aug;30(6):786-93. doi: 10.1007/s00246-009-9442-1. PMID: 19365651.
- Hilton D, Jepson S. Evolution of a youth work service in hospital. *Nurs Child Young People*. 2012 Jul;24(6):14-8. doi: 10.7748/ncyp2012.07.24.6.14.c9187. PMID: 22880309.
- Hislop J, Mason H, Parr JR, et al. Views of Young People With Chronic Conditions on Transition From Pediatric to Adult Health Services. *J Adolesc Health*. 2016 Sep;59(3):345-53. doi: 10.1016/j.jadohealth.2016.04.004. PMID: 27287962.
- Holtz BE, Mitchell KM, Holmstrom AJ, et al. Teen and parental perspectives regarding transition of care in type 1 diabetes. *Children and Youth Services Review*. 2020;110:N.PAG-N.PAG. doi: 10.1016/j.childyouth.2020.104800. PMID: 141754827.
- Honda M, Iijima K, Ishikura K, et al. The problem of transition from pediatric to adult healthcare in patients with steroid-sensitive nephrotic syndrome (SSNS): a survey of the experts. *Clin Exp Nephrol*. 2014 Dec;18(6):939-43. doi: 10.1007/s10157-014-0941-x. PMID: 24488117.
- Houston Y, O Lindsay J, Jenkins H, et al. Perspectives of transition care in inflammatory bowel disease: a survey. *Gastrointestinal Nursing*. 2012;10(1):30-5. doi: 10.12968/gasn.2012.10.1.30. PMID: 73984572.
- Howard AF, Kazanjian A, Pritchard S, et al. Healthcare system barriers to long-term follow-up for adult survivors of childhood cancer in British Columbia, Canada: a qualitative study. *J Cancer Surviv*. 2018 Jun;12(3):277-90. doi: 10.1007/s11764-017-0667-3. PMID: 29222704.
- Howard SW, Zhang Z, Buchanan P, et al. The Effect of a Comprehensive Care Transition Model on Cost and Utilization for Medically Complex Children With Cerebral Palsy. *J Pediatr Health Care*. 2017 Nov - Dec;31(6):634-47. doi: 10.1016/j.pedhc.2017.04.017. PMID: 28622983.
- Howland S, Fisher K. Looking through the patient lens - Improving best practice for young people with juvenile idiopathic arthritis transitioning into adult care. *Springerplus*. 2015;4:111. doi: 10.1186/s40064-015-0888-8. PMID: 25774337.
- Hsieh MH, Wood HM, Dicianno BE, et al. Research Needs for Effective Transition in Lifelong Care of Congenital Genitourinary Conditions: A Workshop Sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases. *Urology*. 2017 May;103:261-71. doi: 10.1016/j.urology.2016.12.052. PMID: 28163084.
- Huang J, Porterfield SL. Changes in health insurance coverage and health care access as teens with disabilities transition to adulthood. *Disabil Health J*. 2019 Oct;12(4):551-6. doi: 10.1016/j.dhjo.2019.06.009. PMID: 31285172.
- Huang JS, Gottschalk M, Pian M, et al. Transition to adult care: systematic assessment of adolescents with chronic illnesses and their medical teams. *J Pediatr*. 2011 Dec;159(6):994-8 e2. doi: 10.1016/j.jpeds.2011.05.038. PMID: 21784450.
- Hussen SA, Chakraborty R, Knezevic A, et al. Transitioning young adults from paediatric to adult care and the HIV care continuum in Atlanta, Georgia, USA: a retrospective cohort study. *J Int AIDS Soc*. 2017 Sep 1;20(1):21848. doi: 10.7448/IAS.20.1.21848. PMID: 28872281.
- Ishizaki Y, Maru M, Higashino H, et al. The transition of adult patients with childhood-onset chronic diseases from pediatric to adult healthcare systems: a survey of the perceptions of Japanese pediatricians and child health nurses. *Biopsychosoc Med*. 2012 Mar 20;6:8. doi: 10.1186/1751-0759-6-8. PMID: 22433283.

- Iversen E, Kolltveit BH, Hernar I, et al. Transition from paediatric to adult care: a qualitative study of the experiences of young adults with type 1 diabetes. *Scand J Caring Sci*. 2019 Sep;33(3):723-30. doi: 10.1111/scs.12668. PMID: 30866071.
- Jackson K. Help for parents in supporting their children through transition. *Community Living*. 2008;21(4):4-. PMID: 105770583.
- Jeganathan J, Lee CH, Rahme A, et al. Pediatric-to-adult Transition and Medication Adherence in Patients with Inflammatory Bowel Disease. *Inflamm Bowel Dis*. 2017 Jul;23(7):1065-70. doi: 10.1097/MIB.0000000000001114. PMID: 28498154.
- Jensen PT, Koh K, Cash RE, et al. Inpatient mortality in transition-aged youth with rheumatic disease: an analysis of the National Inpatient Sample. *Pediatr Rheumatol Online J*. 2020 Mar 30;18(1):27. doi: 10.1186/s12969-020-0416-4. PMID: 32228709.
- Jensen PT, Paul GV, LaCount S, et al. Assessment of transition readiness in adolescents and young adults with chronic health conditions. *Pediatr Rheumatol Online J*. 2017 Sep 9;15(1):70. doi: 10.1186/s12969-017-0197-6. PMID: 28888223.
- Jin YT, Chen CM, Chien WC. Factors influencing transitional care from adolescents to young adults with cancer in Taiwan: A population-based study. *BMC Pediatr*. 2016 Aug 2;16(1):122. doi: 10.1186/s12887-016-0657-z. PMID: 27484184.
- Jones N, Gius B, Daley T, et al. Coordinated Specialty Care Discharge, Transition, and Step-Down Policies, Practices, and Concerns: Staff and Client Perspectives. *Psychiatr Serv*. 2020 May 1;71(5):487-97. doi: 10.1176/appi.ps.201900514. PMID: 32188363.
- Kaehne A, Beyer S. Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability. *J Intellect Disabil Res*. 2014 Jul;58(7):603-13. doi: 10.1111/jir.12058. PMID: 23796061.
- Kakkar F, Van der Linden D, Valois S, et al. Health outcomes and the transition experience of HIV-infected adolescents after transfer to adult care in Quebec, Canada. *BMC Pediatr*. 2016 Jul 26;16(1):109. doi: 10.1186/s12887-016-0644-4. PMID: 27457719.
- Kalinyak CM, Gary FA, Killion CM, et al. The Transition to Independence Process: Promoting Self-Efficacy in Transition-Aged Youths. *J Psychosoc Nurs Ment Health Serv*. 2016 Feb 1;54(2):49-53. doi: 10.3928/02793695-20160119-06. PMID: 27648874.
- Kane DJ, Kasehagen L, Punyko J, et al. What factors are associated with state performance on provision of transition services to CSHCN? *Pediatrics*. 2009 Dec;124 Suppl 4(S):S375-83. doi: 10.1542/peds.2009-1255H. PMID: 19948602.
- Kanter J, Bhor M, Li X, et al. High Healthcare Utilization in Adolescents with Sickle Cell Disease Prior to Transition to Adult Care: A Retrospective Study. *J Health Econ Outcomes Res*. 2019;6(3):174-84. doi: 10.36469/10512. PMID: 32685589.
- Kennedy VL, Mellor KL, Brophy J, et al. Transition from Pediatric to Adult HIV Care for Young Women Living with HIV. *J Int Assoc Provid AIDS Care*. 2020 Jan-Dec;19:2325958220903574. doi: 10.1177/2325958220903574. PMID: 32207355.
- Kenney LB, Melvin P, Fishman LN, et al. Transition and transfer of childhood cancer survivors to adult care: A national survey of pediatric oncologists. *Pediatr Blood Cancer*. 2017 Feb;64(2):346-52. doi: 10.1002/pbc.26156. PMID: 27463688.
- Kerr H, Price J, Nicholl H, et al. Facilitating transition from children's to adult services for young adults with life-limiting conditions (TASYL): Programme theory developed from a mixed methods realist evaluation. *Int J Nurs Stud*. 2018 Oct;86:125-38. doi: 10.1016/j.ijnurstu.2018.06.015. PMID: 30005314.
- Khemka I, Hickson L, Mallory SB. Evaluation of a Decision-Making Curriculum for Teaching Adolescents with Disabilities to Resist Negative Peer Pressure. *J Autism Dev Disord*. 2016 Jul;46(7):2372-84. doi: 10.1007/s10803-016-2770-0. PMID: 26993636.
- Kim G, Choi EK, Kim HS, et al. Healthcare Transition Readiness, Family Support, and Self-management Competency in Korean Emerging Adults with Type 1 Diabetes Mellitus. *J Pediatr Nurs*. 2019 Sep - Oct;48:e1-e7. doi: 10.1016/j.pedn.2019.03.012. PMID: 30929981.
- Kirk J, Clayton P. Specialist services and transitional care in paediatric endocrinology in the UK and Ireland. *Clin Endocrinol (Oxf)*. 2006 Jul;65(1):59-63. doi: 10.1111/j.1365-2265.2006.02546.x. PMID: 16817820.
- Kiziler E, Yildiz D, Eren Fidanci B. Validation of Transition Readiness Assessment Questionnaire in Turkish Adolescents with Diabetes. *Balkan Med J*. 2018 Jan 20;35(1):93-100. doi: 10.4274/balkanmedj.2016.1415. PMID: 29039345.

- Klodnick VV, Clark HBR, Johnson RP, et al. Developing quality assurance practices and measures for implementing and sustaining the Transition to Independence Process (TIP) model. *Psychiatr Rehabil J*. 2019 Mar;42(1):71-8. doi: 10.1037/prj0000324. PMID: 30265068.
- Klodnick VV, Malina C, Fagan MA, et al. Meeting the Developmental Needs of Young Adults Diagnosed with Serious Mental Health Challenges: the Emerge Model. *J Behav Health Serv Res*. 2021 Jan;48(1):77-92. doi: 10.1007/s11414-020-09699-0. PMID: 32394412.
- Klostermann NR, McAlpine L, Wine E, et al. Assessing the Transition Intervention Needs of Young Adults With Inflammatory Bowel Diseases. *J Pediatr Gastroenterol Nutr*. 2018 Feb;66(2):281-5. doi: 10.1097/MPG.0000000000001677. PMID: 28753177.
- Kolehmainen N, McCafferty S, Maniatopoulos G, et al. What constitutes successful commissioning of transition from children's to adults' services for young people with long-term conditions and what are the challenges? An interview study. *BMJ Paediatr Open*. 2017 Sep 11;1:e000085. doi: 10.1136/bmjpo-2017-000085. PMID: 29119142.
- Kollengode MS, Daniels CJ, Zaidi AN. Loss of follow-up in transition to adult CHD: a single-centre experience. *Cardiol Young*. 2018 Aug;28(8):1001-8. doi: 10.1017/S1047951118000690. PMID: 29966538.
- Koumakis E, Cormier C. Organisation de la prise en charge d'une maladie osseuse constitutionnelle lors de la transition de l'enfance à l'âge adulte. *Revue du Rhumatisme Monographies*. 2019;86(1):64-8. doi: 10.1016/j.monrhu.2018.10.001. PMID: 2001285259.
- Kramer JM. Identifying and Evaluating the Therapeutic Strategies Used During a Manualized Self-Advocacy Intervention for Transition-Age Youth. *OTJR (Thorofare N J)*. 2015 Jan;35(1):23-33. doi: 10.1177/1539449214564146. PMID: 26069464.
- Krawczuk-Rybak M, Paszkowska A. Przekazywanie pacjentów leczonych w dzieciństwie z powodu chorób nowotworowych do systemu opieki dla dorosłych. *Pediatr Pol*. 2017;92(5):518-24. doi: 10.1016/j.pepo.2017.05.014. PMID: 616841433.
- Kripke C, Giammona M, Fox A, et al. The CART model: organized systems of care for transition age youth and adults with developmental disabilities. *International Journal of Child & Adolescent Health*. 2010;3(4):473-7. PMID: 104987750.
- Kroner BL, Bumbut A, Berl MM, et al. Parental perspectives on provider adherence to AAN epilepsy quality measures in rural and urban tertiary care centers. *Epilepsy Behav*. 2019 Mar;92:256-9. doi: 10.1016/j.yebeh.2019.01.009. PMID: 30731289.
- Kronschnabel K, Puga A, Eaton L. Preparing to transition from pediatric to adult HIV-related care: qualitative assessment and model development. *Vulnerable Children and Youth Studies*. 2016;11(2):146-59. doi: 10.1080/17450128.2016.1189020. PMID: 116263140.
- Kuhlthau KA, Warfield ME, Hurson J, et al. Pediatric provider's perspectives on the transition to adult health care for youth with autism spectrum disorder: current strategies and promising new directions. *Autism*. 2015 Apr;19(3):262-71. doi: 10.1177/1362361313518125. PMID: 24497626.
- Kulandaivelu Y, Laloo C, Ward R, et al. Exploring the Needs of Adolescents With Sickle Cell Disease to Inform a Digital Self-Management and Transitional Care Program: Qualitative Study. *JMIR Pediatr Parent*. 2018 Sep 25;1(2):e11058. doi: 10.2196/11058. PMID: 31518307.
- Kumagai H, Kudo T, Uchida K, et al. Adult gastroenterologists' views on transitional care: Results from a survey. *Pediatr Int*. 2019 Aug;61(8):817-22. doi: 10.1111/ped.13912. PMID: 31206932.
- Kung TH, Wallace ML, Snyder KL, et al. South African healthcare provider perspectives on transitioning adolescents into adult HIV care. *S Afr Med J*. 2016 Jul 6;106(8):804-8. doi: 10.7196/SAMJ.2016.v106i8.10496. PMID: 27499409.
- Kwarteng-Siaw M, Paintsil V, Toboh CK, et al. Assessment of Transition Readiness in Adolescents with Sickle Cell Disease and their Caretakers, A single institution experience. *Int J Hematol Res*. 2017;3(1):171-9. doi: 10.17554/j.issn.2409-3548.2017.03.47. PMID: 30035240.
- Kyselyova G, Martsynovska V, Volokha A, et al. Young people in HIV care in Ukraine: a national survey on characteristics and service provision. *F1000Res*. 2019;8:323. doi: 10.12688/f1000research.18573.2. PMID: 31105935.
- LaPorte TM, Haber MG, Malloy JM. Wraparound Team Composition, Youth Self-determination, and Youth Satisfaction in Transition Services. *J Behav Health Serv Res*. 2016 Oct;43(4):611-29. doi: 10.1007/s11414-014-9434-7. PMID: 25146241.

- Lapp V, Chase SK. How Do Youth with Cystic Fibrosis Perceive Their Readiness to Transition to Adult Healthcare Compared to Their Caregivers' Views? *J Pediatr Nurs*. 2018 Nov - Dec;43:104-10. doi: 10.1016/j.pedn.2018.09.012. PMID: 30473151.
- Lariviere-Bastien D, Bell E, Majnemer A, et al. Perspectives of young adults with cerebral palsy on transitioning from pediatric to adult healthcare systems. *Semin Pediatr Neurol*. 2013 Jun;20(2):154-9. doi: 10.1016/j.spen.2013.06.009. PMID: 23948690.
- LaRosa C, Glah C, Baluarte HJ, et al. Solid-organ transplantation in childhood: transitioning to adult health care. *Pediatrics*. 2011 Apr;127(4):742-53. doi: 10.1542/peds.2010-1232. PMID: 21382946.
- Larson JA, Doyle EA. Transitional Care for Young Adults With Congenital Heart Disease: A Case Study. *J Pediatr Health Care*. 2018 Mar - Apr;32(2):195-200. doi: 10.1016/j.pedhc.2017.10.005. PMID: 29290410.
- Lau SC, Azim E, Abdul Latiff Z, et al. Transition care readiness among patients in a tertiary paediatric department. *Med J Malaysia*. 2018 Dec;73(6):382-7. PMID: 30647208.
- Lawson EF, Hersh AO, Applebaum MA, et al. Self-management skills in adolescents with chronic rheumatic disease: A cross-sectional survey. *Pediatr Rheumatol Online J*. 2011 Dec 6;9(1):35. doi: 10.1186/1546-0096-9-35. PMID: 22145642.
- Lazaroff SM, Meara A, Tompkins MK, et al. How Do Health Literacy, Numeric Competencies, and Patient Activation Relate to Transition Readiness in Adolescents and Young Adults With Rheumatic Diseases? *Arthritis Care Res (Hoboken)*. 2019 Sep;71(9):1264-9. doi: 10.1002/acr.23739. PMID: 30156761.
- Le Roux E, Gottot S, Aupiais C, et al. Professional's Perspectives on Care Management of Young People with Perinatally Acquired HIV during Transition: A Qualitative Study in Adult Care Setting. *PLoS One*. 2017;12(1):e0169782. doi: 10.1371/journal.pone.0169782. PMID: 28114376.
- Le Roux E, Mellerio H, Jacquin P, et al. Practical generic guidelines for paediatric-to-adult transition for adolescents with chronic disease. *Eur J Public Health*. 2019 Jun 1;29(3):442-8. doi: 10.1093/eurpub/cky258. PMID: 30535247.
- Lincoln AK, Borg R, Delman J. Developing a community-based participatory research model to engage transition age youth using mental health service in research. *Fam Community Health*. 2015 Jan-Mar;38(1):87-97. doi: 10.1097/FCH.000000000000054. PMID: 25423247.
- Lindgren E, Soderberg S, Skar L. The gap in transition between child and adolescent psychiatry and general adult psychiatry. *J Child Adolesc Psychiatr Nurs*. 2013 May;26(2):103-9. doi: 10.1111/jcap.12027. PMID: 23607821.
- Lindgren E, Soderberg S, Skar L. Managing transition with support: experiences of transition from child and adolescent psychiatry to general adult psychiatry narrated by young adults and relatives. *Psychiatry J*. 2014;2014:457160. doi: 10.1155/2014/457160. PMID: 24829900.
- Lindgren E, Soderberg S, Skar L. Being a Parent to a Young Adult with Mental Illness in Transition to Adulthood. *Issues Ment Health Nurs*. 2016;37(2):98-105. doi: 10.3109/01612840.2015.1092621. PMID: 26864840.
- Lindsay S, Hoffman A. A complex transition: lessons learned as three young adults with complex care needs transition from an inpatient paediatric hospital to adult community residences. *Child Care Health Dev*. 2015 May;41(3):397-407. doi: 10.1111/cch.12203. PMID: 25271383.
- Loos S, Walia N, Becker T, et al. Lost in transition? Perceptions of health care among young people with mental health problems in Germany: a qualitative study. *Child Adolesc Psychiatry Ment Health*. 2018;12(1):41. doi: 10.1186/s13034-018-0249-9. PMID: 30093915.
- Lopez AD, Bradley-Klug KL, Quinn GP, et al. Adolescent Survivors of Childhood Cancer and Their Perspectives of the Transition to Early Survivorship: An Exploratory Qualitative Investigation. *Journal of Adolescent and Young Adult Oncology*. 2014;3(3):130-7. doi: 10.1089/jayao.2014.0001. PMID: 600035223.
- Lopez KN, Karlsten M, Bonaduce De Nigris F, et al. Understanding Age-based Transition Needs: Perspectives from Adolescents and Adults with Congenital Heart Disease. *Congenit Heart Dis*. 2015 Nov-Dec;10(6):561-71. doi: 10.1111/chd.12283. PMID: 26171927.

- Lotstein DS, Ghandour R, Cash A, et al. Planning for health care transitions: results from the 2005-2006 National Survey of Children With Special Health Care Needs. *Pediatrics*. 2009 Jan;123(1):e145-52. doi: 10.1542/peds.2008-1298. PMID: 19117836.
- Loukas KM, Raymond L, Perron AR, et al. Occupational transformation: Parental influence and social cognition of young adults with autism. *Work*. 2015;50(3):457-63. doi: 10.3233/WOR-141956. PMID: 25248535.
- Lulu S, Julian L, Shapiro E, et al. Treatment adherence and transitioning youth in pediatric multiple sclerosis. *Mult Scler Relat Disord*. 2014 Nov;3(6):689-95. doi: 10.1016/j.msard.2014.09.088. PMID: 25798373.
- Lundin CS, Danielson E, Ohrn I. Handling the transition of adolescents with diabetes: participant observations and interviews with care providers in paediatric and adult diabetes outpatient clinics. *Int J Integr Care*. 2007 Feb 15;7:e05. PMID: 17377641.
- Luque Ramos A, Hoffmann F, Albrecht K, et al. Transition to adult rheumatology care is necessary to maintain DMARD therapy in young people with juvenile idiopathic arthritis. *Semin Arthritis Rheum*. 2017 Oct;47(2):269-75. doi: 10.1016/j.semarthrit.2017.05.003. PMID: 28583690.
- MacLean WE, Jr., Foley GV, Ruccione K, et al. Transitions in the care of adolescent and young adult survivors of childhood cancer. *Cancer*. 1996 Sep 15;78(6):1340-4. doi: 10.1002/(SICI)1097-0142(19960915)78:6<1340::AID-CNCR25>3.0.CO;2-#. PMID: 8826960.
- Maddux MH, Drovetta M, Hasenkamp R, et al. Using a Mixed-method Approach to Develop a Transition Program for Young Adults With Inflammatory Bowel Disease. *J Pediatr Gastroenterol Nutr*. 2020 Feb;70(2):195-9. doi: 10.1097/MPG.0000000000002478. PMID: 31978016.
- Maddux MH, Ricks S, Bass J. Preparing Patients for Transfer of Care: Practices of Primary Care Pediatricians. *J Community Health*. 2015 Aug;40(4):750-5. doi: 10.1007/s10900-015-9994-3. PMID: 25666868.
- Maddux MH, Ricks S, Bass J. Patient and Caregiver Perspectives on Transition and Transfer. *Clin Pediatr (Phila)*. 2017 Mar;56(3):278-83. doi: 10.1177/0009922816649590. PMID: 27178828.
- Manias E, Gerdtz M, Williams A, et al. Complexities of medicines safety: communicating about managing medicines at transition points of care across emergency departments and medical wards. *J Clin Nurs*. 2015 Jan;24(1-2):69-80. doi: 10.1111/jocn.12685. PMID: 25209739.
- Mannion ML, Xie F, Baddley J, et al. Analysis of health care claims during the peri-transfer stage of transition from pediatric to adult care among juvenile idiopathic arthritis patients. *Pediatr Rheumatol Online J*. 2016 Sep 5;14(1):49. doi: 10.1186/s12969-016-0107-3. PMID: 27596158.
- Marcer H, Finlay F, Baverstock A. ADHD and transition to adult services--the experience of community paediatricians. *Child Care Health Dev*. 2008 Sep;34(5):564-6. doi: 10.1111/j.1365-2214.2008.00857.x. PMID: 18796048.
- Marcoux S, Laverdiere C. Optimizing childhood oncology care transition from pediatric to adult settings: A survey of primary care physicians' and residents' perspectives. *Clin Invest Med*. 2020 Jun 28;43(2):E14-23. doi: 10.25011/cim.v43i2.33566. PMID: 32593272.
- Margolis R, Wiener L, Pao M, et al. Transition From Pediatric to Adult Care by Young Adults With Chronic Granulomatous Disease: The Patient's Viewpoint. *J Adolesc Health*. 2017 Dec;61(6):716-21. doi: 10.1016/j.jadohealth.2017.06.017. PMID: 28947348.
- Marshall SK, Stainton T, Wall JM, et al. Transition to Adulthood as a Joint Parent-Youth Project for Young Persons With Intellectual and Developmental Disabilities. *Intellect Dev Disabil*. 2018 Aug;56(4):263-77. doi: 10.1352/1934-9556-56.5.263. PMID: 30024849.
- Masese RV, Ramos JV, Rugalabamu L, et al. Challenges and facilitators of transition from adolescent to adult HIV care among young adults living with HIV in Moshi, Tanzania. *J Int AIDS Soc*. 2019 Oct;22(10):e25406. doi: 10.1002/jia2.25406. PMID: 31651089.
- Matsui T, Matsumoto T, Hirano F, et al. Survey of the awareness of adult rheumatologists regarding transitional care for patients with juvenile idiopathic arthritis in Japan. *Mod Rheumatol*. 2018 Nov;28(6):981-5. doi: 10.1080/14397595.2018.1430546. PMID: 29347862.

- Mayer K, Junge N, Goldschmidt I, et al. Psychosocial outcome and resilience after paediatric liver transplantation in young adults. *Clin Res Hepatol Gastroenterol*. 2019 Apr;43(2):155-60. doi: 10.1016/j.clinre.2018.08.017. PMID: 30737022.
- Mazzucato M, Visona Dalla Pozza L, Minichiello C, et al. The Epidemiology of Transition into Adulthood of Rare Diseases Patients: Results from a Population-Based Registry. *Int J Environ Res Public Health*. 2018 Oct 10;15(10). doi: 10.3390/ijerph15102212. PMID: 30309015.
- McCann L, Kearney N, Wengstrom Y. "It's just going to a new hospital ... that's it." Or is it? An experiential perspective on moving from pediatric to adult cancer services. *Cancer Nurs*. 2014 Sep-Oct;37(5):E23-31. doi: 10.1097/NCC.0b013e3182a40f99. PMID: 24145251.
- McClellan W, Klemp JR, Krebill H, et al. Understanding the functional late effects and informational needs of adult survivors of childhood cancer. *Oncol Nurs Forum*. 2013 May 1;40(3):254-62. doi: 10.1188/13.ONF.254-262. PMID: 23615138.
- McCurdy C, DiCenso A, Boblin S, et al. There to here: Young adult patients' perceptions of the process of transition from pediatric to adult transplant care. *Prog Transplant*. 2006;16(4):309-16. PMID: 44902090.
- McDonagh JE, Southwood TR, Shaw KL, et al. Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology (Oxford)*. 2004 Jun;43(6):737-43. doi: 10.1093/rheumatology/keh163. PMID: 14997008.
- McDowell ME, Litchman ML, Guo JW. The transition experiences of adolescents with type 1 diabetes from paediatric to adult care providers. *Child Care Health Dev*. 2020 Nov;46(6):692-702. doi: 10.1111/cch.12798. PMID: 32697881.
- McGhee Hassrick E, Shattuck P, Carley K. Network Measures of Collaborative Support for Young Adults With Autism. *Pediatrics*. 2018 Apr;141(Suppl 4):S287-S92. doi: 10.1542/peds.2016-4300E. PMID: 29610409.
- McKenzie RB, Sanders L, Bhattacharya J, et al. Health Care System Factors Associated with Transition Preparation in Youth with Special Health Care Needs. *Popul Health Manag*. 2019 Feb;22(1):63-73. doi: 10.1089/pop.2018.0027. PMID: 29957127.
- McLaren S, Belling R, Paul M, et al. 'Talking a different language': an exploration of the influence of organizational cultures and working practices on transition from child to adult mental health services. *BMC Health Serv Res*. 2013 Jul 3;13:254. doi: 10.1186/1472-6963-13-254. PMID: 23822089.
- McLaughlin SE, Diener-West M, Indurkha A, et al. Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices. *Pediatrics*. 2008 May;121(5):e1160-6. doi: 10.1542/peds.2007-2217. PMID: 18450860.
- McLoughlin A, Matthews C, Hickey TM. "They're kept in a bubble": Healthcare professionals' views on transitioning young adults with congenital heart disease from paediatric to adult care. *Child Care Health Dev*. 2018 Sep;44(5):736-45. doi: 10.1111/cch.12581. PMID: 29882316.
- McPherson M, Thaniel L, Minniti CP. Transition of patients with sickle cell disease from pediatric to adult care: Assessing patient readiness. *Pediatr Blood Cancer*. 2009 Jul;52(7):838-41. doi: 10.1002/pbc.21974. PMID: 19229973.
- McPherson M, Weissman G, Strickland BB, et al. Implementing community-based systems of services for children and youths with special health care needs: how well are we doing? *Pediatrics*. 2004 May;113(5 Suppl):1538-44. PMID: 15121923.
- Meaux JB, Green A, Nelson MK, et al. Transition to self-management after pediatric heart transplant. *Prog Transplant*. 2014 Sep;24(3):226-33. doi: 10.7182/pit2014911. PMID: 25193722.
- Mennito S, Hletko P, Ebeling M, et al. Adolescents with sickle cell disease in a rural community: are they ready to transition to adulthood? *South Med J*. 2014 Sep;107(9):578-82. doi: 10.14423/SMJ.0000000000000162. PMID: 25188623.
- Michalovic A, Anderson C, Thorstad K, et al. Exploring the Perceived Self-management Needs of Young Adults With Osteogenesis Imperfecta. *Clin Nurse Spec*. 2020 May/June;34(3):99-106. doi: 10.1097/NUR.0000000000000517. PMID: 32250991.
- Michel G, Gianinazzi ME, Vetsch J, et al. Physicians' experience with follow-up care of childhood cancer survivors - challenges and needs. *Swiss Med Wkly*. 2017;147:w14457. doi: 10.4414/smw.2017.14457. PMID: 28722079.

- Miles K, Edwards S, Clapson M. Transition from paediatric to adult services: experiences of HIV-positive adolescents. *AIDS Care*. 2004 Apr;16(3):305-14. doi: 10.1080/09540120410001665312. PMID: 15203424.
- Mitchell F. Facilitators and barriers to informed choice in self-directed support for young people with disability in transition. *Health Soc Care Community*. 2015 Mar;23(2):190-9. doi: 10.1111/hsc.12137. PMID: 25233846.
- Miyamae T, Takei S, Itoh Y, et al. Survey of attitudes of non-pediatric rheumatologists among councilors of the Japan College of Rheumatology regarding transitional care. *Mod Rheumatol*. 2017 Nov;27(6):1047-50. doi: 10.1080/14397595.2017.1285846. PMID: 28165841.
- Miyoshi Y, Yorifuji T, Shimizu C, et al. A nationwide questionnaire survey targeting Japanese pediatric endocrinologists regarding transitional care in childhood, adolescent, and young adult cancer survivors. *Clin Pediatr Endocrinol*. 2020;29(2):55-62. doi: 10.1297/cpe.29.55. PMID: 32313373.
- Mondal TK, Muddaluru V, Jaafar A, et al. Transition of adolescents with congenital heart disease from pediatric to adult congenital cardiac care: lessons from a retrospective cohort study. *Journal of Transition Medicine*. 2020;2(1). doi: 10.1515/jtm-2019-0003. PMID: 2005359784.
- Moola FJ, Norman ME. 'Down the rabbit hole': enhancing the transition process for youth with cystic fibrosis and congenital heart disease by re-imagining the future and time. *Child Care Health Dev*. 2011 Nov;37(6):841-51. doi: 10.1111/j.1365-2214.2011.01317.x. PMID: 22007984.
- Moons P, Pinxten S, Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health*. 2009 Apr;44(4):316-22. doi: 10.1016/j.jadohealth.2008.11.007. PMID: 19306789.
- Morsa M, Lombrail P, Boudailliez B, et al. A qualitative study on the educational needs of young people with chronic conditions transitioning from pediatric to adult care. *Patient Prefer Adherence*. 2018;12:2649-60. doi: 10.2147/PPA.S184991. PMID: 30587937.
- Mosallam RA, Metwally S. Patients' views on the quality of transitional care at a health insurance hospital in Alexandria, Egypt. *J Egypt Public Health Assoc*. 2014 Aug;89(2):74-80. doi: 10.1097/01.EPX.0000452045.65890.65. PMID: 25162738.
- Mulchan SS, Valenzuela JM, Crosby LE, et al. Applicability of the SMART Model of Transition Readiness for Sickle-Cell Disease. *J Pediatr Psychol*. 2016 Jun;41(5):543-54. doi: 10.1093/jpepsy/jsv120. PMID: 26717957.
- Munson MR, Cole A, Stanhope V, et al. Cornerstone program for transition-age youth with serious mental illness: study protocol for a randomized controlled trial. *Trials*. 2016 Nov 8;17(1):537. doi: 10.1186/s13063-016-1654-0. PMID: 27825381.
- Mutze U, Roth A, Weigel JF, et al. Transition of young adults with phenylketonuria from pediatric to adult care. *J Inher Metab Dis*. 2011 Jun;34(3):701-9. doi: 10.1007/s10545-011-9284-x. PMID: 21305352.
- Nabbout R, Teng T, Chemaly N, et al. Transition of patients with childhood onset epilepsy: Perspectives from pediatric and adult neurologists. *Epilepsy Behav*. 2020 Mar;104(Pt A):106889. doi: 10.1016/j.yebeh.2019.106889. PMID: 32028125.
- Nah SA, Ong CCP, Lie D, et al. Understanding Experiences of Youth Growing Up with Anorectal Malformation or Hirschsprung's Disease to Inform Transition Care: A Qualitative In-Depth Interview Study. *Eur J Pediatr Surg*. 2018 Feb;28(1):67-74. doi: 10.1055/s-0037-1605351. PMID: 28837998.
- Nakhla M, Bell LE, Wafa S, et al. Improving the transition from pediatric to adult diabetes care: the pediatric care provider's perspective in Quebec, Canada. *BMJ Open Diabetes Res Care*. 2017;5(1):e000390. doi: 10.1136/bmjdr-2017-000390. PMID: 28761657.
- Nandakumar BS, Fardell JE, Wakefield CE, et al. Attitudes and experiences of childhood cancer survivors transitioning from pediatric care to adult care. *Support Care Cancer*. 2018 Aug;26(8):2743-50. doi: 10.1007/s00520-018-4077-5. PMID: 29500581.
- Neu A, Losch-Binder M, Ehehalt S, et al. Follow-up of adolescents with diabetes after transition from paediatric to adult care: results of a 10-year prospective study. *Exp Clin Endocrinol Diabetes*. 2010 Jun;118(6):353-5. doi: 10.1055/s-0029-1246215. PMID: 20140851.

- Newlove-Delgado T, Blake S, Ford T, et al. Young people with attention deficit hyperactivity disorder in transition from child to adult services: a qualitative study of the experiences of general practitioners in the UK. *BMC Fam Pract*. 2019 Nov 20;20(1):159. doi: 10.1186/s12875-019-1046-0. PMID: 31747903.
- Newlove-Delgado T, Ford TJ, Stein K, et al. 'You're 18 now, goodbye': the experiences of young people with attention deficit hyperactivity disorder of the transition from child to adult services. *Emotional and Behavioural Difficulties*. 2018;23(3):296-309. doi: 10.1080/13632752.2018.1461476. PMID: 621755908.
- Nicholas DB, Kaufman M, Pinski M, et al. Examining the Transition from Child to Adult Care in Chronic Kidney Disease: An Open Exploratory Approach. *Nephrol Nurs J*. 2018 Nov-Dec;45(6):553-9. PMID: 30585710.
- Noyes J, Pritchard S, Pritchard A, et al. Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services. *J Adv Nurs*. 2018 Dec;74(12):2871-81. doi: 10.1111/jan.13811. PMID: 30047155.
- Nugent J, Gorman G, Erdie-Lalena CR. Disparities in Access to Healthcare Transition Services for Adolescents with Down Syndrome. *J Pediatr*. 2018 Jun;197:214-20. doi: 10.1016/j.jpeds.2018.01.072. PMID: 29571933.
- O'Brien G. Young adults with learning disabilities: a study of psychosocial functioning at transition to adult services. *Dev Med Child Neurol*. 2006 Mar;48(3):195-9. doi: 10.1017/S0012162206000429. PMID: 16483395.
- O'Connell B, Bailey S, Pearce J. Straddling the pathway from paediatrician to mainstream health care: transition issues experienced in disability care. *Aust J Rural Health*. 2003 Apr;11(2):57-63. doi: 10.1046/j.1440-1584.2003.00465.x. PMID: 12780495.
- O'Hara L, Holme I, Tah P, et al. A cross-cultural qualitative study of the ethical aspects in the transition from child mental health services to adult mental health services. *Child Adolesc Ment Health*. 2020 Sep;25(3):143-9. doi: 10.1111/camh.12377. PMID: 32516495.
- O'Sullivan-Oliveira J, Fernandes SM, Borges LF, et al. Transition of pediatric patients to adult care: an analysis of provider perceptions across discipline and role. *Pediatr Nurs*. 2014 May-Jun;40(3):113-20. PMID: 25134224.
- Ochiai R, Kato H, Misaki Y, et al. Preferences Regarding Transfer of Patients With Congenital Heart Disease Who Attend Children's Hospital. *Circ J*. 2019 Mar 25;83(4):824-30. doi: 10.1253/circj.CJ-18-1144. PMID: 30853685.
- Odling M, Andersson N, Hallberg J, et al. A Gap Between Asthma Guidelines and Management for Adolescents and Young Adults. *J Allergy Clin Immunol Pract*. 2020 Oct;8(9):3056-65 e2. doi: 10.1016/j.jaip.2020.05.034. PMID: 32522564.
- Odling M, Jonsson M, Janson C, et al. Lost in the transition from pediatric to adult healthcare? Experiences of young adults with severe asthma. *J Asthma*. 2020 Oct;57(10):1119-27. doi: 10.1080/02770903.2019.1640726. PMID: 31328590.
- Okumura MJ, Heisler M, Davis MM, et al. Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. *J Gen Intern Med*. 2008 Oct;23(10):1621-7. doi: 10.1007/s11606-008-0716-8. PMID: 18661191.
- Okumura MJ, Kerr EA, Cabana MD, et al. Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics*. 2010 Apr;125(4):e748-54. doi: 10.1542/peds.2008-3451. PMID: 20231189.
- Okumura MJ, Saunders M, Rehm RS. The Role of Health Advocacy in Transitions from Pediatric to Adult Care for Children with Special Health Care Needs: Bridging Families, Provider and Community Services. *J Pediatr Nurs*. 2015 Sep-Oct;30(5):714-23. doi: 10.1016/j.pedn.2015.05.015. PMID: 26228309.
- Onda Y, Nishimura R, Morimoto A, et al. Age at Transition from Pediatric to Adult Care Has No Relationship with Mortality for Childhood-Onset Type 1 Diabetes in Japan: Diabetes Epidemiology Research International (DERI) Mortality Study. *PLoS One*. 2016;11(3):e0150720. doi: 10.1371/journal.pone.0150720. PMID: 26937952.
- Onyewuenyi C, Ely A, Mak J. Exploring facilitators and barriers to condition self-management in young people with perinatal HIV. *HIV Nursing*. 2020;20(1):3-7. PMID: 142453800.
- Orentlicher M, Michaels C. Enlisting occupational therapy practitioners to support students in transition from school to adult life: part I. *Developmental Disabilities Special Interest Section Quarterly*. 2003;26(2):1-4. PMID: 106715377.

- Osterlund CS, Dosa NP, Arnott Smith C. Mother knows best: medical record management for patients with spina bifida during the transition from pediatric to adult care. *AMIA Annu Symp Proc.* 2005;580-4. PMID: 16779106.
- Ostlie IL, Dale O, Moller A. From childhood to adult life with juvenile idiopathic arthritis (JIA): a pilot study. *Disabil Rehabil.* 2007 Mar 30;29(6):445-52. doi: 10.1080/09638280600835994. PMID: 17364799.
- Packel L, Sood M, Gormley M, et al. A pilot study exploring the role of physical therapists and transition in care of pediatric patients with cystic fibrosis to the adult setting. *Cardiopulm Phys Ther J.* 2013 Mar;24(1):24-30. PMID: 23754936.
- Paine CW, Stollon NB, Lucas MS, et al. Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the perspectives of providers. *Inflamm Bowel Dis.* 2014 Nov;20(11):2083-91. doi: 10.1097/MIB.000000000000136. PMID: 25137417.
- Papagianni M, Stanhope R. How should we manage growth hormone deficiency in adolescence? Transition from paediatric to adult care. *J Pediatr Endocrinol Metab.* 2003 Jan;16(1):23-5. doi: 10.1515/jpem.2003.16.1.23. PMID: 12585336.
- Paramsothy P PhD MPH, Herron Ar PhD MA, Lamb MMP, et al. Health Care Transition Experiences of Males with Childhood-onset Duchenne and Becker Muscular Dystrophy: Findings from the Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet) Health Care Transitions and Other Life Experiences Survey. *PLoS Curr.* 2018 Aug 21;10. doi: 10.1371/currents.md.7de8a1c6798d7a48d38ea09bd624e1cd. PMID: 30210936.
- Park MJ, Adams SH, Irwin CE, Jr. Health care services and the transition to young adulthood: challenges and opportunities. *Acad Pediatr.* 2011 Mar-Apr;11(2):115-22. doi: 10.1016/j.acap.2010.11.010. PMID: 21296043.
- Patterson DL, Lanier C. Adolescent Health Transitions: Focus Group Study of Teens and Young Adults with Special Health Care Needs. *Fam Community Health.* 1999;22(2):43-58. doi: 10.1097/00003727-199907000-00006. PMID: 107208113.
- Peter NG, Forke CM, Ginsburg KR, et al. Transition from pediatric to adult care: internists' perspectives. *Pediatrics.* 2009 Feb;123(2):417-23. doi: 10.1542/peds.2008-0740. PMID: 19171604.
- Pickler L, Kellar-Guenther Y, Goldson E. Barriers to transition to adult care for youth with intellectual disabilities. *International Journal of Child & Adolescent Health.* 2010;3(4):575-84. PMID: 104987758.
- Pin TW, Chan WL, Chan CL, et al. Clinical transition for adolescents with developmental disabilities in Hong Kong: a pilot study. *Hong Kong Med J.* 2016 Oct;22(5):445-53. doi: 10.12809/hkmj154747. PMID: 27538386.
- Pinzon-Iregui MC, Ibanez G, Beck-Sague C, et al. "...like because you are a grownup, you do not need help": Experiences of Transition from Pediatric to Adult Care among Youth with Perinatal HIV Infection, Their Caregivers, and Health Care Providers in the Dominican Republic. *J Int Assoc Provid AIDS Care.* 2017 Nov/Dec;16(6):579-87. doi: 10.1177/2325957417729749. PMID: 28895487.
- Pitts, Mark. Attention deficit hyperactivity disorder: Transition to adult care. *Nurse Prescribing.* 2014;12(7):345-7. PMID: 103984386.
- Plotnicki L, Kohl CD, Hocker B, et al. The CERTAIN Registry: a novel, web-based registry and research platform for pediatric renal transplantation in Europe. *Transplant Proc.* 2013 May;45(4):1414-7. doi: 10.1016/j.transproceed.2013.01.007. PMID: 23726585.
- Por J, Golberg B, Lennox V, et al. Transition of care: health care professionals' view. *J Nurs Manag.* 2004 Sep;12(5):354-61. doi: 10.1111/j.1365-2834.2004.00428.x. PMID: 15315492.
- Porter JS, Graff JC, Lopez AD, et al. Transition from pediatric to adult care in sickle cell disease: perspectives on the family role. *J Pediatr Nurs.* 2014 Mar-Apr;29(2):158-67. doi: 10.1016/j.pedn.2013.10.002. PMID: 24188784.
- Porter JS, Wesley KM, Zhao MS, et al. Pediatric to Adult Care Transition: Perspectives of Young Adults With Sickle Cell Disease. *J Pediatr Psychol.* 2017 Oct 1;42(9):1016-27. doi: 10.1093/jpepsy/jsx088. PMID: 28637291.
- Prufe J, Dierks ML, Bethe D, et al. Transition structures and timing of transfer from paediatric to adult-based care after kidney transplantation in Germany: a qualitative study. *BMJ Open.* 2017 Jun 12;7(6):e015593. doi: 10.1136/bmjopen-2016-015593. PMID: 28606904.

- Psihogios AM, Schwartz LA, Deatrick JA, et al. Preferences for cancer survivorship care among adolescents and young adults who experienced healthcare transitions and their parents. *J Cancer Surviv*. 2019 Aug;13(4):620-31. doi: 10.1007/s11764-019-00781-x. PMID: 31273639.
- Quillen J, Bradley H, Calamaro C. Identifying Barriers Among Childhood Cancer Survivors Transitioning to Adult Health Care. *J Pediatr Oncol Nurs*. 2017 Jan/Feb;34(1):20-7. doi: 10.1177/1043454216631953. PMID: 26968661.
- Quinn SM, Ambrosino JM, Doyle EA, et al. Utility of Psychological Screening of Young Adults with Type 1 Diabetes Transitioning to Adult Providers. *Endocr Pract*. 2016 Sep;22(9):1104-10. doi: 10.4158/EP151190.OR. PMID: 27295017.
- Racine E, Lariviere-Bastien D, Bell E, et al. Respect for autonomy in the healthcare context: observations from a qualitative study of young adults with cerebral palsy. *Child Care Health Dev*. 2013 Nov;39(6):873-9. doi: 10.1111/cch.12018. PMID: 23198700.
- Ramchandani N, Way N, Melkus GD, et al. Challenges to Diabetes Self-Management in Emerging Adults With Type 1 Diabetes. *Diabetes Educ*. 2019 Oct;45(5):484-97. doi: 10.1177/0145721719861349. PMID: 31304878.
- Raunsbaek Knudsen L, de Thurah A, Bjerrum M. Transition from child to adult care in an outpatient clinic for adolescents with juvenile idiopathic arthritis: An inductive qualitative study. *Nurs Open*. 2018 Oct;5(4):546-54. doi: 10.1002/nop2.164. PMID: 30338100.
- Raymond JK, Duke DC, Shimomaeda L, et al. Looking forward to transition: perspectives on transition from pediatric to adult diabetes care. *Diabetes Manag (Lond)*. 2013 Jul;3(4). doi: 10.2217/dmt.13.27. PMID: 24416076.
- Reale L, Costantino MA, Sequi M, et al. Transition to Adult Mental Health Services for Young People With ADHD. *J Atten Disord*. 2018 Apr;22(6):601-8. doi: 10.1177/1087054714560823. PMID: 25525158.
- Reilly NR, Hammer ML, Ludvigsson JF, et al. Frequency and Predictors of Successful Transition of Care for Young Adults With Childhood Celiac Disease. *J Pediatr Gastroenterol Nutr*. 2020 Feb;70(2):190-4. doi: 10.1097/MPG.0000000000002568. PMID: 31978015.
- Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics*. 2005 Jan;115(1):112-20. doi: 10.1542/peds.2004-1321. PMID: 15629990.
- Ritholz MD, Wolpert H, Beste M, et al. Patient-provider relationships across the transition from pediatric to adult diabetes care: a qualitative study. *Diabetes Educ*. 2014 Jan-Feb;40(1):40-7. doi: 10.1177/0145721713513177. PMID: 24258251.
- Robertson LP, McDonagh JE, Southwood TR, et al. Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. *Ann Rheum Dis*. 2006 Jan;65(1):74-80. doi: 10.1136/ard.2004.032292. PMID: 15994281.
- Robinson E. Being diagnosed with type 1 diabetes during adolescence. How do young people develop a healthy understanding of diabetes? *Practical Diabetes*. 2015;32(9):339-44a. doi: 10.1002/pdi.1986. PMID: 111244156.
- Rojewski JW. A rural-based transition model for students with learning disabilities: a demonstration. *J Learn Disabil*. 1989 Dec;22(10):613-20. doi: 10.1177/002221948902201005. PMID: 2592864.
- Rosen D, Annunziato R, Colombel JF, et al. Transition of Inflammatory Bowel Disease Care: Assessment of Transition Readiness Factors and Disease Outcomes in a Young Adult Population. *Inflamm Bowel Dis*. 2016 Mar;22(3):702-8. doi: 10.1097/MIB.0000000000000633. PMID: 26841222.
- Roth JD, Szymanski KM, Cain MP, et al. Factors impacting transition readiness in young adults with neuropathic bladder. *J Pediatr Urol*. 2020 Feb;16(1):45 e1- e7. doi: 10.1016/j.jpuro.2019.10.017. PMID: 31761696.
- Rozkalne Z, Mukans M, Vetra A. Transition-Age Young Adults with Cerebral Palsy: Level of Participation and the Influencing Factors. *Medicina (Kaunas)*. 2019 Nov 14;55(11). doi: 10.3390/medicina55110737. PMID: 31739609.
- Ruble L, McGrew JH, Snell-Rood C, et al. Adapting COMPASS for youth with ASD to improve transition outcomes using implementation science. *Sch Psychol*. 2019 Mar;34(2):187-200. doi: 10.1037/spq0000281. PMID: 30284887.
- Rumrill P, Wehman P, Cimera R, et al. Vocational Rehabilitation Services and Outcomes for Transition-Age Youth With Traumatic Brain Injuries. *J Head Trauma Rehabil*. 2016 Jul-Aug;31(4):288-95. doi: 10.1097/HTR.000000000000186. PMID: 26360004.

- Rutishauser C, Sawyer SM, Ambresin AE. Transition of young people with chronic conditions: a cross-sectional study of patient perceptions before and after transfer from pediatric to adult health care. *Eur J Pediatr*. 2014 Aug;173(8):1067-74. doi: 10.1007/s00431-014-2291-9. PMID: 24610395.
- Sagar N, Leithead JA, Lloyd C, et al. Pediatric Liver Transplant Recipients Who Undergo Transfer to the Adult Healthcare Service Have Good Long-Term Outcomes. *Am J Transplant*. 2015 Jul;15(7):1864-73. doi: 10.1111/ajt.13184. PMID: 25707583.
- Sanchez Sanchez C, Tolin Hernani MDM, Alvarez Calatayud G, et al. Status of transition care in inflammatory bowel disease in Spain. Different medical perspectives. *Rev Esp Enferm Dig*. 2019 Nov;111(11):833-8. doi: 10.17235/reed.2019.6310/2019. PMID: 31566409.
- Sanders C, Hall J, Sanders C, et al. Involving Individuals with Disorders of Sex Development and Their Parents in Exploring New Models of Shared Learning: Proceedings from a DSDnet COST Action Workshop. *Sex Dev*. 2018 Jun 23. doi: 10.1159/000490081. PMID: 29936513.
- Sattoe JN, Hilberink SR, Peeters MA, et al. 'Skills for growing up': supporting autonomy in young people with kidney disease. *J Ren Care*. 2014 Jun;40(2):131-9. doi: 10.1002/jorc.12046. PMID: 24373148.
- Savage R, Niemann G. Transition services: building a bridge between adolescence and young adulthood. *Brain Injury Source*. 2001;5(2):24-30. PMID: 106929811.
- Sawicki GS, Garvey KC, Toomey SL, et al. Development and Validation of the Adolescent Assessment of Preparation for Transition: A Novel Patient Experience Measure. *J Adolesc Health*. 2015 Sep;57(3):282-7. doi: 10.1016/j.jadohealth.2015.06.004. PMID: 26299555.
- Sawicki GS, Kelemen S, Weitzman ER. Ready, set, stop: mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents. *Clin Pediatr (Phila)*. 2014 Oct;53(11):1062-8. doi: 10.1177/0009922814541169. PMID: 25006112.
- Sawicki GS, Ostrenga J, Petren K, et al. Risk Factors for Gaps in Care during Transfer from Pediatric to Adult Cystic Fibrosis Programs in the United States. *Ann Am Thorac Soc*. 2018 Feb;15(2):234-40. doi: 10.1513/AnnalsATS.201705-357OC. PMID: 29220199.
- Sawicki GS, Whitworth R, Gunn L, et al. Receipt of health care transition counseling in the national survey of adult transition and health. *Pediatrics*. 2011 Sep;128(3):e521-9. doi: 10.1542/peds.2010-3017. PMID: 21824879.
- Scal P, Evans T, Blozis S, et al. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health*. 1999 Apr;24(4):259-64. doi: 10.1016/s1054-139x(98)00127-x. PMID: 10227345.
- Schraeder K, Dimitropoulos G, McBrien K, et al. Perspectives from primary health care providers on their roles for supporting adolescents and young adults transitioning from pediatric services. *BMC Fam Pract*. 2020 Jul 13;21(1):140. doi: 10.1186/s12875-020-01189-8. PMID: 32660598.
- Schraeder K, Nettel-Aguirre A, Mackie A, et al. Identifying a retrospective cohort of adolescents with chronic health conditions from a paediatric hospital prior to transfer to adult care: the Calgary Transition Cohort. *BMJ Open*. 2019 May 5;9(5):e027045. doi: 10.1136/bmjopen-2018-027045. PMID: 31061046.
- Schraeder KE, Reid GJ. Who Should Transition? Defining a Target Population of Youth with Depression and Anxiety That Will Require Adult Mental Health Care. *J Behav Health Serv Res*. 2017 Apr;44(2):316-30. doi: 10.1007/s11414-015-9495-2. PMID: 26860728.
- Schwartz LA, Tuchman LK, Hobbie WL, et al. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Health Dev*. 2011 Nov;37(6):883-95. doi: 10.1111/j.1365-2214.2011.01282.x. PMID: 22007989.
- Scott L, Vallis TM, Charette M, et al. Transition of care: Researching the needs of young adults with type 1 diabetes. *Canadian Journal of Diabetes*. 2005;29(3):203-10. PMID: 43741136.
- Seo H, Shogren KA, Wehmeyer ML, et al. The Impact of Medical/Behavioral Support Needs on the Supports Needed by Adolescents With Intellectual Disability to Participate in Community Life. *Am J Intellect Dev Disabil*. 2017 Mar;122(2):173-91. doi: 10.1352/1944-7558-122.2.173. PMID: 28257240.
- Serras I, Oliveira JA, Pereira L, et al. Cystic fibrosis - How we reach adult life. *Pulmonology*. 2019 Jan - Feb;25(1):60-1. doi: 10.1016/j.pulmoe.2019.02.001. PMID: 30772263.

- Shamburger A, Rothrock J, Sizemore R, Woodrow Wilson Rehabilitation Center's Life Skills Transition Program. *Contemporary Rehab*. 2010;66(4):1-6. PMID: 105111450.
- Shanske S, Arnold J, Carvalho M, et al. Social workers as transition brokers: facilitating the transition from pediatric to adult medical care. *Soc Work Health Care*. 2012;51(4):279-95. doi: 10.1080/00981389.2011.638419. PMID: 22489554.
- Shaw KL, Baldwin L, Heath G. 'A confident parent breeds a confident child': Understanding the experience and needs of parents whose children will transition from paediatric to adult care. *J Child Health Care*. 2021 Jun;25(2):305-19. doi: 10.1177/1367493520936422. PMID: 32602355.
- Shaw KL, Southwood TR, McDonagh JE, et al. Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. *Rheumatology (Oxford)*. 2004 Aug;43(8):1000-6. doi: 10.1093/rheumatology/keh216. PMID: 15150431.
- Shaw KL, Watanabe A, Rankin E, et al. Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. *Child Care Health Dev*. 2014 Sep;40(5):663-70. doi: 10.1111/cch.12110. PMID: 24148012.
- Sheanon NM, Beal SJ, Kichler JC, et al. Readiness for transition to adult care in adolescents and young adults with Turner syndrome. *J Pediatr Endocrinol Metab*. 2020 Sep 25;33(9):1165-71. doi: 10.1515/jpem-2020-0155. PMID: 32866122.
- Sheehan DW, Birnkrant DJ, Benditt JO, et al. Respiratory Management of the Patient With Duchenne Muscular Dystrophy. *Pediatrics*. 2018 Oct;142(Suppl 2):S62-S71. doi: 10.1542/peds.2018-0333H. PMID: 30275250.
- Sheng N, Ma J, Ding W, et al. Family management affecting transition readiness and quality of life of Chinese children and young people with chronic diseases. *J Child Health Care*. 2018 Sep;22(3):470-85. doi: 10.1177/1367493517753712. PMID: 29361839.
- Shulman R, Chafe R, Guttmann A. Transition to Adult Diabetes Care: A Description of Practice in the Ontario Pediatric Diabetes Network. *Can J Diabetes*. 2019 Jun;43(4):283-9. doi: 10.1016/j.jcjd.2018.10.007. PMID: 30718174.
- Shulman R, Shah BR, Fu L, et al. Diabetes transition care and adverse events: a population-based cohort study in Ontario, Canada. *Diabet Med*. 2018 Nov;35(11):1515-22. doi: 10.1111/dme.13782. PMID: 30022524.
- Sibanda D, Singleton R, Clark J, et al. Adult outcomes of childhood bronchiectasis. *Int J Circumpolar Health*. 2020 Dec;79(1):1731059. doi: 10.1080/22423982.2020.1731059. PMID: 32090714.
- Signorini G, Singh SP, Boricevic-Marsanic V, et al. Architecture and functioning of child and adolescent mental health services: a 28-country survey in Europe. *Lancet Psychiatry*. 2017 Sep;4(9):715-24. doi: 10.1016/S2215-0366(17)30127-X. PMID: 28596067.
- Singh S, Desai R. COVID-19 and new-onset arrhythmia. *J Arrhythm*. 2020 Jun;36(3):547-8. doi: 10.1002/joa3.12354. PMID: 32523637.
- Sliwinski SK, Gooding H, de Ferranti S, et al. Transitioning from pediatric to adult health care with familial hypercholesterolemia: Listening to young adult and parent voices. *J Clin Lipidol*. 2017 Jan - Feb;11(1):147-59. doi: 10.1016/j.jacl.2016.11.001. PMID: 28391881.
- Sohn AH, Chokephaibulkit K, Lumbiganon P, et al. Peritransition Outcomes of Southeast Asian Adolescents and Young Adults With HIV Transferring From Pediatric to Adult Care. *J Adolesc Health*. 2020 Jan;66(1):92-9. doi: 10.1016/j.jadohealth.2019.07.025. PMID: 31627925.
- Son J, Debono D, Leitner R, et al. Pass the parcel: Service provider views on bridging gaps for youth with dual diagnosis of intellectual disability and mental health disorders in regional areas. *J Paediatr Child Health*. 2019 Jun;55(6):666-72. doi: 10.1111/jpc.14266. PMID: 30311314.
- Son MB, Sergeyenko Y, Guan H, et al. Disease activity and transition outcomes in a childhood-onset systemic lupus erythematosus cohort. *Lupus*. 2016 Nov;25(13):1431-9. doi: 10.1177/0961203316640913. PMID: 27013665.
- Sosnowy C, Silverman C, Shattuck P. Parents' and young adults' perspectives on transition outcomes for young adults with autism. *Autism*. 2018 Jan;22(1):29-39. doi: 10.1177/1362361317699585. PMID: 29020791.

- Sparud-Lundin C, Berghammer M, Moons P, et al. Health care providers' attitudes towards transfer and transition in young persons with long term illness- a web-based survey. *BMC Health Serv Res.* 2017 Apr 11;17(1):260. doi: 10.1186/s12913-017-2192-5. PMID: 28399861.
- Speller-Brown B, Patterson Kelly K, VanGraafeiland B, et al. Measuring Transition Readiness: A Correlational Study of Perceptions of Parent and Adolescents and Young Adults with Sickle Cell Disease. *J Pediatr Nurs.* 2015 Sep-Oct;30(5):788-96. doi: 10.1016/j.pedn.2015.06.008. PMID: 26195300.
- Speller-Brown B, Varty M, Thaniel L, et al. Assessing Disease Knowledge and Self-Management in Youth With Sickle Cell Disease Prior to Transition. *J Pediatr Oncol Nurs.* 2018 Dec 19;1043454218819447. doi: 10.1177/1043454218819447. PMID: 30565490.
- Squiers, Amanda. Transitioning to an Adult Healthcare System: Barriers and Opportunities For Youth with Spina Bifida. *Pediatr Nurs.* 2017;43(6):289-98. PMID: 126865171.
- Stabile L, Rosser L, Porterfield KM, et al. Transfer versus transition: success in pediatric transplantation brings the welcome challenge of transition. *Prog Transplant.* 2005 Dec;15(4):363-70. PMID: 16477819.
- Stein KF, Connors EH, Chambers KL, et al. Youth, Caregiver, and Staff Perspectives on an Initiative to Promote Success of Emerging Adults with Emotional and Behavioral Disabilities. *J Behav Health Serv Res.* 2016 Oct;43(4):582-96. doi: 10.1007/s11414-014-9426-7. PMID: 25005428.
- Sterling L, Nyhof-Young J, Blanchette VS, et al. Exploring internet needs and use among adolescents with haemophilia: a website development project. *Haemophilia.* 2012 Mar;18(2):216-21. doi: 10.1111/j.1365-2516.2011.02613.x. PMID: 21797947.
- Sterling LE, Nyhof-Young J, Blanchette VS, et al. Growing Up with Hemophilia: Assessing Teens' Experiences and Needs During Transition to Adult Health Care. *Univ Toronto Med J.* 2013;90(4):149-54. PMID: 91654212.
- Stewart KT, Chahal N, Kovacs AH, et al. Readiness for Transition to Adult Health Care for Young Adolescents with Congenital Heart Disease. *Pediatr Cardiol.* 2017 Apr;38(4):778-86. doi: 10.1007/s00246-017-1580-2. PMID: 28184978.
- Stollon N, Zhong Y, Ferris M, et al. Chronological age when healthcare transition skills are mastered in adolescents/young adults with inflammatory bowel disease. *World J Gastroenterol.* 2017 May 14;23(18):3349-55. doi: 10.3748/wjg.v23.i18.3349. PMID: 28566896.
- Stollon NB, Paine CW, Lucas MS, et al. Transitioning Adolescents and Young Adults With Sickle Cell Disease From Pediatric to Adult Health Care: Provider Perspectives. *J Pediatr Hematol Oncol.* 2015 Nov;37(8):577-83. doi: 10.1097/MPH.0000000000000427. PMID: 26492583.
- Strange G, Rose M, Kermeen F, et al. A binational registry of adults with pulmonary arterial hypertension complicating congenital heart disease. *Intern Med J.* 2015 Sep;45(9):944-50. doi: 10.1111/imj.12821. PMID: 26011062.
- Suddaby JS, Sohaei D, Bell H, et al. Adult patient perspectives on phenylketonuria care: Highlighting the need for dedicated adult management and services. *Eur J Med Genet.* 2020 Apr;63(4):103818. doi: 10.1016/j.ejmg.2019.103818. PMID: 31778858.
- Sun HL, Breakey VR, Straatman L, et al. Outcomes indicators and processes in transitional care in adolescents with haemophilia: A Delphi survey of Canadian haemophilia care providers. *Haemophilia.* 2019 Mar;25(2):296-305. doi: 10.1111/hae.13699. PMID: 30817086.
- Sung C, Connor A. Social-cognitive predictors of vocational outcomes in transition youth with epilepsy: Application of social cognitive career theory. *Rehabil Psychol.* 2017 Aug;62(3):276-89. doi: 10.1037/rep0000161. PMID: 28836808.
- Suris JC, Akre C. Key elements for, and indicators of, a successful transition: an international Delphi study. *J Adolesc Health.* 2015 Jun;56(6):612-8. doi: 10.1016/j.jadohealth.2015.02.007. PMID: 26003575.
- Suris JC, Larbre JP, Hofer M, et al. Transition from paediatric to adult care: what makes it easier for parents? *Child Care Health Dev.* 2017 Jan;43(1):152-5. doi: 10.1111/cch.12405. PMID: 27625071.
- Suzuki S, Kita S, Morisaki M, et al. Nurses' perceptions regarding transitional care for adolescents and young adults with childhood-onset chronic diseases. *Jpn J Nurs Sci.* 2020 Jul;17(3):e12323. doi: 10.1111/jjns.12323. PMID: 31943766.

- Svedberg P, Einberg EL, Warnestad P, et al. Support from healthcare services during transition to adulthood - Experiences of young adult survivors of pediatric cancer. *Eur J Oncol Nurs*. 2016 Apr;21:105-12. doi: 10.1016/j.ejon.2016.02.008. PMID: 26952685.
- Swift KD, Hall CL, Marimuttu V, et al. Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences. *BMC Psychiatry*. 2013 Mar 5;13:74. doi: 10.1186/1471-244X-13-74. PMID: 23497082.
- Szymanski KM, Cain MP, Hardacker TJ, et al. How successful is the transition to adult urology care in spina bifida? A single center 7-year experience. *J Pediatr Urol*. 2017 Feb;13(1):40 e1- e6. doi: 10.1016/j.jpuro.2016.09.020. PMID: 27979598.
- Tanner AE, Philbin MM, Chambers BD, et al. Healthcare Transition for Youth Living With HIV: Outcomes from a Prospective Multi-site Study. *J Adolesc Health*. 2018 Aug;63(2):157-65. doi: 10.1016/j.jadohealth.2018.02.004. PMID: 29887488.
- Tassiopoulos K, Huo Y, Patel K, et al. Healthcare Transition Outcomes Among Young Adults With Perinatally Acquired Human Immunodeficiency Virus Infection in the United States. *Clin Infect Dis*. 2020 Jun 24;71(1):133-41. doi: 10.1093/cid/ciz747. PMID: 31584617.
- Tatlow-Golden M, Gavin B, McNamara N, et al. Transitioning from child and adolescent mental health services with attention-deficit hyperactivity disorder in Ireland: Case note review. *Early Interv Psychiatry*. 2018 Jun;12(3):505-12. doi: 10.1111/eip.12408. PMID: 28488369.
- Taylor JL, Hodapp RM, Burke MM, et al. Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial. *J Autism Dev Disord*. 2017 Mar;47(3):846-57. doi: 10.1007/s10803-016-2994-z. PMID: 28070786.
- Telfair J, Alexander LR, Loosier PS, et al. Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved*. 2004 Aug;15(3):443-61. doi: 10.1353/hpu.2004.0049. PMID: 15453180.
- Thomsen EL, Khoury LR, Moller T, et al. Parents to chronically ill adolescents have ambivalent views on confidential youth consultations - a mixed methods study. *Int J Adolesc Med Health*. 2019 Apr 26. doi: 10.1515/ijamh-2018-0226. PMID: 31026223.
- Tierney S, Kirk S, Deaton C. Transferring young people with cystic fibrosis to adult care. *Nurs Stand*. 2015 Dec 16;30(16):41-7. doi: 10.7748/ns.30.16.41.s45. PMID: 26669406.
- Toft A, Taylor R, Claridge L, et al. The Experiences of Young Liver Patients Transferring From Children's to Adult Services and Their Support Needs for a Successful Transition. *Prog Transplant*. 2018 Sep;28(3):244-9. doi: 10.1177/1526924818781567. PMID: 29898638.
- Tong A, Jones J, Speerin R, et al. Consumer perspectives on pediatric rheumatology care and service delivery: a qualitative study. *J Clin Rheumatol*. 2013 Aug;19(5):234-40. doi: 10.1097/RHU.0b013e31829d4e82. PMID: 23872547.
- Toth G, Mburu G, Tuot S, et al. Social-support needs among adolescents living with HIV in transition from pediatric to adult care in Cambodia: findings from a cross-sectional study. *AIDS Res Ther*. 2018 Mar 28;15(1):8. doi: 10.1186/s12981-018-0195-x. PMID: 29592818.
- Traino KA, Bakula DM, Sharkey CM, et al. The Role of Grit in Health Care Management Skills and Health-related Quality of Life in College Students with Chronic Medical Conditions. *J Pediatr Nurs*. 2019 May - Jun;46:72-7. doi: 10.1016/j.pedn.2019.02.035. PMID: 30856461.
- Trainor AA, Morningstar ME, Murray A. Characteristics of Transition Planning and Services for Students With High-Incidence Disabilities. *Learning Disability Quarterly*. 2015;39(2):113-24. doi: 10.1177/0731948715607348. PMID: 114726238.
- Travis K, Wood A, Yeh P, et al. Pediatric to Adult Transition in Sickle Cell Disease: Survey Results from Young Adult Patients. *Acta Haematol*. 2020;143(2):163-75. doi: 10.1159/000500258. PMID: 31307033.
- Tsondai PR, Sohn AH, Phiri S, et al. Characterizing the double-sided cascade of care for adolescents living with HIV transitioning to adulthood across Southern Africa. *J Int AIDS Soc*. 2020 Jan;23(1):e25447. doi: 10.1002/jia2.25447. PMID: 32003159.
- Tuchman L, Schwartz M. Health outcomes associated with transition from pediatric to adult cystic fibrosis care. *Pediatrics*. 2013 Nov;132(5):847-53. doi: 10.1542/peds.2013-1463. PMID: 24144711.

- Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev.* 2008 Sep;34(5):557-63. doi: 10.1111/j.1365-2214.2008.00844.x. PMID: 18796047.
- Tunnicliffe DJ, Singh-Grewal D, Chaitow J, et al. Lupus Means Sacrifices: Perspectives of Adolescents and Young Adults With Systemic Lupus Erythematosus. *Arthritis Care Res (Hoboken).* 2016 Jun;68(6):828-37. doi: 10.1002/acr.22749. PMID: 26414860.
- Tunnicliffe DJ, Singh-Grewal D, Craig JC, et al. Healthcare and Research Priorities of Adolescents and Young Adults with Systemic Lupus Erythematosus: A Mixed-methods Study. *J Rheumatol.* 2017 Apr;44(4):444-51. doi: 10.3899/jrheum.160720. PMID: 28250139.
- Ufer LG, Moore JA, Hawkins K, et al. Care Coordination: Empowering Families, a Promising Practice to Facilitate Medical Home Use Among Children and Youth with Special Health Care Needs. *Matern Child Health J.* 2018 May;22(5):648-59. doi: 10.1007/s10995-018-2477-2. PMID: 29445982.
- Uzark K, Afton K, Yu S, et al. Transition Readiness in Adolescents and Young Adults with Heart Disease: Can We Improve Quality of Life? *J Pediatr.* 2019 Sep;212:73-8. doi: 10.1016/j.jpeds.2019.04.060. PMID: 31182220.
- Uzark K, Smith C, Donohue J, et al. Assessment of Transition Readiness in Adolescents and Young Adults with Heart Disease. *J Pediatr.* 2015 Dec;167(6):1233-8. doi: 10.1016/j.jpeds.2015.07.043. PMID: 26298627.
- Vallino LD, Louw B. We've Got Some Growing Up to Do: An Evidence-Based Service Delivery Model for the Transition of Care for the Young Adult with Cleft Lip and Palate. *Perspectives of the ASHA Special Interest Groups.* 2017;2(5):4-17. doi: 10.1044/persp2.SIG5.4. PMID: 127837862.
- van der Bent A, Duggan EM, Fishman LN, et al. Reality check: What happens when patients with anorectal malformations grow up? A pilot study of medical care transition from the adult patient perspective. *J Pediatr Surg.* 2018 Sep;53(9):1722-6. doi: 10.1016/j.jpedsurg.2018.02.057. PMID: 29605261.
- van Staa A, Sattoe JN. Young adults' experiences and satisfaction with the transfer of care. *J Adolesc Health.* 2014 Dec;55(6):796-803. doi: 10.1016/j.jadohealth.2014.06.008. PMID: 25149686.
- van Staa AL, Jedeloo S, van Meeteren J, et al. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child Care Health Dev.* 2011 Nov;37(6):821-32. doi: 10.1111/j.1365-2214.2011.01261.x. PMID: 22007982.
- VanHeerwaarden N, Ferguson G, Abi-Jaoude A, et al. The Optimization of an eHealth Solution (Thought Spot) with Transition-Aged Youth in Postsecondary Settings: Participatory Design Research. *J Med Internet Res.* 2018 Mar 6;20(3):e79. doi: 10.2196/jmir.8102. PMID: 29510970.
- Verma A, Sahay S. Healthcare needs and programmatic gaps in transition from pediatric to adult care of vertically transmitted HIV infected adolescents in India. *PLoS One.* 2019;14(10):e0224490. doi: 10.1371/journal.pone.0224490. PMID: 31661535.
- Verma T, Rohan J. Examination of Transition Readiness, Medication Adherence, and Resilience in Pediatric Chronic Illness Populations: A Pilot Study. *Int J Environ Res Public Health.* 2020 Mar 15;17(6). doi: 10.3390/ijerph17061905. PMID: 32183424.
- Viola A, Mitchell HR, Salner A, et al. Survivorship Care Preferences: A Pilot Study of Young Adults With Cancer. *Clin J Oncol Nurs.* 2017 Jun 1;21(3):E71-E8. doi: 10.1188/17.CJON.E71-E78. PMID: 29658261.
- Visentin K, Koch T, Kralik D. Adolescents with Type 1 Diabetes: transition between diabetes services. *J Clin Nurs.* 2006 Jun;15(6):761-9. doi: 10.1111/j.1365-2702.2006.01347.x. PMID: 16684172.
- Wagner JL, Wilson DA, Kellermann T, et al. Behavioral health in young adults with epilepsy: Implications for transition of care. *Epilepsy Behav.* 2016 Dec;65:7-12. doi: 10.1016/j.yebeh.2016.09.028. PMID: 27829187.
- Walch AM, Cobb CE, Tsaih SW, et al. The medical transition of young adults with type 1 diabetes (T1D): a retrospective chart review identifies areas in need of improvement. *Int J Pediatr Endocrinol.* 2020;2020:10. doi: 10.1186/s13633-020-00080-8. PMID: 32514267.

- Walsh C, Jang Y, Currin-McCulloch J, et al. Pilot Use of Selected Measures from the Patient-Reported Outcomes Measurement Information System Social and Mental Health Domains with Young Adult Cancer Patients During the Transition to Survivorship Care. *J Adolesc Young Adult Oncol*. 2019 Oct;8(5):635-9. doi: 10.1089/jayao.2019.0022. PMID: 31242051.
- Walulu R. Transition of Care of HIV-infected Adolescent Patients to Primary Care in South Texas: A Pilot Study. *Journal of Nursing Practice Applications & Reviews of Research*. 2013;5(1):38-49. doi: 10.13178/jnparr.2015.0501.0321. PMID: 110506412.
- Weeks M, Cole B, Flake E, et al. Resident and Staff Satisfaction of Pediatric Graduate Medical Education Training on Transition to Adult Care of Medically Complex Patients. *Mil Med*. 2018 Nov 1;183(11-12):e676-e9. doi: 10.1093/milmed/usy057. PMID: 29659994.
- Weiss JA, Isaacs B, Diepstra H, et al. Health Concerns and Health Service Utilization in a Population Cohort of Young Adults with Autism Spectrum Disorder. *J Autism Dev Disord*. 2018 Jan;48(1):36-44. doi: 10.1007/s10803-017-3292-0. PMID: 28900771.
- Weitzman E, Kaplan W, Bauer S, et al. Strategic directions for transition to adulthood for patients with spina bifida. *J Pediatr Neurol*. 2015;11(04):211-20. doi: 10.3233/jpn-130624. PMID: 372162255.
- Weston C. 'Reaching Out': international models for transitional care for teenage and young adult cancer patients. *International Practice Development Journal*. 2018;8(1):1-10. doi: 10.19043/ipdj81.006. PMID: 133860669.
- While AE, Heery E, Sheehan AM, et al. Health-related quality of life of young people with long-term illnesses before and after transfer from child to adult healthcare. *Child Care Health Dev*. 2017 Jan;43(1):144-51. doi: 10.1111/cch.12410. PMID: 27678488.
- White SW, Smith IC, Miyazaki Y, et al. Improving Transition to Adulthood for Students with Autism: A Randomized Controlled Trial of STEPS. *J Clin Child Adolesc Psychol*. 2021 Mar-Apr;50(2):187-201. doi: 10.1080/15374416.2019.1669157. PMID: 31609666.
- Whitfield E, Adler J, Gebremariam A, et al. Insurance Among Young Adults With Inflammatory Bowel Disease: Changes Under the Affordable Care Act Dependent Provision. *J Pediatr Gastroenterol Nutr*. 2017 Jun;64(6):962-5. doi: 10.1097/MPG.0000000000001378. PMID: 27513697.
- Whitfield EP, Fredericks EM, Eder SJ, et al. Transition readiness in pediatric patients with inflammatory bowel disease: patient survey of self-management skills. *J Pediatr Gastroenterol Nutr*. 2015 Jan;60(1):36-41. doi: 10.1097/MPG.0000000000000555. PMID: 25199036.
- Wiener LS, Kohrt BA, Battles HB, et al. The HIV experience: youth identified barriers for transitioning from pediatric to adult care. *J Pediatr Psychol*. 2011 Mar;36(2):141-54. doi: 10.1093/jpepsy/jsp129. PMID: 20040607.
- Williams EF, Ferrer K, Lee MA, et al. Growing up with perinatal human immunodeficiency virus-A life not expected. *J Clin Nurs*. 2017 Dec;26(23-24):4734-44. doi: 10.1111/jocn.13826. PMID: 28334487.
- Williams S, Shulman R, Allwood Newhook LA, et al. A province wide review of transition practices for young adult patients with type 1 diabetes. *J Eval Clin Pract*. 2021 Feb;27(1):111-8. doi: 10.1111/jep.13399. PMID: 32307818.
- Wilson EV. Engaging young people with a chronic illness. *Aust Fam Physician*. 2017;46(8):572-6. PMID: 28787556.
- Wong K, Zucker J, Fernandes H, et al. Adolescent HIV viral load in an urban hospital in Newark, New Jersey. *Int J Pediatr Adolesc Med*. 2016 Sep;3(3):103-8. doi: 10.1016/j.ijpam.2016.04.001. PMID: 30805478.
- Wray J, Maynard L. Specialist cardiac services: what do young people want? *Cardiol Young*. 2008 Dec;18(6):569-74. doi: 10.1017/S104795110800317X. PMID: 18940027.
- Wright EK, Williams J, Andrews JM, et al. Perspectives of paediatric and adult gastroenterologists on transfer and transition care of adolescents with inflammatory bowel disease. *Intern Med J*. 2014 May;44(5):490-6. doi: 10.1111/imj.12402. PMID: 24589174.

Wright J, Elwell L, McDonagh J, et al. Healthcare transition in pediatric liver transplantation: The perspectives of pediatric and adult healthcare professionals. *Pediatr Transplant*. 2019 Sep;23(6):e13530. doi: 10.1111/ptr.13530. PMID: 31240785.

Wright J, Elwell L, McDonagh JE, et al. Parents in transition: Experiences of parents of young people with a liver transplant transferring to adult services. *Pediatr Transplant*. 2017 Feb;21(1):e12760. doi: 10.1111/ptr.12760. PMID: 27460440.

Wright RJ, Chapman S, Cheer K, et al. Training needs in adolescent and young adult health and transition in UK paediatric and adult higher specialist trainees in endocrinology and diabetes. *British Journal of Diabetes*. 2015;15(4):159-65. doi: 10.15277/bjdv.2015.049. PMID: 111985487.

Xia Q, Abraham B, Shah D, et al. Transition from paediatric to adult care among persons with perinatal HIV infection in New York City, 2006-2015. *AIDS*. 2018 Aug 24;32(13):1821-8. doi: 10.1097/QAD.0000000000001923. PMID: 29894382.

Young CC, Rew L, Monge M. Transition to Self-Management among Adolescents with Polycystic Ovary Syndrome: Parent and Adolescent Perspectives. *J Pediatr Nurs*. 2019 Jul - Aug;47:85-91. doi: 10.1016/j.pedn.2019.04.024. PMID: 31079016.

Young NL, Barden WS, Mills WA, et al. Transition to adult-oriented health care: perspectives of youth and adults with complex physical disabilities. *Phys Occup Ther Pediatr*. 2009;29(4):345-61. doi: 10.3109/01942630903245994. PMID: 19916821.

Zeng S, Strain A, Sung C. Health Care Transition Services and Adaptive and Social-Emotional Functioning of Youth with Autism Spectrum Disorder. *J Autism Dev Disord*. 2021 Feb;51(2):589-99. doi: 10.1007/s10803-020-04564-7. PMID: 32556835.

Zhong Y, Gilleskie DB, van Tilburg MAL, et al. Longitudinal Self-Management and/or Transition Readiness per the TRxANSITION Index among Patients with Chronic Conditions in Pediatric or Adult Care Settings. *J Pediatr*. 2018 Dec;203:361-70 e1. doi: 10.1016/j.jpeds.2018.06.052. PMID: 30201183.

Zhong Y, Patel N, Ferris M, et al. Health literacy, nutrition knowledge, and health care transition readiness in youth with chronic kidney disease or hypertension: A cross-sectional study. *J Child Health Care*. 2020 Jun;24(2):246-59. doi: 10.1177/1367493519831493. PMID: 30866644.

Zillioux JM, Jackson JN, Herndon CDA, et al. Caring for urologic transition patients: Current practice patterns and opinions. *J Pediatr Urol*. 2018 Jun;14(3):242 e1- e5. doi: 10.1016/j.jpuro.2018.02.007. PMID: 29559274.

Zucchetti G, Bellini S, Bertolotti M, et al. The biopsychosocial condition of childhood cancer survivors in the transition towards adult care: a national survey from the joint pediatric and adult transition care group. *Int J Adolesc Med Health*. 2018 Dec 18. doi: 10.1515/ijamh-2018-0189. PMID: 30864415.

Jose K, Le Roux A, Jeffs L, et al. Evaluation of a young adult renal and transplant transition clinic in a regional setting: Supporting young adults and parents' transition to self-management. *Aust J Rural Health*. 2021 Feb;29(1):83-91. doi: 10.1111/ajr.12683. PMID: 33452848.

Other Reason

It Takes a Village. *Exceptional Parent*. 2010;40(1):22-4. PMID: 54391736.

Alper S. Parents' perceptions of transition programs for youth with severe handicaps. *Canadian Journal of Rehabilitation*. 1990;3(4):205-12. PMID: 20317673.

Altman S, O'Connor S, Anapolsky E, et al. Federal and state benefits for transition age youth. *J Pediatr Rehabil Med*. 2014;7(1):71-7. doi: 10.3233/prm-140270. PMID: 373301001.

American Academy of P, American Academy of Family P, American College of Physicians-American Society of Internal M. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002. PMID: 12456949.

Betz CL, Redcay G. Lessons learned from providing transition services to adolescents with special health care needs. *Issues Compr Pediatr Nurs*. 2002;25(2):129-49. PMID: 35595789.

Betz CL, Smith KA, Macias K, et al. Testing the Transition Preparation Training Program: Well-being of relationships outcomes. *J Pediatr Rehabil Med*. 2015. doi: 10.3233/prm-150340. PMID: 26410066.

- Blomquist KB. Healthy and ready to work-- Kentucky: incorporating transition into a state program for children with special health care needs. *Pediatr Nurs*. 2006. PMID: 17256289.
- Bohun CM, Woods P, Winter C, et al. Challenges of intra-institutional transfer of care from paediatric to adult congenital cardiology: the need for retention as well as transition. *Cardiol Young*. 2016;26(2):327-33. doi: 10.1017/s1047951115000220. PMID: 25865899.
- Bolger A, Vargus-Adams J, McMahon M. Transition of Care in Adolescents With Cerebral Palsy: A Survey of Current Practices. *PM and R*. 2017;9(3):258-64. doi: 10.1016/j.pmrj.2016.08.001. PMID: 614287856.
- Bradby, Matthew. Supporting transition to adult services. *British Journal of School Nursing*. 2016;11(9):463-. doi: 10.12968/bjsn.2016.11.9.463. PMID: 119763381.
- Broadhurst S, Yates K, Mullen B. An evaluation of the My Way transition programme. *Tizard Learning Disability Review*. 2012;17(3):124-34. doi: 10.1108/13595471211240960. PMID: 104505394.
- Chugani CD, Goldstein TR, Salk RH, et al. Group Intervention for Young Adults With Mood and Anxiety Disorders Transitioning to College. *J Psychiatr Pract*. 2020. doi: 10.1097/prs.0000000000000456. PMID: 32134884.
- Coburn SS, Eakin MN, Roter D, et al. Patient-provider communication in nephrology care for adolescents and young adults. *Patient Educ Couns*. 2017;100(9):1680-7. doi: 10.1016/j.pec.2017.03.026. PMID: 615533126.
- Cooney, Bernard F. Exploring Perspectives on Transition of Youth With Disabilities: Voices of Young Adults, Parents, and Professionals. *Ment Retard*. 2002;40(6):424-35. doi: 10.1352/0047-6765(2002)040<0425:epotoy>2.0.co;2. PMID: 107929268.
- Cooney BF. Exploring perspectives on transition of youth with disabilities: voices of young adults, parents, and professionals. *Ment Retard*. 2002;40(6):425-35. PMID: 35530536.
- Davis M, Koroloff N, Sabella K, et al. Crossing the Age Divide: Cross-Age Collaboration Between Programs Serving Transition-Age Youth. *The journal of behavioral health services & research*. 2018;45(3):356-69. doi: 10.1007/s11414-018-9588-9. PMID: 626290474.
- DaWalt LS, Greenberg JS, Mailick MR. Transitioning Together: A Multi-family Group Psychoeducation Program for Adolescents with ASD and Their Parents. *J Autism Dev Disord*. 2018. doi: 10.1007/s10803-017-3307-x. PMID: 29032481.
- Dolezalova P, Anton J, Avcin T, et al. The European network for care of children with paediatric rheumatic diseases: care across borders. *Rheumatology*. 2019. doi: 10.1093/rheumatology/key439. PMID: 30668879.
- Gingaras C, Smith C, Radoi R, et al. Engagement in care among youth living with parenterally-acquired HIV infection in Romania. *AIDS Care*. 2019. doi: 10.1080/09540121.2019.1612010. PMID: 31056925.
- Hagner D, Kurtz A, May J, et al. Person-Centered Planning for Transition-Aged Youth with Autism Spectrum Disorders. *J Rehabil*. 2014;80(1):4-10. PMID: 95211302.
- Harder AT, Köngeter S, Zeller M, et al. Instruments for research on transition: Applied methods and approaches for exploring the transition of young care leavers to adulthood. *Children & Youth Services Review*. 2011;33(1):2431-41. doi: 10.1016/j.chilyouth.2011.08.017. PMID: 104619579.
- Hudson MM, Hester A, Sweeney T, et al. A model of care for childhood cancer survivors that facilitates research. *Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses*. 2004;21(3):170-4. PMID: 39074741.
- Jackson J, Rankin A, Siefken S, et al. Options: an occupational therapy transition program for adolescents with developmental disabilities. *Occupational Therapy in Health Care*. 1989;6(2):197-214. PMID: 107512766.
- Javalkar K, Johnson M, Kshirsagar AV, et al. Ecological Factors Predict Transition Readiness/Self-Management in Youth with Chronic Conditions. *J Adolesc Health*. 2016;58(1):40-6. doi: 10.1016/j.jadohealth.2015.09.013. PMID: 607713564.
- Kraus de C. Systems of care: transition from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health. *Child Care Health Dev*. 2011;37(6):792-9. doi: 10.1111/j.1365-2214.2011.01323.x. PMID: 22007978.

- Kunstler R, Thompson A, Croke E. Inclusive Recreation for Transition-Age Youth: Promoting Self-Sufficiency, Community Inclusion, and Experiential Learning. *Ther Recreation J*. 2013;47(2):122-36. PMID: 89454939.
- Kuo AA, Anderson KA, Crapnell T, et al. Introduction to Transitions in the Life Course of Autism and Other Developmental Disabilities. *Pediatrics*. 2018. doi: 10.1542/peds.2016-4300B. PMID: 29610406.
- Lindsay S, McAdam L, Mahendiran T. Enablers and barriers of men with Duchenne muscular dystrophy transitioning from an adult clinic within a pediatric hospital. *Disability and Health Journal*. 2017;10(1):73-9. doi: 10.1016/j.dhjo.2016.10.002. PMID: 613561068.
- Loiselle F, Rochette A, Tétreault S, et al. Social circus program (Cirque du Soleil) promoting social participation of young people living with physical disabilities in transition to adulthood: a qualitative pilot study. *Dev Neurorehabil*. 2019;22(4):250-9. doi: 10.1080/17518423.2018.1474502. PMID: 135826760.
- Lu M, Yee BJ, Fitzgerald DA. Transition to adult care in sleep medicine. *Paediatr Respir Rev*. 2020;33:9-15. doi: 10.1016/j.prrv.2019.09.008. PMID: 31806562.
- Markwart H, Bomba F, Menrath I, et al. Assessing empowerment as multidimensional outcome of a patient education program for adolescents with chronic conditions: A latent difference score model. *PLoS One*. 2020;15(4):e0230659. doi: 10.1371/journal.pone.0230659. PMID: 2005634745.
- McDonald L, McKie F, Webber G. Transition Pilot Project: implications for adult service providers. *Canadian Journal of Rehabilitation*. 1991;5(2):107-11. PMID: 107483758.
- Medforth N, Huntingdon E. Found in Transition. *Comprehensive child and adolescent nursing*. 2018;41(4):237-54. doi: 10.1080/24694193.2017.1323976. PMID: 28590816.
- Mitchell, Fraser. Self-directed support and disabled young people in transition (part 2). *Journal of Integrated Care*. 2012;20(4):223-30. PMID: 104420507.
- Mullholand B, Kelly. Transitional experiences of 16 to 26 year olds with Turner Syndrome. *Transitional Experiences of 16 to 26 Year Olds With Turner Syndrome*. 2014:126 p- p. PMID: 109751885.
- Oertle K, Trach J. Interagency collaboration: the importance of rehabilitation professionals' involvement in transition. *J Rehabil*. 2007;73(3):36-44. PMID: 105946890.
- Paradiz V, Kelso S, Nelson A, et al. Essential Self-Advocacy and Transition. [Review]. *Pediatrics*. 2018. doi: 10.1542/peds.2016-4300P. PMID: 29610420.
- Pilnick A, Clegg J, Murphy E, et al. Questioning the answer: questioning style, choice and self-determination in interactions with young people with intellectual disabilities. *Sociol Health Illn*. 2010;32(3):415-36. doi: 10.1111/j.1467-9566.2009.01223.x. PMID: 20415789.
- Plotner AJ, Shogren KA, Shaw LA, et al. Centers for independent living and secondary transition collaboration: characteristics for enhanced service delivery for adolescents in the United States. *Disabil Rehabil*. 2017. doi: 10.1080/09638288.2016.1193904. PMID: 27345714.
- Rockwell D. Transition services under IDEA: what is OT's role in the high school setting? *OT Practice*. 2006;11(1):18-22. PMID: 106347125.
- Smith KA, Macias K, Bui K, et al. Brief Report: Adolescents' Reasons for Participating in a Health Care Transition Intervention Study. *J Pediatr Nurs*. 2015. doi: 10.1016/j.pedn.2015.05.007. PMID: 26138375.
- Taylor, Sarah J. A difficult transition. *Nurs Stand*. 2017;31(3):29-. doi: 10.7748/ns.31.34.29.s28. PMID: 122564025.
- Thrall RS, Blumberg JH, Beck S, et al. Beyond the medical home: Special Care Family Academy for children and youth. *Pediatr Nurs*. 2012;38(6):331-5. PMID: 23362633.
- Tulloch O, Theobald S, Ananworanich J, et al. From transmission to transition: Lessons learnt from the Thai paediatric antiretroviral programme. *PLoS One*. 2014;9(6):e99061. doi: 10.1371/journal.pone.0099061. PMID: 373323731.
- van Staa A, Sattoe JN, Strating MM. Experiences with and Outcomes of Two Interventions to Maximize Engagement of Chronically Ill Adolescents During Hospital Consultations: A Mixed Methods Study. *J Pediatr Nurs*. 2015;30(5):757-75. doi: 10.1016/j.pedn.2015.05.028. PMID: 616616979.
- Vion Genovese V, Perceval M, Buscarlet-Jardine L, et al. Quality criteria for the transition to adult care in French CF centers - results from the SAFETIM APP study? *Rev Mal Respir*. 2019;36(5):565-77. doi: 10.1016/j.rmr.2019.01.008. PMID: 2002109753.

Yardley IE, Pauniah S-L, Baillie CT, et al. After the honeymoon comes divorce: long-term use of the antegrade continence enema procedure. *J Pediatr Surg*. 2009. doi: 10.1016/j.jpedsurg.2009.02.030. PMID: 19524753.

Outcome

Barron DA, Molosankwe I, Romeo R, et al. Urban adolescents with intellectual disability and challenging behaviour: Costs and characteristics during transition to adult services. *Health and Social Care in the Community*. 2013;21(3):283-92. doi: 10.1111/hsc.12015. PMID: 52441678.

Chi DL. Medical care transition planning and dental care use for youth with special health care needs during the transition from adolescence to young adulthood: a preliminary explanatory model. *Maternal and child health journal*. 2014;18(4):778-88. doi: 10.1007/s10995-013-1322-x. PMID: 601984458.

Population

Aeschbach CJ, Burrough WB, Olejniczak AB, et al. Teaching Adolescents to Manage Their Own Health Care. *J Sch Nurs*. 2019. doi: 10.1177/1059840519867363. PMID: 31426712.

Armstrong-Heimsoth A, Hahn-Floyd M, Williamson HJ, et al. Former Foster System Youth: Perspectives on Transitional Supports and Programs. *J Behav Health Serv Res*. 2020. doi: 10.1007/s11414-020-09693-6. PMID: 32095998.

Beal SJ, Nye A, Marraccini A, et al. Evaluation of readiness to transfer to adult healthcare: What about the well adolescent? *Healthcare*. 2014. doi: 10.1016/j.hjdsi.2014.10.001. PMID: 26250628.

Bemrich-Stolz CJ, Halanych JH, Howard TH, et al. Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease. *International journal of hematology & therapy*. 2015;1(1). doi: 10.15436/2381-1404.15.003. PMID: 26900602.

Benz MR, Halpern AS. Transition services for secondary students with mild disabilities: a statewide perspective. *Except Child*. 1987;53(6):507-14. PMID: 2953606.

Boyle MP, Farukhi Z, Nosky ML. Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatr Pulmonol*. 2001;32(6):428-36. doi: 10.1002/ppul.1154. PMID: 33121653.

Budisavljevic S, Arnarsson A, Hamrik Z, et al. Improving Adolescent Health: Translating Health Behaviour in School-aged Children Evidence Into Policy. *J Adolesc Health*. 2020;66:S9-S11. doi: 10.1016/j.jadohealth.2020.03.010. PMID: 143460312.

Burger, Susan. Using health coaches to help patients manage chronic disease. *Nurse Pract*. 2019;44(9):48-55. doi: 10.1097/01.NPR.0000577960.57843.d2. PMID: 138991890.

Burns T, Catty J, White S, et al. Continuity of care in mental health: understanding and measuring a complex phenomenon. *Psychol Med*. 2009. doi: 10.1017/s0033291708003747. PMID: 18570700.

Cazares MK, Hernández J. Identifying Strategic Entry Points for Services among Transition-aged Mothers who are Homeless. *Child Welfare*. 2019;97(6):187-203. PMID: 142876747.

Chatwin M, Tan H-L, Bush A, et al. Long term non-invasive ventilation in children: impact on survival and transition to adult care. *PLoS ONE [Electronic Resource]*. 2015. doi: 10.1371/journal.pone.0125839. PMID: 25933065.

Clark H, Unruh D. Transition practices for adjudicated youth with E/BDs and related disabilities. *Behavioral Disorders*. 2010;36(1):43-51. PMID: 104957677.

Curran JA, Bishop A, Plint A, et al. Understanding discharge communication behaviours in a pediatric emergency care context: a mixed methods observation study protocol. *BMC Health Serv Res*. 2017. doi: 10.1186/s12913-017-2204-5. PMID: 28412951.

Davis MC, Hopson BD, Blount JP, et al. Predictors of permanent disability among adults with spinal dysraphism. *Journal of Neurosurgery Spine*. 2017. doi: 10.3171/2017.1.Spine161044. PMID: 28548634.

Diplock G, Ward J, Stewart S, et al. The Alice Springs Hospital Readmission Prevention Project (ASHRAPP): a randomised control trial. *BMC Health Serv Res*. 2017. doi: 10.1186/s12913-017-2077-7. PMID: 28219383.

Dunkow LE, Axford KL, Suda KJ, et al. Impact of a stewardship-focused culture follow-up initiative on the treatment of pharyngitis in the emergency department and urgent care settings. *Diagn Microbiol Infect Dis*. 2018;92(2):136-42. doi: 10.1016/j.diagmicrobio.2018.05.014. PMID: 29934074.

- Duroy TH, Schmidt SL, Perry PD. Adolescents' and young adults' perspectives on a continuum of care in a three year drug treatment program. *Journal of Drug Issues*. 2003;33(4):801-32. doi: 10.1177/002204260303300403. PMID: 38018284.
- Dyalchand A, Pande RP, Kulkarni G, et al. Improving use of maternal care services among married adolescent girls: an intervention study in rural India. *J Biosoc Sci*. 2020;1-20. doi: 10.1017/s0021932020000206. PMID: 631623445.
- Enlow E, Herbert SL, Jovel IJ, et al. Neonatal intensive care unit to home: The transition from parent and pediatrician perspectives, a prospective cohort study. *J Perinatol*. 2014;34(1):761-6. doi: 10.1038/jp.2014.75. PMID: 53136697.
- Goldstein M, Peters L, Baillie A, et al. The effectiveness of a day program for the treatment of adolescent anorexia nervosa. *Int J Eat Disord*. 2011;44(1):29-38. doi: 10.1002/eat.20789. PMID: 360176356.
- Gooding TD, Newcomb L, Mertens K. Patient-centered measurement at an academic medical center. *The Joint Commission journal on quality improvement*. 1999;25(7):343-51. doi: 10.1016/s1070-3241(16)30449-7. PMID: 129443555.
- Halpern AS. A systematic approach to transition programming for adolescents and young adults with disabilities. *Australia and New Zealand Journal of Developmental Disabilities*. 1989;15(1):1-13. PMID: 20076073.
- Hatfield M, Falkmer M, Falkmer T, et al. Process Evaluation of the BOOST-A™ Transition Planning Program for Adolescents on the Autism Spectrum: A Strengths-Based Approach. *J Autism Dev Disord*. 2018;48(2):377-88. doi: 10.1007/s10803-017-3317-8. PMID: 127936227.
- Hughes D, Maiden K. Navigating the Health Care System: An Adolescent Health Literacy Unit for High Schools. *J Sch Health*. 2018. doi: 10.1111/josh.12616. PMID: 29609216.
- Iyer SN, Shah J, Boksa P, et al. A minimum evaluation protocol and stepped-wedge cluster randomized trial of ACCESS Open Minds, a large Canadian youth mental health services transformation project. *BMC Psychiatry*. 2019;19(1):273. doi: 10.1186/s12888-019-2232-2. PMID: 629229221.
- Jones RG, Kerr MP. A randomized control trial of an opportunistic health screening tool in primary care for people with intellectual disability. *J Intellect Disabil Res*. 1997. doi: 10.1111/j.1365-2788.1997.tb00728.x. PMID: 9373821.
- Katzenellenbogen JM, Bond-Smith D, Ralph AP, et al. Priorities for improved management of acute rheumatic fever and rheumatic heart disease: analysis of cross-sectional continuous quality improvement data in Aboriginal primary healthcare centres in Australia. *Australian health review : a publication of the Australian Hospital Association*. 2020;44(2):212-21. doi: 10.1071/ah19132. PMID: 32241338.
- Kiran T, Kopp A, Glazier RH. Those Left Behind From Voluntary Medical Home Reforms in Ontario, Canada. *Ann Fam Med*. 2016. doi: 10.1370/afm.2000. PMID: 28376438.
- Knighting K, Kirton JA, Thorp N, et al. A study of childhood cancer survivors' engagement with long-term follow-up care: 'To attend or not to attend, that is the question'. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*. 2020;45:101728. doi: 10.1016/j.ejon.2020.101728. PMID: 32163861.
- Lawrence RH, Apenteng BA, Schueths AM, et al. Defining "Community" from the Perspectives of Individuals with Sickle Cell Disease in Rural Georgia. *J Health Care Poor Underserved*. 2018. doi: 10.1353/hpu.2018.0105. PMID: 30449756.
- Liang L, Pan Y, Wu D, et al. Effects of Multidisciplinary Team-Based Nurse-led Transitional Care on Clinical Outcomes and Quality of Life in Patients With Ankylosing Spondylitis. *Asian Nurs Res (Korean Soc Nurs Sci)*. 2019;13(2):107-14. doi: 10.1016/j.anr.2019.02.004. PMID: CN-01962660.
- Librizzi J, Winer JC, Banach L, et al. Perceived core competency achievements of fellowship and non-fellowship-trained early career pediatric hospitalists. *Journal of Hospital Medicine (Online)*. 2015. doi: 10.1002/jhm.2337. PMID: 25755166.
- Livermore G, Honeycutt T, Mamun A, et al. Insights about the transition system for SSI youth from the national evaluation of Promoting Readiness of Minors in SSI (PROMISE). *Journal of Vocational Rehabilitation*. 2020;52(1):1-17. doi: 10.3233/jvr-191056. PMID: 141602882.
- Lobeck I, Rymeski B, Burns K, et al. Long-term morbidity after staging laparotomy for Hodgkin lymphoma. *J Pediatr Surg*. 2017. doi: 10.1016/j.jpedsurg.2016.11.047. PMID: 27939180.

- Luft P. Assessment and collaboration: Key elements in comprehensive and cohesive transition planning. *Work*. 1999;13(1):31-41. PMID: 29408242.
- Margonary H, Hannan MS, Schlenk EA. Quality Improvement Initiative on Pain Knowledge, Assessment, and Documentation Skills of Pediatric Nurses. *Pediatr Nurs*. 2017. PMID: 29394479.
- Markowitz JT, Laffel LMB. Transitions in care: Support group for young adults with Type1 diabetes. *Diabet Med*. 2012;29(4):522-5. doi: 10.1111/j.1464-5491.2011.03537.x. PMID: 364435345.
- Marsh KK, Bush RA, Connelly CD. Exploring perceptions and use of the patient portal by young adults with type 1 diabetes: A qualitative study. *Health Informatics Journal*. 2020. doi: 10.1177/1460458220911780. PMID: 32301370.
- Mayer DK, Gerstel A, Leak AN, et al. Patient and provider preferences for survivorship care plans. *J Oncol Pract*. 2012;8(4):e80-6. doi: 10.1200/jop.2011.000401. PMID: 23181005.
- McAnaney DF, Wynne RF. Linking user and staff perspectives in the evaluation of innovative transition projects for youth with disabilities. *Journal of Intellectual Disabilities*. 2016. doi: 10.1177/1744629516633574. PMID: 26912504.
- McDonough A, Callans KM, Carroll DL. Understanding the challenges during transitions of care for children with critical airway conditions. *ORL-head and neck nursing : official journal of the Society of Otorhinolaryngology and Head-Neck Nurses*. 2014;32(4):12-7. PMID: 25638960.
- Miklin DJ, Vangara SS, Delamater AM, et al. Understanding of and Barriers to Electronic Health Record Patient Portal Access in a Culturally Diverse Pediatric Population. *JMIR medical informatics*. 2019;7(2):e11570. doi: 10.2196/11570. PMID: 31066681.
- Monti, Marcela D. Growing Pains: Ethical Considerations for Transitioning to Adult Care with Childhood-Onset Conditions. *Pediatr Nurs*. 2016;42(4):201-3. PMID: 29406635.
- Nageswaran S, Radulovic A, Anania A. Transitions to and from the acute inpatient care setting for children with life-threatening illness. *Pediatr Clin North Am*. 2014. doi: 10.1016/j.pcl.2014.04.008. PMID: 25084723.
- Ozer EM, Scott JT, Brindis CD. Seizing the opportunity: improving young adult preventive health care. *Adolesc Med State Art Rev*. 2013;24(3):507-25. PMID: 24654545.
- Packman W, Mehta I, Rafie S, et al. Young adults with MSUD and their transition to adulthood: psychosocial issues. *Journal of genetic counseling*. 2012;21(5):692-703. doi: 10.1007/s10897-012-9490-1. PMID: 22350623.
- Palmer BW, Wisniewski AB, Schaeffer TL, et al. A model of delivering multi-disciplinary care to people with 46 XY DSD. [Review]. *J Pediatr Urol*. 2012. doi: 10.1016/j.jpuro.2011.08.013. PMID: 22078657.
- Patel SJ, Landrigan CP. Communication at Transitions of Care. [Review]. *Pediatr Clin North Am*. 2019. doi: 10.1016/j.pcl.2019.03.004. PMID: 31230621.
- Pierce D, Sakemiller L, Spence A, et al. Effectiveness of Transition Readiness Interventions by School-Based Occupational Therapy Personnel. *OTJR : occupation, participation and health*. 2020;40(1):27-35. doi: 10.1177/1539449219850129. PMID: 31161858.
- Psaila K, Schmied V, Fowler C, et al. Discontinuities between maternity and child and family health services: health professional's perceptions. *BMC Health Serv Res*. 2014. doi: 10.1186/1472-6963-14-4. PMID: 24387686.
- Ruble LA, McGrew JH, Toland M, et al. Randomized Control Trial of COMPASS for Improving Transition Outcomes of Students with Autism Spectrum Disorder. *J Autism Dev Disord*. 2018;48(1):3586-95. doi: 10.1007/s10803-018-3623-9. PMID: 622435118.
- Rynja SP, Bosch JLHR, de Jong TPVM, et al. Coping styles in patients with hypospadias. *J Pediatr Urol*. 2019. doi: 10.1016/j.jpuro.2019.08.007. PMID: 31521557.
- Samuel SM, Nettel-Aguirre A, Soo A, et al. Avoidable hospitalizations in youth with kidney failure after transfer to or with only adult care. *Pediatrics*. 2014. doi: 10.1542/peds.2013-2345. PMID: 24664091.
- Schumacher DJ, Schwartz A, Zenel JAJ, et al. Narrative Performance Level Assignments at Initial Entrustment and Graduation: Integrating EPAs and Milestones to Improve Learner Assessment. *Acad Med*. 2020. doi: 10.1097/acm.0000000000003300. PMID: 32195689.

Schumacher DJ, West DC, Schwartz A, et al. Longitudinal Assessment of Resident Performance Using Entrustable Professional Activities. *JAMA Network Open*. 2020. doi: 10.1001/jamanetworkopen.2019.19316. PMID: 31940042.

Scott, Leslie K. Developmental mastery of diabetes-related tasks in children. *The Nursing Clinics of North America*. 2013;48(2):329-42. doi: 10.1016/j.cnur.2013.01.015. PMID: 23659817.

Senteio C, Marshall KJ, Ritzen EK, et al. Preventing homelessness: an examination of the transition resource action center. *Journal of Prevention & Intervention in the Community*. 2009. doi: 10.1080/10852350902735601. PMID: 19363771.

Siu GE, Kennedy CE, Bakeera-Kitaka S. Young people with HIV attending a transition clinic in Kampala, Uganda: An exploratory study of social context, illness trajectories, and pathways to HIV testing and treatment. *Children & Youth Services Review*. 2016;65:9-16. doi: 10.1016/j.chilyouth.2016.03.015. PMID: 115265471.

Slavens BA, Schnorenberg AJ, Aurit CM, et al. Evaluation of pediatric manual wheelchair mobility using advanced biomechanical methods. *BioMed Research International*. 2015. doi: 10.1155/2015/634768. PMID: 25802860.

Steinkamp G, Ullrich G, Muller C, et al. Transition of adult patients with cystic fibrosis from paediatric to adult care--the patients' perspective before and after start-up of an adult clinic. *Eur J Med Res*. 2001;6(2):85-92. PMID: 33469694.

Stodden RA, Boone R. Assessing transition services for handicapped youth: a cooperative interagency approach. *Except Child*. 1987;53(6):537-45. PMID: 17747935.

Storgion SA, Stutts AL. Transitional care: a multidisciplinary case management-based unit. *Pediatr Nurs*. 2000;26(6):564-8. PMID: 12026355.

Szalda D, Pierce L, Hobbie W, et al. Engagement and experience with cancer-related follow-up care among young adult survivors of childhood cancer after transfer to adult care. *J Cancer Surviv*. 2016. doi: 10.1007/s11764-015-0480-9. PMID: 26303367.

Uhm J-Y, Lim EY, Hyeong J. The impact of a standardized inter-department handover on nurses' perceptions and performance in Republic of Korea. *J Nurs Manag*. 2018. doi: 10.1111/jonm.12608. PMID: 30209878.

Walia J, Qayumi Z, Khawar N, et al. Physician Transition of Care: Benefits of I-PASS and an Electronic Handoff System in a Community Pediatric Residency Program. *Acad Pediatr*. 2016. doi: 10.1016/j.acap.2016.04.001. PMID: 27090859.

Young NL, Barden W, Lefort S, et al. Telehomecare: a comparison of three Canadian models. *Telemed J E Health*. 2004. doi: 10.1089/153056204773644571. PMID: 15104915.

Publication Type

GAO: IDEA adolescents lack access to transition services. *Mental Health Weekly*. 2003;13(3):1-3. PMID: 106687605.

Adolescents: 'orphans of the health service': report identifies gaps in mental health and transition care. *Paediatr Nurs*. 2003;15(6):5-. doi: 10.7748/paed.15.6.5.s7. PMID: 106718803.

Quick as a wink. Visually impaired teens favorably evaluate adult transition program. *Insight: The Journal of the American Society of Ophthalmic Registered Nurses*. 2009;34(3):17-. PMID: 105377073.

New NDEP resource helps with transition from pediatric to adult care. *Diabetes Dateline*. 2010:12-. PMID: 105014772.

Online pilot aims to improve move from child-centred care. *Nurs Child Young People*. 2015;27(1):6-. doi: 10.7748/ncyp.27.1.6.s3. PMID: 100925384.

Transition from Pediatric to Adult Dialysis Care in an Adult with Special Considerations Due to Neurocognitive Aspects of Asperger Syndrome. *Adv Chronic Kidney Dis*. 2018;25(2):215-. doi: 10.1053/j.ackd.2018.02.005. PMID: 128647577.

Abell RL, Winter M, Kreipe RE. Transition from Pediatric to Adult Centered Care: Lessons from the Literature and the Trenches. [Review]. *Adolesc Med*. 2016. PMID: 27363241.

Abidi S. Paving the Way to Change for Youth at the Gap between Child and Adolescent and Adult Mental Health Services. *Canadian Journal of Psychiatry*. 2017;62(6):388-92. doi: 10.1177/0706743717694166. PMID: 616602759.

Abraham BP, Kahn SA. Transition of Care in Inflammatory Bowel Disease. *Gastroenterol Hepatol (N Y)*. 2014. PMID: 27540335.

- ACTRN12615001138572. Implementation and Evaluation of a Systems Navigation Model of Transition and Care for Non-Metropolitan Young Adults with Type 1 Diabetes: youth OutReach for Diabetes (YOur Diabetes) – A Cluster Randomised Controlled Trial in Hunter New England. <http://www.who.int/trialssearch/Trial2.aspx?TrialID=ACTRN12615001138572>. 2015. PMID: CN-01838039.
- Acuna Mora M, Saarijarvi M, Sparud-Lundin C, et al. Empowering Young Persons with Congenital Heart Disease: Using Intervention Mapping to Develop a Transition Program - The STEPSTONES Project. *J Pediatr Nurs*. 2020;50:e8-e17. doi: 10.1016/j.pedn.2019.09.021. PMID: 629727417.
- Acuna Mora M, Sparud-Lundin C, Bratt E-L, et al. Person-centred transition programme to empower adolescents with congenital heart disease in the transition to adulthood: a study protocol for a hybrid randomised controlled trial (STEPSTONES project). *BMJ Open*. 2017. doi: 10.1136/bmjopen-2016-014593. PMID: 28420661.
- Agarwal S, Cardillo S, Schutta M. A pilot intervention of a type 1 diabetes pediatric to adult transitions clinic in the adult healthcare system. *Endocr Rev*. 2016;37(2). doi: 10.1210/endo-meetings.2016.DGM.22.FRI-700. PMID: CN-01295238.
- Allemang B, Allan K, Johnson C, et al. Comprehensive Structured Transition Program With Dedicated Transition Navigator Reduced Lost to Follow-Up and Improved Medication Adherence in Adolescents and Young Adults With Sickle Cell Disease and Thalassemia...Cultivating Connections: The Importance of Relationships in Adolescent and Young Adult Health, 08 March 2017- 11 March 2017. *J Adolesc Health*. 2017;60:S40-S1. doi: 10.1016/j.jadohealth.2016.10.263. PMID: 122721308.
- Ammerlaan JW, Scholtus LW, Bijlsma HJWJ, et al. An urge for change: transitional care for young adults with juvenile idiopathic arthritis. *Patient Educ Couns*. 2013. doi: 10.1016/j.pec.2013.02.006. PMID: 23490174.
- Anderson N, Eckman JR, Ballas SK. Beyond the transition of adolescents and young adults with sickle cell disease to adult care: Role of geography. *Am J Hematol*. 2017. doi: 10.1002/ajh.24718. PMID: 28295532.
- Anderson PAM. "If you build it...": Creating an adequate support system to transition the care of pediatric patients with spina bifida into adulthood. *Canadian Urological Association Journal*. 2016. doi: 10.5489/cuaj.4091. PMID: 27800050.
- Anonymous. Caring for those growing up with HIV. *Lancet*. 2013. doi: 10.1016/s0140-6736(13)61511-1. PMID: 23830327.
- Anonymous. Nurse-led project prepares children for adult services. *Nurs Times*. 2014. PMID: 26016129.
- Anonymous. Transition to adult services for young people with-limiting conditions. *Nurs Child Young People*. 2014. doi: 10.7748/ncyp.26.6.13.s15. PMID: 25004041.
- Anonymous. Committee opinion no. 626: the transition from pediatric to adult health care: preventive care for young women aged 18-26 years. *Obstet Gynecol*. 2015. doi: 10.1097/01.AOG.0000461764.54910.a8. PMID: 25730254.
- Anonymous. Improving transition for young people with cerebral palsy. *Nurs Child Young People*. 2016. doi: 10.7748/ncyp.28.7.19.s20. PMID: 27615583.
- Anonymous. Policy on Transitioning from a Pediatric-centered to an Adult-centered Dental Home for Individuals with Special Health Care Needs. *Pediatr Dent*. 2017. PMID: 29179346.
- Anonymous. White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2018;142(5):e20182587. *Pediatrics*. 2019. doi: 10.1542/peds.2018-3610. PMID: 30705144.
- Anthony SJ, Kaufman M, Drabble A, et al. Erratum: Perceptions of transition care needs and experiences in pediatric heart transplant recipients (*American Journal of Transplantation* (2009) 9:3 (614-619) DOI: 10.1111/j.1600-6143.2008.02515.x). *Am J Transplant*. 2009;9(7):1698. doi: 10.1111/j.1600-6143.2009.02654.x. PMID: 354832580.
- Ardoin SP. Transitions in Rheumatic Disease: Pediatric to Adult Care. *Pediatr Clin North Am*. 2018;65(4):867-83. doi: 10.1016/j.pcl.2018.04.007. PMID: 2000960015.

- Bailey S, O'Connell B, Pearce J. The transition from paediatric to adult health care services for young adults with a disability: an ethical perspective. *Aust Health Rev.* 2003. doi: 10.1071/ah030064. PMID: 15485375.
- Baker-Ericzen MJ, Brookman-Frazee L, Brodtkin ES. Accelerating research on treatment and services for transition age youth and adults on the autism spectrum. *Autism.* 2018. doi: 10.1177/1362361317738646. PMID: 29369717.
- Banta JV. Tribulations of transition care for the developmentally disabled. *Dev Med Child Neurol.* 2004. doi: 10.1017/s0012162204000167. PMID: 14974630.
- Beal SJ, Nye A, Shoreman JM, et al. Implementation of Health Care Transition in Clinical Practice. *Adolesc Med.* 2014. PMID: 27132323.
- Bell, Lorraine. Adolescents with renal disease in an adult world: meeting the challenge of transition of care. *Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association.* 2007;22(4):988-91. PMID: 17210582.
- Bennett DL, Towns SJ, Steinbeck KS. Smoothing the transition to adult care. *Med J Aust.* 2005. PMID: 15850429.
- Berens JC, Jan S, Szalda D, et al. Young Adults With Chronic Illness: How Can We Improve Transitions to Adult Care? *Pediatrics.* 2017. doi: 10.1542/peds.2017-0410. PMID: 28557765.
- Betz CL. Health care transitions: a peek into the future. *J Pediatr Nurs.* 2012. doi: 10.1016/j.pedn.2011.11.001. PMID: 22064213.
- Betz CL. SPN Position Statement: Transition of Pediatric Patients Into Adult Care. *J Pediatr Nurs.* 2017. doi: 10.1016/j.pedn.2017.05.003. PMID: 28576441.
- Bhardwa, Seeta. QNI project to scope smoother transition for children to adult services. *Independent Nurse.* 2016:1-. PMID: 112468172.
- Bhogte C, Nickel R, Hsu L, et al. Pilot intervention to improve sickle cell disease transition with a DVD and website shows education of adolescents should occur in the outpatient clinic. *Pediatric blood and cancer.* 2013;60:S27-S8. doi: 10.1002/pbc.24509. PMID: CN-01027515.
- Bilhartz J, Lopez M, Eder S, et al. Assessing self-efficacy during the transition from pediatric to adult liver transplant care. *Am J Transplant.* 2017;17(S):235. doi: 10.1111/ajt.14305. PMID: 615705228.
- Blazquez ML, Hernani MT, Calatayud GA, et al. Transition Care Program of Adolescents with Inflammatory Bowel Disease: Perceptions from A Survey for Patients. *Inflamm Bowel Dis.* 2019;25(3):E22-E3. doi: 10.1093/ibd/izy210. PMID: 631555647.
- Blum, R W. Transition to adult health care: setting the stage. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine.* 1995;17(1):3-5. PMID: 7578159.
- Bonati M. Transitioning youth to adult age also through health services. *Epidemiology & Psychiatric Science.* 2020. doi: 10.1017/s2045796019000842. PMID: 31915105.
- Bowen ME, Henske JA, Potter A. Health care transition in adolescents and young adults with diabetes. *Clin Diabetes.* 2010;28(3):99-106. doi: 10.2337/diaclin.28.3.99. PMID: 359673259.
- Bower WF, Christie D, DeGennaro M, et al. The transition of young adults with lifelong urological needs from pediatric to adult services: An international children's continence society position statement. *Neurourol Urodyn.* 2017. doi: 10.1002/nau.23039. PMID: 27177245.
- Bowes G, Sinnema G, Suris J-C, et al. Transition health services for youth with disabilities: A global perspective. *J Adolesc Health.* 1995;17(1):23-31. doi: 10.1016/1054-139x%2895%2900076-5. PMID: 25231952.
- Bowes G, Sinnema G, Suris JC, et al. Transition health services for youth with disabilities: a global perspective. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine.* 1995;17(1):23-31. PMID: 7578158.
- Breakey V, Warias A, Ignas D, et al. Usability testing of an online transition program for adolescents with hemophilia. *Blood.* 2011;118(2). PMID: CN-01005255.
- Bretault M, Carette C, Barsamian C, et al. Management of Hypothalamic Obesity during Transition from Childhood to Adulthood. *Endocr Dev.* 2018. doi: 10.1159/000487526. PMID: 29886502.

- Brorsson AL, Bratt E-L, Moons P, et al. Randomised controlled trial of a person-centred transition programme for adolescents with type 1 diabetes (STEPSTONES-DIAB): a study protocol. *BMJ Open*. 2020. doi: 10.1136/bmjopen-2019-036496. PMID: 32295780.
- Callahan ST, Winitzer RF, Keenan P. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. [Review] [54 refs]. *Curr Opin Pediatr*. 2001. doi: 10.1097/00008480-200108000-00004. PMID: 11717554.
- Calvo I, Anton J, Bustabad S, et al. Consensus of the Spanish society of pediatric rheumatology for transition management from pediatric to adult care in rheumatic patients with childhood onset. *Rheumatol Int*. 2015. doi: 10.1007/s00296-015-3273-6. PMID: 25917856.
- Camfield P, Camfield C. Help youth with epilepsy to become competent and happy adults: Transition care. *Seizure*. 2013. doi: 10.1016/j.seizure.2013.04.008. PMID: 23664022.
- Camfield P, Camfield C, Busiah K, et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, and psychological issues. *Epilepsy and Behavior*. 2017;69:170-6. doi: 10.1016/j.yebeh.2016.11.009. PMID: 614115075.
- Camfield PR, Andrade D, Camfield CS, et al. How can transition to adult care be best orchestrated for adolescents with epilepsy?. [Review]. *Epilepsy Behav*. 2019. doi: 10.1016/j.yebeh.2018.12.015. PMID: 30642688.
- Camfield PR, Bahi-Buisson N, Trinkka E. Transition issues for children with diffuse cortical malformations, multifocal postnatal lesions, (infectious and traumatic) and Lennox-Gastaut and similar syndromes. *Epilepsia*. 2014;55:24-8. doi: 10.1111/epi.12704. PMID: 25209082.
- Chadi N, Amaria K, Kaufman M. Expand your HEADS, follow the THRxEADS! *Paediatr Child Health*. 2017;22(1):23-5. doi: 10.1093/pch/pxw007. PMID: 29483791.
- Chanchlani N, Harewood C, Hossain U, et al. Better Transition Readiness for Adolescents Begins With Effective Communication. *J Pediatr Hematol Oncol*. 2015. doi: 10.1097/mp.0000000000000404. PMID: 26207774.
- Chanchlani N, McGEE M, McDONAGH JE. Informational continuity is integral for successful transition of adolescents to adult care. *J Rheumatol*. 2015;42(5):901-2. doi: 10.3899/jrheum.141364. PMID: 605837368.
- Charles S, Rempel G, Rogers L, et al. Teens with congenital heart disease in transition from pediatric to adult care: qualitative evaluation of nurse-led intervention to support transition readiness. *Can J Cardiol*. 2016;32(1):S169-. PMID: CN-01252772.
- Chen C-W, Fanjiang Y-Y, Chiang Y-T, et al. Mobile health program to promote self management in youths with congenital heart disease design and development of the cool randomized controlled trial. *Cardiol Young*. 2017;27(4):S89-. doi: 10.1017/s104795111700110x. PMID: CN-01452349.
- Chesshir C, Brown C, Byerley A, et al. Transition of health care from pediatric to adult care. *J Pediatr Nurs*. 2013. doi: 10.1016/j.pedn.2013.02.025. PMID: 23531470.
- Chira P, Sandborg C. Adolescent rheumatology transitional care: steps to bringing health policy into practice. *Rheumatology*. 2004. doi: 10.1093/rheumatology/keh206. PMID: 15126671.
- Christian BJ. Translational Research--Addressing the Challenge of Healthcare Transitions for Adolescents With Special Health Care Needs. [Review]. *J Pediatr Nurs*. 2015. doi: 10.1016/j.pedn.2015.07.012. PMID: 26293903.
- Clayton PE, Cuneo RC, Juul A, et al. Consensus statement on the management of the GH-treated adolescent in the transition to adult care. *European Journal of Endocrinology*. 2005;152(2):165-70. doi: 10.1530/eje.1.01829. PMID: 40309560.
- Collins J, Richmond L. Residential services in transition: meeting the challenge. *Children's Voice*. 2009;18(6):10-4. PMID: 105291261.
- Colver AF, Merrick H, Deverill M, et al. Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. *BMC Public Health*. 2013;13:675. doi: 10.1186/1471-2458-13-675. PMID: 23875722.
- Cooley WC. Adolescent health care transition in transition. *JAMA Pediatrics*. 2013. doi: 10.1001/jamapediatrics.2013.2578. PMID: 23959327.

- Costello AG, Nugent BD, Conover N, et al. Shared Care of Childhood Cancer Survivors: A Telemedicine Feasibility Study. *Journal of Adolescent and Young Adult Oncology*. 2017;6(4):535-41. doi: 10.1089/jayao.2017.0013. PMID: 619849466.
- Cox S. Age-appropriate care. *Nurs Stand*. 2011. doi: 10.7748/ns.25.20.25.s28. PMID: 28086302.
- Coyne I, Ferris ME. Transition From Child to Adult Services: Current Research, Theory and Practice. *J Pediatr Nurs*. 2015. doi: 10.1016/j.pedn.2015.07.002. PMID: 26253353.
- Crowley EM, Bosslet GT, Khan B, et al. Social complexity negatively influences lung function in cystic fibrosis after transfer to adult care. *Pediatr Pulmonol*. 2020. doi: 10.1002/ppul.24523. PMID: 31531964.
- Cvejic RC, Trollor JN. Transition to adult mental health services for young people with an intellectual disability. *J Paediatr Child Health*. 2018. doi: 10.1111/jpc.14197. PMID: 30294982.
- De Jesus Garcia A, Pham T, Tsai M, et al. 157. Healthcare Transition for Transgender Youth: A Qualitative Study of Patient, Parent, and Provider Perspectives...Society for Adolescent Health and Medicine, Adolescent Health: Transforming Risk to Wellness, 11-14 March 2020, San Diego, California. *J Adolesc Health*. 2020;66:S80-S. doi: 10.1016/j.jadohealth.2019.11.160. PMID: 141170373.
- deShazo RD, Stewart J. Commentary on "resident preferences for a curriculum in healthcare transitions for young adults". *South Med J*. 2012. doi: 10.1097/SMJ.0b013e31826323db. PMID: 22948325.
- Desilva M, Vu CN, Bonawitz R, et al. The Supporting Adolescent Adherence in Vietnam (SAAV) study: Study protocol for a randomized controlled trial assessing an mHealth approach to improving adherence for adolescents living with HIV in Vietnam. *Trials*. 2019;20(1):150. doi: 10.1186/s13063-019-3239-1. PMID: 626550599.
- DeSilva M, Vu CN, Bonawitz R, et al. The Supporting Adolescent Adherence in Vietnam (SAAV) study: study protocol for a randomized controlled trial assessing an mHealth approach to improving adherence for adolescents living with HIV in Vietnam. *Trials [Electronic Resource]*. 2019. doi: 10.1186/s13063-019-3239-1. PMID: 30819228.
- Devinsky O. Transition to adult care for children with epilepsy--a call for action. [Review]. *Epilepsia*. 2014. doi: 10.1111/epi.12630. PMID: 25209089.
- Doyle M, Siegel R, Supe K. Stages of change and transitioning for adolescent patients with obesity and hypertension. *Adv Chronic Kidney Dis*. 2006. doi: 10.1053/j.ackd.2006.07.006. PMID: 17045224.
- Easter S. Transition: Planning for the future starts now. *Living Well*. 2005;5(1):19-22. PMID: 104705493.
- Elias ER. The Trials of Transition: How Well We Are Doing, and How We Can Do Better. *J Grad Med Educ*. 2017. doi: 10.4300/jgme-d-17-00038.1. PMID: 28439358.
- English K, Pajevic E. Adolescents with Hearing Loss and the International Classification of Functioning, Health, and Disability: Children & Youth Version. *Seminars in Hearing*. 2016;37(3):247-56. doi: 10.1055/s-0036-1584407. PMID: 611302053.
- Fair CD, Sullivan K, Dizney R, et al. Knowledge of disease markers and quality of patient-provider interaction among adolescents with perinatally acquired HIV: implications for transition to adult care. *Vulnerable Children & Youth Studies*. 2014;9(2):167-73. doi: 10.1080/17450128.2013.861619. PMID: 94629943.
- Farmer D, Sitkin N. The Maturation of Children With Congenital Anomalies: Who Will Be Their Providers? *JAMA Surgery*. 2014. doi: 10.1001/jamasurg.2013.4873. PMID: 24695816.
- Fegran L, Ludvigsen MS, Aagaard H, et al. Experiences of health care providers in the transfer of adolescent or young adults with a chronic condition from pediatric to adult hospital care: a systematic review protocol. *JBIC Database Of Systematic Reviews And Implementation Reports*. 2016. doi: 10.11124/jbisrir-2016-2496. PMID: 27536792.
- Fleck, Desiree. Correlates of Self-Care in Emerging Adults with Congenital Heart Disease: A Mixed-Methods Study. Correlates of Self-care in Emerging Adults With Congenital Heart Disease: A Mixed-methods Study. 2010:270 p- p. PMID: 109854988.
- Forman SF, Woods ER. Building a strong healthcare infrastructure for adolescents. *Curr Opin Pediatr*. 2013;25(4):437-8. doi: 10.1097/MOP.0b013e328361ca18. PMID: 23744096.
- Forya B. The transition to adult care. *Nurs Times*. 2013. PMID: 23971321.

- Frawley JE, Hebert RS. Seriously Ill Pediatric Patients Who Transition to Adulthood #346. *J Palliat Med*. 2018. doi: 10.1089/jpm.2017.0653. PMID: 29393773.
- Fredericks EM. Transition readiness assessment: The importance of the adolescent perspective. *Pediatr Transplant*. 2017. doi: 10.1111/ptr.12921. PMID: 28370888.
- Fuchs DC, Martel A. Successful Transition to Young Adulthood with Mental Illness: Common Themes and Future Directions. [Review]. *Child Adolesc Psychiatr Clin N Am*. 2017. doi: 10.1016/j.chc.2016.12.015. PMID: 28314463.
- Gabriel P, McManus M, Rogers K, et al. Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review. [Review]. *J Pediatr*. 2017. doi: 10.1016/j.jpeds.2017.05.066. PMID: 28668449.
- Garipey CE, Conwell DL, Afzali A, et al. Establishing a pediatric to adult (p2a) transition for pancreatic disease: connect-ing insppire and proceed. *Gastroenterology*. 2020;158(6):S-608. doi: 10.1016/s0016-5085%2820%2932221-6. PMID: 2005914636.
- Garvey K, Dean T, Berbert L, et al. A group curriculum for teens with type 1 diabetes (T1D) improves transition readiness and diabetes self-efficacy: results of a pilot randomized controlled trial (RCT). *Pediatr Diabetes*. 2019;20:134-. doi: 10.1111/peidi.12924. PMID: CN-02130347.
- Garvey K, Dean T, Christensen S, et al. Improving transition readiness in teens with type 1 diabetes (T1D): feasibility results of a pilot RCT. *Diabetes*. 2019;68. doi: 10.2337/db19-1359-P. PMID: CN-01996719.
- Garvie PA. Transitioning Youth With HIV to Adult HIV Care: Bridging the Gap With Adult Care Clinics for the Life Span. *J Adolesc Health*. 2017. doi: 10.1016/j.jadohealth.2017.07.013. PMID: 28941483.
- Glasper, Alan. Enhancing the experience of transition from child to adult health services. *British journal of nursing* (Mark Allen Publishing). 2018;27(1):958-9. doi: 10.12968/bjon.2018.27.16.958. PMID: 30187795.
- Glasper A. Improving transition from child and adolescent mental health services. *Br J Nurs*. 2018. doi: 10.12968/bjon.2018.27.19.1130. PMID: 30346827.
- Gleeson H, Turner G. Transition to adult services. *Archives of disease in childhood. Education and practice edition*. 2012;97(3):86-92. doi: 10.1136/archdischild-2011-300261. PMID: 21979963.
- Goodson B. Autism Spectrum Uisoraer: A Crisis in Transition of Care. *J Ark Med Soc*. 2016. PMID: 30047627.
- Goossens E, Hilderson D, Moons P. Coaching through transition: a challenge for critical care nurses. *Aust Crit Care*. 2012. doi: 10.1016/j.aucc.2011.08.001. PMID: 21908199.
- Gorter JW. Transition to adult-oriented health care: Perspectives of youth and adults with complex physical disabilities. *Physical and Occupational Therapy in Pediatrics*. 2009;29(4):362-6. doi: 10.3109/01942630903222100. PMID: 355692964.
- Gorter JW, Stewart D, Woodbury-Smith M. Youth in transition: care, health and development. *Child Care Health Dev*. 2011. doi: 10.1111/j.1365-2214.2011.01336.x. PMID: 22007974.
- Greenlee MC, D'Angelo L, Harms SR, et al. Enhancing the Role of Internists in the Transition From Pediatric to Adult Health Care. *Ann Intern Med*. 2017. doi: 10.7326/m16-0514. PMID: 27894127.
- Hageman JR. Transition from Pediatric to Adult Care Is So Important and Challenging. *Pediatr Ann*. 2017. doi: 10.3928/19382359-20170419-02. PMID: 28489220.
- Hakizimana A, Ahmed I, Russell R, et al. Challenges of modern day transition care in inflammatory bowel disease: From inflammatory bowel disease to biosimilars. *World J Gastroenterol*. 2017. doi: 10.3748/wjg.v23.i25.4473. PMID: 28740335.
- Harden PN, Sherston SN. Optimal management of young adult transplant recipients: The role of integrated multidisciplinary care and peer support. *Ann Saudi Med*. 2013;33(5):489-91. doi: 10.5144/0256-4947.2013.489. PMID: 372338214.
- Harris R. Complexities and challenges of transition to adult services in adolescents with vertically transmitted HIV infection. *J Fam Plann Reprod Health Care*. 2015. doi: 10.1136/jfprhc-2014-100996. PMID: 25512353.
- Harrison, Penny. Helping paediatric patients transition to adult services. *Gastrointestinal Nursing*. 2019;17(1):75-. doi: 10.12968/gasn.2019.17.10.75. PMID: 140470164.

- Harry R, Fraser-Irwin C, Mouat S, et al. Long-term follow up of paediatric liver transplant recipients: outcomes following transfer to adult healthcare in New Zealand. *Intern Med J*. 2015. doi: 10.1111/imj.12721. PMID: 25955464.
- Hersh A. Growing up and moving on--transition of care for patients with childhood-onset rheumatic disease. *J Rheumatol*. 2014. doi: 10.3899/jrheum.140140. PMID: 24692518.
- Hewer SCL, Tyrrell J. Cystic fibrosis and the transition to adult health services. *Arch Dis Child*. 2008;93(1):817-21. doi: 10.1136/adc.2008.143578. PMID: 18809702.
- Hibbard A, Flanagan K, Judd A, et al. Clinical outcomes in adolescents with perinatally acquired HIV (PAH) transitioning from paediatric to adult care in a large regional HIV clinic in London. *Sex Transm Infect*. 2017;93(S):A73-A4. doi: 10.1136/sextrans-2017-053232.217. PMID: 617187163.
- Hickam T, White PH, Modrcin A, et al. Implementing a Nationally Recognized Pediatric-to-Adult Transitional Care Approach in a Major Children's Hospital. *Health Soc Work*. 2018. doi: 10.1093/hsw/hlx049. PMID: 29253121.
- Hilderson D, Westhovens R, Wouters C, et al. Transitional care for adolescents with rheumatic diseases: urgent need for more research. *Child Care Health Dev*. 2008. doi: 10.1111/j.1365-2214.2008.00833.x. PMID: 18410646.
- Hilgers MV, Slater ME, Sadak KT. Location, location, location: Does it matter for childhood cancer survivors considering pediatric vs. adult care settings? *Pediatr Blood Cancer*. 2017. doi: 10.1002/pbc.26426. PMID: 28084677.
- Holmberg C. Nonadherence after pediatric renal transplantation: Detection and treatment. *Curr Opin Pediatr*. 2019;31(2):219-25. doi: 10.1097/mop.0000000000000734. PMID: 631561005.
- Hudsmith LE, Thorne SA. Transition of care from paediatric to adult services in cardiology. [Review] [24 refs]. *Arch Dis Child*. 2007. doi: 10.1136/adc.2006.103812. PMID: 17895343.
- Hunt S, Davis T. Preparing for Transition of Youth with Special Health Care Needs. *Curr Probl Pediatr Adolesc Health Care*. 2017;47(8):200-7. doi: 10.1016/j.cpped.2017.07.004. PMID: 28803828.
- Hunter Nolan RE, McLaughlin E, Duane Y, et al. Adolescent feedback on the Haemophilia Transition Programme between Our Lady's Children's Hospital and St. James's Hospital Dublin Ireland [Poster Abstract]. In: 17th International Conference on Integrated Care; May 8-10, 2017; Dublin. 2017;17(5):A569.
- Iannelli-Madigan G. Transitioning the adolescent with type 1 diabetes mellitus. *J Pediatr Nurs*. 2012. doi: 10.1016/j.pedn.2012.06.004. PMID: 22819877.
- Ishizaki Y, Maru M, Higashino H. Editorial: Advances in Health-Care Transition for Patients With Childhood-Onset Chronic Diseases: International Perspectives. *Frontiers in Pediatrics*. 2018. doi: 10.3389/fped.2018.00080. PMID: 29651412.
- Iyer SN, Boksa P, Lal S, et al. Transforming youth mental health: A Canadian perspective. *Ir J Psychol Med*. 2015;32(1):51-60. doi: 10.1017/ipm.2014.89. PMID: 612994805.
- Jameson, Paula L. Adolescent Transition: Challenges and Resources for the Diabetes Team. *Diabetes Spectr*. 2011;24(1):18-21. doi: 10.2337/diaspect.24.1.18. PMID: 104869298.
- Jesus LE. Is the transition possible? *Revista do Colegio Brasileiro de Cirurgioes*. 2014. doi: 10.1590/0100-69912014006001. PMID: 25742402.
- Jorgensen S. Lost in transition. *Learning Disability Practice*. 2008;11(7):30-1. doi: 10.7748/ldp.11.7.30.s23. PMID: 105677553.
- JPRN-UMIN000018136. Building self care system to support transitions for liver transplant children. <http://www.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-UMIN000018136>. 2015. PMID: CN-01880129.
- JPRN-UMIN000028997. Evaluation of the effects of transitional care outpatient clinic among patients with childhood-onset chronic disease: randomized controlled trial. <http://www.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-UMIN000028997>. 2017. PMID: CN-01889682.
- K. B. Older teens with type 1 diabetes face challenges as they transition into adult care. *AHRQ Research Activities*. 2013(3):26-. PMID: 119587131.
- Kaehne, Axel. Integrating children's services - between aspiration and reality. *International Journal of Integrated Care (IJIC)*. 2016;16(6):1-3. doi: 10.5334/ijic.2721. PMID: 120724814.

- Kahn SA. Transition of Care for Adolescents and Young Adults With Inflammatory Bowel Disease: The More We Learn, The Less We Know. *J Pediatr Gastroenterol Nutr.* 2016. doi: 10.1097/mpg.0000000000001285. PMID: 27768650.
- Kalitsi J, Kapoor RR, Kalogirou N, et al. Prolactinomas in children and young adults: 10 year experience in a tertiary regional paediatric - Young Adult - NeuroEndocrine surgical centre. *Horm Res Paediatr.* 2016;86(S):420. doi: 10.1159/000449142. PMID: 615915895.
- Kerecuk L, Lipkin G, Milford D, et al. The west midlands renal transplant transition service: effect on graft function. *Nephrology dialysis transplantation.* 2015;30:iii373. doi: 10.1093/ndt/gfv185.77. PMID: CN-01172939.
- Kerin L, McNicholas F, Lawlor A. Hearing the lived experience of young women with a rare genetic disorder 22q11.2DS regarding integrated care. *International Journal of Integrated Care (IJIC).* 2017;17:1-2. doi: 10.5334/ijic.3537. PMID: 131980859.
- Khunti K, Seidu S. Diabetes research in primary care: fiction, reality or essential? *Diabet Med.* 2018;35(7):832-4. doi: 10.1111/dme.13638. PMID: 130266998.
- Klaas S, Hickey K. Transition to adult care. *SCI nursing : a publication of the American Association of Spinal Cord Injury Nurses.* 2001;18(3):158-60. PMID: 12503463.
- Konsler GK, Jones GR. Transition issues for survivors of childhood cancer and their healthcare providers. *Cancer Pract.* 1993;1(4):319-24. PMID: 24876007.
- Kordonouri O. Transition of care for young adults with chronic diseases. *The Lancet Child & Adolescent Health.* 2017. doi: 10.1016/s2352-4642(17)30102-5. PMID: 30169176.
- Kosmach-Park, Beverly. Transition: changing our approach to care for long-term pediatric transplant survivors. *Progress in transplantation (Aliso Viejo, Calif.).* 2006;16(4):281-2. PMID: 17183933.
- Kovacs AH, Webb GD. Preparing Pediatric Patients for Adult Care: Are We Ready? *J Pediatr.* 2015. doi: 10.1016/j.jpeds.2015.09.034. PMID: 26421488.
- Koyle MA, Golda N, Hillis C, et al. A proposed solution to a urological tightrope walk: The challenge of transition of spina bifida patients from pediatric to adult care in Ontario. *Canadian Urological Association Journal.* 2016;10(9):306-10. doi: 10.5489/cuaj.4070. PMID: 118957916.
- Kreuzer M, Prufe J, Bethe D, et al. The TRANSNephro-study examining a new transition model for post-kidney transplant adolescents and an analysis of the present health care: Study protocol for a randomized controlled trial. *Trials.* 2014;15(1):505. doi: 10.1186/1745-6215-15-505. PMID: 605028723.
- Kripke C, Grumbach K. Transition to adult care for survivors of serious childhood illnesses and disabilities. *Arch Pediatr Adolesc Med.* 2010. doi: 10.1001/archpediatrics.2010.77. PMID: 20530312.
- Kubota W, Honda M, Okada H, et al. A consensus statement on health-care transition of patients with childhood-onset chronic kidney diseases: providing adequate medical care in adolescence and young adulthood. [Review]. *Clin Exp Nephrol.* 2018. doi: 10.1007/s10157-018-1589-8. PMID: 29869191.
- Laffel L. Lost in transition: finding a path forward for young adults with Type 1 diabetes. *Diabet Med.* 2018. doi: 10.1111/dme.13684. PMID: 29790218.
- Lai T, Berry A. A retrospective analysis of met and unmet needs for adolescents with intellectual and developmental disabilities one year post transition into adult services. *J Intellect Disabil Res.* 2016;60(7):794. PMID: 611635775.
- Lai T, Son J, Berry A, et al. Evaluation of the Metro-Regional Intellectual Disability Network Schoolkit Transition Clinics: Parents and carers' formative assessment. *J Intellect Disabil Res.* 2016;60(7):794. PMID: 611635754.
- Lau KK. Transition care in Hong Kong. *Hong Kong Medical Journal.* 2016. doi: 10.12809/hkmj165060. PMID: 27738298.
- Lawson EF, Mellins ED. Paediatric rheumatic diseases: Navigating the transition from paediatric to adult care. *Nature Reviews Rheumatology.* 2017. doi: 10.1038/nrrheum.2017.16. PMID: 28202918.
- Lebensburger JD, Bemrich-Stolz CJ, Howard TH. Barriers in transition from pediatrics to adult medicine in sickle cell anemia. *J Blood Med.* 2012;3:105-12. doi: 10.2147/jbm.S32588. PMID: 23055784.

- Lin JA, Ramundo M, Ben-Zion S, et al. 181 - Rise to Transition: A Structured Transition Protocol for Renal Transplant Recipient Children. *J Adolesc Health*. 2018;62:S93-S4. doi: 10.1016/j.jadohealth.2017.11.189. PMID: 127619161.
- Lowton K, Mathes L, Wyatt H, et al. Evaluation of transition services for young people with cystic fibrosis in Southeast London. *Journal of interprofessional care*. 2005;19(4):408-9. PMID: 16076602. MacKie A, Rankin K, Yaskina M, et al. Randomized controlled trial of a transition intervention program for young adolescents with congenital heart disease [Abstract 12604]. *Circulation*. 2019;140. doi: 10.1161/circ.140.suppl_1.12604. PMID: CN-02087678.
- Mackie AS, Rempel GR, Kovacs AH, et al. A cluster randomized trial of a transition intervention for adolescents with congenital heart disease: Rationale and design of the CHAPTER 2 study. *BMC Cardiovasc Disord*. 2016;16(1):127. doi: 10.1186/s12872-016-0307-2. PMID: 613898865.
- Mahan JD, Betz CL, Okumura MJ, et al. Self-management and transition to adult health care in adolescents and young adults: A team process. *Pediatr Rev*. 2017;38(7):305-19. doi: 10.1542/pir.2016-0074. PMID: 617070131.
- Martins P, Barreira SC, Melo AT, et al. Transition in a paediatric rheumatology unit - experience from a tertiary unit. *Acta Reumatologica Portuguesa*. 2019. PMID: 32008033.
- McBride ME, Foushee MT, Brown RN, et al. Outcomes of pediatric heart transplant recipients transitioned to adult care: An exploratory study. *J Heart Lung Transplant*. 2010;29(1):1309-10. doi: 10.1016/j.healun.2010.06.005. PMID: 50982934.
- McDonagh JE. Young people first, juvenile idiopathic arthritis second: transitional care in rheumatology. [Review] [50 refs]. *Arthritis Rheum*. 2008. doi: 10.1002/art.23928. PMID: 18668608.
- McDonagh JE, Hackett J. Interrelationship of self-management and transitional care needs of adolescents with arthritis: comment on the article by Stinson et al. *Arthritis Rheum*. 2008. doi: 10.1002/art.23921. PMID: 18668616.
- McDonagh JE, Kelly DA. Trans-plan-sition! Transplantation and transition. *Pediatr Transplant*. 2007;11(6):578-81. PMID: 17663677.
- McDonagh JE, Shaw KL. Health care transition counseling for youth with arthritis: comment on the article by Scal et al. *Arthritis Rheum*. 2009. doi: 10.1002/art.24640. PMID: 19644912.
- McDonald G. Transition to adult cystic fibrosis care. *RT: The Journal for Respiratory Care Practitioners*. 2000;13(5):46-8. PMID: 107149589.
- McLaughlin S, Terry C, Neukirch J, et al. Transitions to Adult Care for Rhode Island Youth with Special Healthcare Needs. *R I Med*. 2016. PMID: 27472770.
- McPheeters M. A single nurse-led educational session may facilitate transition from paediatric to adult healthcare for adolescents with heart disease. *Evid Based Nurs*. 2015. doi: 10.1136/eb-2014-101957. PMID: 25563639.
- McRandal M, Arthur A, Whitehouse WP. Young person's epilepsy transition clinic. *Child Care Health Dev*. 2012. doi: 10.1111/j.1365-2214.2012.01364.x. PMID: 22670576.
- Meadows AK, Bosco V, Tong E, et al. Transition and transfer from pediatric to adult care of young adults with complex congenital heart disease. *Curr Cardiol Rep*. 2009;11(4):291-7. doi: 10.1007/s11886-009-0042-8. PMID: 354885302.
- Meininger ET, Ott MA. Slow Steps Toward Transition. *J Pediatr*. 2018. doi: 10.1016/j.jpeds.2018.08.003. PMID: 30170860.
- Melgar T, Brands C, Sharma N. Health care transition. *Pediatrics*. 2005. doi: 10.1542/peds.2005-0275. PMID: 15867079.
- Mencin AA, Loomba R, Lavine JE. Caring for children with NAFLD and navigating their care into adulthood. [Review]. *Nature Reviews Gastroenterology & Hepatology*. 2015. doi: 10.1038/nrgastro.2015.146. PMID: 26323878.
- Middleton PG, Matson AG, Robinson PD, et al. Cystic fibrosis related diabetes: Potential pitfalls in the transition from paediatric to adult care. *Paediatr Respir Rev*. 2014;15(3):281-4. doi: 10.1016/j.prrv.2014.05.003. PMID: 53210249.
- Minicozzi A. Transition to adult care: another view. *Pediatr Nurs*. 2000. PMID: 12026477.
- Minniti CP, Vichinsky E. Lifespan care in SCD: Whom to transition, the patients or the health care system? *Am J Hematol*. 2017. doi: 10.1002/ajh.24685. PMID: 28211097.

- Misseri, Rosalia. Barriers to transition in young adults with neurogenic bladder. *J Pediatr Urol.* 2016;12(4):259. doi: 10.1016/j.jpuro.2016.04.050. PMID: 27524424.
- Misseri R. Comparing transition of care from adolescence to adulthood for patients with congenital urological conditions in Canada and the U.S. *Canadian Urological Association Journal.* 2016. doi: 10.5489/cuaj.4090. PMID: 27800049.
- Mitka M. Young adult cancer survivors face barriers to receiving primary care. *JAMA.* 2012. doi: 10.1001/jama.2012.14197. PMID: 23093148.
- Mixter S, Stewart RW. Commentary on "Lessons Learned from Building a Pediatric-to-Adult Sickle Cell Transition Program". *South Med J.* 2019. doi: 10.14423/smj.0000000000000951. PMID: 30830236.
- Moodie D. Transition--a pediatric cardiology problem. *Congenit Heart Dis.* 2015. doi: 10.1111/chd.12256. PMID: 25876668.
- Moreno MA. JAMA pediatrics patient page. Transition of care from pediatric to adult clinics. *JAMA Pediatrics.* 2013. doi: 10.1001/jamapediatrics.2013.2657. PMID: 23817857.
- Moses R, Vyas A, Shakespeare D, et al. The development of a specialist model of care for transitional paediatric neuromuscular patients: Collaboration between respiratory, neurological and neuro-rehabilitation specialties. *Physiotherapy.* 2016;102(S):e199-e200. doi: 10.1016/j.physio.2016.10.243. PMID: 614123345.
- Moulton D, Rosen M, Beaulieu D, et al. Prospective randomized trial of a progressive pediatric to adult transition of care program in adolescents with inflammatory bowel disease. *Gastroenterology.* 2013;144(5):S532. PMID: CN-01026077.
- Mubanga N, Baumgardner DJ, Kram JJF. Health Care Transitions for Adolescents and Young Adults With Special Health Care Needs: Where Are We Now? *Journal of Patientcentered Research & Reviews.* 2017. doi: 10.17294/2330-0698.1406. PMID: 31413975.
- Mukherjee S, Pasulka J. Care for Adults with Spina Bifida: Current State and Future Directions. *Topics in spinal cord injury rehabilitation.* 2017;23(2):155-67. doi: 10.1310/sci2302-155. PMID: 29339892.
- Nabbout R, Camfield CS, Andrade DM, et al. Treatment issues for children with epilepsy transitioning to adult care. [Review]. *Epilepsy Behav.* 2017. doi: 10.1016/j.yebeh.2016.11.008. PMID: 28188045.
- Nathawad R, Hanks C. Optimizing the Office Visit for Adolescents with Special Health Care Needs. *Curr Probl Pediatr Adolesc Health Care.* 2017. doi: 10.1016/j.cppeds.2017.07.002. PMID: 28844854.
- Nazareth D, Walshaw M. Coming of age in cystic fibrosis - Transition from paediatric to adult care. *Clinical Medicine, Journal of the Royal College of Physicians of London.* 2013;13(5):482-6. doi: 10.7861/clinmedicine.13-5-482. PMID: 370368089.
- Ness TE, Small AT. Do You See Me? *Am J Trop Med Hyg.* 2019. doi: 10.4269/ajtmh.19-0438. PMID: 31971143.
- Nguyen T, Baptiste S. Innovative practice: exploring acculturation theory to advance rehabilitation from pediatric to adult "cultures" of care. *Disabil Rehabil.* 2015. doi: 10.3109/09638288.2014.932443. PMID: 24965211.
- Nguyen T, Gorter JW. Use of the international classification of functioning, disability and health as a framework for transition from paediatric to adult healthcare. *Child Care Health Dev.* 2014;40(6):759-61. doi: 10.1111/cch.12125. PMID: 24304334.
- Nicolarsen J, Weissberg-Benchell J. Transition Medicine-From Pediatric to Adult Care: Part 1. *Pediatr Ann.* 2017. doi: 10.3928/19382359-20170419-01. PMID: 28489222.
- Nishi L, Langman C, Ghossein C. A Nephrology Pediatric to Adult Transition Clinic: A Pilot Program. *Kidney Medicine.* 2019;1(6):405-6. doi: 10.1016/j.xkme.2019.07.012. PMID: 2003861676.
- Niwa, Koichiro. Adults with congenital heart disease transition. *Curr Opin Pediatr.* 2015;27(5):576-80. doi: 10.1097/mop.0000000000000270. PMID: 26262578.
- Nolan VG, Anderson SM, Smeltzer MP, et al. Pediatric to adult care co-location transitional model for youth with sickle cell disease. *Am J Hematol.* 2018;93(1):E30-E2. doi: 10.1002/ajh.24953. PMID: 619677926.
- Nolan VG, Anderson SM, Smeltzer MP, et al. Pediatric to adult care co-location transitional model for youth with sickle cell disease. *Am J Hematol.* 2018;93(1):E30-E2. doi: 10.1002/ajh.24953. PMID: 619677926

- Nugent BD, Moore A, Costello A, et al. Partnering to optimize care of childhood cancer survivors. [Review]. *J Fam Pract*. 2017. PMID: 28375395.
- O'Connell L, Keegan D, Byrne K, et al. Teenagers with IBD in transition: Are we meeting their needs? *Ir J Med Sci*. 2015;184(2):S34. doi: 10.1007/s11845-014-1244-7. PMID: 611622160.
- O'Krafka P, Weir T. Development and implementation of a transition program for youths with disabilities. *Occupational Therapy Now*. 2018;20(2):22-3. PMID: 128370507.
- Pack-Mabien, Ardie V. A Mixed Methods Study Evaluating a Pediatric to Adult Care Transition Program for Sickle Cell Disease. *Mixed Methods Study Evaluating A Pediatric To Adult Care Transition Program For Sickle Cell Disease*. 2018:1-. PMID: 131799111.
- Pahl E, Van'T Hof K, Andrei A, et al. Pediatric heart transplantation: transitioning to adult care. *J Heart Lung Transplant*. 2017;36(4):S265-S6.
- Pahl E. Pediatric heart transplantation: transitioning to adult care TRANSIT. *clinical trials.gov*. 2018;37(4):S392-S3. CN-01570378.
- Palman J, Shoop-Worrall S, Hyrich K, et al. Update on the epidemiology, risk factors and disease outcomes of Juvenile idiopathic arthritis. [Review]. *Best Practice & Research in Clinical Rheumatology*. 2018. doi: 10.1016/j.berh.2018.10.004. PMID: 30527427.
- Patel, Rowlett, Greydanus. Youth with Chronic Conditions in Transition to Adult Health Care: An Overview. *Adolescent medicine (Philadelphia, Pa.)*. 1994;5(3):543-54. PMID: 10358296.
- Patterson D. Promoting successful transition from pediatric to adult-oriented health care. *Exceptional Parent*. 2004;34(3):56-60. PMID: 106754360.
- Petrin, Christine E. Transitioning Youth Living With HIV. *Clin Pediatr (Phila)*. 2020;59(3):225-7. doi: 10.1177/0009922819881193. PMID: 141805305.
- Peycelon M, Misseri R. The basics of transition in congenital lifelong urology. *World J Urol*. 2020. doi: 10.1007/s00345-020-03116-z. PMID: 32076821.
- Rafferty M, Turner G, Tobin A. Co-designing an Integrated Care Pathway for Children and Families with a Neuromuscular Disorder in Ireland. *International Journal of Integrated Care (IJIC)*. 2018;18:1-2. doi: 10.5334/ijic.s2355. PMID: 138001843.
- Raina R, Wang J, Sethi SK, et al. Survey on health care transition services in pediatric nephrology. *Clin Exp Nephrol*. 2018. doi: 10.1007/s10157-017-1426-5. PMID: 28585110.
- Rami B, Schober E, Bozkurt L, et al. Lost in transition? What happens to young adults with DMT1 after the transition from pediatric to adult care? *Hormone research in paediatrics*. 2010;74:179-80. doi: 10.1159/000321348. PMID: CN-01029494.
- Ramstack DW, Faull D, Riley KM, et al. Upgrading Pediatric Transition: Combining Best Practices for Success. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2020;39(4):S493-S4. doi: 10.1016/j.healun.2020.01.075. PMID: 631926612.
- Reilly NR, Green PHR, Ludvigsson JF. No difference in emergency department visits before and after transition for coeliac disease. *Gut*. 2017. doi: 10.1136/gutjnl-2017-313882. PMID: 28232474.
- Reiss J. Health care transition for emerging adults with chronic health conditions and disabilities. *Pediatr Ann*. 2012;41(1):429-35. doi: 10.3928/00904481-20120924-16. PMID: 365940491.
- Resseguier N, Rosso-Delsemme N, Beltran Anzola A, et al. Determinants of adherence and consequences of the transition from adolescence to adulthood among young people with severe haemophilia (TRANSHEMO): study protocol for a multicentric French national observational cross-sectional study. *BMJ Open*. 2018. doi: 10.1136/bmjopen-2018-022409. PMID: 30049701.
- Roemer J. Transitioning to adult care. *Diabetes Self Manag*. 2012. PMID: 22685882.
- Rollins JA. Smooth transitions to adult health care: do all the rules have to change? *Pediatr Nurs*. 2014. PMID: 25929111.
- Rosenberg, Linda. Bridging the Gap Between Adolescence and Adulthood: the Challenges of Emerging Adults. *The journal of behavioral health services & research*. 2016;43(4):518-20. PMID: 27678111.
- Rudgley, Lisa. Left high and dry. Healthcare transition experiences of young adults with attention deficit hyperactivity disorder. *Left high & dry. Healthcare transition experiences of young adults with attention deficit hyperactivity disorder*. 2013:N.PAG p-N.PAG p. PMID: 109865722.

- Saarijarvi M, Wallin L, Moons P, et al. Transition program for adolescents with congenital heart disease in transition to adulthood: protocol for a mixed-method process evaluation study (the STEPSTONES project). *BMJ Open*. 2019. doi: 10.1136/bmjopen-2018-028229. PMID: 31377699.
- Sainz T, Navarro ML. HIV-Infected Youths: Transition in Spain Compared to the Netherlands. *Clinical infectious diseases : an official publication of the Infectious Diseases Society of America*. 2017;64(2):230. doi: 10.1093/cid/ciw702. PMID: 27986681.
- Sam-Agudu NA, Pharr JR, Bruno T, et al. Adolescent Coordinated Transition (ACT) to improve health outcomes among young people living with HIV in Nigeria: study protocol for a randomized controlled trial. *Trials [Electronic Resource]*. 2017. doi: 10.1186/s13063-017-2347-z. PMID: 29237487.
- Sampat K, Losty PD. Transitional care and paediatric surgery. *Br J Surg*. 2016;103(3):163-4. doi: 10.1002/bjs.10118. PMID: 607903294.
- Samuel S, Dimitropoulos G, Schraeder K, et al. Pragmatic trial evaluating the effectiveness of a patient navigator to decrease emergency room utilisation in transition age youth with chronic conditions: The Transition Navigator Trial protocol. *BMJ Open*. 2019;9(1):e034309. doi: 10.1136/bmjopen-2019-034309. PMID: 630188765.
- Sánchez C, Hernani T, Jimenez IM, et al. P094. Current assessment of a transition care program in inflammatory bowel disease in tertiary hospital: perceptions from surveys of pediatric patients. *J Pediatr Gastroenterol Nutr*. 2017;65:S62-S. PMID: 125452097.
- Sanders R, Kuo D, Levey E, et al. Transitioning adolescents to adult care and adulthood: is it time yet?...part 2 of 2. *Contemp Pediatr*. 2009;26(1):46-52. PMID: 105281286.
- Sanders R, Kuo D, Levey E, et al. Transitioning adolescents to adult care and adulthood: is it time yet?...part 1 of 2. *Contemp Pediatr*. 2009;26(1):46-52. PMID: 105259438.
- Sarmah A. Transitional care of young disabled people. *Arch Dis Child*. 1999. doi: 10.1136/adc.81.2.189d. PMID: 10532925.
- Sattoe JNT, Peeters MAC, Hilberink SR, et al. Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open*. 2016. doi: 10.1136/bmjopen-2016-011926. PMID: 27566639.
- Sawyer SM, Blair S, Bowes G. Chronic illness in adolescents: transfer or transition to adult services?. [Review] [22 refs]. *J Paediatr Child Health*. 1997. doi: 10.1111/j.1440-1754.1997.tb01005.x. PMID: 9145346.
- Scal, Peter. Improving Health Care Transition Services. *JAMA Pediatrics*. 2016;170(3):197-9. doi: 10.1001/jamapediatrics.2015.3268. PMID: 113708094.
- Scalzi L, Olsen N. Impact of online education and social media intervention for self-management in adolescents with SLE. *Arthritis and rheumatology*. 2015;67(n). doi: 10.1002/art.39448. PMID: CN-01162650.
- Schlucter J, Dokken D, Ahmann E. Transitions from Pediatric to Adult Care: Programs and Resources. *Pediatr Nurs*. 2015;41(2):85-6. PMID: 605974106.
- Schrans DGM, Abbott D, Peay HL, et al. Transition in Duchenne muscular dystrophy: An expert meeting report and description of transition needs in an emergent patient population: (Parent Project Muscular Dystrophy Transition Expert Meeting 17-18 June 2011, Amsterdam, The Netherlands). *Neuromuscul Disord*. 2013. doi: 10.1016/j.nmd.2012.08.009. PMID: 22989602.
- Shah P. Health and social outcomes for transitioning youth. *J Pediatr Rehabil Med*. 2014. doi: 10.3233/prm-140268. PMID: 24919933.
- Shah PK. Transition, part 2. *J Pediatr Rehabil Med*. 2015. doi: 10.3233/prm-150312. PMID: 25737342.
- Shaw G. Leaving the Nest: Improving Transitions of Care from Child to Adult Neurology. *Neurology Today*. 2016;16(1):16-7. doi: 10.1097/01.nt.0000491143.92222.9b. PMID: 117431092.
- Shaw KL, Southwood TR, McDonagh JE, et al. Growing up and moving on in rheumatology: a multicentre cohort of adolescents with juvenile idiopathic arthritis. *Rheumatology*. 2005. doi: 10.1093/rheumatology/keh603. PMID: 15769786.
- Shepard KF, Barsotti LM. Family focus--transitional health care. *Nurs Outlook*. 1975;23(9):574-7. PMID: 171629.
- Shnorhavorian M. Transitioning patients with disorders of sex development to adult care: the role of the pediatric urologist. *J Urol*. 2012. doi: 10.1016/j.juro.2012.06.070. PMID: 22818341.

- Shulman R, Zenlea I, Shah BR, et al. Testing an audit and feedback-based intervention to improve glycemic control after transfer to adult diabetes care: protocol for a quasi-experimental pre-post design with a control group. *BMC Health Serv Res*. 2019;19(1):885. doi: 10.1186/s12913-019-4690-0. PMID: 31766999.
- Simoes E, Kronenthaler A, Emrich C, et al. Development of a provisional model to improve transitional care for female adolescents with a rare genital malformation as an example for orphan diseases. *BioMed Research International*. 2014;2014:913842. doi: 10.1155/2014/913842. PMID: 600789562.
- Singh SP, Tuomainen H, Girolamo GD, et al. Protocol for a cohort study of adolescent mental health service users with a nested cluster randomised controlled trial to assess the clinical and cost-effectiveness of managed transition in improving transitions from child to adult mental health services (the MILESTONE study). *BMJ Open*. 2017;7(1):e016055. doi: 10.1136/bmjopen-2017-016055. PMID: 618795217.
- Smith, Joetta. A Transition Quick Guide for Educating Youth with Hemophilia. *Transition Quick Guide for Educating Youth with Hemophilia*. 2018:1-. PMID: 136066351.
- Sohn AH, Hazra R. Old Problems for New Providers: Managing the Postpediatric HIV Generation. *Clin Infect Dis*. 2017. doi: 10.1093/cid/cix068. PMID: 28369317.
- Somerville AC, Tanner AM, Weatherburn DL, et al. Continuity of Care in Tertiary Paediatric Rehabilitation: Implications for Social Work Practice. *International Journal of Integrated Care (IJIC)*. 2018;18:1-2. doi: 10.5334/ijic.s1072. PMID: 138115059.
- Spaic T, Mahon JL, Hramiak I, et al. Multicentre randomized controlled trial of structured transition on diabetes care management compared to standard diabetes care in adolescents and young adults with type 1 diabetes (Transition Trial). *BMC Pediatr*. 2013;13(1):163. doi: 10.1186/1471-2431-13-163. PMID: 52808132.
- Spaic T, Goldbloom E, Gallego P, et al. A structured transition program in young adults with type 1 diabetes is associated with improved satisfaction with diabetes care. *Diabetes 77th Scientific Sessions of the American Diabetes Association, ADA 2017*. 2017;66:A77.
- Steinbeck K, Harvey V, Shrewsbury V, et al. Outcomes for adolescents with type 1 diabetes mellitus participating in a comprehensive program to aid transition from pediatric to adult care: a pilot randomized controlled trial. *J Adolesc Health*. 2012;50(2):S77-. doi: 10.1016/j.jadohealth.2011.10.205. PMID: CN-01005873.
- Stinson J, Campillo S, Cellucci T, et al. A Pilot Randomized Controlled Trial of the iCanCope Pain Self-management Application for Adolescents with Juvenile Idiopathic Arthritis. *2017 ACR/ARHP Pediatric Rheumatology Symposium in: Arthritis & Rheumatology*. 2017;69(S4):24-6. doi: 10.1002/art.v69.S4. Abstract Number: 097.
- Stoeck PA, Cheng N, Berry AJ, et al. Health care transition counseling for youth with special health care needs. *Am Fam Physician*. 2012;86(1):1024. PMID: 366234003.
- Stoeck PA, Cheng N, Berry AJ, et al. Health care transition counseling for youth with special health care needs. *Am Fam Physician*. 2012. PMID: 23198669.
- Tanaka ST, Kaufman MR, Brock JW. The aging pediatric urology patient: obstacles and opportunities in transition care. *J Urol*. 2012. doi: 10.1016/j.juro.2012.01.021. PMID: 22335878.
- The L. Transition health care for adolescents. *Lancet*. 2018. doi: 10.1016/s0140-6736(18)32769-7. PMID: 30496064.
- Thomson ABR. Transition of Care between Paediatric and Adult Gastroenterology: Preface. *Best Practice and Research: Clinical Gastroenterology*. 2003;17(2):139-40. doi: 10.1016/s1521-6918%2803%2900013-1. PMID: 41128110.
- Tosi LL, Maher N, Moore DW, et al. Adults with cerebral palsy: A workshop to define the challenges of treating and preventing secondary musculoskeletal and neuromuscular complications in this rapidly growing population. *Dev Med Child Neurol*. 2009;51(S):2-11. doi: 10.1111/j.1469-8749.2009.03462.x. PMID: 355235165.
- Tuchman LK, McCarter R, Khan A, et al. 46. Effects of a Randomized Health Care Transition Care Coordination Intervention on Perception of Chronic Illness Care and Transition Readiness. *J Adolesc Health*. 2015;56:S25-S. doi: 10.1016/j.jadohealth.2014.10.050. PMID: 103871840.

- Tucker LB, Cabral DA. Transition of the adolescent patient with rheumatic disease: issues to consider. *Pediatr Clin North Am.* 2005;52(2):641-viii. PMID: 15820382.
- Valcarcel T. Role of the primary care provider in transitioning patients with juvenile arthritis. *Pediatr Ann.* 2012. doi: 10.3928/00904481-20121022-13. PMID: 23814935.
- Van D, Timothy C. Child and adolescent psychiatrists are experts in transitional aged youth, aren't we? *J Am Acad Child Adolesc Psychiatry.* 2014;53(4):476-7. doi: 10.1016/j.jaac.2014.01.010. PMID: 24655657.
- Vazquez E. No longer a child. Transitioning into adult care terrifies youth with HIV. *Positively Aware: the Monthly Journal of the Test Positive Aware Network.* 2006. PMID: 16886245.
- Versnel, Joan. You're in Charge: an innovative intervention program for families with adolescents with chronic illnesses. *WFOT Bulletin.* 2013;67(1):41-8. doi: 10.1179/otb.2013.67.1.010. PMID: 87562736.
- Vonder Muhll I. Transition to adult care for adolescents with congenital heart disease - Is there a light at the end of the tunnel? *Int J Cardiol.* 2020. doi: 10.1016/j.ijcard.2020.03.073. PMID: 32276772.
- Wallis E, Salek E, Steinway C, et al. Transition from pediatric to adult healthcare for youth with complex chronic conditions: a primary care pilot study. *Journal of adolescent health.* 2015;56(2):S125. doi: 10.1016/j.jadohealth.2014.10.250. PMID: CN-01066946.
- Walsh O, Wynne M, O'Donnell M, et al. The perceptions of patients, their parents and healthcare providers on the transition of young adults with type 1 diabetes to adult services in the West of Ireland. *Ir Med J.* 2018;111(7):787. PMID: 623585527.
- Warady B, Ferris M. The transition of pediatric to adult-centered health care. *Nephrol News Issues.* 2009;23(9):3p-p. PMID: 105279073.
- Warwick J, Bouliotis G, Wells P, et al. Methodological issues in trials of youth mental health: what have we learnt during the MILESTONE study? *Trials.* 2019;20. doi: 10.1186/s13063-019-3688-6. PMID: CN-02009395.
- Watson AR. Continuity in transition from paediatric to adult healthcare. *J R Coll Physicians Edinb.* 2012. doi: 10.4997/jrcpe.2012.101. PMID: 22441054.
- Watts L. Stepping up to adult services. *BMJ.* 2018. doi: 10.1136/bmj.k3886. PMID: 30257916.
- Webb AK, Jones AW, Dodd ME. Transition from paediatric to adult care: Problems that arise in the adult cystic fibrosis clinic. *Journal of the Royal Society of Medicine, Supplement.* 2001;94(4):8-11. doi: 10.1177/014107680109440s04. PMID: 32844179.
- Wein AJ. Re: Adolescent Urology and Transitional Care. *J Urol.* 2017. doi: 10.1016/j.juro.2016.11.010. PMID: 28093163.
- Weinstock M. Transitioning care: H&HN's 'Saves Lives Now' series profiles a better way to handle patient handoffs. *H&HN: Hospitals & Health Networks.* 2005;79(6):27-8. PMID: 106548263.
- Weinstock M. Save lives now. *Patient care. Transitioning care. Hosp Health Netw.* 2005. PMID: 16047617.
- Weissberg-Benchell J, Nicolarsen J. Transition Medicine-From Pediatric to Adult Care: Part 2. *Pediatr Ann.* 2017. doi: 10.3928/19382359-20170517-03. PMID: 28599025.
- Wernovsky G, Lihn SL, Olen MM. Creating a lesion-specific "roadmap" for ambulatory care following surgery for complex congenital cardiac disease. *Cardiol Young.* 2017. doi: 10.1017/s1047951116000974. PMID: 27373527.
- White, Kelly N. Transition experiences of the chronically ill adolescent. *Transition experiences of the chronically ill adolescent.* 2014:122 p- p. PMID: 109786580.
- White H, Langman N, Henderson S. A school-based transition program for high-risk adolescents. *Psychiatr Serv.* 2006;57(8):1211. doi: 10.1176/appi.ps.57.8.1211. PMID: 44204919.
- White M, Northam E, O'Connell M, et al. Personality and mental health assessment: a useful pre-transition tool for youth with type 1 diabetes? *Pediatr Diabetes.* 2015;16:135-6. doi: 10.1111/pedi.12309. PMID: CN-01106579.
- White PH, Ardoin S. Transitioning Wisely: Improving the Connection From Pediatric to Adult Health Care. *Arthritis & Rheumatology.* 2016;68(4):789-94. doi: 10.1002/art.39554. PMID: 114014014.

- White PH, Schmidt A, McManus M, et al. Readyng Youth and Young Adults for Transition to Adult Care During Preventive Care Visits: New Clinician Toolkit. *J Adolesc Health*. 2018;63(6):673-4. doi: 10.1016/j.jadohealth.2018.09.008. PMID: 2001240806.
- Whitman E. Outpatient providers need to consider better care transitions, too. *Mod Healthc*. 2017. PMID: 30399251.
- Whitney J, Costa A. One size does not fit all. *Psychiatric rehabilitation journal*. 2012;35(3):273-4. doi: 10.2975/35.3.2012.273.274. PMID: 22246127.
- Wiemann C, Benavides J, Graham S, et al. Preliminary Feasibility And Acceptability of A Group-Based Peer-Mentor Intervention To Promote Disease Self-Management In Transition-Age Youth (TAY). *J Adolesc Health*. 2019;64(2):S48-. doi: 10.1016/j.jadohealth.2018.10.105. PMID: CN-01788014.
- Wiemann CM, Graham SC, Sanchez-Fournier BE, et al. 191 - In-Depth Interviews to Assess the Relevancy and Fit of a Peer-Mentored Intervention for Transition Age Youth with Chronic Medical Conditions. *J Adolesc Health*. 2018;62:S98-S9. doi: 10.1016/j.jadohealth.2017.11.199. PMID: 127619261.
- Wilcox RD. Transitioning adolescents to adult care can be challenging. *HIV clinician / Delta Region AIDS Education & Training Center*. 2012;24(2):22-3. PMID: 365170738.
- Wilens TE, Rosenbaum JF. Transitional aged youth: a new frontier in child and adolescent psychiatry. *J Am Acad Child Adolesc Psychiatry*. 2013. doi: 10.1016/j.jaac.2013.04.020. PMID: 23972688.
- Williams AN, Walter S. Enchanted voice. *Arch Dis Child*. 2020;105(2):197-8. doi: 10.1136/archdischild-2018-315795. PMID: 30381289.
- Williams MA, van der Willigen T, White PH, et al. Improving health care transition and longitudinal care for adolescents and young adults with hydrocephalus: Report from the Hydrocephalus Association Transition Summit. *J Neurosurg*. 2019;131(4):1037-45. doi: 10.3171/2018.6.Jns188. PMID: 2003128401.
- Williams RG. Fumbling the handoff: managing the transition to adult care for adolescents with chronic conditions. *J Adolesc Health*. 2009. doi: 10.1016/j.jadohealth.2009.01.001. PMID: 19306787.
- Williams RG. Transitioning youth with congenital heart disease from pediatric to adult health care. *J Pediatr*. 2015. doi: 10.1016/j.jpeds.2014.09.054. PMID: 25449216.
- Wilson A, Tuffrey A, McKenzie C, et al. After the flood: young people's perspectives on transition. *The Lancet*. 2015. doi: 10.1016/s2215-0366(15)00126-1. PMID: 26360268.
- Woodward JF, Swigonski NL, Ciccarelli MR. Assessing the health, functional characteristics, and health needs of youth attending a noncategorical transition support program. *J Adolesc Health*. 2012;51(3):272-8. doi: 10.1016/j.jadohealth.2011.12.016. PMID: 51891992.
- Wu K, Szalda D, Trachtenberg S, et al. Transitioning From "Sick Kid" to Community Health Worker: Building Better Bridges to Adult Care. *Pediatrics*. 2018. doi: 10.1542/peds.2018-0962. PMID: 29970385.
- Yee J. Pediatric-to-adult nephrology: the handoff. *Adv Chronic Kidney Dis*. 2011. doi: 10.1053/j.ackd.2011.07.004. PMID: 21896370.
- Zhao JY, Chiu PPL, Dasgupta R, et al. Defining the Need for Transitional Care From Pediatric to Adult Surgery for Young Adult Patients With Surgically Corrected Congenital Anomalies. *JAMA Surgery*. 2016. doi: 10.1001/jamasurg.2015.4417. PMID: 26676379.
- Zurynski YA, Elliott EJ. Challenges of transition to adult health services for patients with rare diseases. *Med J Aust*. 2013. doi: 10.5694/mja13.10424. PMID: 23919688.

Study Type

- Adams-Graves P, Bronte-Jordan L. Recent treatment guidelines for managing adult patients with sickle cell disease: challenges in access to care, social issues, and adherence. [Review]. *Expert Rev Hematol*. 2016. doi: 10.1080/17474086.2016.1180242. PMID: 27098013.
- Anonymous. Applied Theatre in Adolescent Mental Health Transition Care. *Perspectives in public health*. 2018;138(1):16-7. doi: 10.1177/1757913917736663. PMID: 29290160.
- Baca CM, Barry F, Berg AT. The epilepsy transition care gap in young adults with childhood-onset epilepsy. *Epilepsy and Behavior*. 2018;87:146-51. doi: 10.1016/j.yebeh.2018.06.052. PMID: 2001055967.

- Barron D, Hassiotis A. Good practice in transition services for young people with learning disabilities: a review. *Advances in Mental Health & Learning Disabilities*. 2008;2(3):18-22. PMID: 104583220.
- Beacham BL, Deatrick JA. Health care autonomy in children with chronic conditions: implications for self-care and family management. *The Nursing Clinics of North America*. 2013;48(2):305-17. doi: 10.1016/j.cnur.2013.01.010. PMID: 23659815.
- Betz CL. Health care transitions of youth with special health care needs: the never ending journey. [Review] [63 refs]. *Commun Nurs Res*. 2008. PMID: 18822668.
- Bilhartz JL, Lopez MJ, Magee JC, et al. Assessing allocation of responsibility for health management in pediatric liver transplant recipients. *Pediatr Transplant*. 2015. doi: 10.1111/petr.12466. PMID: 25824486.
- Broad KL, Sandhu VK, Sunderji N, et al. Youth experiences of transition from child mental health services to adult mental health services: A qualitative thematic synthesis. *BMC Psychiatry*. 2017;17(1):380. doi: 10.1186/s12888-017-1538-1. PMID: 619448394.
- Cai RA, Chaplin H, Livermore P, et al. Development of a benchmarking toolkit for adolescent and young adult rheumatology services (BeTAR). *Pediatr Rheumatol Online J*. 2019;17(1):23. doi: 10.1186/s12969-019-0323-8. PMID: 31113443.
- Cavanaugh S, Merlo DM, Griffio D, et al. Assisting Transition Through Website Building. *OT Practice*. 2016:17-9. PMID: 119266923.
- Clemente D, Leon L, Foster H, et al. Systematic review and critical appraisal of transitional care programmes in rheumatology. *Semin Arthritis Rheum*. 2016;46(3):372-9. doi: 10.1016/j.semarthrit.2016.06.003. PMID: 613476945.
- Cleverley K, Rowland E, Bennett K, et al. Identifying core components and indicators of successful transitions from child to adult mental health services: a scoping review. [Review]. *Eur Child Adolesc Psychiatry*. 2020. doi: 10.1007/s00787-018-1213-1. PMID: 30294756.
- De Cunto CL, Eymann A, Britos MdLA, et al. Cross-cultural adaptation of the Transition Readiness Assessment Questionnaire to Argentinian Spanish. *Arch Argent Pediatr*. 2017. doi: 10.5546/aap.2017.eng.181. PMID: 28318186.
- Eros A, Soos A, Hegyi P, et al. Spotlight on Transition in Patients With Inflammatory Bowel Disease: A Systematic Review. *Inflamm Bowel Dis*. 2020. doi: 10.1093/ibd/izz173. PMID: 31504524.
- Falcini F, Nacci F. Systemic lupus erythematosus in the young: The importance of a transition clinic. *Lupus*. 2007;16(8):613-7. doi: 10.1177/0961203307078973. PMID: 47359997.
- Feinstein R, Rabey C, Pilapil M. Evidence Supporting the Effectiveness of Transition Programs for Youth With Special Health Care Needs. [Review]. *Curr Probl Pediatr Adolesc Health Care*. 2017. doi: 10.1016/j.cppeds.2017.07.005. PMID: 28895859.
- Ferris ME, Harward DH, Bickford K, et al. A clinical tool to measure the components of health-care transition from pediatric care to adult care: the UNC TR(x)ANSITION scale. *Ren Fail*. 2012. doi: 10.3109/0886022x.2012.678171. PMID: 22583152.
- Flume PA. Smoothing the transition from pediatric to adult care: lessons learned. [Review]. *Curr Opin Pulm Med*. 2009. doi: 10.1097/MCP.0b013e3283314dec. PMID: 19696678.
- Gleeson H, Wisniewski AB. Working with adolescents and young adults to support transition. [Review]. *Endocr Dev*. 2014. doi: 10.1159/000363637. PMID: 25247650.
- Gray WN, Schaefer MR, Resmini-Rawlinson A, et al. Barriers to Transition From Pediatric to Adult Care: A Systematic Review. *J Pediatr Psychol*. 2018;43(5):488-502. doi: 10.1093/jpepsy/jsx142. PMID: 29190360.
- Hart LC, Maslow G. The Medical Transition from Pediatric to Adult-Oriented Care: Considerations for Child and Adolescent Psychiatrists. [Review]. *Child Adolesc Psychiatr Clin N Am*. 2018. doi: 10.1016/j.chc.2017.08.004. PMID: 29157498.
- Hart LC, Patel-Nguyen SV, Merkley MG, et al. An Evidence Map for Interventions Addressing Transition from Pediatric to Adult Care: A Systematic Review of Systematic Reviews. *J Pediatr Nurs*. 2019;48:18-34. doi: 10.1016/j.pedn.2019.05.015. PMID: 31220801.
- Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. [Review]. *Patient Educ Couns*. 2017. doi: 10.1016/j.pec.2016.08.011. PMID: 27693084.

- Heerde JA, Hemphill SA, Scholes-Balog KE. The impact of transitional programmes on post-transition outcomes for youth leaving out-of-home care: a meta-analysis. [Review]. *Health & Social Care in the Community*. 2018. doi: 10.1111/hsc.12348. PMID: 27109440.
- Jones C, Ritchwood TD, Taggart T. Barriers and Facilitators to the Successful Transition of Adolescents Living with HIV from Pediatric to Adult Care in Low and Middle-Income Countries: A Systematic Review and Policy Analysis. *AIDS Behav*. 2019. doi: 10.1007/s10461-019-02621-6. PMID: 31377893.
- Kelly MS, Thibadeau J, Struwe S, et al. Evaluation of spina bifida transitional care practices in the United States. *J Pediatr Rehabil Med*. 2017;10(3):275-81. doi: 10.3233/prm-170455. PMID: 29125516.
- Khavari R, Tokaz MC, Stewart JN, et al. Pelvic Organ Prolapse in Female Patients Presenting to Transitional Urology Care Clinic. *The Journal of urology*. 2015;194(6):1654-8. doi: 10.1016/j.juro.2015.07.086. PMID: 26210885.
- Klassen AF, Grant C, Barr R, et al. Development and validation of a generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions: the TRANSITION-Q. *Child Care Health Dev*. 2015. doi: 10.1111/cch.12207. PMID: 25351414.
- Kossoff EH, Henry BJ, Cervenka MC. Transitioning pediatric patients receiving ketogenic diets for epilepsy into adulthood. *Seizure*. 2013;22(6):487-9. doi: 10.1016/j.seizure.2013.03.005. PMID: 52526423.
- Lemly DC, Weitzman ER, O'Hare K. Advancing healthcare transitions in the medical home: tools for providers, families and adolescents with special healthcare needs. [Review]. *Curr Opin Pediatr*. 2013. doi: 10.1097/MOP.0b013e3283623d2f. PMID: 23770924.
- Low JK, Manias E. Use of Technology-Based Tools to Support Adolescents and Young Adults With Chronic Disease: Systematic Review and Meta-Analysis. [Review]. *JMIR MHealth and UHealth*. 2019. doi: 10.2196/12042. PMID: 31322129.
- Lue Y-J, Chen S-S, Lu Y-M. Quality of life of patients with Duchenne muscular dystrophy: from adolescence to young men. *Disabil Rehabil*. 2017. doi: 10.1080/09638288.2016.1196398. PMID: 27347814.
- Lugasi T, Achille M, Stevenson M. Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies. [Review]. *J Adolesc Health*. 2011. doi: 10.1016/j.jadohealth.2010.10.016. PMID: 21501800.
- Marchak JG, Reed-Knight B, Amaral S, et al. Providers' assessment of transition readiness among adolescent and young adult kidney transplant recipients. *Pediatr Transplant*. 2015. doi: 10.1111/ptr.12615. PMID: 26508553.
- McCartney S. Inflammatory bowel disease in transition: Challenges and solutions in adolescent care. *Frontline Gastroenterol*. 2011;2(4):237-41. doi: 10.1136/fg.2010.002741. PMID: 364449649.
- Miller S. Transition of care in adolescence. *Paediatr Nurs*. 1996;8(9):14-6. doi: 10.7748/paed.8.9.14.s12. PMID: 127231761.
- Montano CB, Young J. Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. *Postgrad Med*. 2012. doi: 10.3810/pgm.2012.09.2591. PMID: 23095423.
- Nardone OM, Iacucci M, Ghosh S, et al. Can a transition clinic bridge the gap between paediatric and adult inflammatory bowel disease care models? *Dig Liver Dis*. 2020;52(5):516-27. doi: 10.1016/j.dld.2020.02.009. PMID: 2005439695.
- Overholser L, Kilbourn K, Liu A. Survivorship Issues in Adolescent and Young Adult Oncology. *The Medical clinics of North America*. 2017;101(6):1075-84. doi: 10.1016/j.mcna.2017.06.002. PMID: 28992855.
- Patel SK, Staarmann B, Heilman A, et al. Growing up with spina bifida: bridging the gaps in the transition of care from childhood to adulthood. *Neurosurg Focus*. 2019;47(4):E16. doi: 10.3171/2019.7.Focus19441. PMID: 31574470.
- Pilkington G, Knighting K, Bray L, et al. The specification, acceptability and effectiveness of respite care and short breaks for young adults with complex healthcare needs: Protocol for a mixed-methods systematic review. *BMJ Open*. 2019;9(6):e030470. doi: 10.1136/bmjopen-2019-030470. PMID: 628150892.

- Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*. 2004;113(3):e197-205. PMID: 38394284.
- Ryan S. The adolescent and young adult with Klinefelter syndrome: ensuring successful transitions to adulthood. *Pediatric endocrinology reviews : PER*. 2010;8:169-77. PMID: 361369951.
- Scal P, Horvath K, Garwick A. Preparing for adulthood: Health care transition counseling for youth with arthritis. *Arthritis Care Res*. 2009;61(1):52-7. doi: 10.1002/art.24088. PMID: 354080573.
- Schultz AT, Smaldone A. Components of Interventions That Improve Transitions to Adult Care for Adolescents With Type 1 Diabetes. [Review]. *J Adolesc Health*. 2017. doi: 10.1016/j.jadohealth.2016.10.002. PMID: 27939878.
- Shaw KL, Southwood TR, McDonagh JE. Development and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care among adolescents with juvenile idiopathic arthritis. *Child Care Health Dev*. 2007;33(4):380-8. doi: 10.1111/j.1365-2214.2006.00699.x. PMID: 46909323.
- Steinbeck KS, Brodie L, Towns SJ. Transition in chronic illness: Who is going where? *J Paediatr Child Health*. 2008. doi: 10.1111/j.1440-1754.2008.01321.x. PMID: 18928466.
- Stinson J, Kohut SA, Spiegel L, et al. A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. [Review]. *Int J Adolesc Med Health*. 2014. doi: 10.1515/ijamh-2013-0512. PMID: 23828488.
- Tepper V, Zaner S, Ryscavage P. HIV healthcare transition outcomes among youth in North America and Europe: a review. [Review]. *J Int AIDS Soc*. 2017. doi: 10.7448/ias.20.4.21490. PMID: 28530041.
- Treadwell M, Johnson S, Sisler I, et al. Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *Int J Adolesc Med Health*. 2016;28(4):381-8. doi: 10.1515/ijamh-2015-0014. PMID: 26226116.
- Treadwell M, Johnson S, Sisler I, et al. Development of a sickle cell disease readiness for transition assessment. *Int J Adolesc Med Health*. 2016;28(2):193-201. doi: 10.1515/ijamh-2015-0010. PMID: 610449663.
- Van Lierde A, Menni F, Bedeschi MF, et al. Healthcare transition in patients with rare genetic disorders with and without developmental disability: Neurofibromatosis 1 and williams-beuren syndrome. *American Journal of Medical Genetics, Part A*. 2013;161(7):1666-74. doi: 10.1002/ajmg.a.35982. PMID: 52602419.
- van Melle MA, van Stel HF, Poldervaart JM, et al. Validation of a questionnaire measuring transitional patient safety climate indicated differences in transitional patient safety climate between primary and secondary care. *J Clin Epidemiol*. 2018. doi: 10.1016/j.jclinepi.2017.09.018. PMID: 28951109.
- Viner RM. Transition of care from paediatric to adult services: one part of improved health services for adolescents. [Review] [17 refs]. *Arch Dis Child*. 2008. doi: 10.1136/adc.2006.103721. PMID: 17942588.
- Warschawsky S, Kaufman JN, Schutt W, et al. Health self-management, transition readiness and adaptive behavior in persons with cerebral palsy or myelomeningocele. *Rehabil Psychol*. 2017;62(3):268-75. doi: 10.1037/rep0000157. PMID: 28836807.
- Webb AK, Jones AW, Dodd ME. Transition from paediatric to adult care: problems that arise in the adult cystic fibrosis clinic. *J R Soc Med*. 2001;94:8-11. PMID: 11601165.
- Wells CK, McMorris BJ, Horvath KJ, et al. Youth report of healthcare transition counseling and autonomy support from their rheumatologist. *Pediatric Rheumatology*. 2012;10:36. doi: 10.1186/1546-0096-10-36. PMID: 52306023.
- West NE, Mogayzel PJ. Transitions in Health Care: What Can We Learn from Our Experience with Cystic Fibrosis. *Pediatr Clin North Am*. 2016;63(5):887-97. doi: 10.1016/j.pcl.2016.06.010. PMID: 613312949.
- Wood D, Rocque B, Hopson B, et al. Transition Readiness Assessment Questionnaire Spina Bifida (TRAQ-SB) specific module and its association with clinical outcomes among youth and young adults with spina bifida. *J Pediatr Rehabil Med*. 2019. doi: 10.3233/prm-180595. PMID: 31744032.
- Wood DL, Sawicki GS, Miller MD, et al. The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity. *Acad Pediatr*. 2014. doi: 10.1016/j.acap.2014.03.008. PMID: 24976354.

Završnik J, Kokol P, Del Torso S, et al. Citation context and impact of 'sleeping beauties' in paediatric research. [Review]. *J Int Med Res*. 2016. doi: 10.1177/0300060516672129. PMID: 27834306.

Duplicates

Alriksson-Schmidt A, Hagglund G, Rodby-Bousquet E, et al. Follow-up of individuals with cerebral palsy through the transition years and description of adult life: the Swedish experience. *J Pediatr Rehabil Med*. 2014. doi: 10.3233/prm-140273. PMID: 24919938.

Bell L. Adolescents with renal disease in an adult world: meeting the challenge of transition of care. *Nephrology Dialysis Transplantation*. 2007. doi: 10.1093/ndt/gfl770. PMID: 17210582.

Clarizia NA, Chahal N, Manlhiot C, et al. Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider. *Can J Cardiol*. 2009;25(9):e317-e22. PMID: 355447697.

Colver A, McConachie H, Le Couteur A, et al. A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Med*. 2018. doi: 10.1186/s12916-018-1102-y. PMID: 30032726.

Goodson, Bradley. Autism Spectrum Uisoraer: A Crisis in Transition of Care. *The Journal of the Arkansas Medical Society*. 2016;113(2):28. PMID: 30047627.

Hill T, Haut C. Adolescents with Chronic Kidney Disease: A Model for Transition to Adult Care. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*. 2019. PMID: 31566348.

Murphy DJ J, Foster E. Recommendations for training in pediatric cardiology. Task Force 6: training in transition of adolescent care and care of the adult with congenital heart disease. *Pediatrics*. 2005;116(6):1592-4. PMID: 106417164.

Murphy Jr. DJ, Foster E. Task Force 6: Training in transition of adolescent care and care of the adult with congenital heart disease. *J Am Coll Cardiol*. 2005;46(7):1399-401. doi: 10.1016/j.jacc.2005.07.020. PMID: 41615575.

Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*. 2004. doi: 10.1542/peds.113.3.e197. PMID: 14993577.

Shepard KF, Barsotti LM. Family focus--transitional health care. *Nurs Outlook*. 1975. PMID: 171629.

Non-English Language

Ariceta G, Camacho JA, Fernandez-Obispo M, et al. A coordinated transition model for patients with cystinosis: from pediatrics to adult care. *Nefrologia*. 2016;36(6):616-30. doi: 10.1016/j.nefro.2016.05.012. PMID: 613760120.

Colinart-Thomas M, Noel V, Roques G, et al. From pediatric care to adult medicine: Transition of sickle cell patients, a French monocentric study. *Arch Pediatr*. 2018;25(3):199-206. doi: 10.1016/j.arcped.2017.12.012. PMID: 2000527156.

Could Not Obtain Full Text

Irvine T. Transitional care for young people with inflammatory bowel disease. *Gastrointestinal Nursing*. 2004;2(8):25-8. PMID: 106677218.

Appendix C. Expanded Eligible Studies Bibliography

Autism

Iannuzzi D, Rissmiller P, Duty SM, et al. Addressing a Gap in Healthcare Access for Transition-Age Youth with Autism: A Pilot Educational Intervention for Family Nurse Practitioner Students. *J Autism Dev Disord.* 2019;49(4):1493-504. doi: 10.1007/s10803-018-3846-9. PMID: 135779446.

Ghanouni, P. and L. Seaker. Healthcare Services During the Transitions to Adulthood Among Individuals with ASD Aged 15-25 Years Old: Stakeholders' Perspectives. *Journal of Autism & Developmental Disorders.* 2021;03:03.

Kuhlthau KA, Delahaye J, Erickson-Warfield M, et al. Health Care Transition Services for Youth With Autism Spectrum Disorders: Perspectives of Caregivers. *Pediatrics.* 2016 Feb;137 Suppl 2(S):S158-66. doi: 10.1542/peds.2015-2851N. PMID: 26908471.

Mazurek MO, Stobbe G, Loftin R, et al. ECHO Autism Transition: Enhancing healthcare for adolescents and young adults with autism spectrum disorder. *Autism.* 2020;24(3):633-44. doi: 10.1177/1362361319879616.

Rast JE, Shattuck PT, Roux AM, et al. The Medical Home and Health Care Transition for Youth With Autism. *Pediatrics.* 2018 Apr;141(Suppl 4):S328-S34. doi: 10.1542/peds.2016-4300J. PMID: 29610414.

Cancer

Croteau SE, Padula M, Quint K, et al. Center-Based Quality Initiative Targets Youth Preparedness for Medical Independence: HEMO-Milestones Tool in a Comprehensive Hemophilia Clinic Setting. *Pediatr Blood Cancer.* 2016 Mar;63(3):499-503. doi: 10.1002/pbc.25807. PMID: 26496140.

Eshelman-Kent D, Kinahan KE, Hobbie W, et al. Cancer survivorship practices, services, and delivery: A report from the Children's Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. *J Cancer Surviv.* 2011;5(4):345-57. doi: 10.1007/s11764-011-0192-8.

Ganju RG, Nanda RH, Esiashvili N, et al. The Effect of Transition Clinics on Knowledge of Diagnosis and Perception of Risk in Young Adult Survivors of Childhood Cancer. *J Pediatr Hematol Oncol.* 2016;38(3):197-201. doi: 10.1097/mpb.0000000000000531. PMID: 26925717.

Meacham LR, Williamson RS, Forehand RL, et al. University health centers and young adult survivors of pediatric cancer: Changes in providers' familiarity with and practice of survivor care. *J Adolesc Young Adult Oncol.* 2014;3(1):12-9. doi: 10.1089/jayao.2013.0029. PMID: 372628683.

Miller KA, Wojcik KY, Ramirez CN, et al. Supporting long-term follow-up of young adult survivors of childhood cancer: Correlates of healthcare self-efficacy. *Pediatr Blood Cancer.* 2017. doi: 10.1002/pbc.26209. PMID: 27567026.

Mouw MS, Wertman EA, Barrington C, et al. Care Transitions in Childhood Cancer Survivorship: Providers' Perspectives. *J Adolesc Young Adult Oncol.* 2017;6(1):111-9. doi: 10.1089/jayao.2016.0035.

Rajala S, Jarvela LS, Huurre A, et al. Use of electronic patient data storage for evaluating and setting the risk category of late effects in childhood cancer survivors. *Pediatr Blood Cancer.* 2020:e28678. doi: 10.1002/pbc.28678. PMID: 32860665.

Rossell, N., et al. (2021). "Survivors of childhood cancer in Latin America: Role of foundations and peer groups in the lack of transition processes to adult long-term follow-up." *Cancer Reports:* e1474.

Sadak KT, Neglia JP, Freyer DR, et al. Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative study of survivorship providers. *Pediatr Blood Cancer.* 2017. doi: 10.1002/pbc.26587. PMID: 28557375.

Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatric Blood and Cancer.* 2013;60(8):1365-8. doi: 10.1002/pbc.24494. PMID: 369155822.

Sadak KT, Szalda D, Lindgren BR, et al. Transitional care practices, services, and delivery in childhood cancer survivor programs: A survey study of U.S. survivorship providers. *Pediatric Blood and Cancer.* 2019;66(8):e27793. doi: 10.1002/pbc.27793.

Sadak, K. T., et al. (2021). Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative interview study of parents. *Cancer Medicine* 10(18): 6239-6248.

Schwartz LA, Hamilton JL, Brumley LD, et al. Development and Content Validation of the Transition Readiness Inventory Item Pool for Adolescent and Young Adult Survivors of Childhood Cancer. [Review]. *J Pediatr Psychol*. 2017. doi: 10.1093/jpepsy/jsx095. PMID: 29046041.

Szalda D, Piece L, Brumley L, et al. Associates of Engagement in Adult-Oriented Follow-Up Care for Childhood Cancer Survivors. *J Adolesc Health*. 2017;60(2):147-53. doi: 10.1016/j.jadohealth.2016.08.018. PMID: 613704978.

Walsh C, Currin-McCulloch J, Simon P, et al. Shifting needs and preferences: Supporting young adult cancer patients during the transition from active treatment to survivorship care. *J Adolesc. Young Adult Oncol*. 2019;8(2):114-21. doi: 10.1089/jayao.2018.0083. PMID: 627171999.

Chronic Conditions

Bauman ME, Kuhle S, Bruce AAK, et al. The journey for adolescents and young adults with chronic conditions transitioning to adult care with successful warfarin management. *Thromb Res*. 2016;141:183-8. doi: 10.1016/j.thromres.2016.03.019.

Beaudry J, Consigli A, Clark C, et al. Getting Ready for Adult Healthcare: Designing a Chatbot to Coach Adolescents with Special Health Needs Through the Transitions of Care. *J Pediatr Nurs*. 2019;49:85-91. doi: 10.1016/j.pedn.2019.09.004. PMID: 629690557.

Beaufils C, Jacquin P, Dumas A, et al. Patients' association programs for adolescents and young adults: The JAP study. *Arch Pediatr*. 2019;26(4):205-13. doi: 10.1016/j.arcped.2019.03.006.

Betz CL, Redcay G. Creating Healthy Futures: an innovative nurse-managed transition clinic for adolescents and young adults with special health care needs. *Pediatr Nurs*. 2003;29(1):25-30. PMID: 36472914.

Betz CL, Smith KA, Van Speybroeck A, et al. Movin' On Up: An Innovative Nurse-Led Interdisciplinary Health Care Transition Program. *J Pediatr Health Care*. 2016;30(4):323-38. doi: 10.1016/j.pedhc.2015.08.005.

Bomba F, Herrmann-Garitz C, Schmidt J, et al. An assessment of the experiences and needs of adolescents with chronic conditions in transitional care: a qualitative study to develop a patient education programme. *Health Soc Care Community*. 2017;25(2):652-66. doi: 10.1111/hsc.12356. PMID: 620864232.

Celona CA. Measuring Acuity and Patient Progress for Youth With Special Health Care Needs in Transition Care Utilizing Nursing Outcomes. *J Pediatr Nurs*. 2015 Sep-Oct;30(5):e15-8. doi: 10.1016/j.pedn.2015.05.005. PMID: 26028567.

Chira P, Nugent L, Miller K, et al. Living Profiles: design of a health media platform for teens with special healthcare needs. *J Biomed Inform*. 2010;43(5):S9-12. doi: 10.1016/j.jbi.2010.05.008. PMID: 20937487.

Chung RJ, Jasien J, Maslow GR. Resident Dyads Providing Transition Care to Adolescents and Young Adults With Chronic Illnesses and Neurodevelopmental Disabilities. *J Grad Med Educ*. 2017;9(2):222-7. doi: 10.4300/jgme-d-16-00292.1. PMID: 622766519.

Coyne I, Prizeman G, Sheehan A, et al. An e-health intervention to support the transition of young people with long-term illnesses to adult healthcare services: Design and early use. *Patient Educ Couns*. 2016 Sep;99(9):1496-504. doi: 10.1016/j.pec.2016.06.005. PMID: 27372524.

Cramm JM, Strating MMH, Nieboer AP. The role of team climate in improving the quality of chronic care delivery: A longitudinal study among professionals working with chronically ill adolescents in transitional care programmes. *BMJ Open*. 2014;4(5):e005369. doi: 10.1136/bmjopen-2014-005369. PMID: 373178358.

Davidson LF, Chhabra R, Cohen HW, et al. Pediatricians Transitioning Practices, Youth With Special Health Care Needs in New York State. *Clin Pediatr (Phila)*. 2015 Oct;54(11):1051-8. doi: 10.1177/0009922815573940. PMID: 25724992.

Fernandes SM, Fishman L, O'Sullivan-Oliveira J, et al. Current practices for the transition and transfer of patients with a wide spectrum of pediatric-onset chronic diseases: results of a clinician survey at a free-standing pediatric hospital. *Int J Child Adolesc Health*. 2010;3(4):507-15. PMID: 104987753.

- Fernandes SM, Landzberg MJ, Fishman LN, et al. Clinician perceptions of transition of patients with pediatric-onset chronic disease to adult medical care: comparing a pediatric facility integrated within an adult institution with a free-standing pediatric hospital. *Int J Child Adolesc Health*. 2012;5(3):281-9. PMID: 108024126.
- Fletcher-Johnston M, Marshall SK, Straatman L. Healthcare transitions for adolescents with chronic life-threatening conditions using a Delphi method to identify research priorities for clinicians and academics in Canada. *Child Care Health Dev*. 2011 Nov;37(6):875-82. doi: 10.1111/j.1365-2214.2011.01318.x
- Gonzalez F, Rodriguez Celin MdLM, Roizen M, et al. Status of the transition/transfer process for adolescents with chronic diseases at a national pediatric referral hospital in Argentina. *Arch Argent Pediatr*. 2017;115(6):562-9. doi: 10.5546/aap.2017.eng.562. PMID: 29087110.
- Grant C, Pan J. A comparison of five transition programmes for youth with chronic illness in Canada. *Child Care Health Dev*. 2011;37(6):815-20. doi: 10.1111/j.1365-2214.2011.01322.x. PMID: 22007981.
- Hergenroeder AC, Wiemann CM, Bowman VF. Lessons learned in building a hospital-wide transition program from pediatric to adult-based health care for youth with special health care needs (YSHCN). *Int J Adolesc Med Health*. 2016 Nov 1;28(4):455-8. doi: 10.1515/ijamh-2015-0048. PMID: 26360495.
- Hess JS, Straub DM. Brief report: Preliminary findings from a pilot health care transition education intervention for adolescents and young adults with special health care needs. *J Pediatr Psychol*. 2011;36(2):172-8. doi: 10.1093/jpepsy/jsq091. PMID: 362086614.
- Hess JS, Straub DM, Mateus JS, et al. Preparing for Transition from Pediatric to Adult Care: Evaluation of a Physician Training Program. *Adv Pediatr*. 2015;62(1):137-64. doi: 10.1016/j.yapd.2015.04.003.
- Jedeloo S, van Staa A, Latour JM, et al. Preferences for health care and self-management among Dutch adolescents with chronic conditions: A Q-methodological investigation. *Int J Nurs Stud*. 2010;47(5):593-603. doi: 10.1016/j.ijnurstu.2009.10.006. PMID: 50696458
- Kelly AM, Kratz B, Bielski M, et al. Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics*. 2002;110(6):1322-7. PMID: 35425174.
- Knapp C, Huang IC, Hinojosa M, et al. Assessing the congruence of transition preparedness as reported by parents and their adolescents with special health care needs. *Matern Child Health J*. 2013;17(2):352-8. doi: 10.1007/s10995-012-0980-4. PMID: 369508519.
- Kuo AA, Ciccarelli MR, Sharma N, et al. A health care transition curriculum for primary care residents: Identifying goals and objectives. *Pediatrics*. 2018;141(S):S346-S54. doi: 10.1542/peds.2016-4300L. PMID: 621528324.
- Langmaid L, Ratner L, Huysman C, et al. Supporting the Medically Fragile: Individualized Approach to Empowering Young Adults With Chronic Disease During the COVID-19 Pandemic. *J Adolesc Health*. 2020;67(3):453-5. doi: 10.1016/j.jadohealth.2020.06.029.
- Maeng DD, Snyder SR, Davis TW, et al. Impact of a Complex Care Management Model on Cost and Utilization Among Adolescents and Young Adults with Special Care and Health Needs. *Popul Health Manag*. 2017;20(6):435-41. doi: 10.1089/pop.2016.0167. PMID: 126519362.
- Maniatopoulos G, Le Couteur A, Vale L, et al. Falling through the gaps: exploring the role of integrated commissioning in improving transition from children's to adults' services for young people with long-term health conditions in England. *J Health Serv Res Policy*. 2018;23(2):107-15. doi: 10.1177/1355819617752744. PMID: 29475369.
- Ma, J., et al. Influence of transition readiness from paediatric to adult health care on quality of life in child-parent dyads with long-term conditions. *Journal of Advanced Nursing* (2021); 77(5): 2340-2352.
- Maslow G, Adams C, Willis M, et al. An evaluation of a positive youth development program for adolescents with chronic illness. *J Adolesc Health*. 2013;52(2):179-85. doi: 10.1016/j.jadohealth.2012.06.020. PMID: 23332482.
- McKeown A, Cliffe C, Arora A, et al. Ethical challenges of integration across primary and secondary care: a qualitative and normative analysis. *BMC Med Ethics*. 2019;20(1):42. doi: 10.1186/s12910-019-0386-6. PMID: 31269930.
- McLaughlin S, Bowering N, Crosby B, et al. Health care transition for adolescents with special health care needs: a report on the development and use of a clinical transition service. *Rhode Island medical journal* (2013). 2013;96(4):25-7.

- McLaughlin SE, Machan J, Fournier P, et al. Transition of adolescents with chronic health conditions to adult primary care: factors associated with physician acceptance. *J Pediatr Rehabil Med*. 2014. doi: 10.3233/prm-140275. PMID: 24919939.
- Mennito, Sarah. Resident preferences for a curriculum in healthcare transitions for young adults. *South Med J*. 2012;105(9):462-6. doi: 10.1097/SMJ.0b013e31826323c2. PMID: 22948324.
- Parfitt G. Proving young person's experience transition: lessons from Wales. *Paediatr Nurs*. 2008. doi: 10.7748/paed2008.11.20.9.27.c6824. PMID: 19006948.
- Nguyen T, Henderson D, Stewart D, et al. You never transition alone! Exploring the experiences of youth with chronic health conditions, parents and healthcare providers on self-management. *Child Care Health Dev*. 2016;42(4):464-72. doi: 10.1111/cch.12334. PMID: 27103590.
- Nurre E, Smith AW, Jenkins A, et al. Barriers and Facilitators to Developing Transition Clinics for Adolescents and Young Adults With Chronic Conditions. *Clin Pediatr (Phila)*. 2019 Nov;58(13):1444-8. doi: 10.1177/0009922819875533. PMID: 31516028.
- Osterkamp EM, Costanzo AJ, Ehrhardt BS, et al. Transition of care for adolescent patients with chronic illness: education for nurses. *J Contin Educ Nurs*. 2013;44(1):38-42. doi: 10.3928/00220124-20121101-52. PMID: 368626213.
- Oswald DP, Gilles DL, Cannady MS, et al. Youth with special health care needs: transition to adult health care services. *Maternal and child health journal*. 2013;17(1):1744-52. doi: 10.1007/s10995-012-1192-7. PMID: 23160763.
- Rauen KK, Sawin KJ, Bartelt T, et al. Transitioning adolescents and young adults with a chronic health condition to adult healthcare - An exemplar program. *Rehabil Nurs*. 2013;38(2):63-72. doi: 10.1002/rnj.74. PMID: 368735120.
- Richmond NE, Tran T, Berry S. Can the Medical Home eliminate racial and ethnic disparities for transition services among Youth with Special Health Care Needs? *Maternal and child health journal*. 2012;16(4):824-33. doi: 10.1007/s10995-011-0785-x. PMID: 365627242.
- Roy, S., et al. "All circuits ended": Family experiences of transitioning from pediatric to adult healthcare for young adults with medical complexity in Oregon. *Journal of Pediatric Nursing* (2021);19: 19.
- Sanabria KE, Ruch-Ross HS, Barger JL, et al. Transitioning youth to adult healthcare: New tools from the Illinois Transition Care Project. *J Pediatr Rehabil Med*. 2015;8(1):39-51. doi: 10.3233/prm-150317. PMID: 602825553.
- Sattoe JNT, Hilberink SR, van Staa A. How to define successful transition? An exploration of consensus indicators and outcomes in young adults with chronic conditions. *Child Care Health Dev*. 2017;43(5):768-73. doi: 10.1111/cch.12436. PMID: 28074484.
- Scal P, Evans T, Blozis S, et al. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health*. 1999;24(4):259-64. doi: 10.1016/s1054-139x%2898%2900127-x. PMID: 29191722.
- Shanahan, P., et al. Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition. *Health & Social Care in the Community*. 2021;29(5): 1429-1438.
- Sharma N, O'Hare K, O'Connor KG, et al. Care Coordination and Comprehensive Electronic Health Records are Associated With Increased Transition Planning Activities. *Acad Pediatr*. 2018;18(1):111-8. doi: 10.1016/j.acap.2017.04.005. PMID: 616977628.
- Singh SP, Anderson B, Liabo K, et al. Supporting young people in their transition to adults' services: summary of NICE guidance. *BMJ*. 2016. doi: 10.1136/bmj.i2225. PMID: 27170336.
- Steinbeck K, Brodie L. Bringing in the voices: a transition forum for young people with chronic illness or disability. *Neonatal Paediatr Child Health Nurs*. 2006;9(1):22-6. PMID: 106460031.
- Syverson EP, McCarter R, He J, et al. Adolescents' Perceptions of Transition Importance, Readiness, and Likelihood of Future Success: The Role of Anticipatory Guidance. *Clin Pediatr (Phila)*. 2016;55(1):1020-5. doi: 10.1177/0009922816666882. PMID: 612208951.
- Szalda DE, Jimenez ME, Long JE, et al. Healthcare system supports for young adult patients with pediatric onset chronic conditions: a qualitative study. *J Pediatr Nurs*. 2015;30(1):126-32. doi: 10.1016/j.pedn.2014.09.015. PMID: 25450439.

Vaks Y, Bensen R, Steidtmann D, et al. Better health, less spending: Redesigning the transition from pediatric to adult healthcare for youth with chronic illness. *Healthcare*. 2016;4(1):57-68. doi: 10.1016/j.hjdsi.2015.09.001.

Volertas SD, Rossi-Foulkes R. Using quality improvement in resident education to improve transition care. *Pediatr Ann*. 2017;46(5):e203-e6. doi: 10.3928/19382359-20170426-01. PMID: 616178769.

White PH, McManus MA, McAllister JW, et al. A primary care quality improvement approach to health care transition. *Pediatr Ann*. 2012 May;41(5):e1-7. doi: 10.3928/00904481-20120426-07. PMID: 22587507.

Wiemann CM, Hergenroeder AC, Bartley KA, et al. Integrating an EMR-based Transition Planning Tool for CYSHCN at a Children's Hospital: A Quality Improvement Project to Increase Provider Use and Satisfaction. *J Pediatr Nurs*. 2015 Sep-Oct;30(5):776-87. doi: 10.1016/j.pedn.2015.05.024. PMID: 26209173.

Wiemann CM, Graham SC, Garland BH, et al. Development of a Group-Based, Peer-Mentor Intervention to Promote Disease Self-Management Skills Among Youth With Chronic Medical Conditions. *J Pediatr Nurs*. 2019;48:1-9. doi: 10.1016/j.pedn.2019.05.013. PMID: 31195183.

Wiemann CM, Graham SC, Garland BH, et al. In-Depth Interviews to Assess the Relevancy and Fit of a Peer-Mentored Intervention for Transition-Age Youth with Chronic Medical Conditions. *J Pediatr Nurs*. 2020;50:121-7. doi: 10.1016/j.pedn.2019.04.028. PMID: 31097229

Congenital Heart Disease (CHD)

Berg SK, Hertz PG. Outpatient nursing clinic for congenital heart disease patients: Copenhagen Transition Program. *J Cardiovasc Nurs*. 2007;22(6):488-92. PMID: 350326293.

de Hosson M, De Backer J, De Wolf D, et al. Development of a transition program for adolescents with congenital heart disease. *Eur J Pediatr*. 2020;179(2):339-48. doi: 10.1007/s00431-019-03515-4. PMID: 2003719674.

Dimopoulos K, Favocchia C, Shaughnessy L, et al. Transition to adult care in adolescents with congenital heart disease. *Prog Pediatr Cardiol*. 2018;51:62-6. doi: 10.1016/j.ppedcard.2018.10.002. PMID: 2001224432.

Du Plessis K, Culnane E, Peters R, et al. Adolescent and parent perspectives prior to involvement in a Fontan transition program. *Int J Adolesc Med Health*. 2017;20170021. doi: 10.1515/ijamh-2017-0021. PMID: 619617161.

Gaydos SS, Chowdhury SM, Judd RN, et al. A transition clinic intervention to improve follow-up rates in adolescents and young adults with congenital heart disease. *Cardiol Young*. 2020;30(5):633-40. doi: 10.1017/s1047951120000682. PMID: 631474307.

Habibi H, Emmanuel Y, Chung N. Process of Transition for Congenital Heart Patients: Preventing Loss to Follow-up. *Clin. Nurse Spec*. 2017;31(6):329-34. doi: 10.1097/nur.0000000000000335. PMID: 619804739.

Harbison AL, Grady S, Chi K, et al. Provision of Transition Education and Referral Patterns from Pediatric Cardiology to Adult Cardiac Care. *Pediatr Cardiol*. 2016;37(2):232-8. doi: 10.1007/s00246-015-1267-5. PMID: 606084737.

Hardy RY, Keller D, Gurvitz M, et al. Patient Sharing and Health Care Utilization Among Young Adults With Congenital Heart Disease. *Med Care Res Rev*. 2020;1077558720945925. doi: 10.1177/1077558720945925. PMID: 32723144.

Knauth A, Verstappen A, Reiss J, et al. Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. *Cardiol Clin*. 2006;24(4):619-vi. PMID: 17098515.

Kovacs AH, Cullen-Dean G, Aiello S, et al. The Toronto congenital heart disease transition task force. *Prog Pediatr Cardiol*. 2012;34(1):21-6. doi: 10.1016/j.ppedcard.2012.05.005. PMID: 52111840.

Murphy DJJ, Foster E, Foundation ACoC, et al. ACCF/AHA/AAP recommendations for training in pediatric cardiology. Task force 6: training in transition of adolescent care and care of the adult with congenital heart disease. *J Am Coll Cardiol*. 2005;46(7):1399-401. PMID: 16198870.

Rempel GR, Ballantyne RT, Magill-Evans J, et al. Texting teens in transition: the use of text messages in clinical intervention research. *JMIR mhealth uhealth*. 2014;2(4):e45. doi: 10.2196/mhealth.3232. PMID: 25379624.

Saarijarvi, M., et al. Mechanisms of impact and experiences of a person-centred transition programme for adolescents with CHD: the Stepstones project. *BMC Health Services Research* 2021;21(1): 573.

Skogby S, Moons P, Johansson B, et al. Outpatient volumes and medical staffing resources as predictors for continuity of follow-up care during transfer of adolescents with congenital heart disease. *Int J Cardiol*. 2020. doi: 10.1016/j.ijcard.2020.01.016. PMID: 31959410.

Strijbosch AMM, Zwart R, Blom NA, et al. Transition from paediatric to adult care of adolescent patients with congenital heart disease: A pathway to optimal care. *Neth Heart J*. 2016;24(1):682-90. doi: 10.1007/s12471-016-0900-0. PMID: 613006901.

Vaikunth SS, Williams RG, Uzunyan MY, et al. Short-term outcomes following implementation of a dedicated young adult congenital heart disease transition program. *Congenit Heart Dis*. 2018;13(1):85-91. doi: 10.1111/chd.12549. PMID: 619329495.

Cystic Fibrosis

Al-Yateem N. Guidelines for the transition from child to adult cystic fibrosis care. *Nurs Child Young People*. 2013;25(5):29-34. doi: 10.7748/ncyp2013.06.25.5.29.e175. PMID: 611464286.

Bourke M, Houghton C. Exploring the need for Transition Readiness Scales within cystic fibrosis services: A qualitative descriptive study. *J Clin Nurs*. 2018;27(1):2814-24. doi: 10.1111/jocn.14344. PMID: 624333432.

Goralski JL, Nasr SZ, Uluer A. Overcoming barriers to a successful transition from pediatric to adult care. *Pediatr Pulmonol*. 2017;52(S):S52-S60. doi: 10.1002/ppul.23778. PMID: 619170392.

Iles N, Lowton K. What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services? *Health Soc Care Community*. 2010;18(1):21-9. doi: 10.1111/j.1365-2524.2009.00871.x. PMID: 358026976.

Madge S, Bryon M. A model for transition from pediatric to adult care in cystic fibrosis. *J Pediatr Nurs*. 2002;17(4):283-8. PMID: 35631347.

Nasr SZ, Campbell C, Howatt W. Transition program from pediatric to adult care for cystic fibrosis patients. *J Adolesc Health*. 1992;13(8):682-5. doi: 10.1016/1054-139x%2892%2990063-h. PMID: 23014597.

Zack J, Jacobs CP, Keenan PM, et al. Perspectives of Patients With Cystic Fibrosis on Preventive Counseling and Transition to Adult Care. *Pediatr Pulmonol*. 2003;36(5):376-83. doi: 10.1002/ppul.10342. PMID: 37296697.

Diabetes

Agarwal S, Raymond JK, Schutta MH, et al. An Adult Health Care-Based Pediatric to Adult Transition Program for Emerging Adults With Type 1 Diabetes. *The Diabetes educator*. 2017;43(1):87-96. doi: 10.1177/0145721716677098. PMID: 620010447.

Allen D, Cohen D, Hood K, et al. Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study. *J Health Serv Res Policy*. 2012;17(3):140-8. doi: 10.1258/jhsrp.2011.011044. PMID: 22767889.

Bridgett M, Abrahamson G, Ho J. Transition, It's More Than Just An Event: Supporting Young People With Type 1 Diabetes. *J Pediatr Nurs*. 2015. doi: 10.1016/j.pedn.2015.05.008. PMID: 26044910.

Burns K, Farrell K, Myszka R, et al. Access to a youth-specific service for young adults with type 1 diabetes mellitus is associated with decreased hospital length of stay for diabetic ketoacidosis. *Intern Med J*. 2018. doi: 10.1111/imj.13649. PMID: 29034986.

Butalia S, McGuire KA, Dyjur D, et al. Youth with diabetes and their parents' perspectives on transition care from pediatric to adult diabetes care services: A qualitative study. *Health science reports*. 2020;3(3):e181. doi: 10.1002/hsr2.181. PMID: 32782975.

Corathers SD, Yi-Frazier JP, Kichler JC, et al. Development and Implementation of the Readiness Assessment of Emerging Adults With Type 1 Diabetes Diagnosed in Youth (READDY) Tool. *Diabetes Spectr*. 2020;33(1):99-103. doi: 10.2337/ds18-0075. PMID: 141790250.

D'Sa, S., et al. Exploring the attitudes and experiences of adolescents with type 1 diabetes towards transition of care. *Journal of Public Health*. (2021).

Dalton J, Burles L, Masding M, et al. The Poole Young People's Diabetes Service. *Journal of Diabetes Nursing*. 2019;23(5):1-5. PMID: 139124435.

Edmunds J, Greenhalgh S, Ghezaiel S, et al. Developing a transition toolkit - the process and outputs. *Journal of Diabetes Nursing*. 2012;16(5):201-3. PMID: 104304062.

- Egan EA, Corrigan J, Shurpin K. Building the bridge from pediatric to adult diabetes care: making the connection. *The Diabetes educator*. 2015;41(4):432-43. doi: 10.1177/0145721715581666. PMID: 615129544.
- Essaddam L, Kallali W, Jemel M, et al. Implementation of effective transition from pediatric to adult diabetes care: epidemiological and clinical characteristics-a pioneering experience in North Africa. *Acta Diabetol*. 2018;55(1):1163-9. doi: 10.1007/s00592-018-1196-x. PMID: 623527527.
- Farrell K, Fernandez R, Salamonson Y, et al. Health outcomes for youth with type 1 diabetes at 18months and 30months post transition from pediatric to adult care. *Diabetes Res Clin Pract*. 2018. doi: 10.1016/j.diabres.2018.03.013. PMID: 29534994.
- Gerber BS, Solomon MC, Shaffer TL, et al. Evaluation of an internet diabetes self-management training program for adolescents and young adults. *Diabetes Technology and Therapeutics*. 2007;9(1):60-7. doi: 10.1089/dia.2006.0058. PMID: 46309708.
- Hilliard ME, Perlus JG, Clark LM, et al. Perspectives from before and after the pediatric to adult care transition: A mixed-methods study in type 1 diabetes. *Diabetes Care*. 2014;37(2):346-54. doi: 10.2337/dc13-1346. PMID: 372220328.
- Holmström, M. R., et al. Supporting young people with type 1 diabetes: experiences from healthcare professionals in Sweden. *British Journal of Child Health*. 2021;2(3): 117-124.
- Johnston P, Bell P, Tennet H, et al. Audit of young people with type 1 diabetes transferring from paediatric to adult diabetic services. *Practical Diabetes International*. 2006;23(3):106-8. doi: 10.1002/pdi.914. PMID: 105942292.
- Kime N. Young people with type 1 diabetes and their transition to adult services. *Br J Community Nurs*. 2013. doi: 10.12968/bjcn.2013.18.Sup10.S14. PMID: 23299142.
- Leung, J. M. W. S., et al. The four I's of adolescent transition in type 1 diabetes care: A qualitative study. *Diabetic Medicine*. 2021; 38(7): 1-11.
- Little JM, Odiaga JA, Minutti CZ. Implementation of a Diabetes Transition of Care Program. *Journal of pediatric health care* 2017;31(2):215-21. doi: 10.1016/j.pedhc.2016.08.009. PMID: 620641562.
- MacDonald C, Friedman S, Marks SD. Creative Arts Diabetes Initiative: Group Art Therapy and Peer Support for Youth and Young Adults Transitioning From Pediatric to Adult Diabetes Care in Manitoba, Canada. *Canadian journal of diabetes*. 2019;43(6):377-83.e3. doi: 10.1016/j.jcjd.2019.04.016. PMID: 31235397.
- Malik FS, Senturia KD, Lind CD, et al. Adolescent and parent perspectives on the acceptability of financial incentives to promote self-care in adolescents with type 1 diabetes. *Pediatr Diabetes*. 2020;21(3):533-51. doi: 10.1111/pedi.12970. PMID: 31863541.
- Mistry B, Van Blyderveen S, Punthakee Z, et al. Condition-related predictors of successful transition from paediatric to adult care among adolescents with Type 1 diabetes. *Diabet Med*. 2015;32(7):881-5. doi: 10.1111/dme.12746.
- Peeters, M. A. C., et al. The added value of transition programs in Dutch diabetes care: A controlled evaluation study. *Journal of Pediatric Nursing* 2021;18:18.
- Pierce JS, Aroian K, Schifano E, et al. Health Care Transition for Young Adults With Type 1 Diabetes: Stakeholder Engagement for Defining Optimal Outcomes. *J Pediatr Psychol*. 2017;42(9):970-82. doi: 10.1093/jpepsy/jsx076.
- Polfuss M, Babler E, Bush LL, et al. Family Perspectives of Components of a Diabetes Transition Program. *J Pediatr Nurs*. 2015;30(5):748-56. doi: 10.1016/j.pedn.2015.05.010. PMID: 616617414.
- Price C, Corbett S, Dovey-Pearce G. Barriers and facilitators to implementing a transition pathway for adolescents with diabetes: a health professionals perspective. *Int J Child Adolesc health*. 2010;3(4):489-98. PMID: 104987752.
- Price CS, Corbett S, Lewis-Barned N, et al. Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. *Child Care Health Dev*. 2011;37(6):852-60. doi: 10.1111/j.1365-2214.2011.01241.x. PMID: 22007985.
- Price CS, Corbett S, Lewis-Barned N, et al. Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. *Child Care Health Dev*. 2011;37(6):852-60. doi: 10.1111/j.1365-2214.2011.01241.x. PMID: 22007985.

Pyatak EA, Sequeira PA, Vigen CLP, et al. Clinical and Psychosocial Outcomes of a Structured Transition Program Among Young Adults With Type 1 Diabetes. *J Adolesc Health*. 2017;60(2):212-8. doi: 10.1016/j.jadohealth.2016.09.004.

Shulman R, Fu L, Knight JC, et al. Acute diabetes complications across transition from pediatric to adult care in Ontario and Newfoundland and Labrador: a population-based cohort study. *CMAJ open*. 2020. doi: 10.9778/cmajo.20190019. PMID: 32046971.

Shulman R, Fu L, Knight JC, et al. Acute diabetes complications across transition from pediatric to adult care in Ontario and Newfoundland and Labrador: a population-based cohort study. *CMAJ open*. 2020. doi: 10.9778/cmajo.20190019. PMID: 32046971

Steinbeck KS, Shrewsbury VA, Harvey V, et al. A pilot randomized controlled trial of a post-discharge program to support emerging adults with type 1 diabetes mellitus transition from pediatric to adult care. *Pediatr Diabetes*. 2015;16(8):634-9. doi: 10.1111/pedi.12229.

Tubiana-Rufi N. Transition in care in type 1 diabetes young patients. Which programs and how effective? *Medecine des Maladies Metaboliques*. 2019;13(5):404-12. doi: 10.1016/s1957-2557%2819%2930112-9. PMID: 2002890962.

Van Walleghem N, MacDonald CA, Dean HJ. The Maestro Project: A Patient Navigator for the Transition of Care for Youth With Type 1 Diabetes. *Diabetes Spectr*. 2011;24(1):9-13. doi: 10.2337/diaspect.24.1.9. PMID: 104869299.

Van Walleghem N, MacDonald CA, Dean HJ. Transition of care for young adults with type 1 and 2 diabetes. *Pediatr Ann*. 2012. doi: 10.3928/00904481-20120426-20. PMID: 22587508.

Vidal M, Jansa M, Giménez M, et al. Impact of a special therapeutic education programme in patients transferred from a paediatric to an adult diabetes unit. *European Diabetes Nursing*. 2004;1(1):23-7. doi: 10.1002/edn.5. PMID: 106270796.

Weitzman ER, Kaci L, Quinn M, et al. Helping high-risk youth move through high-risk periods: personally controlled health records for improving social and health care transitions. *J Diabetes Sci Technol*. 2011 Jan 1;5(1):47-54. doi: 10.1177/193229681100500107. PMID: 21303624.

Yi-Frazier, J. P., et al. The clock is ticking: Parental stress around emerging adulthood for adolescents with type 1 diabetes. *Journal of Pediatric Nursing*. 2021;19:19.

Zack J, Jacobs CP, Keenan PM, et al. Perspectives of Patients With Cystic Fibrosis on Preventive Counseling and Transition to Adult Care. *Pediatr Pulmonol*. 2003;36(5):376-83. doi: 10.1002/ppul.10342. PMID: 37296697.

Zoni S, Verga M-E, Hauschild M, et al. Patient Perspectives on Nurse-led Consultations Within a Pilot Structured Transition Program for Young Adults Moving From an Academic Tertiary Setting to Community-based Type 1 Diabetes Care. *J Pediatr Nurs*. 2018;38:99-105. doi: 10.1016/j.pedn.2017.11.015. PMID: 623790638.

Human Immunodeficiency Virus (HIV)

Andiman WA. Transition from pediatric to adult healthcare services for young adults with chronic illnesses: the special case of human immunodeficiency virus infection. *J Pediatr*. 2011. doi: 10.1016/j.jpeds.2011.06.040. PMID: 21868035.

Fair C, Albright J, Lawrence A, et al. "The pediatric social worker really shepherds them through the process": Care team members' roles in transitioning adolescents and young adults with HIV to adult care. *Vulnerable Child Youth Stud*. 2012;7(4):338-46. doi: 10.1080/17450128.2012.713533. PMID: 82249148.

Gilliam, P. Transitional care for adolescents with HIV: characteristics and current practices of the Adolescent Trials Network systems of care. *Transitional Care for Adolescents With HIV: Characteristics & Current Practices of the Adolescent Trials Network Systems of Care*. 2009:132 p- p. PMID: 109853661.

Gilliam PP, Ellen JM, Leonard L, et al. Transition of Adolescents With HIV to Adult Care: Characteristics and Current Practices of the Adolescent Trials Network for HIV/AIDS Interventions. *J Assoc Nurses AIDS Care*. 2011;22(4):283-94. doi: 10.1016/j.jana.2010.04.003. PMID: 50946669.

Griffith D, Jin L, Childs J, et al. Outcomes of a Comprehensive Retention Strategy for Youth With HIV After Transfer to Adult Care in the United States. *Pediatr. Infect. Dis. J*. 2019;38(7):722-6. doi: 10.1097/inf.0000000000002309. PMID: 627414449.

- Griffith D, Snyder J, Dell S, et al. Impact of a Youth-Focused Care Model on Retention and Virologic Suppression Among Young Adults With HIV Cared for in an Adult HIV Clinic. *J Acquir Immune Defic Syndr*. 2019. doi: 10.1097/qai.0000000000001902. PMID: 30422910.
- Hussen SA, Chakraborty R, Camacho-Gonzalez A, et al. Beyond "purposeful and planned": varied trajectories of healthcare transition from pediatric to adult-oriented care among youth living with HIV. *AIDS Care*. 2019;31(1):45-7. doi: 10.1080/09540121.2018.1488029. PMID: 622600506.
- Jones SC, Ng YC, Ost SR. HIV Health Care Transition Readiness: Embracing the Opportunity and Challenge. *J Assoc Nurses AIDS Care*. 2019;30(5):521-30. doi: 10.1097/01.Jnc.0000552939.89108.22.
- Kim S, Kim SH, McDonald S, et al. Transition to adult services-a positive step. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*. 2017;29(7):885-9. doi: 10.1080/09540121.2016.1268672.
- Lolekha R, Boon-Yasidhi V, Na-Nakorn Y, et al. The Happy Teen programme: A holistic outpatient clinic-based approach to prepare HIV-infected youth for the transition from paediatric to adult medical care services in Thailand. *J Int AIDS Soc*. 2017;20(S):21500. doi: 10.7448/ias.20.4.21500.
- Maturo D, Powell A, Major-Wilson H, et al. Development of a protocol for transitioning adolescents with HIV infection to adult care. [Review]. *J Pediatr Health Care*. 2011. doi: 10.1016/j.pedhc.2009.12.005. PMID: 21147403.
- Maturo D, Powell A, Major-Wilson H, et al. Transitioning Adolescents and Young Adults With HIV Infection to Adult Care: Pilot Testing the "Movin' Out" Transitioning Protocol. *J Pediatr Nurs*. 2015;30(5):e29-e35. doi: 10.1016/j.pedn.2015.06.013.
- Newman C, Persson A, Miller A, et al. Bridging worlds, breaking rules: Clinician perspectives on transitioning young people with perinatally acquired HIV into adult care in a low prevalence setting. *AIDS Patient Care STDS*. 2014;28(7):381-93. doi: 10.1089/apc.2013.0346. PMID: 373457458.
- Njuguna I, Beima-Sofie K, Mburu C, et al. What happens at adolescent and young adult HIV clinics? A national survey of models of care, transition and disclosure practices in Kenya. *Trop Med Int Health*. 2020. doi: 10.1111/tmi.13374. PMID: 31984597.
- Nyabigambo A, Muliira JK, Atuyambe L, et al. Determinants of utilization of a no-cost HIV transition clinic: A cross-sectional study of young adults living with HIV/AIDS. *Adolesc Health Med Ther*. 2014;5:89-99. doi: 10.2147/ahmt.S57950. PMID: 373242798.
- Pettitt ED, Greifinger RC, Phelps BR, et al. Improving health services for adolescents living with HIV in sub-Saharan Africa: a multi-country assessment. *Afr J Reprod Health*. 2013. PMID: 24689314.
- Philbin MM, Tanner AE, Chambers BD, et al. Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: using adolescent and adult providers' insights to create multi-level solutions to address transition barriers. *AIDS Care*. 2017;29(1):1227-34. doi: 10.1080/09540121.2017.1338655. PMID: 616783735.
- Ryscavage P, Macharia T, Patel D, et al. Linkage to and retention in care following healthcare transition from pediatric to adult HIV care. *AIDS Care*. 2016. doi: 10.1080/09540121.2015.1131967. PMID: 26766017.
- Seybolt L. Transition of care for HIV-infected youth can be challenging for both provider and patient. *HIV Clin*. 2014. PMID: 26685340.
- Siu GE, Bakeera-Kitaka S, Kennedy CE, et al. HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*. 2012;24(5):606-11. doi: 10.1080/09540121.2011.630346. PMID: 364854782.
- Tanner AE, Philbin MM, DuVal A, et al. Transitioning HIV-Positive Adolescents to Adult Care: Lessons Learned From Twelve Adolescent Medicine Clinics. *J Pediatr Nurs*. 2016;31(5):537-43. doi: 10.1016/j.pedn.2016.04.002.
- Tanner AE, Philbin MM, Ma A, et al. Adolescent to Adult HIV Health Care Transition From the Perspective of Adult Providers in the United States. *J Adolesc Health*. 2017;61(4):434-9. doi: 10.1016/j.jadohealth.2017.05.011. PMID: 617511743.
- Wiener LS, Zobel M, Battles H, et al. Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: Assessing transition readiness. *Soc Work Health Care*. 2007;46(1):1-19. doi: 10.1300/J010v46n01_01. PMID: 350174518

Yi S, Ngin C, Pal K, et al. Transition into adult care: factors associated with level of preparedness among adolescents living with HIV in Cambodia. *AIDS Res Ther.* 2017. doi: 10.1186/s12981-017-0159-6. PMID: 28716149.

Inflammatory Bowel Disease

Al-Jahdali E, Mosli M, Saadah O. A cross-sectional survey of Saudi gastroenterologists: Transition strategies for adolescents with inflammatory bowel disease. *Saudi J Gastroenterol.* 2017;23(4):233-7. doi: 10.4103/sjg.SJG_77_17. PMID: 617550882.

Benchimol EI, Walters TD, Kaufman M, et al. Assessment of knowledge in adolescents with inflammatory bowel disease using a novel transition tool. *Inflamm Bowel Dis.* 2011;17(5):1131-7. doi: 10.1002/ibd.21464. PMID: 361591010.

Bennett AL, Moore D, Bampton PA, et al. Outcomes and patients' perspectives of transition from paediatric to adult care in inflammatory bowel disease. *World J Gastroenterol.* 2016;22(8):2611-20. doi: 10.3748/wjg.v22.i8.2611. PMID: 608904774.

Bollegala N, Benchimol EI, Griffiths AM, et al. Characterizing the Posttransfer Period Among Patients with Pediatric Onset IBD: The Impact of Academic Versus Community Adult Care on Emergent Health Resource Utilization. *Inflamm Bowel Dis.* 2017. doi: 10.1097/mib.0000000000001200. PMID: 28816756.

Carlsen K, Hald M, Dubinsky MC, et al. A Personalized eHealth Transition Concept for Adolescents With Inflammatory Bowel Disease: Design of Intervention. *JMIR Pediatr Parent.* 2019;2(1):e12258. doi: 10.2196/12258. PMID: 31518331.

Gray WN, Resmini AR, Baker KD, et al. Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflamm Bowel Dis.* 2015;21(7):1641-51. doi: 10.1097/mib.0000000000000419. PMID: 604980805.

Huang JS, Yueh R, Wood K, et al. Harnessing the Electronic Health Record to Distribute Transition Services to Adolescents with Inflammatory Bowel Disease. *J Pediatr Gastroenterol Nutr.* 2020;70(2):200-4. doi: 10.1097/mpg.0000000000002516. PMID: 629613177.

Testa A, Giannetti E, Rispo A, et al. Successful outcome of the transitional process of inflammatory bowel disease from pediatric to adult age: A five years experience. *Dig Liver Dis.* 2019 Apr;51(4):524-8. doi: 10.1016/j.dld.2018.11.034. PMID: 30704905.

Tung J, Grunow JE, Jacobs N. Pilot Development of an Electronic Pediatric Inflammatory Bowel Disease Quiz Game. *J Pediatr Gastroenterol Nutr.* 2015;61(3):292-6. doi: 10.1097/mpg.0000000000000788. PMID: 25793902.

van Rheenen PF, Aloï M, Biron IA, et al. European Crohn's and Colitis Organisation topical review on transitional care in inflammatory bowel disease. *J Crohns Colitis.* 2017;11(9):1032-8. doi: 10.1093/ecco-jcc/jjx010. PMID: 619627415.

Juvenile Idiopathic Arthritis

Ammerlaan JW, van Os-Medendorp H, de Boer-Nijhof NC, et al. The most important needs and preferences of patients for support from health care professionals: A reflective practice on (transitional) care for young adults with Juvenile Idiopathic Arthritis. *Patient Educ Couns.* 2017. doi: 10.1016/j.pec.2017.03.018. PMID: 28363359.

Gray NJ, Shaw KL, Smith FJ, et al. The Role of Pharmacists in Caring for Young People With Chronic Illness. *J Adolesc Health.* 2017;60(2):219-25. doi: 10.1016/j.jadohealth.2016.09.023. PMID: 27913114.

Foster HE, Minden K, Clemente D, et al. EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Ann Rheum Dis.* 2017;76(4):639-46. doi: 10.1136/annrheumdis-2016-210112.

Hilderson D, Westhovens R, Wouters C, et al. Rationale, design and baseline data of a mixed methods study examining the clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: The DON'T RETARD project. *BMJ Open.* 2013;3(1):003591. doi: 10.1136/bmjopen-2013-003591. PMID: 372128496.

McDonagh JE, Shaw KL, Southwood TR. Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *Journal of child health care : for professionals working with children in the hospital and community.* 2006;10(1):22-42. doi: 10.1177/1367493506060203. PMID: 43582034.

Ravelli A, Sinigaglia L, Cimaz R, et al. Transitional care of young people with juvenile idiopathic arthritis in Italy: results of a Delphi consensus survey. *Clin Exp Rheumatol*. 2019. PMID: 31376254.

Kidney Disease

Forbes TA, Watson AR, Zurowska A, et al. Adherence to transition guidelines in European paediatric nephrology units. *Pediatr Nephrol*. 2014;29(9):1617-24. doi: 10.1007/s00467-014-2809-4. PMID: 608051571.

Kreuzer M, Drube J, Prufe J, et al. Current management of transition of young people affected by rare renal conditions in the ERKNet. *Eur J Hum Genet*. 2019;27(1):1783-90. doi: 10.1038/s41431-019-0460-z. PMID: 2002354377.

Mental Health

Belling R, McLaren S, Paul M, et al. The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. *J Health Serv Res Policy*. 2014;19(3):169-76. doi: 10.1177/1355819614527439. PMID: 103966098.

Cappelli M, Davidson S, Racek J, et al. Transitioning Youth into Adult Mental Health and Addiction Services: An Outcomes Evaluation of the Youth Transition Project. *J Behav Health Serv Res*. 2016;43(4):597-610. PMID: 620873574.

Dunn V. Young people, mental health practitioners and researchers co-produce a Transition Preparation Programme to improve outcomes and experience for young people leaving Child and Adolescent Mental Health Services (CAMHS). *BMC Health Serv Res*. 2017;17(1):293. doi: 10.1186/s12913-017-2221-4. PMID: 616696929.

Eke H, Janssens A, Newlove-Delgado T, et al. Clinician perspectives on the use of National Institute for Health and Care Excellence guidelines for the process of transition in Attention Deficit Hyperactivity Disorder. *Child Care Health Dev*. 2020;46(1):111-20. doi: 10.1111/cch.12718. PMID: 31613391.

Hall CL, Newell K, Taylor J, et al. Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: A national survey of mental health trusts in England. *Journal of Psychopharmacology*. 2015;29(1):39-42. doi: 10.1177/0269881114550353.

Hovish K, Weaver T, Islam Z, et al. Transition experiences of mental health service users, parents, and professionals in the United Kingdom: a qualitative study. *Psychiatr Rehabil J*. 2012;35(3):251-7. doi: 10.2975/35.3.2012.251.257. PMID: 364548432.

Leijdesdorff S, Postma MR, van Kersbergen L, et al. No boundaries: a 2 year experience in a specialized youth mental health care program in the Netherlands. *Early Interv Psychiatry*. 2020;14(2):228-34. doi: 10.1111/eip.12887. PMID: 2003549165.

Martin, R., et al. The impact of digital communication on adolescent to adult mental health service transitions. *Journal of Research in Nursing*. 2020;25(3): 277-288.

Nadarajah, A., et al. Impending Transition From Pediatric to Adult Health Services: A Qualitative Study of the Experiences of Adolescents With Eating Disorders and Their Caregivers. *Frontiers in psychiatry* Frontiers Research Foundation. 2021;12:624942.

Oldknow H, Williamson K, Etheridge K. Peer support to assist in transition to adult services. *Nurs Times*. 2014;110(6):20-1. PMID: 1372455797.

Paul M, Ford T, Kramer T, et al. Transfers and transitions between child and adult mental health services. *Br J Psychiatry Suppl*. 2013. doi: 10.1192/bjp.bp.112.119198. PMID: 23288500.

Reale L, Frassica S, Gollner A, et al. Transition to adult mental health services for young people with attention deficit hyperactivity disorder in Italy: Parents' and clinicians' experiences. *Postgrad Med*. 2015;127(7):671-6. doi: 10.1080/00325481.2015.1070658.

Schandrin A, Capdevielle D, Boulenger J-P, et al. Transition from child to adult mental health services: a French retrospective survey. *J Ment Health Train Educ Pract*. 2016;11(5):286-93. doi: 10.1108/jmhtep-09-2015-0041. PMID: 118946015.

Shik, Angela WY. Integrating creative art into a community-based mental health program for Asian American transition age youth. *Child Youth Serv Rev*. 2013;35(3):377-83. doi: 10.1016/j.chilyouth.2012.12.002. PMID: 104241126.

Singh SP, Paul M, Ford T, et al. Transitions of care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): a study of protocols in Greater London. *BMC Health Serv Res.* 2008. doi: 10.1186/1472-6963-8-135. PMID: 18573214.

Singh SP, Paul M, Ford T, et al. Process, outcome and experience of transition from child to adult mental healthcare: multi-perspective study. *Br J Psychiatry.* 2010. doi: 10.1192/bjp.bp.109.075135. PMID: 20884954.

van der Kamp J. The transition between mental health services in Scotland. *Ment Health Rev.* 2018;23(1):12-24. doi: 10.1108/mhrj-05-2017-0020. PMID: 128291462.

Vloet MA, Davidson S, Cappelli M. "We suffer from being lost": formulating policies to reclaim youth in mental health transitions. *Healthc Q.* 2011. doi: 10.12927/hcq.2011.22361. PMID: 24956424.

Webb, H. and U. Schmidt. Facilitators and barriers to supporting young people with eating disorders during their transition to, and time at, university: An exploration of clinicians' perspectives. *European Eating Disorders Review.* 2021;29(3): 443-457.

Young S, Adamou M, Asherson P, et al. Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network. *BMC Psychiatry.* 2016;16:301. doi: 10.1186/s12888-016-1013-4. PMID: 27561259.

Neurological Disorders

Andrade DM, Bassett AS, Bercovici E, et al. Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. *Epilepsia.* 2017;58(9):1502-17. doi: 10.1111/epi.13832.

Boyce DM, Devinsky O, Meskis MA. Barriers to transition from pediatric to adult care for patients with Dravet syndrome: A focus group study of caregivers. *Epilepsy Behav.* 2020;109:107096. doi: 10.1016/j.yebeh.2020.107096.

Carrizosa-Moog J, Isaza-Jaramillo S. Perceptions of adult and child neurologists of transition programs in epilepsy in Latin America: A cross-sectional study. *Epilepsy Behav.* 2020;110:107159. doi: 10.1016/j.yebeh.2020.107159.

Geerlings RPJ, Aldenkamp AP, Gottmer-Welschen LMC, et al. Evaluation of a multidisciplinary epilepsy transition clinic for adolescents. *Eur J Paediatr Neurol.* 2016;20(3):385-92. doi: 10.1016/j.ejpn.2016.01.003.

Hartman LR, McPherson AC, Maxwell J, et al. Exploring the ICF-CY as a framework to inform transition programs from pediatric to adult healthcare. *Dev Neurorehabil.* 2018;21(5):312-25. doi: 10.1080/17518423.2017.1323969.

Hughes-Scalise A, Reger KL, Gergen MA. Pilot data and case example of the initial visit in a multidisciplinary transition-age program (TAP). *Epilepsy Behav.* 2020;111:107242. doi: 10.1016/j.yebeh.2020.107242.

Jurasek L, Ray L, Quigley D. Development and implementation of an Adolescent Epilepsy Transition Clinic. *J Neurosci Nurs.* 2010;42(4):181-9. doi: 10.1097/JNN.0b013e3181e26be6. PMID: 359589814.

Lawrence W B. Practical Tools to Monitor and Evaluate Transition. *Semin Pediatr Neurol.* 2020;36:100852. doi: 10.1016/j.spen.2020.100852. PMID: 33308520.

Lewis SA, Noyes J. Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adult services. *BMC Pediatr.* 2013;13:169. doi: 10.1186/1471-2431-13-169. PMID: 24131769.

Mc Govern EM, Maillart E, Bourgninaud M, et al. Making a 'JUMP' from paediatric to adult healthcare: A transitional program for young adults with chronic neurological disease. *J Neurol Sci.* 2018 Dec 15;395:77-83. doi: 10.1016/j.jns.2018.09.030. PMID: 30296734.

Reger KL, Hughes-Scalise A, O'Connor MA. Development of the transition-age program (TAP): Review of a pilot psychosocial multidisciplinary transition program in a Level 4 epilepsy center. *Epilepsy Behav.* 2018;89:153-8. doi: 10.1016/j.yebeh.2018.10.021

Seaborg K, Wang X, Olson C, et al. Pediatric to Adult Transitions of Ketogenic Dietary Therapy for Epilepsy. *J Child Neurol.* 2020;883073820938587. doi: 10.1177/0883073820938587. PMID: 32698640.

Rheumatic Conditions

Akre C, Suris J-C, Belot A, et al. Building a transitional care checklist in rheumatology: A Delphi-like survey. *Joint Bone Spine*. 2018;85(4):435-40. doi: 10.1016/j.jbspin.2017.09.003. PMID: 619267338.

van Pelt PA, Kruize AA, Goren SS, et al. Transition of rheumatologic care, from teenager to adult: which health assessment questionnaire can be best used? *Clin Exp Rheumatol*. 2010. PMID: 20483054.

Walter M, Hazes JM, Dolhain RJ, et al. Development of a clinical transition pathway for adolescents in the Netherlands. *Nurs Child Young People*. 2017;29(9):37-43. doi: 10.7748/ncyp.2017.e932. PMID: 620172773.

Walter M, Kamphuis S, van Pelt P, et al. Successful implementation of a clinical transition pathway for adolescents with juvenile-onset rheumatic and musculoskeletal diseases. *Pediatr Rheumatol Online J*. 2018;16(1):50. doi: 10.1186/s12969-018-0268-3.

Sickle Cell Disease

Cerns S, McCracken C, Rich C. Optimizing adolescent transition to adult care for sickle cell disease. *Medsurg Nurs*. 2013. PMID: 24147324.

Doulton DM. From cradle to commencement: transitioning pediatric sickle cell disease patients to adult providers. *J Pediatr Oncol Nurs*. 2010. doi: 10.1177/1043454209350155. PMID: 19897836.

Hoegy D, Bleyzac N, Gauthier-Vasserot A, et al. Impact of a paediatric-adult care transition programme on the health status of patients with sickle cell disease: Study protocol for a randomised controlled trial (the DREPADO trial). *Trials*. 2020;21(1):152. doi: 10.1186/s13063-019-4009-9. PMID: 630858295.

Johnson AD, Pines E, Seibenhener S, et al. Improving Transition Readiness in Young Adults With Sickle Cell Disease. *The Journal for Nurse Practitioners*. 2020;16(10):e165-e7. doi: 10.1016/j.nurpra.2020.07.026.

Johnson R, Edwards R, Rivers A, et al. Evaluating literacy levels of patient education materials for a sickle cell transition group education programme. *Health Educ J*. 2020;79(3):253-65. doi: 10.1177/0017896919876668. PMID: 2003468366.

Melita N, Diaz-Linhart Y, Kavanagh PL, et al. Developing a Problem-solving Intervention to Improve Self-Management and Transition Readiness in Adolescents with Sickle Cell Disease. *J Pediatr Nurs*. 2019;46:26-32. doi: 10.1016/j.pedn.2019.02.006. PMID: 627030297.

Porter JS, Lopez AD, Wesley KM, et al. Using Qualitative Perspectives of Adolescents with Sickle Cell Disease and Caregivers to Develop Healthcare Transition Programming. *Clin Pract Pediatr Psychol*. 2017;5(4):319-29. doi: 10.1037/cpp0000212. PMID: 31131180.

Sobota AE, Shah N, Mack JW. Development of quality indicators for transition from pediatric to adult care in sickle cell disease: A modified Delphi survey of adult providers. *Pediatr Blood Cancer*. 2017;64(6):e26374. doi: 10.1002/pbc.26374. PMID: 615670853.

Sobota AE, Umeh E, Mack JW. Young Adult Perspectives on a Successful Transition from Pediatric to Adult Care in Sickle Cell Disease. *J Hematol Res*. 2015;2(1):17-24. PMID: 27175364.

Williams CP, Smith CH, Osborn K, et al. Patient-centered approach to designing sickle cell transition education. *J Pediatr Hematol Oncol*. 2015;37(1):43-7. doi: 10.1097/mpb.000000000000169. PMID: 53128322.

Wills KE, Nelson SC, Hennessy J, et al. Transition planning for youth with sickle cell disease: embedding neuropsychological assessment into comprehensive care. *Pediatrics*. 2010. doi: 10.1542/peds.2010-1466J. PMID: 21123479.

Solid Organ Transplant

Anthony SJ, Martin K, Drabble A, et al. Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *Am J Transplant*. 2009. doi: 10.1111/j.1600-6143.2008.02515.x. PMID: 19260839.

Fredericks EM, Dore-Stites D, Lopez MJ, et al. Transition of pediatric liver transplant recipients to adult care: Patient and parent perspectives. *Pediatr Transplant*. 2011;15(4):414-24. doi: 10.1111/j.1399-3046.2011.01499.x. PMID: 51397899.

Gold A, Martin K, Breckbill K, et al. Transition to adult care in pediatric solid-organ transplant: development of a practice guideline. *Prog Transplant*. 2015;25(2):131-8. doi: 10.7182/pit2015833. PMID: 606765588.

Kreuzer M, Prufe J, Oldhafer M, et al. Transitional Care and Adherence of Adolescents and Young Adults After Kidney Transplantation in Germany and Austria: A Binational Observatory Census Within the TRANSNephro Trial. *Medicine*. 2015. doi: 10.1097/md.0000000000002196. PMID: 26632907.

Nakanishi C, Miyagi S, Tokodai K, et al. Pediatric Living-Donor Liver Transplant Recipients without Transition After Reaching Adulthood. *Ann Transplant*. 2019. doi: 10.12659/aot.911544. PMID: 30617248.

Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. *Prog Transplant*. 2006 Dec;16(4):291-302. PMID: 17183935.

Rieger S, Bethe D, Bagorda A, et al. A need-adapted transition program after pediatric kidney transplantation. *Journal of Transition Medicine*. 2019;1(1):20180004. doi: 10.1515/jtm-2018-0004. PMID: 626839480.

Wright J, Elwell L, McDonagh JE, et al. "Are these adult doctors gonna know me?" Experiences of transition for young people with a liver transplant. *Pediatr Transplant*. 2016. doi: 10.1111/ptr.12777. PMID: 27558645.

Spina Bifida

Hopson B, Rocque BG, Joseph DB, et al. The development of a lifetime care model in comprehensive spina bifida care. *J Pediatr Rehabil Med*. 2018. doi: 10.3233/prm-180548. PMID: 30507593.

Levy S, Wynd AHD, Carachi R. Transition into adult healthcare services in Scotland: findings from a study concerning service users at the Scottish Spina Bifida Association. *Scott Med J*. 2014;59(4):209-13. doi: 10.1177/0036933014556200. PMID: 25358489.

Lindsay S, Cruickshank H, McPherson AC, et al. Implementation of an inter-agency transition model for youth with spina bifida. *Child Care Health Dev*. 2016;42(2):203-12. doi: 10.1111/cch.12303. PMID: 615895250.

Lindsay S, Fellin M, Cruickshank H, et al. Youth and parents' experiences of a new inter-agency transition model for spina bifida compared to youth who did not take part in the model. *Disabil Health J*. 2016. doi: 10.1016/j.dhjo.2016.05.009. PMID: 27346055.

Rauen KK, Sawin KJ, Bartelt T, et al. Transitioning adolescents and young adults with a chronic health condition to adult healthcare - An exemplar program. *Rehabil Nurs*. 2013;38(2):63-72. doi: 10.1002/rnj.74. PMID: 368735120.

West C, Brodie L, Dicker J, et al. Development of health support services for adults with spina bifida. *Disabil Rehabil*. 2011. doi: 10.3109/09638288.2011.568664. PMID: 21492059.

Urological Conditions

Lewis J, Frimberger D, Haddad E, et al. A framework for transitioning patients from pediatric to adult health settings for patients with neurogenic bladder. *NeuroUrol Urodyn*. 2017;36(4):973-8. doi: 10.1002/nau.23053. PMID: 610782174.

Szymanski KM, Misseri R, Whittam B, et al. Current opinions regarding care of the mature pediatric urology patient. *J Pediatr Urol*. 2015. doi: 10.1016/j.jpuro.2015.05.020. PMID: 26148437.

Timberlake MD, Corbett ST, Costabile RA, et al. Identification of adolescent and adult patients receiving pediatric urologic care and establishment of a dedicated transition clinic. *J Pediatr Urol*. 2015;11(2):62. doi: 10.1016/j.jpuro.2014.11.013. PMID: 602992293.

Other Conditions

Aldiss S, Ellis J, Cass H, et al. Transition From Child to Adult Care--'It's Not a One-Off Event': Development of Benchmarks to Improve the Experience. *J Pediatr Nurs*. 2015;30(5):638-47. doi: 10.1016/j.pedn.2015.05.020. PMID: 26209172.

Aldiss S, Cass H, Ellis J, et al. "We Sometimes Hold on to Ours" - Professionals' Views on Factors that both Delay and Facilitate Transition to Adult Care. *Frontiers in pediatrics*. 2016;4:125. PMID: 27933284.

Amaria K, Stinson J, Cullen-Dean G, et al. Tools for addressing systems issues in transition. *Healthcare quarterly (Toronto, Ont)*. 2011;14:72-6. PMID: 560070084.

Antonini TM, Girard M, Habes D, et al. Optimization of the transition process of youth with liver disease in adulthood: A position paper from FILFOIE, the French network for paediatric and adult rare liver diseases. *Clin Res Hepatol Gastroenterol*. 2020;44(2):135-41. doi: 10.1016/j.clinre.2019.07.018. PMID: 2002970622.

- Brown M, Higgins A, MacArthur J. Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities. *J Clin Nurs*. 2020 Jan;29(1-2):195-207. doi: 10.1111/jocn.15077. PMID: 31610045.
- Burns F, Stewart R, Reddihough D, et al. The cerebral palsy transition clinic: administrative chore, clinical responsibility, or opportunity for audit and clinical research? *J Child Orthop*. 2014;8(3):203-13. doi: 10.1007/s11832-014-0569-0. PMID: 24728956.
- Ciccarelli MR, Brown MW, Gladstone EB, et al. Implementation and sustainability of statewide transition support services for youth with intellectual and physical disabilities. *J Pediatr Rehabil Med*. 2014;7(1):93-104. doi: 10.3233/prm-140274. PMID: 373301005.
- Ciccarelli MR, Gladstone EB, Armstrong Richardson EA. Implementation of a Transdisciplinary Team for the Transition Support of Medically and Socially Complex Youth. *J Pediatr Nurs*. 2015 Sep-Oct;30(5):661-7. doi: 10.1016/j.pedn.2015.07.003. PMID: 26233635.
- Connor MJ, Springford LR, Giuliani S. Transition Risk Assessment Score to Stratify Health Care Needs and Interventions in Adolescents with Anorectal Malformations: A Pilot Study. *Eur J Pediatr Surg*. 2017;27(4):361-7. doi: 10.1055/s-0036-1593980. PMID: 613549286.
- Foster L, Holmes Y. Transition from paediatric to adult service in epidermolysis bullosa. *Br J Nurs*. 2007;16(4):244-6. doi: 10.12968/bjon.2007.16.4.22993. PMID: 46612800.
- Freeman M, Stewart D, Shimmell L, et al. Development and evaluation of The KIT: Keeping It Together for Youth (the 'Youth KIT') to assist youth with disabilities in managing information. *Child Care Health Dev*. 2015 Mar;41(2):222-9. doi: 10.1111/cch.12199. PMID: 25338500.
- Giuliani S, Grano C, Aminoff D, et al. Transition of care in patients with anorectal malformations: Consensus by the ARM-net consortium. *J Pediatr Surg*. 2017;52(1):1866-72. doi: 10.1016/j.jpedsurg.2017.06.008. PMID: 617200449.
- Gleeson H, Davis J, Jones J, et al. The challenge of delivering endocrine care and successful transition to adult services in adolescents with congenital adrenal hyperplasia: Experience in a single centre over 18 years. *Clin Endocrinol (Oxf)*. 2013;78(1):23-8. doi: 10.1111/cen.12053. PMID: 366253009.
- Hamdani Y, Proulx M, Kingsnorth S, et al. The LIFEsplan model of transitional rehabilitative care for youth with disabilities: healthcare professionals' perspectives on service delivery. *J Pediatr Rehabil Med*. 2014. doi: 10.3233/prm-140271. PMID: 24919941.
- Hunter Nolan RE, McLaughlin E, Duane Y, et al. Adolescent feedback on the Haemophilia Transition Programme between Our Lady's Children's Hospital and St. James's Hospital Dublin Ireland. *Int J Integr Care*. 2017;17:1-2. doi: 10.5334/ijic.3889. PMID: 131981186.
- Isabel Carrier J, Siedlikowski M, Chougui K, et al. A Best Practice Initiative to Optimize Transfer of Young Adults With Osteogenesis Imperfecta From Child to Adult Healthcare Services. [Review]. *Clin Nurse Spec*. 2018. doi: 10.1097/nur.0000000000000407. PMID: 30299335.
- Iyer A, Appleton R. Transitional services for adolescents with epilepsy in the UK: A survey. *Seizure*. 2013;22(6):433-7. doi: 10.1016/j.seizure.2013.02.014. PMID: 52487821.
- Jones MR, Robbins BW, Augustine M, et al. Transfer from pediatric to adult endocrinology. *Endocr Pract*. 2017;23(7):822-30. doi: 10.4158/ep171753.Or.
- Kerin L, Lynch D, McNicholas F. Participatory development of a patient-clinician communication tool to enhance healthcare transitions for young people with 22q11.2. *Ir J Med Sci*. 2020;189(3):761-9. doi: 10.1007/s11845-019-02104-6. PMID: 2003815386.
- Kingsnorth S, Lindsay S, Maxwell J, et al. Implementation of the LIFE span model of transition care for youth with childhood onset disabilities. *Int J Child Adolesc health*. 2010;3(4):547-60. PMID: 104987760.
- Kingsnorth S, Gall C, Beayni S, et al. Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child Care Health Dev*. 2011;37(6):833-40. doi: 10.1111/j.1365-2214.2011.01294.x. PMID: 22007983.
- Lindsay S, Proulx M, Maxwell J, et al. Gender and transition from pediatric to adult health care among youth with acquired brain injury: Experiences in a transition model. *Arch Phys Med Rehabil*. 2016;97(2):S33-S9. doi: 10.1016/j.apmr.2014.04.032. PMID: 605212381.

- McManus M, White P, Barbour A, et al. Pediatric to adult transition: A quality improvement model for primary care. *J Adolesc Health*. 2015;56(1):73-8. doi: 10.1016/j.jadohealth.2014.08.006.
- Onofri A, Tan HL, Cherchi C, et al. Transition to adult care in young people with neuromuscular disease on non-invasive ventilation. *Ital J Pediatr*. 2019 Jul 23;45(1):90. doi: 10.1186/s13052-019-0677-z. PMID: 31337423.
- Paepgeaey AC, Coupaye M, Jaziri A, et al. Impact of transitional care on endocrine and anthropometric parameters in Prader-willi syndrome. *Endocr Connect*. 2018;7(5):663-72. doi: 10.1530/ec-18-0089. PMID: 622104666.
- Raina R, Wang J, Krishnappa V. Structured Transition Protocol for Children with Cystinosis. *Front Pediatr*. 2017;5:191. doi: 10.3389/fped.2017.00191. PMID: 28913329.
- Rusley J, Tomaszewski K, Kim J, et al. Improvement of Electronic Health Record Integrated Transition Planning Tools in Primary Care. *Pediatric quality & safety*. 2020;5(3):e282. doi: 10.1097/pq9.0000000000000282. PMID: 32656460.
- Solanke F, Colver A, McConachie H, et al. Are the health needs of young people with cerebral palsy met during transition from child to adult health care? *Child Care Health Dev*. 2018;44(3):355-63. doi: 10.1111/cch.12549. PMID: 29377236.
- A, McConachie H, et al. Are the health needs of young people with cerebral palsy met during transition from child to adult health care? *Child Care Health Dev*. 2018;44(3):355-63. doi: 10.1111/cch.12549. PMID: 29377236.
- Spyridakou C, Mendis S, DeVal D. Improving transition outcomes in adolescents with permanent hearing loss. *BMJ Open Qual*. 2019;8(2):e000336. doi: 10.1136/bmjopen-2018-000336. PMID: 630870228.
- Tan MJ, Klimach VJ. Portfolio of health advice for young people with disabilities transferring to adult care. *Child Care Health Dev*. 2004;30(3):291-6. doi: 10.1111/j.1365-2214.2003.000400.x. PMID: 38714425.
- Trout CJ, Case LE, Clemens PR, et al. A transition toolkit for Duchenne muscular dystrophy. *Pediatrics*. 2018;142(S):S110-S7. doi: 10.1542/peds.2018-0333M. PMID: 624146970.
- Velsor-Friedrich, B. and N. S. Hogan. Being Unprepared: A Grounded Theory of the Transition of Asthma Self-Care in College Students. *Journal of Pediatric Nursing*. 2021;61:305-311.
- Willis ER, McDonagh JE. Transition from children's to adults' services for young people using health or social care services (NICE Guideline NG43). *Arch Dis Child Educ Pract Ed*. 2018 Oct;103(5):253-6. doi: 10.1136/archdischild-2017-313208. PMID: 29269436

Appendix D. Evidence Tables and Evidence Maps for Care Interventions for Transition From Pediatric to Adult Medical Services (Chapter 4)

Cancer

Table D.1. Risk of bias assessment: cancer

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|-------------------------------|------------|----------------|
| Bashore 2016 ¹ (2620647) | 6 months | High | X | X | X | X | X | Foundation | High |
| Cox 2021 ² (No PMID) | 24 months | High | X | X | X | X | X | Nonprofit | High |

Note: X=Domain was not assessed.

Abbreviations: PMID=PubMed Identification Number

Table D.2. Characteristics of included studies: cancer

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|---------------------------------------|--|---|--|------------------------------|
| Bashore 2016 ¹ (26206471) United States Quantitative non randomized (pre-post observational with qualitative interview) ROB High Stage I | N=30 17.8 years at study recruitment 60% Female % White Unknown | Transition workbook Includes information about medical information, educational/vocational goals, staying healthy and life skills Intervention duration: 5-6 months Transition Readiness | None | Pediatric tertiary care center 6 months | Worry (worry in general and worry about leaving pediatrics) Transition (ready to transition, ready to make changes) | NR | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|---------------------------------------|---|---|--|------------------------------|
| Cox 2021 ² (No PMID) US Quantitative non- randomized (pre-post observational cohort) ROB High Stage 1 | N=112 year 1 & N=100 year 2 (CSHCN) N=36 parents Age NR Sex NR Race NR | Patient navigator program Transition Readiness; Transition Planning 30 to 60 minute appointments | NA | Children's hospital 24 months | Total number of patients and families who met with patient navigator Total number of patient navigator visit approvals from providers | Program process measures | NA |

Abbreviations: CSHCN=children with special healthcare need; NA=not applicable; NR=not reported; PMID=PubMed identification number; ROB=risk of bias

Table D.3. Characteristics of studies included in evidence map: cancer

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|-----------|---|--|--|
| Linendoll 2020 ³ (32640864) | Cancer | Adolescent and Young Adult Cancer Survivorship Program | CSHCN | United States Cancer Survivorship Clinic |
| Granek 2012 ⁴ (22547096) | Cancer | Cancer Long-term Follow-up Clinic | CSHCN | Canadian Cancer Survivorship Clinic |
| Ryan 2020 ⁵ (32845469) | Cancer | 'Life after the Janeway' educational workbook | CSHCN | Canadian Cancer Survivorship Clinic |
| Glaser 2013 ⁶ (23966026) | Cancer | Pediatric aftercare pathway | CSHCN | Cancer aftercare clinics in the United Kingdom National Health Service |
| Van Laar 2013 (23401266) ⁷ | Cancer | Managed care transition | CSHCN | Pediatric and adult cancer survivor clinics in the United Kingdom |
| Vollmer Dahlke 2017 (28410172) ⁸ | Cancer | After Care Ends, Survivorship Starts for Adolescent and Young Adults (ACCESS AYA) educational programming | CSHCN, health care providers, advocates | United States health system |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number

Chronic Conditions

Table D.4. Risk of bias assessment: chronic conditions

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---|-----------------|--|----------------|------------------|---------------|----------------|--------------------------------|-----------------|----------------|
| Szalda 2019 ⁹ (31277993) | 12 months | High | X | X | X | X | X | Hospital system | High |
| Razon 2019 ¹⁰ (31129412) | | | | | | | | | |
| Lemke 2018 ¹¹ (29650807) | 6, 12 months | Low, but convenience sample | Medium | Medium | Medium | Low | Low (0%; no missing data info) | Government | Medium |
| Gorter 2015 ¹² (25948409) | 15 to 30 months | High | X | X | X | X | X | Hospital system | High |
| Huang 2014 ¹³ (24843066) | 2, 8 months | Low, but 20% "other reason" not eligible | Low | Medium | Medium | Low | Low (7%) | Government | Medium |
| Lestishock 2021 ¹⁴ (33762131) | 24 months | High | X | X | X | X | X | NR | High |
| White 2020 ¹⁵ (33287619) | 12 months | High | X | X | X | X | X | Government | High |

Note: X=Domain was not assessed. **Abbreviations:** PMID=PubMed Identification Number

Table D.5. Characteristics of included studies: chronic conditions

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|--|---|---|--|------------------------------|
| Szalda 2019 (31129412) ⁹ Razon 2019 (31129412) ¹⁰ US Pre/post observational cohort ROB High Stage 2 | Nonspecific chronic conditions; intellectual disability/medically complex N=197 20 years (range 17- 43) Sec NR Race NR 71% intellectual or developmental disability | Multidisciplinary Intervention Navigation Team (MINT) transition program; All six core elements Unclear (2 year pilot) | NA | Pediatric tertiary academic hospital Unclear | Resource Utilization (inpatient admission days and outpatient clinic visits). | NR | NR |
| Lemke 2018 ¹¹ (29650807) US RCT ROB Medium Stage 3 | Youth eligible for SSI N=209 18 years (recruited 16-22) 48% Female 99.5% Black | Healthcare transition model based on the 6 core elements; Designed for complex patient but not disease-specific; All six core elements 12 months | Enhanced usual care: care notebook; blank transition readiness assessment form; local adult physician referral; information on insurance, guardianship, advance directives | Pediatric tertiary referral health system Follow-up 12 months | Perception of care (PACIC) r(), Client Perceptions of Coordination Questionnaire (CPCQ) | NR | NR |
| Gorter 2015 ¹² (25948409) Canada Mixed methods longitudinal prospective cohort ROB High Stage 2 | Nonspecific chronic conditions, full dependence on caregivers excluded N=50 18 years (recruited 17-22) 58% Female Race NR | Keeping It Together for Youth (Youth KIT) toolkit for planning and self-management plus on-line mentoring; Transition readiness, Transition planning; 12-47 months | NA | 2 Pediatric tertiary academic hospitals Unclear | Use-frequency of intervention use, Utility-intervention features, and Impact- satisfaction with transition goals (KIT), Satisfaction with care ((COPM) | NR | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|---|--|---|--|--|
| Huang 2014 ¹³ (24843066) US RCT ROB Medium Stage 2 | IBD, CF, and T1 diabetes, without cognitive impairment; N=81 17 years (recruited 12-20) 54% Female 50% Hispanic 33% White 10%Black 1% American Indian 6% Other | MD2Me, a technology- based disease management tool and resource; healthcare team communication portal for urgent and non-urgent concerns; Designed to be not diagnosis-specific; Transition readiness, Transition planning; 8 months | Monthly messages on general health issues; disease- specific information; usual care communication portals | Pediatric tertiary academic medical center 8 months | Transition Readiness (TRAQ) Self-efficacy (PAM) s; Disease function (disease-specific); Function (Karnofsky Performance Scale)) Quality of Life (PedsQL) | NR | NR |
| White 2020 ¹⁵ (33287619) US Pre/post observational cohort High ROB Stage 1 | N=560 Age NR (recruited 18+) % Female NR 75% African American 25% Hispanic/ Latino | Pilot study to increase school-based health centers' structured transition services All 6 core elements 12 months | None | High school- based health center 12 months | Self-care skills | NR | Assessmen t of six core elements of HCT |

Abbreviations: COPM=Canadian Occupational Performance Measure; CSHCN=children with special healthcare need; N=Number; NR=not reported; PACIC = Patient Assessment of Chronic Illness Care; PAM= Patient-initiated communications; PedsQL = Pediatric Quality of Life Scale; PMID=PubMed identification number; ROB=risk of bias; SSI=Supplemental security income; Youth KIT= Youth Keeping It Together Questionnaire

Table D.6. Outcomes summary, low and medium risk of bias studies: chronic conditions

| Study (PMID) Comparison RoB Category | Outcome Timing | Summary Finding | Intervention | Comparator | p-Value |
|---|--|---|--------------|------------|---------|
| Lemke 2018 ¹¹ (29650807) HCT vs enhanced care Medium Stage 3 | Total Patient Assessment of Chronic Illness Care (PACIC) total score Adjusted mean (SE) 12 months | Favors intervention (Similar finding for participant in high complexity tier.) | 3.6 (0.08) | 3.3 (0.10) | 0.01 |

| Study (PMID) Comparison RoB Category | Outcome Timing | Summary Finding | Intervention | Comparator | p-Value |
|--|--|--|---------------------|-------------------|-------------------|
| Lemke 2018 ¹¹ (29650807) HCT vs enhanced care Medium Stage 3 | Client Perceptions of Coordination Questionnaire (CPCQ) individual items Adjusted % mostly or always 12 months | Favors intervention on 3 of 7 items; not statistically significant difference on 4 of 7. (Table 4, pg 6) | NA | NA | <0.04 for 3 items |
| Huang 2014 ¹¹ (24843066) MD2Me vs attention control Medium Stage 2 | Chronic disease management, Transition Readiness Assessment Questionnaire TRAQ 8 months | Favors intervention | 4.0 (0.8) | 3.8 (0.8) | 0.02 |
| Huang 2014 ¹¹ (24843066) MD2Me vs attention control Medium Stage 2 | Health-related self- efficacy, Patient Activation Measure (PAM) 8 month | Favors intervention | 81 (17) | 71 (14) | 0.02 |
| Huang 2014 ¹¹ (24843066) MD2Me vs attention control Medium Stage 2 | Patient-Initiated Communications 8 months | Favors intervention | 2 contacts | 0 contacts | <0.0001 |
| Huang 2014 ¹¹ (24843066) MD2Me vs attention control Medium Stage 2 | Health outcomes: disease status, functional performance, quality of life 8 months | No difference | NR | NR | NS |

Abbreviations: PMID=PubMed identification number; NR=not reported; NA=not applicable; ROB=risk of bias; TRAQ=transition readiness assessment questionnaire

Table D.7. Summary of strength of evidence: chronic conditions

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/ Conclusion |
|--|---------------|---|---|------------------------------|--------------------|-------------------|------------------|--|
| Total Patient Assessment of Chronic Illness Care (PACIC) HCT vs enhanced care | 12 months | 1 RCT (n=209) ¹¹ | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Client Perceptions of Coordination Questionnaire (CPCQ) HCT vs enhanced care | 12 months | 1 RCT (n=209) ¹¹ | Favors intervention on 3 of 7 items; not statistically significant difference on 4 of 7 | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Transition Readiness Assessment Questionnaire (TRAQ) MD2Me vs attention control | 8 months | 1 RCT (n=81) ¹¹ | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Patient Activation Measure PAM MD2Me vs attention control | 8 months | 1 RCT (n=81) ¹¹ | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Patient-Initiated Communications MD2Me vs attention control | 8 months | 1 RCT (n=81) ¹¹ | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/ Conclusion |
|--|----------|--------------------------------------|------------------------------------|----------------------|-------------|------------|-----------|---------------------------------|
| Health outcomes: disease status, functional performance, quality of life MD2Me vs attention control | 8 months | 1 RCT (n=81) ¹¹ | No difference | Moderate | Unknown | Direct | Imprecise | Insufficient |

Abbreviations: RCT=randomized controlled trial

Table D.8. Characteristics of studies included in evidence map: chronic conditions

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|---------------------------------------|-------------------------------------|--|---------------------------|--|
| Nagra 2015 (26063244) ¹⁶ | Nonspecific chronic conditions | Ready Steady Go Transition Program (structured program) | CSHCN | UK tertiary pediatric services |
| Stinson 2014 (25000507) ¹⁷ | Nonspecific chronic pain conditions | ICanCopeWithPain app on Google Play | CSHCN | Canada pediatric chronic pain clinics |
| Cadogan 2018 (29957451) ¹⁸ | Nonspecific chronic conditions | Social-ecological model of adolescent and young adult readiness for transition (SMART) | CSHCN | US tertiary pediatric academic services |
| Bert 2020 (32843225) ¹⁹ | Nonspecific chronic conditions | Transition consultation service | CSHCN | Italy pediatric hospital |
| Morton 2021 ²⁰ (33711643) | Chronic conditions | Care coordination | CSHCN | Children's hospital |
| Teed 2021 ²¹ (34365163) | Medically complex | Shared Plan of Care for Medical Home Initiative | CSHCN – medically complex | US Urban pediatric care facility with urgent, primary, and tertiary care |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number

Congenital Heart Disease

Table D.9. Risk of bias assessment: congenital heart disease

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|------------------|---------------------------------|----------------|------------------|---------------|----------------|---|--------------------------|--|
| Flocco 2019 ²² (no PMID) | 12 months | High | X | X | X | X | X | Government | High |
| Hergenroeder 2018 ²³ (29542247) | ~26 months | High Historical control | X | X | X | X | X | Government | High |
| Mackie 2018 ²⁴ (29673467) | 6, 12, 18 months | Medium | Low | Medium | Medium | Low | 4/125=3% missing from analysis, but up to 25% missing data unaccounted for. High ROB after 12 months. | Government and Nonprofit | Medium at 6 and 12 months High at 18 months |
| Mackie 2014 ²⁵ (24842870) | 6 months | Medium Systematic, nonrandom | Medium | Medium | Medium | Medium | High 16/66=24% Missing data handling NR | Nonprofit and University | High |
| Bushee 2021 ²⁶ (no PMID) | 12 months | Medium | Medium | Medium | Medium | Medium | High (225/653=34%) | NR | High |
| Tye 2021 ²⁷ (no PMID) | 4 months | High | X | X | X | X | X | nonprofit | High |

Note: X=Domain was not assessed.

Abbreviations: PMID=PubMed Identification Number

Table D.10. Characteristics of included studies: congenital heart disease

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|---|---------------------------------------|---|---|---|---------------------------|
| Flocco 2019 ²² (no PMID) Italy Qualitative nonrandomized ROB High Stage 1 | N=224 15 Years (recruited 11-18) 39% Female 94% White | Transition clinic model. Includes multidisciplinary standardized educational and support interventions. No core elements targeted. Intervention duration NR. | None | Cardiac hospital unit Followup 1 year | Quality of life (EQ-5D, LAS- QOL) Satisfaction (SWLS-C) Health perception (EQ- VAS) and knowledge | NR | NR |
| Hergenroeder 2018 ²³ (29542247) United States Qualitative nonrandomized ROB High Stage 1 | N=45 20 Years (recruited 19-23) 51% Female Race NR | Healthcare transition (HCT) planning program. EMR- based transition planning tool. Unclear if core elements targeted. Intervention duration NR. | No intervention (usual care) | Cardiac hospital unit Timing NR Longest followup reported at 26 months | Heart failure (New York Heart Association Functional Classification of Heart Failure) | NR | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|--|--|--|--|--|-----------------------------------|
| Mackie 2018 ²⁴ (29673467) Canada RCT ROB Medium Stage 1 | N=121 17 Years (recruited 15-17) 49% Female Race NR | Nurse-led transition intervention. Two 1 hour individualized education and self-management skills sessions. Transition readiness and planning. Intervention duration NR. | Usual care | Cardiac hospital unit 18 months | Excess time to adult CHD care CHD knowledge (MyHeart CHD knowledge survey) Transition readiness (TRAQ) | NR | NR |
| Mackie 2014 ²⁵ (24842870) Canada Controlled trial ROB High Stage 1 | N=58 16 Years (recruited 15-17) 83% Female Race NR | One individual education session with a nurse. 1 hour session. Transition readiness and planning. Intervention duration NR. | Usual care | Cardiac hospital unit 6 months | Transition readiness (TRAQ) Disease knowledge (MyHeart score) | NR | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|---|---------------------------------------|--|--|---|---------------------------|
| Bushee 2021 (no PMID) ²⁶ US Observational cohort with historical control High ROB Stage 2 | N=653 Age NR 45% Female 80% White 12% African American | Formal transition program at a children's hospital. Coordination between pediatric and adult nurses, physicians, and a social worker. None Duration unclear | Historical control | Children's hospital 12 months | Additional clinical outcomes Transfer Unplanned cardiac hospitalizations | NR | NR |
| Tye 2021 ²⁷ (no PMID) Malaysia Pre/post observational cohort High ROB Stage 2 | N=14 Age 17 40% Female 63% Malay 25% Chinese 12% Punjabi | HeartBEAT adolescent transition psycho-educational program. None 2 in person sessions, 6 online session | None | Unclear, partially online ~4 months | Self-management knowledge Emotional regulation | NR | NR |

Abbreviations: CSHCN=children with special healthcare need; CHD=congenital heart disease; EMR=electronic medical records; EQ-5D=EuroQol Group 5 Dimension Health Questionnaire; EQ-VAS=EuroQol Visual Analogue Scale; HCT=healthcare transition; LAS-QOL=Linear Analog Scale Quality of Life; NR=not reported; PMID=PubMed identification number; RCT=randomized controlled trial; ROB=risk of bias; SWLS-C=Satisfaction with Life Scale-Child; TRAQ=transition readiness assessment questionnaire

Table D.11. Outcomes summary, low and medium risk of bias studies: congenital heart disease

| Study (PMID) Comparison RoB Category | Outcome Timing | Summary Finding | Intervention | Comparator | P-Value |
|--|---|-----------------|--------------|------------|---------|
| Mackie 2018 ²⁴ (29673467) Education intervention vs usual care Medium Stage 1 | Seen within 3 months of the recommended time interval (excess time ≤3 months) | NA | 68% | 51% | p=0.059 |

| Study (PMID) Comparison RoB Category | Outcome Timing | Summary Finding | Intervention | Comparator | P-Value |
|---|---|---|--|--|---------|
| Mackie 2018 ²⁴ (29673467) Education intervention vs usual care Medium Stage 1 | CHD knowledge (MyHeart CHD knowledge survey) 12 months | Authors report scores higher with intervention at 12 months | NR (data reported in figure only, not extractable) | NR (data reported in figure only, not extractable) | p<0.001 |
| Mackie 2018 ²⁴ (29673467) Education intervention vs usual care Medium Stage 1 | Transition readiness (TRAQ) 12 months | Authors report scores higher with intervention at 12 months | NR (data reported in figure only, not extractable) | NR (data reported in figure only, not extractable) | p=0.032 |

Abbreviations: CHD=congenital heart disease; RCT=randomized controlled trial; TRAQ=Transition Readiness Assessment Questionnaire

Table D.12. Summary of strength of evidence: congenital heart disease

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/ Conclusion |
|--|-----------|--------------------------------------|------------------------------------|----------------------|-------------|------------|-----------|---------------------------------|
| Excess time to adult CHD care Education intervention vs usual care | 12 months | 1 RCT (n=121) ²⁴ | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |
| CHD knowledge (MyHeart CHD knowledge survey) Education intervention vs usual care | 12 months | 1 RCT (n=121) ²⁴ | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/ Conclusion |
|---|-----------|--------------------------------------|------------------------------------|----------------------|-------------|------------|-----------|---------------------------------|
| Transition readiness (TRAQ) Education intervention vs usual care | 12 months | 1 RCT (n=121) ²⁴ | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |

Abbreviations: CHD=congenital heart disease; RCT=randomized controlled trial; TRAQ=Transition Readiness Assessment Questionnaire

Table D.13. Characteristics of studies included in evidence map: congenital heart disease

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|---|-----------|---|-------------------|--|
| Werner 2019 ²⁸ (31262673) | CHD | Transition education program | CSHCN | France pediatric cardiology department |
| Lopez 2018 ²⁹ (30574573) | CHD | Prototype mobile app to facilitate transition | CSHCN | US cardiac hospital department |
| Ladouceur 2017 ³⁰ (28342658) | CHD | Educational intervention targeting knowledge and skills | CSHCN | France pediatric hospital department |

Abbreviations: CHD=congenital heart disease; CSHCN=children with special healthcare need; PMID=PubMed identification number

Cystic Fibrosis

Table D.14. Risk of bias assessment: cystic fibrosis

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---------------------------------------|--|----------------|----------------|------------------|---------------|----------------|-------------------------------|------------|----------------|
| Okumura 2014 ³¹ (24415776) | Authors state 18 months, looks like outcomes assessed at 12 months | High | X | X | X | X | X | Government | High |
| Peeters 2019 ³² (31424181) | 12 months, 24 months | High | X | X | X | X | X | Government | High |
| Skov 2018 ³³ (29729195) | 12 months | High | X | X | X | X | X | NR | High |

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|-------------------------------|---------|----------------|
| Craig 2007 ³⁴ (17937150) | Unclear | High | X | X | X | X | X | NR | High |
| Collins 2021 ³⁵ (33793092) | 24 months | High | X | X | X | X | X | Society | High |
| Bourgeois 2021 ³⁶ (33751837) | 24 months | High | X | X | X | X | X | NR | High |

X=Domain was not assessed.

Abbreviations: NR=not reported; PMID=PubMed Identification Number; ROB=risk of bias

Table D.15. Characteristics of included studies: cystic fibrosis

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|---|--|--|--|---|
| <p>Okumura 2014 (24415776)³¹ United States Program evaluation. Quantitative Pre-post and retrospective chart review ROB High Stage 1</p> | <p>N=18 pediatric patients completed the post intervention survey and N=8 patients completed baseline and post intervention survey</p> <p>N=56 patients or their families responded to program feedback survey at Time 1</p> <p>Chart review group N=9 transitioned during pilot project (Oct. 2009-Dec. 2012)</p> <p>Age NR Gender NR</p> | <p>Transition guide and notebook</p> <p>Joint staff meetings with adult/pediatric centers</p> <p>Transition and Care Policy/Guide; Transition Readiness; Transition Planning</p> <p>Duration unclear</p> | <p>Adult center patients completed TRAQ assessment at Time 1 to serve as a comparison group. (N=10 18-25 years)</p> <p>Chart review comparison group: N=20 transfers to adult program between Mar. 2005 and July 2008</p> | <p>University Cystic Fibrosis Center, Pediatric and Adult.</p> <p>Baseline and 18 months</p> | <p>Transition readiness (TRAQ) Transition perceptions Resource utilization (outpatient visits, hospitalizations)</p> | <p>Parents views/perceptions of transition materials</p> | <p>Barriers for pediatric patients and transfer process</p> |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|--|--|---|--|--|--|
| Peeters 2019 ³² (31424181) Netherlands Quantitative Mixed methods (Chart review + survey and qualitative) ROB High Stage 1 | Transition clinic group sample: N=27 Males (48.1%) 22.56 years RaceNR Direct hand-over group sample: N=19 Males (52.6%) TC group sample providers (N=10) Direct-handover care providers (N=18) | Transition clinic (transition coordinator, joint consultations, Individual Transition Plan) Transition Readiness; Transition Planning Duration unclear | One CF center served as control setting providing direct hand-over care. | CF Centers at 2 University Hospitals Data collected 2 years, 1 year before transfer; 1 year after transfer; and 2 years after transfer | Self- management skills (PIH) Independence during consultations (IBDCS) Self-efficacy (OYOF-SES) Quality of Life (PedsQL-YA) Disease-specific clinical outcomes Treatment adherence (MARS-5) Engagement in care Satisfaction (1-10 scale) Transfer experiences (OYOF-TES) Resource utilization | NR | Qualitative outcomes (differences in structures, daily routines) Barriers and facilitators |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|--|-----------------------------------|---|--|--|-----------------------------------|
| Skov 2018 ³³ (29729195) Denmark Quantitative Pre-post observational ROB High Stage 1 | N=40 total N=15 females 15.7 years N=25 males 14.6 years Race NR | Transition Program 6 monthly nurse led split visit consultation using HEADS interview; Annual event for parents/guardian s; designated contact doctor and nurse; annual assessment by doctor; independent youth consultations Transition Readiness; Transition Planning Duration unclear | NR | CF center at university hospital Baseline and 12- month follow-up | Transition readiness (Danish Readiness Checklist) QoL (CFQ-R) Disease-specific clinical outcomes Engagement in care (% of split consultations) | NR | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|-----------------------------------|--|--|--|-----------------------------------|
| Craig 2007 ³⁴ (17937150) Australia Program Eval. Cross-sectional questionnaire ROB High Stage 1 | <p>N=137 completed questionnaire (youth and parents)</p> <p>Pre-Transition Group N=45 16.2 years Female 29%</p> <p>Post-Transition group N=27 20.9 years 44 % Female</p> <p>Pre-transition group parents(N=45)</p> <p>Post-transition group parents (N=20) Race NR</p> | <p>Transition Program. (Steps include attendance at adolescent clinic; adult services visit; adult services discussed; appointment in Adult Clinic scheduled by TC; Adult clinic joint- meeting; transition referral letter.)</p> <p>Transition Planning Transfer of care</p> <p>Approx. 2 years.</p> | Pre-Transition Group | Pediatric hospital | <p>Pre/post groups: Transition concerns (TTACC)</p> <p>Post Transition group only: QoL (Cystic Fibrosis Questionnaire) Disease severity Patient Participation in transition (CFTQ) Satisfaction with transition program (10-item Satisfaction with Transition questionnaire)</p> | Transition concerns (TTACC- parents form) | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|---|---------------------------|--|--|---|---------------------------|
| Bourgeois 2021 ³⁶ (33751837) France Retrospective ROB High Stage 1 | N=97 18.6 years (median age at transfer) Male 47% Race NR | Transition program (personalized medical summary, handbook, formalized handoff) Transition Readiness (self management skills) Duration unclear | NR | Pediatric and adult CF center 24 months | Disease-specific clinical outcomes; Resource utilization (hospitalization, and outpatient visits) | NR | NR |
| Collins 2021 ³⁵ (33793092) Australia Observational Retrospective ROB High Stage 1 | N=42 18.9 (mean age at transfer) Female 36% Race NR | Structured individual transition process (transition visit, written information, transfer date scheduled) Transition readiness (self management) Duration unclear | NR | Pediatric and adult CF hospital units 2 years | Disease specific clinic outcomes; Resource utilization (inpatient and outpatient visits) | NR | NR |

Abbreviations: CSHCN=children with special healthcare need; CF=Cystic Fibrosis; CFTQ= Cystic Fibrosis Transition Questionnaire; HADS=Hospital Anxiety and depression scale; HEADS= Home, Education/employment, Eating, peer-group Activities, Drugs, Sexuality, Suicide/depression, and Safety; IBDCS= Independent Behaviors During Consultations; MARS-5= Medication Adherence Rating Scale w/ 5-point Likert scales; NA=not applicable; NR=not reported; OYOF-SES= On Your Own Feet Self-Efficacy Scale; OYOF-TES= On Your Own Feet Transition Experience Scale; PQoLI-YA= Paediatric Quality of Life Inventory Young Adult; PIH= Partners in Health Scale w/ 9-point Likert scales PMID=PubMed identification number; ROB=risk of bias; TTACC= Transition To Adult Care Concerns Questionnaire; TRAQ=transition readiness assessment questionnaire; QoL=quality of life; CFQ-R=Cystic Fibrosis Questionnaire-Revised

Table D.16. Characteristics of studies included in evidence map: cystic fibrosis

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|---|-----------------|--|-----------------------|------------|
| Gravelle 2014 ³⁷ (25089835) | Cystic Fibrosis | transition care clinical pathway | CSHCN | CF Clinic |
| Askew 2017 ³⁸ (28365620) | Cystic Fibrosis | Transition clinic | CSHCN | CF Center |
| Baker 2015 ³⁹ (No PMID) | Cystic Fibrosis | Transition Program | Health care providers | CF Centers |
| Chaudhry 2013 ⁴⁰ (29516552) | Cystic Fibrosis | Transition Program | CSHCN | CF Clinic |
| Gerardin 2018 ⁴¹ (29799382) | Cystic Fibrosis | Therapeutic Patient Education (TPE) sessions | Health care providers | CF Centers |
| Genovese 2021 ⁴² (33863608) | Cystic Fibrosis | Pre-Transfer Interviews | CSHCN and parents | CF Centers |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; CF=cystic fibrosis

Diabetes

Table D.17. Risk of bias assessment: diabetes

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------------|----------------|---|------------------|---------------|----------------|---|------------------------|----------------|
| Bindiganvle 2021 ⁴³ | 12 months | High | X | X | X | X | X | Health System | High |
| White 2017 ⁴⁴ (30169183) | 12 months, 24 months | Low | Low | Medium | Medium | Low | Low for Primary outcomes (13%); Medium for Secondary outcomes (30%) | Not-for-profit, Pharma | Medium |
| Cadario 2009 ⁴⁵ (19178523) | 12 months | High | X | X | X | X | X | Government, University | High |
| Sequeira 2015 ⁴⁶ (No PMID) | 6 months, 12 months | Medium | X – due to differential attrition in IG vs CG | X | X | X | Medium (to high) (27% IG; 13% CG) | Program, Government | High |

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|---|----------------|---|------------------------------------|---------------|----------------|---|-----------------------|----------------|
| Spaic 2019 ⁴⁷ (31010873) | 12 months, 18 months | Low | Low | Medium (or High? Please check ITT) | Low | Low | Medium (20% at 12 months, 33% at 18 months) | Nonprofit, Government | Medium |
| Williams 2020 ⁴⁸ (632001083) | 3 months | High | X | X | X | X | X | Nonprofit, Government | High |
| Butalia 2021 ⁴⁹ (33439284) | 12 months | Medium | X | X | X | X | <i>Unclear</i> | Nonprofit | High |
| Weigensberg 2018 ⁵⁰ (29552422)– | 12 week (based on 6 month, 12 month RCT) | Medium | X – due to differential attrition in IG vs CG | X | X | X | Medium (to high) (27% IG; 13% CG) – (at 12 mos) | Program, Government | High |
| Pyatak 2014 ⁵¹ (24798586) | 6 months, 12 months | Medium | X – due to differential attrition in IG vs CG | X | X | X | Medium (to high) (27% IG; 13% CG) | Program, Government | High |
| Vanelli 2004 ⁵² | 8 years | High | X | X | X | X | Low (8%) | Health system | High |
| Van Wallegghem 2008 ⁵³ (354454701) | 7 years | High | X | X | X | X | NR | NR | High |

Note: X=Domain was not assessed.

Abbreviations: CG=control group; IG=intervention group; NR=not reported; PMID=PubMed Identification Number; RCT=randomized controlled trial

Table D.18. Characteristics of included studies: diabetes

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|--|--|--|---|--|------------------------------|
| Bindiganvle 2021 ⁴³ US Pre/Post ROB High Stage 4 | N=51 Age NR (recruited 14+) Sex NR Race NR | Care Everywhere program that enables access to medical information; enhancement to electronic health records; change in work processes to increase time available for of transition readiness assessment questionnaire (TRAQ) Transition Planning Transfer of Care | Usual Care in specialty clinic | Pediatric diabetes clinic in urban medical center | Use of TRAQ | NA | NA |
| White 2017 ⁴⁴ (30169183) Australia RCT ROB Medium Stage 4 | N=120 18.8 years (recruited 17-19) 51% Female Race NR | TrACeD. Transition program: care coordination with appointment management, appointment reminders by call and SMS, automatic rebooking of missed appointments; Transfer of care; 24 months Transition Planning Transfer of Care | Usual care Current care continued, referral discussed between patient and provider, patients advised to contact their pediatric diabetes team if they had any issues during the transition process, no contact with coordinator/intervention, routine practice for missed appointments. | Tertiary pediatric diabetes service / Children's Hospital ITT 12 months, 24 months | Attendance Disengagement Clinical outcomes/ glycated hemoglobin; | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|--|--|--|--|--|---------------------------------------|
| Spaic 2019 ⁴⁷ (31010873) Canada RCT ROB Medium Stage 4 | N=205 17.9 years (recruited 17- 20) 49% Female Race NR | Transition program: Care coordination including diabetes educators, clinical support, transition coordinator using technology (phone, text, email). 2.5 years. Transition Planning Transfer of Care | Usual care | 2 tertiary, 1 secondary pediatric centers 0-18 months, 18-30 months. | Attendance Disengagement/Loss to follow-up Diabetes-related distress Satisfaction HbA1C | NA | NA |
| Cadario 2009 ⁴⁵ (19178523) Italy Retrospective observational ROB High Stage 0 | N=62 18.3 years (range 18-20) 45% Female Race NR | Structured transition via transfer planned with adult physicians. 4 years. Transition Planning Transfer of Care | Unstructured transfer Patients discharged at the end of adolescence by a letter summarizing their clinical history and with a fixed appointment in the ADS. | Pediatric hospital pediatric diabetes clinic; 10 years | HCT duration/ duration of transfer Attendance Benefit for HbA1c Opinion of transition / experience of transition | NA | NA |
| Williams 2020 ⁴⁸ (32518677) Canada Pre/Post ROB High Stage 3 | Patient N=15 Parent N=15 Age NR Sex NR Race NR | Half-day transfer clinic, after tailoring care based on participant feedback. 3 months. Transition Planning Transfer of Care | Half-day transfer clinic. | Pediatric diabetes clinic; 3 months | Patient satisfaction HCT skills and knowledge, Attendance (NR) | Acceptability Satisfaction | Satisfaction |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|---|--|------------------------------------|---|--|------------------------------|
| Weigensberg 2018 ⁵⁰ (29552422) US RCT ROB High Stage 4 | N=51 19 years 45% Female 17% Hispanic 13% White 10% Black 13% Other | LEAP. Care coordination, education and case management-based transition program plus cultural council process based on indigenous community practices, stress-reduction guided imagery, narrative medicine modalities, simple ritual, and other integrative modalities. 12 weeks. Transition Planning Transfer of Care | Care coordination, education and case management-based transition program (without council component). | Children's hospitals; 12 months | Self-acceptance Stress reduction Relatedness/social integration Motivation New activities/ New behaviors New meaning/ New purpose Psychosocial Global wellbeing Depression A1C Life satisfaction | NA | NA |
| Sequeira 2015 ⁴⁶ (25906787) US RCT ROB High Stage 4 | N=81 19 years (18-25 recruited) 44% Female 53% Hispanic (64% IG, 13% CG) 47% Non-Hispanic 25% White 7% Black 15% Other | LEAP. Care coordination at large urban hospital. 1 year. Transition Planning Transfer of Care | Usual care at large children's hospital in neighboring county. | Children's hospitals; 12 months | Self-reported and medical record review accessed number of diabetes clinic visits. A1C, Incidence of hypoglycemia, Utilization, Diabetes Empowerment Scale-Short Form, Diabetes Knowledge Test (adapted), Perceived Stress Scale (adapted), Patient Health Questionnaire-9, Satisfaction With Life Scale, Arizona Integrative Outcomes Scales. | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|---|---|---|--|------------------------------|
| Pyatak 2014 ⁵⁴ (24798586) US Mixed-methods ROB High Stage 1 | n=20 N=81 19 years (18-25 recruited) 30% Female 53% Hispanic (64% IG, 13% CG) 18% Non- Hispanic 24% white 7% Black 14% Other | LEAP. Care coordination at large urban hospital among rescue participants. 1 year. Transition Planning Transfer of Care | NC | Children's hospital; 12 months | HbA1c Psychosocial adjustment Loss to follow-up Utilization Life satisfaction | NA | NA |
| Vanelli 2004 ⁵² (16295053) Italy Mixed method observational plus interview ROB High Stage 1 | N=73 21 years (range 20 to 23) 42% Female Race NR | Protocol for transfer. 6 years. Transition Planning Transfer of Care | Unclear | Pediatric diabetes center 2 years | Satisfaction HbA1C Attendance | NA | NA |
| Van Wallegghem 2008 ⁵³ (18458141) Canada Mixed method pre/post cohort study ROB High Stage 1 | N=84 18 years (19 to 25 range in comparison group) Sex NR Race NR | Maestro. Care coordination/ Systems navigator service Including telephone and e- mail contact, support, barrier identification, integrated community-based diabetes education services, follow-up facilitation, community linkages. Transition Planning Transfer of Care | Older cohort transferred to adult care prior to care coordination/ systems navigator. | Unspecified general pediatric diabetes care | Chronic complications, Diabetes-related hospitalizations for diabetic ketoacidosis Severe hypoglycemia, Barriers to adult care access | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|---|--|---|--|------------------------------|
| Butalia 2021 ⁴⁹ (33439284) Canada Non-randomized trial ROB High Stage 2 | N=203 18 years (recruited 17 to 18) 50% Female Race NR | Care coordination, support from transition coordinator who used communication technology. Similar to LEAP, Maestro, and TrACeD 2.5 years; 12 months, 18 months post transfer Transition Planning Transfer of Care | Usual care cohort not exposed to the communication transition coordinator for a period equivalent to the intervention prior to start of the intervention. | 1 Tertiary care paediatric hos pital 1 Adult community hospital 1 Regional diabetes center | Attendance w/in 1 year of transfer Loss to follow-up Diabetes-related emergency department visits for diabetic ketoacidosis HbA1C Alumin/creatinine ratio | NR | NA |

Abbreviations: CSHCN=children with special healthcare need; HIV=human immunodeficiency virus; NR=not reported; PGWB=Psychological General Well-Being Index; PMID=PubMed identification number; ROB=risk of bias; TRAQ=Transition readiness assessment questionnaire; TWA=Multidimensional Self-Esteem Test

Table D.19. Outcomes summary, low and medium risk of bias studies: diabetes

| Study (PMID) Comparison RoB Category | Outcome Timing | Summary Finding | Intervention | Comparator | P-Value |
|---|---|-----------------|--------------|--------------|----------|
| White 2017 ⁴⁴ (30169183) Transition clinic vs usual care ROB Medium Stage 4 ⁵⁵ | Clinic attendance/ appointment keeping 0-12 months | NR | 2.3 (SD 1.1) | 2.3 (SD 1.4) | p=0.84 |
| White 2017 ⁴⁴ (30169183) Transition clinic vs usual care ROB Medium Stage 4 ⁵⁵ | Clinic attendance/ appointment keeping 12-24 months | NR | 2.5 (SD 1.3) | 1.4 (SD 1.8) | p=0.0089 |

| Study (PMID) Comparison RoB Category | Outcome Timing | Summary Finding | Intervention | Comparator | P-Value |
|---|--|--|--|--|-----------------------------|
| ⁵⁵ White 2017 ⁴⁴ (30169183) Transition clinic vs usual care ROB Medium Stage 4 | HbA1C 0-12 months | NR | % 8.4 (SD 1.9) mmol/mol 68 (SD 20.8) | % 8.6 (SD 1.5) mmol/mol 70 (SD 16.4) | % p=0.53 mmol/mol p=0.53 |
| White 2017 ⁴⁴ (30169183) Transition clinic vs usual care ROB Medium Stage 4 | HbA1C 12-24 months | NR | % 8.2 (SD 1.9) mmol/mol 66 (SD 20.8) | % 8.5 (SD 1.3) mmol/mol 69 (SD 14.2) | % p=0.56 mmol/mol p=0.56 |
| Spaic 2019 ⁴⁷ (31010873) Transition clinic vs usual care ROB Medium Stage 4 | Scheduled visits 0-18 months | NR | 4.1 (SD 1.1) | 3.6 (SD 1.2) | p-value unclear |
| Spaic 2019 ⁴⁷ (31010873) Transition clinic vs usual care ROB Medium Stage 4 | Scheduled visits 18-30 months | NR | 1.3 (SD 0.8) | 1.3 (SD 0.8) | p-value unclear |
| Spaic 2019 ⁴⁷ (31010873) Transition clinic vs usual care ROB Medium Stage 4 | HbA1C, change from baseline 0-18 months | Difference between groups % -0.04 (-0.49, 0.40) mmol/mol -0.40 (-5.40, 4.40) | % -0.20 (SD 1.24) mmol/mol -2.20 (SD 13.6) | % -0.19 (SD 1.29) mmol/mol -2.10 (SD 14.1) | p=0.848 |
| Spaic 2019 ⁴⁷ (31010873) Transition clinic vs usual care ROB Medium Stage 4 | HbA1C, change from baseline 18-24 months | Difference between groups % 0.37 (-0.04, 0.78) mmol/mol 4.00 (-4.40, 8.50) | % 0.03 (SD 1.09) mmol/mol 0.30 (SD 11.9) | % -0.28 (SD 1.64) mmol/mol -3.10 (SD 17.9) | p=0.073 |

Abbreviations: CSHCN=children with special healthcare need; NA=not applicable; NR=not reported; PMID=PubMed identification number; ROB=risk of bias; SD=standard deviation

Table D.20. Summary of strength of evidence: diabetes

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|--|-----------------------------|--|------------------------------|-------------------|--------------|------------|-----------|--------------------------|
| Clinic Attendance/Appointment keeping Transition clinic vs usual care | 0-12 months, 0-18 months | 2 RCTs ^{44, 47} (n=309, 153 intervention; n=156 control) | Favors intervention | Moderate | Inconsistent | Direct | Imprecise | Insufficient |
| Clinic Attendance/Appointment keeping Transition clinic vs usual care | 24-36 months | 2 RCTs ^{44, 47} (n=274, 136 intervention; n=138 control) | Favors intervention | Moderate | Inconsistent | Direct | Imprecise | Insufficient |
| HbA1C Transition clinic vs usual care | 0-12 months, 0-18 months | 2 RCTs ^{44, 47} (n=309, 153 intervention; n=156 control) | NS | Moderate | Consistent | Direct | Imprecise | Low |
| HbA1C Transition clinic vs usual care | 24-36 months | 2 RCTs ^{44, 47} (n=274, 136 intervention; n=138 control) | NS | Moderate | Consistent | Direct | Imprecise | Low |

Abbreviations= NS=not significant; RCT=randomized controlled trial

Table D.21. Characteristics of studies included in evidence map: diabetes

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|-----------|--|-------------------|--|
| Levy-Shraga 2016 ⁵⁶ (25794880) | Diabetes | Transition clinic | CSHCN | Large tertiary medical center |
| Logan 2008 ⁵⁷ (No PMID) | Diabetes | Multidisciplinary structured transition clinic and program | CSHCN | Large regional pediatric diabetes clinic |
| Holmes-Walker 2007 ⁵⁸ (17535294) | Diabetes | Transition coordinator and education | CSHCN | Adult hospital, young adult diabetes clinic |
| Gerber 2007 ⁵⁹ (17316099) | Diabetes | Internet self-management training program | CSHCN | Adult endocrinology clinic and diabetes registry |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number

Human Immunodeficiency Virus (HIV)

Table D.22. Risk of bias assessment: HIV

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|----------------------------|----------|----------------|
| Continisio 2020 ⁶⁰ (32714885) | 12, 18 months | High | X | X | X | X | X | Industry | High |
| Ryscavage 2021 ⁶¹ (33832366) | Timing Unclear | High | X | X | X | X | X | NR | High |

Note: X=Domain was not assessed.

Abbreviations: PMID=PubMed Identification Number

Table D.23. Characteristics of included studies: HIV

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|---|------------------------------------|--|--|-----------------------------------|------------------------|
| Continisio 2020 ⁶⁰ (32714885) Italy Observational cohort ROB High Stage 1 | N=13 17 Years (recruited ages 13-20) 62% Female 85% White 15% African | Joint pediatric/adult clinic. Bundle of initiatives run by a multidisciplinary team (pediatric, infectious disease, dedicated nurse, psychologist, social assistant) who met periodically. No core elements targeted. Intervention duration NR. | None | Specialty HIV clinic Baseline, 12 months, and 6 months after transition to adult center (18 months) | Transition Readiness (Disease knowledge) General health (PGWB) Self-esteem (TMA) Additional clinical outcomes (viro-immunological parameters) | NR | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|--|---|---|---|---------------------------|
| Ryscavage 2021 ⁶¹ (33832366) US Pre/post observational cohort High ROB Stage 2 | N=84 Age 26 at linkage (median) 50% Female 95% African American 5% White | STEP integrations adult HIV providers into a pediatric clinic. Retrospective chart review cohort 2017- 2020 None | Pre-STEP Retrospective chart review 2004-2012 | University Pediatric/adult HIV clinic Timing unclear | Clinical outcomes Successful transition Retention | NR | NR |

Abbreviations: AYA=adolescent and young adult; HIV=human immunodeficiency virus; NR=not reported; PGWB=Psychological General Well-Being Index; PMID=PubMed identification number; ROB=risk of bias; TWA=Multidimensional Self-Esteem Test

Table D.24. Characteristics of studies included in evidence map: HIV

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|---|-----------|---|-------------------|-----------------------|
| Righetti 2015 ⁶² (26116060) | HIV | Single day multimodal intervention | CSHCN | Outpatient HIV clinic |
| Campbell 2010 ⁶³ (20390505) | HIV | Looking Forward Project – informational and discussion events | CSHCN | Outpatient HIV clinic |

Abbreviations: CSHCN=children with special healthcare need; HIV=human immunodeficiency virus; PMID=PubMed identification number

Inflammatory Bowel Disease (IBD)

Table D.25. Risk of bias assessment: IBD

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---------------------------------------|-------------------|----------------|-------------------|---------------------|------------------|-------------------|----------------------------------|---|-------------------|
| Gray 2019 ⁶⁴ (30964817) | 12 months | High | X | X | X | X | X | Crohn's and Colitis Foundation and internal grant | High |
| Otto 2019 ⁶⁵ (0745207) | 12 months | High | X | X | X | X | X | EFOP-3.6.3- VEKOP-16- 2017-00009 | High |

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|------------------------|----------------|----------------|------------------|---------------|----------------|-------------------------------|---|----------------|
| Sattoe 2020 ⁶⁶ (31911522) | 12 months 24 months | High | X | X | X | X | X | Innovation Alliance (SIA-RAAK) and govt | High |
| Testa 2019 ⁶⁷ (30704905) | 12 months | High | X | X | X | X | X | NR | High |
| Scaldferrri 2020 ⁶⁸ (32894553) | 24 months | High | X | X | X | X | X | none | High |
| Schutz 2019 ⁶⁹ (1324228) | 24 months | High | X | X | X | X | X | NR | High |
| Van den Brink 2019 ⁷⁰ (29926962) | 12 months | High | X | X | X | X | X | none | High |
| Cole 2015 ⁷¹ (26206442) | NR | High | X | X | X | X | X | NR | High |
| Fu 2017 ⁷² (28839441) | NR | High | X | X | X | X | X | NR | High |

Note: X=Domain was not assessed.

Abbreviations: PMID=PubMed Identification Number

Table D.26. Characteristics of included studies: IBD

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|--|---------------------------|--|--|---|---------------------------|
| Gray 2019 ⁶⁴ (30964817) United States Retrospective chart review ROB High Stage 1 | N=135 Intervention Group: Age 16.39 years (T1) 17.56 (T2) 63.70% male 36.30% female 88.9% White Control Group: N=18 Age 15.40 years (T1) 16.21 years (T2) 77.78% male 22.22% female 88.89% White | Transition coordinator (TC) (single face to face session and follow up phone call) Transition Readiness Duration unclear | Did not meet with TC. | IBD specialty clinic at pediatric academic medical center. 12 months before and 12 months after intervention | Transition readiness (TRAQ) Self- management skills Disease-related clinical outcomes % of patients who bounced back to pediatrics | NA | NA |
| Otto 2019 ⁶⁵ (0745207) Retrospective Chart review Hungary ROB High Stage 1 | N=45 total Intervention group N=21 Age at diagnosis: 13.7 29% male Control group: N=24 Age at diagnosis: 15.1 50% male | Transition Clinic- multiple joint transition visits. Transition Readiness Duration Six months | Direct handover care | pediatric gastroenterology outpatient clinic, at department of Pediatrics Academic Center. 12 months follow up | v | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|-----------------------------------|---|--|--|---|
| Sattoe 2020 ⁶⁶ (31911522) Mixed methods Retrospective Chart review Netherlands ROB High Stage 1 | Intervention Group: N=56 Age at time of survey: 20.89 55.4% male Control group: N=54 Age at time of survey 21.02 55.6% male | Transition clinic- transition consultations Transition Readiness | Direct handover care | Tertiary setting (two outpatient IBD clinics) Second year before transfer; year before transfer; year after transfer; second year after transfer | Self- management (PIH Scale) Independence in Consultations (1- 10 Visual Analogue Scale) QoL (PQoLI-YA) Disease-specific clinical outcomes Adherence to treatment (MARS) Transfer experiences (OYOF-TES) Transition satisfaction (1-10 scale) Perceived patient- centeredness (subscale of ACAHP survey) Resource utilization | NA | Qualitative comparison of service structures and daily routines between TC setting (May- July 2014) and control setting (June-Aug 2015). Barriers and facilitators- Semi- structured interviews with professionals. |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|---|--|---|--|-----------------------------------|
| Cole 2015 ⁷¹ (26206442) UK Retrospective ROB High Stage 1 | N=72 included in analysis 56.9% male 18 years (median age at diagnosis) | Transition Clinic (attendance and services, joint consultations, education on disease, individualized transition plan, referral letter) Transition Planning Duration unclear | Non transition clinic attendance – before TC was set up | IBD pediatric and adult outpatient setting\ Unclear | Disease activity Medication adherence Resource utilization (clinic attendance, surgery, hospitalizations) | NA | NA |
| Fu 2017 ⁷² (28839441) Canada Retrospective ROB High Stage 1 | N=112 transition group: N=59 40.4% female 19.7 current age (mean) 13 years age at diagnosis | Transition clinic, joint patient assessment, joint consultation, transition discussion, take home patient summary. Transition planning Duration unclear | Control group: patients who did not attend TC | IBD Pediatric Clinic in tertiary academic medical center | Disease specific knowledge Self-reported medication adherence Attitudes and beliefs about medical therapy (BMQ) | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|--|---|---|--|--|-----------------------------------|
| Van den Brink 2019 ⁷⁰ (29926962) Netherlands Retrospective ROB High Stage 1 | N=35 participants Age 21.9 42.9% male Age at diagnosis: 13 (12-15) | Transition clinic - joint appointments with pediatric and adult specialists. (4 TC visits- CP checks disease knowledge, self- efficacy, self- management. Appointment made after transfer. Transfer letter with medical history.) Transition Readiness, and Transfer of Care. Duration unclear | Compared to group that did not transition successfully | Tertiary setting outpatient adult gastroenterology department. 12 months after transfer | Disease-related knowledge Self-efficacy (IBD-Yourself) Medication adherence Quality of transition (Transition Yourself Score) Resource Utilization (time to adult visit, non-attendance rates) | NA | NA |
| Testa 2019 ⁶⁷ (30704905) Italy Retrospective ROB High Stage 1 | N=106 enrolled Age NR Gender NR | Transition program, joint transition outpatient appts, transition discussion. Transition Planning Duration unclear | NA | IBD Center 2013-2018 Comparison of clinical data collected 12 months before and 12 months after transition | BMI Clinical activity of disease (pCDAI; pUCAI; pMAYO) Disease activity Smoker Status Pharmacological Therapy Health care utilization | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|---|---------------------------|--|--|---|---------------------------|
| Schutz 2019 ⁶⁹ (1324228) Germany Retrospective ROB High Stage 1 | N=35 chart reviews N=24 patients transition group Age at diagnosis: 14 years 58% males 42% females N=11 patients non-transition group Age at diagnosis: 14 64% male 36% female | Transition Program: (Joint consultation; transition discussion; patient summary; guided by NASGHA transition checklist, structured medical summary.) Transition Planning Duration unclear | Transfer group | Pediatric department in tertiary academic hospital. Retrospective review of medical records 24 months | QoL (IBDQ-32) Disease specific clinical outcomes Nicotine consumption Resource utilization (surgical interventions) Cost Socioeconomic parameters | NA | NA |
| Scaldfarri 2020 ⁶⁸ (32894553) Longitudinal cohort Italy ROB HIGH Stage 1 | N=20 Mean age at transition 20.45 Age range: 18-25 years 12 males 8 females | Transition Clinic Model (three joint visits, one month apart, questionnaires at each visit) Transition Readiness Duration unclear | No | Tertiary adult and pediatric IBD academic centers; Follow up at least 2 years in pediatric center | Generalized self-efficacy (GSES) QoL (IBDQ-32) Disease activity and current state of patient health (VAS) Depression & Anxiety (HADS) Resilience (CD- RISC) | NA | NA |

Abbreviations: AMAHPS= American Consumer Assessment of Health Plan Surveys (validated 5-item scale with 4-point Likert scales; CSHCN=children with special healthcare need; CD-RISC= Connor-Davidson Scal(e); GSES= Generalized Self-Efficacy Scale; HADS= Hospital Anxiety and Depression Scale; IBDQ=Inflammatory Bowel Disease Questionnaire; QOL=quality of life; MARS= Medication Adherence Rating Scale w/ 5-point Likert scales; NA=not applicable; NR=not reported; OYOF-SES= On Your Own Feet Self-Efficacy Scale; OYOF-TES= On Your Own Feet Transition Experience Scale; PQoLI-YA= Paediatric Quality of Life Inventory Young Adult with 5-point Likert scales; PGA=Physician Global Assessment; PIH= Partners in Health Scale w/ 9-point Likert scales; PMID=PubMed identification number; ROB=risk of bias TRAQ=Transition

Readiness Assessment Questionnaire; VAS=Visual Analogic Scale; ACAHP=American Consumer Assessment of Health Plan; BMQ=Beliefs about Medicine Questionnaire; CP=care provider; pCDAI=Pediatric Crohn’s Disease Activity Index; pUCAI=Pediatric Ulcerative Colitis Activity Index; pMAYO=partial MAYO score

Table D.27. Characteristics of studies included in evidence map: IBD

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|---|----------------------------|-----------------------------|-------------------|---------------------------------------|
| Greveson 2011 ⁷³ (No PMID) | Inflammatory Bowel Disease | Transition Clinic | CSHCN | Gastroenterology pediatric clinic |
| Corsello 2021 ⁷⁴ (33509223) | Inflammatory Bowel Disease | Joint Transition Visits | CSHCN | IBD pediatric and adult hospital unit |
| Waschmann 2021 ⁷⁵ (34280734) | Inflammatory Bowel Disease | Virtual Transition Workshop | CSHCN | Gastroenterology pediatric clinic |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number

Juvenile Idiopathic Arthritis (JIA)

Table D.28. Risk of bias assessment: JIA

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---|----------------|----------------|----------------|------------------|---------------|----------------|-------------------------------|------------|----------------|
| Hilderson 2016 ⁷⁶ (26320142) | 9.1 months | Medium | Low | Medium | Medium | High | Medium 18.18% | Foundation | High |
| Hilderson 2013 ⁷⁷ (24302502) | | | | | | | | | |
| McDonagh 2007 ⁷⁸ (16790451) | 12 months | High | X | X | X | X | X | Foundation | High |
| McDonagh 2006 ⁷⁹ (16464931) | | | | | | | | | |
| Shaw 2007 ⁸⁰ (17584391) | 12 months | High | X | X | X | X | X | Foundation | High |
| Hanghoj 2018 ⁸¹ (No PMID) | NR | Medium | Low | Medium | Medium | Medium | Medium 18.97% | NR | Medium |
| Relas, 2019 ⁸² (30374749) | NR | High | X | X | X | X | X | NA | High |

Note: X=Domain was not assessed.

Abbreviations: NR=not reported; PMID=PubMed Identification Number; NA=not applicable

Table D.29. Characteristics of included studies: JIA

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|---------------------------|--|--|---|---------------------------|
| Hilderson 2016 ⁷⁶ (26320142) Belgium Mixed methods (Quasi- experimental with qualitative) ROB High Stage 2 Hilderson 2013 ⁷⁷ (24302502) | N=27 (longitudinal cohort) Age (med) 16.1 74.1% female N=23 (intervention) Age (med) 17.7 78.3% female N=23 (control) Age (med) 18.9 73.9% female | Transition program Transition Readiness; Transition Planning; Transition of Care | Usual care | Pediatric rheumatology outpatient clinic Baseline, 6.8 months, and 9.1 months | Perceived health status (PedsQL 4.0) Medication adherence (SHCS-AQ) Illness-related knowledge (Modified Patient Knowledge Questionnaire) Global quality of life (Linear Analogue Scale) Fatigue (MFI-20) Parenting dimension/promo tion of independence (PI) Support of autonomy (PVF) Behavioral control (revised PRS-YSR) Psychological control (revised PCS-YSR) Absence of disease activity | Usability | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|---|---------------------------|--|--|---|---------------------------|
| | | | | | Clinical remission (on/off medication) Functional status (Childhood Health Assessment) Usability | | |
| McDonagh 2007 ⁷⁸ (16790451) UK Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 McDonagh 2006 ⁷⁹ (16464931) | N=308 (adolescents) Age (med) 14.2 91% white/European N=303 (parents) | Program of transitional care Transition and Care Policy/Guide; Transition Readiness | Pseudo-control | Pediatric rheumatology center Baseline, 6 months, and 12 months | Health related quality of life (JAQQ) Juvenile arthritis quality of life Arthritis-related knowledge Satisfaction Independent health behaviors Pre-vocational experience Acceptability | Juvenile arthritis quality of life Arthritis-related knowledge Satisfaction | NA |
| Shaw 2007 ⁸⁰ (17584391) UK Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | N=308 (adolescent) Age (med) 14.2 91% white/European N=301 (parent/caregiver) Age (med) 41.5 95% white/European | Program of transitional care Transition and Care Policy/Guide; Transition Readiness | NA | Pediatric rheumatology center 12 months | Satisfaction (Mind the Gap scale) Health related quality of life (JAQQ) Arthritis-related knowledge | Satisfaction (Mind the Gap scale) Arthritis-related knowledge | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|---------------------------------|--|--|---|---------------------------|
| Hanghoj 2018 ⁸¹ (No PMID) Denmark Mixed methods (RCT with qualitative) ROB Medium Stage 2 | N=116 (total) N=64 (intervention) N=52 (control) | Transition clinic Transition Readiness | Usual care | Pediatric rheumatology clinic Timing NR | Retention | NA | NA |
| Relas, 2019 ⁸² (30374749) Finland Quantitative non- randomized (Observational cohort (retrospective chart review) ROB High Stage 1 | N=130 (transition clinic) Age (med) 18 71% female N=161 (respective outpatient clinic) Age (med) 39 71% female | Transition clinic Transition Readiness | Respective outpatient clinic | Rheumatology outpatient transition clinic Timing NR | Health related quality of life (15D) Disease outcome (HAQ-DI) Disease activity (DAS28) | NA | NA |

Abbreviations: CSHCN=children with special healthcare need; NA=not applicable; NR=not reported; PMID=PubMed identification number; ROB=risk of bias; PedsQL 4.0=Pediatric Quality of Life Inventory; SHCS-AQ=SWISS HIV Cohort Study Adherence Questionnaire; MFI-20=Multidimensional Fatigue Inventory; PI=Promotion of Independence Scale; PVF=Autonomy Support Scale; PRS-YSR=Parental Regulation Scale; PCS-YSR=Psychological Control Scale; JAQQ=Juvenile Arthritis Quality of Life Questionnaire; 15D=15 dimensions; HAQ-DI=Health Assessment Questionnaire Disability Index; DAS28=Disease Activity Score 28

Table D.30. Outcomes summary, low and medium risk of bias studies: JIA

| Study (PMID) Comparison ROB Category | Outcome Timing | Summary Finding | Intervention | Comparator | P-Value |
|---|-------------------------|-----------------|--------------|------------|---------|
| Hanghoj 2018 ⁸¹ (No PMID) Transition clinic vs usual care Medium Stage II | Retention 9.1 months | NA | 18.97% | NR | NR |

Abbreviations: ES=effect size (Continuous scores: an effect of 0.1 to 0.3 is considered to be small; 0.3 to 0.5 is a medium effect; and 0.5 or higher is a large effect); OR=odds ratio

Table D.31. Summary of strength of evidence: JIA

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|--|--------|--|------------------------------|-------------------|-------------|------------|-----------|--------------------------|
| Retention Transition clinic vs usual care | NR | 1 RCT with qualitative ⁸¹ (n=64 intervention; n=52 control) | NA | Moderate | Unknown | Direct | Imprecise | Insufficient |

Abbreviations: NR=not reported; NA=not applicable

Table D.32. Characteristics of studies included in evidence map: JIA

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--------------------------------------|--------------------------------|----------------------|-------------------|--------------------------------|
| Grande 2019 ⁸³ (30794202) | MHealth Patient Support System | University hospital | CSHCN | Rheumatology clinic |
| Relas 2018 ⁸⁴ (29251024) | Juvenile idiopathic arthritis | Transition clinic | CSHCN | Rheumatology outpatient clinic |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number

Kidney Disease

Table D.33. Risk of bias assessment: kidney disease

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|------------------------------------|----------------|----------------|----------------|------------------|---------------|----------------|----------------------------|--------|----------------|
| Tong 2015 ⁸⁵ (25641116) | 6 months | High | X | X | X | X | X | NR | High |
| Hill 2019 ⁸⁶ (31566348) | 6 months | High | X | X | X | X | X | NR | High |

Note: X=Domain was not assessed.

Abbreviations: NR=not reported; PMID=PubMed Identification Number

Table D.34. Characteristics of included studies: kidney disease

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description Duration 6 Core Elements | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|--|---------------------------|---|--|---|---------------------------|
| Tong 2015 ⁸⁵ (25641116) Australia Mixed methods (pre-post observational cohort and qualitative) ROB High Stage 1 | N=15 Age 21.1 53% female Race NR | Young adult clinic Transition Readiness | NA | Young adult renal clinic 6 months | Kidney disease quality of life (KDQO-36) Medication adherence (MAQ) Time Trade-Off (TTO) | NA | NA |
| Hill 2019 ⁸⁶ (31566348) US Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | N=19 Age (mean) 20.15 53% female Race NR | Transition model Transition Readiness; Transition Planning | NA | Pediatric nephrology outpatient specialty clinic 6 months | Type of illness Medications Nutrition Self- management Adherence New health provider Insurance Informed- reproduction Trade/school issues Ongoing support | NA | NA |

Abbreviations: CSHCN=children with special healthcare need; KDQOL-36=Kidney Disease Quality of Life; MAQ=Medication Adherence Questionnaire; NA=not applicable; NR=not reported; PMID=PubMed identification number; ROB=risk of bias; TTO=Time Trade-OFF

Table D.35. Characteristics of studies included in evidence map: kidney disease

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--------------------------------------|----------------|----------------------|-------------------|-------------------|
| Joslin 2020 ⁸⁷ (31928529) | Kidney disease | Transition clinic | CSHCN | Nephrology clinic |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number

Neurological Conditions

Table D.36. Risk of bias assessment: neurological conditions

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---|----------------|----------------|----------------|------------------|---------------|----------------|----------------------------|------------|----------------|
| Geerlings 2016 ⁸⁸ (26818400) | 2.5 years | High | X | X | X | X | X | Government | High |
| Murdaugh 2019 ⁸⁹ (29063818) | 4 years | High | X | X | X | X | X | NR | High |
| Andreoli 2021 ⁹⁰ (33242830) | Timing unclear | High | X | X | X | X | X | NR | High |

Note: X=Domain was not assessed.

Abbreviations: PMID=PubMed Identification Number

Table D.37. Characteristics of included studies: neurological conditions

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|---|---------------------------------------|---|---|---|---------------------------|
| Murdaugh 2019 ⁸⁹ (29063818) United States Observational pre-post ROB High Stage 1 | N=41 12 Years (recruited ages 9-15) 39% Female 71% white 19% Black 7% Hispanic 24% Asian | Cognitive remediation summer program. Transition readiness, transition planning. 4 years. | None | Summer program. 12 months/ year 1, 24 months / year 2, 36 months / year 3, 48 months / 4 years. | Adaptive Behavior (ABAS-II), Executive Control (TEC), Executive Function (D-KEFS), Problem solving (CCT-2) | Parenting Styles and Dimensions Questionnaire (PSDQ) Parent involvement & engagement | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|---------------------------------------|--|---|---|--|
| Geerlings 2016 ⁸⁸ (26818400) The Netherlands Observational ROB High Stage 2 | N=66 19 years (range 15-25) 47% Female Race NR | Transition clinic. | None | Tertiary referral center. 2.5 years. | Referral, Prescription, Consultation, Remission > 1 year, Diagnosis change | NA | NA |
| Andreoli 2021 ⁹⁰ (33242830) US Mixed-methods Survey and chart review High ROB Stage 1 | N=35 patients Age NR 48% Female Race NR N=21 providers Age NR Sex NR Race NR | Electronic medical records used to share transition flowchart and facilitate communication None Duration unclear | None | Children's hospital neurology clinic Retrospective | Transition Health knowledge | NR | Understanding of transition process |

Abbreviations: ABAS-II= Adaptive Behavior Assessment System; CCT-2=Children's Category Test – Level 2; CSHCN=children with special healthcare need; D-KEFS=Delis–Kaplan Executive Function System; NA=not applicable; NR=not reported; PSDQ= Parenting Styles and Dimensions Questionnaire; PMID=PubMed identification number; ROB=risk of bias; TEC= Tasks of Executive Control; COPM=Canadian Occupational Performance Measure; PACIC = Patient Assessment of Chronic Illness Care; PAM= Patient-initiated communications; PedsQL = Pediatric Quality of Life Scale; SSI=Supplemental security income; Youth KIT= Youth Keeping It Together Questionnaire

Rheumatic Conditions

Table D.38. Risk of bias assessment: rheumatic conditions

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---|----------------|----------------|----------------|------------------|---------------|----------------|-------------------------------|--------|----------------|
| Jensen 2015 ⁹¹ (26003474) | 6-8 months | High | X | X | X | X | X | NR | High |

Note: X=Domain was not assessed.

Abbreviations: NR=not reported; PMID=PubMed Identification Number

Table D.39. Characteristics of included studies: rheumatic conditions

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|----------------------------|---|-------------------|---|---------------------------|
| Jensen 2015 ⁹¹ (26003474) US Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | N=210 (participants of transition program) Age NR Race NR N=26 (non- participants of transition program) Age NR Race NR | Transition program Transition Readiness; Transition Planning; Transfer Completion | Pre-intervention cohort | Pediatric rheumatology clinic Baseline and 6-8 months | Satisfaction | NA | NA |

Abbreviations: CSHCN=children with special healthcare need; NA=not applicable; NR=not reported; PMID=PubMed identification number; ROB=risk of bias

Table D.40. Characteristics of studies included in evidence map: rheumatic conditions

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|----------------------|------------------------------------|-------------------|------------------------------|
| Stringer 2015 ⁹² (26063057) | Rheumatic conditions | Rheumatology transition clinic | CSHCN | Tertiary children's hospital |
| Rettig 1991 ⁹³ (11188605) | Rheumatic conditions | Rheumatology transition program | CSHCN | Adult Rheumatology center |
| Tattersall 2012 ⁹⁴ (23124284) | Rheumatic conditions | Rheumatology service: MAGICC | CSHCN | Hospital clinic |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; NA=not applicable

Sickle Cell Disease

Table D.41. Risk of bias assessment: sickle cell disease

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performanc e Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---|---------------------|-------------------|-------------------|----------------------|---------------|-------------------|----------------------------------|------------------|-------------------|
| Howell 2021 ⁹⁵ | 12 and 24 months | High | X | X | X | X | X | Foundation | High |
| Manwani 2021 ⁹⁶ (34389516) | 6-12 months | High | X | X | X | X | X | Health System | High |

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|-------------------------------|------------|----------------|
| Calhoun 2019 ⁹⁷ (30907500) | 161-882 days | High | X | X | X | X | X | NR | High |
| Smith 2011 ⁹⁸ (21602723) | NR | High | X | X | X | X | X | Hospital | High |
| Rodgers-Melnick 2019 ⁹⁹ (28779565) | 12 months | High | X | X | X | X | X | Foundation | High |
| Saulsberry 2019 ¹⁰⁰ (31808907) | NR | High | X | X | X | X | X | NR | High |
| Allemang 2018 ¹⁰¹ (31045326) | 12 months | High | X | X | X | X | X | Foundation | High |
| Johnson, 2020 ¹⁰² PMID NA | 8 weeks | High | X | X | X | X | X | NR | High |
| Viola 2021 ¹⁰³ (33779756) | 6 months | High | X | X | X | X | X | Government | High |

Note: X=Domain was not assessed.

Abbreviations: NA=not applicable; NR=not reported

Table D.42. Characteristics of included studies: sickle cell disease

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|--|---|-------------------------|---|---------------------------|
| Howell 2021 ⁹⁵ US Quantitative non- randomized (pre/post) ROB High Stage 1 | N=311 Age 18 (mean) 49% female Race NR | Co-located care delivery; pediatric provider into young adulthood 2 years Transition completion | Transfer to regular adult care model | Adult hematology clinic 24 months | Adult care retention | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|---|--|--|---|--|-----------------------------------|
| Manwani 2021 ⁹⁶ (34389516) US Quantitative non- randomized (pre/post) ROB High Stage 1 | N=60 Age 18 (median) (range 17-20) 48% female 79% Black | Transition program with transition navigator 2 years Transition and Care Policy/Guide; Tracking and Monitoring; Transition Readiness; Transition Planning; Transfer of Care | NA | Pediatric hematology clinic 6-12 months | Transition readiness (TRAQ); Confidence managing disease; Pain management; Adolescent medication barriers (AMBS); Participant experience, Acceptability, Satisfacion | NA | NA |
| Calhoun 2019 ⁹⁷ (30907500) US Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | N=122 Age (mean) 16.1 50% female Race NR | Adolescent autonomy checklist (AAC) modified to include SCD specific tasks (AAC-SCD) a skills-based educational handout Transition Readiness | NA | Pediatric hematology clinic 161-882 days | Transition readiness (AAC- SCD) Self- management (AAC-SCD) | NA | NA |
| Smith 2011 ⁹⁸ (21602723) US Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | N=33 Age 17 (median) 63.6% male Race NR | Transition program Transition Readiness; Transfer of Care | NA | Pediatric sickle cell clinic Timing NR | SCD knowledge (SCDQ) Transition concerns (SCTQ) Emotions (SCTQ) | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|--|--|--|--|-----------------------------------|
| Rodgers-Melnick 2019 ⁹⁹ (28779565) US Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | N=30 Age (mean) 21.04 50% female 100% Black | Music therapy intervention Transition Readiness | NA | Adult sickle cell clinic Baseline, 3, 6, 9, 12 months | Self-efficacy (SCSES) Trust (Wake Forest Trust in the Medical Profession Scale) SCD knowledge (Sickle Cell Knowledge Quiz) Adherence | NA | NA |
| Saulsberry 2019 ¹⁰⁰ (31808907) US Quantitative non- randomized (observational cohort) ROB High Stage 1 | N=568 Age NR 46% female Race NR | Transition program Transition and Care Policy/Guide; Tracking and Monitoring; Transition Readiness; Transition Planning; Transfer of Care; Transfer Completion | Pre-transition program patients | Medical home Timing NR | Pediatric abandonment Matriculation to adult care Adult care abandonment | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|--|--|---|--|-----------------------------------|
| Allemang 2018 ¹⁰¹ (31045326) Canada Quantitative non- randomized (observational cohort (retrospective chart review) ROB High Stage 1 | N=51 (post transition program cohort) Age 18 at transfer Sex NR Race NR N=61 (pre- transition program cohort) Age 18 at transfer Sex NR Race NR | Transition program with transition navigator Transition Readiness; Transition Planning; Transfer of Care; Transfer Completion | Pre-transition program cohort | Pediatric hemoglobinopath y care center 12 months | Lost to follow-up Hospitalizations Medication adherence Appointment attendance | NA | NA |
| Johnson 2020 ¹⁰² PMID NA US Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | N=10 Age NR 50% Female Race NR | Educational videos Transition Readiness Four- and 15- minute video series | NA | Pediatric hematology clinic 4, 6, or 8 weeks | Transition readiness (TRAQ) | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description Duration | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|---------------------------------------|---|---|---|---------------------------|
| Viola 2021 ¹⁰³ (33779756) US ROB High Quantitative non- randomized (pre- post observational cohort) Stage 1 | N=24 Age 20 46% Female 88% Black | SHIFT Program, medical student mentor intervention Transition Readiness; Transition Planning Six-month duration | NA | Pediatric sickle cell clinic 6 months | Transition readiness SCD knowledge Health literacy (The Newest Vital Sign) Self-efficacy (SCSES) Health-related quality of life (ASCQ-Me) Medication adherence (MMAS-8) Satisfaction (5- point Likert scale) Enrollment rates Reasons for refusal Retention rates Engagement with the intervention Reasons for drop-out | NA | NA |

Abbreviations: AAC-SCD=Adolescent Autonomy Checklist Sickle Cell Disease-specific tasks; AMBS= Adolescent medication barriers scale); CSHCN =children with special healthcare need; NA=not applicable; NR=not reported; PMID=PubMed identification number; ROB=risk of bias; SCD=sickle cell disease; SCDQ=Sickle Cell Disease Quiz; SCSES=Sickle Cell Self-Efficacy Scale; SCTQ=Sickle Cell Transfer Questionnaire TRAQ=Transition Readiness Assessment Questionnaire; SHIFT=Students Helping Individuals Facilitate Transition; ASCQ-Me=The Adult Sickle Cell Quality of Life Measurement System; MMAS-8=The Morisky Medication Adherence Scale

Table D.43. Characteristics of studies included in evidence map: sickle cell disease

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|---------------------|---|-------------------|--|
| Saulsberry 2020 ¹⁰⁴ (31909718) | Sickle cell disease | Web-based educational intervention | CSHCN | St. Jude Children's Research Hospital |
| Porter 2014 ¹⁰⁵ (No PMID) | Sickle cell disease | Transition readiness assessment tool | CSHCN | St. Jude Children's Research Hospital |
| Andemariam 2014 ¹⁰⁶ (24347402) | Sickle cell disease | Transition program | CSHCN | SCD clinic |

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|---------------------|---|-------------------|---------------------------|
| Darbari 2019 ¹⁰⁷ (31429531) | Sickle cell disease | Pediatric to adult hematology services | CSHCN | Hospital |
| Latzman 2010 ¹⁰⁸ (No PMID) | Sickle cell disease | Transitional sickle cell clinic | CSHCN | University medical center |
| Smith 2019 ¹⁰⁹ (30830235) | Sickle cell disease | Transition intervention program + transition intervention program readiness assessment tool | CSHCN | SCD clinic |
| Sobota 2014 ¹¹⁰ (24517960) | Sickle cell disease | Transition clinic + transition readiness tool | CSHCN | SCD clinic |
| Hankins 2012 ¹¹¹ (22819193) | Sickle cell disease | Transition pilot program | CSHCN | SCD clinic |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; SCD=sickle cell disease

Solid Organ Transplant

Table D.44. Risk of bias assessment: solid organ transplant

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|---|--------------------------------|----------------|
| Kosola 2019 ¹¹² (30431669) | 60 months | High | X | X | X | X | X | Hospital & University Hospital | High |
| Annunziato 2013 ¹¹³ (23993138) | 12 months | High | X | X | X | X | X | NR | High |
| Annunziato 2015 ¹¹⁴ (26308783) | 12 months | High | X | X | X | X | X | NR | High |
| Anton 2019 ¹¹⁵ (31347255) | NR | High | X | X | X | X | X | F | High |
| Pape 2013 ¹¹⁶ (23730905) | 12 months | High | X | X | X | X | X | NR | High |
| Grady 2019 ¹¹⁷ (29098353) Grady 2018 ¹¹⁸ (29098353) | 6 months | Low | Low | Medium | Medium | Low | Medium 18.92% intervention 12.20 control | Government | Low |

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|-------------------------------|------------------------|----------------|
| Fredericks 2015 ¹¹⁹ (26231289) | 12 months | High | X | X | X | X | X | NR | High |
| Remorino 2006 ¹²⁰ (17183936) | 12 months | High | X | X | X | X | X | NR | High |
| Michaud 2019 ¹²¹ (31062926) | NR | High | X | X | X | X | X | Pharmaceutical company | High |
| Belair 2011 ¹²² (No PMID) | NR | High | X | X | X | X | X | NR | High |
| Prestidge 2012 ¹²³ (21823039) | NR | High | X | X | X | X | X | Funding NA | High |
| Harden 2012 ¹²⁴ (22661725) | 5 years | High | X | X | X | X | X | Nonprofit | High |
| McQuillan 2015 ¹²⁵ (26672951) | 12 months | High | X | X | X | X | X | Funding NR | High |
| Weitz 2015 ¹²⁶ (26260514) | 36 months | High | X | X | X | X | X | Funding NR | High |
| Shapiro 2020 ¹²⁷ (32997866) | 6 months | High | X | X | X | X | X | Grant, Federal | High |

Note: X=Domain was not assessed.

Abbreviations: NR=not reported; NA=not applicable; PMID=PubMed Identification Number

Table D.45. Characteristics of included studies: solid organ transplant

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|--|-----------------------------------|--|---------------------------|--|-----------------------------------|
| Kosola 2019 ¹¹² (30431669) Finland Quantitative non- randomized (pre- post observational cohort (retrospective chart review) ROB High Stage 1 | Kidney transplant participants N=78 (cohort post implementation) Age NR 35% female Race NR N=54 (cohort prior to implementation) Age NR 26% Female Race NR | Transition model Transition Readiness; Transition Planning; Transfer of Care; Transfer Completion | Cohort prior to implementation | Transition outpatient clinic 60 months | Clinical outcomes | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|-----------------------------------|--|--|--|-----------------------------------|
| Annunziato 2013 ¹¹³ (23993138) US Quantitative non- randomized (pre- post observational cohort) ROB High Stage 1 | Liver transplant participants N=34 Age 22 53% Female N=20 (intervention) Age (mean) 22.42 45% Female 45% Black 25% Hispanic 20% White 10% Other N=14 (control) Age (mean) 22.00 64% Female 36% Black 50% Hispanic 14% Caucasian | Transition coordinator Transition Readiness; Transition Planning; Transfer of Care; Transfer Completion | Cohort prior to intervention | Setting NR 12 months | Quality of life (Short Form 36 Health Survey) Medication adherence Health care management (Developmentally Based Skills Checklist) Patient perspectives on transfer and preferences | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|-----------------------------------|--|---|--|-----------------------------------|
| Annunziato 2015 ¹¹⁴ (26308783) US Quantitative non- randomized (pre- post observational cohort (retrospective chart review) ROB High Stage 1 | Kidney transplant participants N=22 Age 21 59% Female N=12 (intervention) Age (mean) 21.68 Female 58% 25% White 17% African American 17% Hispanic 33% Asian 8% other N=10 (control) Age (mean) 21.03 60% Female NR 10% African American 70% Hispanic 20% other | Transition coordinator Transition Readiness; Transition Planning | Pre-transition clinic cohort | Setting NR 12 months | Medication adherence Clinical outcomes | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|--|-----------------------------------|--|--|---|-----------------------------------|
| Anton 2019 ¹¹⁵ (31347255) US Quantitative non-randomized (pre-post observational cohort (retrospective chart review)) ROB High Stage 1 | Heart transplant participants N=12 (youth) Age (median) 17.42 41.7% female 50% Caucasian 42% Hispanic 8% African American N=12 (caregiver) | Transition program Transition Readiness 7 quarterly 2-hour education sessions | NA | Hospital clinic 2 years | Transition readiness (TRAQ) Medical knowledge Medication knowledge Medication adherence Self-reported confidence | • Caregiver perception of participant readiness (PC-TRAQ) | NA |
| Pape 2013 ¹¹⁶ (23730905) Germany Quantitative non-randomized (pre-post observational cohort (retrospective chart review)) ROB High Stage 1 | Kidney transplant participants N=15 (specialized transition clinic) Age NR 46.7% female Race NR N=25 (general transplantation clinic) Age NR 68% female Race NR N=19 (a nephrologist) Age NR 36.8% female Race NR | 3 models of transition (1) specialized transition clinic (2) general transplantation clinic (3) a nephrologist Transition Readiness | NA | Adult outpatient clinic 12 months | Patient satisfaction Clinical outcomes | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|--|--|--|--|--|-----------------------------------|
| Grady 2019 ¹⁷ 31276804 US Quantitative randomized (RCT) Government ROB Low Stage 2 Grady 2018 ¹⁸ (29098353) | Heart transplant participants N=88 Age 21 47% Female 79% White N=37 (intervention) Age (mean) 21.3 44% female 81% Caucasian N=41 (control) Age (mean) 21.5 49% female 76% Caucasian | Transitioning to Adult Care (TRANSIT) program Transition Readiness; Transition Planning; Transfer of Care; Transfer Completion | Usual care | Pediatric heart transplant center Baseline, 3, 6 months | Transition readiness (TRAQ) Efficacy Heart transplant related knowledge Social support (SSI) Adherence to medical regimen Retention | NA | NA |
| Fredericks 2015 ¹⁹ (26231289) Canada Quantitative non- randomized (pre- post observational cohort/ quality improvement (retrospective chart review)) ROB High Stage 1 | Liver transplant participants N=45 Age 20 Sex NR Race NR N=26 (intervention) Age (mean) 20.86 Sex NR Race NR N=19 (control) Age (mean) 19.99 Sex NR Race NR | Transition readiness skills program Transition Readiness | Cohort prior to program implementation | Adult liver transplant clinic 12 months | Clinic attendance Medication adherence Health status | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|--|-----------------------------------|--|---|--|-----------------------------------|
| Remorino 2006 ¹²⁰ (17183936) UK Quantitative non- randomized (pre- post observational cohort (retrospective chart review)) ROB High Stage 1 | Kidney transplant participants N=16 Age 19 50% female Race NR | Transitional care program Transition Readiness; Transition Planning | NA | Pediatric transplant clinic 12 months | Adherence Clinicians subjective assessment of overall graft stability Transitional clinic attendance | NA | NA |
| Michaud 2019 ¹²¹ (31062926) Canada Mixed methods (Retrospective chart review and qualitative) ROB High Stage 1 | Kidney transplant participants N=31 Age 27 32% Female 87% White 3% Black 3% Hispanic N= 17 (intervention) Age (mean) 26.5 35.3% female 82.4% White 5.9% Black 5.9% Hispanic 5.9% unknown N=14 (control) Age (mean) 26.6 28.5% female 92.9% White 7.1% unknown | Young adult clinic Transition Readiness; Transition Planning | Regular adult care | Transplant outpatient clinic Timing NR | Perceived autonomy support (HCCQ) Autonomous or controlled motivation (TSRQ) Perceived competence (PCS) Quality of life (SF-12v2 (PCS- 12 & MCS-12)) Treatment adherence (BAASIS & MLVI) Attendance rate Episodes of rejection Graft loss Hospitalizations related to graft issues | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|--|-----------------------------------|--|---------------------------|--|-----------------------------------|
| Belair 2011 ¹²² (No PMID) US Quantitative non- randomized (Observational cohort) ROB High Stage 1 | <p>Kidney transplant participants</p> <p>N=21 Age 21 33% Female 66% White 33% Black</p> <p>N=10 (pre-transition patients) Age (mean) 20.60 20% female 80% Caucasian 20% African American</p> <p>N=11 (post-transition patients) Age (mean) 21.57 45.5% female 54.5% Caucasian 45.5% African American</p> | <p>Adolescent kidney transplant transitional clinic</p> <p>Transition Readiness; Transition Planning</p> | Pre-transition patients | <p>Adolescent-focused transition clinic</p> <p>Timing NR</p> | Patient satisfaction | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|-----------------------------------|---|------------------------------|--|-----------------------------------|
| Prestidge 2012 ¹²³ (21823039) Canada Quantitative non- randomized (pre- post observational cohort (retrospective chart review) ROB High Stage 1 | Kidney transplant participants N=34 Age 19 64% Female 72% White 6% Aboriginal 15% Asian N=12 (transition clinic cohort) 8% female 67% Caucasian 25% Aboriginal 8% Asian N=33 (pre- transition clinic cohort) 36.4% female 72.7% Caucasian 6% Aboriginal 15.2% Asian 6% other | Multidisciplinary transition clinic Transition Readiness; Transition Planning | Pre-transition clinic cohort | Renal outpatient clinic Baseline, 3, 6, 9, 12, 24 months | Clinical outcomes Cost | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|--|-----------------------------------|---|--|--|-----------------------------------|
| <p>Harden 2012¹²⁴ (22661725) UK Quantitative non-randomized (pre-post observational cohort (retrospective chart review)) ROB High Stage 1</p> | <p>Kidney transplant participants</p> <p>N=22 Age 18 50% 11 Females Race NR</p> <p>N=12 (integrated pediatric-adult transition clinic) 41.7% female Age (med) 17.5 Race NR</p> <p>N=9 (standard adult care) Age (med) 18 66.7% female Race NR</p> | <p>Integrated pediatric-adult transition clinic</p> <p>Transition Readiness; Transition Planning</p> | Standard adult nephrology clinic | <p>Adult renal center</p> <p>5 years</p> | <p>Rates of acute rejection Loss of kidney transplants</p> | NA | NA |
| <p>McQuillan 2015¹²⁵ (26672951) Canada Quantitative non-randomized (pre-post observational cohort (retrospective chart review)) ROB High Stage 1</p> | <p>Kidney transplant participants</p> <p>N=32 Age NR 34% Female</p> <p>N=16 (transfer clinic cohort) Age NR 37% Female Race NR</p> <p>N=16 (pre-transfer clinic cohort) Age NR 31% Female Race NR</p> | <p>Transfer clinic</p> <p>Transition Readiness; Transition Planning</p> | Pre-transfer clinic cohort | <p>Pediatric renal transplant center</p> <p>12 months</p> | <p>Clinical outcomes</p> <p>Non-adherent behavior</p> | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|----------------------------------|--|---|---|---------------------------|
| Weitz 2015 ¹²⁶ (26260514) Switzerland Quantitative non- randomized (pre- post observational cohort (retrospective chart review)) ROB High Stage 1 | Kidney transplant participants N=59 Age 19 36% Female 100% White N=33 (transition program cohort) Age (median) 19 36.4% female 100% White N=26 (pre- transition program cohort) Age (med) 19 34.6% female 100% White | Transition program Transition Readiness; Transition Planning | Pre-transition program cohort | Outpatient clinic 36 months | Clinical outcomes | NA | NA |
| Shapiro 2020 ¹²⁷ (32997866) US Quantitative descriptive (quality improvement, retrospective chart review) ROB High Stage 1 | Liver transplant participants N=24 Age (median) 11 42% Female 54% White 38% Hispanic 8% African American | Liver transplant transition program Transition Policy; Tracking and Monitoring; Transition Readiness; Transition Planning; Transfer of Care; Transition Completion | NA | Pediatric and adult healthcare systems 6 months | Transition readiness (RTQ) Clinical outcomes Non- adherence to clinic visits and medication Continuity of care Retention Bounce backs | NA | NA |

Abbreviations: BAASIS=Basal Assessment of Adherence to Immunosuppressive Medication Scale; CSHCN=children with special healthcare need; HCCQ=Health Care Climate Questionnaire; MCS-12=Mental Component Summary; MLVI=Medication Level of Variability Index; NA=not applicable; NR=not reported; PCS=Perceived Competence Scale; PCS-12=Physical Component Summary; PC-TRAQ=Parent and Caregiver-Transition Assessment Questionnaire; PMID=PubMed identification number; ROB=risk of bias; RTQ=readiness to transition questionnair SF-12v2=Health Survey; SSI=Social Support Index; TSRQ=Treatment Self-regulation questionnaire; TRAQ=Transition Readiness Assessment Questionnaire; e

Table D.46. Outcomes summary, low and medium risk of bias studies: solid organ transplant

| Study (PMID) Comparison ROB Category | Outcome Timing | Summary Finding | Intervention | Comparator | P-Value |
|---|---|-------------------|-------------------------------------|-------------------------------------|---|
| Grady 2019 ¹⁷ (31276804) Transitioning to Adult Care (TRANSIT) program vs usual care Low Stage 2 | Heart transplant related knowledge 6 months | No difference | 74% item-level correct responses | 74% item-level correct responses | Intervention effect p=0.77 Time effect p=0.79 |
| Grady 2019 ¹⁷ (31276804) Transitioning to Adult Care (TRANSIT) program vs usual care Low Stage 2 | Transition readiness (TRAQ)-Self Advocacy 6 months | No difference | NA | NA | Intervention effect p=0.54 Time effect p=0.33 |
| Grady 2019 ¹⁷ (31276804) Transitioning to Adult Care (TRANSIT) program vs usual care Low Stage 2 | Transition readiness (TRAQ)-Self Management 6 months | Favors usual care | 4.4 | 4.4 | Intervention effect p=0.88 Time effect p=0.007 |
| Grady 2019 ¹⁷ (31276804) Transitioning to Adult Care (TRANSIT) program vs usual care Low Stage 2 | Social support (SSI) 6 months | No difference | 3.9 | 3.9 | Intervention effect p=0.38 Time effect p=0.08 |
| Grady 2019 ¹⁷ (31276804) Transitioning to Adult Care (TRANSIT) program vs usual care Low Stage 2 | Adherence to medical regimen (overall score) 6 months | No difference | 3.9 | 3.9 | Intervention effect p=0.88 Time effect p=0.045 |

| Study (PMID) Comparison ROB Category | Outcome Timing | Summary Finding | Intervention | Comparator | P-Value |
|---|--|---|---------------------|-------------------|--------------------|
| Grady 2019 ¹⁷ (31276804) Transitioning to Adult Care (TRANSIT) program vs usual care Low Stage 2 | Retention | NA | 86% retention | 91% retention | NR |
| Grady 2019 ¹⁷ (31276804) Transitioning to Adult Care (TRANSIT) program vs usual care Low Stage 2 | Efficacy: (1) within-participant standard deviation (SD) of average tacrolimus blood levels at specific time points (primary endpoint); (2) tacrolimus levels within target range (determined by HT cardiologists); (3) self-report of adherence to the medical regimen; (4) episodes of adverse events (including acute rejection); and (5) use of health care resources) | Not statistically significant difference on 5 out of 5. (Table 3) | NA | NA | p>0.05 for 5 items |

Abbreviations: PMID=PubMed identification number; NA=not applicable; ROB=risk of bias

Table D.47. Summary of strength of evidence: solid organ transplant

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|--|----------|---|------------------------------------|----------------------|-------------|------------|-----------|-----------------------------|
| Heart transplant related knowledge Transitioning to Adult Care (TRANSIT) program vs usual care | 6 months | 1 RCT ¹¹⁷ (n=37 intervention; n=41 control) | No difference | Low | Unknown | Direct | Imprecise | Insufficient |
| Transition readiness (TRAQ)-Self Advocacy Transitioning to Adult Care (TRANSIT) program vs usual care | 6 months | 1 RCT ¹¹⁷ (n=37 intervention; n=41 control) | No difference | Low | Unknown | Direct | Imprecise | Insufficient |
| Transition readiness (TRAQ)-Self Management Transitioning to Adult Care (TRANSIT) program vs usual care | 6 months | 1 RCT ¹¹⁷ (n=37 intervention; n=41 control) | Favors usual care | Low | Unknown | Direct | Imprecise | Insufficient |
| Social support (SSI) Transitioning to Adult Care (TRANSIT) program vs usual care | 6 months | 1 RCT ¹¹⁷ (n=37 intervention; n=41 control) | No difference | Low | Unknown | Direct | Imprecise | Insufficient |

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|---|----------|--|------------------------------------|----------------------|-------------|------------|-----------|-----------------------------|
| Adherence to medical regimen Transitioning to Adult Care (TRANSIT) program vs usual care | 6 months | 1 RCT ¹¹⁷ (n=37 intervention; n=41 control) | Favors usual care | Low | Unknown | Direct | Imprecise | Insufficient |
| Feasibility Transitioning to Adult Care (TRANSIT) program vs usual care | 6 months | 1 RCT ¹¹⁷ (n=37 intervention; n=41 control) | NA | NA | NA | NA | NA | NA |
| Efficacy Transitioning to Adult Care (TRANSIT) program vs usual care | 6 months | 1 RCT ¹¹⁷ (n=37 intervention; n=41 control) | NA | NA | NA | NA | NA | NA |

Abbreviations: NR=not reported; NA=not applicable; RCT=randomized controlled trial

Table D.48. Characteristics of studies included in evidence map: solid organ transplant

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|------------------------|---|-------------------|------------------------------|
| Annunziato 2008 ¹²⁸ (18435606) | Solid organ transplant | Educational intervention | CSHCN | Transplant outpatient clinic |
| Hubbard 2016 ¹²⁹ (No PMID) | Solid organ transplant | Nurse-led young person's and transition clinics | CSHCN | Pediatric hospital |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; NA=not applicable

Spina Bifida

Table D.49. Risk of bias assessment: spina bifida

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---------------------------------------|----------------|----------------|----------------|------------------|---------------|----------------|----------------------------|------------|----------------|
| Seeley 2017 ¹³⁰ (28760316) | 4-6 months | High | X | X | X | X | X | NR | High |
| Sawin 2015 ¹³¹ (24443345) | 6 & 12 months | High | X | X | X | X | X | NR | High |
| Betz 2010 ¹³² (22229060) | 4 months | Medium | Low | Medium | Medium | Low | Medium 18.75% | Government | Medium |

Note: X=Domain was not assessed.

Abbreviations: PMID=PubMed Identification Number

Table D.50. Characteristics of included studies: spina bifida

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|--|------------------------|-------------------------------------|-----------------------------|-----------------------------------|------------------------|
| Seeley 2017 ¹³⁰ (28760316) US Quantitative non-randomized (pre-post observational cohort/ Quality improvement (pilot)) ROB High Stage 1 | N=14 (youth-parent pair) Age NR 27.2% female Race NR | Transition care coordination program Transition Readiness | NA | Outpatient clinic 4-6 months | Transition readiness (TRAQ) | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|--|-----------------------------------|---|---------------------------|--|-----------------------------------|
| Sawin 2015 ¹³¹ (24443345) US Mixed methods (pre- post observational cohort and qualitative) ROB High Stage 1 | N=24 (CSHCN) Age (mean) 23 50% female 92% Caucasian N=16 (Parent) Age (mean) 50 88% female 94% Caucasian | Spina bifida transition program Transfer of Care | NA | Outpatient clinic 6 and 12 months | Barriers | • Barriers | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|--|---------------------------|---|---|---|---------------------------|
| Betz 2010 ¹³² (22229060) US Quantitative randomized (RCT) ROB Medium Stage 2 | <p>N=65 (total youth)</p> <p>N=31 (intervention youth) Age (mean) 16.19 58% female 87% Latino 3% White 4% Multiethnic</p> <p>N=34 (control youth) Age (mean) 15.71 60% female 91% Latino 3% White, Multiethnic & Asian</p> <p>N=65 (total parents)</p> <p>N=31 (intervention parents) Age (mean) 43.25 87% Latino 10% White 3% Black</p> <p>N=34 (control parents) Age (mean) 40.15 89% Latino 6% White 1% Asian, Multiethnic & Black</p> | <p>Transition Preparation Training in combination with spina bifida management</p> <p>Transition Readiness</p> | Usual management | <p>Pediatric spina bifida clinic</p> <p>Baseline and 4 months</p> | Well-being (PARS III) Role mastery (CLSS) Self-care practice (DSCPI-90) | NA | NA |

Abbreviations: CSHCN=children with special healthcare need; NA=not applicable; NR=not reported; PMID=PubMed identification number; ROB=risk of bias; TRAQ=transition readiness assessment questionnaire; RCT=randomized controlled trial; PARS III=Personal Adjustment and Role Skills Scale; CLSS=Community Life Skills Scale; DSCPI-90=Denyes Self-Care Practice Instrument

Table D.51. Outcomes summary, low and medium risk of bias studies: spina bifida

| Study (PMID) Comparison ROB Category | Outcome Timing | Summary Finding | Intervention* | Comparator* | P-Value |
|--|---|-----------------|---------------|---------------|---------|
| Betz 2010 ¹³² (22229060) Transition Program Training (TPT) vs usual care Medium Stage 2 | Subjective well-being (PARS III) 4 months | No difference | 82.95 (12.44) | 84.56 (10.44) | 0.942 |
| Betz 2010 ¹³² (22229060) Transition Program Training (TPT) vs usual care Medium Stage 2 | Role mastery (CLSS) 4 months | No difference | 19.12 (4.25) | 18.35 (3.42) | NR |
| Betz 2010 ¹³² (22229060) Transition Program Training (TPT) vs usual care Medium Stage 2 | Self-care practice (DSCPI-90) 4 months | No difference | 63.29 (13.73) | 66.99 (17.61) | 0.894 |

*Mean (SD)

Abbreviations: PMID=PubMed identification number; NA=not applicable; NR=not reported; ROB=risk of bias; PARS III=Personal Adjustment and Role Skills Scale; CLSS=Community Life Skills Scale; DSCPI-90=Denyes Self-Care Practice Instrument

Table D.52. Summary of strength of evidence: spina bifida

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|--|----------|---|------------------------------------|----------------------|-------------|------------|-----------|-----------------------------|
| Subjective well-being (PARS III) Transition Program Training (TPT) intervention in combination with spina bifida management vs only spina bifida management | 4 months | 1 RCT ¹³² (n=31 intervention; n=34 control) | No difference | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Role mastery (CLSS) Transition Program Training (TPT) intervention in combination with spina bifida management vs only spina bifida management | 4 months | 1 RCT ¹³² (n=31 intervention; n=34 control) | No difference | Moderate | Unknown | Direct | Imprecise | Insufficient |

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|---|----------|--|------------------------------------|----------------------|-------------|------------|-----------|-----------------------------|
| Self-care practice (DSCPI-90) Transition Program Training (TPT) intervention in combination with spina bifida management vs only spina bifida management | 4 months | 1 RCT ¹³² (n=31 intervention; n=34 control) | No difference | Moderate | Unknown | Direct | Imprecise | Insufficient |

Abbreviations: NR=not reported; RCT=randomized controlled trial; PARS III=Personal Adjustment and Role Skills Scale; CLSS=Community Life Skills Scale; DSCPI-90=Denyes Self-Care Practice Instrument

Table D.53. Characteristics of studies included in evidence map: spina bifida

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|---|--------------|---|-------------------|-----------------------|
| Aguilera 2016 ¹³³ (26496631) | Spina bifida | Jacksonville Health and Transition Services | CSHCN | Spinal defects clinic |
| Roth 2019 ¹³⁴ (31109884) | Spina bifida | Spina bifida transition clinic | CSHCN | Spina bifida clinic |
| Betz 2018 ¹³⁵ (29398163) | Spina bifida | Movin' on Up Health Care Transition Program | CSHCN | Spina bifida clinic |
| Betz 2016 ¹³⁶ (26483330) | | | | |
| Hopson 2019 ¹³⁷ (31574471) | Spina bifida | Individualized transition plan | CSHCN | Spina bifida clinic |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; NA=not applicable

Urological Conditions

Table D.54. Characteristics of studies included in evidence map: urological conditions

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|---|--------------------------------------|-------------------|---------------------------------------|
| Harhuis 2018 ¹⁵⁴ (29170077) | Neuropathic bladder, bladder exstrophy or other rare congenital or acquired chronic bladder disorders | Patient Transition Protocol | CSHCN | Pediatric Urology Hospital Department |
| Shalaby 2015 ¹⁵⁵ (25797859) | Neurogenic bladder diseases | Adolescent Transition Urology Clinic | CSHCN | Pediatric Urology Clinic |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; NA=not applicable; NR=not reported

Other Conditions

Table D.55. Risk of bias assessment: other conditions

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|---|------------|---|
| Witvliet 2017 ¹³⁸ (28674948) | 12 months | High | X | X | X | X | X | NR | High |
| Nair 2017 ¹³⁹ (29060130) | NR | High | X | X | X | X | X | NR | High |
| Croteau 2016 ¹⁴⁰ (26496140) | 3 months | High | X | X | X | X | X | NR | High |
| Schmidt 2016 ¹⁴¹ (26597543) | 6 months | Medium | High | X | X | X | Medium 15.69% | Government | High |
| Dale 2020 ¹⁴² (31971666) | 12 months | High | X | X | X | X | X | Government | High |
| Downing ¹⁴³ 2013 (22734661) | 12 months | High | X | X | X | X | X | Government | High |
| Dingemann 2017 ¹⁴⁴ (27522121) | 4 weeks | High | X | X | X | X | X | NR | High |
| Breakey 2014 ¹⁴⁵ (25311370) | Timing NR | Low | Low | Medium | Medium | Low | High 38% (total) 25% (intervention) 54% (control) | Nonprofit | Medium (for attrition-related outcomes) |
| Schmidt 2018 ¹⁴⁶ (29340756) | 6 months | High | X | X | X | X | X | Ministry | High |
| Peres 2021 ¹⁴⁷ (33671057) | 24 months | High | X | X | X | X | X | National | High |

Note: X=Domain was not assessed.

Table D.56. Characteristics of included studies: other conditions

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|---|----------------------------|---|--|---|---------------------------|
| Witvliet 2017 ¹³⁸ (28674948) Netherlands Quantitative nonrandomized (pre-post observational cohort) ROB High Stage 1 | Hirschsprung disease and anorectal malformations patients N=27 Age (mean) 28 41% female Race NR | Transitional outpatient clinic Transition Readiness; Transition Planning | NA | Pediatric outpatient clinic 12 months | Disease-specific functioning (C- FIQ) Quality of life (WHOQOL-100) | NA | NA |
| Nair 2017 ¹³⁹ (29060130) US Quantitative nonrandomized (case-control) ROB High Stage 1 | Asthma participants N=20 Age NR Sex NR Race NR | Web-based interactive application Transition Readiness | Reading material | Children's immunology clinic Timing NR | Asthma related knowledge, Symptoms, Adherence | NA | NA |
| Croteau 2016 ¹⁴⁰ (26496140) US Quantitative nonrandomized (observational cohort, retrospective chart review, quality improvement) ROB High Stage 1 | Hemophilia patients N=60 Age 13 2% Female Race NR N=31 (intervention) Age (mean) 10.2 N=29 (pre- intervention) Age (mean) 13.5 | HEMO- milestones tool Transition Readiness | Pre-intervention cohort | Hemophilia clinic 3 months | Rate per clinic of completed patient competency assessment documentation Rate of completed patient skill development plan documentation | NA | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|---------------------------|---|---|--|---------------------------|
| Schmidt 2016 ¹⁴¹ (26597543) Germany Quantitative randomized (RCT) ROB High Stage 2 | Type I diabetes, cystic fibrosis and IBD patients N=325 Age 17 46% Female Race NR N=172 (intervention) 45.3% female Race NR N=153 (control) 47.1% female Race NR | Transition workshops Transition Readiness | Treatment as usual | Pediatric outpatient clinic 6 months | Transition competence (TCS) Self-efficacy (GSE, 32) Patient engagement (PAM13-D, 34) Satisfaction (CHS-SUN self) QOL (EUROHIS QOL-8) | NA | NA |
| Dale 2020 ¹⁴² (31971666) Canada Quantitative non- randomized (observational longitudinal) ROB High Stage 1 | Ventilator assisted patients N=12 AYA- caregiver dyads (N=24 individuals) N=12 ventilator- assisted adolescents Age 18 50% female Race NR N=12 caregivers Age NR 92% female Race NR | Transition program Transition Readiness | No control | Joint pediatric- adult LTV clinic Baseline, 1, 12 months | Transition readiness, Barriers/ facilitators | <ul style="list-style-type: none"> • Transition readiness • Barriers/ facilitators | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|---|---------------------------|---|--|---|---------------------------|
| Downing 2013 ¹⁴³ (22734661) UK Quantitative nonrandomized (Observational cohort, retrospective chart review) ROB High Stage 1 | Endocrine condition patients N=103 Age 18 (median) 53% Female Race NR N=75 (YPC visitor) Age NR 72.7% female Race NR N=18 (No YPC visits) Age NR 27.3% female Race NR | Young person's clinic Transition Readiness; Transition Planning | No YPC visits | Adult service setting in hospital 12 months | Clinic attendance | NA | NA |
| Dingemann 2017 ¹⁴⁴ (27522121) Germany Quantitative nonrandomized (pre-post observational cohort) ROB High Stage 1 | Esophageal atresia patients N=29 patients, 25 parents Age 18 55% Female Race NR N=10 (intervention) Age (mean) 18.4 40% female Race NR N=19 (control) Age (mean) 18.1 55.2% female | Patient education program with web-based component (includes parental training) Transition Readiness | Standard care | Setting NR 4 weeks | Satisfaction (ZUF-8) Disease knowledge HRQOL Commitment to own health care (Patient Activation Measure-13D) | Satisfaction (ZUF-8) Knowledge | NA |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|---|-----------------------------------|---|--|--|-----------------------------------|
| Breakey 2014 ¹⁴⁵ (25311370) Canada Quantitative (RCT-pilot) randomized ROB Medium Stage 2 | Hemophilia participants N=29 Age 16 0% Female Race NR N=16 (intervention) Age (mean) 16 N=13 (control) Age (mean) 16.1 | Online self- management program Transition Readiness | No intervention | Children's hospital Timing NR | Disease-specific knowledge, HRQL (CHO- KLAT), Self-efficacy (GSE-S 12), Self- management (Self- Management Skills Assessment Guide), Satisfaction, Retention | NA | NA |
| Schmidt 2018 ¹⁴⁶ (29340756) Germany Quantitative nonrandomized (pre-post observational cohort) ROB High Stage 1 | IBD and diabetes patients N=285 (total) N=99 (IBD) N=153 (diabetes) Age (mean) 16.57 54.7% female Race NR | Transition- oriented patient education program (2-day transition workshop) Transition Readiness | Treatment as usual | Pediatric tertiary care hospital 6 months | Quality of life (DCGM; EUROHIS QOL- 8) Self- management (TCS) | NA | NA |
| Peres 2021 ¹⁴⁷ (33671057) Portugal Quantitative non- randomized (pre- post observational cohort) ROB-High Stage 1 | Phenylketonuria patients N=55 Age NR 55% female Race NR | Transition program with structured transition process and a multidisciplinary approach Transition Readiness; Transition Planning Duration NR | NA | Joint pediatric and adult hospital 24 months | Metabolic control Adherence Loss of follow-up | NA | NA |

Abbreviations: C-FIQ= Comprehensive Fecal Incontinence Questionnaire; CHO-KLAT=Canadian Hemophilia Outcomes Kids Life Assessment Tool; CHS-SUN: Child Health Care Questionnaire on Satisfaction, Utilization and Needs; CSHCN=children with special healthcare need; DCGM=DISABKIDS Chronic Generic Measure; EUROHIS QOL-8=European Health Interview Survey-Quality of Life; GSE, 32=General Self-efficacy Scale; GSE-S 12=Generalized Self-Efficacy-Sherer Scale; HRQL=health related quality of life; HRQOL=health-related quality of life; IBD=inflammatory bowel disease; LTV=long-term ventilation; NA=not applicable; NR=not reported; PAM13-D, 34: Patient Activation Measure 13; PMID=PubMed identification number; ROB=risk of bias; TCS=Transition Competence Scale; WHO-QoL-100=World Health Organization Quality of Life 100 item assessment; YPC=young person's clinic; ZUF-8=Client Satisfaction Questionnaire; ;

Table D.57. Outcomes summary, low and medium risk of bias studies: other conditions

| Study (PMID) Comparison ROB Category | Outcome Timing | Summary Finding | Intervention* | Comparator* | P-Value* |
|--|--|---------------------|---------------|-------------|-------------------------|
| Breakey 2014 ¹⁴⁵ (25311370) Online self- management program vs no intervention Medium Stage 2 | Disease-specific knowledge NR | Favors intervention | p=0.004 | p=0.5355 | 0.01 (CI -4.47, -0.57) |
| Breakey 2014 ¹⁴⁵ (25311370) Online self- management program vs no intervention Medium Stage 2 | HRQL (CHO-KLAT) NR | NA | NR | NR | NR |
| Breakey 2014 ¹⁴⁵ (25311370) Online self- management program vs no intervention Medium Stage 2 | Self-efficacy (GSE-S 12) NR | No difference | p=0.007 | p=0.459 | 0.7355 (CI -4.03, 5.59) |
| Breakey 2014 ¹⁴⁵ (25311370) Online self- management program vs no intervention Medium Stage 2 | Self-management (Self- Management Skills Assessment Guide) NR | No difference | p=0.046 | p=0.413 | 0.068 (CI -28.39, 1.12) |

| Study (PMID) Comparison ROB Category | Outcome Timing | Summary Finding | Intervention* | Comparator* | P-Value* |
|--|--------------------|-------------------|---------------|-------------|----------|
| Breakey 2014 ¹⁴⁵ (25311370) Online self- management program vs no intervention Medium Stage 2 | Satisfaction NR | High satisfaction | 91% | NR | NR |
| Breakey 2014 ¹⁴⁵ (25311370) Online self- management program vs no intervention Medium Stage 2 | Feasibility NR | No difference | 25% | 54% | 0.47 |

*Significant at P<0.05.

Abbreviations: CI=confidence interval; PMID=PubMed identification number; NA=not applicable; NR=not reported; ROB=risk of bias; HRQL=health-related quality of life; CHO-KLAT=Canadian Hemophilia Outcomes Kids Life Assessment Tool; GSE-S 12=Generalized Self-Efficacy-Sherer Scale

Table D.58. Summary of strength of evidence: other conditions

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|--|--------|---|------------------------------------|----------------------|-------------|------------|-----------|-----------------------------|
| Disease- specific knowledge Online self- management program vs no intervention | NR | 1 RCT ¹⁴⁵ (pilot) (n=16 intervention; n=13 control) | Favors intervention | Moderate | Unknown | Direct | Imprecise | Insufficient |
| HRQL (CHO- KLAT) Online self- management program vs no intervention | NR | 1 RCT ¹⁴⁵ (pilot) (n=16 intervention; n=13 control) | NR | NA | NA | NA | NA | NA |

| Outcome Comparison | Timing | # Studies/ Design (n Analyzed) | Finding or Summary Statistic | Study Limitations | Consistency | Directness | Precision | Overall Grade/Conclusion |
|--|--------|--|------------------------------|-------------------|-------------|------------|-----------|--------------------------|
| Self-efficacy (GSE-S 12) Online self-management program vs no intervention | NR | 1 RCT ¹⁴⁵ (pilot) (n=16 intervention; n=13 control) | No difference | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Self-management (Self-Management Skills Assessment Guide) Online self-management program vs no intervention | NR | 1 RCT ¹⁴⁵ (pilot) (n=16 intervention; n=13 control) | No difference | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Satisfaction Online self-management program vs no intervention | NR | 1 RCT ¹⁴⁵ (pilot) (n=16 intervention; n=13 control) | High satisfaction | Moderate | Unknown | Direct | Imprecise | Insufficient |
| Feasibility Online self-management program vs no intervention | NR | 1 RCT ¹⁴⁵ (pilot) (n=16 intervention; n=13 control) | No difference | Moderate | Unknown | Direct | Imprecise | Insufficient |

Abbreviations: NR=not reported; HRQL=health-related quality of life; CHO-KLAT=Canadian Hemophilia Outcomes Kids Life Assessment Tool; GSE-S 12=Generalized Self-Efficacy-Sherer Scale

Table D.59. Characteristics of studies included in evidence map: other conditions

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|--|-------------------------|--|-------------------|----------------------|
| Twito 2019 ¹⁴⁸ (31028713) | Endocrine conditions | Transition clinic | CSHCN | Endocrinology clinic |
| Dogba 2014 ¹⁴⁹ (25366588) | Osteogenesis imperfecta | Transition program | CSHCN | Hospital |
| Downing 2017 ¹⁵⁰ (28619024) | Endocrine conditions | Pediatric Consultation Assessment Tool | CSHCN | Endocrinology clinic |

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|---|----------------------|-----------------------------|--------------------------|-----------------------------|
| Zahra 2021 ¹⁵¹ (33647195) | Turner syndrome | Transition clinic | CSHCN | Children's hospital |
| Hart 2021 ¹⁵² (34215949) | Autism spectrum | Transition clinic | CSHCN | Primary care / medical home |
| Pedersen 2021 ¹⁵³ (34066432) | Prader-Willi syndrom | Transition checklist | CSHCN | Children's hospital |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; NA=not applicable; NR=not reported

Appendix E. Evidence Tables and Evidence Maps for Implementation Strategies and Communication Tools for Care Interventions for Transition, Including Provider-Related Training (Chapter 5)

All Conditions

Table E.1. Risk of bias assessment: all conditions

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|---|------------------|--------------------------------|----------------|------------------|---------------|----------------|---|--------------------------|--|
| Jones 2019 ¹⁵⁶ (31029928) | 12-18 months | High | X | X | X | X | X | Unclear | High |
| Le Marne 2019 ¹⁵⁷ (30474164) | 11 months | High | X | X | X | X | X | Health system | High |
| Hergenroeder 2018 ²³ (29542247) | ~26 months | High Historical control | X | X | X | X | X | Government | High |
| Mackie 2018 ²⁴ (29673467) | 6, 12, 18 months | Medium | Low | Medium | Medium | Low | 4/125=3% missing from analysis, but up to 25% missing data unaccounted for. High ROB after 12 months. | Government and Nonprofit | Medium at 6 and 12 months High at 18 months |
| Phillips 2018 ¹⁵⁸ (No PMID) | Unclear | High | X | X | X | X | X | NR | High |
| Disabato 2015 ¹⁵⁹ (26260696) | 8 months | High | X | X | X | X | X | Health system | High |
| McManus 2015 ¹⁶⁰ (26239121) | 18 months | High | X | X | X | X | X | Government | High |
| Moosa 2015 ¹⁶¹ (No PMID) | 12 month | High | X | X | X | X | X | Unclear | High |

| Study (PMID) | Outcome Timing | Selection Bias | Detection Bias | Performance Bias | Fidelity Bias | Reporting Bias | Attrition Bias Attrition % | Funder | Overall Rating |
|--|----------------|----------------|----------------|------------------|---------------|----------------|----------------------------|--------------------------------|----------------|
| Meacham 2014 ¹⁶² (No PMID) | 6-21 months | High | X | X | X | X | X | Private foundation | High |
| Okumura 2014 ³¹ (24415776) | 18 months | High | X | X | X | X | X | Government, Private foundation | High |
| Lestishock 2021 ¹⁴ (33762131) | 24 months | High | X | X | X | X | X | NR | High |

Note: X=Domain was not assessed.

Abbreviations: PMID=PubMed Identification Number; NR=not reported

Table E.2. Characteristics of included studies: all conditions

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|---|--|---------------------------|---|----------------|---|-------------------------------------|
| Jones 2019 ¹⁵⁶ (31029928) US Pre/post Observational Cohort/QI ROB High Stage NA | Young adult “children with special health care needs” with mental health, developmental, and complex medical conditions, SSI-eligible N=35 Age 95% 18-21 years Sex NR Race NR | Health care Got Transition program based on the 6 Core Elements 18 months | NA | Seven learning health systems nationally 18 months | NA | NA | Implementation of Six Core Elements |
| Le Marne 2019 ¹⁵⁷ (30474164) Australia Pre/post Observational Cohort/QI ROB High Stage 2 | Epilepsy patients N=45 Age NR Sex NR Race NR | Provider training and patient education Transition readiness 11 months | NA | Children’s hospital 11 months | Acceptability | Acceptability | NR |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|---|--|-----------------------------------|--|---|--|--|
| Hergenroeder 2018 ²³ (29542247) United States Qualitative nonrandomized ROB High Stage 1 | N=45 20 Years (recruited 19-23) 51% Female Race NR | Healthcare transition (HCT) planning program for CSHCN with congenital heart disease. EMR-based transition planning tool. Unclear if core elements targeted. Intervention duration NR. | No intervention (usual care) | Cardiac hospital unit Timing NR Longest followup reported at 26 months | Heart failure (New York Heart Association Functional Classification of Heart Failure) | NR | NR |
| Phillips 2018 ¹⁵⁸ (No PMID) US Pre/post survey ROB High Stage 1 | Providers of outpatient pediatric rehabilitation N=10 Age NR Sex NR Race NR | Nurse-led 60 minute training session Transition and care policy/guideline Unclear | NA | Pediatric rehabilitation outpatient clinic Unclear | NR | NR | Knowledge, Confidence, Experience |
| Disabato 2015 ¹⁵⁹ (26260696) US Pre/post observational cohort/QI ROB High Stage 2 | Providers of patients with refractory epilepsy N=18 Age NR Sex NR Race NR | Electronic medical record tracking and best practice advisory, and patient education Tracking and information Transition readiness 8 months | NA | Academic medical center neurology clinic 8 months | NR | NR | Knowledge, Comfort, Satisfaction, Communication between team members |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|--|--|---|--|--|---|---|--|
| McManus 2015 ¹⁶⁰ (26239121) US Pre/post observational cohort/QI ROB High Stage 2 | Young adult “children with special health care needs” with mental health, developmental, and complex medical conditions, SSI- eligible N=35 Age 95% 18-21 years Sex NR Race NR | Health care Got Transition program based on the 6 Core Elements 18 months | NA | Pediatric primary care practices in an urban specialty managed care plan 18 months | NA | NA | Implementation of Six Core Elements |
| Moosa 2015 ¹⁶¹ (No PMID) UK Observational ROB High Stage I | ADHD diagnosis N=247 15.9 years (range 15 to 16) Sex NR Race NR | Joint clinic for case review and transition planning. Transition Readiness | NC | General pediatric, adult mental health services 12 months | Waiting time Referral rate Handover/ transition | NA | NA |
| Meacham 2014 ¹⁶² (No PMID) US Pre/post observational cohort ROB High Stage 2 | Providers of care to pediatric cancer survivors N=30 63% over 45 years 66% Female Race NR 50% Physician | Training to establish network of university health centers as sites for transition to adult care for university-bound pediatric cancer survivors Transition and care policy/guideline 6-21 months | Contrasted University Health Care systems with established engagement versus emergent engagement | University health centers Unclear | NR | NR | Familiarity with survivor care, health plan, guidelines; comfort providing survivor care; provide survivor care |

| Study (PMID) Country Study Design RoB Rating Stage Model | Participants N= Age (Mean) Sex (% Female) Race (%) | Intervention Description 6 Core Elements Duration | Comparison Description | Setting Outcome Timing(s) | CSHCN Outcomes | Parents and/or Caregiver Outcomes | Care Provider Outcomes |
|---|--|--|---------------------------|--|---|--|---------------------------|
| Okumura 2014 ³¹ (24415776) US Quantitative Pre- post ROB High Stage 1 | Cystic fibrosis N=18 pediatric patients completed the post intervention survey and N=8 patients completed baseline and post intervention survey.. N=56 patients or their families responded to program feedback survey at Time 1 Age NR Gender NR Race NR | Transition program with guide and notebook; joint staff meetings with adult/pediatric centers Elements 1 Guide,3 Readiness, and 4 Planning Duration unclear | NA | Academic cystic fibrosis center, pediatric and adult. 18 months | Acceptability | Acceptability | NR |
| Lestishock 2021 (33762131) ¹⁴ US Observational, quality improvement project ROB High Stage 1 | N=719 26% chronic conditions Ages: 14-16 years 67% 17- 18 years 30% 19-20 years 4% 55% Female 85% Hispanic | Transition planning training for care providers, Transition Policy, Tracking & Monitoring, Readiness Training sessions April 2018 through Aug 2018. | NA | Family health center (medical home) 24 months | Readiness and perception (Got Transition's 4 sample readiness assessment tools) | Readiness and perception (Got Transition's 4 sample readiness assessment tools) | NA |

Table E.3. Characteristics of studies included in evidence map: all conditions

| Study (PMID) | Condition | Program/Intervention | Target Population | Setting |
|-------------------------------------|-----------|--|-------------------|-------------------------------------|
| Lopez 2018 ²⁹ (30574573) | CHD | Prototype mobile app to facilitate transition | CSHCN | Pediatric Urology Hospital Dept. |

Abbreviations: CSHCN=children with special healthcare need; PMID=PubMed identification number; CHD=congenital heart disease

Appendix F. Study Sources for Barriers and Facilitators for Implementing Effective Interventions and Tools for Transition From Pediatric to Adult Medical Services

Table F.1. Study sources for barriers and facilitators

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|------------------------------|--|---|--|---|
| Intervention Characteristics | Optimal model and configuration for care transitions for children with special healthcare needs likely depend on the local population needs and demographics | <p>'Other clinics developing their own transition programmes will differ in the specificity of 'mini-interventions' needed to address barriers in transition' (Okumura 2014)³¹</p> <p>'Optimal model and configuration is thought to depend on local population demographics and needs, as well as the configuration of other related services (Moosa 2015)¹⁶¹</p> <p>'Centers' catchment area, patient volume, affiliation with adult medicine, and funding shaped LTF [long-term follow-up] arrangements...was an important logistical consideration' (Mouw 2017)¹⁶³</p> | Bring clinicians and managers together map the current state and create a shared vision for the future that includes new models or interventions | 'Bringing clinicians and managers together to map the current state and create a vision for the future.' (Moosa 2015) ¹⁶¹ |
| | No model of healthcare transition or group of services are consistently or widely used in pediatric services | <p>'No generally accepted guidelines to assure smooth transfer from paediatric to adult centres' (Okumura 2014)³¹</p> <p>There is no model of health care transition provision that is widely used in pediatric health care practices (Rast 2018)¹⁶⁴</p> | Interventions and tools should equip providers, particularly primary care providers, with additional support and resources to provide best practice care | 'Providers, especially patient navigators, expanding their knowledge base in an effort to provide answers to the most frequently asked questions on health insurance and survivorship care' (Sadak 2013) ¹⁶⁵ |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|--------|---|---|--|---|
| | Physicians and other healthcare providers lack time and resources to meaningfully participate in intervention implementation | <p>'Lack of time, lack of support from administration' (Mazurek 2020)¹⁶⁶</p> <p>'Main barriers were lack of time' (Peeters 2019)³²</p> | Interventions should be implemented alongside the streamlining of systems, processes and people to effectively implement transition practices and programs | <p>'Streamlining systems and processes' (Moosa 2015)¹⁶¹</p> <p>'Approximately half disengage from care while transitioning to adult clinics, in part due to fragmented care systems and lack of streamlined protocols' (Philbin 2017)¹⁶⁷</p> |
| | Single component or brief interventions may not provide the breadth and/or depth of training necessary to address a range of common medical, mental health, social and transition-related needs | <p>'We did not observe significant improvements in knowledge...as... it covered a wide range of topics relevant to understanding ASD and providing care for a range of common medical, mental health, and transition-related needs' (Mazurek 2020)¹⁶⁶</p> <p>'The workbook is just one component to the process of transition, and participants indicated they need more information, discussion, and overall preparedness to move on.' (Bashore 2016)¹</p> | Importance of adaptability of interventions, such as the need to implement appointment reminders to address changes to the volume and complexity of new healthcare appointments or varying the days/times of transition clinics and programs to accommodate patient preferences and need | <p>'Issues related to...clinic team composition, services offered and scheduling..[with]...survivors highly rating flexibility in scheduling for the decision to transition care' (Sadak 2013)¹⁶⁵</p> <p>'Make pre-visit appointment reminder welcoming new young adult' (Got Transitions)¹⁶⁸</p> |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|----------------|---|--|--|--|
| Outer Settings | As patients reach eligibility for transition, they are simultaneously experiencing complex social and medical challenges, such as issues with employment, income, insurance education, comorbid disease, and higher risk for mental health challenges (e.g., anxiety, depression) and substance abuse relative to children without special healthcare needs | <p>'Public insurance, as it's generally associated with higher rates of insurance loss and gaps' (Darbari 2019)¹⁰⁷</p> <p>'Increased hospitalization rates were associated with poor transition to adult care' (Darbari 2019)¹⁰⁷</p> <p>'Adding psychological services as a high priority due to the typical learning disabilities in individuals with SB' (Sawin 2014)¹³¹</p> <p>'Have higher rates of educational underachievement, lower employment status, in-creased risk of driving accidents and delinquency, and fewer friendships. Comorbid problems, such as anxiety, depression and substance misuse also persist from adolescence into adulthood or develop anew in adulthood' (Moosa 2015)¹⁶¹</p> <p>'Many transition-age youth (TAY) with ASD [autism spectrum disorder] present with complex medical, behavioral and sensory processing challenges' (Iannuzzi 2018)¹⁶⁹</p> | Developing and implementing initiatives to increase awareness of the importance of availability of social and medical services to support children with special healthcare needs across the lifespan | <p>Develop 'consultations focused on daily life, psychosocial risk, resilience and patients' knowledge about medication and adherence' (Skov 2018)³³</p> <p>'Educational efforts to increase awareness of the importance of HCTS [healthcare transitions and services] and the medical home could help compensate for the lack of specific knowledge' (Rast 2018)¹⁶⁴</p> |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|--------|--|---|--|---|
| | Many individuals are also reluctant to disclose their need for support to address these challenges | 'Many young adults with disabilities may not disclose their need for educational and vocational support.' (Bashore 2016) ¹ | Creating a comprehensive set of programs and social supports that address the wide range of social and emotional needs of CSHCN with capacity to engage with this population | 'Desire for a multi-disciplinary care team that offers care across multiple specialties and subspecialties' (Sadak 2013) ¹⁶⁵ |
| | Individuals experience significant changes in the availability of and their eligibility for resources and supportive services to facilitate transition | <p>'Need more resources/discussions in areas of employment, housing, independent living, obtaining adaptive equipment...' (Sawin 2014)¹³¹</p> <p>'Availability of ASD services and community supports declines sharply as individuals age out of the child and adolescent services system' (Mazureck 2020)¹⁶⁶</p> <p>Have a harder time during this transition because changes in eligibility for supportive services pose unique challenges. (Rast 2018)¹⁶⁴</p> | Importance of continued support and guidance from parents and pediatric healthcare professional, reducing feelings of abandonment through the process | <p>'Designated contact doctor and nurse known to the patient and guardians' (Skov 2018)³³</p> <p>'Participants said they would like the pediatric consultant to attend their first adult appointment to provide reassurance and help answer any questions the adult consultant had about the child medical history or care' (Hubbard 2016)¹²⁹</p> <p>'They require continuing support and guidance from their parents and health care professionals' (Moosa 2015)¹⁶¹</p> |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|--------|--|---|--|--|
| | Many community and social supports for CSHCN become unavailable as individuals age out of the child and adolescent services system | <p>'Thus to prepare for transfers, patients needed to be empowered to advocate for themselves, as well as access community resources and navigate insurance and unfamiliar organizations' (Mouw 2017)¹⁶³</p> <p>'Difficult to secure adequate and affordable insurance coverage after they age out of childhood plans' (Hess 2015)¹⁷⁰</p> | New strategies must be implemented to create adequate reimbursement and administrative models supportive of these task | 'Ideally, care coordination would be better reimbursed' (Mouw 2020) ¹⁶³ |
| | Perceptions of abandonment and disruption as transition from pediatric to adult services is proposed | <p>'Worry about separation from familiar paediatric providers' (Okumura 2014)³¹</p> <p>'Participants described the adult clinic as 'harsh' and 'dull' (Tong 2015)⁸⁵</p> | NA | NA |
| | Pediatric providers who are reluctant or unwilling to 'let go' of their children with special healthcare needs | <p>'But our brain tumor patients, who have all kinds of social and emotional and intellectual and hormonal and all those kinds of issues, you know, I'm scared to send them out when they're 30. I don't wanna send them.' (Mouw 2017)¹⁶³</p> <p>'Fear of 'letting go' because we do not trust the independence of the young person' (Remorino 2006)¹²⁰</p> | NA | NA |
| | Lack of external policies and incentives to encourage comprehensive transition services and interventions | <p>'Identified a lack of divisional transition policies' (Szalda 2019)⁹</p> <p>'Lack of clarity in access procedures, separate access policies' (Belling 2014)¹⁷¹</p> | NA | NA |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|---------------|---|---|---|--|
| | Lack of reimbursement and resources for transition medical services | <p>'Ideally, care coordination would be better reimbursed' (Mouw 2017)¹⁶³</p> <p>'Resource allocation for LTF varied across sites and was not entirely dictated by pediatric oncology volume. Some clinics were self-supported, others were supported by philanthropic or research grants, and some received direct funding from the cancer centers. Funding influenced staffing, particularly for those professionals who did not bill directly for services' (Mouw 2017)¹⁶³</p> <p>'Transition activities are currently not reimbursable' (Saulsberry 2019)¹⁰⁰</p> | NA | NA |
| Inner Setting | Overall lack of communication between pediatric and adult providers | 'Lack of communication between the two services' (Moosa 2015) ¹⁶¹ | Building a workforce of practitioners (e.g., family nurse practitioners) who are specifically trained to provide healthcare across the lifespan | 'Family nurse practitioners (FNPs) are specifically trained to provide healthcare services across the lifespan' (Iannuzzi 2018) ¹⁶⁹ |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|--------|---|---|--|---|
| | Lack of available internal resources to manage and coordinate the transition, lack of time to provide care coordination for transition and lack of administrative support | <p>'Difficulty coordinating medical appointments across multiple adult specialists and care settings" (Dale 2020)¹⁴²</p> <p>'Lack of teaching materials geared toward adolescents in providing developmentally appropriate care' (Hilderson 2016)⁷⁶</p> <p>'Lack of available resources for support through transition and into adulthood... including the inability to provide care coordination, lack of time,' (Rast 2018)¹⁶⁴</p> | Integration of content on caring for children with special healthcare needs within health profession training and continued professional education | 'The trends we observed lend support for the integration of [disease]-specific curriculum into educational programming for ...students to impact self-efficacy and knowledge' (Iannuzzi 2018) ¹⁶⁹ |
| | Dearth of available adult providers with expertise in caring for CSHCN | <p>'Lack of adult healthcare providers with adequate training or comfort in caring for patients..[with special healthcare needs]' (Mazurek 2020)¹⁶⁶</p> <p>'Lack of interest by adult care' (Shalaby 2015)¹⁵⁵</p> | Importance of creating a culture to sensitize clinicians to the medical needs of this population to reduce stigma | 'sensitize participants to the myriad medical needs of this population' (Rast 2018) ¹⁶⁴ |
| | Lack of follow-up from adult providers one a referral is made | <p>'Referrals... were often not being acknowledged by the receiving service and there was no follow-up by those who made the referral' (Moosa 2015)¹⁶¹</p> <p>'We never get back anything from the primary care provider. I mean I'm sure they're incredibly busy with droves of patients. So, that makes this kind of thing hard because we don't have any follow-up' (Mouw 2017)¹⁶³</p> | Increasing patient comfort with the clinical environment by creating a welcoming and inclusive space for care | <p>'Adolescent friendly environment and publicity' (Skov 2018)³³</p> <p>'Care should ideally be age-appropriate and reflect the desires for care of young adult[s]' (Sadak 2013)¹⁶⁵</p> |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|--------|--|---|--|--|
| | Patient anxiety while waiting for a transition to adult providers | 'Anxiety about leaving the pediatric team and adapting to adult services' (Hubbard 2016) ¹²⁹ | Enhancing communication strategies to accommodate needs and preferences of patients during the transition | <p>'Opportunities to speak directly with pediatric and adult health care providers during appointments' (Dale 2020)¹⁴²</p> <p>'Activities that enable understanding of health condition and build communication skills' (Dale 2020)¹⁴²</p> <p>'Joint pediatric-adult clinic visits, in order to be able to communicate health history and medical needs' (Dale 2020)¹⁴²</p> <p>'In order to develop patient independence families felt that young people needed more opportunities to see their pediatric consultant independently in the build-up to adult services' (Hubbard 2016)¹²⁹</p> |
| | Lost confidence in the transition to adult services by patients and pediatric providers who are then less likely to make referrals | 'Lack of referral to adult specialty providers' (Dale 2020) ¹⁴² | Creating processes and incentives to facilitate good information transfer between pediatric and adult teams as well as between specialists | <p>'Receipt of print informational resources detailing adult health services comprising the names and contact information of adult providers' (Dale 2020)¹⁴²</p> <p>'They specifically appreciated the transfer of documents, either delivered in person or electronically to the adult clinic' (Sawin 2015)¹³¹</p> <p>'Summary of current status, physical transfer of x-rays films, orientation to the new setting including background of the new HCP, and an explanation of how the new setting would be different' (Sawin 2015)¹³¹</p> <p>Optimal transition requires adequate transition planning, good information transfer across teams, joint working between teams and continuity of care following transition (Moosa 2015)¹⁶¹</p> |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|--------|--|--|-------------|-----------------------------------|
| | <p>Adult providers note that they lack available educational and training content focused on the healthcare needs of children with special healthcare needs</p> | <p>Providers 'unable, unwilling or not trained to provide care to young adults' (Sadak 2013)¹⁶⁵</p> <p>'The lack of educational content focused on the healthcare needs of individuals with ASD and other developmental disabilities within health professional education programs contributes to the low levels of self-efficacy reported by healthcare professionals' (Iannuzzi 2018)¹⁶⁹</p> | NA | NA |
| | <p>Adult models of care that cannot accommodate the influx of new CSHCN transitioning from pediatric services</p> | <p>'Lack of specialized and interested providers' (Saulsberry 2019)¹⁰⁰</p> <p>'A paucity of adult providers with the skills and/or interest to care for...'</p> <p>(Rodgers-Melnick 2019)⁹⁹</p> | NA | NA |
| | <p>Lack of sensitivity about special healthcare needs (e.g., autism) among adult providers, leading to a lack of trust by patients for the provider to effectively care for their healthcare needs</p> | <p>'Sensitivity to the dynamics of chronic illness management through adolescence' (Okumura 2014)³¹</p> <p>'Should include comprehensive culturally competent care' (Rast 2018)¹⁶⁴</p> | NA | NA |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|-----------------------------------|---|--|--|---|
| Characteristics of the Individual | Self-efficacy to engage in the transition process including. Patients/caregivers feel uncertain about where to find appropriate healthcare services, feel overwhelmed by the steps to seek services and lack comprehensive information about the healthcare transition process. | 'Not sure they can do their treatments...Not sure how to contact their providers' (Okumura 2014) ³¹ 'Knowledge gaps in the area of independent living and health benefit skills sets' (Sobota 2014) ¹¹⁰ 'Establishing effective communication patterns with new providers' (Sawin 2014) ¹³¹ | Create opportunities for dedicated training prior to the transition that include discussion of medical histories, navigating adult-oriented clinics and how to choose community providers and services | "Dedicated time for talking about patients' medical histories, navigating adult-oriented clinics and choosing community providers" (Mouw 2017) ¹⁶³ |
| | Providers lack of knowledge about available community and healthcare resources to support transitions | 'Lack of knowledge among health service providers about what constitutes culturally appropriate services' (Henderson 2011) ¹⁷² 'Lack of training' (Seybolt 2014) ¹⁷³ | Implementing training around the unique needs and preferences of children with special healthcare needs can improve self-efficacy and improve their confidence in providing care | 'Needs for validation, recognition, autonomy support and stability (e.g., being followed by the same clinicians)' (Michaud 2019) ¹²¹ 'Methods to help young people remember to take medications consistently are frequently discussed among other components of medication management' (Hubbard 2016) ¹²⁹ 'Tour of the adult hospital with both their pediatric and adult providers before transfer, as they felt this would give them more confidence about moving to a new environment' (Hubbard 2016) ¹²⁹ |
| | Clinicians note a lack of training and education about the medical needs of this population, when and how to refer to specialists and available resources to support referral | The lack of specific knowledge of ASD [autism spectrum disorder] on the part of the provider (including ASD services and community resources) are all barriers. (Rast 2018) ¹⁶⁴ | NA | NA |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|---------|---|--|---|---|
| | Adult providers feel ill-prepared to manage the transition from pediatric to adult services due to the lack of a clear process to move CSHCN to adult services as well as incomplete transfer of information regarding past treatments in the pediatric setting and future risks of the condition | 'Behavioral struggles of young patients and may not be prepared to provide a multidisciplinary approach' (Hill 2019) ⁸⁶ | NA | NA |
| Process | Lack of clear, detailed protocols for transitioning from pediatric to adult services. | 'Produce a transition service where each process step links seamlessly to the next' (Moosa 2015) ¹⁶¹ 'Importance of a purposeful planned transition process' (Prestidge 2012) ¹²³ | Appointment of formal internal implementation leaders or champions to answer questions, ensure protocols are implemented correctly and serve as a support or encouragement for those considering implementing the intervention | 'Physician champions provided the opportunity to address the transition process..[with] inherent buy-in created by responsibility for assessing and improving process' (Okumura 2014) ³¹ |
| | Providers and organizations adapt and change due to other external and internal factors, processes may necessarily become outdated | 'A transition protocol between the two services was in existence but was outdated.' (Moosa 2015) ¹⁶¹ | Ensuring ready access to transition protocols, medical and social documents to all providers who care for children with special healthcare needs (with considerations for technology or tools that can cross health systems and electronic medical records) | 'Review current systems, protocols and processes' (Moosa 2015) ¹⁶¹ |

| Domain | Barrier | Barrier Study Text and Source | Facilitator | Facilitator Study Text and Source |
|--------|---|---|--|---|
| | Challenges with missing or inadequate information for patients and providers to successfully transition from pediatric services (e.g., incomplete treatment history or transition planning documents) | 'Information about their childhood cancer diagnosis and treatment is often missing or minimized in health documents' (Meacham 2014) ¹⁶² | Process for transition must ensure adequate time for facilitated preparation and planning between providers and patients | 'Transition planning meetings were held between the transition team' (Moosa 2015) ¹⁶¹ 'Coordinating with providers outside their systems through faxed documents and phone calls required time and effort.' (Mouw 2017) ¹⁶³ Visit adult centers, meet adult providers, and then having the opportunity to talk about their experience and work out issues in transition may be helpful in their successful transition (Bashore 2016) ¹ |
| | Backlog of individuals transitioning to adult services due to limited capacity among adult providers | 'The goals were to clear the backlog' (Moosa 2015) ¹⁶¹ 'Institutions' capacities are strained by the number of childhood cancer survivors' (Mouw 2017) ¹⁶³ 'Lack of specialized providers' (Allemang 2019) ¹⁰¹ | NA | NA |

Abbreviations: NA=not applicable

Appendix G. Measures Used To Evaluate the Effectiveness of Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs

Table G.1. Measure used to evaluate effectiveness

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|---|--|--------------------|---|---|-----------------------------|
| TR | Worry | 5-point Likert type scale to assess worry in general and worry about leaving pediatrics | General | Unknown | Transition Readiness | Patient | Bashore 2016 ¹ |
| TR | Transition Readiness | 5-point Likert type scale to assess readiness to transition and readiness to make changes | General | Unknown | Transition Readiness | Patient | Bashore 2016 ¹ |
| TR | Familiarity with Cancer Survivorship Care and Guidelines | 5-point Likert type scale to assess familiarity with cancer survivor care, survivor healthcare plans, and the Children's Oncology Group Long-Term Follow-Up Guidelines | Disease Specific-Cancer | Unknown | Transition Readiness/Ongoing Care | Provider | Meacham 2014 ¹⁶² |
| TR | Current Practice and Comfort in Providing Cancer Survivorship Care | 5-point Likert type scale to assess current practice and comfort with providing cancer survivor care | Disease Specific-Cancer | Unknown | Transition Readiness/Ongoing Care | Provider | Meacham 2014 ¹⁶² |
| TR | Program Process | Count of the number of divisions/individuals identified as transition champions, drafted transition policies, use electronic medical record based transition support tools and have clinical pathways | General | Unknown | Transition and Care Policy/Guide , Transition Readiness | Provider | Szalda 2019 ⁹ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|---|--|--------------------|---------------------------------------|---|---|
| TR | Test of Functional Health Literacy in Adults | Provides information on both reading comprehension and numerical ability to indicate health literacy | General | Yes | All | Patient | Huang 2014 ¹³ |
| TR | Readiness for Transition Questionnaire (RTQ) | 22-item survey assessing readiness and independence | General | Yes | Transition readiness | Patient and Caregiver | Shapiro 2020 ¹²⁷ |
| TR | Transition Readiness Assessment Questionnaire (TRAQ) | Measure of readiness for transition and assesses performance of chronic disease self-management skills using a Likert scale | General | Yes | Transition readiness | Patient | Huang 2014 ¹³ Mackie 2014 ²⁵ Mackie 2018 ²⁴ Okumura 2014 ³¹ Gray 2019 ⁶⁴ Seeley 2017 ¹³⁰ Saulsberry 2019 ¹⁰⁰ Anton 2019 ¹¹⁵ Grady 2018 ¹¹⁸ Dale 2020 ¹⁴² |
| TR | Patient Activation | Gauges participants' self-efficacy and confidence in managing one's own health and health care on a scale of 0 to 100 | General | Yes | Transition Readiness/ Ongoing Care | Patient | Huang 2014 ¹³ |
| TR | Got Transition's Current Assessment of Healthcare Transition Activities | Self-assessment tool that allows practices to rank their level of implementation in each core element domain for the Six Core Elements of Healthcare Transition | General | Yes | All | Provider | Jones 2019 ¹⁷⁴ |
| TR | Comprehensive Heart Disease Knowledge Questionnaire | Evaluates degree of knowledge of heart disease regarding their clinical condition; also investigates the patient's willingness to talk about their condition with parents and friends | Disease specific- Congenital Heart Disease | Yes | Transition Readiness/Ongoing care | Patient | Flocco 2019 ²² |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|--|--|--------------------|-----------------------------------|---|--|
| TR | Congenital Heart Disease (MyHeart) Scale | Consists of seven short answer and multiple-choice questions to assess individual knowledge of their heart condition | Disease specific-Congenital Heart Disease | Yes | Transition Readiness/Ongoing care | Patient | Mackie, 2014 ²⁵ Mackie, 2018 ²⁴ |
| TR | Partners in Health Scale | 12-item scale to assess chronic disease self-management | General | Yes | Transition Readiness/Ongoing care | Patient | Peeters, 2019 ³² Sattoe, 2020 ⁶⁶ |
| TR | Independent Behaviors During Consultations | 7-item scale to assess self-reported independent behaviors during consultations with healthcare providers | General | Yes | Transition Readiness/Ongoing care | Patient | Peeters, 2019 ³² Sattoe, 2020 ⁶⁶ |
| TR | On Your Own Feet Self-Efficacy Scale (OYOF-SES) | Assesses disease-related self-efficacy on four domains: (1) knowledge about the condition, (2) coping, (3) competencies during consultations, and (4) medication | General | Yes | Transition Readiness/Ongoing care | Patient | Peeters, 2019 ³² Sattoe, 2020 ⁶⁶ |
| TR | Diabetes Empowerment Scale- Short Form | 8-item measure of diabetes self-efficacy | Disease specific-diabetes | Yes | Transition Readiness/Ongoing care | Patient | Pyatak 2017 ⁵⁴ |
| TR | Patient Activation Measure (PAM) | 13-item measure to assess knowledge, skills and confidence in chronic disease self-management | General | Yes | Transition Readiness/Ongoing care | Patient | Dingemann 2017 ¹⁴⁴ Schmidt 2016 ¹⁴¹ Disabato 2015 ¹⁵⁹ |
| TR | Knowledge of HIV infection | Six multiple choice questions to awareness of HIV transmission and importance of treatment | Disease specific-HIV | Unknown | Transition Readiness/Ongoing care | Patient | Continisio 2020 ⁶⁰ |
| TR | Modified Patient Knowledge Questionnaire | Measures illness related knowledge | General | Yes | Transition Readiness/Ongoing care | Patient | Hilderson 2016 ⁷⁶ |
| TR | Promotion Independence Scale (PI) | Scale to evaluate reported promotion of independence | General | Yes | Transition Readiness/Ongoing care | Caregiver | Hilderson 2016 ⁷⁶ |
| TR | Autonomy Support Scale (PVF) | Scale to evaluate reported support more autonomy | General | Yes | Transition Readiness/Ongoing care | Caregiver | Hilderson 2016 ⁷⁶ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|--|--|--------------------|-----------------------------------|---|---|
| TR | Parental Regulation and Psychological Control Scale (PRS-YSR revised to parent self-report) | Scale to evaluate reported behavioral and psychological control | General | Yes | Transition Readiness/Ongoing care | Caregiver | Hilderson 2016 ⁷⁶ |
| TR | Arthritis related Knowledge | 16-item disease specific multidimensional measure | Disease specific-JIA | Unknown | Transition Readiness/Ongoing care | Patient/Caregiver | McDonagh 2007 ⁷⁸ |
| TR | Danish Readiness Checklist | 23 questions to address ability to tell others about cystic fibrosis, understand the course of their illness to date, ability to make medical appointments and whether they can make medical appointments or pick up prescriptions | Disease specific-cystic fibrosis | Unknown | Transition Readiness/Ongoing care | Patient | Skov 2018 ³³ |
| TR | Transition to Adult Care Concerns Questionnaire (TTACC) | 15-item questionnaire to rate level of concern about different aspects of adult care | General | Unknown | Transition Readiness | Patient | Craig 2007 ³⁴ |
| TR | Generalized Self-Efficacy | 10 item scale to measure perceived self-efficacy | General | Yes | Transition Readiness | Patient | Scaldaferri 2020 ⁶⁸ Schmidt 2016 ¹⁴¹ |
| TR | CD-RISC | 25 item scale used to assess resilience | General | Yes | Transition Readiness | Patient | Scaldaferri 2020 ⁶⁸ |
| TR | Arthritis disease related knowledge | 16-item disease specific multidimensional measure to assess arthritis knowledge | Disease Specific-JIA | Unknown | Transition Readiness | Patient | Shaw 2007 ¹⁷⁵ |
| TR | University of North Carolina TRANSITION Scale | Health care provider-administered questionnaire that measure healthcare transition and self-management skills in youth and young adults with chronic disease | General | Yes | Transition Readiness | Patient | Hill 2019 ⁸⁶ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|--|--|--------------------|------------------------|---|--|
| TR | Adolescent Autonomy Checklist (AAC) | 100-item measure to assess the skill level of adolescents in completing activities necessary for self-care and independent living | General | Yes | Transition Readiness | Patient | Calhoun 2019 ⁹⁷ |
| TR | Sickle Cell Disease (SCD) Knowledge Quiz | 12-question multiple-choice measure of the patient's knowledge of SCD | Disease Specific-Sickle Cell Disease | Unknown | Transition Readiness | Patient | Smith 2011 ⁹⁸ Saulsberry 2019 ¹⁰⁰ |
| TR | Sickle Cell Transfer Questionnaire (SCTQ) | Checklist of 15 potential concerns about transitioning to adult care for patients with SCD | Disease Specific-Sickle Cell Disease | Unknown | Transition Readiness | Patient | Smith 2011 ⁹⁸ |
| TR | Sickle Cell Self-Efficacy Scale (SCSES) | 9-item Likert scale developed for adults with SCD to measure self-efficacy | Disease Specific-Sickle Cell Disease | Yes | Transition Readiness | Patient | Rodgers-Melnick 2019 ⁹⁹ |
| TR | Seidman Sickle Cell Knowledge Quiz | 12-item multiple choice test evaluating knowledge of disease | Disease Specific-Sickle Cell Disease | Unknown | Transition Readiness | Patient | Rodgers-Melnick 2019 ⁹⁹ |
| TR | Developmentally Based Skills Checklist | General checklist of skills that adolescents with a special healthcare need should progressively master | General | Yes | Transition Readiness | Patient | Annunziato 2013 ¹¹³ |
| TR | Medical Condition and Medication Knowledge Questionnaire | Assesses participant medical knowledge, medication knowledge, medication adherence and self-reported confidence in readiness to transition | General | Unknown | Transition Readiness | Patient | Anton 2019 ¹¹⁵ |
| TR | Social Support Index (SSI) | Assesses social support (emotional and tangible) and overall support | General | Yes | All | Patient | Grady 2018 ¹¹⁸ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|---|--|--------------------|------------------------|---|----------------------------------|
| TR | Heart Transplant Knowledge Questionnaire | 20-item questionnaire assessing knowledge of medications, appointment keeping, healthy lifestyle, benefits and risks of heart transplant and transition to adult care | Disease specific-solid organ transplant | Yes | Transition Readiness | Patient | Grady 2018 ¹¹⁸ |
| TR | Haemophilia Knowledge Questionnaire | 20-item questionnaire measuring disease-specific knowledge | Disease specific-Haemophilia | Unknown | Transition Readiness | Patient | Breakey 2014 ¹⁴⁵ |
| TR | Transition Readiness Skills Survey (TRS) | Assesses self-management skills, regimen knowledge and psychosocial adjustment | General | Yes | Transition Readiness | Patient | Fredericks 2015 ¹¹⁹ |
| TR | Health-related transition competence scale (TCS) | 10-item scale assessing self-management and competence | General | Yes | All | Patient | Schmidt 2016 ¹⁴¹ |
| TR | Perceived Competence for Diabetes Scale (PCDS) | 4-item scale measuring perceived ability to manage Diabetes | Disease Specific-Diabetes | Unknown | Transition Readiness | Caregiver | Allen 2012 ¹⁷⁶ |
| TR | Adaptive Behavior Assessment Scale-II (ABAS-II) | Assesses perceived skills and abilities | General | Unknown | Transition Readiness | Caregiver | Murdaugh 2019 ⁸⁹ |
| TR | IBD-Yourself | IBD knowledge and self-efficacy | Disease-specific IBD | Yes | All | Patient | van den Brink 2019 ⁷⁰ |
| TR | Health Care Climate Questionnaire (HCCQ) | 15-item instrument to assess patient perceptions that their doctor is autonomy supportive | General | Yes | Transition Readiness | Patient | Michaud 2019 ¹²¹ |
| TR | Treatment Self-Regulation Questionnaire | Scale to assess autonomous self-regulation | General | Yes | Transition Readiness | Patient | Michaud 2019 ¹²¹ |
| TR | Perceived Competence Scale | 4-item questionnaire to assess participants feelings of competence | General | Yes | Transition Readiness | Patient | Michaud 2019 ¹²¹ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|--|--|--------------------|------------------------|---|---|
| QOL | EQ-5D Health Questionnaire | Designed to elucidate patient's quality of life according to the following domains: mobility, self-care, daily activities, pain/discomfort and anxiety/depression | General | Yes | All | Patient | Flocco, 2019 ²² |
| QOL | Satisfaction with Life Scale Child Version (SWLS-C) | Five-item self-report questionnaire to assess life satisfaction in childhood | General | Yes | All | Patient | Flocco 2019 ²² Pyatak 2014 ⁵¹ |
| QOL | Linear Analog Scale for Quality of Life | Vertically oriented ruler ranging from worst imaginable quality of life to best imaginable quality of life | General | Yes | All | Patient | Flocco 2019 ²² Hilderson 2016 ⁷⁶ |
| QOL | Pediatric Quality of Life Inventory (PedsQL) | 23-item scale to assess Health-related quality of life on four domains: (1)physical, (2) emotional, (3) social, and (4) school/work Note: different modules used across studies | General | Yes | All | Patient | Flocco2019 ²² Sattoe 2020 ⁶⁶ Hilderson 2016 ⁷⁶ |
| QOL | Diabetes Quality of Life-Youth | Measures quality of life issues relevant to adolescents and young adults with diabetes including disease-related worries, life satisfaction and disease impact | Disease Specific-Diabetes | Yes | All | Patient | Levy-Shraga 2016 ⁵⁶ Spaic 2019 ⁴⁷ Allen 2012 ¹⁷⁶ |
| QOL | Juvenile Arthritis Quality of Life Questionnaire (JAQQ) | 74 item assessment of quality of life across four dimensions: gross motor function, psychosocial function, fine motor function and systematic symptoms | Disease specific-JIA | Yes | All | Patient | McDonagh 2007 ⁷⁸ Shaw 2007 ¹⁷⁵ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|---|--|--------------------|------------------------|---|--|
| QOL | Cystic Fibrosis Questionnaire-revised teen/adult version | Measures 12 domains of functioning with a total of 50 items to measure health-related quality of life | Disease specific-cystic fibrosis | Yes | All | Patient | Skov 2018 ³³ Craig 2007 ³⁴ |
| QOL | Inflammatory Bowel Disease Questionnaire (IBDQ) | 32 items that explore four dimensions of quality of life for patients with inflammatory bowel disease | Disease Specific-IBD | Yes | All | Patient | Scaldaferri 2020 ⁶⁸ Schutz 2019 ⁶⁹ |
| QOL | Kidney Disease Quality of Life (KDQOL) | 36-item multidimensional quality of life measure for kidney disease | Disease specific-kidney disease | Yes | All | Patient | Tong 2015 ⁸⁵ |
| QOL | Time trade off (TTO) | Instrument used to assess quality of life to compare how much life expectancy a respondent would be willing to give up in exchange for perfect health | General | Yes | All | Patient | Tong 2015 ⁸⁵ |
| QOL | Short Form Health Survey (SF12, SF36) | questionnaire that evaluates health related quality of life | General | Yes | All | Patient | Annunziato 2013 ¹¹³ Allen 2012 ¹⁷⁶ Michaud 2019 ¹²¹ |
| QOL | World Health Organization Quality of Life Assessment (WHO-QOL-100) | 100-items measuring 6 domains of quality of life (physical health, psychological health, level of independence, social relationships, environment and spirituality/personal belief) | General | Yes | All | Patient | Witvliet 2017 ¹³⁸ |
| QOL | EUROHIS QOL-8 | 8 items measuring generic health-related QOL | General | Yes | All | Patient | Schmidt 2016 ¹⁴¹ |
| QOL | DISABKIDS Chronic Generic Measure-37 | 37 items measuring independence, emotion, inclusion, exclusion, physical limitations, and treatment | General | Yes | All | Patient | Dingemann 2017 ¹⁴⁴ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|--|--|--------------------|-------------------------------|---|--|
| QOL | Canadian Haemophilia Outcomes – Kid's Life Assessment Tool (CHO-KLAT) | 35-item tool measuring health-related quality of life | Disease specific-Haemophilia | Yes | All | Patient | Breakey 2014 ¹⁴⁵ |
| MT | Mortality | Death, measured at various time-points relative to transition | General | Unknown | All | Patient | Kosoloa 2019 ¹¹² Fredericks 2015 ¹¹⁹ Pape 2013 ¹¹⁶ Prestidge 2012 ¹²³ |
| MB | Visual Analog Scale (VAS)-general health | Self-reported health on a vertical visual analog scale during the last day | General | Yes | All | Patient | Flocco 2019 ²² Scaldaferrì 2020 ⁶⁸ Tong 2015 ⁸⁵ |
| CO | New York Heart Association Functional Classification of Heart Failure | Functional classification of heart failure status | Disease specific-Congenital Heart Disease | Yes | All | Patient | Hergenroeder 2018 ²³ |
| CO | Body Mass Index (BMI) | Differences in body mass index across time | General | Unknown | Transfer of Care/Ongoing Care | Patient | Okumura 2014 ³¹ Peeters 2019 ³² Levy-Shraga 2016 ⁵⁶ Skov 2018 ³³ Craig 2007 ³⁴ Testa 2019 ⁶⁷ Schutz 2019 ⁶⁹ |
| CO | Pulmonary Functioning | Change in pulmonary functioning (forced expiratory volume (FEV1)) over time and forced vital capacity | Disease specific-Cystic Fibrosis | Yes | Transfer of Care/Ongoing Care | Patient | Peeters 2019 ³² Skov 2018 ³³ Craig 2007 ³⁴ |
| CO | Acute pulmonary exacerbations | Use of antibiotics (yes/no), frequency over time | Disease specific-Cystic Fibrosis | Yes | Transfer of Care/Ongoing Care | Patient | Peeters 2019 ³² |
| CO | HbA1c | Measure of how well controlled your blood sugar is over a period of time, measured at various time points across studies | Disease specific-diabetes | Yes | Transfer of Care/Ongoing Care | Patient | Cadario 2009 Weigensberg 2018 Sequeira 2015 Levy-Shraga 2006 Pyatak 2017 |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|-----------------------------------|---|--|--------------------|-------------------------------|---|---|
| CO | Severe Hypoglycemia | Requiring assistance and/or change in mental status, evaluated at varying time-points throughout studies | Disease specific-diabetes | Yes | Transfer of Care/Ongoing Care | Patient | Cadario 2009 Weigensberg ²⁰¹⁸ Sequeira 2015 Levy-Shraga 2016 Pyatak 2017 Van Wallenghem 2008 |
| CO | HIV Viral Load | HIV RNA measured as the number of HIV copies/ml of blood | Disease specific-HIV | Yes | Transfer of Care/Ongoing Care | Patient | Continisio 2020 ⁶⁰ |
| CO | CD4+ Count | Number of CD4+ cells/mm ³ of blood | Disease specific-HIV | Yes | Transfer of Care/Ongoing Care | Patient | Continisio 2020 ⁶⁰ |
| CO | Physician Global Assessment (PGA) | Physician-based categorization of clinical disease activity (i.e., quiescent, mild, moderate or severe disease) | General | Yes | Transfer of Care/Ongoing Care | Patient | Gray 2019 ⁶⁴ Shaw 2007 ¹⁷⁵ |
| CO | Laboratory Panel | Laboratory values for at least one: hemoglobin (Hb), hematocrit (Htc), C-reactive-protein (CRP), albumin, platelet counts (PLT) and erythrocyte sedimentation rate (ESR), blood urea nitrogen (BUN), Creatinine, tacrolimus, cyclosporine, bilirubin aspartate aminotransferase (AST), alanine aminotransferase (ALT) | General and Disease specific (tests varied by study) | Yes | Transfer of Care/Ongoing Care | Patient | Otto 2019 ⁶⁵ Shaw 2007 ¹⁷⁵ Hill 2019 ⁸⁶ Annunziato 2015 ¹¹⁴ Fredericks 2015 ¹¹⁹ Pape 2013 ¹¹⁶ Remorino 2006 ¹²⁰ Prestidge 2012 ¹²³ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|--|--|--------------------|-------------------------------|---|--|
| CO | Disease Activity During Transfer | Measured by global physician assessment in four categories (remission, mild, moderate and severe) dichotomised as being active (moderate or severe) or not (remission or mild) | Disease Specific-IBD | Unknown | Transfer of Care/Ongoing Care | Patient | Sattoe 2020 ⁶⁶ |
| CO | Crohn's Disease Activity Index (wPCDAI), | Measures disease activity for Crohn's Disease | Disease Specific-IBD | Unknown | Transfer of Care/Ongoing Care | Patient | Sattoe 2020 ⁶⁶ Testa 2019 ⁶⁷ |
| CO | Paediatric Ulcerative Colitis Activity Index (PUCAI) | Measures disease activity for Crohn's Disease | Disease Specific-IBD | Unknown | Transfer of Care/Ongoing Care | Patient | Sattoe 2020 ⁶⁶ Testa 2019 ⁶⁷ |
| CO | Partial MAYO Score (pMAYO) | Measures disease activity for Crohn's Disease | Disease Specific-IBD | Unknown | Transfer of Care/Ongoing Care | Patient | Testa 2019 ⁶⁷ |
| CO | Relapse | Defined as whether young people had a <i>relapse</i> in the year before transfer or after transfer | Disease Specific-IBD | Unknown | Transfer of Care/Ongoing Care | Patient | Sattoe 2020 ⁶⁶ |
| CO | Multidimensional Fatigue Inventory (MFI-20) | Inventory to assess degree of fatigue | General | Yes | Transfer of Care/Ongoing Care | Patient | Hilderson 2016 ⁷⁶ |
| CO | Childhood Health Assessment Questionnaire (CHAQ) | Assesses functional status from good to poor | General | Yes | Transfer of Care/Ongoing Care | Patient | Hilderson 2016 ⁷⁶ Shaw 2007 ¹⁷⁵ Relas 2019 ⁸² |
| CO | Deteriorating Kidney Function | Defined as increase in serum creatinine concentration of over 50% | Disease Specific-Solid Organ Transplant | Unknown | Transfer of Care/Ongoing Care | Patient | Kosola 2019 ¹¹² |
| CO | Paris Classification of Ulcerative Colitis | Extension of inflammation and disease severity evaluation for ulcerative colitis | Disease Specific-IBD | Yes | Transfer of Care/Ongoing Care | Patient | Schutz 2019 ⁶⁹ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|--|--|--------------------|--------------------------------|---|--|
| CO | Estimated Glomerular Filtration Rate (eGFR) | Measures level of kidney function | Disease specific-kidney disease | Yes | Transfer of Care/Ongoing Care | Patient | Weitz 2015 ¹²⁶ McQuillan 2015 ¹²⁵ |
| CO | Acute Rejection | Rejection of a transplanted organ | Disease specific-solid organ transplant | Unknown | Transfer of Care/Ongoing Care | Patient | Weitz 2015 ¹²⁶ Harden 2012 ¹²⁴ Pape 2013 ¹¹⁶ Remorino 2006 ¹²⁰ Prestidge 2012 ¹²³ |
| HBWS | Hospital Anxiety and Depression Scale | 14 items exploring depression and anxiety in the last two weeks | General | Yes | All | Patient | Scaldaferri 2020 ⁶⁸ |
| HBWS | Smoking | Assessment of smoking status | General | Unknown | All | Patient | Testa 2019 ⁶⁷ |
| TCA | Receipt of Healthcare Transitions Services | Receipt of 4 Adolescent Health Measurement Initiative indicators for HCTS receipt including: 1) discussing the switch to a doctor who treats adults if necessary, 2) discussing changing health care needs as an adult, 3) planning how to get or keep insurance coverage as an adult, and 4) encouragement by the doctor for the child to take age-appropriate responsibility for his/her health. | General | Unknown | Transition Readiness/ Planning | Patient | Rast, 2018 ¹⁶⁴ |
| TCA | Number of healthcare visits at a specialty clinic | Number of routine diabetes clinic visits, including both pediatric and adult (Sequeira 2015) Number of visits over a 12 month visit where hemoglobin A1c was taken (Pyatak 2017) | General | Unknown | Transfer of Care/Ongoing Care | Patient | Sequeira 2015 ⁴⁶ Pyatak 2017 ⁵⁴ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|--|--|--------------------|-------------------------------|---|---|
| TCA | Medication adherence | Adherence to prescribed medications as reported by patient to the provider | General | Unknown | Transfer of Care/Ongoing Care | Patient | Allemang 2019 ¹⁰¹ Annunziato 2013 ¹¹³ Annunziato 2015 ¹¹⁴ Anton 2019 ¹¹⁵ Fredericks 2015 ¹¹⁹ Le Marne 2019 ¹⁵⁷ Pape 2013 ¹¹⁶ |
| TCA | Basel Assessment of Adherence to Immunosuppressive Medications | Self-reported scale to measure adherence in transplantation | Disease specific-solid organ transplant | Yes | Transfer of Care/Ongoing Care | Patient | Michaud 2019 ¹²¹ |
| TCA | SWISS HIV Cohort Study Adherence Questionnaire (SHCS-AQ) | Evaluates medication adherence as adherent or non-adherent | General | Yes | Transfer of Care/Ongoing Care | Patient | Hilderson 2016 ⁷⁶ |
| TCA | Adherence to Medications to manage IBD | Use of disease specific medications such as: aminosalicylates, corticosteroids; immunomodulators; biologicals/biosimilar, nutritional therapy, mesalazine, steroids, azathioprine, methotrexate, 5ASA, thiopurines, anti-TNF | Disease Specific-IBD | Unknown | Transfer of Care/Ongoing Care | Patient | Sattoe 2020 ⁶⁶ Testa 2019 ⁶⁷ Schutz 2019 ⁶⁹ Cole 2015 ⁷¹ Fu 2017 ⁷² |
| TCA | Medication Adherence Rating Scale (MARS-5) | 5-item scale to assess self-reported adherence to medical treatment | General | Yes | Transfer of Care/Ongoing Care | Patient | Peeters 2019 ³² Sattoe 2020 ⁶⁶ |
| TCA | Use of recommended resources and referrals | Nurse documented use of recommended transition resources and referrals | General | Unknown | Transfer of Care/Ongoing Care | Patient | Seeley 2017 ¹³⁰ |
| TCA | Medication Adherence Questionnaire (MAQ) | Assesses self-reported medication adherence | General | Yes | Transfer of Care/Ongoing Care | Patient | Tong 2015 ⁸⁵ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|---|--|--------------------|-------------------------------|---|--|
| TCA | Patient Assessment of Problems with the Heart Transplant Regimen | Measures adherence to 15 components of the heart transplant medical regimen | Disease specific-solid organ transplant | Yes | Transfer of care/ongoing care | Patient | Grady 2018 ¹¹⁸ |
| TCA | Non-adherent behavior | Composite measure of self-reported medication non-adherence, non-attendance at clinic, non-attendance for blood work visits, or undetectable calcineurin inhibitor levels | Disease specific-solid organ transplant | Unknown | Transfer of care/ongoing care | Patient | McQuillan 2015 ¹²⁵ |
| TCA | Transition Yourself Score | Composite of adherence to visits at the gastroenterology outpatient clinic, adherence to medication and qualitative evaluation of transition by the patient | Disease-specific IBD | Unknown | Transfer of care/ongoing care | Patient | van den Brink 2019 ⁷⁰ |
| EC | Waiting Time from Pediatric to Adult Services | Waiting time for transition from pediatric to adult services | General | Unknown | Transfer of Care | Patient | Moosa 2015 ¹⁶¹ |
| EC | Lost to Follow-up/Drop out | Percentage of individuals who were lost to transition services or dropped out of the program, measured in various ways | General | Unknown | Ongoing Care | Patient | Moosa 2015 ¹⁶¹ Van Wallanghem 2008 ⁵³ Allemang 2019 ¹⁰¹ |
| EC | Patient-Initiated Health Care Communications | Frequency and mode of communication between adolescents and the healthcare system | General | Unknown | All | Patient | Huang 2014 ¹³ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|--|--|--------------------|-------------------------------|---|---|
| EC | Time between last pediatric and first adult care visit (Actual and Recommended) | Number of months/days between the last pediatric visit and first adult visit (actual number of months and recommended number of months), slight variations in measurement across studies | General | Unknown | Transfer of Care | Patient | Hergenroeder 2018 ²³ Cadario 2009 ⁴⁵ Disabato 2015 ¹⁵⁹ |
| EC | Excess time between pediatric and adult care | Time interval (in months) between the final pediatric visit and the first adult visit, minus the recommended time interval. Recommended time interval was defined as the interval suggested by the specialist at the final pediatric visit | General | Unknown | Transfer of Care | Patient | Mackie 2018 ²⁴ |
| EC | No-show at first appointment in adult care | Indicator of whether someone no-showed for their first appointment in adult care (yes/no) | General | Unknown | Transfer of Care | Patient | Peeters 2019 ³² |
| EC | Scheduled Consultation | Number of scheduled consultations with adult providers per year | General | Unknown | Transfer of Care | Patient | Peeters 2019 ³² |
| EC | Entry into adult services | Percentage of eligible patients who have entered or 'successfully transitioned' into adult services, with slight variations in definitions across studies | General | Unknown | Transfer of Care | Patient | Cadario 2009 ⁴⁵ Jensen 2015 ⁹¹ |
| EC | Visit Attendance | Attending a threshold of disease specific visits per year | General | Unknown | Transfer of Care/Ongoing Care | Patient | Downing 2013 ¹⁴³ Levy-Shraga 2016 ⁵⁶ Cole 2015 ⁷¹ Fredericks 2015 ¹¹⁹ White 2017 ⁴⁴ Spaic 2019 ⁴⁷ Butalia 2020 ¹⁷⁷ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|---|--|--------------------|-------------------------------|---|---|
| EC | Social Work Referral | Indicator of whether an order has been placed for a transition social work consultation | General | Unknown | Transfer of Care | Provider | Disabato 2015 ¹⁵⁹ |
| EC | Cystic Fibrosis Transition Questionnaire (CFTQ) | Assesses post-transition patient's participation in each step of the transition program | General | Unknown | Transfer of Care | Patient | Craig 2007 ³⁴ |
| EC | Successful Transition | Completion of three meetings in a transition clinic | General | Unknown | Transfer of Care | Patient | Scaldafeeri 2020 ⁶⁸ |
| EC | Beliefs about Medicine Questionnaire (BMQ) | 17-question tool evaluating patient opinions on medical therapy | General | Yes | All | Patient | Fu 2017 ⁷² |
| EC | Wake Forest Trust in the Medical Profession Scale | 5-item scale evaluating trust in their doctors and medical professionals | General | Yes | Transfer of Care/Ongoing Care | Patient | Rodgers-Melnick 2019 ⁹⁹ |
| EC | Adherence to Recommended Care | Extent to which individual's behavior coincides with medical or prescribed health advice | General | Unknown | Transfer of Care/Ongoing Care | Patient | Rodgers-Melnick 2019 ⁹⁹ |
| SEC | Client Satisfaction Questionnaire (ZUF-8) | 8 items measuring satisfaction with the program | General | Yes | All | Patient | Dingemann 2017 ¹⁴⁴ Spaic 2019 ⁴⁷ |
| SEC | Satisfaction with Health Care (CHS-SUN) | 41-items measuring provision and satisfaction with care | General | Yes | All | Patient | Schmidt 2016 ¹⁴¹ |
| SEC | Patient Assessment of Chronic Illness Care (PACIC) | 20 question, self-report that asks about patient activation, delivery system design, goal setting, problem solving and follow-up and/or coordination in the last 6 months | General | Yes | All | Patient | Lemke 2018 ¹¹ |
| SEC | Client Perceptions of Coordination Questionnaire (CPCQ) | 31 question assessment asking about how often aspects of care were experienced, perceptions of care and preferences for care | General | Yes | All | Patient | Lemke 2018 ¹¹ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|---|--|--------------------|------------------------|---|---|
| SEC | Utility, Impact and Use of Intervention | Likert scales used to assess use, Utility (organization, ease of use, ease of understanding, and relevance) and impact (several domains of self-management) of an intervention | General | Unknown | All | Patient | Gorter 2015 ¹² |
| SEC | Mind the Gap | Measures the difference or 'gap' between a young person's ideal service and the service they have received (with subdomains for management of the environment, provider characteristics and process issues) | General | Yes | All | Patient | Sattoe 2020 ⁶⁶ Shaw 2007 ¹⁷⁵ |
| | On Your Own Feet Transfer Experiences Scale (OYOF-TES) | Examines experiences across two domains: 1) organization of health care related to transition and 2) satisfaction with preparation to transfer | General | Yes | Transfer of Care | Patient | Peeters 2019 ³² Sattoe 2020 ⁶⁶ |
| SEC | Trust in Healthcare Providers | Measure of trust of pediatric and adult healthcare providers measured on a 10-point scale | General | Unknown | All | Patient | Peeters 2019 ³² |
| SEC | American Consumer Assessment of Health Plan Surveys "Patient-Centeredness" Subscale (CAHPS) | Perceived patient-centeredness of care as measured by the patient-centeredness subscale of the CAHPS survey | General | Yes | All | Patient | Peeters 2019 ³² Sattoe 2020 ⁶⁶ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|---|--|--------------------|------------------------|---|--|
| SEC | Transition Care Experience | Participants reported their experience with the following domains: (i) the medical care during the transition period; (ii) insulin prescriptions; (iii) frequency of physical examinations; (iv) assessment of glycaemia tests; (v) retinal and foot screening; (vi) number of HbA1c determinations and microalbuminuria tests for year; and (vii) the last changes in insulin therapy (self-made or proposed by a general practitioner or an endocrinologist). Patients' feeling about their diabetes care in PDS and their transition was also investigated (summarized as an overall qualitative judgement: good, sufficient, or bad). | Disease specific-diabetes | Unknown | All | Patient | Cadario 2009 ⁴⁵ |
| SEC | Satisfaction with knowledge, skills and comfort with current transition practice | 10-item survey rated on a 5-point Likert scale to assess individual satisfaction with knowledge, skills and comfort of transition practices | General | Unknown | Transfer of Care | Provider | Disabato 2015 ¹⁵⁹ |
| SEC | Satisfaction with Care | Survey to assess satisfaction with care received | General and disease specific | Unknown | All | Patient | Pape 2013 ¹¹⁶ Remorino 2006 ¹²⁰ Belair 2011 ¹²² |
| SEC | Satisfaction with Transition | Self-reported satisfaction with transition process | General | Unknown | Transfer of Care | Patient | Sattoe 2020 ⁶⁶ Nair 2017 ¹³⁹ Jensen 2015 ⁹¹ Craig 2007 ³⁴ Vanelli 2004 ⁵² |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|---|---|--|--------------------|------------------------|---|---|
| SEC | Satisfaction with Rheumatology Care | 22-27 item measure about the physical environment, clinic procedures, relationships with healthcare personnel, information and support | Disease specific-JIA | Unknown | Transfer of Care | Patient | McDonagh 2007 ⁷⁸ |
| PH | Perceived Stress Scale | Assesses an individual's perception of stress within the last month | General | Yes | All | Patient | Weigensberg 2018 ⁵⁰ Pyatak 2017 ⁵⁴ Pyatak 2014 ⁵¹ |
| PH | Patient Health Questionnaire-9 | 9-tiem depressive symptom severity index | General | Yes | All | Patient | Weigensberg 2018 ⁵⁰ Pyatak 2017 ⁵⁴ Pyatak 2014 ⁵¹ |
| PH | General Well-Being Index | Measures psychosocial well-being | General | Yes | All | Patient | Weigensberg 2018 ⁵⁰ |
| PH | PARS III Subjective Well-being | 28 items measuring peer relations, dependency, hostility, productivity, anxiety-depression and withdrawal. | General | Unknown | All | Patient | Betz 2010 ¹³² |
| PH | Arizona Integrative Outcomes Scales | Single-item visual analogue scales measuring a person's global state of physical, emotional and spiritual well-being in the last 24 hours and 30 days | General | Yes | All | Patient | Weigensberg, 2018 ⁵⁰ Pyatak 2017 ⁵⁴ Pyatak 2014 ⁵¹ |
| PH | Satisfaction with Life Scale | 5-item global life satisfaction measure | General | Yes | All | Patient | Weigensberg 2018 ⁵⁰ Pyatak, 2017 ⁵⁴ |
| PH | Psychological General Well-Being (PGWB) Index | 22-item instrument to assess general well-being across six domains: anxiety, depressed mood, positive well-being, self-control, general health and vitality | General | Yes | All | Patient | Continisio 2020 ⁶⁰ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|--|--|--|--------------------|------------------------|---|--|
| PH | Multidimensional Self-Esteem Test (TMA) | 25-item questionnaire for self-esteem assessment in six areas (personal, school, emotional, skills, family and body) | General | Yes | All | Patient | Continisio 2020 ⁶⁰ |
| PH | Visual analog scale- global and pain | Visual analog scales to assess general well being and pain | General | Unknown | All | Patient | Shaw 2007 ¹⁷⁵ |
| PH | Harter Self-perception Profile | 36-item scale measuring scholastic competence, athletic competence, social competence, physical appearance, and behavioral conduct | General | Yes | All | Patient | Steinbeck 2015 ¹⁷⁸ |
| RU | Hospitalization/Inpatient Days | Hospitalizations one year after transfer to adult center (Okumura, 2014); Hospitalizations in the three year period before and after the 18 th birthday (Williams 2020) plus other timeframes | General | Unknown | Ongoing Care | Patient | Okumura 2014 ³¹ Williams 2020 ⁴⁸ Sequeira 2015 ⁴⁶ Pyatak 2017 ⁵⁴ Testa 2019 ⁶⁷ Cole 2015 ⁷¹ Fredericks 2015 ¹¹⁹ Pape 2013 ¹¹⁶ Remorino 2006 ¹²⁰ |
| RU | Hospitalization Related to the Condition | Number of hospitalizations related to the individual health condition, measured at various time points across studies | General | Unknown | Ongoing Care | Patient | Peeters 2019 ³² Van Wallenghem 2008 ⁵³ |
| RU | Diabetes-related use of paramedics | Number of instances of diabetes-related use of paramedics | Disease-specific-Diabetes | Unknown | Ongoing Care | Patient | Sequeira 2015 ⁴⁶ |
| RU | Emergency Department Visits | Number of emergency department visits | General | Unknown | Ongoing Care | Patient | Sequeira 2015 ⁴⁶ Pyatak 2017 ⁵⁴ Van Wallenghem 2008 ⁵³ |
| RU | Length of Hospitalization | Length of admission to discharge from hospital | General | Unknown | Ongoing Care | Patient | Otto 2019 ⁶⁵ |

| Domain | Measure | Measure Description | Disease Specific Vs. General Transition Measure? | Validated Measure? | Got Transition Element | Measure Target (Patient, Caregiver, Provider) | Studies Utilizing Measure |
|--------|-----------------------------|---|--|--------------------|-------------------------------------|---|--|
| RU | Reason for Hospitalization | Reasons for admission were categorized, as follows: (1) acute flare, (2) emergency surgery, (3) elective surgery (e.g., seton insertion), and (4) elective procedures and investigations (i.e., disease-reassessment, infusion, and planned colonoscopy). | Disease specific-IBD | Unknown | Ongoing Care | Patient | Otto 2019 ¹⁷⁹ |
| RU | Number of outpatient visits | Number of outpatient visits overall or for a condition | General | Unknown | Ongoing Care | Patient | Testa 2019 ⁶⁷ Schutz 2019 ⁶⁹ |
| RU | Number of surgeries | Number of surgeries for a given condition | Disease specific-IBD | Unknown | Ongoing Care | Patient | Testa 2019 ⁶⁷ Schutz 2019 ⁶⁹ Cole 2015 ⁷¹ |
| OTH | Performance score | Performance score along three transitional domains: medical, educational/vocational, and independence/separation/identity | Disease specific-epilepsy | Unknown | Transition of care/ Ongoing Care | Patient | Geerlings 2016 ¹⁸⁰ |

Acronyms: TR=Transition Readiness; QOL=Quality of Life; MT=Mortality; MB=Morbidity; CO=Clinical Outcomes; HBWS=Health Behaviors and Wellness Screenings; TCA=Treatment or Care Adherence; EC=Engagement in Care; SEC=Satisfaction or Experience with Care; PH=Psychosocial Health; RU=Resource Utilization; OTH=Other; IBD=Inflammatory Bowel Disease; JIA=Juvenile Idiopathic Arthritis; HIV=Human Immunodeficiency Virus

Appendix H. References for Evidence Tables

1. Bashore L, Bender J. Evaluation of the Utility of a Transition Workbook in Preparing Adolescent and Young Adult Cancer Survivors for Transition to Adult Services: A Pilot Study. *J Pediatr Oncol Nurs.* 2016;33(2):111-8. doi: 10.1177/1043454215590102. PMID: 615601995.
2. Cox KH, Morgan J, Russo C. Using a Nonclinical Patient Navigator Program in a Pediatric Oncology Network. *Journal of Oncology Navigation & Survivorship.* 2021;12(3):77-81.
3. Linendoll N, Murphy-Banks R, Barthel E, et al. The Creation of a Comprehensive Adolescent and Young Adult Cancer Survivorship Program: "Lost in Transition" No More. *J Adolesc Young Adult Oncol.* 2020. doi: 10.1089/jayao.2020.0024. PMID: 632310062.
4. Granek L, Nathan PC, Rosenberg-Yunger ZRS, et al. Psychological factors impacting transition from paediatric to adult care by childhood cancer survivors. *J Cancer Surviv.* 2012;6(3):260-9. doi: 10.1007/s11764-012-0223-0. PMID: 51997440.
5. Ryan D, Moorehead P, Chafe R. Evaluating a Transition Workbook for Childhood Cancer Survivors: a Pilot Study. *Journal of cancer education : the official journal of the American Association for Cancer Education.* 2020. doi: 10.1007/s13187-020-01850-x. PMID: 632704280.
6. Glaser A, Levitt G, Morris P, et al. Enhanced quality and productivity of long-term aftercare of cancer in young people. *Arch Dis Child.* 2013;98(1):818-24. doi: 10.1136/archdischild-2013-304348. PMID: 23966026.
7. Van Laar M, Glaser A, Phillips RS, et al. The impact of a managed transition of care upon psychosocial characteristics and patient satisfaction in a cohort of adult survivors of childhood cancer. *Psychooncology.* 2013;22(9):2039-45. doi: 10.1002/pon.3248. PMID: 52443591.
8. Vollmer Dahlke D, Fair K, Hong YA, et al. Adolescent and Young Adult Cancer Survivorship Educational Programming: A Qualitative Evaluation. *JMIR Cancer.* 2017. doi: 10.2196/cancer.5821. PMID: 28410172.
9. Szalda D, Steinway C, Greenberg A, et al. Developing a Hospital-Wide Transition Program for Young Adults With Medical Complexity. *J Adolesc Health.* 2019;65(4):476-82. doi: 10.1016/j.jadohealth.2019.04.008. PMID: 2002205287.
10. Razon AN, Greenberg A, Trachtenberg S, et al. A Multidisciplinary Transition Consult Service: Patient Referral Characteristics. *J Pediatr Nurs.* 2019;47:136-41. doi: 10.1016/j.pedn.2019.04.021. PMID: 31129412.
11. Lemke M, Kappel R, McCarter R, et al. Perceptions of health care transition care coordination in patients with chronic illness. *Pediatrics.* 2018;141(5):e20173168. doi: 10.1542/peds.2017-3168. PMID: 622038911.
12. Gorter JW, Stewart D, Cohen E, et al. Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: a mixed-methods longitudinal prospective cohort study. *BMJ open.* 2015;5(5):e007553. doi: 10.1136/bmjopen-2014-007553. PMID: 25948409.
13. Huang JS, Terrones L, Tompane T, et al. Preparing adolescents with chronic disease for transition to adult care: A technology program. *Pediatrics.* 2014;133(6):e1639-e46. doi: 10.1542/peds.2013-2830. PMID: 373234573.
14. Lestishock L, Nova S, Disabato J. Improving Adolescent and Young Adult Engagement in the Process of Transitioning to Adult Care. *J Adolesc Health.* 2021 Mar 21;21:21. doi: <https://dx.doi.org/10.1016/j.jadohealth.2021.01.026>. PMID: 33762131.
15. White PH, Ilango SM, Caskin AM, et al. Health Care Transition in School-Based Health Centers: A Pilot Study. *The Journal of school nursing : the official publication of the National Association of School Nurses.* 2020 08 Dec;1059840520975745. doi: <http://dx.doi.org/10.1177/1059840520975745>. PMID: 633651124.
16. Nagra A, McGinnity PM, Davis N, et al. Implementing transition: Ready Steady Go. *Arch Dis Child Educ Pract Ed.* 2015;100(6):313-20. doi: 10.1136/archdischild-2014-307423. PMID: 604925567.

17. Stinson JN, Lalloo C, Harris L, et al. ICanCope with PainTM: User-centred design of a web- and mobile-based self-management program for youth with chronic pain based on identified health care needs. *Pain Research and Management*. 2014;19(5):257-65. doi: 10.1155/2014/935278. PMID: 600143275.
18. Cadogan K, Waldrop J, Maslow G, et al. S.M.A.R.T. Transitions: A Program Evaluation. *J Pediatr Health Care*. 2018;32(4):e81-e90. doi: 10.1016/j.pedhc.2018.02.008. PMID: 628699056.
19. Bert F, Camussi E, Gili R, et al. Transitional care: A new model of care from young age to adulthood. *Health Policy*. 2020. doi: 10.1016/j.healthpol.2020.08.002. PMID: 2007560821.
20. Morton B, Damato EG, Ciccarelli MR, et al. Care coordination for children with special healthcare needs anticipating transition: A program evaluation. *J Pediatr Nurs*. 2021 09 Mar;61:7-14. doi: <http://dx.doi.org/10.1016/j.pedn.2021.02.024>. PMID: 634560877.
21. Teed M, Bekx A, Paul M, et al. Health Care Transition for Children with Medical Complexity: Challenges and Lessons Learned. *J Pediatr Nurs*. 2021 Nov-Dec;61:275-9. doi: <https://dx.doi.org/10.1016/j.pedn.2021.07.022>. PMID: 34365163.
22. Flocco SF, Dellafiore F, Caruso R, et al. Improving health perception through a transition care model for adolescents with congenital heart disease. *J Cardiovasc Med*. 2019;20(4):253-60. doi: 10.2459/jcm.0000000000000770. PMID: 627001851.
23. Hergenroeder AC, Moodie DS, Penny DJ, et al. Functional classification of heart failure before and after implementing a healthcare transition program for youth and young adults transferring from a pediatric to an adult congenital heart disease clinics. *Congenit Heart Dis*. 2018;13(4):548-53. doi: 10.1111/chd.12604. PMID: 623614407.
24. Mackie AS, Rempel GR, Kovacs AH, et al. Transition Intervention for Adolescents With Congenital Heart Disease. *J Am Coll Cardiol*. 2018;71(1):1768-77. doi: 10.1016/j.jacc.2018.02.043. PMID: 29673467.
25. Mackie AS, Islam S, Magill-Evans J, et al. Healthcare transition for youth with heart disease: a clinical trial. *Heart (British Cardiac Society)*. 2014;100(1):1113-8. doi: 10.1136/heartjnl-2014-305748. PMID: 24842870.
26. Bushee C, Ginde S, Earing MG, et al. Changes in care patterns associated with a transition program in adolescents with congenital heart disease: A single center study. *Prog Pediatr Cardiol*. 2021;article in press. doi: <http://dx.doi.org/10.1016/j.ppedcard.2021.101343>. PMID: 2011122778.
27. Tye SK, Wan Ahmadul Badwi SA, Alwi A, et al. The development and evaluation of a "heartBEAT" Adolescent Transition Psychoeducational Program for adolescents with congenital heart defects: A preliminary study. *Cardiol Young*. 2021;31(1):166-73. doi: <http://dx.doi.org/10.1017/S1047951120004722>. PMID: 633929076.
28. Werner O, Abassi H, Lavastre K, et al. Factors influencing the participation of adolescents and young adults with a congenital heart disease in a transition education program: A prospective multicentre controlled study. *Patient Educ Couns*. 2019;102(1):2223-30. doi: 10.1016/j.pec.2019.06.023. PMID: 2002189786.
29. Lopez KN, O'Connor M, King J, et al. Improving Transitions of Care for Young Adults With Congenital Heart Disease: Mobile App Development Using Formative Research. *JMIR Formative Research*. 2018. doi: 10.2196/formative.9963. PMID: 30574573.
30. Ladouceur M, Calderon J, Traore M, et al. Educational needs of adolescents with congenital heart disease: Impact of a transition intervention programme. *Arch Cardiovasc Dis*. 2017;110(5):317-24. doi: 10.1016/j.acvd.2017.02.001. PMID: 614976186.
31. Okumura MJ, Ong T, Dawson D, et al. Improving transition from paediatric to adult cystic fibrosis care: programme implementation and evaluation. *BMJ quality & safety*. 2014;23:i64-i72. doi: 10.1136/bmjqs-2013-002364. PMID: 24415776.
32. Peeters MAC, Sattoe JNT, van Staa A, et al. Controlled evaluation of a transition clinic for Dutch young people with cystic fibrosis. *Pediatr Pulmonol*. 2019;54(1):1811-20. doi: 10.1002/ppul.24476. PMID: 2002601462.

33. Skov M, Teilmann G, Damgaard IN, et al. Initiating transitional care for adolescents with cystic fibrosis at the age of 12 is both feasible and promising. *Acta Paediatrica, International Journal of Paediatrics*. 2018;107(1):1977-82. doi: 10.1111/apa.14388. PMID: 622389368.
34. Craig SL, Towns S, Bibby H. Moving on from paediatric to adult health care: An initial evaluation of a transition program for young people with cystic fibrosis. *Int J Adolesc Med Health*. 2007;19(3):333-43. doi: 10.1515/ijamh.2007.19.3.333. PMID: 350186415.
35. Collins R, Singh B, Payne DN, et al. Effect of transfer from a pediatric to adult cystic fibrosis center on clinical status and hospital attendance. *Pediatr Pulmonol*. 2021;56(7):2029-35. doi: <http://dx.doi.org/10.1002/ppul.25398>. PMID: 2011197779.
36. Bourgeois G, Magne F, Nove Josserand R, et al. A formalized transition program for cystic fibrosis: A 10-year retrospective analysis of 97 patients in Lyon. *Pediatr Pulmonol*. 2021 Mar 10;10:10. doi: <https://dx.doi.org/10.1002/ppul.25364>. PMID: 33751837.
37. Gravelle AM, Paone M, Davidson AG, et al. Evaluation of a multidimensional cystic fibrosis transition program: a quality improvement initiative. *J Pediatr Nurs*. 2015;30(1):236-43. doi: 10.1016/j.pedn.2014.06.011. PMID: 615282450.
38. Askew K, Bamford J, Hudson N, et al. Current characteristics, challenges and coping strategies of young people with cystic fibrosis as they transition to adulthood. *Clin Med*. 2017;17(2):121-5. doi: 10.7861/clinmedicine.17-2-121. PMID: 28365620.
39. Baker AM, Riekert KA, Sawicki GS, et al. CF RISE: Implementing a Clinic-Based Transition Program. *Pediatric, Allergy, Immunology, and Pulmonology*. 2015;28(4):250-4. doi: 10.1089/ped.2015.0594. PMID: 607440735.
40. Chaudhry SR, Keaton M, Nasr SZ. Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatr Pulmonol*. 2013;48(7):658-65. doi: 10.1002/ppul.22647. PMID: 52156322.
41. Gerardin M, Pesle A, Pougheon-Bertrand D, et al. A quality improvement program for adolescents with cystic fibrosis: Focus on psychosocial skills. *Orphanet J Rare Dis*. 2018;13(S):7. doi: 10.1186/s13023-017-0747-5. PMID: 620583638.
42. Genovese VV, Perceval M, Buscarlet-Jardine L, et al. Smoothing the transition of adolescents with CF from pediatric to adult care: Pre-transfer needs. *Arch Pediatr*. 2021 May;28(4):257-63. doi: <https://dx.doi.org/10.1016/j.arcped.2021.03.008>. PMID: 33863608.
43. Bindiganavle A, Manion A. Creating a sustainable pediatric diabetes transition program. *J Pediatr Nurs*. 2021 Jun 07;07:07. doi: <https://dx.doi.org/10.1016/j.pedn.2021.05.010>. PMID: 34112532.
44. White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *The Lancet Child and Adolescent Health*. 2017;1(4):274-83. doi: 10.1016/s2352-4642%2817%2930089-5. PMID: 619313830.
45. Cadario F, Prodam F, Bellone S, et al. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: A hospital-based approach. *Clin Endocrinol (Oxf)*. 2009;71(3):346-50. doi: 10.1111/j.1365-2265.2008.03467.x. PMID: 355131215.
46. Sequeira PA, Pyatak EA, Weigensberg MJ, et al. Let's empower and prepare (LEAP): Evaluation of a structured transition program for young adults with type 1 diabetes. *Diabetes Care*. 2015;38(8):1412-9. doi: 10.2337/dc14-2577. PMID: 609627328.
47. Spaic T, Robinson T, Goldbloom E, et al. Closing the gap: Results of the multicenter Canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. *Diabetes Care*. 2019;42(6):1018-26. doi: 10.2337/dc18-2187. PMID: 2002045490.
48. Williams S, Newhook LAA, Power H, et al. Improving the transitioning of pediatric patients with type 1 diabetes into adult care by initiating a dedicated single session transfer clinic. *Clinical Diabetes and Endocrinology*. 2020;6(1):11. doi: 10.1186/s40842-020-00099-z. PMID: 632001083.

49. Butalia S, Crawford SG, McGuire KA, et al. Improved transition to adult care in youth with type 1 diabetes: a pragmatic clinical trial. *Diabetologia*. 2021. doi: 10.1007/s00125-020-05368-1. PMID: 33439284.
50. Weigensberg MJ, Vigen C, Sequeira P, et al. Diabetes Empowerment Council: Integrative Pilot Intervention for Transitioning Young Adults With Type 1 Diabetes. *Global advances in health and medicine*. 2018;7:2164956118761808. doi: 10.1177/2164956118761808. PMID: 29552422.
51. Pyatak EA, Sequeira PA, Whittemore R, et al. Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with Type 1 diabetes. *Diabet Med*. 2014;31(1):1615-24. doi: 10.1111/dme.12485. PMID: 600477213.
52. Vanelli M, Caronna S, Adinolfi B, et al. Effectiveness of an uninterrupted procedure to transfer adolescents with Type 1 diabetes from the Paediatric to the Adult Clinic held in the same hospital: Eight-year experience with the Parma protocol. *Diabetes, Nutrition and Metabolism - Clinical and Experimental*. 2004;17(5):304-8. PMID: 40124181.
53. Van Walleggem N, MacDonald CA, Dean HJ. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. *Diabetes Care*. 2008;31(8):1529-30. doi: 10.2337/dc07-2247. PMID: 354454701.
54. Pyatak EA, Sequeira PA, Vigen CLP, et al. Clinical and Psychosocial Outcomes of a Structured Transition Program Among Young Adults With Type 1 Diabetes. *J Adolesc Health*. 2017;60(2):212-8. doi: 10.1016/j.jadohealth.2016.09.004. PMID: 613872919.
55. !!! INVALID CITATION !!! 18.
56. Levy-Shraga Y, Elisha N, Ben-Ami M, et al. Glycemic control and clinic attendance of emerging adults with type 1 diabetes at a transition care clinic. *Acta Diabetol*. 2016;53(1):27-33. doi: 10.1007/s00592-015-0734-z. PMID: 603274719.
57. Logan J, Peralta E, Brown K, et al. Smoothing the transition from paediatric to adult services in type 1 diabetes. *Journal of Diabetes Nursing*. 2008;12(9):12p-p. PMID: 104982498.
58. Holmes-Walker DJ, Llewellyn AC, Farrell K. A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with type 1 diabetes aged 15-25 years. *Diabet Med*. 2007;24(7):764-9. doi: 10.1111/j.1464-5491.2007.02152.x. PMID: 47012129.
59. Gerber BS, Solomon MC, Shaffer TL, et al. Evaluation of an internet diabetes self-management training program for adolescents and young adults. *Diabetes Technology and Therapeutics*. 2007;9(1):60-7. doi: 10.1089/dia.2006.0058. PMID: 46309708.
60. Continisio GI, Lo Vecchio A, Basile FW, et al. The Transition of Care From Pediatric to Adult Health-Care Services of Vertically HIV-Infected Adolescents: A Pilot Study. *Frontiers in Pediatrics*. 2020;8:322. doi: 10.3389/fped.2020.00322. PMID: 632397640.
61. Ryscavage P, Herbert L, Roberts B, et al. Stepping up: retention in HIV care within an integrated health care transition program. *AIDS Care*. 2021 Apr 09:1-5. doi: <https://dx.doi.org/10.1080/09540121.2021.1909696>. PMID: 33832366.
62. Righetti A, Prinapori R, Nulvesu L, et al. Transitioning HIV-infected children and adolescents into adult care: an Italian real-life experience. *J Assoc Nurses AIDS Care*. 2015. doi: 10.1016/j.jana.2015.05.003. PMID: 26116060.
63. Campbell T, Beer H, Wilkins R, et al. "I look forward. I feel insecure but I am ok with it". The experience of young HIV+ people attending transition preparation events: a qualitative investigation. *AIDS Care*. 2010;22(2):263-9. doi: 10.1080/09540120903111460. PMID: 20390505.
64. Gray WN, Holbrook E, Dykes D, et al. Improving IBD Transition, Self-management, and Disease Outcomes With an In-clinic Transition Coordinator. *J Pediatr Gastroenterol Nutr*. 2019;69(2):194-9. doi: 10.1097/mpg.0000000000002350. PMID: 627316402.
65. Otto C, Tarnok A, Eros A, et al. Planned Transition of Adolescent Patients with Inflammatory Bowel Disease Results in Higher Remission Rates. *J Pediatr Nurs*. 2019;45:62-6. doi: 10.1016/j.pedn.2019.02.003. PMID: 627027990.

66. Sattoe JNT, Peeters MAC, Haitsma J, et al. Value of an outpatient transition clinic for young people with inflammatory bowel disease: A mixed-methods evaluation. *BMJ Open*. 2020;10(1):e033535. doi: 10.1136/bmjopen-2019-033535. PMID: 630526377.
67. Testa A, Giannetti E, Rispo A, et al. Successful outcome of the transitional process of inflammatory bowel disease from pediatric to adult age: A five years experience. *Dig Liver Dis*. 2019. doi: 10.1016/j.dld.2018.11.034. PMID: 30704905.
68. Scaldaferrri F, Angelino G, Romeo EF, et al. A transition clinic model for inflammatory bowel disease between two tertiary care centers: outcomes and predictive factors. *Eur Rev Med Pharmacol Sci*. 2020 Aug;24(16):8469-76. doi: 10.26355/eurrev_202008_22644. PMID: 32894553.
69. Schutz L, Radke M, Menzel S, et al. Long-term implications of structured transition of adolescents with inflammatory bowel disease into adult health care: A retrospective study. *BMC Gastroenterol*. 2019;19(1):128. doi: 10.1186/s12876-019-1046-5. PMID: 628577774.
70. van den Brink G, van Gaalen MAC, Zijlstra M, et al. Self-efficacy did not predict the outcome of the transition to adult care in adolescents with inflammatory bowel disease. *Acta Paediatrica, International Journal of Paediatrics*. 2019;108(2):333-8. doi: 10.1111/apa.14471. PMID: 623220494.
71. Cole R, Ashok D, Razack A, et al. Evaluation of Outcomes in Adolescent Inflammatory Bowel Disease Patients Following Transfer from Pediatric to Adult Health Care Services: Case for Transition. *J Adolesc Health*. 2015;57(2):212-7. doi: 10.1016/j.jadohealth.2015.04.012. PMID: 605294019.
72. Fu N, Jacobson K, Round A, et al. Transition clinic attendance is associated with improved beliefs and attitudes toward medicine in patients with inflammatory bowel disease. *World J Gastroenterol*. 2017;23(2):5405-11. doi: 10.3748/wjg.v23.i29.5405. PMID: 28839441.
73. Greveson K, Morgan N, Furman M, et al. Attitudes and experiences of adolescents in an innovative IBD transition service. *Gastrointestinal Nursing*. 2011;9(1):35-40. doi: 10.12968/gasn.2011.9.1.35. PMID: 104842956.
74. Corsello A, Pugliese D, Bracci F, et al. Transition of inflammatory bowel disease patients from pediatric to adult care: an observational study on a joint-visits approach. *Ital J Pediatr*. 2021 Jan 28;47(1):18. doi: 10.1186/s13052-021-00977-x. PMID: 33509223.
75. Waschmann M, Lin HC, Stellway JE. 'Adulthood' with IBD: Efficacy of a Novel Virtual Transition Workshop for Pediatric Inflammatory Bowel Disease. *J Pediatr Nurs*. 2021 Sep-Oct;60:223-9. doi: <https://dx.doi.org/10.1016/j.pedn.2021.07.002>. PMID: 34280734.
76. Hilderson D, Moons P, Van der Elst K, et al. The clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: Results of the DON'T RETARD project. *Rheumatology (United Kingdom)*. 2016;55(1):133-42. doi: 10.1093/rheumatology/kev284. PMID: 608878427.
77. Hilderson D, Westhovens R, Wouters C, et al. Rationale, design and baseline data of a mixed methods study examining the clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: The DON'T RETARD project. *BMJ Open*. 2013;3(1):003591. doi: 10.1136/bmjopen-2013-003591. PMID: 372128496.
78. McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology*. 2007;46(1):161-8. doi: 10.1093/rheumatology/ke1198. PMID: 44932806.
79. McDonagh JE, Shaw KL, Southwood TR. Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *Journal of child health care : for professionals working with children in the hospital and community*. 2006;10(1):22-42. doi: 10.1177/1367493506060203. PMID: 43582034.
80. Shaw KL, Southwood TR, McDonagh JE. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child Care Health Dev*. 2007;33(4):368-79. doi: 10.1111/j.1365-2214.2006.00698.x. PMID: 46909322.

81. Hanghoj S, Boisen KA, Schmiegelow K, et al. Feasibility of a transition intervention aimed at adolescents with chronic illness. *Int J Adolesc Med Health*. 2018;30(3):20160047. doi: 10.1515/ijamh-2016-0047. PMID: 622761138.
82. Relas H, Kosola S. Acceptable quality of life and low disease activity achievable among transition phase patients with rheumatic disease. *Clin Rheumatol*. 2019. doi: 10.1007/s10067-018-4351-4. PMID: 30374749.
83. Grande SW, Longacre MR, Palmblad K, et al. Empowering Young People Living With Juvenile Idiopathic Arthritis to Better Communicate With Families and Care Teams: Content Analysis of Semistructured Interviews. *JMIR mhealth uhealth*. 2019;7(2):e10401. doi: 10.2196/10401. PMID: 30794202.
84. Relas H, Luosujarvi R, Kosola S. Outcome of transition phase patients with juvenile idiopathic arthritis. *Mod Rheumatol*. 2018. doi: 10.1080/14397595.2017.1416890. PMID: 29251024.
85. Tong A, Gow K, Wong G, et al. Patient perspectives of a young adult renal clinic: A mixed-methods evaluation. *Nephrology*. 2015;20(5):352-9. doi: 10.1111/nep.12396. PMID: 603785181.
86. Hill T, Haut C. Adolescents with Chronic Kidney Disease: A Model for Transition to Adult Care. *Nephrology nursing journal : journal of the American Nephrology Nurses' Association*. 2019;46(5):533-41. PMID: 629460180.
87. Joslin B, Langman C, Nishi L, et al. Assessing success in transitioning of young adults from pediatric to adult kidney practice. *BMC Nephrol*. 2020;21(1):8. doi: 10.1186/s12882-019-1665-7. PMID: 630610227.
88. Geerlings RPJ, Aldenkamp AP, Gottmer-Welschen LMC, et al. Evaluation of a multidisciplinary epilepsy transition clinic for adolescents. *Eur J Paediatr Neurol*. 2016;20(3):385-92. doi: 10.1016/j.ejpn.2016.01.003. PMID: 607881117.
89. Murdaugh DL, King TZ, O'toole K. The efficacy of a pilot pediatric cognitive remediation summer program to prepare for transition of care. *Child Neuropsychol*. 2019;25(2):131-51. doi: 10.1080/09297049.2017.1391949. PMID: 618941363.
90. Andreoli A, Klingbeil C. Implementing Pediatric Transition Education Initiative During Inpatient Admissions in the Epilepsy Monitoring Unit. *J Pediatr Nurs*. 2021 Mar-Apr;57:50-5. doi: 10.1016/j.pedn.2020.10.010. PMID: 33242830.
91. Jensen PT, Karnes J, Jones K, et al. Quantitative evaluation of a pediatric rheumatology transition program. *Pediatric Rheumatology*. 2015;13(1):17. doi: 10.1186/s12969-015-0013-0. PMID: 604640538.
92. Stringer E, Scott R, Mosher D, et al. Evaluation of a rheumatology transition clinic. *Pediatric Rheumatology*. 2015;13(1):22. doi: 10.1186/s12969-015-0016-x. PMID: 604889697.
93. Rettig P, Athreya BH. Adolescents with chronic disease: Transition to adult health care. *Arthritis Care Res*. 1991;4(4):174-80. doi: 10.1002/art.1790040407. PMID: 22079468.
94. Tattersall RS, McMahon A-M. The MAGICC and practical approach to rheumatology transition. *British Journal of Hospital Medicine (17508460)*. 2012;73(1):552-7. doi: 10.12968/hmed.2012.73.10.552. PMID: 86880648.
95. Howell KE, Saulsberry-Abate AC, Mathias JG, et al. Transition care continuity promotes long-term retention in adult care among young adults with sickle cell disease. *Pediatr Blood Cancer*. 2021 Oct;68(10):e29209. doi: <https://dx.doi.org/10.1002/pbc.29209>. PMID: 34286896.
96. Manwani D, Doyle M, Davidson L, et al. Transition Navigator Intervention improves transition readiness to adult care for youth with Sickle Cell Disease. *Acad Pediatr*. 2021 Aug 10;10:10. doi: <https://dx.doi.org/10.1016/j.acap.2021.08.005>. PMID: 34389516.
97. Calhoun CL, Abel RA, Pham HA, et al. Implementation of an educational intervention to optimize self-management and transition readiness in young adults with sickle cell disease. *Pediatric Blood and Cancer*. 2019;66(7):e27722. doi: 10.1002/pbc.27722. PMID: 626912966.

98. Smith GM, Lewis VR, Whitworth E, et al. Growing up with sickle cell disease: A pilot study of a transition program for adolescents with sickle cell disease. *J Pediatr Hematol Oncol.* 2011;33(5):379-82. doi: 10.1097/MPH.0b013e318211bb2e. PMID: 51435181.
99. Rodgers-Melnick SN, Pell TJG, Lane D, et al. The effects of music therapy on transition outcomes in adolescents and young adults with sickle cell disease. *Int J Adolesc Med Health.* 2019;31(3):20170004. doi: 10.1515/ijamh-2017-0004. PMID: 619716532.
100. Saulsberry AC, Porter JS, Hankins JS. A program of transition to adult care for sickle cell disease. *Hematology (United States).* 2019;2019(1):496-504. doi: 10.1182/hematology.2019000054. PMID: 2004196131.
101. Allemang B, Allan K, Johnson C, et al. Impact of a transition program with navigator on loss to follow-up, medication adherence, and appointment attendance in hemoglobinopathies. *Pediatric Blood and Cancer.* 2019;66(8):e27781. doi: 10.1002/pbc.27781. PMID: 627600170.
102. Johnson R, Edwards R, Rivers A, et al. Evaluating literacy levels of patient education materials for a sickle cell transition group education programme. *Health Educ J.* 2020;79(3):253-65. doi: 10.1177/0017896919876668. PMID: 2003468366.
103. Viola AS, Drachtman R, Kaveney A, et al. Feasibility of Medical Student Mentors to Improve Transition in Sickle Cell Disease. *J Pediatr Psychol.* 2021;article in press. doi: <https://dx.doi.org/10.1093/jpepsy/jsab031>. PMID: 33779756.
104. Saulsberry AC, Hodges JR, Cole A, et al. Web-Based Technology to Improve Disease Knowledge Among Adolescents With Sickle Cell Disease: Pilot Study. *JMIR Pediatrics and Parenting.* 2020. doi: 10.2196/15093. PMID: 31909718.
105. Porter JS, Carroll YM, Anderson S, et al. Transition readiness assessment for sickle cell patients: A quality improvement project. *J Clin Outcomes Manag.* 2014;21(6):263-9. PMID: 373595094.
106. Andemariam B, Owarish-Gross J, Grady J, et al. Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care. *Pediatr Blood Cancer.* 2014. doi: 10.1002/pbc.24870. PMID: 24347402.
107. Darbari I, Jacobs E, Gordon O, et al. Correlates of successful transition in young adults with sickle cell disease. *Pediatr Blood Cancer.* 2019. doi: 10.1002/pbc.27939. PMID: 31429531.
108. Latzman RD, Majumdar S, Bigelow C, et al. Transitioning to adult care among adolescents with sickle cell disease: a transitioning clinic based on patient and caregiver concerns and needs. *Int J Child Adolesc Health.* 2010;3(4):537-45. PMID: 104987757.
109. Smith WR, Sisler IY, Johnson S, et al. Lessons Learned from Building a Pediatric-to-Adult Sickle Cell Transition Program. *South Med J.* 2019;112(3):190-7. doi: 10.14423/smj.0000000000000950. PMID: 626607940.
110. Sobota A, Akinlonu A, Champigny M, et al. Self-reported transition readiness among young adults with sickle cell disease. *J Pediatr Hematol Oncol.* 2014;36(5):389-94. doi: 10.1097/mph.000000000000110. PMID: 53002390.
111. Hankins JS, Osarogiagbon R, Adams-Graves P, et al. A Transition Pilot Program for Adolescents With Sickle Cell Disease. *J Pediatr Health Care.* 2012;26(6):e45-e9. doi: 10.1016/j.pedhc.2012.06.004. PMID: 52120555.
112. Kosola S, Ylinen E, Finne P, et al. Implementation of a transition model to adult care may not be enough to improve results: National study of kidney transplant recipients. *Clin Transplant.* 2019;33(1):e13449. doi: 10.1111/ctr.13449. PMID: 625447115.
113. Annunziato RA, Baisley MC, Arrato N, et al. Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. *The Journal of pediatrics.* 2013;163(6):1628-33. doi: 10.1016/j.jpeds.2013.07.031. PMID: 23993138.
114. Annunziato RA, Parbhakar M, Kapoor K, et al. Can transition to adult care for transplant recipients be improved by intensified services while patients are still in pediatrics? Progress in transplantation (Aliso Viejo, Calif). 2015;25(3):236-42. doi: 10.7182/pit2015599. PMID: 621750556.

115. Anton CM, Anton K, Butts RJ. Preparing for transition: The effects of a structured transition program on adolescent heart transplant patients' adherence and transplant knowledge. *Pediatr Transplant*. 2019;23(7):e13544. doi: 10.1111/petr.13544. PMID: 628839471.
116. Pape L, Lammermuhle J, Oldhafer M, et al. Different models of transition to adult care after pediatric kidney transplantation: a comparative study. *Pediatr Transplant*. 2013. doi: 10.1111/petr.12102. PMID: 23730905.
117. Grady KL, Andrei A-C, Shankel T, et al. Pediatric Heart Transplantation: Transitioning to Adult Care (TRANSIT): Feasibility of a Pilot Randomized Controlled Trial. *J Card Fail*. 2019;25(1):948-58. doi: 10.1016/j.cardfail.2019.06.011. PMID: 2002367508.
118. Grady KL, Hof KV, Andrei A-C, et al. Pediatric Heart Transplantation: Transitioning to Adult Care (TRANSIT): Baseline Findings. *Pediatr Cardiol*. 2018;39(2):354-64. doi: 10.1007/s00246-017-1763-x. PMID: 619137474.
119. Fredericks EM, Magee JC, Eder SJ, et al. Quality Improvement Targeting Adherence During the Transition from a Pediatric to Adult Liver Transplant Clinic. *J Clin Psychol Med Settings*. 2015;22(2):150-9. doi: 10.1007/s10880-015-9427-6. PMID: 605500773.
120. Remorino R, Taylor J. Smoothing things over: the transition from pediatric to adult care for kidney transplant recipients. *Progress in transplantation (Aliso Viejo, Calif)*. 2006;16(4):303-8. PMID: 17183936.
121. Michaud V, Achille M, Chainey F, et al. Mixed-methods evaluation of a transition and young adult clinic for kidney transplant recipients. *Pediatr Transplant*. 2019;23(4):e13450. doi: 10.1111/petr.13450. PMID: 31062926.
122. Belair C, Gilleland J, Amaral S. Assessing the Satisfaction of Teens with Kidney Transplants who have Attended an Adolescent Transition Clinic. *Int J Child Adolesc health*. 2011;4(3):257-63. PMID: 108207347.
123. Prestidge C, Romann A, Djurdjev O, et al. Utility and cost of a renal transplant transition clinic. *Pediatr Nephrol*. 2012;27(2):295-302. doi: 10.1007/s00467-011-1980-0. PMID: 21823039.
124. Harden PN, Walsh G, Bandler N, et al. Bridging the gap: An integrated paediatric to adult clinical service for young adults with kidney failure. *BMJ (Online)*. 2012;344(7):e3718. doi: 10.1136/bmj.e3718. PMID: 365023203.
125. McQuillan RF, Toulany A, Kaufman M, et al. Benefits of a transfer clinic in adolescent and young adult kidney transplant patients. *Canadian Journal of Kidney Health and Disease*. 2015;2(1):45. doi: 10.1186/s40697-015-0081-6. PMID: 613401208.
126. Weitz M, Heeringa S, Neuhaus TJ, et al. Standardized multilevel transition program: Does it affect renal transplant outcome? *Pediatr Transplant*. 2015;19(7):691-7. doi: 10.1111/petr.12570. PMID: 610736550.
127. Jordan M S, Ryan H, Saira K, et al. A multidisciplinary approach to improving transition readiness in pediatric liver transplant recipients. *Pediatr Transplant*. 2020:e13839. doi: 10.1111/petr.13839. PMID: 32997866.
128. Annunziato RA, Emre S, Shneider BL, et al. Transitioning health care responsibility from caregivers to patient: a pilot study aiming to facilitate medication adherence during this process. *Pediatr Transplant*. 2008. doi: 10.1111/j.1399-3046.2007.00789.x. PMID: 18435606.
129. Hubbard, Rhona. Evaluation of liver transition services for young people at a UK paediatric hospital. *Gastrointestinal Nursing*. 2016;14(s):S16-S23. doi: 10.12968/gasn.2016.14.Sup10.S16. PMID: 120270005.
130. Seeley A, Lindeke L. Developing a Transition Care Coordination Program for Youth With Spina Bifida. *J Pediatr Health Care*. 2017;31(6):627-33. doi: 10.1016/j.pedhc.2017.04.015. PMID: 622863603.
131. Sawin KJ, Rauen K, Bartelt T, et al. Transitioning adolescents and young adults with spina bifida to adult healthcare: initial findings from a model program. *Rehabilitation nursing : the official journal of the Association of Rehabilitation Nurses*. 2015;40(1):3-11. doi: 10.1002/rnj.140. PMID: 603209921.
132. Betz CL, Smith K, Macias K. Testing the transition preparation training program: A randomized controlled trial. *Int J Child Adolesc health*. 2010;3(4):595-607. PMID: 22229060.

133. Aguilera AM, Wood DL, Keeley C, et al. Young adults with spina bifida transitioned to a medical home: A survey of medical care in Jacksonville, Florida. *J Neurosurg Pediatr.* 2016;17(2):203-7. doi: 10.3171/2015.7.Peds14694. PMID: 610580671.
134. Roth JD, Szymanski KM, Ferguson EJ, et al. Transitioning young adults with neurogenic bladder-Are providers asking too much? *J Pediatr Urol.* 2019;15(4):384. doi: 10.1016/j.jpuro.2019.04.013. PMID: 2001979011.
135. Betz CL, Smith K, Van Speybroeck A, et al. Descriptive Analysis and Profile of Health Care Transition Services Provided to Adolescents and Emerging Adults in the Movin' On Up Health Care Transition Program. *J Pediatr Health Care.* 2018;32(3):273-84. doi: 10.1016/j.pedhc.2017.11.006. PMID: 628698167.
136. Betz CL, Smith KA, Van Speybroeck A, et al. Movin' On Up: An Innovative Nurse-Led Interdisciplinary Health Care Transition Program. *J Pediatr Health Care.* 2016;30(4):323-38. doi: 10.1016/j.pedhc.2015.08.005. PMID: 620104110.
137. Hopson B, MSHA, Alford EN, et al. Development of an evidence-based individualized transition plan for spina bifida. *Neurosurg Focus.* 2019;47(4):E17. doi: 10.3171/2019.7.Focus19425. PMID: 31574471.
138. Witvliet MJ, Petersen N, Ekkerman E, et al. Transitional health care for patients with Hirschsprung disease and anorectal malformations. *Tech Coloproctol.* 2017;21(7):547-54. doi: 10.1007/s10151-017-1656-2. PMID: 617172381.
139. Nair AS, DeMuth K, Chih-Wen C, et al. Asthma Academy: Developing educational technology to improve Asthma medication adherence and intervention efficiency. Conference proceedings : Annual International Conference of the IEEE Engineering in Medicine and Biology Society IEEE Engineering in Medicine and Biology Society Annual Conference. 2017;2017:1364-7. doi: 10.1109/embc.2017.8037086. PMID: 625115830.
140. Croteau SE, Padula M, Quint K, et al. Center-Based Quality Initiative Targets Youth Preparedness for Medical Independence: HEMO-Milestones Tool in a Comprehensive Hemophilia Clinic Setting. *Pediatr Blood Cancer.* 2016. doi: 10.1002/pbc.25807. PMID: 26496140.
141. Schmidt S, Herrmann-Garitz C, Bomba F, et al. A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults. *Patient Educ Couns.* 2016;99(3):421-8. doi: 10.1016/j.pec.2015.10.024. PMID: 608678062.
142. Dale CM, Carbone S, Amin R, et al. A transition program to adult health services for teenagers receiving long-term home mechanical ventilation: A longitudinal qualitative study. *Pediatr Pulmonol.* 2020;55(3):771-9. doi: 10.1002/ppul.24657. PMID: 2004169204.
143. Downing J, Gleeson HK, Clayton PE, et al. Transition in endocrinology: the challenge of maintaining continuity. *Clin Endocrinol (Oxf).* 2013. doi: 10.1111/j.1365-2265.2012.04473.x. PMID: 22734661.
144. Dingemann J, Szczepanski R, Ernst G, et al. Transition of Patients with Esophageal Atresia to Adult Care: Results of a Transition-Specific Education Program. *Eur J Pediatr Surg.* 2017;27(1):61-7. doi: 10.1055/s-0036-1587334. PMID: 611707854.
145. Breakey VR, Ignas DM, Warias AV, et al. A pilot randomized control trial to evaluate the feasibility of an Internet-based self-management and transitional care program for youth with haemophilia. *Haemophilia.* 2014;20(6):784-93. doi: 10.1111/hae.12488. PMID: 606154213.
146. Silke S, Henriette M, Franziska B, et al. Differential effect of a patient-education transition intervention in adolescents with IBD vs. diabetes. *Eur J Pediatr.* 2018;177(4):497-505. doi: 10.1007/s00431-017-3080-z. PMID: 29340756.
147. Peres M, Almeida MF, Pinto EJ, et al. Implementing a Transition Program from Paediatric to Adult Services in Phenylketonuria: Results After Two Years of Follow-Up with an Adult Team. *Nutrients.* 2021 Feb 28;13(3):28. doi: <https://dx.doi.org/10.3390/nu13030799>. PMID: 33671057.

148. Twito O, Shatzman-Steuerman R, Dror N, et al. The "combined team" transition clinic model in endocrinology results in high adherence rates and patient satisfaction. *J Pediatr Endocrinol Metab.* 2019;32(5):505-11. doi: 10.1515/jpem-2019-0056. PMID: 627601276.
149. Dogba MJ, Rauch F, Wong T, et al. From pediatric to adult care: strategic evaluation of a transition program for patients with osteogenesis imperfecta. *BMC Health Serv Res.* 2014;14:489. doi: 10.1186/s12913-014-0489-1. PMID: 609517779.
150. Downing KF, Oster ME, Farr SL. Preparing adolescents with heart problems for transition to adult care, 2009-2010 National Survey of Children with Special Health Care Needs. *Congenit Heart Dis.* 2017 Jul;12(4):497-506. doi: 10.1111/chd.12476. PMID: 28523852.
151. Zahra B, Lyall H, Sastry A, et al. Evaluating transition in Turner syndrome in the West of Scotland. *J Pediatr Endocrinol Metab.* 2021 Apr 27;34(4):473-7. doi: <https://dx.doi.org/10.1515/jpem-2020-0242>. PMID: 33647195.
152. Hart LC, Saha H, Lawrence S, et al. Implementation and Evolution of a Primary Care-Based Program for Adolescents and Young Adults on the Autism Spectrum. *J Autism Dev Disord.* 2021 Jul 02;02:02. doi: <https://dx.doi.org/10.1007/s10803-021-05171-w>. PMID: 34215949.
153. Pedersen M, Hoybye C. An Adapted Model for Transition to Adult Care in Young Adults with Prader-Willi Syndrome. *Journal of Clinical Medicine.* 2021 May 06;10(9):06. doi: <https://dx.doi.org/10.3390/jcm10091991>. PMID: 34066432.
154. Harhuis A, Cobussen-Boekhorst H, Feitz W, et al. 5 years after introduction of a transition protocol: An evaluation of transition care for patients with chronic bladder conditions. *J Pediatr Urol.* 2018;14(2):150. doi: 10.1016/j.jpuro.2017.09.023. PMID: 619361647.
155. Shalaby MS, Gibson A, Granitsiotis P, et al. Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. *J Pediatr Urol.* 2015;11(2):89. doi: 10.1016/j.jpuro.2014.11.024. PMID: 603089843.
156. Jones SC, Ng YC, Ost SR. HIV Health Care Transition Readiness: Embracing the Opportunity and Challenge. *J Assoc Nurses AIDS Care.* 2019;30(5):521-30. doi: 10.1097/01.Jnc.0000552939.89108.22. PMID: 629180960.
157. Le Marne FA, Towns SJ, Gaskin C, et al. Implementing a new adolescent epilepsy service: Improving patient experience and readiness for transition. *J Paediatr Child Health.* 2019;55(7):819-25. doi: 10.1111/jpc.14301. PMID: 625142053.
158. Phillips, Leslie. Development and Evaluation Of a Training Program for Adolescents With Special Healthcare Needs. *Pediatr Nurs.* 2018;44(2):89-94. PMID: 129092695.
159. Disabato JA, Cook PF, Hutton L, et al. Transition from Pediatric to Adult Specialty Care for Adolescents and Young Adults with Refractory Epilepsy: A Quality Improvement Approach. *J Pediatr Nurs.* 2015;30(5):e37-e45. doi: 10.1016/j.pedn.2015.06.014. PMID: 616617788.
160. McManus M, White P, Barbour A, et al. Pediatric to adult transition: A quality improvement model for primary care. *J Adolesc Health.* 2015;56(1):73-8. doi: 10.1016/j.jadohealth.2014.08.006. PMID: 600335945.
161. Moosa F, Sandhu T. Transition from children's to adult services for patients with ADHD: A model of care. *Adolesc Psychiatry.* 2015;5(1):22-30. PMID: 604494967.
162. Meacham LR, Williamson RS, Forehand RL, et al. University health centers and young adult survivors of pediatric cancer: Changes in providers' familiarity with and practice of survivor care. *J Adolesc Young Adult Oncol.* 2014;3(1):12-9. doi: 10.1089/jayao.2013.0029. PMID: 372628683.
163. Mouw MS, Wertman EA, Barrington C, et al. Care Transitions in Childhood Cancer Survivorship: Providers' Perspectives. *J Adolesc Young Adult Oncol.* 2017;6(1):111-9. doi: 10.1089/jayao.2016.0035. PMID: 614848099.
164. Rast JE, Shattuck PT, Roux AM, et al. The Medical Home and Health Care Transition for Youth With Autism. *Pediatrics.* 2018 Apr;141(Suppl 4):S328-S34. doi: 10.1542/peds.2016-4300J. PMID: 29610414.

165. Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatric Blood and Cancer*. 2013;60(8):1365-8. doi: 10.1002/pbc.24494. PMID: 369155822.
166. Mazurek MO, Stobbe G, Loftin R, et al. ECHO Autism Transition: Enhancing healthcare for adolescents and young adults with autism spectrum disorder. *Autism*. 2020;24(3):633-44. doi: 10.1177/1362361319879616. PMID: 2003478413.
167. Philbin MM, Tanner AE, Chambers BD, et al. Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: using adolescent and adult providers' insights to create multi-level solutions to address transition barriers. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*. 2017;29(1):1227-34. doi: 10.1080/09540121.2017.1338655. PMID: 616783735.
168. Got Transition: Six Core Elements of health care transition™. <https://www.gottransition.org/six-core-elements/>. Accessed on April 30, 2021.
169. Iannuzzi D, Rissmiller P, Duty SM, et al. Addressing a Gap in Healthcare Access for Transition-Age Youth with Autism: A Pilot Educational Intervention for Family Nurse Practitioner Students. *J Autism Dev Disord*. 2019;49(4):1493-504. doi: 10.1007/s10803-018-3846-9. PMID: 135779446.
170. Hess JS, Straub DM, Mateus JS, et al. Preparing for Transition from Pediatric to Adult Care: Evaluation of a Physician Training Program. *Adv Pediatr*. 2015;62(1):137-64. doi: 10.1016/j.yapd.2015.04.003. PMID: 610715912.
171. Belling R, McLaren S, Paul M, et al. The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. *J Health Serv Res Policy*. 2014;19(3):169-76. doi: 10.1177/1355819614527439. PMID: 103966098.
172. Henderson S, Kendall E, See L. The effectiveness of culturally appropriate interventions to manage or prevent chronic disease in culturally and linguistically diverse communities: a systematic literature review. *Health Soc Care Community*. 2011 May;19(3):225-49. doi: 10.1111/j.1365-2524.2010.00972.x. PMID: 21208326.
173. Seybolt L. Transition of care for HIV-infected youth can be challenging for both provider and patient. *HIV Clin*. 2014. PMID: 26685340.
174. Jones MR, Hooper TJ, Cuomo C, et al. Evaluation of a Health Care Transition Improvement Process in Seven Large Health Care Systems. *J Pediatr Nurs*. 2019;47:44-50. doi: 10.1016/j.pedn.2019.04.007. PMID: 31029928.
175. Shaw KL, Southwood TR, McDonagh JE. Development and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care among adolescents with juvenile idiopathic arthritis. *Child Care Health Dev*. 2007;33(4):380-8. doi: 10.1111/j.1365-2214.2006.00699.x. PMID: 46909323.
176. Allen D, Cohen D, Hood K, et al. Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study. *J Health Serv Res Policy*. 2012;17(3):140-8. doi: 10.1258/jhsrp.2011.011044. PMID: 22767889.
177. Butalia S, McGuire KA, Dyjur D, et al. Youth with diabetes and their parents' perspectives on transition care from pediatric to adult diabetes care services: A qualitative study. *Health science reports*. 2020;3(3):e181. doi: 10.1002/hsr2.181. PMID: 32782975.
178. Bennett DL, Towns SJ, Steinbeck KS. Smoothing the transition to adult care. *Med J Aust*. 2005. PMID: 15850429.
179. Eros A, Veres G, Tarnok A, et al. A Cross-Sectional Survey on the Transitional Care of Adolescents with Inflammatory Bowel Disease in Hungary. *J Pediatr Nurs*. 2020 Nov - Dec;55:e279-e85. doi: 10.1016/j.pedn.2020.06.002. PMID: 32624314.
180. Geerlings RPJ, Aldenkamp AP, Gottmer-Welschen LMC, et al. Long-term effects of a multidisciplinary transition intervention from paediatric to adult care in patients with epilepsy. *Seizure*. 2016;38:46-53. doi: 10.1016/j.seizure.2016.04.004. PMID: 27131211.

