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

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None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of systematic reviews to assist public- and private-sector organizations in their efforts to improve the quality of healthcare in the United States. These reviews provide comprehensive, science-based information on common, costly medical conditions, and new healthcare technologies and strategies. The EPCs systematically review scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments. 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 Institutes of Health funded this report from the EPC Program at AHRQ.

Systematic reviews are the building blocks underlying evidence-based practice; they focus attention on the strength and limits of evidence from research studies about the effectiveness and safety of a clinical intervention. In the context of developing recommendations for practice, systematic reviews can help clarify whether assertions about the value of the intervention are based on strong evidence from clinical studies. For more information about AHRQ EPC systematic reviews, see www.effectivehealthcare.ahrq.gov/reference/purpose.cfm

AHRQ expects that these systematic reviews will be helpful to health plans, providers, purchasers, government programs, and the healthcare system as a whole. Transparency and stakeholder input are essential to the Effective Health Care Program. Please visit the website (www.effectivehealthcare.ahrq.gov) to see draft research questions and reports or to join an e-mail list to learn about new program products and opportunities for input.

If you have comments on this systematic review, 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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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 healthcare services.

Data Sources. We searched Ovid Medline®, Ovid Embase®, the Cochrane Central trials (CENTRAL) registry, and CINAHL to identify studies through May, 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, 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 9,226 unique references, 417 of which represented empirical research; of these, 147 (16 major disease categories) described or examined a care transition intervention with enough detail to be potentially eligible for inclusion in any of the Key Questions. Of these, 93 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, due to the uncertainty of the evidence we found the evidence insufficient to draw meaningful conclusions. Some approaches to address 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.

Contextually, 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. A limited number of available training and other implementation strategies have been identified through the literature, generally focused on specific clinical specialties in targeted settings. None of the eligible studies measured the effectiveness of providing linguistic and culturally competent healthcare care for CSHCN. Identified transition care training, and care interventions to prepare pediatric patients and their families for transitioning CSHCN to adult care varied considerably.

Conclusions. Little rigorous evidence is available to inform care interventions and implementation strategies. Significant barriers exist to implement effective interventions, tools, and trainings to transition CSHCN. This review highlights the lack of sufficient evidence and need for more-rigorous studies across the diverse populations of CSHCN to provide clearer answers for CSHCN, their families, caregivers, providers, funders, and policymakers

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Evidence 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.
- 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 exist to implement effective interventions, some approaches 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 linguistic 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) health care 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 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 May 2021.

Results

We identified 9,226 unique references of which 417 represented empirical research using quantitative or qualitative method; of these, we categorized 147 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 147 potentially eligible studies, which comprised 16 major disease categories, 93 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 CSHCNs 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 effective 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), a lack of dedicated resources to support transitions, lack of care team training, and a 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 linguistic 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 healthcare populations and settings. None is available specific for 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 healthcare services. The lack of sufficient evidence provides no clear answers for CSHCN, their families, caregivers and providers, and funders and policymakers. Currently, stakeholders have little to rely on beyond local and institutional policies to determine whether to disseminate or implement these interventions in their populations or care settings.

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 work in 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.

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, approximately 4.5 million children ages 12 – 18 with special healthcare needs (CSHCN) 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]

Some of the difficulty in transitioning from pediatric to adult healthcare services stems from lack of clarity around managing such transitions. 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).[6] Subsequently, Got Transitions® (a federally funded national resource center on healthcare transitions) developed a structured clinical approach for transitioning patients from pediatric to adult healthcare services. Called "Six Core Elements of Health Care Transition," this approach includes transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer completion.[7]

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 the Six Core Elements has raised questions about the best transition intervention designs, implementation tools, and strategies. 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), condition type and severity, provider/hospital features (e.g., access to specialty services, specialty training) and care setting (e.g., specialty center, telemedicine).[8, 9]

While CSHCN often experience significant barriers to effectively transitioning from pediatric to adult healthcare services,[4, 9-11] 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. 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, leading to 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).[12] 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 health care for all CSHCN. The key decisional dilemmas addressed by the review include the effectiveness and harms of 1) health care 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 (KQ) 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 to provide information on the context within which care transitions happen.

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 is 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 linguistic- 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?

Table 1.1 provides detailed information on the populations, interventions, comparators, outcomes, timing, and settings.

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 (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	Transition readiness (e.g., patient, family, provider, and system level) Quality of life Mortality Morbidity Disease-specific clinical outcomes Wellness visits/screenings (e.g., depression, anxiety, STIs, other risk and resiliency factors such as alcohol use, substance abuse, violence) Treatment or care adherence Engagement in care (e.g., no shows, time between providers, satisfaction, loss to follow-up, time between leaving pediatric setting to going to adult) Satisfaction (patient and family) Family caregiver outcomes Harms Unintended consequences (e.g., ethics of transition) Psychosocial (e.g., social-emotional, mental health, etc.) Insurance Cost Resource utilization (ER visit, hospitalization, length of stay)	Intervention Adoption Fidelity Sustainability Feasibility Acceptability Satisfaction (physician and other formal caregiver) Quality of life Mortality Morbidity Disease-specific clinical outcomes Family caregiver outcomes Harms Unintended consequences (e.g., ethics of transition) Cost of implementation Insurance	Transition readiness Quality of life Mortality Morbidity Disease-specific clinical outcomes Treatment or care adherence Engagement in care (e.g., no shows, time between providers, satisfaction, loss to follow-up, time between leaving pediatric setting to going to adult) Satisfaction (patient and family) Family Caregiver outcomes Harms Unintended consequences (e.g., ethics of transition) Insurance Cost Resource utilization (ER visit, hospitalization, length of stay)
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.

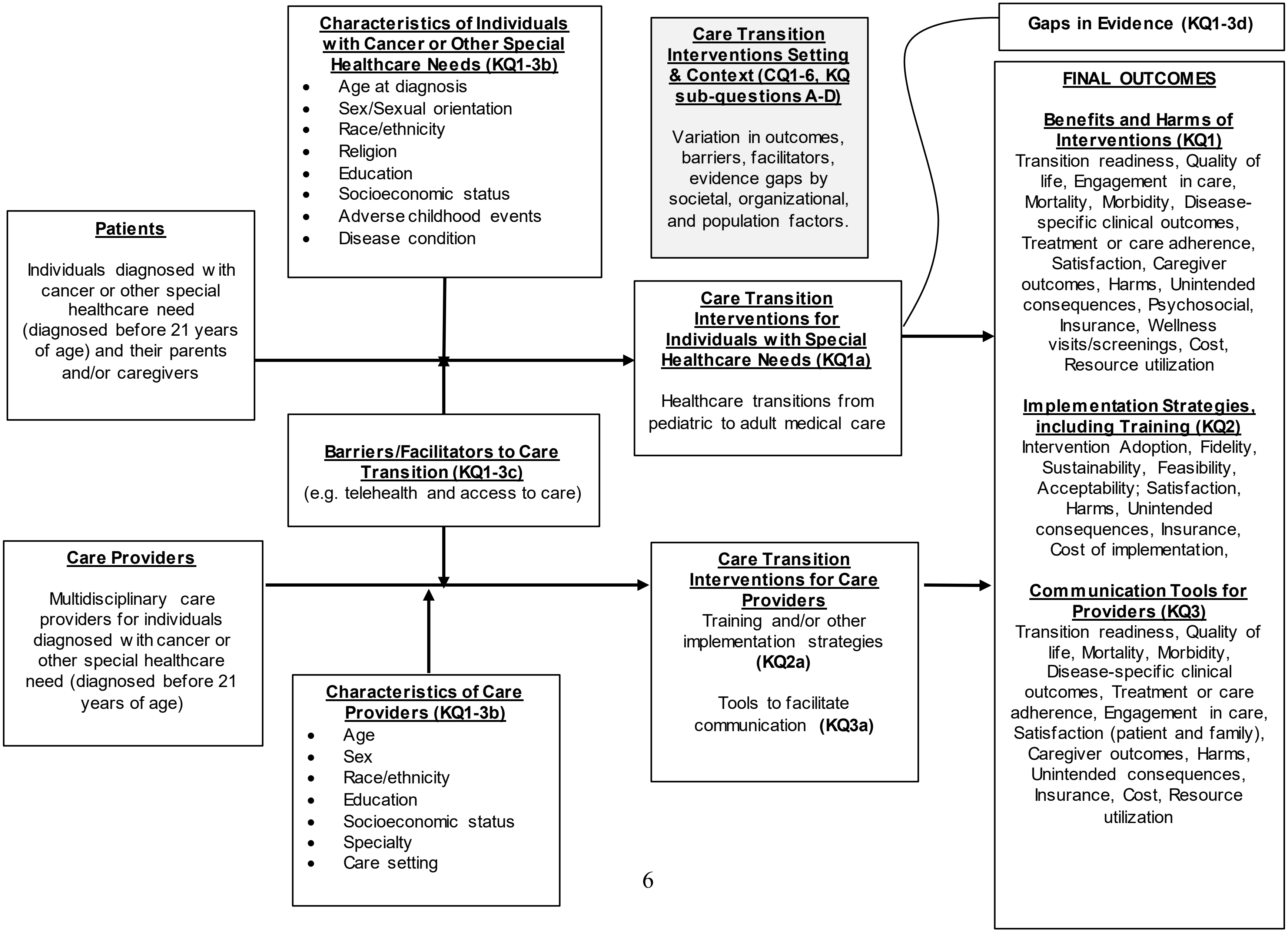
Element	KQ1: Benefits and Harms of Care Intervention	KQ2: Implementation Strategies	KQ3: Communication Tools
Setting	All settings (e.g., primary care, specialty care, schools, rural, resource limited settings, and telehealth)	All settings (e.g., primary care, specialty care, schools, rural, resource 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 KQ 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 Contextual Questions 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 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 healthcare services 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.
Health care transition	Health care transition, or HCT, is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician.[7]
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 assistant, 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/cer-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).[13] 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 PICOTS framework outlined above in Table 1.1 if they were published in English in a peer-reviewed journal. Any quantitative or qualitative study design examining transition to adult care 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 (KQ) or Contextual Questions (CQ). Studies that described or examined a care transition intervention, implementation strategy, or tool were considered specifically eligible for KQs. 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 May 2021) searching Ovid Medline®, Ovid Embase®, the Cochrane Central Register of Controlled Trials, and CINAHL databases. 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,[14] 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 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 a 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,[15] 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, and study funding source. 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.

Additional identified articles of either quantitative or qualitative design not used for KQs might still have contributed data toward barriers and facilitators extraction, if they provided particularly clear examples. 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 C.

Data Synthesis

We categorized studies using the National Institutes of Health (NIH) Stage Model for Behavioral Interventions.[16] 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.[17] 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

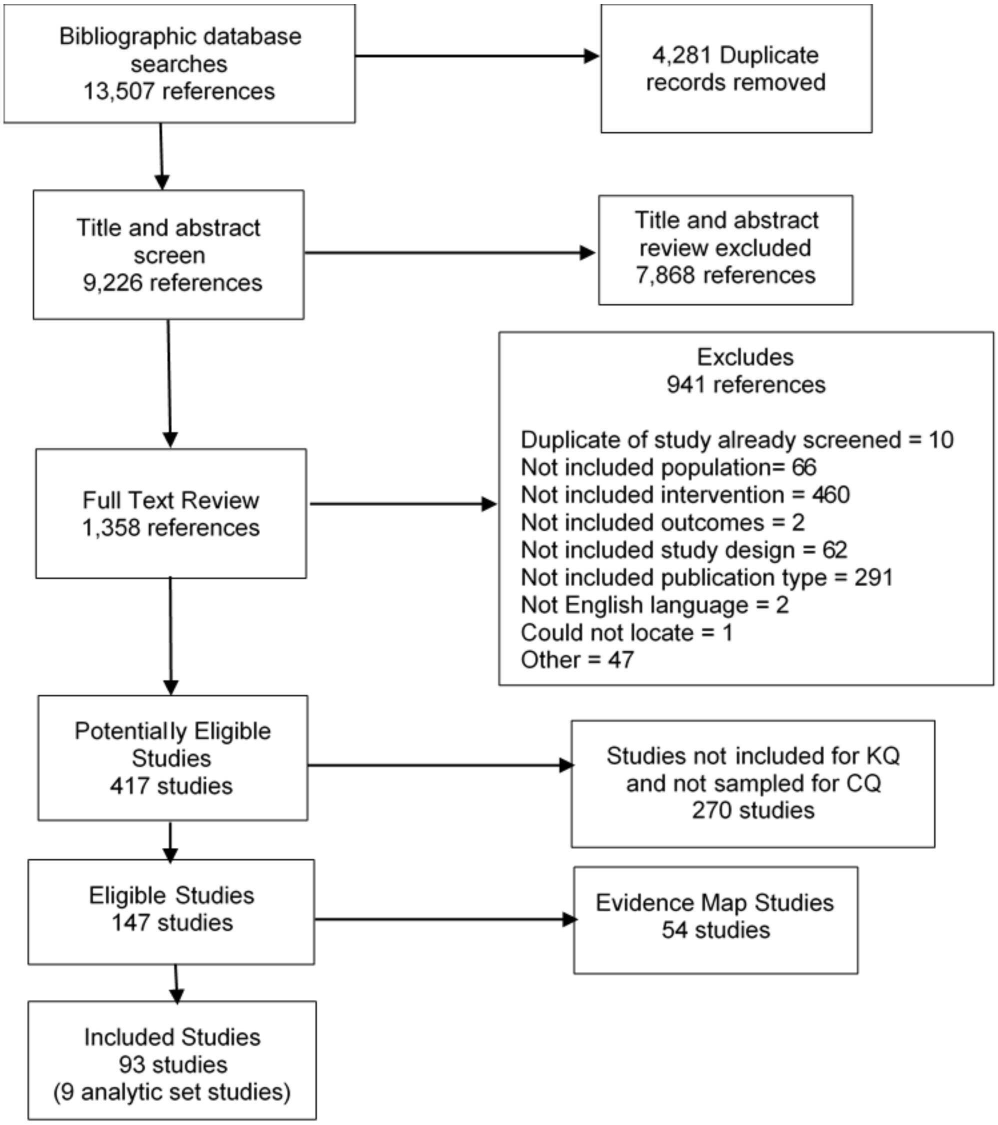
We evaluated overall strength of evidence for select quantitative outcomes for KQs within each comparison based on five required domains: (1) study strengths and limitations (risk of bias); (2) directness (single, direct link between intervention and outcome); (3) consistency (similarity of effect direction and size); (4) precision (degree of certainty around an estimate); and (5) reporting bias.[18] 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



Of the 417 identified studies of empirical research using quantitative or qualitative methods, representing 55 disease conditions, we categorized 147 as describing or examining a care transition intervention with enough detail to be eligible for potential inclusion in any of the Key Questions. The 270 studies on transitioning CSHCN that did not explicitly describe or examine care transition interventions (e.g., described the characteristics CSHCN transitioning, identified challenges with transition but did not propose an intervention) are listed in Appendix C. A further 54 studies failed the threshold criteria of comparing outcomes with different groups or time points; some of these studies supported a contextual question. The remaining 93 studies that did meet the threshold criteria were assessed for risk of bias; only nine studies were assessed to have 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. Conditions that had very few studies are presented together as Other conditions. Medical conditions were the most commonly represented conditions. Solid organ transplant, sickle cell, and cystic fibrosis were the most commonly studied. 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	10	5	2	5
	Congenital heart disease	9	6	1	3
	Cystic fibrosis	12	6	0	6
	Diabetes Mellitus	14	10	2	4
	HIV	4	2	0	2
	Inflammatory bowel disease	11	9	0	2
	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	15	7	0	8
	Solid organ transplant	17	15	1	2
	Spina bifida	7	3	1	4
	Urological conditions	2	0	0	2
	Other conditions	14	10	1	4
	Chapter 4 TOTAL	**140**	**86**	**9**	**54**
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 147 (140+9-2) unique studies and 93 (86+9-2) that were assessed for risk of bias. **Abbreviations:** HIV=human immunodeficiency virus

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).

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 were unable to 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 140 unique transition interventions describing or examining care interventions for transition from pediatric to adult medical services among CSHCN. Eighty-six 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	86 Total studies
Study Design*	12 Randomized controlled trials 2 Other controlled trials 64 Observational studies 8 Mixed methods studies
NIH Stage Model	1 Stage 0 65 Stage I 15 Stage II 2 Stage III 4 Stage IV
Study Risk of Bias	77 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 10 Diabetes Mellitus 2 HIV 9 Inflammatory Bowel Disease 5 Juvenile Idiopathic Arthritis 2 Kidney Disease 3 Neurological Conditions 1 Rheumatic Conditions 7 Sickle Cell Disease 15 Solid Organ Transplant 3 Spina Bifida 10 Other Conditions
Setting	36 Tertiary centers or clinics, unknown pediatric or adult 33 Pediatric tertiary centers, clinics or hospitals 6 Pediatric and adult tertiary centers and clinics 5 Adult tertiary centers 1 Summer program 1 Music program 1 School-based health center 3 Not reported
Intervention Type	69 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	76 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

Abbreviations: NIH=National Institutes of Health

Intervention Research Context

Of the 86 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 conditions 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 86 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 the outcome is reported, we find the level of uncertainty regarding the evidence too high to draw conclusions.

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

	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

	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

Abbreviations: K=number of studies; M=number of measures; QoL=quality of life; TRAQ=transition readiness assessment questionnaire

Care Interventions by Disease Condition

Cancer

Key Points

- No transition interventions for CSHCN with 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 cancer.[19-26] Six did not meet comparator criteria and were not eligible for risk of bias assessment,[21-26] and are reported 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[19, 20] 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 KQ 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: 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,[20] while the other took place in a large children's research hospital.[19] 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.[19] 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

Ten unique transition interventions from nine publications described or examined care interventions for transition from pediatric to adult medical services among CSHCN with broadly-defined chronic conditions.[27-37] Five studies did not meet comparator criteria, were not eligible for risk of bias assessment, and are thus excluded from the analytic set.[28-30, 34, 36] The brief evidence map of these studies can be found in Appendix D.[28-30, 34, 36] Table 4.4 summarizes the characteristics of the KQ literature set. Of the five studies that used comparators, three studies (from four publications) were assessed as high risk of bias.[27, 31, 35, 37] Two studies were assessed as medium risk of bias and included in the analytic set.[32, 33] 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 KQ literature set: chronic conditions

Characteristic	Information
Total Included Studies	5 Studies
Study Design	2 Randomized controlled trials 2 Observational study 1 Mixed methods study

Characteristic	Information
NIH Stage Model	4 Stage II 1 Stage III
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: 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 health care team communication portal) for disease management and decision support. The Canadian intervention used a toolkit and online mentor to promote organization, goal setting, and self-management. Outcomes did not focus on health status/disease outcomes. 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[33] (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[33] (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[32] (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[32] (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[32] (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[32] (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: HCT=healthcare transition; n=number; 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.[38-46] Three studies did not meet comparator criteria, were not eligible for risk of bias assessment, and excluded from the analytic set.[42, 43, 46] 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).[38-41, 44, 45] 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 KQ 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 1 Transition clinic 1 Electronic medical record healthcare transition tool
Mode	6 In-person clinic based

Characteristics	Information
Outcomes Evaluated	9 Transition Readiness (2 time to transition, 2 general transition readiness, 2 health knowledge, 1 self-management knowledge, 1 emotional regulation; 1 transfer) 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; 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 an electronic medical record-embedded transition planning tool to improved clinical outcomes.

CSHCN Outcomes

Evidence was insufficient 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 to the control (usual care).[45] 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[45] (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: 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.[47-58] Six studies did not meet comparator criteria, were not eligible for risk of bias assessment.[47-49, 51, 52, 58] 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.[50, 53-57] 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 KQ 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	3 Transition program 1 Transition program (notebook & guide) 1 Transition clinic 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 Follow-up Time	1 12 months 1 18 months 3 24 months 1 Not applicable

Characteristics	Information
Got Transitions ® Six Core Elements Targeted	1 Transition and Care Policy/Guide 5 Transition Readiness 3 Transition Planning 1 Transfer of Care
Analytic Set Studies	0 Studies

Abbreviations: NIH=National Institutes of Health

Intervention Research Context

Of the six included studies, five examined interventions conducted at cystic fibrosis centers, one in the United States,[53] Australia,[56] France,[57] the Netherlands,[54] and Denmark.[55] One study was conducted at a children's hospital in Australia.[50] One study implemented a transition guide and notebook and assessed transition readiness and healthcare use.[53] One study examined the implementation of a transition clinic that employed a transition coordinator, evaluating its effects on health care use, clinical outcomes, and self-management related skills.[54] One study implemented staff training, a parents' evening, and youth-friendly environment and consultations.[55] One study conducted a preliminary evaluation of a transition program, and examined patient concerns.[50] 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

Fourteen eligible studies examined care interventions for transition from pediatric to adult medical services among individuals with diabetes mellitus.[59-72] Four studies did not meet comparator criteria and were not eligible for risk of bias assessment.[61-63, 70, 73-76] The brief evidence map of these studies can be found in Appendix D. Table 4.9 summarizes the characteristics of the KQ literature set. Eight studies were assessed as high risk of bias,[59-64, 66, 67, 69] and two studies were assessed as medium risk of bias and included in the analytic set.[65, 68] 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 KQ literature set: diabetes mellitus

Characteristics	Information
Total Included Studies	10 studies
Study Design	4 Randomized controlled trials 1 Nonrandomized controlled trials 5 Observational studies
NIH Stage Model	1 Stage 0 3 Stage I 1 Stage II 1 Stage III 4 Stage IV

Characteristics	**Information**
Study risk of bias	8 High risk of bias 2 Medium risk of bias
Included Disease Stages/Types	10 Type 1 diabetes mellitus
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) 1 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	10 Transition program or clinic
Mode	8 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) 2 Resource Utilization (2 utilization) 3 Satisfaction or Experience with Care (3 satisfaction)
Maximum Intervention Followup Time	1 12 weeks 1 3 months 1 1 year 2 2 years 3 2.5 years 1 4 years 1 6 years
Got Transitions ® Six Core Elements Targeted	10 Transition Planning 10 Transfer of Care
Analytic Set	2 Studies

Abbreviations: NIH=National Institutes of Health

Intervention Research Context

Ten studies describing or examining interventions for health care transition from pediatric to adult health care for diabetes mellitus. These interventions were conducted at urban tertiary pediatric academic health centers in North America or Australia; three in the United States, one in Canada, and one in Australia. Outcomes included clinic attendance, loss to follow up / 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.[65] 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.[77] 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[65, 68] (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[65, 68] (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[65, 68] (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[65, 68] (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[65, 68] (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.[78-81] Two studies did not meet comparator criteria, were not eligible for risk of bias assessment, and were excluded from the analytic set.[79, 80] 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).[78, 81] Appendix D provides evidence tables, and summary risk of bias assessments.

Table 4.11. Basic characteristics of KQ literature set: HIV

Characteristics	Information
Total Included Studies	2 Studies

Characteristics	Information
Study Design	2 Observational
NIH Stage Model	1 Stage I 1 Stage II
Study risk of bias	2 High risk of bias
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	1 Transition clinic 1 Transition program
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: HIV=human immunodeficiency virus; NIH=National Institutes of Health

Intervention Research Context

Of the two included studies, one conducted in Italy at a tertiary HIV center examined a bundle of initiatives run by a multidisciplinary team,[78] while one U.S. study was conducted in a university pediatric/adult HIV clinic; most participants were Black. No core elements were targeted. Outcomes focused on disease knowledge, self-esteem, and general health. No outcomes were collected 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

Eleven eligible studies described or examined care interventions for transition from pediatric to adult medical services for CSHCN with IBD.[82-92] Two did not meet comparator criteria and were not eligible for risk of bias assessment.[85, 92] 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.[82-84, 86-91] 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 KQ 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

Characteristics	Information
Included Disease Stages/Types	7 Crohn's disease and ulcerative colitis 2 Unclassified IBD 2 Indeterminate colitis
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 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 month 4 24 months
Got Transitions ® Six Core Elements Targeted	4 Transition Readiness 4 Transition Planning 1 Transfer of Care
Analytic Set	0 Studies

Abbreviations: 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.[93-99] Two studies did not meet comparator criteria and were not eligible for risk of bias assessment.[93, 98] 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.[95-97] One study was assessed as medium risk of bias.[94] 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 KQ 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	3 Transition program 2 Transition 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: 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 components of the Six Core Elements which include transition readiness while two studies in addition incorporated transition and care policy/guide and one incorporated 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 useable outcomes were available from the medium risk of bias study conducted in Denmark.[94]

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 individuals with kidney disease.[100-102] One study did not meet comparator criteria and were not eligible for risk of bias assessment.[101] 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 strengths of evidence for key comparisons and outcomes.

Table 4.14. Basic characteristics of KQ 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

Characteristics	Information
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: 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 and were conducted between 2015 and 2019. One study was conducted in the United States while the other was conducted in Australia. Both studies were conducted in a renal clinic. Both interventions included components of the Six Core Elements which include transition readiness, while one study in addition 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.[103-105] 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 KQ 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

Characteristics	Information
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: NIH=National Institutes of Health

Intervention Research Context

Of the three included studies, two examined transition interventions for CSHCN individuals 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; 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.[106-109] Three studies did not meet comparator criteria and were not eligible for risk of bias assessment.[107-109] The brief evidence map of these studies can be found in Appendix D. Table 4.16 summarizes the characteristics of the literature set.[106] 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 KQ 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
Mode	1 In-person
Outcomes Evaluated	1 Satisfaction or Experience with Care (1 satisfaction)

Characteristics	Information
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: NIH=National Institutes of Health

Intervention Research Context

This study examined a transition program and was conducted in 2015.[106] The study was conducted in the United States and took place in a rheumatology clinic. The intervention included components of the Six Core Elements which include transition readiness; transition planning; and transfer completion. The outcome only focused on satisfaction.

Sickle Cell Disease

Key Points

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

Eligible Studies

Fifteen studies examined transition interventions CSHCN with sickle cell disease.[110-124] Eight studies did not meet comparator criteria and were not eligible for risk of bias assessment.[111, 113-116, 118, 121, 122] The brief evidence map of these studies can be found in Appendix D. Table 4.17 summarizes the characteristics of the KQ literature set. Seven studies were assessed as high risk of bias and were excluded from the analytic set.[110, 112, 117, 119, 120, 123, 124] 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 KQ literature set: sickle cell disease

Characteristics	Information
Total Included Studies	7 Studies
Study Design	7 Observational studies
NIH Stage Model	7 Stage I
Included Disease Stages/Types	7 All sickle cell disease types and stages
Study risk of bias	7 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 18-23 years old 1 18-25 years old 1 18+ years
Setting	5 Pediatric tertiary centers, clinics or hospitals 1 Adult tertiary centers or clinics 1 Tertiary centers or clinics, unknown pediatric or adult setting
Intervention Type	4 Transition program 1 Adolescent autonomy checklist 1 Music therapy intervention 1 Educational videos
Mode	6 In-person 1 Online

Characteristics	Information
Outcomes Evaluated	13 Transition Readiness (3 general transition readiness, 1 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) 3 Treatment or Care Adherence (1 adherence, 2 medication adherence) 8 Engagement in Care (1 pediatric abandonment, 1 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) 1 Satisfaction or Experience with Care (1 satisfaction) 3 Resource utilization (1 hospitalizations, 1 enrollment rates, 1 retention rates)
Maximum Intervention Follow-up Time	1 8 weeks 1 6 months 2 12 months 1 161-882 days 2 Not reported
Got Transitions ® Six Core Elements Targeted	1 Transition and Care Policy/Guide 1 Tracking and Monitoring 7 Transition Readiness 3 Transition Planning 3 Transfer of Care 2 Transition Completion
Analytic Set Studies	0 Studies

Abbreviations: NIH=National Institutes of Health

Intervention Research Context

Of the seven included studies, two examined transition programs, one 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. Six studies were conducted in the United States and one in Canada. Interventions were conducted in various settings (hematology clinic, sickle cell disease clinics, medical home and hemoglobinopathy care center). All interventions included components of the Six Core Elements which mainly included 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 follow-up, 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.[125-141] Two studies did not meet comparator criteria and were not eligible for risk of bias assessment.[126, 133] 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.[131] 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 KQ 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
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	6 Transition program 3 Transition 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)

Characteristics	Information
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: NIH=National Institutes of Health

Intervention Research Context

Of the 15 included studies, six examined transition program interventions while 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. Six studies were conducted in the United States while nine studies were conducted in Finland, Germany, Canada, United Kingdom, and Switzerland. Interventions were conducted in various settings which include 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.[131] 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. Patient retention of the program identified 86 percent retention in the intervention group and 91 percent retention 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[131] (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*
Transition readiness (TRAQ)-Self-advocacy **Transitioning to Adult Care (TRANSIT) program vs usual care**	1 RCT[131] (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[131] (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[131] (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
Adherence to medical regimen **Transitioning to Adult Care (TRANSIT) program vs usual care**	1 RCT[131] (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[131] (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[131] (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.[131, 142-148] Four did not meet comparator criteria and were not eligible for risk of bias assessment.[142, 144-146] 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.[147, 148] One study was assessed as medium risk of bias and included in the analytic set.[143] 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 KQ 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
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: NIH=National Institutes of Health

Intervention Research Context

Of the three included studies, one examined a transition care coordination program, one examined a transition program, and the third a transition preparation training program. All studies were conducted in the United States between 2010 and 2017. Two took place in an outpatient clinic and one took place 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, well-being, role-mastery, and self-care.

CSHCN Outcomes

Evidence was insufficient to draw conclusions about the effects of interventions for care transitions for CSHCN. One study reported on subjective well-being, role mastery, and self-practice care. Table 4.21 provides a summary of findings.[143] 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[143] (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

Outcome Comparisons	#Studies/Design (n analyzed) Timing	Population	Findings	Strength of the Evidence*
Role mastery (CLSS) **Transition Program Training (TPT) intervention in combination with management vs only management**	1 RCT[143] (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[143] (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: PARSIII=Personal Adjustment and Role Skills Scale; CLSS=Community Life Skills Scale; DSCPI-90=Denyes Self-Care Practice Instrument

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.[149, 150] These studies did not meet comparator criteria; they are reported 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

Fourteen studies examined transition interventions for CSHCN with various conditions.[73-76, 151-160] Four studies did not meet comparator criteria and were not eligible for risk of bias assessment.[73-76] 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.[152-160] 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 KQ literature set: other conditions

Characteristics	Information
Total Included Studies	10 Studies
Study Design	2 Randomized controlled trials 8 Observational studies

Characteristics	Information
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
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 1 Transitional outpatient 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

Characteristics	Information
Analytic Set Studies	1 Study

Abbreviations: NIH=National Institutes of Health; IBD=inflammatory bowel disease; QoL=quality of life

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. Two studies were conducted in the United States and the rest were conducted in the Netherlands, Germany, Canada, United Kingdom, Portugal, and Germany. Settings included outpatient clinics, immunology clinic, hemophilia clinic, LTV 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.[151] Table 4.23 provides a summary of findings. The study reported increased disease-specific knowledge in 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)[151] (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)[151] (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)[151] (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)[151] (n=16 intervention; n=13 control) Timing NR	Individuals recruited age 12-18 with hemophilia in Canada.	91% satisfied	Insufficient

Outcome Comparisons	#Studies/Design (n analyzed) Timing	Population	Findings	Strength of the Evidence*
Retention **Online self-management program vs no intervention**	1 RCT (pilot)[151] (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

KQ2 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.[53, 161-168] Diseases and conditions included childhood cancer survivors, epilepsy, cystic fibrosis, and chronic conditions. Table 5.1 summarizes the characteristics of the Key Question (KQ) 2 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: 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.[165] 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.[167] One Australian study paired training for providers with patient education for young patients with epilepsy.[163] 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 systems[162] 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.[53] 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.[161] A fifth used a quality improvement approach and plan-do-study-act cycles to improve CSHCN engagement.[168] The remaining study of adolescents with attention deficit/hyperactivity disorder (ADHD) of unknown demographic composition (e.g., sex, race).[166] 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 Points

- 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.[41, 43] Both studies enrolled CSHCN with congenital heart disease (CHD). One study did not meet comparator criteria and was not eligible for risk of bias assessment.[43] The brief evidence map of this study can be found in Appendix E. Table 5.2 below summarizes the characteristics of the remaining high risk of bias study.[41] 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; NA=not applicable; NIH=National Institutes of Health

Intervention Research Context

One study was conducted in the United States.[41, 169] 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 effective 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.

This chapter includes Key Questions 1-3 subquestion C, which address barriers and facilitators to implementing effective interventions and tools for transitioning children with special healthcare needs (CSHCN) from pediatric to adult services. We identified barriers and facilitators from included studies 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 147 studies were supplemented by literature (identified during the review) 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).[17] 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.[17] Within the context of transitions for CSHCNs, 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.[12, 166] This barrier is compounded by the fact that no model of healthcare transition or group of services is consistently or widely used in pediatrics.[170] 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.[54, 171] 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.[20, 171]

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.[166] 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.[166, 172] 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 .[17] 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 are simultaneously experiencing 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.[113, 147, 166, 173] 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.[147, 170, 171] Therefore, CSHCN face decreased availability of and eligibility for resources and supportive services to facilitate their care transition.[12, 174] Unfortunately, many CSHCN are reluctant to disclose their need for support,[20] and they report feelings of disruption and abandonment around the transition from pediatric to adult services.[53, 102] This, in turn, can result in additional barriers as pediatric providers become reluctant or unwilling to "let go" of CSHCN.[12, 139] 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.[12, 37, 119, 175]

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.[55, 170] 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.[55, 133, 166]

Strategies may include the incorporation of nurse coordinators to serve as transition navigators into the care process.[176] 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 supportive of these tasks.[12]

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).[17] Several studies noted overall lack of communication between pediatric and adult providers at the beginning of the transition process.[166] Underlying reasons for lack of communication are complex and include inadequate internal resources to manage and coordinate transitions, inadequate time to coordinate care for transitions, and lack of administrative support.[95, 153, 170] 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 follow-up from adult providers.[12, 150, 166, 171] Both of these factors increase patient anxiety at the time of transition.[133] 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.[153] 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, 173] This results in adult models of care that cannot effectively accommodate CSHCN transitioning from pediatric services,[117, 119] 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.[53, 170]

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) specifically trained to provide healthcare across the lifespan.[173] This requires that content on caring for CSHCN be integrated within health profession training and continued professional education.[173] Toward this end, studies note the importance of reducing stigma by sensitizing clinicians to the medical needs of CSHCN transitioning to adult care.[170] Additional strategies may include increasing patient comfort by creating a welcoming and inclusive space within the clinical setting.[4, 55] 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 health care (e.g. electronic medical records or other technologies).[133, 153] 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.[147, 153, 166]

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.[17] Both patients and caregivers note challenges with self-efficacy to engage in the transition process.[53, 122, 147] Notably, patients and caregivers feel uncertain about where to find appropriate healthcare services, overwhelmed by the steps to seek services, and frustrated by the lack of comprehensive information about the healthcare transition process. Providers note similar barriers including the lack of knowledge about available community and healthcare resources to support transitions for CSHCN.[177, 178] 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.[170] 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.[179]

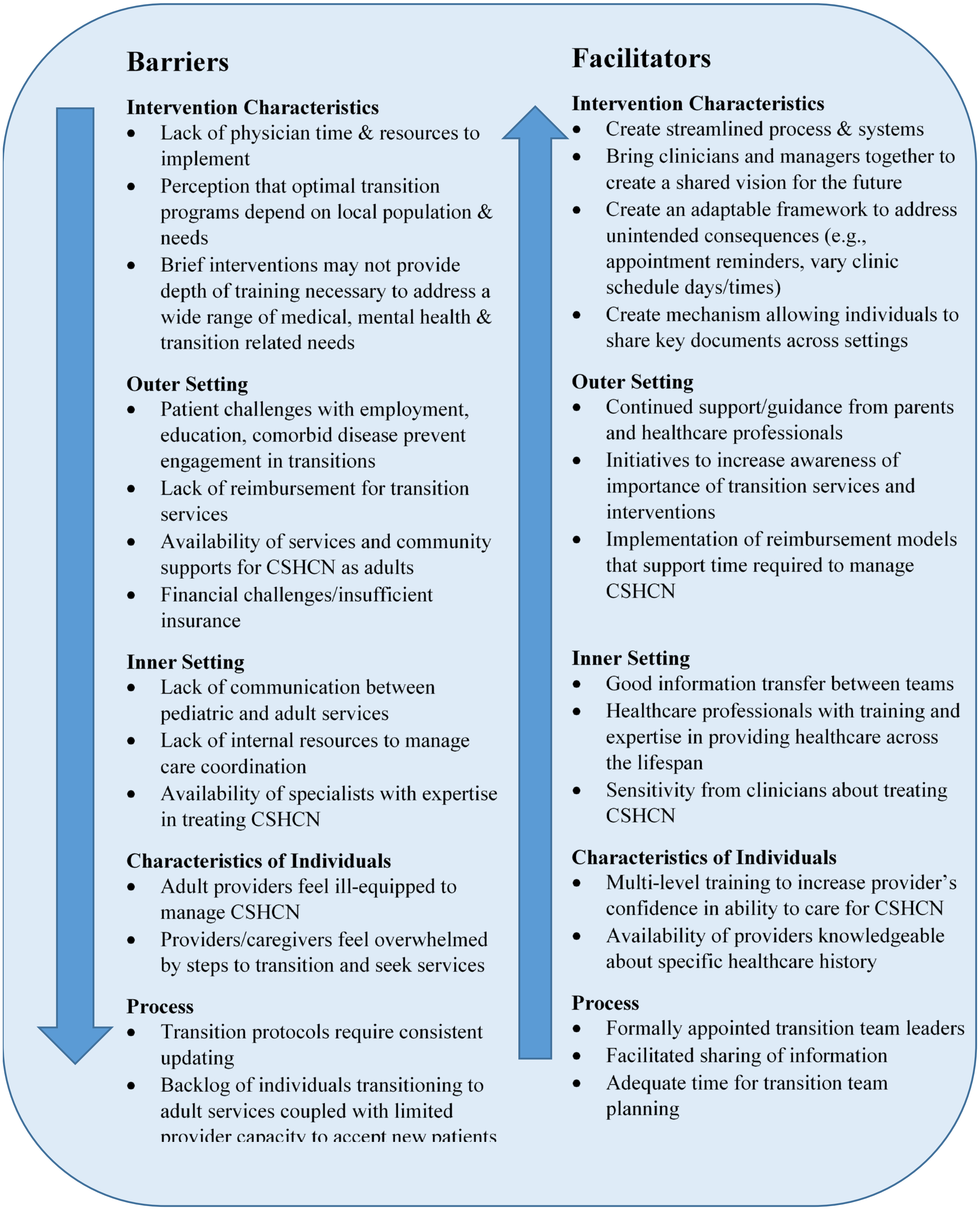
Strategies to enhance self-efficacy of patients, caregivers, and providers in effectively managing the transition to adult services for CSHCN focus on training. Specifically, providers need to create opportunities for dedicated pre-transition training that includes discussion of medical histories, navigating adult-oriented clinics, and choosing community providers and services.[12] 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.[133, 136] 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.[17] 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.[138, 166] 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).[166] These challenges are exacerbated by transition delays stemming from limited capacity among adult providers.[12, 110, 166]

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.[53] 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).[166] One example consistently cited in the literature is the adoption of toolkits such as Got Transitions® to facilitate adoption of transition protocols.[7] Finally, the process for transition must ensure adequate time for facilitated preparation and planning between providers and patients.[12, 20, 166]

Figure 6.1. Example Barriers and Facilitators for Implementing Effective Interventions and Tools for Transition Services



Barriers

Intervention Characteristics
- Lack of physician time & resources to implement
- Perception that optimal transition programs depend on local population & needs
- Brief interventions may not provide depth of training necessary to address a wide range of medical, mental health & transition related needs

Outer Setting
- Patient challenges with employment, education, comorbid disease prevent engagement in transitions
- Lack of reimbursement for transition services
- Availability of services and community supports for CSHCN as adults
- Financial challenges/insufficient insurance

Inner Setting
- Lack of communication between pediatric and adult services
- Lack of internal resources to manage care coordination
- Availability of specialists with expertise in treating CSHCN

Characteristics of Individuals
- Adult providers feel ill-equipped to manage CSHCN
- Providers/caregivers feel overwhelmed by steps to transition and seek services

Process
- Transition protocols require consistent updating
- Backlog of individuals transitioning to adult services coupled with limited provider capacity to accept new patients

Facilitators

Intervention Characteristics
- Create streamlined process & systems
- Bring clinicians and managers together to create a shared vision for the future
- Create an adaptable framework to address unintended consequences (e.g., appointment reminders, vary clinic schedule days/times)
- Create mechanism allowing individuals to share key documents across settings

Outer Setting
- Continued support/guidance from parents and healthcare professionals
- Initiatives to increase awareness of importance of transition services and interventions
- Implementation of reimbursement models that support time required to manage CSHCN

Inner Setting
- Good information transfer between teams
- Healthcare professionals with training and expertise in providing healthcare across the lifespan
- Sensitivity from clinicians about treating CSHCN

Characteristics of Individuals
- Multi-level training to increase provider's confidence in ability to care for CSHCN
- Availability of providers knowledgeable about specific healthcare history

Process
- Formally appointed transition team leaders
- Facilitated sharing of information
- Adequate time for transition team planning

Chapter 7. Definitions and Measures for Transitions of Care

Key Points

- 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.

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. 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 health care 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*[6]
- 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*[180]
- [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, 2018[181]
- "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, 2016*[182]
- 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, 1993*[183]

Measures of Effective Transitions of Care

Studies that evaluate the effectiveness of transitions from pediatric to adult healthcare services 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 primary quantitative outcomes 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[32] Mackie 2014[44] Mackie 2018[45] Okumura 2014[53] Gray 2019[84] Seeley 2017[148] Saulsberry 2019[119] Anton 2019[128] Grady 2018[184]
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[54] Sattoe 2020[87]
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[40]
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[40] Sattoe 2020[87] Hilderson 2016[95]
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[96] Shaw 2007[99]

Measure	Measure Description	Disease Specific vs General Transition Measure	Validated Measure	Got Transitions® Element	Measure Target (Patient, Caregiver, Provider)	Studies Utilizing Measure
Mortality	Death, measured at various time-points relative to transition	General	Unknown	All	Patient	Kosola 2019[134] Fredericks 2015[130]
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[40] Scaldaferri 2020[88] Tong 2015[102]
Body Mass Index (BMI)	Differences in body mass index across time	General	Unknown	Transfer of Care/Ongoing Care	Patient	Okumura 2014[53] Peeters 2019[54] Levy-Shraga 2016[62] Skov 2018[55] Craig 2007[50] Testa 2019[90] Schultz 2019
Childhood Health Assessment Questionnaire (CHAQ)	Assesses functional status from good to poor	General	Yes	Transfer of Care/Ongoing Care	Patient	Hilderson 2016[95] Shaw 2007[99]
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[54] Sattoe 2020[87]
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[45]
Visit Attendance	Attending a threshold of disease specific visits per year	General	Unknown	Transfer of Care/Ongoing Care	Patient	Levy-Shraga 2016[62] Cole 2015[82] Fredericks 2015[130]

Measure	**Measure Description**	**Disease Specific vs General Transition Measure**	**Validated Measure**	**Got Transitions® Element**	**Measure Target (Patient, Caregiver, Provider)**	**Studies Utilizing Measure**
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[185] Sattoe 2020[87] Shaw 2007[99]
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[54] Sattoe 2020[87]
Satisfaction with Life Scale	5-item global life satisfaction measure	General	Yes	All	Patient	Weigensberg 2018[67] Pyatak, 2017[186]
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[78]
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[53] Williams 2020[69] Sequeira 2015[64] Pyatak 2017[186] Testa 2019[90] Cole 2015[82] Fredericks 2015[130]
Emergency Department Visits	Number of emergency department visits	General	Unknown	Ongoing Care	Patient	Sequeira 2015[64] Pyatak 2017[186] Van Walleghem 2008[72]

Chapter 8: Training and Implementation Strategies to Prepare Pediatric and Adult Medical Providers

Key Points

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

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 available training and other implementation strategies that have been identified. 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 health care 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.[162, 164] Other trainings included educational sessions and lectures.[163, 165, 167] One study used joint pediatric adult meetings in order to facilitate communication.[53] The implementation of a Best Practice Advisory guideline tool in the electronic medical record was also seen.[161] 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
Health care Got Transitions®program based on the Six Core Elements **Jones 2019**[162]	Structured HCT process implementation using the Six Core Elements within several health systems: six integrated health care delivery systems (four ACOs, a federally qualified health center, and a military health facility) and one free-standing children's hospital. The National Alliance to Advance Adolescent Health's Got Transitions®	General transition	Various clinical backgrounds (e.g., physician's, nurse practitioners, social workers, etc.)	Got Transition's co-director facilitated conversation with the LN health system leaders on monthly one-hour phone calls.
Education session **Le Marne 2019**[163]	Group epilepsy education sessions. Education components include: current evidence regarding teratogenicity and driving regulations; mental health supports; and the transition process. Children's hospital	Disease specific	Epilepsy clinical nurse consultant, epilepsy coordinator, neurology fellow, and transition staff	80 min face-to-face
Nurse-led 60-minute education session **Phillips 2018**[167]	The following education topics were included: Review purpose and goals of the AYAHT program. Consensus statement by the AAP, AFNP, 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. Teaching and research hospital	Disease specific	Pediatric rehabilitation providers	Nurse-led 60-minute education session

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 2015**[161]	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 2015**[164]	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 2014**[165]	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 2014[53]**	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: HCT=health care transition; LN=learning network; EMR=electronic medical record

Grey Literature Search Results

The majority of 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, 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).

Table 8.2. 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
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

Training/ Strategy	Training/ Strategy Description Developer/ Source of Training	Disease specific vs. General Transition?	Training Population Target	Duration/ Delivery Method/ Availability
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/patient-resources/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. Caroling Health and Transition Program (CHAT)	Disease specific (YSHCN)	Health care providers	Educational materials available for download at https://mahec.net/innovation-and-research/special-initiatives/chat-project
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

Training/ Strategy	Training/ Strategy Description Developer/ Source of Training	Disease specific vs. General Transition?	Training Population Target	Duration/ Delivery Method/ Availability
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 subspeciality 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

Abbreviations: CSHCN=children with special health care need: YSHCN=youth with special health care need

Chapter 9: Training Available for Linguistic and Culturally Competent Care

Key Points

- None of the studies included in Key Questions 1 – 3 measured the effectiveness of providing linguistic 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 they are not specific to CSHCN.

This chapter addresses Contextual Question 3 on available training for linguistic 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 supplemented this literature with a grey literature search in Google Scholar and a scan of organizational websites for information about linguistic and cultural competency training and guidance. See Appendix A for a complete search strategy.

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.[187] 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.[188] Both culturally and linguistically competent healthcare are critical to the effective delivery of healthcare services—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.[189] Additionally, culture influences help-seeking behaviors and attitudes toward providers.[189] 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.[189] Each of these factors can influence appropriate access to and use of healthcare services for transition age CSHCN.

No studies included in Key Questions 1 – 3 specifically examined the effectiveness of providing linguistic 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 linguistic 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.[190] 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.[67]

A number of systematic reviews have been published in the past 20 years on interventions to improve cultural competence in health care, but not specifically for CSHCN transition care outcomes.[177, 191-198] Other reviews have examined the effectiveness of patient-centered care models that incorporate a cultural competence component.[197] Several organizations also provide linguistic and cultural competence training; however, these trainings are not specific to transition age CSHCN (Table 9.1).

Overall, the evidence for effectiveness of training for linguistically and culturally competent care for health care providers of CSHCN is scarce. 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[199]	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[200]	Department of HHS Office of Minority Health	No	Health care providers	Free, continuing education e-learning programs, designed to provide culturally and linguistically appropriate services (CLAS). https://thinkculturalhealth.hhs.gov/education
National CLAS Standards[201]	HHS Office of Minority Health	No	Health organizations (ambulatory care, hospital, public health	Toolkit to guide health care 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)[202]	Georgetown University Center for Child & Human Development	Yes	Health centers, health care 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[203]	National Transitions of Care Coalition (NTOCC)	Yes	Patients and caregivers, policy makers, Health care professional	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)
Culturally competent care for practices[204]	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/Pages/For-Practices.aspx

Abbreviations: HHS= Health and Human Services

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

Key Points

- Considerable variation exists among transition care trainings, as well as care interventions to prepare pediatric patients and their families for transitioning children with special healthcare needs to adult care (CSHCN).

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

Considerable variation existed among transition care trainings, and 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., LEAP).[64, 186] A number of studies also developed targeted clinics in various modes such as multidisciplinary transition clinics, young adult clinics, and half-day transfer clinic.[69, 136, 138] The use of a transition navigator and transition coordinator was often incorporated into program designs.[110, 127] Educational interventions in the form of transition workbooks, educational sessions, and workshops to prepare pediatric patients were also common.[20, 44, 143] Recently published studies have examined interventions that incorporate technology to promote patient autonomy (such as appointment management systems and online self-management programs).[68, 151] Studies of implementation strategies were rare.

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[20] (26206471)	Transition workbook	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[64] (25906787) Pyatak 2017[186] (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 YA clinic; participants had access to carbohydrate counting classes; and invited to join a private social networking website. Hospital
White 2017[68] (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 Walleghem 2011[205] (18458141)	Systems navigator model (The Maestro Project)	NR 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. NR
Grady 2019[131] (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 HT 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 HT 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[143] (22229060)	Transition Preparation Training in combination with SB 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. SB clinic
Allemang 2019[110] (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[127] (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 NR
Prestidge 2012[138] (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[44] (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[151] (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[69] (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[136] (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; SB=spina bifida; CHD=congenital heart disease; YAC=young adult clinic

Chapter 11. Strategies to Increase Availability of Adult Providers

Key Points

- 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.

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.[10, 12, 37, 171, 173, 206] 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.[207]

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 are not comfortable 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.[208] Some organizations are focused 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 health care transition services for their enrollee populations.[209] 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.[210] 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 CMS 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,[211] and 2) expanding or making permanent telehealth policies implemented due to the COVID-19 pandemic.[212]

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 services. 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 potentially useful. Rather, it means that current available evidence cannot yet provide clear answers about which interventions and implementation strategies offer consistent benefits.

This is as true at the universal level for drawing broader guidance as it is the 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 that were 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 silo-ed approaches. In an ideal state, the combination of generalized and specific transition research would have allowed individual decision-makers to import what would help address their specific decisional dilemma, out of the wide range of disease conditions and individual and system-level characteristics 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 a variety of approaches such as online training modules, workshops and toolkits. While some trainings and implementation strategies were 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.

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, their families, caregivers and providers, and funders and policymakers. Currently, stakeholders have little to rely on beyond local and institutional policies 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, 213] 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,[180] 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 healthcare services, 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 Stage Model.[16] 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. 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.[214]

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, 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 were focused on populations seen in specialty clinics and tertiary care settings, while 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 is different than 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.

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. Additionally helpful would be if studies were more easily adapted across populations of CSHCN by assessing the appropriateness 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). 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.

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. 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 CHSCN 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 and the lack of adult providers for this population. These challenges, highlighted in the barriers of Chapter 6, are coupled with the ongoing challenges faced by CSHCN as they age out of pediatric care (e.g., insurance, availability of social support programs). 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 must be coupled with 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 healthcare services. 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. This decision resulted in excluding the majority of the literature addressing autism and other intellectual and physical disabilities. While educational or vocational interventions may provide an important component of successful transition for CSHCN, but these were beyond the scope of our review.

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. 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).

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 Health Care 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
PICOTS	population, intervention, comparator, outcome, timing and setting
PRISMA	Preferred Items for Reporting in Systematic Reviews and Meta-Analyses
RCT	randomized controlled trial
SAHM	Society for Adolescent Health and Medicine
STAR	Childhood Cancer Survivorship, Treatment, Access, and Research Act

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. 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.
7. Got Transition: Six Core Elements of health care transition™. https://www.gottransition.org/six-core-elements/. Accessed on April 30, 2021.
8. 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.
9. 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.
10. 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.
11. 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.
12. 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.
13. 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.
14. PICO Portal. picoportal.org; 2020.
15. 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/.
16. 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.
17. 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.

18. 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/.

19. 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.

20. 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.

21. 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.

22. 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.

23. 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.

24. 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.

25. 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.

26. 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.

27. 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.

28. 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.

29. 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.

30. 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.

31. 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.

32. 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.

33. 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.

34. 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.

35. 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.

36. 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.

37. 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.

38. 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.

39. 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.

40. 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.

41. 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.

42. 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.

43. 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.

44. 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.

45. 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.

46. 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.

47. 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.

48. 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.

49. 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.

50. 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.

51. 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.

52. 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.

53. 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.

54. 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.

55. 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.

56. 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.

57. 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.

58. 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.

59. 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.

60. 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.

61. 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.

62. 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.

63. 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.

64. 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.

65. 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.

66. 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.

67. 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.

68. 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.

69. 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.

70. 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.

71. 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.

72. Van Walleghem 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.

73. 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.

74. 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.

75. 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.

76. 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.

77. 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.

78. 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.

79. 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.

80. Tomas C, Hannah B, Rebecca W, 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.

81. 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.

82. 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.

83. 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.

84. 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.

85. 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.

86. 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.

87. 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.

88. Scaldaferri 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.

89. 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.

90. 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.

91. 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.

92. 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.

93. 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.

94. 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.

95. 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.

96. 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.

97. 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.

98. 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.

99. 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.

100. 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.

101. 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.

102. 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.

103. 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.

104. 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.

105. 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.

106. 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.

107. 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.

108. 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.

109. 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.

110. 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.

111. 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.

112. 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.

113. 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.

114. 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.

115. 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.

116. 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.

117. 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.

118. 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.

119. 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.

120. 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.

121. 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.

122. 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.0000000000000110. PMID: 53002390.

123. 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.

124. 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.

125. 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.

126. 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.

127. 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.

128. 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.

129. 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.

130. 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.

131. 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.

132. 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.

133. 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.

134. 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.

135. 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.

136. 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.

137. 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.

138. 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.

139. 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.

140. 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.

141. 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.

142. 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.

143. 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.

144. 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.

145. 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.

146. 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.jpurol.2019.04.013. PMID: 2001979011.

147. 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.

148. 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.

149. 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.jpurol.2017.09.023. PMID: 619361647.

150. 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.jpurol.2014.11.024. PMID: 603089843.

151. 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.

152. 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.

153. 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.

154. 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.

155. 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.

156. 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.

157. 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.

158. 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.

159. 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.

160. 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.

161. 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.

162. 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.

163. 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.

164. 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.

165. 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.

166. 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.

167. Phillips, Leslie. Development and Evaluation Of a Training Program for Adolescents With Special Healthcare Needs. Pediatr Nurs. 2018;44(2):89-94. PMID: 129092695.

168. 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.

169. 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.

170. 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.

171. 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.

172. 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.

173. 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.

174. 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.

175. 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.

176. 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.

177. 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.

178. Seybolt L. Transition of care for HIV-infected youth can be challenging for both provider and patient. HIV Clin. 2014. PMID: 26685340.

179. 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.

180. 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/.

181. 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.

182. 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.

183. Blum, R W. Transition to adult health care: setting the stage. J Adolesc Health. 1995;17(1):3-5. PMID: 7578159.

184. 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.

185. 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.

186. 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.

187. 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.

188. 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.

189. 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

190. 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.childyouth.2012.12.002. PMID: 104241126.

191. 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.

192. 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.

193. 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.

194. 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.

195. 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.

196. 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.

197. 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.

198. Butler M, McCreedy E, Schwer N, et al. Improving cultural competence to reduce health disparities [Internet]. 2016.

199. Cora-Bramble D. Culturally Effective Care Toolkit. https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/effective-care.aspx.

200. 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.

201. 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

202. 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

203. National Transitions of Care Coalition. Cultural Competence: Essential Ingredient for Successful Transitions of Care . https://www.ntocc.org/s/CulturalCompetence.pdf

204. 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.

205. 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.

206. 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.

207. 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.

208. 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.

209. 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: Septermber 2020. https://www.thenationalalliance.org/s/Medicaid-Managed-Care-Contract-Language-to-Expand-the-Availability-of-Pediatric-to-Adult-Transitiona.pdf

210. Special CCIFoCfCaYw, Health Care Needs. A Primer on Value-based Strategies for Improving Financing of Care for Children and Youth with Special Health Care Needs. 2017 June.

211. 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

212. Honsberger K, VanLandeghem K, Girmash E. Supporting States To Improve Care For Children With Special Health Care Needs During COVID-19. Health Affairs; 2021.

213. 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

Available from: https://www.ncbi.nlm.nih.gov/books/NBK132160/.

214. Collins LM. Optimization of behavioral, biobehavioral, and biomedical interventions : the Multiphase Optimization Strategy (MOST). Cham, Switzerland: Cham, Switzerland : Springer; 2018.