

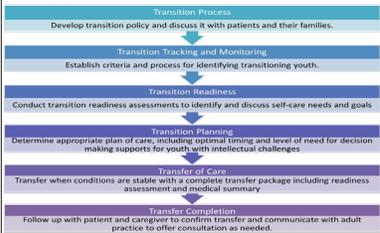
Evaluation of transition from pediatric to adult care in patients with Down syndrome: Grading the evidence and identifying research gaps

Mary M. Stephens, M.D., M.P.H.¹, Kayla Morrell², Karan Varshney³, Jennifer Jett, M.D.⁴, Alexander Fossi, M.P.H.⁵

1 Department of Family and Community Medicine, Thomas Jefferson University; Center for Special Healthcare Needs, Christiana Care; 2 Sidney Kimmel Medical College, Thomas Jefferson University; 3 College of Population Health, Thomas Jefferson University; 4 Department of Family Medicine, Christiana Care; 5 Center for Autism and Neurodiversity, Thomas Jefferson University

BACKGROUND

Health care transition (HCT) from pediatric to adult care is a critical time for individuals with special health care needs (SHCN). A structured transition process is associated with improved population health outcomes, patient experience and appropriate utilization of healthcare.⁵ Recommended steps in healthcare transition for youth, particularly those with SHCN:²



OBJECTIVES/AIMS

1. Identify original research articles in peer-reviewed medical journals that focus on key questions about transitioning from pediatric to adult healthcare providers for adults with DS
2. Evaluate the quality of the existing evidence, identify deficiencies in current clinical knowledge and suggest directions for future research
3. Begin to formulate practical guidelines to support best medical practices for transitioning adults with DS from pediatric to adult healthcare providers

DESIGN/METHODS

Using a PubMed search from 1960 to Present with Daily Update Search Strategy in April 2020, we performed a literature search. The MeSH terms [Down syndrome] and [Transition to Adult Care] were used. Case series involving fewer than 5 subjects and review articles were not included. Additional searches were performed using a PubMed search for topics "Down syndrome" and "transition to adult care".

By consensus the following key questions were formulated:

- Are youth/young adults with DS more likely to have a gap in transition services?
- Do individuals with DS have more high-risk criteria for transition?
- Does an appropriate transition of care impact morbidity and mortality?
- Are there indicators of high risk besides DS?
- What are the harms/cost of transition services?

RESULTS/SUMMARY

Search Term: DS + Transition to Adult Care No limits applied	PubMed Limits applied (English)
Unfiltered Hits = 20 articles	Filtered Hits = 18 articles
Reviewed Title/Abstract = 18 articles	Excluded articles=15 <ul style="list-style-type: none"> • Not addressing a key Q (14) • Case report (1)
Reviewed Articles = 3	Included articles = 3

DATA SUMMARY

- Compared to other patients with SHCN, individuals with Down syndrome appear to be more likely to incompletely transition to the adult-care model and have more high-risk criteria for HCT.
- Patients with both DS and congenital heart disease (CHD) seem to be at higher risk than those without CHD.
- Other markers of high risk include co-morbidities and functional limitations, race (Hispanic or Black), male sex, and insurance status (no insurance/public only).
- Patients with incomplete HCT have higher annualized cost of care, especially when hospitalized.

PubMedID (PBID)	22775057	25737343	29571933
Included Articles	Health care in adults with Down syndrome: a longitudinal cohort study	Implementation of an Academic Adult Primary Care Clinic for Adolescents and Young Adults With Complex, Chronic Childhood Conditions	Disparities in Access to Healthcare Transition Services for Adolescents With Down Syndrome
Publication Year	2013	2015	2018
Subjects studied (N)	205	332	17,114
Age range	18-45 y	14-54 y	12-17 y
Source of subjects	Single academic health center	Transition Medical Clinic (TMC) associated with Baylor College of Medicine	2009-2010 National Survey of Children with Special Healthcare Needs
Methods	Chart review of longitudinal cohort	Retrospective chart review	Survey
HCT aspect considered	Care provider (only-child focused, only-adult focused, mixed child- and adult-focused providers, unknown)	Specialist utilization, demographics in TMC by diagnosis	Previous discussion regarding shifting to adult care provider, changing healthcare needs, maintaining insurance, taking responsibility for self-care

Key Questions

Likelihood of gap in transition services	Probably, majority of adults with DS had incompletely transitioned	At baseline, no patients at the TMC were receiving primary care from an adult-focused provider and were either receiving care from a pediatrician or had been without medical care	Only 11% of adolescents with DS met transition core outcomes, compared to 40% of adolescents with other SHCN
High-risk transition criteria	Similar pattern of healthcare utilization between patients in both provider groups	Patients with DS had an especially high prevalence of sleep apnea and the majority received care from cardiologists and pulmonologists	Adolescents with DS were less likely to be encouraged to take responsibility for their health than adolescents with other SHCN
Morbidity and Mortality affected	Patients seeing child-focused providers had increased complexity of CHD compared to peers with only adult-focused providers	Not discussed	Diagnosis of DS associated with more comorbid conditions than adolescents with other SHCN
High-risk indicators	Increased complexity or severity of illness	Sleep apnea, heart disease and associated complications, lung disease, obesity, thyroid disease	Male sex, black or Hispanic race, poverty, lack of insurance coverage, public insurance, functional limitations
Costs, benefits, harms	Increased financial cost to those with mixed care providers, only in the case of hospitalization	Outside funding to the TMC is required due to the greater amount of clinical resources required	Those who have private insurance or come from a medical home may be more likely to receive transition services

USPSTF Rating⁶

Research design	Level III	Level III	Level III
Internal Validity	Fair	Fair	Fair
External Validity	Good	Fair	Good

CONCLUSIONS

Gaps in clinical knowledge: Research required to address key questions

- There are currently large gaps in the literature with very minimal work completed on the topic of HCT for patients with DS.
- The available evidence is only of fair quality (Level III) and only of fair to good external validity; it is insufficient to answer all key research questions.

Additional questions include the following:

- Do patients with both DS and CHD receive higher quality care by remaining with pediatric cardiologists or do they stay with pediatric cardiologists because adult cardiologists are unwilling to see them?
- How does SES impact the ability for complete HCT?
- What provider and patient factors are associated with adolescents with DS taking more responsibility for their own health?

Toward practical guidelines: for further consideration by DSMIG-USA

- Structured HCT is beneficial because it results in improved quality of life, greater adherence to and satisfaction with care, and appropriate healthcare utilization.
- The current major gaps in the research evidence make it both difficult to formulate evidence-based guidelines for HCT for young patients with DS and point to a need, based on improved outcomes from a structured HCT for other individuals with SHCN. With the anticipated release of updated pediatric and adult healthcare guidelines that could be incorporated into HCT planning, now may be an optimal time for focused attention on this critical issue.

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