

Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review

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Objective To identify statistically significant positive outcomes in pediatric-to-adult transition studies using the triple aim framework of population health, consumer experience, and utilization and costs of care.

Study design Studies published between January 1995 and April 2016 were identified using the CINAHL, Ovid MEDLINE, PubMed, Scopus, and Web of Science databases. Included studies evaluated pre-evaluation and postevaluation data, intervention and comparison groups, and randomized clinic trials. The methodological strength of each study was assessed using the Effective Public Health Practice Project Quality Assessment Tool.

Results Out of a total of 3844 articles, 43 met our inclusion criteria. Statistically significant positive outcomes were found in 28 studies, most often related to population health (20 studies), followed by consumer experience (8 studies), and service utilization (9 studies). Among studies with moderate to strong quality assessment ratings, the most common positive outcomes were adherence to care and utilization of ambulatory care in adult settings. **Conclusions** Structured transition interventions often resulted in positive outcomes. Future evaluations should consider aligning with professional transition guidance; incorporating detailed intervention descriptions about transition planning, transfer, and integration into adult care; and measuring the triple aims of population health, experience, and costs of care. (*J Pediatr 2017;188:263-9*).

ransitioning from pediatric to adult care encompasses preparation for managing one's health and needed health care, transferring to adult-centered care with current medical information, and engaging in adult health care. Establishing a continuum of transition support that is coordinated between pediatric and adult care settings can be challenging, however.

Published literature consistently shows that most youths and young adults, including those with special health care needs and their parents, receive limited or no transition preparation, transfer assistance, and facilitated integration into adult care.¹⁻³ As a result, many are at risk for lower-than-expected health literacy,⁴ discontinuity of care,^{5,6} delays in securing an adult medical home and specialty care,⁷ problems with treatment adherence,^{8,9} dissatisfaction with care,¹⁰⁻¹² excess morbidity,¹² and even mortality.¹³ To ameliorate these adverse outcomes, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) developed a joint clinical report on health care transition in 2011.¹⁴ This professional consensus calls for specific transition activities beginning at age 12 years and continuing through young adulthood.

Various interventions have been used to improve the transition process, most of which have been of limited scope and generalizability. In 2014, the Agency for Healthcare Research and Quality (AHRQ) reported difficulties in determining which transition interventions are most effective because of limited evidence. The Institute of Medicine, also in 2014, identified transition as a persistent problem with "minimal systematic implementation and evaluation of institutional change."

Recent systematic reviews have focused on effectiveness of health care transition interventions^{17,18} and measurable outcomes.¹⁹ Crowley et al²⁰ studied health outcomes of transition programs and found that 6 of 10 included studies showed statistically significant improvements in outcomes. These positive improvements were found only in studies of patients with diabetes; the interventions associated with significant outcomes were patient education and transition clinics.

This review, which builds on Crowley's 2012 study, examines significant outcomes of health care transition using the triple aim framework, including a quality assessment of included evaluation studies. This review also addresses evidence gaps and implications for future studies, building on previous work related to transition measures using the triple aim domains of

population health, patient experience, and costs of care.²¹

AAFP American Academy of Family Physicians
AAP American Academy of Pediatrics
ACP American College of Physicians
AHRQ Agency for Healthcare Research and Quality

EPHPP Effective Public Health Practice Project Quality Assessment Tool for Quantitative

Studies
HbA1c Hemoglobin A1c

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Methods

Following the PRISMA checklist,²² we conducted a search strategy of articles published between January 1995 and April 2016 using the CINAHL, Ovid MEDLINE, PubMed, Scopus, and Web of Science databases. Only English-language articles were included, and a combination of medical subject headings and keywords were used, as described in the **Figure** (available at www.jpeds.com).

Included studies described a transition intervention for youths transferring from pediatric to adult outpatient health care. Studies that addressed only self-care skills without reference to transition planning or transfer were excluded. The primary outcome was health care transition (not vocational or educational transition). Studies included preintervention and postintervention data, intervention and nonintervention comparisons, and randomized controlled trials. Prospective and retrospective studies were included. Excluded studies relied only on qualitative data or failed to specify the sample size, impeding quality rating.

One reviewer screened the initial identified titles and abstracts. Articles meeting the inclusion criteria were read in their entirety by 2 reviewers. When there were differences in opinion, 2 additional reviewers examined the full article in question.

The Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies (EPHPP) was used to assess methodological strength of each study.²³ This tool and its accompanying dictionary are available at http://www.ephpp.ca. The study components analyzed were selection bias, study design, confounders, blinding, data collection methods, withdrawals, and dropouts. Intervention integrity and analyses also were evaluated, but were not included in the global rating. Component ratings of strong, moderate, or weak were assigned along with an overall study rating based on the summation of ratings; a strong rating indicates no weak rating, a moderate rating indicates 1 weak rating, and a weak rating indicates 2 or more weak ratings (Table I; available at www.jpeds.com). Two assessors independently scored each included study for quality; differences were resolved by discussing the rationale for the rating and sharing information used to justify the rating. The 2 reviewers resolved all discordant ratings using this approach.

The following data were extracted from each study (**Table II**; available at www.jpeds.com): study design and population, medical condition(s) of the study population, US or international-based study, type of transition intervention, outcome measures and results, and overall quality assessment ratings. Study results are summarized in **Table II** in terms of statistically significant outcomes as an increase, a decrease, or no change, except for 1 study in which results were reported in terms of positive or negative effect sizes. A Special designations were assigned to outcome results with incomplete data. Statistically significant outcomes were confirmed by 2 reviewers.

Statistical Analyses

Outcomes from the included studies were categorized according to population health, experience of care, and utilization/

cost domains. This triple aim framework was used in previous work,²¹ but the categorization of results could differ in this study to align with statistically positive outcome criteria. This study also follows the framework of the Institute for Healthcare Improvement's Guide to Measuring the Triple Aim⁶⁵ and the AHRQ's Early Evidence on the Patient-Centered Medical Home.⁶⁶ In Table II, population health outcomes are organized according to adherence to care (including disease-specific outcomes), patient-reported health and quality of life, and self-care skills. Experience of care outcomes are organized according to satisfaction with care and barriers to care. Utilization/ cost measures are classified into service utilization (including clinic, hospital, surgery, and procedures), process of care (including communications among providers and documentation of transition clinical processes), and costs of care. Only those studies with significant positive transition outcomes are reported in Table III.

Transition interventions were analyzed in terms of activities aligned with the AAP/AAFP/ACP Clinical Report: transition preparation, transfer of care, and integration into adult care. Article descriptions, albeit limited, were used. With respect to transition preparation, the following activities were counted when mentioned: transition process/policy, transition readiness assessment, self-care/disease education, plan of care, transition clinic in pediatric setting, and community resource linkages. With respect to transfer, the following activities were counted when mentioned: appointment scheduling assistance, preparation of a transfer package/medical summary, communication between pediatric and adult provider, and joint pediatric/adult clinic. With respect to integration into adult care, the following activities were counted when mentioned: welcome/orientation process, appointment scheduling and follow-up assistance, self-care assessment, self-care/disease education, plan of care, and young adult clinic. The presence of a designated coordinator to assist with the transition process was noted as well.

Results

This systematic review examined the evidence from 43 articles out of 3844 articles initially identified (**Figure**). **Table II** provides a summary of each study's characteristics. All but 5 studies^{26,27,35,41,52} evaluated transition interventions for youths with a single condition, most often type 1 diabetes, followed by kidney or liver transplants and juvenile idiopathic arthritis. Among the handful of multiple-condition studies, only 1 study³¹ included youths with neurodevelopmental conditions. No included study examined transition outcomes for youths with mental/behavioral health conditions or common chronic conditions, such as asthma. In addition, no study focused on youths without chronic conditions.

US studies accounted for one-third of the studies in this systematic review, with almost as many from the United Kingdom. Two of the UK studies^{11,12} were conducted with the same study population using the same intervention, but evaluating different outcomes. Study population sizes of 100 or more were found in approximately one-quarter of the 43 studies.

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