

# Transition Care for Children With Special Health Care Needs



**WHAT'S KNOWN ON THIS SUBJECT:** More children with special health care needs are surviving to adulthood and entering the adult health care system. Effective transition of care can promote continuity of developmental and age-appropriate care for these individuals.



**WHAT THIS STUDY ADDS:** Existing studies provide modest transition care support. Methods for providing transition care warrant attention, and future research needs are wide ranging. Consistent and accepted measures of transition success are critical to establishing an adequate body of literature to affect practice.

## abstract

**BACKGROUND:** Approximately 750 000 children in the United States with special health care needs will transition from pediatric to adult care annually. Fewer than half receive adequate transition care.

**METHODS:** We had conversations with key informants representing clinicians who provide transition care, pediatric and adult providers of services for individuals with special health care needs, policy experts, and researchers; searched online sources for information about currently available programs and resources; and conducted a literature search to identify research on the effectiveness of transition programs.

**RESULTS:** We identified 25 studies evaluating transition care programs. Most ( $n = 8$ ) were conducted in populations with diabetes, with a smaller literature ( $n = 5$ ) on transplant patients. We identified an additional 12 studies on a range of conditions, with no more than 2 studies on the same condition. Common components of care included use of a transition coordinator, a special clinic for young adults in transition, and provision of educational materials.

**CONCLUSIONS:** The issue of how to provide transition care for children with special health care needs warrants further attention. Research needs are wide ranging, including both substantive and methodologic concerns. Although there is widespread agreement on the need for adequate transition programs, there is no accepted way to measure transition success. It will be essential to establish consistent goals to build an adequate body of literature to affect practice. *Pediatrics* 2014;134:900–908

**AUTHORS:** Alaina M. Davis, MD,<sup>a,b</sup> Rebekah F. Brown, MD,<sup>b,c</sup> Julie Lounds Taylor, PhD, MA,<sup>a,b,d</sup> Richard A. Epstein, PhD, MPH,<sup>b,e</sup> and Melissa L. McPheeters, PhD, MPH<sup>b,f</sup>

<sup>a</sup>Division of General Pediatrics, and <sup>c</sup>Division of Allergy, Immunology and Pulmonary Medicine, Department of Pediatrics; <sup>d</sup>Division of Child and Adolescent Psychiatry, Department of Psychiatry; and <sup>f</sup>Department of Health Policy, Vanderbilt University School of Medicine, Nashville, Tennessee; <sup>b</sup>Evidence-Based Practice Center, Institute for Medicine and Public Health, Vanderbilt University Medical Center, Nashville, Tennessee; and <sup>e</sup>Vanderbilt University Kennedy Center for Research on Education and Human Development, Nashville, Tennessee

### KEY WORDS

special health care needs, transition to adult care, self-management, adolescent health services

### ABBREVIATIONS

CSHCN—children with special health care needs

HbA1c—glycosylated hemoglobin

Drs Davis, Brown, Taylor, Epstein, and McPheeters assisted with conceptualizing and designing the study, analyzing studies identified, drafting the report and manuscript, and reviewing and revising the manuscript; all authors approved the final manuscript as submitted.

The authors of this report are responsible for its content. Statements in the report should not be construed as endorsement by the Agency for Healthcare Research and Quality or the US Department of Health and Human Services.

[www.pediatrics.org/cgi/doi/10.1542/peds.2014-1909](http://www.pediatrics.org/cgi/doi/10.1542/peds.2014-1909)

doi:10.1542/peds.2014-1909

Accepted for publication Aug 12, 2014

Address correspondence to Melissa L. McPheeters, PhD, MPH, Vanderbilt Evidence-based Practice Center, Institute for Medicine and Public Health, Vanderbilt University Medical Center, Nashville, TN 37203-1738. E-mail: [melissa.mcpheeters@vanderbilt.edu](mailto:melissa.mcpheeters@vanderbilt.edu)

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** All authors received support from Contract No. 290-2012-00009-I from the Agency for Healthcare Research and Quality, US Department of Health and Human Services. Dr Taylor was supported by a career development award from the National Institute of Mental Health (K01 MH092598, Taylor, PI). The other authors have indicated they have no financial relationships relevant to this article to disclose.

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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 (CSHCN). As a result of the increasing prevalence of childhood chronic conditions and life expectancy for CSHCN,<sup>1,2</sup> estimates now suggest ~750 000 CSHCN transition to adult care annually.<sup>3,4</sup>

There is conceptual agreement that transition involves more than the “transfer” of care and optimally begins before the point of transfer and that transitions from pediatric to adult care can be associated with adverse health outcomes.<sup>5–12</sup> Fewer than 50% of CSHCN aged 12 to 17 years indicate they received adequate support and services for their transition to adult care,<sup>13–16</sup> and ethnic minorities and children living in poverty appear to be at significantly increased risk for suboptimal care during this period.<sup>17,18</sup> The low rates of transition support reported by families may reflect the fact that only one-third of pediatricians report making referrals to adult physicians, and <15% report providing transition education materials.<sup>19</sup>

Despite reasonably strong conceptual agreement on the importance of transition for CSHCN, there is a lack of rigorous research. Because there are limited data and too few research studies to support a full systematic review of this emerging intervention, we conducted interviews with experts in the field and searched sources of published and gray literature on the topic. This work was funded by the Agency for Healthcare Research and Quality. In this article, we summarize findings from the published literature evaluating transition care programs. The full report is available at <http://www.effectivehealthcare.ahrq.gov>.

## METHODS

We had discussions with key informants and searched the published and “gray” literature. In consultation with the investigative team and the Agency for

Healthcare Research and Quality, we assembled a list of individuals representing a clinical, policy, research, or advocate perspective for transition care. We held 1 group discussion with these key informants by telephone to help refine our a priori guiding questions.

We used controlled vocabulary terms and key words to search the published literature for studies that evaluated transition programs 2000 to 2013 and reviewed the reference lists of retrieved publications for other relevant publications. We augmented the searches in bibliographic databases by searching for gray literature from the Internet, government Web sites, clinical trial databases, trade publications, and meeting abstracts. We did not limit our search by clinical condition, but we did limit by type of care, excluding studies of transition care in the context of palliative or hospice care. We also limited our search for empirical articles to those evaluating transition care programs. Table 1 summarizes the inclusion and exclusion criteria for the evaluation studies that were included in the empirical literature review.

## RESULTS

### Patients and Conditions Represented in Evaluation Studies

Of the 699 articles reviewed, we identified 25 studies<sup>20–44</sup> reported in 30

publications<sup>20–49</sup> that evaluated a system of purposeful transition care from the peer-reviewed literature.

We included studies of any approach to transition care even if the evaluation outcome was defined as successful transfer or if the system focused primarily on the transfer process. To be clear, we use the term “transfer” generally to describe the point-in-time when a case is transferred from pediatric to adult care, and we use the term “transition” to communicate a more comprehensive set of support processes and care that ideally begin before and extend after transfer.

Among the 25 studies, 8 studied transition care for adolescents with diabetes,<sup>27–32,39,40</sup> 5 studied adolescents who had undergone organ transplant<sup>22,23,26,33,34</sup> (all but 1 of these focused on kidney transplant), and 2 studied adolescents with sickle cell disease.<sup>36,41</sup> The remainder studied a variety of conditions including congenital adrenal hyperplasia,<sup>21</sup> HIV,<sup>24</sup> epilepsy,<sup>25</sup> juvenile idiopathic arthritis,<sup>38</sup> spina bifida,<sup>42</sup> cystic fibrosis,<sup>37</sup> or inflammatory bowel disease<sup>43</sup> or included a patient population comprising >1 chronic disease.<sup>20,35,44</sup> Twelve studies were conducted in Europe: 8 in the United Kingdom,<sup>21,22,29,32,35,36,39,50</sup> 1 in Germany,<sup>33</sup> 1 in Spain,<sup>40</sup> and 2 in

**TABLE 1** Inclusion and Exclusion Criteria for Evaluation Studies

Category	Criteria
Study population	Children with special health care needs
Publication languages	English only
Admissible evidence (study design and other criteria)	<p>Admissible designs</p> <p>Randomized controlled trials (including wait-list control), cohorts with comparison, pre-post cohort without comparison, stepped wedge designs, case-control, case series, and case reports</p> <p>Other criteria</p> <p>Original research studies that provide sufficient detail regarding methods and results to enable use and adjustment of the data and results</p> <p>Studies must address the following for transitions in care:</p> <p>Transitions of care from pediatric to adult services</p> <p>CSHCN as defined by the American Academy of Pediatrics</p> <p>A special health need that arises from a chronic physical, developmental, or intellectual condition or disability</p>

Italy.<sup>27,31</sup> Eight studies were conducted in the United States<sup>20,28,34,36,37,41,42,44</sup>; 3 studies were conducted in Canada<sup>23,25,45</sup>; and 1 study was conducted in Australia.<sup>26</sup> One study included data from the United Kingdom and Australia.<sup>24</sup>

Few studies used a concurrent comparison group. Some studies compared survey responses of individuals who had participated in transition care with those of individuals who had not, with transition generally not occurring concurrently. Because most interventions are implemented at the system level and are provided to all relevant patients at the same time, these studies generally relied on data from individuals who transitioned before the services were available as comparators to the intervention group.

Outcomes were generally patient-reported and focused on issues such as satisfaction with the process or health-related quality of life. Some clinical outcomes are available in the literature; these include objective measures such as glycosylated hemoglobin (HbA1c) levels for patients with diabetes and rates of organ rejection among transplant patients. Generally, however, studies defined successful transition as attendance in adult care (eg, successful transfer) or continued medication adherence. Thus, although most of the described programs offered comprehensive support rightly regarded as “transition care,” evaluation of these programs often focused on outcomes traditionally regarded as indices of the more limited concept of “transfer.”

In addition to the evaluation information on transition care for youth with special health needs that we found in the indexed literature, we also cataloged relevant transition care resources, programs, and projects found in the gray literature. A detailed list of projects and resources can be found in the full report.

## Length of Follow-up and Outcomes Measured in Evaluation Studies

### Diabetes

The most commonly studied group of transitioning youth was individuals with diabetes (Table 2).<sup>27–32,39,40</sup>

Interventions included use of a transition coordinator ( $n = 2$ ),<sup>27,29</sup> attendance of the pediatrician at the adult care visit(s) ( $n = 2$ ),<sup>27,31</sup> education and skill building ( $n = 3$ ),<sup>28,39,40</sup> a specialized young adult clinic ( $n = 4$ ),<sup>28,29,32,39</sup> and use of technology for education and reminders ( $n = 2$ ).<sup>29,30</sup> In 5 models, patients transferred directly into an adult clinic.<sup>27,30–32,40</sup> Two programs used practical assistance with scheduling.<sup>29,40</sup> No 2 studies evaluated the same transition intervention, although some intervention components were common across studies.

The most common diabetes-related outcomes were HbA1c levels (a marker for glycemic control),<sup>32</sup> diabetes-related hospitalizations,<sup>29,30</sup> and adult service attendance.<sup>27,30–32</sup> Seven studies used HbA1c levels as outcomes.<sup>27–29,31,32,39,40</sup> Patient satisfaction was the focus of 2 studies.<sup>27,31</sup>

Five studies included some sort of comparison group,<sup>27,28,30,32,39</sup> with 3 using concurrent comparators,<sup>27,28,32</sup> although the analyses were retrospective. Three studies did not use a comparison group.<sup>29,31,40</sup> Most studies were published as quality improvement evaluations and reported either improved health outcomes or maintenance of health.

### Solid Organ Transplant

A small body of literature<sup>22,23,26,33,34</sup> is available on the transition of pediatric patients with organ transplants to adult care (Table 3). Four of the 5 studies<sup>22,23,26,33</sup> focus on kidney transplant patients, with the remaining study<sup>34</sup> on liver transplant. All of the studies on kidney transplant patients include the evaluation of a specific transition-oriented

clinic—either one for youth alone or a joint pediatric-adult clinic. The 1 study on liver transplant patients evaluated the role of a transition coordinator.<sup>34</sup> This was the only prospective study, but the study did not use a concurrent control group, relying on historical comparators who had transitioned before implementation of the coordinator role.<sup>34</sup> The four studies on kidney transplant patients report clinical outcomes, including organ rejection and mortality.<sup>22,23,26,33</sup> The study on liver transplant patients reports on patient satisfaction, psychological benefits, and medication adherence, confirmed via blood draw.<sup>34</sup> Although some studies reported improved rates of organ rejection and medication adherence, others reported clinical worsening.

### Other Conditions.

We identified an additional 12 studies<sup>20,21,24,25,35–38,41–44</sup> on a range of conditions (Table 4). Three studies included patients with a variety of conditions,<sup>20,35,44</sup> and 2 studies focused on sickle cell disease<sup>36,41</sup>; the remainder of the studies had 1 clinical focus.<sup>21,24,25,37,38,42,43</sup> The transition care programs evaluated in these studies included use of a transition coordinator,<sup>37,38</sup> multidisciplinary teams to provide care jointly,<sup>24,35,37,41,43</sup> and a separate young adult clinic.<sup>21</sup> One transition intervention provided direct scheduling of visits,<sup>36</sup> one was a mentoring group that met over 10 months,<sup>20</sup> and the other used a generic 2-month intensive Internet- and text-message-based intervention followed by a 6-month review period.<sup>44</sup> Patient education was a common component of transition.<sup>20,25,37,38,41–44</sup> Although many of these studies report positive results, the range of clinical conditions, transition care programs, and evaluation designs precludes making definitive conclusions.

## DISCUSSION

Despite identifying numerous descriptions of existing transition programs or services, we identified only 25 empirical

**TABLE 2** Overview of Diabetes Transition Studies

Citation (Location)	Design <sup>a</sup>	Transition Care Elements	Summary of Findings
Cadario et al 2009 <sup>27</sup> (Italy)	Retrospective cohort	<ul style="list-style-type: none"> <li>• Transition coordinator</li> <li>• Structured transfer plan</li> <li>• Pediatrician attendance at the adult care visit</li> </ul>	Shorter transition; better clinic attendance; lower HbA1c; favorable experience
Gholap et al 2006 <sup>39</sup> (United Kingdom)	Other	<ul style="list-style-type: none"> <li>• Patient education and skill building</li> <li>• Specialized transition clinic (Young Persons Clinic)</li> <li>• Alphabet mnemonic approach to care</li> </ul>	Better clinic attendance; lower HbA1c; higher screening rates for nephropathy; lower rates of nephropathy
Holmes-Walker et al 2007 <sup>29</sup> (Australia)	Other	<ul style="list-style-type: none"> <li>• Transition coordinator</li> <li>• Specialized transition clinic (Transition Support Program)</li> <li>• Patient education; technology for education and reminders</li> </ul>	Lower HbA1c; better attendance; decrease in diabetic ketoacidosis admissions
Kipps et al 2002 <sup>32</sup> (United Kingdom)	Retrospective cohort	<ul style="list-style-type: none"> <li>• Specialized transition clinic (initial move to an adolescent clinic before moving to an adult clinic)</li> <li>• Introduction to the adult provider before transfer</li> </ul>	Posttransfer clinic attendance was highest in the districts in which patients met the adult provider pretransfer
Lane et al 2007 <sup>28</sup> (United States)	Retrospective cohort	<ul style="list-style-type: none"> <li>• Patient education and skill building</li> <li>• Specialized young adult clinic</li> </ul>	HbA1c levels did not change in either clinic overall; Decrease in HbA1c levels larger in patients from the young adult clinic for subgroup with the highest levels of HbA1c
Van Walleggham et al 2006 <sup>30</sup> (Canada)	Prospective cohort	<ul style="list-style-type: none"> <li>• Systems navigator model with administrative coordinator</li> <li>• Patient education; technology for education and reminders</li> </ul>	Higher dropout rate (40%) among individuals without access to navigator compared with 11% of individuals with access.
Vanelli et al 2004 <sup>31</sup> (Italy)	Other	<ul style="list-style-type: none"> <li>• Protocol for an uninterrupted transfer</li> <li>• Pediatrician attendance at the adult care visit</li> </ul>	Higher patient satisfaction; improvement in HbA1c levels at 1-year posttransition
Vidal et al 2004 <sup>40</sup> (Spain)	Other	<ul style="list-style-type: none"> <li>• Patient education and skill building</li> </ul>	Decrease in HbA1c and in the number of hypoglycemic episodes

<sup>a</sup> Design types are classified as randomized controlled trial, prospective cohort, retrospective cohort, and other.

evaluation studies, only 2 of which were randomized controlled trials. Because most transition care interventions are implemented at the system level and are delivered to all relevant patients at the same time, few of the studies included a concurrent comparison group; most of the studies relied on data from patients who transitioned before the transition-specific services were available as comparators.

Common components of care included educational materials, sometimes using computer-based programming, a special clinic for young adults in transition, and the use of a transition coordinator. Outcomes were generally patient-reported and focused mostly on issues such as satisfaction with the transition process or health-related quality of life, but also include objective measures such as HbA1c levels for patients with diabetes and rates of organ rejection among transplant patients. Generally, however,

successful transition is defined as attendance in adult care (transfer) or continued adherence to medication. Thus, although the programs offered comprehensive support rightly regarded as transition care, evaluation outcomes focused (at least in large part) on outcomes traditionally regarded as an index of the more limited concept of transfer.

Future research must address both methodologic and substantive issues. Methods issues include the need for a common and validated definition of transition success, more rigorous study designs, dedicated funding, and inclusion of a broader range of clinical research perspectives (ie, involvement of pediatric and adult researchers). The lack of well-defined outcome measures is a major barrier.<sup>51–54</sup> Possible metrics to evaluate success could include clinician, adolescent, and parent perception of success and satisfaction with the transition process, improved or stable

disease-specific medical outcomes,<sup>55,56</sup> decreased or stable cost of health care, or educational milestones in patients' ability to care for themselves or navigate the health care setting.<sup>54,57,58</sup> Without clear clinical or functional outcomes identified, most studies have focused on qualitative measures including clinicians' or patients' perceptions of success without objective measurements to support the claims of success of individual transition processes. No validated measures of transition have been developed.<sup>51</sup>

Future methodologic research should focus on identifying or developing objective measures of successful transition as well as transition tools.<sup>59,60</sup> Quality-of-life and personalized outcomes identified by the adolescents participating in transition care could be significant outcome measures, but others should be developed as well.<sup>51,52,54,61,62</sup> In addition, few studies provided data on

**TABLE 3** Overview of Transplant Transition Studies

Citation (Location)	Design <sup>a</sup>	Transition Care Elements	Summary of Findings
Annunziato et al 2013 <sup>34</sup> (United States)	Other	<ul style="list-style-type: none"> <li>• Transition coordinator</li> </ul>	Improved medication adherence for patients with access to the transition coordinator
Chaturvedi et al 2009 <sup>26</sup> (Australia)	Other	<ul style="list-style-type: none"> <li>• Specialized transition clinic</li> <li>• Patient education</li> </ul>	No change in organ rejection; medication adherence worsened after care transfer
Harden et al 2012 <sup>22</sup> and 2013 <sup>48</sup> (United Kingdom)	Other	<ul style="list-style-type: none"> <li>• Specialized transition clinic</li> <li>• Joint pediatric and young adult provider visits</li> </ul>	Lower organ rejection in patients with access to the transition clinic
Pape et al 2013 <sup>33</sup> (Germany)	Retrospective cohort	<ul style="list-style-type: none"> <li>• Specialized transition clinic</li> </ul>	No change in clinical outcomes; patient satisfaction was higher with transition clinic
Prestidge et al 2012 <sup>25</sup> (Canada)	Other	<ul style="list-style-type: none"> <li>• Specialized transition clinic (Transition Clinic)</li> </ul>	Lower organ rejection and death in patients with access to the transition clinic; lower cost

<sup>a</sup> Design types are classified as randomized controlled trial, prospective cohort, retrospective cohort, and other.

long-term follow-up, which could be important for considering the ultimate success of transitioning.

Randomization in transition research can be problematic because medical care is multidisciplinary, and isolating any 1 intervention or holding constant concomitant interventions is difficult.<sup>34,35,58,63</sup> However, rigorous evaluation of multidisciplinary transition programs is needed. Ideal designs would evaluate participants before, during, and after the transition period. These studies would therefore need to be long and thus may be cost-prohibitive.<sup>52,58,64,65</sup> One method to obtain prospective data for evaluation of transition would be the development of disease-specific or location-specific core transition data sets that could be used for research of the transition process over the short and long terms.<sup>58</sup> An alternative to using longitudinal studies to evaluate the impact of transition on patient outcomes and assess overall improvement in the transition process is quality improvement initiatives and evaluation designs.<sup>66–69</sup> Quality improvement research could help identify best practices for transition,<sup>66</sup> factors within transition that affect outcomes positively or negatively,<sup>52,56,57</sup> and individual predictors for successful transition.<sup>52,56</sup>

Funding streams generally focus on specific diseases, but the field of transition research would benefit from

more generalized research that can identify effective methods across disease groups. Identifying funding streams that are not disease-specific may be challenging but important.<sup>58</sup>

Traditionally, transition efforts and research have been led by pediatric providers even though adult providers are an essential part of the process. Future research should include both pediatric and adult researchers<sup>58</sup> and require involvement of primary care providers and subspecialty care providers when applicable. No research has identified an optimal timing of transfer when multiple provider specialties are involved in an individual patient's care. Therefore, future research involving primary and subspecialty care providers could help guide which service should transfer first during the transition process and the overall timing of transitions.

Areas and opportunities for future research include technology, information about health care systems, disease progression, patient-specific transition, educational research, and cost research. The use of technology in transition has particular promise for adolescents, who may be more comfortable users of technology than some adults. Novel uses of technology to improve adherence to medications, to provide education regarding their medical disease, to identify medical deterioration earlier, and to

communicate with their health care providers should be further considered in future studies.<sup>44,53,58,70</sup> Some of the disparities in access to care as CSHCN transition to adulthood may be minimized by expansion and evaluation of uses of technology such as telemedicine, text messaging, or social media.<sup>44,58</sup>

Although research focusing on generalizable transition care processes is essential, the development of validated tools to aid a variety of health care systems in implementing successful transition is also necessary. Evaluations of transition care programs will need to specify the type of systems in which the transition was performed and what resources or tools were required to implement the program.

Documentation of resources could include specific programs such as city-based transportation programs and institutional resources such as personnel, educational opportunities, and electronic medical record support. Identifying the differences and similarities within successful transition processes could be beneficial to the medical community as individual clinical systems modify components of the transition processes to work within their systems.

With improved clinical outcomes, many chronic diseases that were formerly seen only in pediatrics are now affecting adults. The adult course of these diseases is largely unknown, and therefore,



**TABLE 4** Overview of Other Special Health Needs Transition Studies

Citation (Location)	Health Need	Design <sup>a</sup>	Transition Care Elements	Summary of Findings
Andemariam et al 2013 <sup>41</sup> (United States)	Sickle cell disease	Other	<ul style="list-style-type: none"> <li>• Patient education (family meetings)</li> <li>• Multidisciplinary team</li> </ul>	Majority of patients successfully transitioned
Bent et al 2002 <sup>35</sup> (United Kingdom)	Physical disability	Other	<ul style="list-style-type: none"> <li>• Multidisciplinary team (Young Adult Team)</li> <li>• Patient education (cognitive-behavioral transition preparation training)</li> </ul>	Increased participation in society No between-group differences
Betz et al 2010 <sup>42</sup> (United States)	Spina bifida	Randomized controlled trial	<ul style="list-style-type: none"> <li>• Specialized transition clinic (Creating Healthy Futures)</li> </ul>	
Bundock et al 2011 <sup>24</sup> (United Kingdom and Australia)	HIV, diabetes	Other	<ul style="list-style-type: none"> <li>• Multidisciplinary team</li> <li>• Outpatient services with sequential approach to transition (HIV) or direct transfer approach (diabetes)</li> </ul>	Patients in both groups reported that transition went smoothly and was associated with improved health care
Chaudhry et al 2013 <sup>37</sup> (United States)	Cystic fibrosis	Other	<ul style="list-style-type: none"> <li>• Transition coordinator</li> <li>• Patient education</li> </ul>	Improved satisfaction with transfer to adult care
Gleeson et al 2013 <sup>21</sup> (United Kingdom)	Congenital adrenal hyperplasia	Other	<ul style="list-style-type: none"> <li>• Multidisciplinary team</li> <li>• Specialized transition clinic (Young Persons Clinic)</li> </ul>	No change in successful transfer
Greveson et al 2011 <sup>43</sup> (United Kingdom)	Inflammatory bowel disease	Other	<ul style="list-style-type: none"> <li>• Multidisciplinary team</li> <li>• Patient education (joint bimonthly visit focused on transition-related issues)</li> </ul>	Mean time spent in transition clinic was 8 mo
Hankins et al 2012 <sup>36</sup> (United States)	Sickle cell disease	Other	<ul style="list-style-type: none"> <li>• Transition program (tour of adult clinic, social events, pediatric and adult collaboration)</li> <li>• Direct scheduling</li> </ul>	Majority attended their first adult appointment
Huang et al 2014 <sup>44</sup> (United States)	Diabetes, inflammatory bowel disease, and cystic fibrosis	Randomized controlled trial	<ul style="list-style-type: none"> <li>• Patient education (technology-based disease management)</li> <li>• Specialized transition clinic; nurse-led (Adolescent Epilepsy Transition Clinic)</li> <li>• Patient education</li> </ul>	Relative to controls, transition program patients had improved disease management task performance, health-related self-efficacy and patient-initiated communication Patients and caregivers report satisfaction
Jurasek et al 2010 <sup>25</sup> (Canada)	Epilepsy	Other	<ul style="list-style-type: none"> <li>• Patient education</li> </ul>	Improved self-advocacy and transition readiness
Maslow et al 2012 <sup>20</sup> (United States)	Chronic illness	Other	<ul style="list-style-type: none"> <li>• Mentoring program (Adolescent Leadership Council)</li> <li>• Patient education</li> <li>• Transition care coordinator</li> <li>• Patient education</li> </ul>	Improved satisfaction scores; higher acceptability with use of coordinator
McDonagh et al 2006, <sup>49</sup> 2007 <sup>38</sup> ; Shaw et al 2006 <sup>75</sup> (United Kingdom)	Juvenile idiopathic arthritis	Other		

<sup>a</sup> Design types are classified as randomized controlled trial, prospective cohort, retrospective cohort, and other.

aspects of transition specific for these diseases remain unclear. For these diseases, prospective tracking of the natural course and complications of these diseases will be necessary to determine what components of transition will be required when caring for adults with these diseases.<sup>55,61,63</sup>

Appropriate timing and tools for successful transition may vary by severity or type of disease. Research of transition programs would need to control for these differences in care and outcomes. In addition, the hypothesis that children with different diseases may require different transition processes requires further investigation because no study has evaluated the efficacy of disease-specific versus general transition processes in a comparative manner.

Intellectual disability can be associated with some chronic diseases that affect children transitioning to adult care. The severity of disability influences the degree with which a young adult can manage his or her own care and therefore affects measures of successful transition. Physical and developmental delays or impairment can affect the ability of individuals to navigate the medical system independently. Transition research needs to include stratification for cognitive ability and developmental delay for

the subjects, if variability exists. Future research efforts should evaluate the success of transition program modifications for patients with cognitive or physical impairments.

Behavioral health care is important in the transition process to provide support and services to address coping with chronic medical diseases and treatment, nonadherence, and psychological effects of their chronic disease. Few studies have addressed this aspect of transition care. Studies evaluating the role of behavioral health within the transition process are critical.

We identified 1 cost study. The study took place in England, so the relevance of the results to the US health care system may be limited. The study identified increased costs associated with the transition period but did not find that an organized transition program was more resource-intensive than ad hoc services.<sup>55</sup> With future transition research, researchers should attempt to report the costs associated with transition implementation and service. This information can then be compared with the costs of unsuccessful transition in this patient population.<sup>62,65</sup>

We note that our search was restricted to articles published in English, and we did not include a review of literature on

palliative or hospice care. Although our conclusions are limited by the small number of studies included in the review, the generally poor methodologic quality of the included studies, and difficulties inherent to evaluating complex and multicomponent interventions such as comprehensive transition care programs, we also note that our findings are consistent with those from previous reviews.<sup>71–74</sup>

The issue of how to provide good transition care for CSHCN warrants further attention. The number of CSHCN reaching adulthood is increasing, and the diversity of their clinical conditions is expanding. Future research needs are wide ranging, including both substantive and methodologic improvements. At this time, the field lacks even a consistent and accepted way of measuring transition success, and it will be essential to establish consistent goals to build an adequate body of literature to affect practice.

## ACKNOWLEDGMENTS

Tanya Surawicz contributed to the data collection; Rebecca Jerome contributed to data collection and interpretation; and Shannon Potter designed the data collection instruments, coordinated and supervised data collection, and assisted in the preparation of the manuscript.

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**FUNDING:** This project was supported by the Agency for Healthcare Research and Quality (contract number HHS290-2012-00009-I). Dr Taylor was also supported by a career development award from the National Institute of Mental Health (K01 MH092598, Taylor, PI).

**POTENTIAL CONFLICT OF INTEREST:** Dr Taylor was supported by a career development award from the National Institute of Mental Health (K01 MH092598, Taylor, PI). The other authors have indicated they have no financial relationships relevant to this article to disclose.