

# Evaluating Continuity During Transfer to Adult Care: A Systematic Review

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abstract

**CONTEXT:** Appropriate outcomes are required to evaluate transition programs' ability to maintain care continuity during the transfer to adult care of youths with a chronic condition.

**OBJECTIVE:** To identify the outcomes used to measure care continuity during transfer, and to analyze current evidence regarding the efficacy of transition programs.

**DATA SOURCES:** PubMed (1948–2014), Web of Science (1945–2014), Embase (1947–2014), and the reference lists of the studies identified.

**STUDY SELECTION:** Screening on titles and abstracts; full-text assessment by 2 reviewers independently.

**DATA EXTRACTION:** By 2 reviewers independently, by using a Cochrane form adapted to observational studies, including bias assessment.

**RESULTS:** Among the 23 studies retrieved, all but 5 were monocentric, 16 were cohorts (15 retrospective), 6 cross-sectional studies, and 1 randomized trial. The principal disease studied was diabetes ( $n = 11$ ). We identified 24 indicators relating to 2 main aspects of continuity of care: engagement and retention in adult care. As designed, most studies probably overestimated engagement. A lack of adjustment for confounding factors was the main limitation of the few studies evaluating the efficacy of transition programs.

**LIMITATIONS:** The assessment of bias was challenging, due to the heterogeneity and observational nature of the studies.

**CONCLUSIONS:** This review highlights the paucity of knowledge about the efficacy of transition programs for ensuring care continuity during the transfer from pediatric to adult care. The outcomes identified are relevant and not specific to a disease. However, the prospective follow-up of patients initially recruited in pediatric care should be encouraged to limit an overestimation of care continuity.



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Dr Rachas conceptualized and designed the review, designed and tested the data collection form, reviewed all articles, carried out the analyses, and drafted the initial manuscript; Dr Lefevre reviewed articles; Dr Warszawski tested the data collection form, reviewed articles, and drafted the initial manuscript; Drs Faye, Mahlaoui, de La Rochebrochard, and Meyer reviewed the final manuscript as submitted; Dr Durieux conceptualized and designed the review and reviewed articles; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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In high-income countries, the prognosis of childhood-onset chronic conditions has improved in recent decades, such that larger numbers of patients now reach adulthood. For instance, the proportion of patients with cystic fibrosis reaching adulthood (>18 years of age) increased from 27% to 56% between 1982 and 2007<sup>1</sup> and forecasts indicate an expected increase in the overall number of adult patients with cystic fibrosis of ~75% by 2025 in Western European countries.<sup>2</sup> It is estimated that almost 90% of children with congenital heart diseases will survive into adulthood,<sup>3</sup> together with 94% of children with sickle cell anemia.<sup>4</sup> The population of perinatally HIV-infected patients is also aging.<sup>5</sup>

For several reasons, including the occurrence of adult-specific issues, such as reproduction, these patients need to be transferred from pediatric to adult care. However, several studies have suggested that this transfer may be associated with poor outcomes, including a low frequency of medical visits,<sup>6,7</sup> a lack of compliance with treatment regimens,<sup>8,9</sup> and a higher risk of unplanned health care use.<sup>10,11</sup> It has been recommended, to avoid such events, the planning and implementation of the transfer into adult care should be carefully prepared and smoothed.<sup>12</sup> The concept of “transition to adult care” covers the purposeful process beginning in childhood and ending in adulthood, during which the patient switches to, and is accepted by, adult health care services.

In a comprehensive approach to patient management, evaluations of successful transition to adult care should be multidimensional, both for individual patients and for evaluations of the transition program. Relevant outcomes, identified by the Delphi method<sup>13</sup> and literature reviews,<sup>14,15</sup> may include the patient building a trusting relationship with an adult care provider, continuing

attention to self-management, clinical outcomes (such as unplanned health care use), biological outcomes (HbA1c in diabetes), the satisfaction of patients and their parents, quality of life, and continuity of care.

Experts have almost unanimously identified 1 particular indicator as critical: the patients lost to follow-up.<sup>13</sup> Indeed, continuity of care is a core issue for patients transferring from pediatric to adult care systems. It has been shown to be related to patient satisfaction, a lower frequency of hospital admissions and emergency department visits, and a greater use of preventive services.<sup>16</sup> Appropriate outcomes are therefore required for the evaluation of continuity of care in patients with childhood-onset chronic diseases transferring to adult care. Such outcomes are required, in particular, for the comparison of processes and transfer success by time period, country and care organization with or without structured transition programs, and according to disease-related and sociodemographic factors. Appropriate outcomes are also required for evaluating the efficacy of transition programs in randomized studies.

In 2006, a systematic review identified various continuity of care indices used in pediatric studies, which could be grouped into 5 categories: duration, density, dispersion, sequence, and subjective.<sup>17</sup> The most common were density indices, measuring contacts with the usual provider of care. However, this review did not focus on patients with chronic diseases and, more importantly, did not consider continuity of care at the time of transfer to adult care. As this period may correspond to changes in the medical team and, in some cases, in the geographic site at which care is provided, specific continuity of care outcomes would probably be more appropriate.

We carried out a systematic literature review, addressing the issue of care continuity in patients with a chronic disease, during the transfer to adult care. Our main objective was to identify the strengths and limitations of the various continuity of care outcomes used in both interventional and noninterventional studies, to harmonize and improve the quality of future research on the transition to adult care. A secondary objective was to analyze whether published studies provide evidence regarding the efficacy of structured transition programs in terms of care continuity.

## METHODS

### Criteria for the Identification of Studies for This Review

We considered original studies (interventional or noninterventional) including quantitative data and addressing the transition from pediatrics to adult care of patients with chronic diseases.

Studies had to meet the following criteria for inclusion in this review: (1) some or all of the patients included had to have a long-term health condition requiring ongoing health care, (2) patient care was initiated in a pediatric department, (3) at least 1 indicator of continuity of care with the usual provider of care was reported, and (4) the study was not limited to continuity of care in a pediatric department.

We excluded studies that included only fully institutionalized patients, patients suffering from a primary mental disease, or treated for cancer in childhood. In the 2 first cases, the conditions concerned have a direct impact on the autonomy of the patient in terms of care continuity and transfer to adult services. For patients with cancer, long-term follow-up is justified principally by the need to check for relapses and complications of treatment in the long term.

## Search Methods for Identification of Studies

We searched for references with PubMed (1948–2014), Web of Science (1945–2014), and Embase (1947–2014) by using the search strategy described in Supplemental Table 6 together with an algorithm developed by McPheeters et al.<sup>14</sup> Sensitivity was maximized by the use of an algorithm searching for articles addressing the topic of the transition to adult care. As we wished to identify all the studies dealing with chronic diseases, no matter what the disease, and all the continuity of care outcomes studied, we did not use keywords to select specific diseases or specific outcomes. The articles selected had to have been published in English or French. Finally, we searched the reference lists of the selected articles.

## Data Collection and Analysis

### Selection of Studies

One reviewer (the first author, AR) downloaded all records identified by the electronic searches to the reference management database Zotero (version 4.0, <https://www.zotero.org/>), and removed duplicates. He performed a preliminary screening of the titles and abstracts and excluded irrelevant references (those not corresponding to original articles addressing any aspect of the transition to adult care in patients with a chronic condition). The full-text articles of the selected references were downloaded when possible. If not, we contacted the corresponding authors by E-mail to obtain a copy of the article. If no response was obtained after 2 e-mails had been sent, the article was considered to be unavailable.

Two reviewers, systematically including AR and 1 of DL, JW, and PD, independently assessed the full texts for the inclusion criteria and extracted data, and evaluated the risks of bias of each of the studies included. Disagreements were

resolved by discussion between reviewers, or arbitration by a third reviewer.

### Data Extraction and Management

A standardized electronic data extraction form was adapted from the Cochrane Effective Practice and Organization of Care data extraction form (<http://epoc.cochrane.org/epoc-specific-resources-review-authors>), which was created for reviews of interventional studies. AR and JW tested this form with 3 articles and adapted it according to the results obtained. The data extracted included study design and settings, study population, continuity of care outcomes, their mode of collection, and a comprehensive risk of bias assessment.

### Assessment of the Risk of Bias for the Studies Included

We used the criteria defined in the “Cochrane handbook for systematic reviews of interventions” (<http://handbook.cochrane.org/>). However, these criteria were defined for interventional trials and do not cover all potential sources of bias found in observational studies. We therefore assessed 4 additional standardized criteria: inadequate measurement of risk factors (whereas only the inadequate measurement of outcomes was considered in the Cochrane Handbook), inappropriate eligibility criteria according to the target population, lack of participation of eligible subjects, and confounding bias (which is not explicitly mentioned in the Cochrane Handbook). Each type of bias was assessed only when appropriate, according to the study design. For instance, risk of confounding was assessed for nonrandomized comparative studies only. The detailed definitions and applicability of the risk of bias assessment are reported in Supplemental Table 7.

### Review Synthesis

We first described the characteristics of the studies included. By informal consensus, we grouped the indicators used in the different studies into several types of outcome corresponding to different aspects of continuity of care. The results of the studies are presented by type of outcome and according to whether the patients were cared for within a structured transition program (ie, which refers to an explicit transition policy).<sup>14</sup> For example, this was the case in a study evaluating a young person clinic (structured transition) compared with no young person clinic (unstructured transition).<sup>6</sup> Because of the heterogeneity of the study designs, we assessed the risks of bias separately for cross-sectional studies (repeated or not), cohort studies, and randomized controlled trials, by using Cochrane reports figures. Justifications given by the authors who assessed the risks of bias were also summarized.

The review protocol is available on demand (in French).

## RESULTS

### Results of the Search

As shown on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (<http://prisma-statement.org>) flowchart (Fig 1), the electronic searches yielded 3736 nonduplicate records, 3539 of which were deemed irrelevant after a preliminary screening of titles and abstracts. We excluded 173 of the remaining 197 records after full-text assessment: 168 of the excluded studies focused exclusively on outcomes other than continuity of care, such as readiness for transfer, patient satisfaction, quality of life, perceived needs, or biological (often HbA1c in patients with diabetes) or clinical health status. Finally, 24 articles relating to 23 studies were considered eligible and were

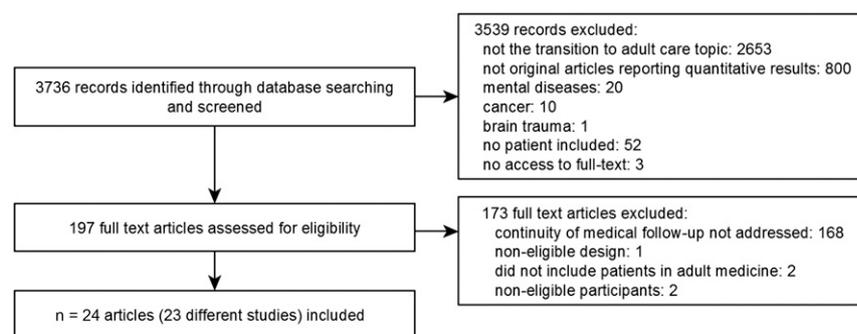
included in this review. Two articles reported results from the same study.<sup>18,19</sup> No additional articles were retrieved from searches of the reference lists of these 24 articles.

### Study Designs, Settings, and Study Populations

The objective was exclusively descriptive in 4 studies (17%). In the others, the aim was to identify factors associated with outcome (12 studies, 52%) or to evaluate structured transition programs (7 studies, 30%) (Supplemental Tables 8 and 9). With the exception of 1 randomized trial, all the studies were observational: 15 retrospective cohorts, 1 cohort that was both retrospective and prospective, and 6 cross-sectional studies. Most of the studies were performed in North America and Europe ( $n = 22$ ). Three of the studies focused on the general population, whereas the others involved patient recruitment at hospitals (pediatric units in 8 studies, adult care units in 6, and both types of unit in 4). All but 5 of the studies were carried out at single centers. The principal diseases studied were diabetes (11 studies<sup>7,18,20–28</sup> with 26 to 250 patients; 1148 overall), congenital heart disease (4 studies<sup>29–32</sup> with 153 to 794 patients; 1465 overall), and sickle cell disease (3 studies<sup>33–35</sup> with 18 to 83 patients; 148 overall). The other diseases studied were rheumatic diseases (131 patients in 2 studies<sup>36,37</sup>), congenital adrenal hyperplasia (53 patients<sup>6</sup>) and cystic fibrosis (68 patients<sup>38</sup>). One study<sup>39</sup> included youths with special health care needs ( $n = 1865$  participants) due to various diseases (ie, it was not specific to a particular disease).

### Outcomes Measuring Continuity of Care

A total of 24 different indicators of continuity of care were reported in the included studies (Table 1): 7 related to engagement in adult care, 14 to retention in adult care, and 3 corresponding to a combination of



**FIGURE 1**  
Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart.

outcomes. Engagement in adult care comprised indicators of attendance at the first or the first 2 adult care unit visits and indicators of time between the last pediatric and the first adult visit. Retention in adult care was measured by the frequency of visits and attendance at scheduled clinic appointments.

### Engagement in Adult Care

The percentages of patients attending the first or the first 2 adult care visits were reported in 8 studies (Table 2). The proportion of patients attending the first adult care visit ranged from 56% to 79% with a structured transition and from 47% to 100% with an unstructured transition. The proportion of patients attending the first 2 adult care visits was reported in only 1 study: 56% of 34 patients with congenital adrenal hyperplasia.<sup>6</sup> Two studies, including the latter, compared structured and unstructured transitions and reported no significant difference between these 2 types of transition.<sup>6,22</sup>

The time between the last pediatric visit and the first adult visit, reported in 10 studies (Table 3), was highly variable, as were the results, even for a single disease. Structured and unstructured transitions were compared in 3 studies: there was a shorter time between these 2 visits in structured transition conditions in 2 studies, on diabetes<sup>26</sup> and sickle cell disease,<sup>34</sup> whereas no

significant difference was found between structured and unstructured transitions in the third study,<sup>22</sup> which focused on diabetes.

### Retention in Adult Care After Transfer

Retention in adult care once the first contact had been established was reported in 14 studies, evaluated at 1 year after transfer in 8 studies, 15 to 18 months in 1 study, 2 years in 3 studies, and at least 3 years after transfer in 4 studies.

The frequency of visits, reported in 8 studies (Table 4), was lower in adult than pediatric care in 2 studies on diabetes,<sup>7,24</sup> whereas it was the opposite in 1 study on cystic fibrosis.<sup>38</sup> The frequency of adult care visit did not differ significantly between structured and unstructured transitions in 2 studies.<sup>20,22</sup>

Attendance at scheduled clinic appointments after transfer, reported in 5 studies (Table 5), was measured as the mean percentage of scheduled appointments attended per year in 2 studies,<sup>6,26</sup> as the proportion of patients attending appointments at 1 year<sup>36</sup> or 2 years,<sup>37</sup> or as the number of failed appointments.<sup>27</sup> One study on diabetes found a trend toward better attendance after structured than after unstructured transition.<sup>26</sup>

### Combined Outcomes (Not Shown in Tables)

Three studies used more complex outcomes (Table 1). In 1 study, also cited in Tables 2 and 5, the authors

**TABLE 1** Reported Outcomes and Indicators of Continuity of Care

Type of Outcome	Outcome	Indicator	Source (Ref. No.)
Engagement in adult care	Attendance at the first visit in adult care	Proportion	Andemariam 2014 <sup>35</sup> , Kipps 2002 <sup>24</sup> , Hazel 2010 <sup>37</sup> , Hersh 2009 <sup>36</sup> , Reid 2004 <sup>30</sup> , Wojciechowski 2002 <sup>33</sup> , Steinbeck 2014 <sup>22</sup> , Gleeson 2013 <sup>6</sup>
	Attendance at the first 2 visits in adult care	Proportion	
	Time between the last pediatric visit and the first adult visit	Mean ( $\pm$ SD)	Vanelli 2004 <sup>21</sup> , Wojciechowski 2002 <sup>33</sup> , Cadario 2009 <sup>26</sup>
		Median ( $\pm$ IQR)	Hersh 2009 <sup>36</sup> , Wojciechowski 2002 <sup>33</sup> , Yeung 2008 <sup>29</sup> , Steinbeck 2014 <sup>22</sup>
Retention in adult care	Frequency of visits	Proportion <3 mo	Stanczyk 2014 <sup>23</sup> , Hankins 2012 <sup>34</sup>
		Proportion <6 mo	Garvey 2012 <sup>18</sup> , Garvey 2013 <sup>19</sup> , Garvey 2013 <sup>25</sup> , Stanczyk 2014 <sup>23</sup>
		Proportion <24 mo	Yeung 2008 <sup>29</sup>
		Mean ( $\pm$ SD) per year	Dugueperoux 2008 <sup>38</sup> , Busse 2007 <sup>7</sup>
		Median ( $\pm$ IQR) per year	Steinbeck 2014 <sup>22</sup>
		Proportion $\geq$ 3–4 monthly	Kipps 2002 <sup>24</sup>
		Proportion $\geq$ 6 monthly	Kipps 2002 <sup>24</sup>
		Proportion with $\geq$ 1 cardiology clinic visit within 2 y of study interview	Norris 2013 <sup>31</sup>
		Proportion with no 2-y interval without cardiac care	Norris 2013 <sup>31</sup>
		Proportion with no delay >12 mo between 2 visits	Pacaud 2005 <sup>28</sup>
	Attendance at scheduled clinic appointments	Proportion with $\geq$ 1 visits per year	Van Wallegghem 2008 <sup>20</sup>
		Proportion with $\geq$ 2 visits per year	Pacaud 2005 <sup>28</sup>
		Proportion with 1–2 or $\geq$ 3 visits per year	Stanczyk 2014 <sup>23</sup>
Attendance at scheduled clinic appointments	Mean percentage of scheduled clinic appointments attended by year	Gleeson 2013 <sup>6</sup> , Cadario 2009 <sup>26</sup>	
	Proportion with 0–1/2/ $\geq$ 3 failed appointments	Johnston 2006 <sup>27</sup>	
	Proportion attending at least one scheduled clinic appointment in the 2 y after transfer	Hazel 2010 <sup>37</sup>	
Other	Unsuccessful transfer: failure to make initial contact with an adult rheumatologist, or failure to continue to follow up with an adult rheumatologist 2 years after transfer (no contact for a 1-year period after the last scheduled appointment)	Proportion attending all their scheduled clinic appointments	Hersh 2009 <sup>36</sup>
		Proportion	Hazel 2010 <sup>37</sup>
	Follow-up in adult care: patients indicated that they were currently in cardiac follow-up or they could be contacted by mail or phone	Proportion	Goossens 2011 <sup>32</sup>
Successful transition: (has usual health care source or has usual routine preventive care source or has a personal doctor or nurse) and (his/her doctor does not treat only children, teens, or young adults) and (he/she has had continuous health insurance coverage for the past 12 mo) and (health insurance benefits meet his/her needs) and (he/she had at least 1 preventive health care visit in the last 12 mo) and (he/she is satisfied with health services) and (needed health care was not delayed/foregone in the last 12 mo)	Proportion	Oswald 2013 <sup>39</sup>	

IQR, interquartile range.

**TABLE 2** Engagement in Adult Care: Attendance at the First or First 2 Adult Care Visits (*n* = 8 Studies)

Source (Ref. No.)	Population and Design	Data Collection	Type of Transition	Indicator of Attendance at the First <sup>a</sup> Adult Care Visit
Andemariam 2014 <sup>35</sup>	SCD; USA; Retrospective cohort; <i>n</i> = 47	Retrospective chart review	Structured	Proportion: 68%
Kipps 2002 <sup>24</sup>	Diabetes; UK; Retrospective cohort; <i>n</i> = 141	Retrospective chart review	Structured	Proportion: 79%
Hazel 2010 <sup>37</sup>	Rheumatic disease; Canada; Retrospective cohort; <i>n</i> = 100	Retrospective chart review, Interview with health care provider	Unstructured	Proportion: 83%
Hersh 2009 <sup>36</sup>	Rheumatic disease; USA; Cross-sectional; <i>n</i> = 31	Retrospective chart review, administrative database	Unstructured	Proportion: 71%
Reid 2004 <sup>30</sup>	CHD; Canada; Retrospective cohort; <i>n</i> = 360	Administrative database	Unstructured	Proportion: 47%
Wojciechowski 2002 <sup>33</sup>	SCD; USA; Retrospective cohort; <i>n</i> = 47	Interview with health care provider	Unstructured	Proportion: 61%
Gleeson 2013 <sup>6</sup>	CAH; UK; Retrospective cohort; <i>n</i> = 34	Retrospective chart review, administrative database	Young person clinic versus no young person clinic	Proportion: 56% <sup>§§</sup> (not reported by group)
Steinbeck 2014 <sup>22</sup>	Diabetes; Australia; RCT; <i>n</i> = 26	Unclear	Comprehensive transition program versus standard clinical practice	Proportions: 79% vs 100% <sup>§§</sup>

CAH, congenital adrenal hyperplasia; CHD, congenital heart disease; RCT, randomized controlled trial; SCD, sickle cell disease.

<sup>a</sup> Except for Gleeson 2013 (5), who reported attendance at the first 2 adult care visits.

<sup>§§</sup> *P* ≥ .10 (or reported as no significant difference with no *P* value).

**TABLE 3** Engagement in Adult Care: Time Between Last Pediatric and First Adult Visit (*n* = 10 Studies)

Source (Ref. No.)	Population and Design	Data Collection	Type of Transition	Indicators of Time Between Last Pediatric and First Adult Visit
Vanelli 2004 <sup>21</sup>	Diabetes; Italy; Cross-sectional; <i>n</i> = 64	Telephone interview with the patient	Structured	Mean ± SD: 26.4 ± 25.2 mo
Garvey 2012 <sup>18</sup> & 2013 <sup>19</sup>	Diabetes; USA; Cross-sectional; <i>n</i> = 250	Web-based and non-Web-based autoquestionnaires	Unstructured	Proportion ≤6 mo: 66%
Garvey 2013 <sup>25</sup>	Diabetes; USA; Retrospective cohort; <i>n</i> = 61	Web-based and non-Web-based autoquestionnaires	Unstructured	Proportion ≤6 mo: 74%
Hersh 2009 <sup>36</sup>	Rheumatic disease; USA; Cross-sectional; <i>n</i> = 31	Retrospective chart review, administrative database	Unstructured	Median: 7.1 mo
Stanczyk 2014 <sup>23</sup>	Diabetes; Poland; Retrospective cohort; <i>n</i> = 114	Telephone interview with the patient, non-Web-based autoquestionnaire	Unstructured	Proportion <3 mo: 84% Proportion ≤6 mo: 91%
Wojciechowski 2002 <sup>33</sup>	SCD; USA; Retrospective cohort; <i>n</i> = 18	Interview with health care provider	Unstructured	Mean ± SD: 6.2 ± 7.7 mo Median: 2 mo
Yeung 2008 <sup>29</sup>	CHD; USA; Cross-sectional; <i>n</i> = 158	Face-to-face interview with the patient, proxy interview (eg, parents)	Unstructured	Proportion <24 mo: 37% Median: 120 mo
Hankins 2012 <sup>34</sup>	SCD; USA;  Retrospective cohort; <i>n</i> <sup>a</sup>	Unclear	Before Transition Pilot Program implementation: unstructured ( <i>n</i> = 75) Participation to Transition Pilot Program versus no participation ( <i>n</i> = 83)	Proportion <3 mo: 15% Proportions <3 mo: 74% vs 33% <sup>***</sup>
Cadario 2009 <sup>26</sup>	Diabetes; Italy; Cross-sectional; <i>n</i> = 62	Administrative database	Structured versus unstructured transition	Mean ± SD: 9.6 ± 7.2 mo vs. 55.2 ± 14.4 mo <sup>***</sup>
Steinbeck 2014 <sup>22</sup>	Diabetes; Australia; RCT; <i>n</i> = 18	Unclear	Comprehensive transition program versus standard clinical practice	Median (IQR): 3.4 (1.8–4.4) mo vs 3.2 (2.5–4.6) mo <sup>§§</sup>

CHD, congenital heart disease; IQR, interquartile range; RCT, randomized controlled trial; SCD, sickle cell disease.

<sup>a</sup> *n* specified in "type of transition" column.

<sup>\*\*\*</sup> *P* < .001.

<sup>§§</sup> *P* ≥ .10 (or reported as no significant difference with no *P* value).

**TABLE 4** Retention in Adult Care After Transfer: Frequency of Visits (*n* = 8 Studies)

Source (Ref. No.)	Population and Design	Data Collection	Type of Transition	Indicators of Frequency of Visits <sup>a</sup>
Dugueperoux 2008 <sup>38</sup>	CF, France; Repeated cross-sectional; <i>n</i> = 68	Retrospective chart review	Structured	1 y before transfer: mean 3.8 /y 1 y after transfer: mean 8.7 /y <sup>***</sup> Proportion ≥3–4 monthly: 2 y before transfer: 77%
Kipps 2002 <sup>24</sup>	Diabetes; UK; Retrospective cohort; <i>n</i> = 96	Retrospective chart review	Structured	1 y before transfer: 54% 1 y after transfer: 45% 2 y after transfer: 24% <sup>***</sup> Proportion ≥6 monthly: 2 y before transfer: 98% 1 y before transfer: 87% 1 y after transfer: 81% 2 y after transfer: 61% <sup>***</sup>
Busse 2007 <sup>7</sup>	Diabetes; Germany; Retrospective cohort; <i>n</i> = 101	Telephone interview with the patient, retrospective chart review	Unstructured	Before transfer: mean ± SD: 8.5 ± 2.3/y After transfer: mean ± SD: 6.7 ± 3.2/y <sup>*</sup>
Norris 2013 <sup>31</sup>	CHD; USA; Retrospective cohort; <i>n</i> = 153	Telephone interview with the patient, retrospective chart review, proxy interview (parents, etc.)	Unstructured	Proportion with ≥ 1 cardiology clinic visit within 2 y of study interval: 82%; Proportion with no 2-y interval without cardiac care: 76% Proportion with no delay > 12 mo between 2 visits: 90%; proportion with ≥2 visits/y: 87%
Pacaud 2005 <sup>28</sup>	Diabetes; Canada; Retrospective cohort; <i>n</i> = 214	Non-Web-based autoquestionnaire	Unstructured	
Stanczyk 2014 <sup>23</sup>	Diabetes; Poland; Retrospective cohort; <i>n</i> = 132	Telephone interview with the patient, non-Web-based autoquestionnaire	Unstructured	Proportion with 1–2 visits/y: 87% ≥ 3 visits/y: 13%
Steinbeck 2014 <sup>22</sup>	Diabetes; Australia; RCT; <i>n</i> = 18	Unclear	Comprehensive transition program versus standard clinical practice	Median (IQR): 3 (2–5) /y vs 2 (1–4) /y <sup>\$\$</sup>
Van Wallegghem 2008 <sup>20</sup>	Diabetes; Canada; Retrospective and prospective cohort; <i>n</i> = 64	Telephone interview with the patient, retrospective chart review, administrative database	Before versus after Maestro	Proportion with ≥ 1 visits/y: 89% vs. 95% <sup>\$\$</sup>

CF, cystic fibrosis; CHD, congenital heart disease; IQR, interquartile range; RCT, randomized controlled trial.

<sup>a</sup> In adult care unless otherwise specified.

\*\*\* *P* < .001.

\* *P* < .05.

\$\$ *P* ≥ .10 (or reported as no significant difference with no *P* value).

**TABLE 5** Retention in Adult Care After Transfer: Attendance at Scheduled Clinic Appointments (*n* = 5 Studies)

Source (Ref. No.)	Population and Design	Data Collection	Type of Transition	Indicators of Attendance at Scheduled Clinic Appointments <sup>a</sup>
Gleeson 2013 <sup>6</sup>	CAH; UK; Retrospective cohort; <i>n</i> = 23	Retrospective chart review, administrative database	Structured	Mean percentage of scheduled clinic appointments attended by year <sup>b</sup> : 3 y before transfer: 81% 2 y before transfer: 90% 1 y before transfer: 90% 1 y after transfer: 20% 2 y after transfer: 25% 3 y after transfer: 40%**
Johnston 2006 <sup>27</sup>	Diabetes; UK;	Administrative database	Structured	2 y before transfer, proportion with 0–1 failed appointment: 52% 2 failed appointments: 18% ≥3 failed appointments: 30% 15–18 mo after transfer, proportion with 0–1 failed appointment: 20% 2 failed appointments: 40% ≥3 failed appointments: 40%
Hazel 2010 <sup>37</sup>	Rheumatic disease; Canada; Retrospective cohort; <i>n</i> = 100	Retrospective chart review, interview with the health care provider	Unstructured	Proportion attending at least 1 scheduled clinic appointment in the 2 y after transfer: 65%
Hersh 2009 <sup>36</sup>	Rheumatic disease; USA; Cross-sectional; <i>n</i> = 31	Retrospective chart review, administrative database	Unstructured	Proportion attending all their scheduled clinic appointments: 1 y before transfer: 68% 1 y after transfer: 68%
Cadario 2009 <sup>26</sup>	Diabetes; Italy; Cross-sectional; <i>n</i> = 62	Administrative database	Structured vs unstructured transition	Mean ± SD percentage of scheduled clinic appointments attended by year: Before transfer: 79% ± 3% vs 80% ± 4% <sup>§§</sup> After transfer: 80% ± 12.5% vs 57% ± 5%*

CAH, congenital adrenal hyperplasia; RCT, randomized controlled trial.

<sup>a</sup> In adult care unless otherwise specified.

<sup>b</sup> Values not given (approximations from a figure).

\*\* *P* < .01.

§§ *P* ≥ .10 (or reported as no significant difference with no *P* value).

\* *P* < .05.

defined a combined indicator based on both engagement and retention in adult care: “failure to make initial contact with an adult rheumatologist, or failure to continue to follow-up with an adult rheumatologist 2 years after transfer (no contact for a 1-year period after the last scheduled appointment).”<sup>37</sup> The other 2 studies are cited in Table 1 only. The first addressed current follow-up in adult care, without indicating the proportions of patients lost to follow-up before and after the first contact with the adult care unit.<sup>32</sup> The second used a composite outcome, including clinical attendance, access to a health insurance, self-perception of care, and delayed care.<sup>39</sup>

### Risk of Bias

The risks of bias are presented by study on Fig 2 and according to type

of design in Supplemental Figs 3 and 4.

All cross-sectional studies presented a high risk of selection bias, because they involved the recruitment of patients from adult services. Those who were lost to clinical follow-up during the transfer were thus missing. There was a high risk of confounding for all studies with comparative objectives, because multivariate analyses were either absent or inappropriate in these studies (often due to the limited data or number of patients included). Classification bias due to errors in the measurement of outcome and/or risk factors, which were collected retrospectively by interview, were also frequent.

In cohort studies, the most frequent bias was confounding, for the same

reasons as in cross-sectional studies. The second main limitation was a potential selection bias due to high nonparticipation rates for eligible patients (eg, 82.5% in Oswald et al<sup>39</sup>). In most of these studies, patients were identified retrospectively from their previous pediatric files and some did not respond to letters or phone calls, with these attempts at contact made several years after transfer to adult care in some cases. Finally, there may have been a potential classification bias, due to the retrospective collection of data relating to transfer history.

The main limitation of the only randomized trial included in this review related to the extremely low proportion of eligible patients who agreed to participate, corresponding to only half the

	Eligibility criteria (selection bias)	Recruitment (selection bias)	Incomplete outcome data (attrition bias)	Outcome assessment (classification bias)	Measure of risk factors (classification bias)	Confounding	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Selective reporting (reporting bias)	Other bias
Andemariam 2014	?	-	+	+	?	-				+	+
Busse 2007	-	-	+	-						?	+
Cadario 2009	-	+	?	+		-				+	-
Dugueperoux 2008	-	+	+	+	+	-				?	+
Garvey 2012	-	-	+	-	-	-				?	+
Garvey 2013	+	-	+	-	-	-				?	+
Gleeson 2013	+	+	+	+	+	-				-	+
Goossens 2011	+	+	+	+	+	-				?	+
Hankins 2012	+	+	+	?		-				?	-
Hazel 2010	+	+	-	-	+	-				?	+
Hersh 2009	-	+	-	+	-	-				?	+
Johnston 2006	+	+	?	+						+	+
Kipps 2002	+	+	+	+		-				?	+
Norris 2013	+	-	+	-						?	+
Oswald 2013	+	-	?	+	-	-				+	+
Pacaud 2005	+	-	+	-	+	-				+	+
Reid 2004	+	+	+	+	+	-				?	+
Stanczyk 2014	+	-	?	-	-	-				-	+
Steinbeck 2014	+	-	-	?			+	+	?	?	+
Vanelli 2004	-	-	+	-						?	+
Van Walleghem 2008	?	?	-	-						?	+
Wojciechowski 2002	-	-	+	+						?	+
Yeung 2008	-	+	+	-	?	-				?	+

**FIGURE 2**

Risk of bias summary. Review authors' judgments about each risk of bias item for each included study. Red circles: high risk; green circle: low risk; yellow circles: unclear; empty: not concerned.

planned number, resulting in insufficient statistical power and calling into question the generalizability of the results.

## DISCUSSION

We retrieved only 23 studies addressing the issue of care continuity in youths with chronic conditions transferring from pediatric to adult health care services. Although the transition issue concerns a large spectrum of chronic diseases, most of these studies included patients with diabetes or congenital heart disease, and many chronic diseases were not studied (eg, HIV infection, hemophilia, inflammatory bowel disease). All the studies reported indicators related to either engagement or retention in adult care.

Engagement in adult care was measured by using probability of, and/or time to, attendance at the first visit to adult care. Delays in adult care attendance has been pointed out by a panel of experts, who considered as "very important" to measure "patient's first visit in adult care no later than 3 to 6 months after transfer."<sup>13</sup> This was done in 5 of the studies reported here. Furthermore, these timelines seem to reflect follow-up periods advocated by various disease organizations.<sup>40,41</sup> By using a, partly arbitrary, time cutoff provides a goal to be achieved in transition programs. Follow-up of patients initially recruited in a pediatric department and the use of survival analysis to take into account censored data due to deaths and patients lost to follow-up are required to avoid an overestimation of the probability of attendance and underestimation of transfer time. Nine cohorts that included patients in pediatrics measured engagement, but none of them performed a survival analysis.

Retention in adult care after transfer was measured by using the frequency of visits and the attendance at scheduled appointments. Both are indicators of health care use, which is likely to be positively associated with disease severity. Attendance at scheduled appointments measures more specifically compliance with care and was considered as very important by the panel of experts, who defined it as “no missed consultations previously canceled and rescheduled.”<sup>13</sup> It was reported in 5 of the studies reviewed here. However, such an indicator is hard to collect because missed visits are rarely indicated in patient records. Measuring retention indicators in both pediatric and adult departments for each patient, as done in 7 studies, is the only way to study whether adherence with care is maintained, improved, or altered after transfer.

Interestingly, engagement and retention in adult care correspond to 2 key challenges of transfer: ensuring continuity between pediatric and adult care, a type of “cross-boundary continuity,”<sup>42</sup> and build a new patient-provider relationship (ie, initiate a new “relational continuity”).<sup>43,44</sup> Some authors have also considered informational continuity, corresponding to the availability of information about medical history to ensure appropriate care.<sup>43</sup> This aspect was not described in the studies reviewed here.

Several instruments measuring care continuity have been developed in other contexts, including the Diabetes Continuity of Care Questionnaire, Alberta Continuity of Services Scale-Mental Health, Heart Continuity of Care Questionnaire, and Nijmegen Continuity Questionnaire.<sup>42</sup> Their relevance to the transfer to adult care and their validity in youths with chronic diseases should be evaluated. Also, several authors suggested

developing subjective measures of continuity.<sup>42,43</sup>

There were few data available to evaluate the difference in continuity of care outcomes between structured and unstructured programs. Two studies found a shorter transfer time<sup>26,34</sup> and better attendance in adult care<sup>34</sup> for patients involved in a structured transition program than those with no structured transition. However, both studies were not randomized, so we cannot exclude that these encouraging results are partly explained by an indication bias. No difference was reported in the 3 other studies that compared structured and unstructured transition, including the randomized controlled trial.<sup>6,20,22</sup> Nevertheless they concerned small numbers of patients. We cannot rule out that there would have been a significant difference if the studies had been more highly powered. Finally, it seems impossible to perform interstudy comparisons of continuity of care across various types of transition, because of the large heterogeneity of care context, study populations, designs, and indicators used. The methodological limitations of the studies impede the extrapolation of the results for the same disease in other contexts, and even more so for other diseases.

One limitation of this review is the lack of inclusion of gray literature (kind of material that is not published in easily accessible journals or databases). However, our electronic search strategy was very sensitive, as reflected by the lack of identification of any other eligible studies in the reference lists of the articles included. Assessment of the risk of bias was challenging, due to the heterogeneity and observational nature of the studies included. We tried to

limit the subjective dimension of assessment, by developing a standardized questionnaire based on the Cochrane risk of bias assessment, with additional criteria more specific to observational epidemiologic studies (Supplemental Table 7). This questionnaire was completed independently, by 2 reviewers. This extended risk of bias assessment tool is not specific to the issue addressed here. It could thus be used in systematic reviews of observational studies in other contexts.

## CONCLUSIONS

This review highlights the current lack of knowledge about the efficacy of structured transition programs for ensuring continuity of care during transfer from pediatric to adult care. The outcomes identified in this review are relevant and can be used for any other chronic conditions or other types of health care transitions, because they are not specific to a particular disease. This may facilitate comparisons of results obtained in different contexts and at different times. To avoid an overestimation of successful engagement in adult care, all patients lost to clinical follow-up during the transfer from pediatric care have to be identified. However, there are few prospective cohorts with the initial recruitment of patients in pediatric departments. Such designs and randomized trials are needed to compare adherence with care before and after the transfer and to evaluate the role of structured transition programs.

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**Evaluating Continuity During Transfer to Adult Care: A Systematic Review**  
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