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THE GUIDED TRANSFER OF CARE IMPROVES ADULT CLINIC SHOW RATE

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Abstract

Objective—Every year 500,000 youths in the U.S. with chronic disease turn 18 and eventually require transfer to adult subspecialty care. Evidence-based interventions on the organization of transfer of care are limited, although engagement and retention in adult clinic are considered appropriate outcomes. Sustained continuity of care improves patient satisfaction and reduces hospitalization.

Methods—We conducted a prospective non-randomized cohort study of patients with pediatric endocrine conditions, age 16–26 years, enrolled upon referral to the adult endocrine clinic of a physician trained in both adult and pediatric endocrinology (Med+Peds Endocrinologist). Patients differed based on whether their referral originated from another pediatric endocrinologist (traditional transfer) or if the Med+Peds Endocrinologist previously saw the patient in his pediatric endocrine clinic (guided transfer). Rather than relying on arbitrary age criteria, guided transfer to adult clinic occurred when physician and patient considered it appropriate. The primary outcome was show rate at the first and second adult visits.

Results—Of 36 patients, 21 were referred by another pediatric endocrinologist and 15 underwent guided transfer. For traditional transfer, show rate to the first and second visit was 38% compared to 100% in the guided transfer group ($p = 0.0001$). Subgroup analysis of 27 patients with diabetes revealed that both groups had similar initial HbA1c ($p = 0.38$) and the guided transfer group maintained HbA1c.

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Disclosures

CD, TA, and MB have nothing to declare. RAL has consulted for GlySens Incorporated and Abbott Diabetes Care. DMM has consulted for Abbott, the Helmsley Charitable Trust, Sanofi, Eli Lilly, Novo Nordisk, and has served on an advisory board for Insulet. His institution has research support from Medtronic, Dexcom, Insulet, Bigfoot Biomedical, and Roche.

Conclusions—Most traditional transfers were unsuccessful. Guided transfer was significantly more effective, with every patient successfully transferring, and could be implemented with adult endocrinologists willing to see patients in the pediatric clinic.

Keywords

Diabetes Mellitus; General Endocrinology and Metabolism; organization and administration; Pediatrics

Introduction

Every year approximately 500,000 youths in the United States with special health care needs turn 18 years of age and eventually require transition to adult care (1). Young people with chronic medical conditions are transferred from pediatric to adult services at a time of significant life changes. A 2016 Cochrane review analyzing transition programs identified only four small studies that provided low quality evidence for education interventions and no studies on the organization of care (2). A 2016 meta-analysis by Rachas and colleagues established engagement and retention of patients in adult care as appropriate and comparable outcome measures (3). Despite the great need, there is a paucity of evidence-based interventions. Well-designed research studies are needed to evaluate new models of care for this large, vulnerable population (4).

Many chronic endocrine conditions are diagnosed in childhood and transcend age. Previous studies have suggested that sustained continuity of care improves patient satisfaction while decreasing hospitalizations and emergency department visits (5). Gleeson and colleagues published an 18-year retrospective analysis of a transition clinic for patients with congenital adrenal hyperplasia aged 16 years and older. They found that merely introducing the adult endocrinologist at a pediatric visit did not increase show rate at the first two adult clinic visits and 50% of patients were lost to follow-up (6).

Type 1 diabetes, has been a particular focus in the transition literature (7–9). Among individuals with type 1 diabetes, 58% reported a negative transition experience and more than half changed their adult provider at least once. They had a 21% decrease in clinic attendance and felt that their glycemic control was better than it really was (10). Additional retrospective studies suggest that unstructured transfers resulted in significantly worse Hemoglobin A1c (HbA1c) than transition programs (11), thus increasing their chances for microvascular complications (12) and cardiovascular disease (13). There is an increased rate of hospitalizations in this age group, which may be assuaged by physician continuity (14). It is likely that transition represents a period where those with type 1 diabetes are likely to be lost to follow-up. Indeed, at least 2,000 adults with type 1 diabetes among 23 primary care practices in California and Florida do not receive care from an endocrinologist (15).

Even though transition is a shared responsibility of pediatric and adult providers, most tested interventions have targeted pediatrics and had limited success in adult care retention (9). Recently, it has been proposed that the adult provider plays an essential “receivership” role, critical to successful transition of care (16). In addition, systematic review of primary care continuity reveals increased patient satisfaction with decreased hospitalization and

emergency department visits (5). Given the importance of the adult provider and continuity, a possible solution utilizes a provider with endocrinology subspecialty training in both internal medicine and pediatrics (Med+Peds Endocrinologist). The provider could initiate care in the familiar pediatric clinic setting and then transfer the patient's care to his or her adult clinic when both the provider and patient felt comfortable. We hypothesized that having the adult subspecialty provider see patients in the pediatric setting will result in greater engagement and retention in the adult clinic. A positive finding could support larger clinical trials utilizing adult subspecialists in the pediatric setting.

Materials & Methods

We conducted a pilot prospective non-randomized cohort study of patients with a pediatric chronic endocrine condition, age 16–26 years, enrolled upon referral to a specific Med+Peds Endocrinologist in the Stanford adult endocrinology clinic. Following patients upon referral to adult endocrine clinic offered several practical advantages over recruitment from the pediatric clinic. This design does not require tracking patients who leave the institution and it eliminates patient preference for a specific adult endocrinologist as a covariate. Patients differ based on whether their referral originated from: (1) a different pediatric endocrinologist (traditional transfer) or (2) the Med+Peds Endocrinologist previously saw the patient in the pediatric endocrine clinic (guided transfer). Traditional transfer occurred at the pediatric endocrinologist's discretion informed by patient age and discussion with the patient. Those in the guided transfer group were moved to the adult clinic whenever the physician and patient felt it was appropriate, regardless of age. The primary outcome was show rate at the first and second scheduled adult endocrine clinic visits. Study duration was 18 months from the first adult endocrine appointment because follow-up time depended on the specific condition and some required only annual appointments. A subanalysis of those patients with diabetes included secondary measures of HbA1c and hospitalizations for diabetic ketoacidosis (DKA).

We based sample size calculations on the 2016 systematic review by Rachas and colleagues (3) that included 598 participants with a variety of chronic diseases undergoing unstructured transfer. Show rate for the first two visits from this systematic review was $57 \pm 16\%$. We considered a 20% increase in show rate to be a meaningful improvement. Assuming an alpha level of 5% and power of 95% we required a sample size of 36, with 18 patients in each referral group.

Demographics collected included age at transfer to adult care, chronic disease duration, gender, ethnicity and insurance type (public or private). For individuals with diabetes, HbA1c prior to transfer was collected and, where available, HbA1c after two adult diabetes clinic visits was obtained. We summarize quantitative measures using mean and standard deviation with comparisons made using unpaired two-sample t-test. A two-proportion z-test is used to compare differences in qualitative measures.

Results

Thirty-six patients, age 16–26 years, were referred to the Med+Peds Endocrinologist's adult endocrine clinic. Demographic data for the group are presented in Table 1 and further sub-divided by diagnosis of diabetes or other endocrine condition. Among the patients with diabetes, there were 26 with type 1 diabetes and 1 patient with cystic fibrosis-related diabetes. Endocrine conditions included (individual patients with the following diagnoses): hirsutism, primary hypogonadism and hypopituitarism secondary to iron overload, adrenal insufficiency and poor bone health from a disorder of peroxisome metabolism, papillary thyroid cancer, hypothyroidism in association with Trisomy 21, Graves' disease, autoimmune primary adrenal insufficiency with hypothyroidism, and diabetes insipidus from treated Langerhans cell histiocytosis.

Of these patients, 21 (58%) underwent traditional transfer from a different pediatric endocrinologist and 15 (42%) took part in guided transfer. Variations in demographics between those undergoing traditional and guided transfer are presented in Table 2. With the exception of one patient, most traditional transfers originated from pediatric endocrinologists within the Stanford system. The guided transfer group saw the Med+Peds endocrinologist in pediatric clinic 1–4 (average 1.7 ± 1.0) times prior to transfer to the adult endocrine clinic and were previously seen by another pediatric endocrinologist in the same clinic. Six patients (40% of the guided transfer group) remained in the pediatric clinic for more than 1 visit. From open-ended discussion with these patients, this was due to preference for pediatric clinic location and the availability of additional resources in the pediatric clinic including psychology, social work and point-of-care hemoglobin A1c. The traditional and guided transfer groups were not significantly different in terms of gender ($p = 0.09$), ethnicity ($p = 0.20$) or insurance ($p = 0.09$). For traditional transfer, the show rate to both the first and second visit was 38% compared to 100% in the guided transfer group ($p = 0.009$). This is in spite of the guided transfer group (mean 19.4 ± 1.8 years) being younger ($p = 0.005$) than those in the traditional transfer cohort (mean 21.7 ± 2.5 years).

Subgroup analysis for the 26 patients with diabetes are presented in Table 3. Both traditional ($8.7 \pm 2.7\%$) and guided transfer ($7.9 \pm 2.0\%$) groups had similar HbA1c prior to transfer ($p = 0.38$). All guided transfer patients received HbA1c testing at the second adult diabetes clinic visit. Hemoglobin A1c was maintained in the guided transfer group ($7.9 \pm 2.0\%$; $7.9 \pm 1.7\%$; $p \approx 1.0$, $n = 26$). The traditional transfer cohort did not consistently return for follow-up and so follow-up HbA1c data was unavailable for comparison (for the 6/13 patients who did follow-up HbA1c $9.1 \pm 2.0\%$). There were no hospitalizations for DKA in the guided transfer cohort. In the traditional transfer group at least three individuals who missed all adult clinic visits were hospitalized for DKA following referral, although the study was not powered to detect this outcome ($p = 0.06$). For patients with diabetes traditional and guided transfer groups were not significantly different in terms of gender ($p = 0.07$), ethnicity ($p = 0.09$) or insurance ($p = 0.17$).

Discussion

The objective of this study was to assess whether the guided transfer increased show rate at the first two adult endocrinology visits. The results show a significantly greater show rate in the guided transfer group versus traditional transfer. Every patient in the guided transfer group presented for follow-up in adult subspecialty clinic. Prior attempts at simply introducing the adult provider in the pediatric setting were ineffective (6). The guided transfer intervention involves the adult subspecialist providing care in the familiar pediatric clinic. By establishing a therapeutic rapport, the patient may have a deeper stake in continuing follow-up in the adult clinic and overcoming barriers to these visits.

The transition to adult care can be trying as delivery of care differs between pediatric and adult endocrinology clinics. The pediatric endocrinologist is often familiar to the patient; visits may be longer in pediatrics with an emphasis on developing self-care skills and access to multidisciplinary resources. The adult endocrinologist starts as a new provider and visits tend to focus on concerns that the patient must bring to the visit. Many past efforts have focused on creating transition programs isolated to the pediatric or adult endocrinology setting. Pediatric transition programs help prepare patients but the additional resources further connect the patient to pediatrics. Adult transition programs may improve disease-specific outcomes but only for the patients that make it to clinic (17). The chronic diseases presented are serious and demand close subspecialty care. The guided transfer suggested in this study is based upon building a connection between the patient and the adult subspecialist. This requires extra effort on the part of the adult providers and healthcare system, but can significantly increase show rate to the adult subspecialty clinic. Med+Peds subspecialists are ideally suited for this niche and simplify the necessary effort.

There are several limitations to the current study. It involved a single Med+Peds Endocrinologist with type 1 diabetes himself. The referring providers for the traditional transfer cohort often shared the Med+Peds provider's training and diabetes background prior to transfer. While the particular provider may introduce a bias, show rates in the traditional transfer group were actually lower than previously published data (3). Given the prospective cohort design, participants are sometimes lost to follow-up so comparing outcomes between groups is biased depending on the features of the group who remains in the study. To avoid the bias, the present study's primary outcome was show rate that can be quantified regardless of follow-up. This in contrast to other outcome measures such as HbA1c that would not be available in those who did not follow up. Subjects were not randomized and observations were collected in the course of routine real-world clinical care. The guided transfer group was younger than the traditional transfer group, and although other demographic characteristics were not substantially different, we cannot rule out the possibility of confounding by characteristics such as gender, ethnicity, or insurance type. Finally, the limited follow-up time raises the question of continued retention. Of note, one patient in the guided transfer cohort switched to a different adult endocrinologist within the Stanford adult endocrine clinic and made it to subsequent follow-up. Another patient in the guided transfer group changed healthcare systems after the intervention and made it to subsequent follow-up appointments with a new adult provider. The guided transfer is only possible if patients remain within the same healthcare system, but if guided transfer occurs

prior to insurance or location changes, it may facilitate the transfer to a new healthcare system. Appointments may also be scheduled when patients return home for vacation or via telehealth.

Future studies are needed to validate the guided transfer process. Med+Peds subspecialists with privileges in both clinics greatly simplify the implementation. This is especially important when the two practice environments are not well connected. This training requires 4 years of residency and 4 years of fellowship, which limits the number of dual-trained providers. However, the present study demonstrates the value of this training. If training can be abbreviated, it may also increase the number of available Med+Peds subspecialists. Adult endocrinologists willing to see patients in the pediatric endocrine clinic can also conduct the guided transfer intervention. A unique benefit of this arrangement is the sharing of knowledge that occurs when adult and pediatric providers come together. Adult providers can benefit from the clinical knowledge of their pediatric colleagues and evaluate the effectiveness of transition practices. The pediatric providers will keep apprised of their former patients, the effect of the transition interventions they implement and share their own clinical knowledge. Potential interested adult providers would need privileges at a nearby pediatric clinic with access to the medical record system. The number of pediatric visits need not be protracted; for the majority of guided transfer patients a single pediatric visit was sufficient. Randomized prospective trials with multiple providers recruiting patients in the pediatric endocrine setting are required. The guided transfer should be generalized and tested in other subspecialties. Children with chronic disease receive close and meticulous pediatric care, but we risk losing the benefits of this rigorous care if young adult patients never make it to adult subspecialty care. Adult subspecialists are crucial to the transfer process.

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Abbreviations:

HbA1c	Hemoglobin A1c
Med+Peds	Internal Medicine and Pediatrics
DKA	Diabetic Ketoacidosis

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Table 1.

Baseline demographic data sub-divided by diagnosis

	All Participants	Diabetes	Other Endocrine Conditions
n	36	27 (75%)	9 (25%)
Age at Transfer (years)	20.7 ± 2.5	20.3 ± 2.4	21.9 ± 2.3
Disease Duration (years)	9.6 ± 6.1	9.1 ± 5.6	11.1 ± 7.7
Gender			
Male	23 (64%)	19 (70%)	4 (44%)
Female	13 (36%)	8 (30%)	5 (55%)
Ethnicity			
Hispanic/Latino	14 (39%)	12 (44%)	2 (22%)
Not Hispanic/Latino	22 (61%)	15 (56%)	7 (78%)
Insurance			
Public	13 (36%)	9 (33%)	4 (44%)
Private	23 (64%)	18 (67%)	5 (55%)

Table 2.

Comparison of those undergoing traditional transfer and guided transfer.

	Traditional Transfer	Guided Transfer	p-value (* p < 0.05)
N	21 (58%)	15 (42%)	N/A
Show rate at first and second adult endocrine clinic appointment	8 (38%)	15 (100%)	0.0001*
Age at Transfer (years)	21.7 ± 2.5	19.4 ± 1.8	0.005*
Disease Duration (years)	9.7 ± 6.1	9.5 ± 6.4	0.92
Gender			
Male	11 (52%)	12 (80%)	0.09
Female	10 (48%)	3 (20%)	0.09
Ethnicity			
Hispanic/Latino	10 (48%)	4 (27%)	0.20
Not Hispanic/Latino	11 (52%)	11 (73%)	0.20
Insurance			
Public	10 (48%)	3 (20%)	0.09
Private	11 (52%)	12 (80%)	0.09

Table 3.

Comparison of those with diabetes undergoing traditional transfer and guided transfer.

	Traditional Transfer	Guided Transfer	p-value (* p < 0.05)
N	13 (48%)	14 (52%)	N/A
Show rate at first and second adult endocrine clinic appointment	6 (46%)	14 (100%)	0.001*
Age at Transfer (years)	21.3 ± 2.7	19.4 ± 1.8	0.04*
Diabetes Duration (years)	9.3 ± 5.0	9.0 ± 6.3	0.89
HbA1c Prior to Transfer	8.7 ± 2.7%	7.9 ± 2.0%	0.38
HbA1c After 2 Adult Diabetes Visits	Unknown	7.9 ± 1.7%	N/A
Number with known DKA hospitalizations	3	0	0.06
Gender			
Male	7 (54%)	12 (86%)	0.07
Female	6 (46%)	2 (14%)	0.07
Ethnicity			
Hispanic/Latino	8 (62%)	4 (29%)	0.09
Not Hispanic/Latino	5 (38%)	10 (71%)	0.09
Insurance			
Public	6 (46%)	3 (21%)	0.17
Private	7 (54%)	11 (79%)	0.17