Evaluating a multidisciplinary inpatient program for youth with type 1 diabetes mellitus

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Abstract
Among youth with type 1 diabetes mellitus (T1D), older adolescents demonstrate more dysglycemia and less adherence to disease management. Poor disease management during this time of development can continue into adulthood, perpetuating the economic and health burden to the individual, health care system and society. This study aimed to evaluate the effectiveness of an inpatient multidisciplinary approach to treating youth with T1D. All T1D admissions to the 4 week Chronic Illness Management Program (CIMP) between 1 January 2016 and 31 December 2017 were eligible for inclusion. Data related to physiological and psychosocial outcomes were compared between admission and discharge. Follow-up data, including hemoglobin A1c (HbA1c), psychosocial measures, and health care utilization, were collected at 3, 6, and 12 months after discharge to assess sustained changes. Fifty-seven T1D admissions were included in the sample. There was a significant reduction in mean HbA1c from admission (11.1%/98 mmol/mol) to discharge (9.1%/76 mmol/mol). Patients also demonstrated significant improvements in all psychosocial outcome measures. Improvements in HbA1c were sustained at 3 months follow-up; however, average values returned to baseline by 6 months follow-up. In contrast to pre-admission history, the majority of the sample reported reduced crisis health care utilization 1 year after discharge. The inpatient setting provides an intensive treatment model for diabetes management that promotes sustainable behavior change 3 months after discharge. While additional community supports are needed for long-term improvement, this program model may benefit patients who have been unable to manage their diabetes with outpatient treatment and therapy alone.

Keywords
disease management, inpatient, type 1 diabetes, youth

1 | INTRODUCTION

Type 1 diabetes mellitus (T1D) is an autoimmune disease that often develops in young people and is characterized by high-blood glucose levels resulting from little or no insulin production by the pancreas.¹ According to the American Diabetes Association (ADA), approximately 193 000 Americans under the age of 20 years have a diabetes diagnosis, with a T1D incidence rate estimated at 17 900 new cases
annually. Non-adherence to medical treatment can lead to a range of comorbidities, high-medical costs and lost productivity.

Given the chronic nature of T1D, youth diagnosed with the condition will be responsible for managing it for the rest of their lives. This underlines the importance of successful disease and lifestyle management and treatment adherence as early as possible.

Adolescence is a unique time in disease management given developmental, hormonal, and psychosocial changes that impact metabolic stability. According to follow-up data from the Diabetes Complications and Control Trial (DCCT), it is especially important for young people to achieve glycemic control because poor control during this time of development can lead to increased risk for future vascular, renal, and neurologic complications. The DCCT found that intensive diabetes treatment, compared to conventional treatment, "delayed the onset and slowed the progression" of diabetic complications, including diabetic ketoacidosis (DKA).

In addition, pediatric care models are further complicated by the critical role the family and community play in the care of a child with a chronic illness. Research has shown that positive family involvement in the care of chronic illness can improve adherence, glycemic control, and health outcomes. However, it can be difficult for families to take on multicomponent treatment regimens, often required in the management of diabetes.

Among youth with T1D, older adolescents have exhibited greater dysglycemia and less adherence to disease management. According to multiple studies, the majority of adolescents with T1D do not meet the age-specific guidelines of <7.5% for target hemoglobin A1c (HbA1c) recommended by organizations such as the ADA and International Society for Pediatric and Adolescent Diabetes. Indeed, a 2019 report of adults and youth with T1D found HbA1c was highest among 15 to 18 year olds with an average of 9.3% (78 mmol/mol) and only a small proportion achieved the ADA recommendations.

The purpose of this study was to evaluate the impact on physiological indicators of diabetes control, psychosocial outcome measures, and health care utilization, of a multidisciplinary inpatient program for youth with T1D who demonstrated unsuccessful diabetes management despite outpatient treatment. A review of the available literature did not yield any record of an evaluation of an identical program.

2 | METHODS

2.1 | Population/sample

The Chronic Illness Management Program (CIMP) is an elective inpatient program housed within a New Jersey pediatric acute rehabilitation hospital. The program provides the patient and family with a structured, comprehensive service plan to address medical, physical, nutritional, and psychological well-being to effectively manage their illness, maximize quality of life, and achieve family-centered goals of care. All T1D admissions to the CIMP between 1 January 2016 and 31 December 2017 were included in the sample. Patients were referred to the 4 week inpatient program due to failure to control diabetes symptoms with outpatient care alone as evidenced by a history of glycemic instability, DKA events, emergency department (ED) visits, and/or hospitalizations. The program design combines classroom-based education with experiential learning, community reintegration, and psychotherapy. The program provided each patient with the following: daily medical oversight by a physician or advanced practice nurse; 24/7 nursing care; oversight for insulin dosing and administration, carbohydrate counting and glucose monitoring by a nurse or medical provider; diabetes-specific education by a pharmacist or nurse for 60 minutes per day on weekdays; (a certified diabetes educator was integrated into the delivery of diabetes education beginning October 2017); nutritional counseling by a dietitian for 60 minutes per day on weekdays; individual and group psychotherapy up to three times per week for 30 minute sessions; at least 30 minutes each of occupational therapy and physical therapy five times per week; 60 minute sessions of recreational therapy 6 days per week and 60 minute sessions of child life therapy 3 days per week; weekly community-integration activity; ongoing social work/case management; and weekly team feedback meetings. Each week the caregivers were provided with at least 60 minutes of disease specific education, 60 minutes of nutrition education, and 60 minutes of family therapy.

2.2 | Data collection/management

Demographic characteristics, including date of birth, sex, race/ethnicity, age at diagnosis and/or duration of diagnosis, insurance status, insulin administration method, and residence were collected upon admission and extracted from the electronic medical record. 2016 median household income by zip code from the American Community Survey was matched to the patient’s home address zip code as a socioeconomic indicator. The staff psychologist conducted psychosocial assessments of patients at admission and discharge. Follow-up data were collected from the patient’s referring provider and the patient at 3, 6, and 12 months following discharge from the inpatient setting. All data for the present study were stored in a secure REDCap database.

2.3 | Physiological outcome measures

The physiological samples of interest included HbA1c, serum fructosamine, high-density lipoprotein (HDL), low-density lipoprotein (LDL), and triglycerides. Blood samples were collected by staff as part of routine medical care in the CIMP. The samples were collected within approximately 48 hours of admission and approximately 48 hours before discharge and were analyzed by an external laboratory using the Roche Cobas C501 analyzer. Serum fructosamine was analyzed by a different external laboratory and processed using the Roche Fructosamine reagent.
2.4 | Psychosocial outcome measures

Psychological testing of disease burden, diabetes-related stress, overall mental health, and compliance with diabetes management was conducted utilizing validated tools, including the Pediatric Symptom Checklist (PSC), Problem Areas in Diabetes (PAID), and the Self-Care Inventory-revised (SCI-R) at admission, discharge, and at 6 and 12 months after discharge from the inpatient setting.

The PSC is a psychosocial screening tool designed to facilitate the recognition of cognitive, emotional, and behavioral problems. Format and scoring of the PSC are described elsewhere. The youth self-report (Y-PSC) can be administered to adolescents aged 11 years and older. A score of 30 or higher suggests clinically significant psychological impairment.

The PAID assesses diabetes-specific distress and has been adapted for use with patients aged 8 to 17 years. Scores were calculated using the full 26-item test and an abbreviated 14-item version with a preliminary cutoff score of ≥44. This cutoff was associated with higher HbA1c, depressive symptoms, and anxiety.

The SCI-R is a 15-item self-report questionnaire assessing patients’ perceptions of diabetes-related health behaviors and is described elsewhere.

The Pediatric Quality of Life Inventory Version 4.0 Short Form (SF15) (PedsQL) measures age-specific health related quality of life from 2 years and is an abbreviated version of the original 23-item instrument. The 15-item total score version contains a physical health subscale, emotional functioning subscale, social functioning subscale, and school functioning subscale and is described in greater detail elsewhere.

2.5 | Disease knowledge measure

Objective testing of the patient’s disease-related fund of knowledge was collected at admission and discharge, using the Revised Brief Diabetes Knowledge Test (DKT2). The DKT2 is a 23-item validated tool used to determine diabetes-specific fund of knowledge. The first 14 items are appropriate for all participants with diabetes, while the remaining nine items are intended for participants using insulin. All DKT2 assessments in this study were scored as a cumulative result of both sections, as all participants were using insulin. Scoring was not intended to correlate with clinical outcomes but to serve as criterion to develop a customized education plan.

2.6 | Health care utilization measures

Data related to impact on health care utilization, including frequency of disease-related DKA events, disease-related ED visits, and disease-related hospitalizations, were collected during interviews prior to admission as well as after discharge from referring providers at scheduled follow-up intervals.

2.7 | Data analysis

Means and frequencies were calculated for demographic and outcome variables. Data were tested for normality using the Shapiro-Wilk test for normality. Test results indicated non-normal distributions for HDL and LDL; therefore non-parametric tests (i.e., Wilcoxon signed rank test) were used to assess differences between discharge and admission scores. For all other normally distributed outcome measures, Student’s t test was used to determine differences between discharge and admission scores. McNemar’s test was used to compare differences in proportions scoring above or below cutoff values on psychosocial assessments between admission and discharge. All analyses were conducted using SAS Enterprise Guide 7.1 (SAS Institute, Cary, North Carolina).

3 | RESULTS

3.1 | Sample characteristics

All T1D admissions to the CIMP between 1 January 2016 and 31 December 2017 were included in the analysis. The sample included 57 admissions (64.9% female) with an average length of stay of 27.9 days. Four (7.0%) of the total admissions represented a readmission to the CIMP; three were admitted twice during the 2 year study period contributing data from two separate admissions; while one patient participated originally prior to study inception and therefore only their second admission was included in the sample. No significant differences in subject characteristics were found when comparing the sample with readmissions included vs readmissions excluded; therefore, all 57 admissions were included in the analysis. A third of the sample (33.3%) reported Black or African American race and 15.8% identified Hispanic ethnicity. The average age at admission was approximately 15.0 years, and the average age of diagnosis was approximately 8.0 years, indicating that patients had been living with T1D for an average of 7.0 years at the time of admission. Approximately one quarter (24.6%) of the sample administered insulin via subcutaneous pump at the time of admission, while the majority (71.9%) administered insulin via intermittent subcutaneous injection. Two subjects used a combination of both administration methods at admission. Nearly three-quarters of the sample received health insurance through Medicaid (73.7%), and the same proportion reported residency in a zip code with a median annual household income less than $75 000 (Table 1).

3.2 | Outcome measures

(Table 2) Significant improvements in mean HbA1c were observed between admission and discharge, decreasing by approximately two percentage points from 11.1% (98 mmol/mol) to 9.1% (76 mmol/mol). Patients also experienced significant improvements in serum fructosamine levels, which is more reflective of recent changes in
glycemic control, between admission and discharge, 468.3 μmol/L compared to 333.7 μmol/L, respectively.

Patterns of glycemic control from admission to 12 months post-discharge are illustrated in Figure 1. Improvements in glycemic control were sustained through the 3 month follow-up as demonstrated by an average HbA1c of approximately 9.9% (76 mmol/mol). Average HbA1c levels returned to baseline admission values by the 6 month follow-up. In addition to improved glycemic control between

Significant changes in psychosocial assessments were observed following treatment. Patients reported less emotional distress related to their diabetes, as measured using the PAID, reporting a mean score of 84.6 at admission compared to 62.9 at discharge. The proportion of patients scoring below 44 on the abbreviated PAID, and therefore not demonstrating clinically significant signs of diabetes-related distress, increased from 36.0% at admission to 73.9% at discharge. Clinically significant levels of mental health symptoms on the Y-PSC, represented by a score of 30 or higher, were found in nearly 19% of patients at admission compared to about 2% at discharge. Sample sizes for follow-up data at 6 and 12 months were limited; however, trends suggested maintenance of gains on the PAID (full assessment mean = 69.2, 95% confidence interval = [53.7, 84.7]) 6 months after discharge.

Patient perceptions of their self-care behaviors as indicated by the SCI-R significantly improved over the 4 week program, increasing from an average score of 48.5 at admission to 66.3 at discharge. Patients also reported a significantly higher level of knowledge of their diabetes, as measured by the DKT2, as well as improved patient reported quality of life scores from admission to 3 months after discharge (Table 3).

The patient population often referred by outpatient providers for this program is one with above average health care utilization in the form of adverse health events, including DKA, ED visits, and hospitalizations. For example, prior to CIMP admission 73.2% of the sample reported experiencing at least one DKA event, 51.6% reported at least one visit to the ED, and 84.0% reported at least one prior hospitalization due to their T1D (Table 4). At 3 months follow-up, only one participant had any reported adverse health events. One year after discharge, there was increased crisis health care utilization, although utilization was still below pre-program levels (Table 4).

4 | DISCUSSION

Upon discharge from the CIMP, patients with T1D experienced significant improvements in disease management as reflected by both physiological and psychosocial outcomes. Patients also demonstrated less disease-related distress, and improved perceptions of diabetes-related health behaviors, mental health symptoms, and overall knowledge of their condition. While their HbA1c levels returned to baseline values within 6 months of discharge, the resulting reduction in health care utilization suggests that most patients in the CIMP were able to avoid crises leading to acute hospital visits.

The program offers an environment in which peers and staff members provide opportunities for daily disease management free of disagreement, frustration, and other negative emotions typical of interactions with caregivers. In addition, the camaraderie experienced with peers can decrease the sense of isolation felt by these young
people. Brief family therapy may lead to better diabetes management among youth whose families demonstrate conflict and lack strong social support.12

While the majority of the sample in this study was referred for psychotherapy prior to inpatient treatment, patients, and their caregivers had difficulty attending outpatient appointments. Research has shown treatment engagement of adolescents in psychotherapy can be challenging in outpatient settings, with dropout rates approaching 50%.27 Harris and Mertlich identified a subgroup of adolescents with diabetes who did not respond to traditional office-based Behavioral Family System Therapy and were characterized by missing appointments and utilizing a disproportionate share of health care resources.28 For patients who are unable to consistently participate or gain insight in outpatient psychotherapy, an inpatient program offers

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>Physiological outcomes at admission and discharge among T1D admissions to the CIMP between 2016 and 2017, NJ</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Admission n mean (95% CI)</strong></td>
<td><strong>Discharge n mean (95% CI)</strong></td>
</tr>
<tr>
<td>HbA1c (%)</td>
<td>49</td>
</tr>
<tr>
<td>Serum fructosamine (µmol/L)</td>
<td>49</td>
</tr>
<tr>
<td>HDL (mg/dL)</td>
<td>43</td>
</tr>
<tr>
<td>LDL (mg/dL)</td>
<td>43</td>
</tr>
<tr>
<td>Triglycerides (mg/dL)</td>
<td>41</td>
</tr>
</tbody>
</table>

Abbreviations: CI, confidence interval; CIMP, Chronic Illness Management Program; HbA1c, hemoglobin A1c; HDL, high-density lipoprotein; LDL, low-density lipoprotein; NJ, New Jersey; T1D, type 1 diabetes mellitus.

*HbA1c conversions: 11.1% (10.4, 11.7)% = 98 (90, 104) mmol/mol; 9.1% (8.7, 9.5)% = 76 (72, 80) mmol/mol.

FIGURE 1 This figure demonstrates observed changes in mean HbA1c over approximately 13 months from admission to 12 months after discharge among T1D admissions to the CIMP between January 1, 2016 and December 31, 2017. A significant decrease was observed from admission to discharge from the inpatient setting where HbA1c values decreased by 2 percentage points or 22 mmol/mol. Seventy-nine percent of the sample contributed at least one HbA1c post-discharge data point.11

1 Estimates presented are means and 95% confidence intervals
2 HbA1c conversions: 11.1% = 98 mmol/mol; 9.1% = 76 mmol/mol; 9.9% = 85 mmol/mol; 9.9% = 85 mmol/mol; 11.1% = 98 mmol/mol; 11.0% = 97 mmol/mol
3 Statistically significant difference (p < .05) observed between admission HbA1c and discharge HbA1c estimates
4 The number of observations at each time point diverge from the total due to missing data
an opportunity to experience the physiological, emotional, and social benefits of medical compliance. The role of the clinical psychologist in the inpatient program is important to reinforce positive emotional and psychological aspects of treatment adherence as the prevalence of psychiatric diagnoses has been shown to increase with age in adolescents and is higher among youth with diabetes.29,30 Psychological issues are often significant barriers for adherence to diabetes management.31

TABLE 3  Psychosocial outcomes at admission and discharge among T1D admissions to the CIMP between 2016 and 2017, NJ

| TABLE 4  Proportion of T1D admissions to the CIMP between 2016 and 2017 reporting adverse health care utilization |

<table>
<thead>
<tr>
<th>Preadmission</th>
<th>3 mo follow-up</th>
<th>6 mo follow-up</th>
<th>12 mo follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>DKA event</td>
<td>41/56 (73.2)</td>
<td>1/32 (3.1)</td>
<td>3/29 (10.3)</td>
</tr>
<tr>
<td>ED visit</td>
<td>16/31 (51.6)</td>
<td>5/32 (15.6)</td>
<td>6/29 (20.7)</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>42/50 (84.0)</td>
<td>1/32 (3.1)</td>
<td>3/30 (10.0)</td>
</tr>
</tbody>
</table>

Note: Sample size is number of patients for which data were reported at each time point; denominators diverge from total sample due to missing data. Abbreviations: CIMP, Chronic Illness Management Program; DKA, diabetic ketoacidosis; ED, emergency department; NJ, New Jersey; T1D, type 1 diabetes mellitus.

Abbreviations: CI, confidence interval; CIMP, Chronic Illness Management Program; DKT-2, Diabetes Knowledge Test - 2; NJ, New Jersey; PAID, Problem Areas in Diabetes; PedsQL, Pediatric Quality of Life Inventory; SCI-R, Self-Care Inventory-revised; T1D, type 1 diabetes mellitus; Y-PSC, Youth Pediatric Symptom Checklist.

aPedsQL discharge scores were taken 3 months after discharge from program during follow-up.
bToo few matched pairs to conduct test of significance.

While trends indicate maintenance of gains in the level of emotional distress experienced by the youth in this program, more research is needed to delineate the long-term impact of inpatient psychotherapy on diabetes-related distress, self-care behaviors, and mental health symptoms. These results can be an impetus for families to recreate and foster the support and structure that patients receive in an inpatient treatment program, seek ways to provide their children with behavioral interventions, encouragement, and effective communication that contribute to decreased levels of emotional distress.

In an IMS Institute for Healthcare Informatics publication, it was estimated that poor adherence to treatment regimens for chronic illness may cost $100 to $300 billion annually in the United States.32 Research has shown support for both the economic and clinical benefit of psychosocial interventions, involving multidisciplinary approaches, for
pediatric and adolescent chronic illness. For example, a study by Distelberg et al found a 73% reduction in annual medical expenses and estimated the total cost benefit of a multidisciplinary approach to be over $30 000, including direct and indirect benefits.33 From a clinical perspective, several studies have found that multicomponent interventions, which involve both behavioral and educational methods, demonstrated larger effect sizes on health outcomes than those interventions that used education alone.34–36

This study had several strengths. First, this study describes a novel program that dedicates 4 weeks to diabetes education and management for patients and their caregivers. Both physiological and psychosocial measures were used to measure patient progress. Physiological data were objective and indicative of both short and long-term glycemic control. Data were presented from multiple time points, including admission, discharge, 3, 6, and 12 month follow-up appointments and represented self-reports from patients and referring providers, lending a more holistic view of each child’s health. Median household income by zip code was used as a proxy measure for income level.

This study was subject to several limitations. First, some data collected were based on self-reported measures, which may be subject to bias. Second, as a measure of average glucose levels over the lifespan of a red blood cell, HbA1c is not the most appropriate indicator for a 28 day program. This was addressed by also measuring serum fructosamine, a more accurate measurement of immediate glucose levels that can reflect recent changes in disease management. Third, the variable sample size at each follow-up time point affected the ability to detect significant differences in all outcome measures, including HbA1c. True HbA1c values may have been higher or lower as patients lost to follow-up may have been doing more poorly or, if they were doing well and managing their condition effectively, may have not seen the need to follow-up with their providers. Fourth, much of the preadmission health care utilization data were sourced from the electronic medical records and timeframes for medical events were not consistently available, affecting comparisons. It is essential that future study capture the preadmission health care utilization timeline to strengthen comparisons with post-discharge events. Finally, we did not measure missed school days, missed days of work for caregivers or attendance at outpatient visits, which could provide additional information about the level of impact of the CIMP. The population of adolescents included in this sample represented a subset of patients whose management and adherence needed improvement as determined by their referring providers as well as for whom insurance coverage was secured, limiting the generalizability of the study results.

Improvements in diabetes biomarkers and psychosocial assessments were observed from admission to discharge; however, more data is needed to assess the impact of this program on disease management outcomes and health care utilization after discharge. This program model may be beneficial for some patients who have been unable to successfully manage their diabetes with outpatient treatment and therapy alone as the inpatient setting promotes an intensive, multidisciplinary treatment model for disease management and education. Given nearly three-quarters of the patients in this program reported insurance coverage by Medicaid, this approach may offer lower income families access to comprehensive programs and services.33 Future study includes the evaluation of a follow-up clinic, established subsequently and secondarily to this research, in which the patients and families are provided support to sustain the gains made in the CIMP or to recover from relapse; however, additional community level supports are necessary to help patients maintain long-term improvements.

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CONFLICT OF INTEREST
The authors declare no potential conflict of interest.

AUTHOR CONTRIBUTIONS
Colin O’Reilly proposed the study design and reviewed and revised the manuscript. Claire M. Marchetta oversaw the design and development of the data collection instruments, conducted data analysis, drafted the initial manuscript and reviewed and revised the manuscript. Ryotaro Maruyama collected data, drafted the initial manuscript, and reviewed and revised the manuscript. Lauren Galifi interpreted results and critically reviewed and revised the manuscript. All authors are responsible for the final content of the manuscript.

ETHICAL STATEMENT
The IRB deemed this study exempt from review.

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