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Evaluation of a Diabetes Coach Program Aimed to Improve the Care of Children and Youth with Type 1 Diabetes with Compromised Control

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Running Head: Pediatric Diabetes Coach Program
Key Messages: Management of Type 1 Diabetes (T1D) in youth can be challenging. Health coaching can be an effective way to improve the self-management of diabetes. Working with a health coach decreased A1C values in our pediatric patient population, however this was not sustained after visits stopped.

Key Words: Type 1 Diabetes; hemoglobin A1C; health coach; self-management

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Abbreviations:

Type 1 Diabetes (T1D)

hemoglobin A1C (A1C)

Diabetes Coach Program (DCP)

International Society for Pediatric and Adolescent Diabetes (ISPAD)

Canadian Diabetes Association (CDA)

type 2 diabetes (T2D)

diabetic ketoacidosis (DKA)

Diabetes Coach (DC)

Registered Nurse (RN)
Abstract

**Background:** Management of Type 1 Diabetes (T1D) in youth can be challenging, and a minority of patients achieve hemoglobin A1C (A1C) targets. Health coaching can be effective to improve the self-management of diabetes.

**Objective:** To evaluate the impact of the Diabetes Coach Program (DCP) on A1C levels in youth with T1D.

**Subjects:** Youth who were referred to and participated in the DCP from October 2011 to May 2016.

**Methods:** The Diabetes Coach visited families in their homes every 1-2 weeks and updated patients’ diabetes teams regularly. A1C prior to the DCP were compared to A1C during and after discharge from the DCP. Six participating families completed a telephone satisfaction survey.

**Results:** Twenty-three patients participated in the DCP (43% male; median age 11 years, range 8.8-14.5 years); median duration of T1D 1.7 years (range 0.1-6.3 years); median time in the DCP 1.5 years (range 0.2-2.5 years). During involvement in the program, median A1C decreased from baseline of 11.1% (range 8.9-15.3%) to 10.2% (range 7.6-12.4%) (p=0.0028). For 11/13 patients discharged from the DCP, the most recent median A1C, 11.2% (range 9.1-13.6%), an average of 2.4 years later, was not different from the initial A1C (p=0.85). Family feedback was overwhelmingly positive.

**Conclusions:** Participation in the DCP decreased A1C values in pediatric patients, however this was not sustained after visits stopped. Pediatric health coaches may play an important role in the management of T1D, however, further research is needed to explore their benefits and how positive effects can be sustained.
Introduction

The management of Type 1 Diabetes (T1D) in children and adolescents can be challenging for patients and parents. The T1D Exchange Clinic Registry in the United States identified that only a minority of participants are achieving the target hemoglobin A1C (A1C) of <7.5% recommended by the International Society for Pediatric and Adolescent Diabetes (ISPAD) [1, 2]. The mean A1C for children 6 to <13 years of age was 8.4%, and in adolescents 13 to <18 years of age was 8.8% [1]. Factors associated with excellent versus poor control have been identified and include being of a younger age, having shorter T1D duration, having a higher annual household income, and having a higher parental education [3]. In terms of diabetes management, factors associated with better control include more frequent blood glucose levels monitoring, lower daily insulin doses, less frequent insulin omission, or use of an insulin pump [3].

Diabetes clinic visits are an opportunity to focus on improving these behaviours, however, they may be limited by time constraints and lack of available data. More recently, the concept of health coaching has been identified as one strategy to improve patient adherence in diabetes management [4]. The Canadian Diabetes Association (CDA) describes a health coach as a health care professional who “collaborates in joint goal setting, problem solving, and following up on the patients’ choices” [4]. In adults with conditions including T1D, type 2 diabetes (T2D) and heart disease, there is increasing evidence that supports coaching as an effective way to improve the self-management of chronic illness, through either disease-related education-focused, behaviour change-focused, or psychosocial-focused coaching [5]. However, at the time this study was undertaken, there were no reported study on using this strategy in youth with diabetes.
As a means to engage and support families who are struggling with diabetes management, the Pediatric Diabetes team at Alberta Children’s Hospital developed an in-home support program for children and youth with T1D with compromised control called the Diabetes Coach Program (DCP). The program started as a pilot program in October 2011 and has continued based on positive feedback from allied health members and families. Families are identified as candidates for the program by their Diabetes clinic team members (their nurse, dietitian, endocrinologist, social worker and/or psychologist), and referred for home visits. Frequent reasons for referral are a persistently elevated A1C ≥10%, recurrent episodes of diabetic ketoacidosis (DKA) and/or a challenging home or social situation. The program is externally funded by a private donor.

The objective of this study is to report the impact of the DCP on A1C levels in children with T1D who are receiving visits from an in-home support worker.

**Methods**

**Subjects**

We included patients who were referred to and participated in the DCP since it started in October 2011 up to May 2016. One patient was referred in 2013 and participated for 1.3 years, and was re-referred in 2015. Three patients were excluded as they were not typical referrals to the program (one patient was referred as her father missed diabetes teaching, one patient was seen once only and one patient only required an insulin regimen change).

**Diabetes Coach Program**

The Diabetes Coach (DC) is a Registered Nurse (RN) with previous pediatric experience including the management of T1D in the acute care setting. Prior to commencing the position, the DC completed an orientation with pediatric home care and underwent an extensive two week
orientation in the Diabetes clinic at the Alberta Children’s Hospital to ensure an adequate knowledge base, an understanding of team dynamics, and consistent messaging during home visits. She did not have formal training in health coaching. Outside of her hours for the DCP, she also works on a casual basis in the Diabetes clinic building upon her knowledge and expertise. Each family in the DCP is seen by the DC in their home with visits conducted every 1-2 weeks if possible and decreased to monthly if progress is made or after discussion with the family based on preference/scheduling. Visits are 60 minutes in duration on average. At the initial and subsequent visits, the DC discusses with families their overall goals for diabetes management and what they would like to focus on. At each visit, she sets one or more goals to work on before the next visit. At the following visit, she assesses what went well and what prevented them from meeting their goal. She assesses these barriers to diabetes self-management and determines other variables that may be affecting glycemic control by observing diabetes routines at home. Common barriers include socioeconomic status, language, mental health disorders, insufficient supervision and perceived fears about diabetes. Based on what is identified, the DC provides more education and works collaboratively with the family and/or patient on different strategies to overcome these barriers and achieve the identified goals. Insulin dose adjustment is also part of the visits. To follow up on insulin dose adjustment or if she has specific concerns, the DC sets up a time for a phone call with herself or the clinic nurses between visits. She also provides reminders of upcoming appointments and encourages follow-up with the Diabetes team. The DC connects with each patient’s diabetes team on a regular basis to keep them informed about identified barriers, goals and progress. If a change in management is felt to be beneficial (e.g. a change in insulin regimen or a referral to the team psychologist), the DC reviews this with the patient’s diabetes team and facilitates the change.
Measurements

We collected demographic information including date of birth, gender, date of diagnosis of T1D, date of referral to and date of discharge from the Coach program, A1C prior to the start of the Coach program, A1C closest to the discharge date where applicable, and the most recent A1C (up to May 4, 2016). For the one patient who was referred at diagnosis, the baseline A1C used in the study was measured 5 months after diagnosis. For the patient who was referred to the program twice, A1C prior to the initial referral and A1C at initial discharge were included as well as A1C prior to the second referral and most recent A1C. We also collected data on total daily dose (TDD) of insulin before and after the DCP, as well as number of hospital or Emergency department (ED) visits for DKA or hyperglycemia pre and post the DCP. Telephone surveys with five parents and one patient participant of the Coach program were conducted by a nurse in the Diabetes clinic who is not involved in the program.

Data Analysis

Data is descriptive and presented as medians and ranges for patient demographics and A1C values. A1C values prior to the Coach program were compared to A1C values after joining the Coach program using the Wilcoxon signed rank test. For patients who are still followed by the DC, the most recent A1C was used. For patients who are discharged, the A1C closest to the discharge date was used. To assess the sustained impact of the program on a subset of discharged patients, A1C values prior to the Coach program were compared to the most recent A1C value. Statistics were performed using Microsoft Excel 2010 and SAS v9.4. The results of the telephone survey were compiled and described qualitatively.

Ethics
The project was a quality improvement initiative and was reviewed by ARECCI (A Project Ethics Community Consensus Initiative) through Alberta Innovates Health Solutions.

Results

Twenty-three patients participated in the DCP from October 2011-May 2016. Of these 23 patients, 11 continue to be seen by the in-home support worker as of May 2016. At the time of the referral, the median age of the patients was 11 years (range 8.8-14.5 years) and 43% were male. The median duration of T1D was 1.7 years (range 0.1-6.3 years) and the median time spent in the program was 1.5 years (range 0.2-2.5 years). The median A1C prior to being referred to the Coach program was 11.1% (range 8.9-15.3%). After participating in the program, the median A1C decreased to 10.2% (7.6-12.4%) (p=0.0028). Of the 13 patients who were discharged, the most recent A1C was available for 11 patients (one patient moved and one patient was re-referred to the program). The median A1C was 11.2% (range 9.1-13.6%), an average of 2.4 years later, and was not significantly different from the initial A1C prior to joining the program (p=0.85). Figure 1 illustrates individual patients’ A1C values before participating in the DCP, his/her last A1C in the program and his/her most recent A1C after discharge from the program (for 11 patients).

The median TDD of insulin before the DCP was 45 units (range 16-115) and the median TDD after the DCP was 62 units (range 26-122). Eighteen patients did not have any hospital visits for DKA before, during or after the DCP; two patients had a decrease in hospital and/or ED visits for DKA or hyperglycemia after joining the program; one patient had 3 episodes of DKA during the program and 2 episodes after participation in the DCP ended; one patient had an episode of DKA while in the DCP and none after; and two patients had 1 and 2 episodes of DKA respectively after participation in the DCP ended.
Five out of 6 families strongly agreed they would recommend the Coach program to other families and 1 out of 6 agreed with this statement. All families agreed or strongly agreed that their child’s diabetes management improved as a result of the Coach program. All families agreed or strongly agreed that they feel more confident managing their child’s T1D since receiving visits from the DC and they all agreed that the coach taught them skills and knowledge to manage their child’s diabetes. Comments from families about the Coach program included: “provided me with tips and education”, “helped me feel more comfortable and has helped me work through my fears”, “helped learn how to count carbs and keep on top of things”, the program has “eased the pain”, provided “comfort”, and is “there for the whole family”.

**Discussion**

To our knowledge, this is the first pediatric study looking at the impact of a health coach on glycemic control in children and adolescents with T1D. We found that, after receiving home visits from the DC for an average of 1.4 years, patients’ median A1C decreased significantly by 0.9%. However, the median A1C increased back to baseline after the in-home visits stopped. Families who participated in the program reported positive feedback about the Coach Program and felt more confident in managing their child’s diabetes. They agreed that their child’s diabetes management improved as a result of the program and would recommend the program to other families. While we cannot attribute the improvement in A1C with certainty to the DC due to the lack of a control group, the results are promising that a health coach may be an effective means of improving glycemic control in pediatric patients who are struggling with diabetes management.

Using coaching as an effective way to improve the self-management of chronic illness is a new initiative with minimal reported outcome studies in the literature. Specifically for diabetes,
the impact of health coaches has been studied more extensively in adult patients with T2D. Wolever RQ et al. (2010) evaluated the effectiveness of integrative health (IH) coaching in 56 patients with T2D who were randomized to receive either 6 months of IH coaching or usual care [6]. The intervention group received coaching over fourteen 30 minute telephone sessions [6]. Two coaches carried out the intervention and encouraged patients to set the coaching agenda and specific goals [6]. Compared to the control group, those who received the intervention reported a reduction in perceived barriers to medication adherence, and an increase in patient activation, perceived social support and identifying benefits of having T2D [6]. In addition, the intervention group also had improvements in self-reported adherence, frequency of exercise, stress level and perception of their own health [6]. Of the coaching participants with an A1C ≥7% at baseline, A1C decreased by 0.64% over 6 months of coaching, whereas the control group maintained an average A1C of 8.8% throughout the study [6]. Although not directly comparable to our study population, the outcomes of health coaching in this study on patient engagement, medication adherence, social support and stress are relevant in both T1D and T2D, and support the role of health coaches in the management of a chronic disease.

More recently, Ali et al. (2017) performed a systematic review and meta-analysis looking at the effect of a Diabetes Health Coach on adults with T2D [7]. The authors found that health coaching was effective and resulted in a pooled decrease in A1C by -0.32%; if the intervention was longer than 6 months, the reduction in A1C was even greater (-0.57%) [7]. Similar to our program, the coaching programs included goal setting, education about diabetes, personalized care and ongoing follow up [7].

Several studies have also looked at the role of community health workers (CHWs) in chronic disease management, a concept similar to health coaches. CHWs are trained community
members who work jointly with health care providers to provide education, resources, case
management and care coordination to patients [8]. A pediatric study evaluated a community-
based outreach worker program for children with asthma [9]. Here, a community-based asthma
outreach worker (AOW) provided free home visits and phone follow-up to families, targeting
those of low-income, diverse cultures, and having children with moderate to severe asthma [9].
Sixty parents received visits from the AOW for a mean of 5 weeks (range 2-26 weeks) and
reported significantly higher quality of life at follow-up versus baseline and were highly satisfied
with the AOW. Self-reported hospitalizations were significantly reduced, and 93% of children
had asthma management plans at follow-up versus 31% at baseline [9].

The effectiveness of CHWs in the management of T2D has also been studied, particularly
for ethnic minority communities who may lack access to health care [8]. African American and
Latino adults with T2D received diabetes education (eleven 2 hour culturally-tailored group
sessions) and two 60 minute home visits per month for 6 months from CHWs who applied an
empowerment-based approach that involved training in motivational interviewing and engaging
patients during diabetes education class [8]. The CHWs also accompanied the participants to one
clinic visit with his/her primary care provider and contacted patients by phone once every 2
weeks [8]. Using a randomized, 6-month delayed control group design, the authors found that the
intervention group had a decrease in A1C of 0.8% whereas the control group had no change in
mean A1C [8]. Those receiving visits from CHWs also had greater improvements in self-
reported diabetes understanding compared to the control group [8].

Similarly, a CHW-led structured program for adult Latinos with T2D was assessed for its
short and long-term effects on glycemic control [10]. Here, the intervention consisted of 17
individual sessions delivered at home over 12 months, and was patient-centred, individualized,
and based on stages of change, problem-solving theory and motivational interviewing [10]. Of note, the CHWs were well integrated into the healthcare management team; they provided updates to the healthcare professionals regularly that resulted in management changes for the participants [10]. Compared to the control group, patients who received visits from CHWs had a decrease in A1C at 3 months (-0.42%), 6 months (-0.47%), 12 months (-0.57%) and 18 months (-0.55%), demonstrating the sustained impact of the program 6 months after its completion [10]. The CHW group also had lower fasting glucose values compared with the control group [10].

Recently, a systematic review looked at the role of lay health workers in pediatric chronic disease including asthma, T1D, obesity and failure to thrive [11]. Overall, the authors found that lay health workers can modestly improve urgent care use, symptoms, and parental psychosocial outcomes [11]. Of 2 studies in T1D that looked at clinic outcomes, the intervention groups had improved glycemic control as well as an increase in attending outpatient clinics and a decrease in hospitalizations and emergency department visits [11].

In addition, a review of psychological interventions (supportive or counselling therapy, cognitive behaviour therapy including goal setting and problem solving, psychoanalytically informed therapies, family systems therapy) to improve glucose control in patients with T1D found that mean A1C was significantly reduced by 0.48% in children and youth who had received an intervention versus the control group [12]. In comparison, adults had a smaller and non-significant reduction in A1C of 0.22%, and psychological distress was lowered in the children and youth intervention groups but not in adults [12]. These reports provide some foundation for the potential benefits of a health coach approach in chronic diseases such as diabetes.
Consequently, there is a rising body of evidence demonstrating that health coaches and CHWs can play an important role in providing individualized care in chronic disease management that engages patients and families and increases self-management. Results from our study further support the role of a health coach in the management of T1D, particularly someone who is integrated into the health care team of the family, is able to have frequent interactions with both groups and carry out management changes between scheduled visits, and provide psychosocial support. In our clinic, alternative treatment strategies for families struggling with diabetes care include more frequent clinic visits, more education sessions with the multi-disciplinary team, increased involvement from the clinic social worker and/or psychologist, and elective admissions to hospital for close monitoring of insulin administration and dosing. The DC is certainly a more cost-effective strategy than an elective hospital admission, and with longer follow-up, likely to have a more sustained effect.

The effect of the DCP on A1C levels was not sustained in our population, however, at the end of the study approximately half of the patients were still in the DCP and we had recent A1C results from the small number of discharged patients which reduced the power of this result. Other possible reasons are the natural history of worsening glycemic control in adolescence due to insulin resistance and psychosocial factors typically associated with young adulthood [13]. Further possibilities are that knowledge from the DC may have transferred to the parent and not necessarily the child, a loss of motivation and accountability with the cessation of home visits, and the absence of regular blood glucose review and insulin adjustment by the DC.

A strength of our study is that the same health coach visited each family, thus minimizing the variability in the intervention. The study is limited by the small sample size and the lack of a control group. This was a quality assurance project and we focused on A1C outcomes and did
not look at the effect of the DCP on changes in insulin regimen or complication rates. We did not 
look at the number of visits received by each family to see if this played a role in the effect of the 
program on reduction in A1C. Although the telephone survey was conducted by a nurse not 
involved in the program, responses from families may have been biased and are limited by the small number of families participating in the survey. At a local level, based on the results of our study, modifications to the DCP that we are considering include formal health coach training for the DC, a formal system of telephone follow ups and increased joint involvement with the psychosocial team and the DC.

Future research is needed to look at health coaching to determine which models of care are most effective including frequency and duration of visits, and in particular, their role in the pediatric population. Although A1C reduction was not sustained in our patient population after participation in the Coach program ended, health coaching as a health care strategy for children and adolescents with T1D has promising preliminary results.

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References


Figure Legend
Figure 1: Individual patients’ A1C values before participating in the Diabetes Coach Program (DCP), individual patients’ last A1C in the DCP, and individual patients’ most recent A1C after discharge from the DCP (n=11 patients).