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Care utilization in a pediatric diabetes clinic: cancellations, parental attendance, and mental health appointments

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Abstract

Objective—To examine care utilization, family attendance, and A1c in a multi-disciplinary pediatric diabetes clinic.

Study design—Retrospective electronic record review of de-identified data included patients (99% type 1 diabetes) with established diabetes care, aged <30 years (mean 15±5.2) and diabetes duration >1 year (mean 8.5±5.1) at first visit during a two-year period. Outcomes included care utilization, family attendance, and glycemic control (A1c). Analyses included t-tests, ANOVAs, chi-square analyses, odds ratios (95% CI), and multivariate analyses.

Results—Among 1771 patients, there were 5.8±2.8 visits/patient; 15% of scheduled appointments resulted in cancellation or no-show; 61% of patients missed 1 visit. Patients with 2 missed appointments had higher A1c and were older than those with <2 missed visits. Almost half of visits were attended by mothers alone; fathers attended 22% of visits. Patients whose fathers attended 1 visit had lower A1c than patients whose fathers never attended. Eighteen percent of patients had on-site mental health visits. Patients with 1 mental health visit(s) had higher mean A1c, shorter diabetes duration, and were younger than those with no mental health visits.

Conclusions—Our observations suggest a need to encourage attendance at diabetes visits and include fathers to improve A1c. The high rate of missed visits, especially in patients with poor glycemic control, identifies wasted provider effort when late cancellations/no-shows yield vacant clinic time. It is important to explore reasons for missed visits and to find approaches to maximize attendance, e.g., extended evening/weekend clinic hours or virtual visits.

Keywords

Health care delivery; fathers; visit history; glycemic control; mental health

Because of the demanding nature of diabetes management, psychosocial issues commonly arise within families (1-11). There are anticipated periods during childhood and adolescence

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(e.g. puberty) when diabetes control may be more challenging (12-16), and, subsequently, we might expect more frequent medical visits, as well as referrals to mental health specialists. Frequent visits can add to family burden in the form of additional missed school days for youth and lost work for parents (17). In addition to the daily demands of diabetes care, youth with diabetes are at risk for psychological disorders such as depression, anxiety (18), and disordered eating, which are more common in youth with diabetes than in those without (9, 19, 20).

Despite advances in treatment, glycemic control in children is sub-optimal (21, 22). Previous investigations have assessed the relationship between care seeking behaviors and glycemic control and have found that patients with more frequent visits have better glycemic control (23, 24). A meta-analysis examined paternal involvement (25) and found that fathers had less responsibility than mothers for diabetes care and fathers' perceptions of greater family dysfunction were associated with poorer metabolic control (26-28). Other reports suggest that fathers participated in less than half of their child's diabetes care (29) and that greater paternal involvement was associated with greater treatment adherence and better quality of life in teenage youth (7). Increased paternal involvement is associated with better outcomes in terms of marital satisfaction, less maternal depression, and greater youth adherence to treatment (30). There are little data, however, on differences in clinic attendance rates between mothers and fathers and whether paternal involvement in diabetes care, marked by paternal attendance at diabetes visits, may be associated with lower A1c levels.

With the widespread use of electronic health records (EHR), it is possible to analyze utilization of care data and associations with glycemic control in large patient populations. We assessed frequency of clinic visits, types of pediatric providers seen, cancellation rates, mother and/or father attendance at visits, and glycemic control. We hypothesized that patients with more missed visits would have poorer control and that youth who attended visits with both parents would have better control than those who attended visits with only 1 parent. In addition, we hypothesized that visits with mental health would be more frequent in teens and in those with less optimal glycemic control.

Methods

The Joslin Diabetes Center is located in Boston, MA, in an urban setting. Approximately 95% of pediatric patients reside in Massachusetts or in neighboring New England states. These patients reflect the ethnic mixture of New England and represent all socioeconomic strata.

Our multidisciplinary pediatric diabetes team recommends visits according to ADA guidelines (roughly every 3-4 months) with a medical provider (MD or NP or RN/CDE who follows protocols for insulin dosing). In addition, we aim to have patients see an RD at least once a year, although often this does not occur. Mental health visits are scheduled as needed, often in conjunction with other clinic visits. Mental health providers are social workers, psychologists, or psychiatrists.

Data were extracted from the Joslin Center's EHR for a two year period (11/1/2009 – 11/1/2011). Criteria for data extraction included patients with previously established care in the Pediatric, Adolescent, and Young Adult Section who were seen at least once during the two year period for a diagnosis of diabetes (ICD 9 codes 250.X0, 250.X1, 250.X2, 250.X3) and were aged <30 years at the first visit during the two year period. Visit status was ascertained from the electronic appointment scheduling system with visit categories including: (1) completed (visit occurred as scheduled); (2) rescheduled (patient/family called office to reschedule); (3) cancelled (patient/family called office to cancel); and (4) no-show (patient/family did not arrive at visit and did not call to cancel or reschedule). Visits that were categorized as either cancelled or no-show were grouped together and defined as missed visits. Visits solely for research purposes were excluded from these analyses; at the time of this investigation, the majority of our patients with type 2 diabetes were participating in a research study and, because of this, were not included. In addition, we included only “active patients”, which was defined by having 1 visit at Joslin within the year prior to the period of observation. Mental health visits are considered a visit with a social worker, psychologist, or psychiatrist at the center. Only visits with the center's mental health providers were counted in these analyses, as we do not have an accurate way to capture outside mental health visits. We received approval from the Institutional Review Board to collect this retrospective chart review data without informed consent.

Data collected from the EHR included date of birth, sex, diagnosis (type 1 diabetes or type 2 diabetes), date of diagnosis, clinic visit dates, discipline of provider from multidisciplinary pediatric team seen during the clinic visit (medical doctor [MD], nurse practitioner [NP], registered nurse/certified diabetes educator [RN/CDE], registered dietician [RD], mental health provider), insulin regimen, A1c, and who (mother, father, other) was present at the appointment with the patient. A1c was obtained at all diabetes medical and nursing visits using a laboratory assay, standardized to Diabetes Control and Complications Trial (DCCT) guidelines (reference range 4-6%). An individual's glycemic control was based upon the mean of the individual's A1c values obtained during the two year period of observation.

Data were analyzed using SAS (v.9.2 for Windows; SAS Institute Inc., Cary, NC) and are presented as mean±SD, percent, and/or median (interquartile range). Statistics included t-tests, ANOVAs, chi-square analyses, odds ratios, 95% confidence intervals, and multivariate analyses. A p-value of <0.05 indicates significance.

Results

For 1,771 individual patients eligible for inclusion in this observational study, there were 17,984 scheduled appointments during the two years. At the time of the first visit during the two year period, patients (51% female) were 15±5.2 years old. Three percent of patients were young children (0-5 years), 31% school aged children (6-12 years), 32% were teenagers (13-17 years), and 35% were young adults (18-29 years). Mean duration of diabetes was 8.5±5.1 years. At the first visit during the observation period, 8% of patients had diabetes <2 years, 22% had diabetes for 2-<5 years, 39% had diabetes for 5-<10 years, and 32% had diabetes for 10 years. The majority of patients (99%) had a diagnosis of type 1 diabetes. Patients had a mean A1c during the two year period of 8.7±1.4%. The mean

number of A1c results per patient over the two year period was 5.5 ± 2.7 , median=6.0 (4.0-7.0). More than half (55%) of the patients received insulin pump therapy.

Visits were scheduled with various providers, including MD (35%), NP (25%), RN/CDE (25%), RD (7%), and mental health (8%). Mean number of completed medical visits per person over the two year period (MD, NP, RN/CDE) was 5.8 ± 2.8 . The majority (60%) of patients had ≥ 6 medical visits (MD, NP, RN/CDE) over the two years. Over this time, 15% of all scheduled appointments (MD, NP, RN/CDE, RD, mental health care provider) (2758) resulted in a cancellation or no-show, with an average of 1.6 ± 2.1 missed visits per patient (median=1 (0-2.0), range=0-22). Patients often have more than one visit scheduled on a day and they may cancel one or all appointments; thus, each individually cancelled appointment is counted as a unique cancellation for these analyses. Overall, 61% of patients had at least 1 missed visit. Missed visit rate differed across disciplines with mental health and RDs experiencing a significantly higher missed visit rate (23% and 25%, respectively) than MDs, NPs, and RN/CDEs (13%, 15%, 13%, respectively; $X^2=202.5$, $df=4$, $p<0.0001$). Only 35% of the population had ≥ 1 RD visit during the observation period (Figure 1).

Participant characteristics by A1c

The average of all A1c values over the study period was used to assign each participant an A1c category. Significant differences emerged between patients according to A1c category ($<8\%$, $8.0-8.9\%$, $\geq 9\%$; $p<0.0001$ for all). Patients with A1c ≥ 9 were older, had longer diabetes duration, and were more likely to receive mental health care. In particular, 28% of patients in the highest A1c category had mental health visits at a rate 1.5-3.0-fold higher than for patients in the lower 2 A1c categories. They also had the lowest ratio of completed to scheduled visits with a missed visit rate of almost 40% compared with $<30\%$ for patients in the two lower A1c categories ($p<0.0001$; Table).

Factors associated with missed appointments (including MD, NP, RN/CDE, RD, mental health care providers)

Overall, more than one third (37%) of patients missed ≥ 2 appointments over the two years. Those with ≥ 2 missed appointments had higher mean A1c (9.3 ± 1.7 vs $8.3 \pm 1.1\%$, $p<0.0001$) and were older (16.1 ± 5.0 vs 15.4 ± 5.4 , $p=0.005$) than those with <2 missed visits. Females were more likely to miss ≥ 2 appointments than males (OR=1.4, 95% CI=1.2-1.7). Youth with type 2 diabetes were more likely to miss ≥ 2 appointments than youth with type 1 diabetes (OR=5.8, 95% CI=1.9-17.9). In addition, youth whose mean A1c over the two year period did not meet ADA's age-specific guidelines (3) were more than twice as likely to miss ≥ 2 appointments than youth whose A1c did meet ADA guidelines (OR=2.3, 95% CI=1.8-2.9).

Parental attendance at medical visits

Almost one-half (48%) of non-mental health visits (MD, NP, RN/CDE, RD) were attended by mothers alone; fathers alone attended only 11% of visits. Overall, 12% of visits were attended by both parents, with 30% of visits being attended by neither parent (guardian, other relative, other adult, or no other adult, for young adult patients). Fathers (either alone or with mothers) attended almost one quarter of all non-mental health visits. Paternal

attendance varied with patient age and duration. Fathers attended 45% of visits for children under 6, and 9% of visits for their adult children, ages 18-29 ($p<0.0001$). For patients ages 6-17, 16% of visits were attended by both parents, with 13% being attended by neither parent. Similarly, paternal attendance at visits decreased with increasing duration of diabetes (Figure 2). However, age is the major predictor of fathers' attendance at visits, confirmed in a multivariate analysis with both age and duration as independent variables.

Notably, fathers (alone or with a 2nd parent) were less likely to attend RD appointments than other non-mental health visit types (MD, NP, RN/CDE). Fathers attended less than one in five RD visits (18%) compared with 24% of MD visits, 23% of NP visits, and 21% of RN/CDE visits ($p<0.0028$).

For patients whose fathers attended 1 clinic visit during the 2 year period, the youth's mean A1c was lower than for patients whose fathers never attended visits ($8.5\pm1.2\%$ vs $8.8\pm1.5\%$, $p<0.0001$). In addition, when fathers attended the majority of visits ($>50\%$), patients' A1c was also lower than the A1c for patients whose fathers rarely or never attended visits ($8.4\pm1.2\%$ vs $8.7\pm1.5\%$, respectively, $p<0.0001$).

Mental health care utilization

During the two year observation period, more than one in five (22%) of the sample scheduled a visit with a mental health provider, and 82% followed through with their mental health appointments, thus, almost one out of five (18%) of the patients received on-site mental health support. The majority (62%) of mental health visits occurred on the same day as another pediatric visit. Of the patients receiving mental health support, 48% had 1 mental health visit, 39% had 2-4 visits, 8% had 5-8 visits, and 5% had 9 visits. The proportion of patients in each age group that attended mental health visits differed (using age at first mental health visit during the two year period), with 18% of those in the 2 youngest groups (0-5 and 6-12 years old), 23% of those in the teen group (13-17), and 13% of those in the young adult group (18-29) utilizing mental health care ($X^2=16.9$, $df=3$, $p=0.001$; Figure 3). Patients who had 1 mental health visit during the two years had a higher mean A1c than those with no mental health visits ($9.3\pm1.6\%$, vs $8.5\pm1.3\%$ respectively, $p<0.0001$) and had shorter diabetes duration (7.1 ± 4.5 vs 8.9 ± 5.2 years, $p<0.0001$). In addition, those with 1 mental health visit were younger than those who had no mental health visits (14.8 ± 4.6 vs 16.0 ± 5.3 years, $p<0.0001$). Females were more likely than males to have mental health visits ($OR=1.4$, 95% $CI=1.1-1.8$). The proportion of those with mental health visits did not differ according to diabetes type (T1D vs T2D, $OR=0.44$, 95% $CI=0.2-1.27$).

Discussion

Over a two year observation period, 15% of scheduled visits at an outpatient pediatric diabetes clinic yielded a cancellation or no-show, with an average of 1.6 ± 2.1 missed visits per patient. Sixty-one percent of patients missed at least one visit over the two year period although the majority (60%) completed 6 or more visits over the two year period, consistent with ADA recommendations for visits every 3-4 months (31). Missed visit rates were higher for mental health providers and dietitians and lower for medical providers (doctors, nurse practitioners, nurses). Those patients with more missed appointments had higher mean A1c

values over the two year period; females and youth with type 2 diabetes were also more likely to miss appointments.

Our findings support the importance of parental involvement on glycemic control, especially when the father (7) or two parents are involved. Unfortunately, one limitation of these data is that we do not have information about single parent families or the marital status of the parents. In addition, because this is an observational study, we cannot assign causality of paternal attendance to youth glycemic control, as paternal attendance at visits may indicate other factors, such as SES and family resources. A1c data for this sample mirrors that of the SEARCH study (21) and Type 1 Diabetes Exchange (22, 32). One continues to observe suboptimal glycemic control in children across the US. In the current study, participants with A1cs ≥ 9 were older, had longer diabetes duration, were more likely to see a mental health provider, and had more missed visits. In efforts to improve glycemic control and optimize health outcomes, patients with elevated A1c values require extra support from multiple members of the pediatric team. Indeed, almost 30% of the group with A1cs ≥ 9 received mental health support. Unfortunately, this group also had the lowest rate of completed to scheduled visits with only 61% of scheduled visits completed, suggesting missed opportunities for these patients to receive additional education, support, and management guidance in efforts to improve control.

Overall, one-fifth of patients received mental health care during the two year study period. Patients utilizing mental health services had worse glycemic control than those not utilizing these services, suggesting that mental health services were sought as an intervention to improve glycemic control and to prevent further deterioration. However, the majority of patients with suboptimal control did not receive mental health support, although our data are unable to inform whether these patients were accessing mental health support locally or at other facilities. Nonetheless, our findings highlight opportunities to encourage greater referrals to the various members of the pediatric multidisciplinary team in efforts to improve glycemic control for our pediatric and young adult patients, especially for those with A1cs ≥ 9 . Additionally, one might consider routine screening for psychological distress in the pediatric population as has been advocated by others (33, 34). Given that youth with T1D have twice the risk for depression as youth without diabetes (35), screening to identify mental health issues may offer opportunities for early intervention or preventive treatment in order to avoid deterioration in glycemic control.

Our findings related to missed visits underscore a number of issues. First, it is likely that the need for frequent, in-person diabetes visits for patients and parents/guardians adds to the daily burdens of diabetes management for families already struggling to improve glycemic control (17). Next, the high rate of missed visits identifies potentially wasted provider time and effort when there are late cancellations or no-shows and clinic time remains vacant. Given the limited pediatric diabetes expertise nationwide and the greater missed visit rate in patients with higher A1cs who need additional support, it is important to explore reasons for missed visits with families and to find approaches to maximize attendance. One might consider extending clinic hours to evenings/weekends to accommodate the schedules of working families with the aim to encourage parents to attend visits. However, evening appointments are a predictor of no-shows in a pediatric autism clinic (36); it is unclear if this

would generalize to a pediatric diabetes clinic. In addition, one might consider opportunities to provide virtual visits, with appropriate reimbursement for provider time and effort, as a means to reduce the burdens of clinic attendance upon families (37).

As older teens and young adults transfer their care to adult diabetes providers and parents/guardians are less or uninvolved in their child's diabetes care, gaps in care become even more commonplace (13, 38-40). Another approach to maximizing clinic attendance to avoid missed visits and gaps in care may be to use a care ambassador program (41), in which a dedicated person within the clinic helps with appointment scheduling and reminders. Such a care ambassador program, which is similar to the patient navigator utilized in oncology settings (42), has been demonstrated to optimize visit frequency and reduce the need for acute hospitalizations and emergency visits (43, 44). Technologies such as text messaging reminders and internet-based portals may also help to improve treatment adherence, as well as possibly enhance communication with medical providers. Ensuring appropriate follow-up is necessary to reduce and prevent non-attendance and loss to follow-up care (45).

Limitations of this study include the relatively short follow-up period and the use of an EHR that was intended for clinical care. Secondly, our EHR did not include data regarding the referral rate to mental health. Thirdly, many of our patients with type 2 diabetes were participating in a study during this time period and, therefore, were not included in the current analyses. In addition, incidence cases were excluded from the dataset.

Future research should focus on reducing cancellation/no-show rates in pediatric clinics and encouraging paternal attendance at visits. In addition, future studies should examine the impact of mental health interventions as prevention for avoiding the recognized deterioration in glycemic control that accompanies the older school age and teen years.

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List of abbreviations

A1c	Hemoglobin A1c (measure of glycemic control)
ADA	American Diabetes Association
CDE	Certified Diabetes Educator
EHR	Electronic Health Record

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Figure 1.
Distribution of medical visits, as percentage of patients, during the 2 year observation period.

Figure 2.

Proportion of fathers in attendance either alone or with a second parent decreased as children's age increased and as diabetes duration increased ($p < 0.0001$).

Figure 3.

Proportion of each age group attending mental health visits (by age at first mental health visit). Teens utilized mental health care more than the other three age groups, with young adults utilizing mental health care less often.

Table 1

Participant characteristics by A1c category

A1c category	<8.0% (n=653)	8.0-8.9% (n=570)	9.0% (n=548)	p
Age (years)	15.3±5.9	14.9±5.1	16.8±4.3	<0.0001
Diabetes duration (years)	8.0±5.5	8.2±4.7	9.5±4.9	<0.0001
% with MH visits	9%	18%	28%	<0.0001
Number of completed medical visits over study period	5.5±2.7	6.1±2.5	5.8±3.3	<0.0003
Ratio of completed visits to scheduled visits	72%	72%	61%	<0.0001
Ratio of cancelled visits to missed visits	77%	73%	63%	<0.0001
Ratio of no show visits to missed visits	23%	27%	37%	<0.0001