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Running Title: State of Pediatric Diabetes Practices in the US

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Pediatric Endocrine Society Survey of Diabetes Practices in the United States: What is the Current State?

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Abstract:

The Practice Management Committee (PMC) of the Pediatric Endocrine Society (PES) conducted a survey of its membership in February/March 2016 to assess the current state of pediatric diabetes care delivery across multiple practice types in the United States.

Research Design and Methods: The PES distributed an anonymous electronic survey (Survey Monkey) via email to its membership and requested that only one survey be completed for each practice.

Results: Ninety-three unique entries from the US were entered into analysis. Care is predominantly delivered by multi-disciplinary teams, based at academic institutions (65.6%), with >85% of the provider types being physicians. Each 1.0 Full Time Equivalent Certified Diabetes Educators (CDE) serves on average 367 diabetic youth. Fee-for-service (FFS) remains the standard method of reimbursement with 57% of practices reporting financial loss. Survey respondents identified under-reimbursement as a major barrier to improving patient outcomes and lack of behavioral health providers as a key gap in services provided.

Conclusions: Our survey reveals wide variation in all aspects of pediatric diabetes care delivery in the United States. Pediatric Endocrinologists responding to the survey identified a lack of resources and the current FFS payment model as a major impediment to practice and the lack of integrated behavioral health (BH) staff as a key gap in service. The respondents strongly support its organizations' involvement in the dissemination of standards for care delivery and advocacy for a national payment model aligned with chronic diabetes care in the context of our emerging value-based healthcare system.

Key words: Diabetes practice, care delivery

Introduction

Type 1 diabetes, one of the most common chronic disorders of childhood, is increasing in incidence (1), affecting 1 in 300 children in the United States by the age of 18 (2). Type 2 diabetes, a condition virtually unknown in children until the 1990's, is rising in prevalence as well, requiring additional resources within pediatric endocrine practices (3).

According to the International Society for Pediatric and Adolescent Diabetes (ISPAD) 2014 Clinical Practice Consensus Guidelines Compendium, the ultimate goal in diabetes care delivery is to "provide care that results in normal growth and development, high quality of life (QoL), and lowest possible risk of acute and long-term complications. This is best accomplished by helping

children and families become proficient in self-management, remain motivated throughout childhood and adolescence while mentoring children to develop into independent, healthy adults” (4).

Despite significant advances in diabetes therapeutic options and technology in the past 2 decades, optimal care delivery models that empower patients to benefit from these advances have not been well-described or standardized nationwide. One well-recognized challenge to optimizing diabetes care delivery in the United States is the progressive decline in traditional fee for service (FFS) payment, resulting in a greater need for institutional support. This decline has impeded pediatric endocrinologists’ ability to financially implement their care teams and to maintain and evaluate optimal care models. Under-resourced diabetes practices result in inadequate staffing and lack of key professional team members whose role is to engage in education and care coordination, while addressing social stressors and behavioral health concerns.

Optimizing diabetes care requires that we expand our understanding of current care delivery models, their strengths and weaknesses, and the barriers to meeting patients’ needs. To address this, the Practice Management Committee (PMC) of the Pediatric Endocrine Society (PES) surveyed the membership to determine clinical and financial information, including the average number of patients with either type 1 or type 2 diabetes served in their practices, the type of staff providing care, and how they are reimbursed. Most of the questions focused on care delivery for

patients with type 1 diabetes, as they constitute the majority in most diabetes practices. The membership was also asked if they felt their current staffing levels and reimbursement enabled them to achieve the ISPAD goals. In addition, the survey authors were interested in knowing to what extent survey responders desire PES to engage on their behalf in advocacy efforts toward healthcare policy makers and payers.

Methods

An anonymous, self-report survey of pediatric diabetes practices was formulated on SurveyMonkey by members of the PMC and distributed by PES to its members from February to March of 2016. Although sent to all members, survey instructions requested that the senior member (division chief or head of diabetes section) complete the survey as both the scope and

complexity of the survey (>70 complex questions) warranted practice-wide versus individual provider participation. The project was reviewed by the Research Advisory Council (RAC) of the PES, who determined it was a quality improvement rather than a research initiative and did not require IRB approval. Survey questions were grouped into four sections addressing the following topics: 1) practice settings and staffing characteristics; 2) behavioral/mental health care; 3) pediatric endocrinologists' satisfaction with and concerns about current state of practice; and 4) patient outcome data. Data requested in this last section was similar to data requested by US News & World Report for its Best Children's Hospital rankings, and thus the data was reported only for those institutions who participated in this survey. Participants were allowed to report the data using the databases of their choice, and we were not able to independently verify the accuracy of the submitted answers. Respondents were permitted to skip questions, so we reported the number of respondents for each item. Responses were transferred to SAS Enterprise version 6.1 for further statistical analyses. Non-structured information was categorized into themes and reported as such.

Results

Surveys were sent out to all the membership of the PES. There were 101 responses from the US. Thirteen responses (12.9%) were from the same practices with identical internet protocol (IP) addresses: 5 were double entries, and 1 was a triple entry. The final dataset included 93 unique entries. Because respondents were not required to respond to each item, there were substantial missing values; hence, the number of responding participants is stated for each item. In total, data regarding the care of 73,170 pediatric patients with type 1 diabetes and 10,440 patients with type 2 diabetes were reported. There is currently no reliable database that would specify the number of Pediatric Endocrinology practices in the US, but we estimate that our survey covered practices that take care of approximately 30% -40% of all youth with diabetes in the US (1).

Practice Type and Key Characteristics:

The majority of responders were academic medical centers (65%), accounting for a total of 66,120 patients (Table 1). The majority of respondents (85%) were hospital based, with few (12%) private practice respondents. Primary providers in most practices were physicians – 86.0% of 57 academic centers, 83.3% of 18 non-academic centers, and 100% of 10 private practices. Advanced practice providers (Nurse Practitioners and Physician Assistants) accounted for a much smaller fraction of primary providers.

Characteristics of responding academic, non-academic and private practices are displayed in Table 1 (practice size) and Table 2 (patient load/staff ratio).

New Onset Care:

The average (\pm SD) number of newly diagnosed type 1 and 2 diabetes patients per year was 97.4 ± 84.2 ($n=89$) and 22.3 ± 25.4 ($n=82$), respectively.

Initial education of newly diagnosed patients with T1D was predominantly provided in the inpatient setting in 71.0% of 89 responding centers. The duration of new patient education was difficult to determine because respondents described a wide variety of practices, often reporting combining inpatient- and outpatient-administered modules. Diabetes education was provided by Certified Diabetes Educator (CDE) employed by the clinics in 72% of clinics and by hospital inpatient nursing staff alone in 11.8%. The remaining 16.2% of practices reported using different types of resources. Group sessions were used by less than half respondents (48%) during their education process, either at onset or shortly after the onset of type 1 diabetes. Of 91 respondents, 55.0% reported that their practices did not have a specific, separate education process for the initial education of type 2 diabetes patients.

Established Ambulatory Care:

Patients time slots scheduled with physicians varied, with 30 minutes per patient the most common (60%), while 15 to 20 minutes slots were reported by 22.6% of physicians and >30minutes by 17.2%. Advanced care providers had more time allotted for appointments; among the 64 respondents, 42.2% reported having 30 minutes and 46.9% reported having 45 minutes or

longer. Survey responders found it difficult to quantify visit time with CDE's, who often do not schedule free standing appointments, but rather see patients together with other providers.

The average (\pm SD) time that a patient with diabetes spends in a follow up appointment, from check-in to check-out, was estimated to be 67.7 ± 27.8 minutes in the main clinic by 89 respondents and 57.2 ± 20.8 minutes in satellite clinics by 54 respondents. Seventy-eight percent of 91 responding practices reported utilizing care coordination, and 70.7% of 65 practices reported having specific interventions for patients with socio-economic status (SES) challenges/poor adherence and services to aid with transition to adult care. Very few practices (18.9% of 90 reporting) reported utilizing videoconference telemedicine visits, and 35.9% of 89 practices reported having a patient/family advisory board.

Adherence to Standards of Care:

Of the 47 reporting centers, practices regarding adherence to standards of care showed that 56.4% of type 1 diabetes patients had 4 or more visits per year, as recommended by ADA, and 86.8% of primary diabetes patients (including both type 1 and 2) had a face-to-face visit with a CDE in the preceding year. Of the 46 reporting practices, 71.3% and 46.4% of patients had face-to-face visits with a dietitian and a mental health specialist, respectively, in the preceding year. Median A1c value in patients with commercial insurance was $8.3 \pm 0.22\%$ (68 nmol/mol) in academic medical centers ($n=25$), $8.41 \pm 0.27\%$ (68 nmol/mol) in non-academic centers ($n=8$) and $7.75 \pm 0.4\%$ (61 nmol/mol) in private practices ($n=4$). In patients with Medicaid, those values were $8.80 \pm 0.45\%$ (73 nmol/mol) in academic medical centers ($n=27$), $8.98 \pm 0.47\%$ (75

nmol/mol) in non-academic centers ($n=8$) and $8.18 \pm 0.72\%$ (66 nmol/mol) in private practices ($n=4$). Among 48 reporting practices, 93.1% of eligible type 1 diabetes patients had thyroid tests performed in the past 2 years. Of type 1 and 2 diabetes patients >10 years, 89.7% had lipid screen performed in the past 5 years; among those who additionally had a duration of diabetes >5 years, 85.1% had urine microalbumin screen in the past year and 58.7% had retinal exam done in the preceding year. Patients of private practices ($n=8$) tended to be more adherent to standards of screening; however, the number of private practices respondents was too small to draw conclusions about importance of this finding.

Reimbursement:

Fee-for-service was the main method of reimbursement as was reported by 82.0% of 89 responding practices. Table 3 illustrates the billing practices for support services.

Eighty-nine percent of 84 respondents reported that their practices received no reimbursement for non-face-to-face services. Of 86 practices, 15.1% reported financial profit from providing diabetes services, 57.0% reported loss and 27.9% reported not having access to the information. Of 13 profit-reporting practices, 53.8% were private practices, 15.4% were academic and 23.1% were non-academic practices. Thus the rate of taking care of patients with diabetes for a loss is a staggering 96.6% in academic centers and 84.3% in nonacademic, hospital based practices.

Behavioral Health Services:

Of 87 respondents, 56.3% reported having one or more behavioral health (BH) specialists integrated in their team, 26.4% reported having access to those services within their institution and 17.2% reported no access to BH services. Of 81 respondents, 40.7% indicated that BH specialists in their practice see all new patients, and 43.5% of 85 respondents reported screening type 1 diabetes patients for mental health problems using a validated screening tool. Four barriers to mental health services were reported to be either significant or very significant barriers by most respondents: lack of insurance coverage by 76.5% of 81 respondents, lack of BH providers in the area by 61.4% of 83 respondents, lack of BH providers trained in diabetes in 69.5% of 82 respondents, and lack of institutional support for multi-disciplinary approach by 59.3% of 81 respondents.

Eighteen (23.7%) of 76 practices reported having BH specialists routinely see all clinic patients for prevention and guidance, with the rest reporting that those services are offered to psychologically challenged patients only. Of 65 participants reporting how BH services were reimbursed, 55.4% indicated the clinic covering the costs, 58.5% indicated fee-for-service (FFS), 6.2% indicated grant, and 6.2% indicated foundation support.

Provider Satisfaction and Concerns:

Seventy-six (89.4%) of 85 responders indicated that they were very or somewhat satisfied with the duration and quality of care provided to their patients with type 1 diabetes at diagnosis.

Among those 9 respondents who reported not being satisfied, 88.9% indicated that they would prefer more education to be available to the patients after the initial diagnosis on the outpatient

basis and 87.5% of 8 responders would like to see a more consistent process of education, provided by specialized providers, with CDE qualification. Sixty-one (71.7%) of 85 responders were satisfied with the time allotted for follow up clinic visits and the current composition of their team. Table 4 illustrates major areas of concern. When asked for improvement suggestions, the greatest needs were expressed for BH support and higher reimbursement, so the staff can spend the time they need with the patient .

Regarding the reimbursement climate, 59.8% of 82 responders indicated that they are either very or somewhat dissatisfied with the current FFS model.

Lastly, 78.8% of 85 respondents thought it was somewhat or very important to create staffing guidelines for care of children with Type 1 diabetes, that would be recognized as best practice and >90% of 85 respondents indicated that PES should take the lead in establishing the standards.

Discussion

Our survey captured quantitative and qualitative data from all forms of clinical practices caring for over 80,000 children with diabetes . Based on the SEARCH study data from 2010, 179 387 US youth were estimated to have the diagnosis type 1 diabetes and 22 820 of the type 2 diabetes (1). We found that pediatric diabetes care facilities in the US are concentrated in academic health centers and hospital based practices. It is not clear if the lack of private practice centers reporting is due to the fact that many do not care for patients with diabetes or that they

did not respond to the survey. Physicians constitute the majority of primary providers across all practice settings with advanced practice providers significantly less frequently employed in that role. Consistent with their central role in diabetes care and education, we found that CDEs are the most common non-physician diabetes team professional employed, with an approximate ratio of 1 full-time educator per 367 children in the practice. Registered dietitians (RDs) are the next most commonly employed non-MD professional, with an approximate ratio of 1 RD for every 2 CDEs, although it was not possible to determine to what extent the RDs were utilized in a combined CDE/RD role. Behavioral health (BH) providers are less commonly employed within the care team. Although no correlations were observed between staffing ratios and A1c, we recommend caution in accepting this negative finding, due to the insufficient number of practices reporting A1c values to our survey. Future prospective studies are needed to ascertain which provider types and interventions result in the best outcomes. Registries, similar to one used for patients with cystic fibrosis (CF) would allow for more consistent data collection and a more accurate analysis.

Our A1c dataset is consistent with that of the T1D Exchange (5) and demonstrates that over 50% of children with diabetes do not achieve the ADA published A1c target of <7.5%. In addition, as has been reported for other pediatric chronic conditions, Medicaid-insured patients experience worse outcomes, irrespective of practice type.

A 30 minute visit time with the team professional was deemed to be adequate by a majority of providers, but the length of visit might be more dependent to the institutional constraints, rather

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than physicians' preference, so this information should be interpreted with caution. Patient-reported outcomes (PROs) were not captured by our survey.

Only 56% of patients met the standard of care for quarterly visits, despite the fact that missed visits are associated with poor glycemic control and preventable episodes of diabetic ketoacidosis. (DKA) (6). This finding underscores the need to explore the causes for missed visits and to guide potential interventions such as telehealth visits, flexible hours, and employing BH and social work (SW) as well as care coordinators to ensure that high risk patients keep their appointments

Meeting the needs of the most vulnerable patients and families requires access to care coordinators trained on linking patients and families to available community-based and BH services. Typically it is the role of SW, however only 56.3% of practices (primarily academic institutions) have those team members available.

Similarly, the implementation of a staged transition to adult care is not standardized, nor is the adoption of a specific new-onset process for type 2 diabetes patients whose medical and behavioral-social needs differ from the typical type 1 diabetes patient.

It is our opinion that the observed variability in staffing levels and other aspects of care delivery likely reflects leadership decisions, patient demographics, local culture, and financial resources.

It is possible that this variability could be reduced if there was a national consensus statement

establishing best practices for team composition, staffing ratios and core components of care delivery. We attribute the fact that 89% of the responders express satisfaction with the quality of care provided, while 90% recognize the need for additional BH support, to “cognitive dissonance” related to a “learned helplessness” among under-resourced pediatric endocrinologists within their organizations. (7).

Slightly more than half of surveyed practices had a BH specialist integrated within their team, and only 23.7% reported those specialists providing preventive care and guidance within the diabetes clinic, indicating an understaffed and largely “reactive” model of BH intervention. The prevalence of psychological issues in diabetic youth is significantly higher than those without diabetes and is associated with decreased self-care, higher A1C, poor diabetes outcomes, and increased health costs (8,9). Psychosocial screening is recommended as a standard part of initial and ongoing care to identify families at risk for early emerging complications and non-adherence (10). Systematic reviews and meta-analyses found that the most effective interventions were those delivered to the family or groups of families, leading to improved health outcomes and lower cost of care (11,12, 13). Despite this evidence, cost and low reimbursement are expressed by most respondents as the main barriers to integrating sufficient BH services within diabetes care teams. (Table 4)

Survey results indicate that 71% of diabetes care teams admit their new -onset patients for education, despite the fact that ambulatory new-onset care for metabolically stable patients is equally effective and dramatically cheaper (15, 16).. The reality is that high-cost inpatient new-

onset care will predominate until new payment models are in place that reward healthcare entities to transition new-onset care to the outpatient setting. (17, 18).

Although FFS represents a substantial portion of care delivered by diabetes teams nationwide, it does not cover laborious non-face-to-face care (19) . At least 57% of practices report negative margins on providing diabetes care which validates previous analyses by The Diabetes Working Group (20), and Melzer et al (21). We speculate that this is due to the low rate of billing for diabetes education, clinical behavioral therapy and social work services in the current system (Table 3) and by the huge amount of uncompensated time spent by CDE's on phone triage, insurance paperwork and education.

Most of the survey responders consider change in reimbursement model a high priority (Table 4). Although local innovation has established a proof-of-concept for a longitudinal bundled payment model for youth with T1D in one pediatric institution, it became unsustainable in the face of current health reform trends that are shifting more of the cost burden to families (22). As we adopt population health strategies and demonstrate the value diabetes care teams provide, we will be able to join the growing ranks of provider organizations that are implementing and evaluating value-based care and payment models. Until then, optimization of FFS reimbursement for RDs, CDEs, SWs and psychologists can partially offset the costs of care for youth with diabetes.

At the same time we aim for financial sustainability, we need to find ways to deliver quality care at lower costs. The introduction of new efficiencies and technology into care delivery will

become increasingly important. Telemedicine is a rapidly expanding mode of care delivery, shown to increase patient engagement and expand touch points with their care team. A recent study by Wood et al demonstrated an improvement in ADA standard adherence with telemedicine visits. (22). Low (19%) adoption of telemedicine, indicated by our survey respondents represents another strategy to pursue ,as more and more states and payers reimburse direct to patient remote visits. Based on our survey data and current healthcare trends, future areas of focus might also include how best to integrate the patient and family perspective into the care team, the development and validation of PROs, and the analysis of the key aspects of care delivery, technology , and payment models that optimize key diabetes outcomes across diverse healthcare settings (23).

Succeeding in our rapidly changing and disruptive healthcare environment calls upon organizations and advocacy groups to partner together. PES recently formed a Special Interest Group (SIG) for pediatric diabetes to represent the views of its membership, advocate on their behalf, and serve as a PES representative in relevant joint initiatives. Similarly, the T1D Exchange and the Juvenile Diabetes Research Foundation have partnered together to develop and disseminate a set of standardized diabetes outcome measures beyond A1c, to be used as common language to assess outcomes and conduct research (24).

In summary, our survey results provides information not recently or previously gathered on 93 US diabetes practices and demonstrates a wide variability in care delivery and team composition

across practices. The greatest perceived barrier among respondents to improving care is the lack of financial resources and the greatest care gap is BH.

A major limitation to interpreting the results of our survey is that responders were allowed to respond to questions of their choosing, and that the data reported could not be independently verified. This certainly brings up a concern for observational bias, which we acknowledge. Despite these limitations, the consistent themes that emerged resonate with the collective experience of front-line practicing pediatric endocrinologists and leads the authors to conclude that the survey findings represent the status of pediatric diabetes care teams in the US.

We thank PES for acknowledging the importance of diabetes care to its members, and for increasing its diabetes infrastructure. These survey findings underscore the need for PES and its “sister” organizations, like ISPAD and ADA to work together and transform pediatric diabetes care across the care continuum.

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Table 1-Descriptive statistics for numbers of type 1 and type 2 diabetes patients by region and provider type

Region	Diabetes	Total			Academic		Non-Academic		Private	
		<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>n</i>	<i>M</i>	<i>n</i>	<i>M</i>
Total	Total	90	929	723	58	1140	19	664	11	374
	Type 1		813	661		1002		571		325

	Type 2		116	112		138		92		49
Midwest	Total	19	1126	729	13	1398	4	677	2	255
	Type 1		1027	675		1267		641		243
	Type 2		99	82		131		36		13
Northeast	Total	22	712	446	17	733	3	780	2	423
	Type 1		611	390		644		564		400
	Type 2		100	114		89		215		23
South	Total	29	931	677	18	1036	7	887	3	497
	Type 1		770	585		847		780		367
	Type 2		161	121		189		107		130
West	Total	20	978	977	10	1682	5	271	4	318
	Type 1		892	916		1542		228		298
	Type 2		86	108		140		43		20

Table 2- Number of patients with T1D per provider type

	Total			Academic			Non-Academic			Private		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
Type 1 Patients Per...												
Social Worker	61	2032	2831	48	2246	3150	12	1255	614	1	1083	
Dietitian	75	750	545	54	824	581	16	514	344	4	761	587
Psychologist	38	3455	3549	33	3601	3540	3	3827	4805	1	500	
Educators	83	367	385	55	395	447	19	274	217	7	453	166

Table 3-Billing and payment for services

Service	Which of these Services are Billed for in Your Practice?			If Billing, are They Collecting Reimbursement?		
	<i>n</i>	%Yes	%No	<i>n</i>	%Yes	%No
CDE						
One-on-One	88	63%	38%	46	91%	9%
Group Classes	84	40%	60%	25	96%	4%
Clinical (Behavior) Therapy						
One-on-One Encounter	82	43%	57%	29	90%	10%
Drop-by Services	79	11%	89%	7	100%	0%
Services						
Social Work	83	12%	88%	5	80%	20%
Nutrition	85	71%	29%	53	92%	8%

Table 4-Likert ratings for staffing and payment questions

Question	n	%				
		1	2	3	4	5
Rate Your Agreement with the Following Statements*						
Need More MD Providers	83	8%	20%	28%	13%	30%
Need More non-MD Providers (APN/PA)	80	14%	14%	36%	18%	19%
Need More RN/CDE Support	84	4%	8%	15%	27%	45%
Need More Dietitian Support	83	4%	5%	23%	35%	34%
Need More Mental Health Support	84	1%	1%	10%	25%	63%
Need More Reimbursement	83	5%	0%	8%	24%	63%
Rate the Importance of Each of the Following †						
Increase Fee Via Value-Added Payment System	77	1%	1%	17%	35%	45%
Availability of More Coding Options	77	8%	5%	25%	32%	30%
Reimbursement for non-Face-to-Face Services	79	0%	0%	3%	19%	78%
Bundled Payments/Capitation	73	5%	4%	36%	32%	23%

*1, strongly disagree; 2, disagree; 3, neutral; 4, agree; 5, strongly agree

† 1, very unimportant; 2, somewhat unimportant; 3, neither important nor unimportant; 4, somewhat important; 5, very important