On a Different Page! Perceptions on the Onset, Diagnosis, and Management of Type 2 Diabetes Among Adolescent Patients, Parents, and Physicians

Jinyu Xu, PhD, MPH, RD[1] (iD), Keeley Pratt, PhD[2] (iD), Monika Chaudhari, MD[1,2],
Rohan Henry, MD, MS[1,2] (iD), Rebecca A. Hubbard, PhD[3],
Robert Siegel, MD[4,5] (iD), and Ihuoma Eneli, MD, MS[1,2];
on behalf of the PEPPER Research Advisory Group

Abstract

To examine perceptions about the diagnostic process and post-diagnosis care of type 2 diabetes (T2D) from adolescent patients, parents, and diabetes care physicians, semi-structured interviews were conducted with 8 individuals from each group. Interview transcripts were coded using content analysis. Emerged categories were compared among 3 groups. Half of adolescent patients and parents were surprised by the T2D diagnosis, despite most reporting that patients experienced common symptoms of T2D prior to diagnosis. Adolescents and parents recognized diet, exercise, and weight gain as risk factors after diagnosis, whereas physicians noted weight gain as a common risk factor pre-diagnosis. All 3 groups noted the importance of maintaining a healthy lifestyle and adherence to T2D management, though physicians noted the challenges from socioeconomic structural inequalities. Adolescent and parents were surprised by the T2D diagnosis, suggesting the need for increasing awareness of risk factors and symptomatology of T2D among at-risk adolescents and parents.

Previously thought of as a rare occurrence in the adolescent population, the diagnosis of type 2 diabetes mellitus (T2D) is no longer considered as such. From 2002 to 2012, the incidence of adolescent (ages 10-19) T2D rose from 9.0 cases per 100 000 youths to 12.5 cases per 100 000 adolescents.[1] Consequently, the management of T2D in adolescents now presents a major challenge to the health community. This increase in diagnosis may be driven by the parallel rise in the prevalence of obesity, especially severe obesity in adolescents.[1] It is still estimated that another 3.3% to 14.3% of adolescents are living with undiagnosed prediabetes,[2] which places them at great risk of complications to nearly every organ system. Further, when prediabetes or T2D is diagnosed in adolescents, they often respond poorly to traditional treatment in lifestyle modification programs, and drug (ie, Metformin) or insulin therapy.[3,4]

One inherent challenge to diagnosis is lack of knowledge in the general population about the pathophysiology and risk factors of T2D in adolescents.[5] This is in part because symptoms of T2D often appear as nonspecific and are attributed to common adolescent behavioral and mood characteristics (ie, change in mood, irritability, fatigue, and increased hunger). Over 35% of

[1]Nationwide Children's Hospital, Columbus, OH, USA
[2]The Ohio State University, Columbus, OH, USA
[3]University of Pennsylvania, Philadelphia, PA, USA
[4]Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA
[5]University of Cincinnati, Cincinnati, OH, USA

Corresponding Author:
Ihuoma Eneli, Center for Healthy Weight and Nutrition, Nationwide Children's Hospital, 380 Butterfly Garden's Drive, Columbus, OH 43215, USA.
Email: Ihuoma.eneli@nationwidechildrens.org

Mexican-American parents of adolescents with acanthosis nigricans were not aware that their child had the cutaneous marker of diabetes, which was misinterpreted as being due to poor skin hygiene.[6] Even among high schoolers who correctly described diabetes as "a problem with moving sugar out of the blood," only 48.5% were able to identify obesity as a risk factor.[7] Unless addressed through screening and education in routine primary care, adolescents, and their parents are unlikely to identify risk factors and symptoms of T2D. As a result, they may not participate in screening and as such the T2D diagnosis will be delayed.[8] Furthermore, investigations on adolescents and parents' perceptions prior to, and at the point when a diagnosis of T2D is made were rare, as studies have mainly focused on the perceptions about self-management after diagnosis.[9-12]

Based on previous studies, the perceived likelihood of receiving a T2D diagnosis among the general population of adolescents and their parents appears to be low, even when adolescents have existing risk factors like obesity.[13] The perceived risk of T2D not only affects the process of receiving a diagnosis, but also plays an important role in adolescents' participation in health promoting behaviors that contribute to T2D prevention and management.[14] Considering the paradigm of family centered care, with T2D being a chronic disease, the participation of the adolescent, individuals playing a significant role in the patient's life (the family), and the provider is important in ensuring success. Until adolescents, parents, and health care providers are on the same page with respect to T2D risk factors, symptoms, diagnosis, and management, the diagnosis of adolescent T2D will continue to be delayed or missed.[15] However, no study has included all 3 parties to compare perceptions of those who participated in the course of diagnosis and management. Thus, the objective of this study is to examine congruence in perceptions of adolescent patients with T2D, parents of adolescent patients with T2D, and physicians primarily working with adolescents with T2D about the path to receiving a T2D diagnosis, the diagnostic process, and post-diagnosis care.

Method

Participants

In order to reduce selection bias, separate and unrelated groups of adolescent patients with a T2D diagnosis, parents with an adolescent with a T2D diagnosis, and physicians with medical expertise in T2D primarily working with adolescents (called physician hereon) were recruited. Each participant completed a 30-minute phone interview to discuss their perceptions in depth.[10] About 24 participants were recruited from 3 healthcare facilities in the Midwestern US through convenience sampling; 8 were adolescents, 8 were parents (not of participating adolescents), and 8 were physicians (not of participating adolescents). The study was approved by the Institutional Review Board.

Procedures

Physicians were recruited from endocrinology clinics at children's hospitals. Interested parents and adolescent patients were referred by health care providers in an endocrinology clinic and a tertiary weight management clinic and were contacted via phone. The 30-minute telephone interview was recorded, and verbal consent was obtained.

Measures

The interviews assessed perspectives on the path to adolescent T2D diagnosis, including the onset of signs and symptoms, diagnostic process, and management of T2D post-diagnosis. Interview questions were adapted for each group of adolescents, parents, and physicians (Table 1).

Analysis

Interviews were analyzed using summative content analysis.[16] About 2 of the authors (JX and KP) coded the transcribed interviews. To verify coding, each author independently recoded 25% of the interviews that were coded by the other author. The interrater reliability for the interviews coded by both authors was 100%.

Analysis began by reading each interview, selecting the unit of analysis within each question, and deciding on the strategy for analysis of content. Then open coding was conducted in which categories were created based on groupings of codes using higher order rankings within each question. Then, main and subcategories were developed under each question stem in Table 1. Themes that represented <25% of a participant groups' (ie, adolescent, parent, or physician) responses were dropped, except for the exhaustive descriptive results of categories and subcategories in Table 2. The subcategory "common T2D signs and symptoms" in Table 2 and in the text below was based on the Centers for Disease Control and Prevention (CDC) common T2D signs and symptoms.[17] Resulting themes were compared between adolescent patient, parent, and physician participant groups across questions. The results are organized by theme, noting which questions the theme represents, with representative quotations from adolescents, parents, and physicians where applicable.

Table 1. Questions and Number of Reponses for Adolescents, Parents, and Physicians.

Interview Questions	Adolescent	Parent	Physician
1. Were you or your family surprised that you/your child were/was diagnosed with type 2 diabetes (T2D)?	8	8	—
2. Were your friends surprised that you were diagnosed with T2D?	8	—	—
3. Who did you tell about this situation, or about this thing that happened?	7	6	—
4. How did you decide to make an appointment for the things that you/your child were/was experiencing?	8	8	—
5. What are some of the symptoms or complaints/concerns that you/your patients noticed happening before the diagnosis?	8	8	7
6. What were the main symptoms or concerns that you/your patients talked to the doctor about at diagnosis?	8	8	7
7. Why do you think you/your child got T2D?	8	8	—
8. What kinds of questions do you think are important for the medical team to follow up after the diagnosis? (What kinds of outcomes does your team monitor?)	8	8	7
9. What types of treatment have/has you/your child had for T2D since the day of diagnosis?	8	8	—
10. In an ideal situation, are there any additional questions or testing that you would recommend or screening and monitoring of T2D in adolescents.	—	—	7

—=Not asked of a given participant group.

Results

Adolescent patients, parents and physicians (8 in each group) completed the interviews; however, due to technical issues with the recording for 1 physician, the interview was not usable, resulting in 7 total physicians with usable interview data (Table 1). Demographic characteristics of participants are presented in Table 3. Adolescents were on average 18 years-old (median 17, range 16-21), female (75%), identified as non-Hispanic (87.5%), Black/African American (50%), or multi-racial (37.5%), in high school (75%), and had Medicaid insurance (87.5%). The average age that adolescents reported being diagnosed was 12 years-old (median 13, range 8-15), and all adolescents identified having a family history of T2D (half identified having 1 parent and grandparent with T2D). Parents had an average age of 44 (median 44.5, range 37-51), all were female and identified as non-Hispanic, half identified as Black/African American and half identified as White/Caucasian. The majority had above a high school education (75%). The majority of physicians were female (75%), non-Hispanic (63.5%), and identified as White (62.5%), Asian (25%), or multi-racial (12.5%). The mean age since medical school graduation was 18 years (median 11 year, range 5-39 years), with half being 10 years or more post-graduation.

The interviews yielded 4 main themes across all questions: (1) Adolescents and parents were surprised with adolescents' T2D diagnosis; (2) Discordance in symptoms was noted prior to diagnosis among adolescents, parents, and the physicians; (3) Adolescents, parents, and physicians had different perspectives on risk factors associated with T2D; and (4) Adolescents and parents focused on healthy lifestyle factors after T2D diagnosis, while physicians raised concerns about length of visit, access to allied health care providers, and the impact of social determinants of health on short and long term outcomes of treatment. Detailed results for questions 5, 6, and 8 including the question stem, codes (frequency of participant responses), and categories (frequency of participant responses) are provided in Table 2.

Theme 1: Adolescents and Parents Were Surprised With Adolescents' T2D Diagnoses (Responses to Questions 1-4)

Adolescent patients reported that they were surprised about their T2D diagnosis, and the majority noted that their friends were also surprised that they received this diagnosis. Slightly less than half of adolescents reported that their family was surprised. When asked specifically, about why they were diagnosed with T2D, none of the adolescents identified family history as a possible reason for their diagnosis, although family history of T2D emerged as a risk factor at diagnosis when authors coded their answers to subsequent questions (see Table 2).

Adolescent 206: I was super surprised because I would never think that I would be the type of person that has to take multiple shots a day.. . .They (my friends) were surprised. They thought like I was pretty healthy I guess.

Adolescents 207: I was surprised. I was very shocked, because I really, I guess because it's kind of in a way that you

Table 2. Categories and Subcategories for Unique Adolescent Patient, Parent, and Physician Responses.

Question stem	Category	Sub-category	Response count		
			Adolescent	Parent	Physician
Symptoms pre-diagnosis	Common type 2 diabetes (T2D) signs or symptoms				
		Fatigue	6	4	3
		Polyuria	1	3	7
		Acanthosis Nigricans	0	4	3
		Polydipsia	0	2	7
		Blurry vision	1	1	0
		Weight loss	0	0	3
	Less common symptoms				
		Numbness/trembling	2	0	0
		Headache	1	0	0
		Mood	1	2	3
		Nausea	1	0	0
		Nocturnal polyuria	0	0	1
		Hunger	0	1	0
	Biometric values				
		Blood glucose	1	0	1
		Hemoglobin A1C	0	0	2
		Diabetic ketoacidosis	0	0	1
	Risk factor	Weight gain/obesity	1	3	3
	Asymptomatic		1	1	5
Main symptoms at diagnosis	Common T2D symptom				
		Fatigue	2	0	4
		Polyuria	1	1	7
		Polydipsia	0	1	7
		Blurry vision	1	0	1
		Weight loss	0	0	2
		Acanthosis Nigricans	1	1	2
	Less common symptoms				
		Trembling	1	0	0
		Headache	1	0	0
		Mood	1	0	1
		Nausea	1	0	0
		Increased hunger	0	0	2
		Dehydration	0	0	1
		Nocturnal enuresis	0	0	1
		Obstructive sleep apnea	0	0	2
	Biometric values				
		Blood Glucose/hemoglobin A1C	2	3	1
		Blood pressure	0	1	0
	Risk factor				
		Weight gain/obesity	1	3	3
		Family history of T2D	2	0	0
	Asymptomatic		1	0	0
	Healthy lifestyle				
		Diet	0	4	0
		Exercise	0	3	0
		Weight management	0	3	0

(continued)

Table 2. (continued)

Question stem	Category	Sub-category	Response count		
			Adolescent	Parent	Physician
Important to monitor post-diagnosis	Adherence				
		Blood glucose	2	3	3
		Medication/insulin	3	1	5
		Meters/checks	2	0	3
		Hemoglobin A1C	0	0	3
		Access/finances	0	0	2
		Ketones	0	0	1
	Symptoms				
		Symptoms/review of symptoms	1	2	6
	Healthy lifestyle				
		Diet	2	4	0
		Exercise	1	2	0
		Weight loss	0	2	5
		Stress	1	1	0
		Progression of T2D	0	1	0
	Comorbid disease				
		Heart disease	0	0	1
		Fatty liver	0	0	1
		Retinopathy	0	0	2
		Neuropathy	0	0	2
		Kidney function	0	0	2
		Patient mood	0	0	3
	Referral				
		Weight management	0	0	3
		Bariatric surgery	0	0	1
		Social work	0	0	2
		Sleep study	0	0	2
		Ophthalmologic	0	0	1
	Biometric value				
		Lipid Profile/enzymes	0	0	3
		Cholesterol	0	0	3
		Blood pressure	0	0	3
		Urinary albumin and creatine	0	0	2
	Family/household				
		Barriers	0	0	1
		Support	0	0	4

feel kind of out of nowhere, even though it wasn't. . . She (my mom) was not too surprised, my mom could tell because of some things I was telling her, but she's a diabetic herself.

Half of adolescents believed that people didn't notice anything different about them, that they were asymptomatic, prior to their diagnosis. However, in response to another questions, half of adolescents reported telling their parent about the symptoms they experienced, which resulted in their parent making an appointment with their primary care provider.

Adolescent 204: They (some friends at school) said I wasn't acting like myself, I didn't have the same energy level. . .We were at a high blood pressure appointment, and I guess they found sugar in my urine, so that's how we knew something was wrong.

Adolescent 205: No, no, no one really noticed anything. Even I didn't (notice) anything was wrong until I started vomiting. . .my mom had called up my primary care, . . . then when they transferred me over to Children's, just to be sure if it was type 2 diabetes or if it was something else.

Adolescent 207: No one really did (notice things that are different about me) besides my doctors. . .I was diagnosed over around winter break when I would go to the hospital, they found out I was a diabetic.

Most parents reported that they learned about their adolescents' problematic symptoms at a routine primary care appointment, and all parents reported being surprised that their adolescent was diagnosed with T2D.

Parent 301: By the third time (she got sick) I took her to the ER, then they send us to Children's to (Endocrinology clinic). . .I was surprised because and stuff, because I didn't think, I could see as she got older, she would end up with it, but not as young as she was.

Parent 303: I took him to the doctor's, and they couldn't even get a reading his sugar was so high. . .. Sadly, no (I was not surprised). He gained 100 pounds in six weeks, and I had a feeling that would affect him in that way.

Parent 306: went to a Healthy Weight appointment and they did blood work and his A1C level. . .was really high and so they hospitalized him to get his sugars under control.

Theme 2: Discordance in Noted Symptoms Prior to Diagnosis Among Adolescents, Parents, and Physicians (Responses to Questions 5-6)

Despite adolescents and parents reporting that they were surprised with adolescents' T2D diagnosis, they all could identify symptoms of T2D retrospectively upon receiving the diagnosis, likely because they were not aware these were symptoms of T2D prior to their diagnosis and interviews were conducted sometime after receiving a diagnosis of T2D. For example, upon recollection prior to diagnosis, parents reported that their adolescent was primarily asymptomatic, and many physicians also reported that adolescents were asymptomatic prior to T2D diagnosis (see Table 3). The top common T2D symptom that adolescents and parents reported prior to diagnosis was "fatigue" which was also a common T2D symptom that physicians reported. Parents and physicians also reported "polyuria," and "polydipsia" as top common T2D symptoms and "acanthosis nigricans" as a common sign prior to diagnosis.

Adolescent 204: I was tired all the time. I just felt weird, I just didn't feel like myself. Just kind of grouchy, irritable at times. . .I talked to him (the doctor) about the irritability. . . and the tiredness.

Parent 302: Honestly, we didn't really pick up on anything.

Parent 304: . . .the weight gain, and very just tired and fatigued all the time. . . like a little of discoloration, a darkening around her neck and stuff. . .Well beside her sleeping all the time, and she would get irritated, very irritable at times.

Parent 305: She was getting in trouble for having to go to the bathroom a lot before she had got diagnosed. . . She's been seeming a lot more crankier a little bit. . . She has darkened spots around the back of her neck.

There was some congruence in reporting of common T2D related symptoms between adolescents, parents, and physicians, though at times 1 group was not congruent with the others. For example, at diagnosis adolescents and physicians reported fatigue as a symptom, but not the parents. Most physicians also reported "polyuria" and "polydipsia" at diagnosis, but adolescents did not. Adolescents, parents, and physicians noted challenges with adolescents being asymptomatic prior to diagnosis or reporting common traits like fatigue and mood changes which they felt were often associated with adolescence. Table 2 displays the discordance between adolescents, parents, and physicians in greater detail.

Physician 103: And, to those, you know, asymptomatic, or sometimes, you know, they get referred for weight concerns, or maybe primary care doctor did some screening lab and found that, you know, they had high blood sugar, or high A1C, and they send to us, and then we did more work-up to make sure they don't have type 1, and so now they have type 2.

Physician 104: It's tricky. It's very tricky. There are some people who are asymptomatic that are diabetics, and who haven't had, you know, haven't had any symptoms.

Physician 105: Many of them do not have symptoms, they're discovered through routine screening of obese individuals. Some have polyuria, polydipsia occasionally, but those, you know, it's not polyuria, polydipsia but many of them are discovered through routine symptoms. Screening I mean.

Physician 107: A lot of times they like think that it's [the fatigue] just because they're like a teenager, and they're not sleeping enough, and that's typically what we hear.

Theme 3: Adolescents, Parents, and Physicians Had Different Perspectives on Risk Factors Associated With T2D (Responses to Questions 5-7)

About half of parents and physicians reported the risk factor "weight gain" prior to and when adolescents

Table 3. Participant Demographics.

Characteristic	Adolescent (N = 8)	Parent (N = 8)	Physician (N = 8)
Age (years) at interview, median (range)	17 (16-21)	44.5 (37-51)	—
Age (years) at Diagnosis of Type 2 Diabetes (T2D), median (range)	13 (8-15)	—	—
Female, n (%)	6 (75)	8 (100)	6 (75)
Hispanic/Latino, n (%)	1 (12.5)	0	3 (37.5)
Race/Ethnicity, n (%)			
White	1 (12.5)	4 (50)	5 (62.5)
Black/African American	4 (50)	4 (50)	0
Asian	0	0	2 (25)
Other/Multiracial	3 (37.5)	0	1 (12.5)
Highest Education, n (%)			
GED	2 (25)	0	—
Some/in high school	6 (75)	2 (25)	—
Some college	0	2 (25)	—
Associates/tech degree	0	1 (12.5)	—
College degree	0	3 (37.5)	—
Insurance status, n (%)			
Medicaid	7 (87.5)	—	—
Private	1 (12.5)	—	—
Identified family history of T2D, n (%)			
Yes	8 (100)	—	—
If yes, who: at least one parent	4 (50)	—	—
At least one grandparent	4 (50)	—	—
At least one other relative	4 (50)	—	—
Years since MD graduation, median (range)	—	—	11 (5-39)
≤ 10 Years, n (%)	—	—	4 (50)
Years since medical specialty graduation, median (range)	—	—	4 (1-33)
Medical specialty, n (%)			
Pediatric endocrinology	—	—	8 (100)
Obesity medicine	—	—	1 (12.5)

—= Not asked of a given participant group.

received a T2D diagnosis, with only 1 adolescent reporting this; at diagnosis parents reported issues with eating habits, exercise, and weight management. Nearly all adolescents believed they were diagnosed with T2D due to their eating habits, with half connecting their exercise/physical activity habits to their T2D diagnosis. About half of parents attributed their adolescents' T2D diagnosis to their family history, with very few noting eating habits and/or physical activity habits as contributing factors. Only 1 adolescent and parent attributed adolescent T2D diagnosis to obesity.

Adolescent 203: Probably because of how I wasn't eating healthy and exercising well and stuff.

Adolescent 208: . . .because of all the weight gain that I had.

Parent: 304: Because we weren't active, we weren't doing what we were supposed to do, as in watching what our eating habits, we weren't.

Parent 306: I think it is hereditary. . .because he's not a big soda drinker. He overeats, but I think a lot of it has to do with the genes.

Physician 103: So, yeah, the presentation is, you know, of course almost always is obesity, you know, and high BMI, and some, you know, may have polyuria, polydipsia bust some may not.

Physician 106: Usually, if they are overweight or heavy, usually that's more long standing. Leading up into the diagnosis of type 2 diabetes, I would say probably years of struggling with weight.

Theme 4: Adolescents and Parents Focused on Healthy Lifestyle Factors After T2D Diagnosis, While Physicians Raised Concerns About Length of Visit, Access to Allied Health Care Providers, and the Impact of Social Determinants of Health on Short- and Long-Term Outcomes of Treatment (Responses to Questions 8-10)

In terms of important things to monitor after T2D diagnosis, the majority of adolescent and parent responses were focused on adherence, such as monitoring "blood sugar," "medication/insulin," and "blood sugar meters" (see Table 2). Interestingly, parents noted few risk factors, but half noted healthy lifestyle factors that should be followed up on post-diagnosis like "diet," "exercise," or "weight loss." About half of adolescent patients and parents reported that adolescents' received lifestyle-based treatment and the majority reported taking some form of medication.

Adolescent 206: . . .about how much I poke myself. . .I received metformin. . .and insulin.

Adolescent 208: . . .to see how the medication is working. . . I've changed my diet and I try to exercise. . . I think it's (metformin) helping me lose weight.

Parent 301: I think it's important that they keep an eye on her AIC levels to see how they're going. . .she takes her Metformin. . .and her glimepiride. . .she watches what she eats and exercise. And sometimes get out your routine, exercise outside.

Parent 302: I would say diet and activity. . . how he handles stress, his pain,. . . because I guess all that can raise your sugar a little bit. . . they (the doctors) put him on Metformin.

Parent 303: How his testing is going. . .and just having any of the symptoms that he had before, what's his diet like. . . they (the doctors) started making him go to Healthy Weight and Nutrition, which he eats pretty healthy most of the time. . . he takes Metformin, and two kinds of insulin.

Parents also raised important issues related to long term care such as peer support and transition to adult care. While only 2 parents raised these concerns, both were discussed in response to factors which the parent felt may affect their child's outcome with T2D.

Parent 306: I would say that I just wish they had more support groups for the kids, so they have, you know someone that they can talk to that maybe wasn't an adult that maybe they can get to kind of express how they feel or

dealing with diabetes in their school setting, because like I said, in the beginning it was hard for my son. He didn't want to test his sugars or take his insulin at school because he didn't want other people to know, so it would be nice if he had someone maybe his own age or a support group where he could talk to other kids.

Parent 307: . . .she's 20 now, so she's going to be transitioning from the Children's Hospital to an adult main care hospital, so I'm just kind of hoping that the all of the cares that she has received and everything will be transferred over with her to her new doctors

Physicians also noted the importance of weight loss and adherence, monitoring "Hemoglobin A1C" and "access to or finances for supplies." Finally, physicians mentioned monitoring for several comorbid diseases and biometric values over time.

Physician 103: They need to report blood sugar, and talk to our diabetes team, you know, to go over the numbers, and, you know, make some adjustments. So, for follow up, you know, of course we check A1C, we screen lipid profile, we check liver enzymes, and, you know, make sure they have sleep study done, check their blood pressure.

Physician 106: So, if every patient could have like a continuous glucose monitor, that's like a, you know, technology piece that.

Over half of physicians also detailed broader social determinants of health like family/household "support" and referrals that they would pursue including "weight management," "social work," and for a "sleep study." Physicians noted that adolescent patients and/or parents brought up concerns about financial support, support for mental health, engaging in support groups or behavioral health care following a T2D diagnosis. In an ideal situation, physicians noted that they would like to have extra time for clinical visits (both frequency and length), increased access to dietitians and avenues to increase access for support services that address social determinants of health.

Physician 101: So, especially if you have to start insulin, home life and family support is like probably the biggest deciding factor in how a patient does. So, a patient whose parents aren't too overbearing but are, you know, involved, definitely is going to do better than a patient who, you know, maybe at the beginning parents are helping but then start giving all the responsibility to the child, those patients seem to not do as well. Same thing with mealtime, you know, if there's scheduled family meals versus just, you know, they can help themselves to whatever they want, or they're going out all the time is going to make a big difference. So, I'd say family support,

at least for treatment, and, you know, in treatment sometimes is going to be a big part.

Physician 105: Well, clearly we try to, you know, get family support for the patient in doing this, which, you know, and following, and making lifestyle changes, and also in terms of making sure that the patients follow through with taking their medication, and testing their blood sugars as they need to do, we're clearly looking to try to get, you know, support for that.

Physician 106: Oh, I think the big problem that I feel like is that we don't have much time with the patient. So, if we can have an hour for every patient that would be great versus 30 minutes. I think if the patients could see the dietician at every visit, I think that would be great, but that doesn't always happen. I know there are program in which dieticians go to the grocery store to help families shop I think that would be great for every patient too. I think it's just, we're just kind of limited in what we can offer.

Physician 107: Like making sure they're able to get to their appointments, and have transportation, and like time to get there because a lot of families are busy.

Discussion and Conclusion

Overall, adolescents and parents were surprised by adolescents' T2D diagnosis, despite being able about to recall symptoms consistent with T2D onset at the time of the interview. This illustrates the insidious onset which is often associated with T2D, in contrast to the situation in type 1 diabetes where profound lack of insulin often results in ketoacidosis which presents with recognizable symptoms.[18] Further, adolescents may have risk factors for T2D such as a positive family history and obesity, but in the absence of knowledge about the signs and symptoms of T2D, may not recognize these as risk factors for T2D.[19] In this context, the importance of providing anticipatory guidance to adolescents and parents about risk factors of T2D and routine screening for at-risk adolescents, such as those with obesity, in primary care cannot be overemphasized.[18,19]

There was noted discordance between adolescents', parents', and physicians' reports about signs and symptoms experienced before and at diagnosis, with all groups noting the challenge with adolescents being asymptomatic. This challenge is expected based on the insidious course of T2D even though for some adolescents complications may exist at the time of diagnosis.[20] It is also not surprising that fatigue, a non-specific symptom was perceived as the most common T2D symptom reported by adolescents and parents prior to diagnosis; whereas physicians reported polyuria and polydipsia, which are more specific symptoms for T2D.[17] Providing education to adolescents and parents about these more specific symptoms and what they portend in high risk individuals, such as those with obesity, could potentially result in earlier reporting of symptoms and subsequent diagnosis for adolescents. As such, this could decrease the potential for the development of T2D complications prior to the actual diagnosis.

The results of this study also point to the need for screening in primary care in the absence of adolescents and parents recognizing more specific symptoms of T2D prior to diagnosis. With routine screening and the subsequent identification of adolescents with prediabetes, a precursor for T2D, lifestyle changes can be instituted early through weight management programs, thus averting progression or the need for pharmacotherapy as the initial modality in management.[21]

The contribution of family history and modifiable factors like eating habits and physical activity to the adolescents' T2D diagnosis was incongruent among parents and adolescents. Dietary modifications, increased physical activity and lifestyle interventions have been proven to be effective in decreasing the progression of persons having prediabetes from ultimately developing T2D.[22] There was a different level of focus among adolescents, parents, and physicians after the adolescents' T2D diagnosis. Both adolescents and their parents were focused on the day to day rudiments of diabetes care, whereas the physicians were not only concerned about these issues, but recognized the broader issues impacting care such as social determinants of health (SDH) factors. Lack of insurance, food security, transportation for doctor's visits, and inadequate finances ultimately impact the outcomes seen in T2D regardless of the medical treatment provided. In addition, SDH highlight health disparities seen in outcome and is especially important with T2D as it's a disease that disparately affects minority populations, a subgroup already likely to lack resources, finances, and social support.[23] Adolescents and parents did not recognize these factors as important to monitor post T2D diagnosis.

Noteworthy among responses from adolescents and parents was the lack of concern regarding the development of diabetes-related comorbidities for example, heart disease, fatty liver, retinopathy, neuropathy, and nephropathy, the additional risk for obesity-related comorbidities and the importance of monitoring these comorbidities.[18,19] Again, this highlights the need for a greater emphasis on anticipatory guidance during the diabetes care visits and also at the primary care practices.

Limitations

Limitations of the present study include the convenience sample. Thus, the findings obtained may not be representative of all adolescents with T2D, parents, and diabetes care providers. Because the physicians were all pediatric endocrinologists, the information may not reflect the experience of the primary care provider who may be the patient's initial contact with the health system. Though the interview information was not usable for 1 physician, there was a clear emergence of themes in the study, hence, it is unlikely that this lack of inclusion would have changed the findings.

Implications

Clear differences were observed in perception about the onset, diagnosis, and management of T2D among adolescent patients, parents, and physicians with medical expertise in pediatric endocrinology. With early education of adolescents at risk and their parents to the symptomatology of T2D, coupled with routine primary care screening, there could be earlier recognition of symptoms and diagnosis, and as such the initiation of earlier management of T2D. Given diagnosis and management for T2D often occur in clinical settings, the perceptions identified in this study can inform data that needs to be included in clinic records such as in the electronic health record (EHR) before and after diagnosis. The opportunity to enhance EHR documentation for T2D can be a potentially valuable source of data especially for prospective cohort studies.[24] Finally, along with clinical care, targeted public health messaging for children and adolescents can be synergistic in improving awareness of common risk factors, signs, and symptoms associated with a T2D diagnosis.

Authors' Note

The study was approved by the Nationwide Children's Hospital Institutional Review Board (IRB18-00404).

Acknowledgments

Author Contributions

IE and RAH was responsible for acquisition of funding; KP, MC, RH, RAH, RS, and IE contributed to study conception and design; JX and KP contributed to data collection and analysis; JX, KP, and IE contributed to drafting the manuscript; all authors contributed to revision of the manuscript for intellectual content.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

ORCID iDs

Jinyu Xu https://orcid.org/0000-0002-0385-324X

Keeley Pratt https://orcid.org/0000-0002-8800-4326

Rohan Henry https://orcid.org/0000-0002-4514-2702

Robert Siegel https://orcid.org/0000-0002-0249-6041

References

1. Mayer-Davis EJ, Lawrence JM, Dabelea D, et al. Incidence trends of type 1 and type 2 diabetes among youths, 2002-2012. *New Engl J Med*. 2017;376(15):1419-1429.

2. Spurr S, Bally J, Hill P, Gray K, Newman P, Hutton A. Exploring the prevalence of undiagnosed prediabetes, type 2 diabetes mellitus, and risk factors in adolescents: a systematic review. *J Pediatr Nurs*. 2020;50:94-104.

3. Pulgaron ER, Delamater AM. Obesity and type 2 diabetes in children: epidemiology and treatment. *Curr Diab Rep*. 2014;14(8):508.

4. TODAY Study Group, Zeitler P, Hirst K, Pyle L, et al. A clinical trial to maintain glycemic control in youth with type 2 diabetes. *New Engl J Med*. 2012;366(24):2247-2256.

5. Nadeau KJ, Anderson BJ, Berg EG, et al. Youth-onset type 2 diabetes consensus report: current status, challenges, and priorities. *Diabetes Care*. 2016;39(9):1635-1642.

6. Su D, Huang TT, Anthony R, Ramos A, Toure D, Wang H. Parental perception of child bodyweight and health among Mexican-American children with acanthosis nigricans. *J Immigr Minor Health*. 2014;16(5):874-881.

7. Mahajerin A, Fras A, Vanhecke TE, Ledesma J. Assessment of knowledge, awareness, and self-reported risk factors for type II diabetes among adolescents. *J Adolesc*. 2008;43(2):188-190.

8. Cullen KW, Buzek BB. Knowledge about type 2 diabetes risk and prevention of African-American and Hispanic adults and adolescents with family history of type 2 diabetes. *Diabetes Educ*. 2009;35(5):836-842.

9. Mulvaney SA, Schlundt DG, Mudasiru E, et al. Parent perceptions of caring for adolescents with type 2 diabetes. *Diabetes Care*. 2006;29(5):993-997.

10. Auslander WF, Sterzing PR, Zayas LE, White NH. Psychosocial resources and barriers to self-management in African American adolescents with type 2 diabetes: a qualitative analysis. *Diabetes Educ*. 2010;36(4): 613-622.

11. St George SM, Pulgarón ER, Ferranti D, et al. A qualitative study of cognitive, behavioral, and psychosocial challenges associated with pediatric type 2 diabetes in ethnic minority parents and adolescents. *Diabetes Educ*. 2017;43(2):180-189.

12. Jacquez F, Stout S, Alvarez-Salvat R, et al. Parent perspectives of diabetes management in schools. *Diabetes Educ*. 2008;34(6):996-1003.

13. Wright DR, Lozano P, Dawson-Hahn E, Christakis DA, Haaland WL, Basu A. Parental optimism about childhood obesity-related disease risks. *Int J Obes*. 2017;41(10):1467-1472.

14. Fischetti N. Correlates among perceived risk for type 2 diabetes mellitus, physical activity, and dietary intake in adolescents. *Pediatr Nurs*. 2015;41(3):126-131.

15. Committee on Hospital Care and Institute for Patient- and Family-Centered Care, Institute For P. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012;129(2):394-404.

16. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.

17. Diabetes Symptoms. Centers for Disease Control and Prevention. https://www.cdc.gov/diabetes/basics/symptoms.html. Updated 3/24/2020. Accessed 7/27/2020, 2020.

18. Zeitler P, Arslanian S, Fu J, et al. ISPAD clinical practice consensus guidelines 2018: type 2 diabetes mellitus in youth. *Pediatr Diabetes*. 2018;19 Suppl 27(Suppl 27): 28-46.

19. American Diabetes Association. 2. Classification and diagnosis of diabetes: standards of medical care in diabetes-2019. *Diabetes Care*. 2019;42(Suppl 1):S13-S28.

20. Lascar N, Brown J, Pattinson H, Barnett AH, Bailey CJ, Bellary S. Type 2 diabetes in adolescents and young adults. *Lancet Diabetes Endocrinol*. 2018;6(1):69-80.

21. Arslanian S, Bacha F, Grey M, Marcus MD, White NH, Zeitler P. Evaluation and management of youth-onset type 2 Diabetes: a position statement by the American Diabetes Association. *Diabetes Care*. 2018;41(12):2648-2668.

22. Knowler WC, Barrett-Connor E, Fowler SE, et al. Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *New Engl J Med*. 2002;346(6):393-403.

23. Walker RJ, Smalls BL, Campbell JA, Strom Williams JL, Egede LE. Impact of social determinants of health on outcomes for type 2 diabetes: a systematic review. *Endocrine*. 2014;47(1):29-48.

24. Hubbard RA, Huang J, Harton J, et al. A Bayesian latent class approach for EHR-based phenotyping. *Stat Med*. 2019;38(1):74-87.