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# Institutional role conflict in the digital age: The case of diabetes management at school

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ABSTRACT

As the prevalence of pediatric diabetes grows and new technologies to manage diabetes emerge, there is increasing concern about consistency in health management across institutional settings, particularly in schools. While much is known about barriers at school, there are still gaps in understanding the institutional dynamics that shape health management in this setting. Using focus groups with 19 youth with type 1 diabetes (T1D) and applying institutional role theory, we find healthcare providers' recommendations conflict with school rules and norms, making it difficult to enact both the "sick role" and the "student role." These conflicts elicit negative responses from teachers and peers and stigmatize youth with T1D in school. Caregiver involvement often heightens rather than ameliorates conflict and teachers do not intervene in effective ways. Ultimately, youth must manage conflicts and stigma. By reframing challenges in health management as institutional role conflict, this paper contributes to sociological research by highlighting the importance of institutional roles, especially beyond healthcare. More broadly, the study suggests health research and policy should investigate how to better align institutional roles—rather than relying on youth and their families—to support health management of chronic illnesses across institutional settings.

## 1. Introduction

As pediatric diabetes grows in prevalence and new health management technologies emerge, there is increasing concern about consistency in health management across institutional settings, particularly in schools (American Academy of Pediatrics, 2014; American Diabetes Association and JDRF, 2013). While laws govern how schools must support youth with disabilities, including medical disabilities like diabetes, there are continuing challenges (Jackson et al., 2015). Specifically, the Americans with Disabilities Act (ADA) prohibits schools from discriminating against youth with disabilities; they have the right to go to school and do everything other students do, as well as receive reasonable accommodation. Section 504 of the Rehabilitation Act of 1973 also says schools must deliver free and appropriate education to youth with disabilities. Finally, the Individual with Disabilities Education Act (IDEA) covers cases where disabilities impair academic performance, which may apply to youth with diabetes.

Based on these laws, schools that receive public funding must have personnel trained in diabetes management and, with caregivers and healthcare providers, develop a care plan for each student. In California where our study is based, state law specifically allows unlicensed school staff to administer insulin and glucagon (American Diabetes Association, 2022a). The medical professional must give written orders and the parent must consent, but the state law does not require a school nurse to be present. Healthcare providers prepare a diabetes management plan for schools providing medical information and orders for routine and emergency care (American Diabetes Association, 2002). Additionally, caregivers may work with schools to develop a 504 Plan, a legal document enumerating modifications and accommodations schools must provide to keep students with disabilities medically safe and ensure equitable educational access. The 504 Plan includes individually-tailored details about school diabetes management (e.g., time/place for blood glucose monitoring, allowances for eating). If IDEA applies, schools must develop Individualized Education Programs (IEPs), which are similar to 504 Plans but include steps to support academic performance.

Yet, despite these legal measures, diabetes management in school remains a challenge. Research shows many schools are unprepared to support youth with diabetes; personnel lack training, communication

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among personnel and with caregivers can be poor, and there is often little management support (e.g., few health resources) (An et al., 2022; Willgerodt et al., 2020). Especially challenging is enacting the American Diabetes Association "standard of care" of digital device use, like insulin pumps and continuous glucose monitoring (CGM) devices (March et al., 2020). Given these challenges, during the early part of the COVID-19 pandemic some studies showed that when students were quarantined at home and not in school, diabetes management improved overall or specifically improved in more affluent populations (Abdulhussein et al., 2021; Kaushal et al., 2022; Schiaffini et al., 2020).

While much is known about school challenges, research frames these problems as deficits in school supports for diabetes management, rather than understanding schools as institutions with elaborate logics governing practices and examining how logics operating in schools might conflict with logics in healthcare (Florian Gutzweiler et al., 2020). Indeed, little research considers day-to-day incompatibilities in institutional logics, how these incompatibilities can create moment-to-moment classroom conflicts, and with whom responsibility rests for resolving conflicts. Therefore, we ask: How might institutional logics in healthcare and schools create conflict during the school day and how do these conflicts shape health management for youth with diabetes?

To answer this question, we examine the case of youth with type 1 diabetes (T1D) who use insulin pumps. T1D is characterized by autoimmune destruction of pancreatic β-cells leading to insulin deficiency (Mayer-Davis et al., 2018). Management involves insulin replacement through multiple daily injections (MDI) or externally worn insulin pumps (American Diabetes Association, 2022b). It also requires frequent glucose monitoring using manual blood glucose meters or CGM devices attached to the body which can transmit data to a receiver (i.e., a receiver provided by the manufacturer, smart phone, or insulin pump with automated insulin delivery capabilities, depending on the brand and type of sensor). Intensive diabetes management is necessary to achieve optimal glycemic control essential for preventing long-term microvascular and macrovascular complications (DCCT/EDIC, 2009). Therefore, understanding what shapes management across institutional settings is critical to health outcomes.

While using MDI and blood glucose meters can help people with diabetes achieve glycemic goals, more advanced technology can support intensive management. Studies show numerous benefits: pumps and CGM can improve glycemic control, reduce hypoglycemia, and reduce diabetes burden when used regularly (Pańkowska et al., 2009; Pickup & Sutton, 2008; Tamborlane et al., 2008; Wong et al., 2014). Pumps allow for flexible, convenient, and precise insulin dosing; CGM provides moment-by-moment information about glucose levels and trend data to assist with dosing adjustments and understanding the effects of food, exercise, or stress; and pumps and CGM can improve quality of life. In addition, some technologies allow data sharing so adults can remotely monitor children's glucose levels or insulin dosing through Wi-Fi and smartphones, including at school. As a result, device use is increasing (Foster et al., 2019). But, the extent youth can use devices to enact treatment recommendations depends on the school environment, including rules and norms governing behavior (An et al., 2022; March et al., 2020).

Using qualitative data from focus groups with 19 youth with T1D, we find recommendations from providers often conflict with school rules and norms. These conflicts make it difficult for youth with T1D to simultaneously enact the "sick role," or the expectation individuals diagnosed with illnesses follow providers' recommendations (Parsons, 1951), and the "student role" where youth must adhere to school rules and norms (Gracey, 1972). Conflicts between institutional roles elicit negative responses from teachers and peers and stigmatize these "student-patients," a term we use to note their simultaneous role definition in each institution. This conflict and ensuing stigma is heightened when caregivers demand adherence vis-à-vis devices (i.e., monitor, text and call for immediate action). Student-patients must manage conflicts and stigma, especially when caregivers intervene. These dynamics create significant barriers to health management in school.

Overall, this paper contributes to health research by applying an institutional lens to the challenges youth with diabetes face across institutional settings. We describe how institutional roles—patients in healthcare and students in schools—conflict and how "student-patients" must labor to meet different institutional demands. Given these dynamics, we argue schools should be conceptualized as part of healthcare systems and future research should examine cross-institutional dynamics for youth with diabetes. At a policy and practice level, policymakers and stakeholders (healthcare providers, educators, technology designers) should work to align institutions on behalf of youth with diabetes to better support their health. More broadly, our findings can apply to other pediatric chronic illnesses like asthma, where new technologies are emerging and device use for health management across settings is increasing (Katwa & Rivera, 2018).

## 2. Background

### 2.1. Schools and T1D management

Managing health across settings is of great concern to medical research and policy for children with chronic conditions like diabetes and school health services have the potential to support management (Allensworth et al., 1997; American Academy of Pediatrics CoCWD, 1999). But research shows many school-based health services are lacking. The U.S. Department of Education reported in 2020 that 18% of schools have no school nurse and 52% have a full time nurse (National Center for Educational Statistics, 2020). School personnel often must provide supervision instead of health professionals, despite having minimal knowledge of diabetes and how support student-patients (Wright & Chopak-Foss, 2020). Furthermore, regardless of the presence of a school nurse, caregivers and their children are often responsible for ensuring consistency in management across settings, including the flow of information from healthcare providers to schools and alignment of day-to-day school practices with management plans (de Cássia Sparapani et al., 2017; Mandali & Gordon, 2009).

While past research on diabetes care points to challenges, it focuses on deficits in school support for diabetes management and does not theorize or examine management across settings as an effort to align institutional expectations (Mukherjee et al., 2002; Willgerodt et al., 2020). A 2022 comprehensive review of school diabetes care notes little research on how policies and practices shape care in schools (An et al., 2022). While some studies show "inconsistent" state, district, and school policies and practices can conflict with the standard of care in pediatric diabetes, they do not draw broader conclusions about how school rules and norms might conflict with the logic of healthcare (March et al., 2020).

In studies focusing on diabetes technology in schools, caregivers, teachers, and youth find the devices helpful; parents in particular report greater peace of mind with remote access to their children's blood glucose data (Burckhardt et al., 2019; Erie et al., 2018). However, youth with diabetes find devices disruptive, particularly CGM alerts—even more so when caregivers text about alerts (Benassi et al., 2013; Fremont & Miller, 2021). While studies suggest these problems might be solved with greater caregiver-children dialogue (Fremont & Miller, 2021), they do not examine if what youth experience as "disruption" might be institutional incompatibilities in role expectations.

Instead, when studies examine "institutional factors" they focus on school resources for diabetes management, rather than examining how schools differ from healthcare institutions with respect to expectations for behavior (Florian Gutzweiler et al., 2020). When youth report more "disruption" they may be referring to a heightened awareness of incompatibilities between the health management practices recommended by providers, which they may wish to follow, and school rules and norms policed by adults and peers (August 2018). Therefore, we apply an institutional lens to understand the challenges youth with T1D face and the between-institutional dynamics shaping diabetes management.

### 2.2. *Institutional role theory and T1D technologies in schools*

In this paper we draw upon theory conceptualizing institutions as “inhabited,” where behavior is shaped by institutional-level logics or rules and norms that govern organizations and people within (Friedland et al., 1991; Hallett & Ventresca, 2006; Scott et al., 2000). Research typically applies this perspective within individual institutions, examining alignment across organizations within the same institution or how institutions produce inequities in institutional benefits. For example, healthcare research taking an institutional approach examines how institutional logics shape care coordination across different healthcare organizations (Scott, 2014; Shaw et al., 2017) and how patients’ treatment depends on interaction styles aligning with institutional expectations (Gage-Bouchard, 2017; Shim, 2010). In education, research using an institutional lens examines how logics shape policy implementation across schools (Woulfin, 2016) and how students and families benefit when their interaction style prompts institutions to meet their demands (Calarco, 2018; Lareau, 2011, p. 2003).

Some scholars characterize these institutional expectations as institutional “roles.” In healthcare, Parsons (1951) identified the “sick role,” an institutional role freeing individuals diagnosed with an illness from some societal expectations, but demanding they submit to medical experts' recommendations (Parsons, 1951). Scholars critiqued the sick role's early conceptualization for depicting patients as passive (Cheshire et al., 2021; Frank, 2016) and, later, for being incompatible with healthcare's increasing emphasis on self-management and shared decision making, particularly with chronic illness (Charles et al., 1997; Montori et al., 2006). Yet, the broader notion that healthcare institutions expect patients to take on particular roles and reward particular interaction styles remains undisputed and critical to understanding healthcare challenges (Cheshire et al., 2021; Williams, 2005). The role youth with T1D should take on according to recent recommendations is one of intensive self-management to maintain optimal glycemic control, which device use can support (American Diabetes Association, 2022b).

In education, while less research has used the term, Gracey (1972) proposed a parallel concept, the “student role.” This role includes specific behaviors and attitudes to ensure smooth school functioning (Gracey, 1972). Gracey argued children are socialized for the student role to adhere to school expectations and, later, work expectations. The role defines “good” students as those who follow bureaucratic rules and “bad” students who do not. The student role is similar to sick role in being an institutionally-defined expectation shaping access to rewards (e.g., diplomas, health resources). Gracey noted children might identify with the role, submit to it, or rebel—but they cannot ignore it.

In schools, students’ technology use is tightly monitored, including devices like the cell phones youth with T1D use for health management. In a recent study of cell phone policies in US middle and high schools, Tandon et al. (2020) found 96% of schools restrict their use and 78% prohibit use during class. Consequences for policy violations include getting the phone taken away (85%), calling a caregiver (79%), receiving a warning (71%), or even suspension (26%). Therefore, to fulfill the “student role,” youth must carefully navigate school technology policies (Tandon et al., 2020).

Yet, youth with T1D must manage their health across institutional contexts and attend to multiple roles. For example, the institutional “grammar” of schooling demanding students sit all day might be at odds with health management protocols, as can rules and norms about technology use (Tandon et al., 2020; Tyack & Tobin, 1994). Youth must also navigate caregivers’ expectations about playing the sick role and/or the student role. But, little research applies an institutional lens to understand how incompatibilities in institutional roles can create conflicts in school youth with T1D must navigate, which can be observed using individual-level data as we do in this study. Thus, we investigate different institutional roles in healthcare and schools, how these roles can conflict during day-to-day diabetes management in school, and how youth with diabetes shoulder the burden of managing these conflicts.

## 3. Methods

### 3.1. *Data collection*

For this paper, we draw upon focus group data from a larger study on how pediatric patients with T1D and their caregivers think about devices and data used to manage T1D. We chose qualitative methods to capture the perspectives of youth with T1D and their caregivers. We conducted focus groups to invite interaction and provide youth and their caregivers an opportunity to share information and connect (Onwuegbuzie et al., 2009). Focus groups can diffuse attention and pressure on any single participant, allow participants to answer how they want, and empower youth to share ideas as experts (Heary & Hennessy, 2002).

The research team collected data over a two-month period in Northern California. We obtained caregiver and youth consent and caregivers completed a demographic survey asking about their child's age, self-identified gender, length of T1D diagnosis, time since starting diabetes devices, caregiver occupation, insurance type, household income, and device training received. We organized youth focus groups by age (11–12, 12–13, or 13–14) anticipating experiences might differ (Kennedy et al., 2001). We limited groups to 4–6, since smaller groups help quieter participants, focus discussion, and minimize overlapping comments (Heary & Hennessy, 2002).

For all focus groups, we designed a semi-structured, open-ended discussion protocol. Two moderators started with introductions and ground rules and alternated between asking questions and taking notes. They encouraged participants to share stories, inspired by comments and interactions with others (Onwuegbuzie et al., 2009). They also incorporated activities such as listing thoughts independently and in pairs (Kennedy et al., 2001). Topics included experiences of T1D; perceptions of diabetes devices (pumps and CGM); experiences with data; experiences sharing responsibility with caregivers; and resources utilized to learn about devices and diabetes management skills. Groups lasted 60–75 min and were audio-recorded and transcribed. The study team debriefed afterwards to capture interactive data and observations difficult to audio-record.

### 3.2. *Data analysis*

To understand how youth with T1D and their caregivers experience devices and data (the goal of the larger study), the interdisciplinary research team of medical researchers and social scientists used a grounded-theory approach to data analysis (Charmaz, 2014). The team independently analyzed focus group data using constant comparison analysis. We created codes, categories of codes, and broader themes that express findings across focus groups, as well as compared findings across team members (Onwuegbuzie et al., 2009; Strauss & Corbin, 1998).

In this process we noted the salience of student-patients’ experiences in schools, how youth worked to meet providers’ recommendations, how alerts enforced provider recommendations (coded as “provider protocols – device alerts”), and how caregivers exerted pressure to meet provider expectations vis-à-vis digital devices (coded as “caregiver pressure – text messages,” “caregiver pressure – phone calls,” and “caregiver pressure – calling teachers”). We noted how student-patients simultaneously tried to meet school expectations by maintaining compliance with rules and norms (coded as “school rules – backpacks,” “school rules – devices,” etc.). When student-patients failed to meet institutional expectations at school, we noted this provoked stigma from teachers and peers (coded as “rule breaking – devices,” “rule breaking – peer stigma,” etc.). Through this analysis we came to understand institutional conflicts and the extent student-patients carry the burden of resolving conflicts.

Table 1 lists general categories of codes, their description and if they were included in the focus group protocol, and their frequencies. While these counts are not mutually exclusive—many comments about devices, for example, also included mention of school—frequency provides an overall sense of the amount youth discussed each topic. Notably, the

**Table 1**
Coding.

| Categories of codes | Description | Frequency |
|---|---|---|
| General experiences with T1D | Instances where youth described positive, negative, and neutral experiences with T1D, as well as advice about how to make management easier, things adults can do to support, and what others with T1D should know. Topic included in focus group protocol to introduce and conclude discussion. | 17 |
| Experiences with devices | Instances where youth described experiences with insulin pumps, CGM, and various apps (e.g., CalorieKing), including insurance coverage for devices, training, issues with usage, advanced features, and ideas for improvement. Topic was primary feature of focus group protocol. | 96 |
| Experiences with data/metrics | Experiences with "numbers" (i.e., blood glucose levels), including when and how they think about "their numbers," and how they respond. Topic included in protocol. | 27 |
| Experiences with caregivers | Experiences with management of T1D and caregivers. Includes discussion of who is "in control" of management, as part of focus group protocol. Approximately 30% of codes pertained to caregivers' monitoring and interactions during in school, like "caregiver pressure – text messages," "caregiver pressure – phone calls," and "caregiver pressure – calling teachers." Topic included in focus group protocol in one question about "working with data" with parents and one question about "Who teaches you the most about diabetes?" | 62 |
| Experiences with friends | Interactions with friends about T1D (outside of school); ~90% positive. Part of one focus group question about "Who teaches you the most about diabetes?" | 25 |
| Healthcare providers | Experiences with healthcare providers, including medical device representatives. Included such codes as "providers' recommendations" and "provider protocols – device alerts." Part of one question about "working with data" with providers. | 39 |
| Experiences in school | Experiences with T1D management in school. Includes mention of teachers, the school nurse, school peers, and interactions with caregivers at school, as well as heightened awareness of numbers at school and use of devices during school. Included such codes related to diabetes management as "school rules – backpacks," "school rules – devices," "rule breaking – devices," and "rule breaking – peer stigma." Approximately ~90% of comments described negative experiences. Topic was not included in protocol; there was one question in the protocol about "favorite classes at school," but this was not discussed. | 43 |

focus group protocol did not include specific questions about school, but youth discussed it at length.

### 3.3. *Participants*

We recruited youth with T1D and their caregivers through a specialty clinic, diabetes advocacy groups, and an educational seminar for caregivers. Participants could receive their care anywhere. Inclusion criteria were youth 11–14 years old, T1D diagnosis, and insulin pump use for ≥1 year (to capture experience beyond initiation and early use). Participants could also use CGM, but this was not required. We aimed for a heterogeneous sample with regard to gender, race/ethnicity, insurance type, pump brand, and pump use length, but limited participation to English speakers. Table 2 presents participant demographics and pseudonyms.

**Table 2**
Patient demographics.

| Pseudonym | Age | Gender | Insurance Type | Race/ethnicity | Devices Used |
|---|---|---|---|---|---|
| Ashley | 13 | Female | Private | White | Insulin pump, CGM |
| Beau | 11 | Male | Other | White | Insulin pump, CGM |
| Chris | 11 | Male | Private | White | Insulin pump, CGM |
| Corey | 11 | Male | Private | White, Latinx | Insulin pump, CGM |
| Gabriel | 13 | Male | Private | White | Insulin pump, CGM |
| Harriet | 13 | Female | Private | White | Insulin pump, CGM |
| Ignacio | 12 | Male | CCS; MediCal | Latinx | Insulin pump |
| Jacob | 12 | Male | Private | Other | Insulin pump, CGM |
| Leila | 11 | Female | Private | White, Latinx, Asian American | Insulin pump, CGM |
| Lexi | 14 | Female | Private | White | Insulin pump, CGM |
| Mae | 14 | Female | Private | White | Insulin pump, CGM |
| Margaret | 11 | Female | Private | Asian American | Insulin pump, CGM |
| Nicholas | 11 | Male | Private | White | Insulin pump, CGM |
| Nolani | 13 | Female | MediCal | Latinx | Insulin pump |
| Parker | 12 | Male | Private | White | Insulin pump, CGM |
| Rebecca | 12 | Female | CCS[a]; MediCal | White/Pacific Islander | Insulin pump, CGM |
| Sydney | 11 | Female | Private | Black | Insulin pump |
| Toni | 11 | Female | Private | White | Insulin pump, CGM |
| Wesley | 13 | Male | Other | Preferred not to answer | Insulin pump, CGM |

[a] California Children's Services (CCS), is a program of the California Department of Health Care Services providing treatment services, medical case management, and physical and occupational therapy to children <21 years with certain conditions, including T1D. Currently ~70% of CCS-eligible children are also eligible for the California Medicaid program (MediCal). (California Department of Healthcare Services. 2021. "CCS Program Overview." https://www.dhcs.ca.gov/services/ccs/Pages/ProgramOverview.aspx.).

## 4. Results

### 4.1. *Rules, norms, and institutional role conflict*

School rules and norms governing behavior often conflict with diabetes management protocols in many ways. They shape where and when student-patients can check glucose levels and deliver insulin, as well as students-patients' supply and device access and use (e.g., glucose test strips, cell phones). For example, diabetes supply bags can be subject to school rules determining if they can be nearby, despite being essential to management. Eleven-year-old "Chris" [2] explained,

> I have this one class where the teacher doesn't let me bring my backpack in, because she says there isn't enough space, even though it's the exact same size as every other classroom in the school. But then I always end up leaving my pack—my diabetes supplies in there. So then, if I need to go get them, I have to walk all the way up to the opposite side of the school where I leave my backpack.

When asked if he told the principal or his caregivers, he said the

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[2] All names are pseudonyms.

principal wasn't aware of the issue. But, even if the principal knew “she'd probably think it's just the teacher's rules in her classroom … So, I don't think she would think it was that much of a big deal.” Ultimately, Chris said “it's not that big of a deal” but “annoying to have to walk all the way up to the other side of the school” for supplies; something counter to providers' recommendations. Other student-patients described similar problems, including 11-year-old “Corey” who said he'd tried to leave his backpack “behind the classroom in a bush.” However, his teacher found out and “got really mad.” In this way, basic provider recommendations conflict with school and classroom rules. Even with a 504 Plan specifying students can carry supplies, protected by law, institutional norms about teachers' classroom rules can create inconsistencies in enacting plans. For the participants in our study, it was unclear if they had 504 Plans in place and, if they did, what the conditions were for carrying supplies, but regardless of legal protection at minimum this created conflict.

Besides supplies, school structure and expectations for academic participation can conflict with diabetes management protocols. Some diabetes management plans specify student-patients be supervised as they check their glucose levels, deliver insulin doses, and/or operate devices. Many youth reported an uneasy balancing act between this protocol and school's academic expectations. They missed instruction, for example, when required to go to the front office for management. Thirteen-year-old “Wesley” said,

> Wesley: I don’t like changing the set or site. I don’t like checking the blood sugar during school, before lunch or PE [Physical Education] because you have to go to the office and leave early.
>
> Moderator: So they tell you to go to the office to do it? Is there a nurse that wants to watch or anything?
>
> Wesley: Yeah. She has to watch.

Wesley's management plan required he visit the school nurse so she could supervise him checking his glucose levels or tasks like changing his pump infusion set (tubing and cannula connecting the pump to the body). This meant Wesley missed class instruction, free time (lunch), or part of the next class (PE). Twelve-year-old “Parker” said the same; to meet one institution's expectations (healthcare), Parker sacrificed some aspects of schooling. He explained,

> I miss school and parts of school because I have to go all the way across the entire school to get to the nurse. And if they’re explaining how to do the homework, I don’t know how to do it, and then I get behind some stuff. And not being able to do things when you’re low—like you want to do something and you can’t because – like fitness and stuff like exercising and you can’t.

Thus, youth with T1D struggle to meet the expectations for one institutional role (patient) at the same time as another institutional role (student).

Accommodations documented in Section 504 Plans or IEPs help student-patients meet providers’ recommendations at school, but in many cases student-patients still struggle to align institutional expectations. Both Parker and 13-year-old “Gabriel” said accommodations allow them to check their glucose level before exams so if they do poorly and their level was low, they can take retake them.

> Gabriel: I always write my blood sugar number on the corner of my tests so if I do get a bad grade, if my blood sugar is low, they allow me to retake it.
>
> Moderator: Did that ever happen?
>
> Gabriel: Yeah, it’s happened before.
>
> Parker: … Yeah, I would take my history—
>
> Moderator: You do that too?
>
> Parker: Yeah, I would have to leave because I went low and I had to finish that. You always do worse when you’re low.
>
> Gabriel: Yeah, I’ve always—but one time I was 73 and it was just low enough where it starts to mess with you and then I just couldn’t concentrate. My teachers are pretty good about knowing if I’m low so they come and check on me and then if it’s really bad I just be like “I can’t do it” so I’ll just sit there for the rest of the class.

However, student-patients said accommodations are not guaranteed—even with caregiver intervention—necessitating repeated negotiations, particularly with unknown teachers.

Student-patients said diabetes devices provoked challenges to school and classroom rules. Eleven-year-old “Sydney” said her mom talked to “all the teachers and the principal” about T1D management. Her mom explained, “My child has to take [test] their sugars, and so please let them take their backpack inside.” However, Sydney still had to navigate negative reactions from teachers and peers about devices prescribed by her doctors. As a result, Sydney was unable to follow providers' recommendations and did not wear her CGM during class. She said she put her pump “on vibrate, because I don't really want to disturb the other people.” She worried about managing teacher and peer reaction based on past experiences.

> Sydney: Like they’ll all look, because if they hear a weird noise, like a beeping, then they’ll look and say, “What’s that?” And then the teacher will say, “What’s that? What’s that?”
>
> Moderator: And if you explain, what do you think? Would they understand?
>
> Sydney: [The teacher] will just say, “Okay, don’t do it again.”
>
> Moderator: Even though it’s not up to you, right?
>
> Sydney: Yeah … Like a couple times the teachers called me out in front of the whole class. It was kind of embarrassing to explain the whole thing … Yeah, out loud … With everyone staring at me.
>
> Moderator: So, you have to explain the whole things in front of the class?
>
> Sydney: Like, out loud. Yeah, because one of the—I was helping the preschoolers, and so the lady was like, because she gave me ice cream. And I … said I couldn’t eat the ice cream right now, I had to check my sugars first. And she was like, “Why? Why? Can’t you eat the ice cream now? It’s going to melt.” And I was like, “Well, I have to check my sugars.” And she was like, “Oh.” She said it so loud.

Even as Sydney attempted to follow providers’ recommendations, her teacher pressured her to acquiesce to her authority and provide an explanation for noncompliance to school norms (i.e., eating shared food). By chastising student-patients for breaking school norms, teachers increased the stigma youth with T1D faced and posed a significant barrier to health management.

Several other student-patients said they got in trouble for “rule breaking” by using their devices, despite being prescribed by providers; youth had to navigate differences in the definition of appropriate behavior across institutional contexts. Eleven-year-old Chris described difficulties when teachers he didn't know saw him using his phone to monitor glucose levels with an app linked to his CGM.

> Chris: … Sometimes I’m using Dexcom [CGM]. The teachers that I don’t have, they don’t really know me. So, if I’m on my phone, they’ll come up and they’ll take it, because they think I’m just playing video games. So, then I have to wait until the end of the day to go and get it.
>
> Moderator: … how do you feel about that?
>
> Chris: It’s annoying, but it’s not that big of a deal.

> Moderator: Okay. And have you even—so, how often does it happen?
>
> Chris: … I signed up for this special thing. Every time I start my fifth period, it's a different class. So, then I have to keep explaining it to the new teacher, and that's kind of annoying … I feel like once teachers sort of starting to understand it, then I have to go to the next teacher and start the whole thing again ….The thing about my school is, if you have your phones out, it goes to the principal and then your parents have to sign it out. And it's dumb.

Student-patients struggle with school and classroom rules and norms, especially as they encounter new teachers.

While some schools and teachers allowed phone use for medical purposes, other schools went so far as to disallowing any device. For example, 13-year-old "Harriet" said her private Waldorf school—which might not receive public funds and therefore may not be subject to laws concerning diabetes care in schools—would not allow a phone, so she had no way to share CGM data with her parents.

> Harriet: I'm not allowed to bring my phone to school because it's a Waldorf school so you're not allowed to have phones. So my parents actually can't get alerted when I'm high.
>
> Moderator: Is that a good thing?
>
> Harriet: Ah, I don't know. I feel like because then every time I have to read [my parents] all of my numbers when I get home. So I think it would be better but my school would never agree to letting me bring my phone.
>
> Moderator: Even if you have—
>
> Harriet: No, they won't even let me bring it on trips with me like when my parents aren't there I don't think they … because it's like they're very anti-media.

Overall, these instances show how school rules and norms can conflict with diabetes management protocols to structure where and when student-patients can check glucose levels and deliver insulin, as well as their access to supplies and devices. In a school like Harriet's, for example, it was difficult to meet healthcare recommendations to share data with her parents and not fail to meet school expectations.

### 4.2. *Institutional role conflicts, interaction style, and stigma*

The conflict between institutional demands outlined above, particularly with device use, elicited negative responses from teachers and students and stigmatized student-patients. Although device alerts when glucose levels go out of "target range" are recommended for better management and are created through a shared decision-making process, in school their demanding nature can be disruptive and draw unwanted attention (Pals et al., 2021). Many student-patients reported problems with alerts in class, drawing attention to otherwise forbidden phone use and provoking stigma (Tandon et al., 2020). This places them in a difficult position because they often want to use devices to better manage their T1D, but the stigma of appearing to break school rules can make this impossible. Eleven-year-old Corey explained he got in trouble at school for CGM alerts, which upset him. He said,

> Corey: I got in trouble once.
>
> Moderator: Oh. Tell us more about that.
>
> Corey: It just kept ringing, and I left it in class. And my teacher had to have a talk with me saying it interrupts the classroom, even though it's on the silent mode, and it's not on.
>
> Moderator: So what did you do? What did you tell your teacher?
>
> Corey: Just took it out.
>
> Moderator: And you turned it off?
>
> Corey: Yeah. I had to turn it out; just put it outside.
>
> Moderator: Does this happen a lot?
>
> Corey: Um-hm … Angry.
>
> Moderator: You feel angry about it? Okay. Why? Is it because they don't understand? Why do you think?
>
> Corey: They don't understand, and people laugh because it keeps ringing.
>
> Moderator: Oh, like your classmates?
>
> Corey: Yes.

In this instance, Corey was stuck between two institutions' demands—trying to meet healthcare expectations and school expectations, then managing stigma when falling short. While past studies of diabetes technology note parents identifying problems with CGM alarms, studies characterized such problems as "disruptions" rather than conflicts between healthcare protocols and institutional rules and norms concerning device use in school (Brew-Sam et al., 2021; Lawton et al., 2018; Pickup et al., 2015).

Learning to use devices and managing alerts is a significant challenge to school T1D management. Several others described similar situations, where CGM or pumps alerted them to high or low glucose levels. Fourteen-year-old "Mae" said her CGM device went off during standardized testing because she was "nervous" so her "blood sugar went super high" which was "really awkward" especially because she was "new to diabetes [and] hadn't even been diagnosed a year." Thirteen-year-old Gabriel explained navigation between institutions started when he was diagnosed, when he knew very little about devices, and his teacher didn't realize he had diabetes and his device was prescribed by his provider. Gabriel said,

> [W]hen I was in second grade, first grade so I didn't know how to do any of it, so it started—I didn't have any insulin or whatever in my pump, like it ran out, and it was beeping. I didn't know how to turn off the beep, I didn't know how to suspend your pump at the time so it just kept beeping and she kept yelling at me to turn off my phone and it wasn't my phone and I got upset. But then she finally realized it wasn't because I'm like … [breaking rules; it was diabetes].

Although these alerts are suggested by providers, student-patients must manage how they are interpreted at school, where rules and norms often prohibit device use and disruption. They have to learn how to use devices to manage T1D according to providers' recommendations and how to negotiate their use at school, as well as how to manage teachers' and peers' negative reactions.

Further, when caregivers monitored vis-à-vis medical devices, student-patients noted conflicts in institutional role expectations heightened, despite research showing caregiver vigilant advocacy can benefit children in healthcare (Gage-Bouchard, 2017; Gengler, 2014; Shim, 2010) and education (Calarco, 2018; Lareau, 2011, p. 2003). It added pressure to adhere to providers when surveilled by caregivers from afar, which providers may encourage. Eleven-year-old Rebecca said her physician recommended a phone app to share data with her caregivers. She explained, "My doctor wanted us to get this glucose app … so that [my parents] can see my numbers. Like when I check, they can see all my data on my PDM [i.e., a Personal Diabetes Manager, a handheld device controlling insulin patch pumps]." To follow providers' recommendations, Rebecca and others said they share their data with caregivers who share data with providers, linking student-patients' in-school data to healthcare institutions and making them simultaneously responsible for student and patient roles.

Along with shared data, caregivers can set their own alerts for out-of-range glucose levels. Eleven-year-old Chris said he uses the "Dexcom share app" to send data to his mother's phone and "alarm her" based on settings she determines on her own app. He explained, "[I]t will pop up on her phone and will pop up on my phone and stuff." As a result, caregivers may text or call their child, the teacher, and/or the school to check on their child and ensure they adhere to treatment, which past research shows can provide peace of mind for caregivers (Erie et al., 2018). However, parents' monitoring can cause further problems for youth in maintaining the student role. Fourteen-year-old Mae described a school event where her parents were monitoring her glucose at home and texting their concerns. Mae said,

> At my school, we do residential and we spend the night at school so we have dorms and it is like really fun … it's a lot of bonding and stuff, and at the end of the week, we will always have pizza and my parents always text me at night and they are always like "Your blood sugar is high." I'm just like "Stop texting me. I just want to be here." I want to be in the moment and I don't want to have to worry about this … I'm just like let me be; let me do my own thing.

Similarly, 11-year-old "Nicholas" said his mom sends texts during school. When asked how he felt about it, he said, "It's just really annoying to me. Sometimes I forget to silence my phone and then it goes off." The noise becomes something else to manage in class. Twelve-year-old "Jacob" agreed, saying, "It just gets annoying. They do it a lot during class and I have to stop what I'm doing and just check my phone and do all that." As a result, student-patients must then manage their caregivers' reactions to their data as well.

When this happens, student-patients are caught between institutional demands. Responding to text messages in class, for example, is at odds with school rules and norms. Eleven-year-old Corey said he shares his data with his parents but it was "annoying" and risky because his parents' response might get his phone taken away—creating more barriers to management at school.

> Corey: [My parents] want me to check every time I see it.
>
> Moderator: So, they text you "[Corey], check now," or something?
>
> Corey: Yeah. I don't really look at it … Because even though I guess [people with diabetes] have a special right in school where they can bring their phones to call their parents … I don't want to do that because I feel like I could still get my phone taken away."

Corey implied whatever choice he made—whether turning off alerts and data sharing and disappointing his parents and providers or keeping them on and facing academic and interpersonal consequences—would result in failure to meet an institutional role and elicit stigma (from caregivers and providers or from teachers and peers).

### 4.3. Student-patient management of institutional conflict and stigma

Finally, our findings suggest the day-to-day management of institutional role conflict and stigma are often left to student-patients, even when caregivers try to intervene. In many cases, caregiver intervention can heighten conflict and stigma, rather than alleviate it, and teachers appear to follow student-patients' lead rather than intervening. In particular, peer stigma is a significant burden and barrier to management during school, especially when devices provoked questions. Fourteen-year-old Lexi said she had to continually explain her illness to her peers,

> I go to a small school, so once I got diagnosed everyone knew and it was just like – and we have 40 people in my school. It's so small. But some kids – it's so funny because they always ask for my juice and I'm like "Do you know what this is? This is like keeping me alive." And they're like "Okay." Some people thought – some people are like "Oh yeah my grandfather had diabetes and he had to have his foot cut off" or whatever, and for me that's like for me that's the worst part when someone goes up to you and asks you what your thing that you are wearing is and I'm like yeah it's a pager.

All student-patients told stories of peers asking about devices, often with no intervention by school personnel.

For example, 11-year-old "Margaret" said much of what the devices do are beyond her control, and provoked stares from peers while teachers did nothing and instead checked in with her later to see how she was managing peer response. She explained when her CGM device buzzed, "all the kids in class stare at me" and "then the pump, it just randomly beeps. And, then it's just beeping to say I have to change my set, which I already know."

> Moderator: … So, in class do they get it? What happens if something beeps?
>
> Margaret: They'll turn around and look at me like what's that. I won't say anything. I'll just stare at them back …
>
> Moderator: I'm wondering how do the teachers act? What do they say?
>
> Margaret: Well, they already know so they don't really say anything. Sometimes after class they'll come up to me and just ask me if I'm okay and I'll be like "Yeah."

Other student-patients also felt the negative consequences of managing multiple, conflicting demands and peer perceptions. Twelve-year-old Jacob said his devices alert him in class and he felt responsible for both adhering to what providers recommend (i.e., using devices) and following school rules to avoid peer stigma.

> Jacob: The pump beeps when you leave. [And] if you have low insulin or low batteries, it just beeps and beeps. Everyone stares at you and you just feel like "Oh my God what have I done?" …
>
> Moderator: So, your classmates, they don't know? They don't get it?
>
> Jacob: Not really. Only one person knows. Just the teacher.

Like Margaret, Jacob said his teacher does not intervene and he has to manage peers' responses to his devices on his own.

Some stigma comes from peers believing they are enforcing school policy. Twelve-year-old "Ignacio" explained when using his phone students ask questions and tell the teacher on him, thinking he is breaking rules. Other student-patients shared similar experiences.

> Ignacio: Well, it was in the beginning of the trimester when nobody knew. I was in a class, and it went off. And everybody was "What's that? What's that? Ignacio has his phone out." And I was like "It's a pump." I had to explain to everyone.
>
> Moderator: You had to explain. And did they understand?
>
> Ignacio: Yeah. My teacher understands. It's just the kids keep on asking those annoying questions.
>
> Corey (11-year-old): I feel like I explain to a kid five times, and they just—
>
> Rebecca (11-year-old): They just don't understand.
>
> Corey: They don't understand. That's like one of my friends who I hang out with, I feel like they don't even try to understand really. They're like "Oh, what's that?" And I'm trying to explain it, and they just aren't even caring. They're just like staring at something else.
>
> Moderator (to Ignacio): … Do [the teachers] ask you to silence your pump and sensor?
>
> Ignacio: No, my teachers understand fully about me … Because I talk to them one on one in the beginning of the year and tell them what I have going on.

In this way, Ignacio worked to align how his teacher understood his behaviors with providers' recommendations, as did other student-patients, and alleviate peer stigma. The same was true of 11-year-old “Leila” who said if she did something on her pump, students would tell the teacher “I'm using my phone in class or something … [T]hey think I'm breaking the rules or something by doing it.” When asked about teachers, Leila said “yeah, my teachers know,” but that did not prevent students from reporting her. Leila said she had to hide her management because of this stigma.

Like Ignacio, 14-year-old Lexi worked to align day-to-day classroom norms with diabetes management protocols. She said once she was “going to see the doctor that week” and had to bring multiple devices to school; they all started beeping when her glucose level went out of target range. She had to navigate demanding devices, teachers’ expectations, and peer stigma.

> Lexi: … I was bringing my [CGM] receiver so that he [the healthcare provider] could download the data. So I had my receiver and my phone and I was in class, and my phone was like beep-beep-beep and my receiver starts beeping and I turned this one off, and that one started beeping and I turned that one off, and this one started beeping and it was a total disaster.
>
> Moderator: Well, what happened? Did they tell you that you have to explain?
>
> Lexi: My school – my teachers know. I talked to them about it. Sometimes when that happens they will be like “Turn off your phone” or something but I’ll just look at them and it’s like “I’m dealing” and so they are "Okay you’re fine," but it’s just I feel bad because it’s like everyone is in class and it’s like some noise over here like some girl with her devices over there distracting everyone.

Lexi said it made her “feel bad” even though her teachers were aware of her T1D and understood she was following providers’ recommendations. But, teachers mostly did not intervene beyond telling student-patients to turn off their phones.

In some cases, peers' questions were instigated by teachers' reactions to device noises. Fourteen-year-old Mae said her teachers’ responses could provoke peer attention. On one school trip her teacher was monitoring her glucose levels and called her out to tell her they were low. While helpful in assisting in management, Mae then had to explain to peers what was going on. She said,

> I was hiking in the front of the group, and my teacher had to stop me because my blood sugar was 40, and I was really mad because I wanted to keep going and that was good, but my blood sugar was really low so it is like kind of holding back because of my health. And then just people asking questions about it. Like I had it where somebody thought I was contagious which was so awkward. It was really – yeah but it was funny, kind of funny.

In this case, although Mae framed it as “funny” it was clear this was a painful event. Having to manage institutional conflicts and stigma posed a significant burden.

Findings from caregiver focus groups confirmed that youth primarily manage institutional conflicts. Caregivers said they monitor their children's data and often ask their children to explain data trends. For example, several said they would have discussions with their children after school about what their children were doing in real time and how they responded to alerts. In fact, caregivers seemed to contact the school only under specific circumstances. For example, one parent said,

> [I]f [an alert] goes off at work or I might look at it at work. Oftentimes you see something high, I just let it go and give it [time] to see if she [her child] is taking care of it. Now if I saw a pattern where it was going up and up and up and two hours in it is still not down I’d be calling the school.

As a result, unlike youth focus groups, few caregivers talked about issues at school. The one exception was Gabriel's caregiver, who commented that school conflict escalated and they discontinued device use. They said,

> [We used devices] when Gabriel was young and it kind of freaked the teachers out. We are in a private school so we don’t have a school nurse, so the bells and whistles –it was kind of more disruptive so we stopped.

After a few years, their doctor encouraged the family to try again once Gabriel was older and, presumably, could better manage these conflicts.

## 5. Discussion

In this study, we examined how youth with T1D navigate the institutional demands of healthcare and schools and how conflicts shape health management. While much is known about barriers to care coordination, less understood are the institutional dynamics shaping diabetes management at school (An et al., 2022). Using focus group data with youth with T1D and their caregivers we found institutional roles between healthcare and school conflict, eliciting negative responses from teachers and students, and leaving youth with T1D to manage conflicts and stigma. While past research notes the weight of these demands on caregivers, little research considers how youth shoulder this burden. These dynamics create significant barriers to health management, with important implications for short- and long-term health outcomes.

In terms of study implications for policy and practice implications, findings suggest institutions should work to align management protocols on behalf of patients, rather than relying on youth and families to resolve institutional conflicts. While professional guidelines recommend the diabetes teams, caregivers, and schools work together to create and follow diabetes management plans, school rules and norms create barriers to recommendations (Jackson et al., 2015; March et al., 2020). Alignment is especially important with technologies, as new healthcare innovations emerge and offer improvements in quality of life and health outcomes. While devices can provoke heightened conflict and stigma if institutional roles do not align, they can also offer new ways to support alignment across institutional settings.

In this regard, researchers and device companies should design products that work better within and across institutions, supporting communication between schools, providers, and families, and providing features that avoid stigmatizing student-patients. Diabetes technology is moving towards systems requiring even less input and attention. Multiple automated insulin delivery systems are now available, where algorithms integrate CGM data with pumps, allowing automated dosing adjustments based on CGM glucose levels (American Diabetes Association, 2022b). While innovations can reduce the diabetes management burden, children still must respond to out-of-range glucose levels, account for carbohydrates they eat, and enter carbohydrate amounts into pumps.

Developers should continue to innovate to reduce the management burden and help student-patients focus on school and life in general, an idea promoted by advocates with T1D (Naranjo et al., 2017). This includes continuing to work towards fully closed-loop systems and faster-acting insulins, which would eliminate the need for carbohydrate entry and entering high glucose values. Until these systems are available, designers might refine features to make management more discreet and less disruptive in schools. This might include dosing from a smartwatch rather than the pump or a phone, currently only possible with certain open-source “do-it-yourself” (DIY) automated insulin delivery systems which are not FDA-approved (Kesavadev et al., 2020). Such advances might resolve institutional conflicts and avoid the stigma of device use, rather than requiring student-patients and their caregivers take on responsibility for resolving these issues. Designs would need flexibility to adapt to challenges in different contexts (e.g., resource-limited schools).

Our study has some limitations. There may be selection bias in terms of youth who volunteered for the study. The goal of the study was to understand what youth thought about their diabetes technologies (pumps and/or CGM), so youth or families with particularly strong positive or negative opinions might be more likely to participate. However, understanding experiences in school was not specifically stated as an objective of the study, so the fact that school challenges were so salient for the majority of participants is notable. Second, the sample is limited in size and demographics. While not the focus, this paper leaves unanswered how conflicting institutional demands might exacerbate inequities by race/ethnicity and class, especially families in poverty who can be trapped in a "maze" of institutions (Paik, 2021). Research has long documented health disparities by race and class, including with T1D (Deaton, 2002; Hill-Briggs et al., 2021; Williams & Collins, 1995) and new technologies can exacerbate inequities, particularly illnesses experiencing rapid technological change—perhaps due to the institutional conflicts we describe in this paper (Glied & Lleras-Muney, 2008; Lipman & Hawkes, 2021).

Patients and families whose cultural capital is more rewarded at school, such as higher socioeconomic white families, may have more success in aligning schools with healthcare. While many student-patients and caregivers encountered problems with regard to vigilant advocacy vis-à-vis device use, groups with interaction styles commonly unrewarded by institutions may face even greater barriers (Calarco, 2018; Gage-Bouchard, 2017). However, these inequities can vary by organizational culture and the extent they require vigilant advocacy (Puckett et al., 2020). Future research should compare institutional conflicts shaping health for different socioeconomic and racial/ethnic groups and different organizational configurations to better understand the ways dynamics between institutions contribute to health inequities.

More broadly, this paper contributes to research on child and adolescent health by pointing to the importance of institutional conflicts between healthcare and schools in healthcare management, particularly for youth with chronic illnesses. Our findings may apply to other chronic illnesses, like asthma, where digital technologies are advancing (Katwa & Rivera, 2018). In fact, scholars argue research on diabetes technologies can provide important information and "set the stage" for technology use with other chronic conditions like asthma or depression (Mann et al., 2020). But, given numerous studies documenting barriers, using devices to manage any chronic illness "should be done intentionally" and with "realistic expectations, clear boundaries of use, and plans to promote maintenance." (Mann et al., 2020).

Our findings show that critical to this intentionality is consideration of how technologies' design, features, and use can help student-patients meet role expectations in school and expectations based on recommendations from healthcare providers. Otherwise, youth will be continually caught in institutional conflicts and be more likely to discontinue device use for manual alternatives, given that resolving these conflicts requires considerable labor. Further, our study suggests researchers, policy makers, and practitioners (healthcare workers, educators) should treat schools a part of health systems and work to better understand and align institutional rules and norms to support patient health.

## CRediT author statement

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**Sloan Talbot:** Writing – original draft, Writing – review & editing.

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## Ethics statement

All research included in this article was approved by the Emory University and University of California San Francisco Institutional Review Boards and performed in a way consistent with the ethical standards articulated in the 1964 Declaration of Helsinki and its subsequent amendments and Section 12 ("Informed Consent") of the American Sociological Association Code of Ethics. All participants gave informed consent prior to research participation and all information was kept confidential.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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