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Developing a personal and social identity with type 1 diabetes during adolescence: A hypothesis generative study

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Abstract

This study explored the incorporation of type 1 diabetes mellitus (T1DM) into self-identity among adolescents. Guided interviews explored 40 adolescents' views of T1DM in relation to their sense of self and relationships with others. Responses were analyzed using thematic analysis. Results revealed that the entire sample described T1DM as a significant burden; many described how T1DM made them feel less "normal." Adolescents described both positive and negative aspects of self-management in social relationships, though most reported benefits in sharing T1DM with friends. Females were more likely to share information about T1DM and to describe positive changes in self-perception as a result of T1DM. The psychosocial processes related to integration of T1DM into self-identity described in these qualitative data provide hypothesis-generating findings that can guide future quantitative research examining incorporation of T1DM into adolescent self-identity in relation to measures of self-esteem, peer orientation, self-management, and glycemic control.

Keywords

diabetes; adolescents; youth; young adults; lived experience; health; self; stigma; qualitative; thematic analysis; USA

Background

Type 1 diabetes mellitus (T1DM) is one of the most common endocrine disorders diagnosed in childhood or adolescence (National Diabetes Education Program, 2014). T1DM is currently an incurable chronic illness with no known preventive measures. It is caused by the autoimmune destruction of beta cells in the pancreas, resulting in insulin deficiency

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and consequently hyperglycemia (American Diabetes Association, 2009). Insulin injections or a continuous subcutaneous insulin pump in combination with glucose self-monitoring, diet, and exercise are required to control glucose concentrations. Failure to take adequate amount of insulin can result in hyperglycemia and diabetic ketoacidosis, while an excess of insulin can lead to hypoglycemia with neuroglycopenic symptoms such as shakiness, nausea, sweating, irritability, fatigue, excessive thirst or hunger, weakness, seizure, and coma. Long-term microvascular complications of diabetes such as retinopathy, nephropathy, and neuropathy can be prevented or delayed by intensive diabetes management. However, these self-management tasks required to control glucose levels are burdensome and difficult, particularly for adolescents. Perhaps not surprisingly, adolescence marks a time of deteriorating glycemic control and self-management in T1DM (Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007; Johnson, 1995).

Traditionally, adolescence is known as a challenging time of life due to hormonal changes that affect emotions and physical development. Adolescents typically go through this physical and emotional development while attempting to establish autonomy and challenge authority. They may engage in rebellious and pleasure-seeking behavior, value privacy, have a greater awareness of self-image, and be more sensitive to peer pressure (Hamilton & Daneman, 2002). Adolescents with T1DM experience all the above typical challenges associated with this period of development, while attempting to manage a challenging illness, which often involves greater parent involvement and oversight, appearing different from peers, and time-consuming self-management requirements (Helgeson et al., 2007). Understandably, parents often become more involved in their adolescent's life to closely supervise the adolescent's T1DM and self-management. However, excessive parent involvement may be viewed by the adolescent as a barrier to autonomy and typical development. Studies have shown that the transfer of responsibility for diabetes care tends to occur in early adolescence, between the ages of 11 and 15 (Schilling, Knafl, & Grey, 2006). However, it has also been shown that independence with diabetes care too early in development can lead to poorer self-management and negative health outcomes (Wysocki & Greco, 2006; Wysocki et al., 1996). The burden of managing T1DM challenges the adolescent to change his or her life in ways that may conflict with developmentally appropriate priorities of adolescence, such as fitting in with peers while trying to develop a sense of self in relation to others (Silverstein et al., 2005).

In developing a personal and social sense of self, adolescents with T1DM may find it challenging to prioritize diabetes and its self-management without feeling as though they are being forced to sacrifice who they are or their future plans. The conceptualization of the self becomes relevant to personal development as early as the transition years between childhood and adolescence (Steinberg & Morris, 2001). Self-concept represents important aspects of the adolescent's perceived identity, such as social acceptance, behavior, physical ability, appearance, self-esteem, and self-worth (Harter, 1985), that are formed through experiences and comparisons with others, and the expectations and perceptions of significant others (Skaalvik & Bong, 2003; Harter, 1990). Identity development becomes the forefront of psychosocial personal development in late adolescence, as adolescents transition to adulthood and attempt to clearly define themselves in their various roles (as friends, students, employees, etc.). The influence of environmental factors and personal feelings during the adolescent period is integral to identity development, affecting feelings of competence, motivation, and decisions about the future (Wigfield & Wagner, 2005). Adolescents with a chronic illness may be more likely to experience declines in self-concept because of their additional health burdens (Ferro & Boyle, 2013).

Individuals vary in the degree to which they define themselves in terms of their illness, or what is referred to as “illness centrality” (Helgeson & Novak, 2007). For young people with diabetes, there is a struggle to develop an identity that incorporates their diabetes so that they become “a person with diabetes” rather than “a diabetic person” (Olshansky et al., 2008). Adolescents may think of their illness and self-management regimen as external to themselves, especially shortly after diagnosis (Balfe, 2009). When diabetes is not viewed as part of the self, it can be perceived more negatively and can result in lower well-being (Skinner, John, & Hampson, 2000). Charmaz (1995) suggested that some individuals will adapt to their illness and integrate it into their self-concepts by accepting their status as a person with a chronic illness and altering their identity in socially and personally acceptable ways, while others will ignore, minimize, or struggle against the illness in an effort to regain or preserve a pre-illness identity. Examining this process of how one identifies with T1DM may improve our understanding of why adolescence can be such a difficult time for diabetes self-management and control and may identify factors that promote resilience among adolescents with T1DM (Weissberg-Benchell, Wolpert, & Anderson, 2007).

Social relationships also become increasingly important to self-concepts because adolescents are becoming independent from their parents and relating more to their peers (Cheung, Cureton, & Canham, 2006). Thus, peer acceptance becomes especially important in developing social connections and friendships, and by extension, a positive sense of self. The self-conceptualization that begins in early adolescence is shaped through experiences and comparisons with others and influenced by the expectations and perceptions of peers (Skaalvik & Bong, 2003; Harter, 1990). However, adolescents with T1DM may feel self-conscious about their diabetes around their peers and may attempt to hide their illness in social settings. Peers can potentially exert a negative influence on diabetes management, particularly if concern over peer reactions becomes more important to adolescents than managing their diabetes (Wysocki & Greco, 2006). Hains, Berlin, Davies, Parton, and Alemzadeh (2006) and Hains et al. (2007) found that adolescents with T1DM had worse glycemic control and anticipated more difficulty adhering to their self-management if they believed their friends would think negatively of their self-management behaviors (e.g., avoiding sugary foods and self-injecting insulin). Adolescents may be less likely to disclose their T1DM when they fear they will not be accepted by their peer group or will be excluded from peer activities (Szydio, Van Wattum, & Woolston, 2003), which, in turn, may lead them to ignore self-management (Davidson, Penney, Muller, & Grey, 2004). Acceptance by peers may be even more important than longer-term health consequences to adolescents with T1DM and some may disregard self-management in an effort to fit in (Carroll, Downs, & Marrero, 2007; Herrman, 2006; Wang, Brown, & Horner, 2010; Youniss & Haynie, 1992).

The purpose of the current study was to explore adolescent personal and social identity development in relation to T1DM. We conceptualize identity as an adaptable framework in which adolescents perceive themselves in relation to others, their goals, and their future.

This conceptualization of identity is described by Christiansen (1999) as, "the person we think we are. It is the self we know." Christiansen indicated that identity was a composite of self-esteem, self-efficacy, our roles in our interpersonal relationships, values and priorities, and possibilities for our futures. Such factors may be affected by a diagnosis of T1DM. Informed by Charmaz's (1995) work on incorporation of illness into self-identity, we sought to explore how T1DM affects self-concepts, social interactions, and self-management during adolescence. Results may add to the growing literature addressing the steep decline in glycemic control in adolescence, and generate hypotheses for potential areas for intervention to improve self-management and adjustment.

Method

All participants were part of a larger mixed-methods, clinical-research study and completed both audio-recorded interviews, as well as validated self-reported measures assessing a variety of psychosocial constructs (e.g., diabetes-specific self-esteem, social competency, quality of life with diabetes, etc.). The study design utilized a sequential exploratory QUAL → quan design; qualitative data collection was emphasized and analyzed first, while quantitative data collected were used to supplement and support findings from the interviews (Hanson, Creswell, Clark, Petska, & Creswell, 2005). Surveys were given after the interview portion of the study, so as not to influence the results of the interviews. However, this manuscript focuses solely on the results of the qualitative portion of the study. We used Braun and Clarke's (2006) method of thematic analysis to identify, analyze, and report major overarching themes within data. The aim of the interviews was to explore adolescents' views on the experience of living with diabetes and how living with T1DM affects self-concepts from a personal and social standpoint.

Participants

Participants were the initial 40 of 85 adolescents (ages 13–20) recruited as part of the larger mixed-methods study. All were required to have had T1DM for at least 1 year. They were recruited through direct referrals from their physicians or nurse practitioners during their prescheduled standard medical appointment at the diabetes clinic. Children below the age of 12 and adults above the age of 20 were excluded. Participants were also required to be fluent in English. Those with a medical condition (other than T1DM), psychiatric diagnoses, or intellectual disability that may affect their ability to consent or participate in the study were excluded from the study. For every 10 participants who completed the study (both surveys and interview), a raffle was held for a US$25 gift card. At the completion of the study, a raffle was held for all 85 participants recruited for the larger mixed-methods study for a US$50 gift card.

Data Collection

Written informed consent from the parent and assent from the child were obtained prior to administering the in-person interview or self-report measures. The full study session (including consent, interview, and completion of questionnaires) was approximately 40 minutes in length and was conducted at the time of the participant's medical appointment, while they waited for their health care provider to see them. The Albert Einstein College of

Medicine of Yeshiva University Institutional Review Board approved all study procedures prior to data collection.

Each participant began the session with a guided interview, conducted by a trained interviewer, either a clinical psychology doctoral student or licensed research nurse. Interviewers were kept blind to the participant's glycemic control, as measured by the amount of glycated hemoglobin (HbA1c) in their blood, which provides an index of blood glucose over the prior approximately three months. The interview consisted of five broad, open-ended questions designed to prompt a larger discussion of participants' feelings about diabetes, their treatment regimen, diabetes-related effects on their peer relationships, and how they define their experience of living with diabetes. See list of questions below.

1. Tell me about what it has been like for you to live with diabetes.
2. How do you think you have changed from before you got diabetes until now? [If specific to health behaviors] Any other ways? Have you changed as a person?
    a. Has this changed over time?
3. How do you think your diabetes has affected the way other people view/think of you? [prompt] How about your friends or teachers? How about your family?
    a. Has this changed over time?
4. How do you think of yourself compared to your friends or classmates? For example, how does it feel knowing you have diabetes and they don't?
    a. Has this changed over time?
5. How do you think the way you see yourself as someone living with type 1 diabetes, the way you said [describing the way the participant may have discussed earlier], influences the way you take care of your diabetes?
    a. Why [or why not]?

Questions were designed to lead a discussion of life with diabetes and how the illness affected perception of oneself individually and in social situations. Follow-up questions were asked if the adolescent did not understand the question or to probe a response with the goal of facilitating a full understanding. Interviews ranged in time from 5 to 22 minutes (M = 6.41, SD = 3.87). Participants were offered the option of having a parent present in the room during the interview, depending on their level of comfort; however, presence of parent was not systematically recorded.

Data Analysis

Thematic analysis was used to identify patterns in the interview transcripts. Thematic analysis is a method for identifying patterns within the data (Braun & Clarke, 2006); the interview was guided by Charmaz's (1995) theoretical work to explore how daily life, senses of self, and social relationships are affected by T1DM. Thematic analysis was conducted using the Braun and Clarke (2006) guidelines: familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Each interview was digitally recorded and transcribed.

Transcripts were analyzed by three coders in an initial session to generate basic initial codes. Coders were doctoral students in clinical health psychology, supervised by a licensed clinical psychologist. Each coder open-coded each interview using the process described by Glaser (1978), by analyzing line-by-line to code as many of the conceptual and theoretical ideas that emerged from the data as possible. After highlighting keywords and phrases while reading the transcript, these notes were then compared among coders, transcribed onto coding sheets, and grouped into overarching themes. Themes were compared to minimize selective perception and interpretive bias (Patton, 1999). Discrepancies between coders were discussed and adjusted until a consensus was reached. Final themes were refined and defined through extensive discussion among coders and the senior author (JSG). The findings were also subject to analyst triangulation; triangulating with multiple analysts was used to reduce potential selective perception and interpretive bias (Patton, 1999). Overall results and select de-identified transcripts were reviewed by a pediatric endocrinologist, research nurse, and a nurse practitioner, as noted in the informed consent.

Of note, two particular themes were interpreted using a deductive approach based on the work of Charmaz (1995). Specifically, Charmaz detailed ways in which an illness was maintained in relation to the self: through acceptance and adjustment of identity and lifestyle or through a variety of maladaptive behaviors such as, ignoring the illness, minimizing its impact on life, or struggling against the illness in an effort to maintain pre-illness normalcy. For the purposes of this study, we conceptualized adolescents who demonstrated acceptance of their illness as those who had “incorporated” the illness into their identities, while those who did not demonstrate acceptance were conceptualized as “containing” the illness within self-imposed limits, apart from their identities. The remaining themes pertaining to life with T1DM were coded using an inductive approach to explore how adolescents perceived the impact of T1DM on their lives. Demographic characteristics of the sample were analyzed using statistical package IBM Statistics SPSS 22.

Results

Forty adolescents participated in the study. Approximately 47% were female (19 participants). The mean age of the sample was 16.15 ± 1.89 years. The sample was predominantly comprised of ethnic minorities, with nearly 53% identifying as Latino/Hispanic and 18% as Black. Nearly 68% of the sample used an insulin pump and the average duration of illness was 6.87 ± 3.58 years. Overall glycemic control was suboptimal (HbA1c: 9.68 ± 1.89%). Based on observational differences between genders during the interviews, a *t*-test was conducted to determine whether genders differed in any demographic characteristics. However, there were no statistically significant differences between genders in age, ethnicity, duration of illness, method of insulin use, or glycemic control. Demographic characteristics can be found in Table 1.

Themes From Qualitative Analysis

Results from thematic analysis suggest that T1DM was a burdensome aspect of daily life and often triggered a desire to “feel normal.” This burden was described as existing despite frequently positive peer reactions and support for self-management. Adolescents described self-management of T1DM as a burden on their daily life, as it forced major health behavior changes into their routines and activities. T1DM also made adolescents feel different from their friends and peers, though many also reported sharing their T1DM status with friends and receiving support from them. Finally, two particular themes emerged from the data, suggesting adolescents viewed diabetes as part of themselves in different ways: incorporating the illness into their identities versus containing the illness within limits, outside their identities.

Burden of diabetes.—An overarching theme in this sample was the characterization of life with diabetes as being difficult, complex, hard, or a burden. All respondents characterized T1DM with at least one of these terms.

> "I guess it’s like going through an epic journey where you know you’re not going to reach a finish line, but everybody tells you it’s about trying. It’s difficult to look yourself in the face in the morning if you know you haven’t done what you need to do, and so I feel like diabetes is partnered with a big guilt trip, and it’s life-long, and it sucks, hard."
>
> (19-year-old female)

Diabetes self-management was a major aspect of diabetes-related burden. Adolescents spoke about difficulties in controlling blood sugars and conflicts involved in depending on parents for support with self-management while trying to become more independent.

> "They [people who don’t have diabetes] think I have to check my insulin, that’s all I have to do. But that’s not it. There’s diet, taking care of your whole body, you can’t walk without shoes on. There’s so many things people don’t see or understand."
>
> (17-year-old female)

Participants described feelings related to a perceived conflict between the demands of diabetes self-management and other valued goals and activities when describing the burdens of T1DM self-management.

> "I don’t want to like be outside and have to worry about stopping what I’m doing just to go check yourself. It’s weird. It’s not weird, it’s like, I find it annoying, to sit there like “We gotta stop, you gotta go check yourself.” Nah, I’m just going to keep doing this, and then I’ll check myself [later]."
>
> (16-year-old male)

Burden also covered the negative health-related effects of diabetes, including a restrictive impact on social life, worry about complications, and negative mood changes that were ascribed to hyperglycemia. Although the majority of participants focused on the negative and difficult aspects of their illness, some adolescents reported that the burden eased over time or described gaining mastery in dealing with diabetes. For example, some adolescents focused on the responsibilities of T1DM self-management as source of feeling different from others and described how these responsibilities were less disruptive to their self-concepts when they were part of a routine.

> "Living with diabetes is basically like living a normal life, just with a little bit of extra work. Like on the side you're checking your blood sugar. You're basically normal, just a little extra step you have to do to eat and stuff."
>
> (15-year-old male)

Incorporation of diabetes into identity.—Adolescents who incorporated their diabetes into their self-concepts viewed their disease as a part of themselves, and its associated treatment as an active and necessary part of their daily life. Mastery of the skills involved in diabetes self-management was described as an integral part of accepting the illness and incorporating it into a new identity.

> "Now I'm at a place where it's just I've accepted it. It's something I know I'm going to live with for the rest of my life, I know there's nothing I can do except learn to take care of it and be healthier about it … you just have to learn the steps necessary for you to be a healthy member of society and for you to learn that this is what you have to deal with. And then you learn to take care, you learn to count carbs, you give yourself insulin whether through a pump or through injections or however it is. You learn the importance of doing everything."
>
> (18-year-old female)

Adolescents who incorporated their T1DM did not let the negative reactions of peers affect their self-management; they took direct, active roles in addressing diabetes in social situations, shared their diabetes status, and educated others about their illness.

> "If I've never met a person, [who] doesn't know I have diabetes, then I lift up my shirt, and they see the catheter for the first time and they don't know what it is … They freak out. They think it's something crazy. I just go through and explain it to them."
>
> (20-year-old male)

These adolescents also tended to give descriptions of self-management as requiring the learning of behavioral steps that needed to be integrated with pre-existing routines. Rather than conflicting with other valued goals and interests, these behaviors could be successfully integrated into new routines that facilitated continued engagement.

> "I can eat what I want, but I have to be on top with the injecting myself. If I play sports, I have to buy something to eat or something immediately. I can't just do what I want like nothing happened."
>
> (14-year-old male)

Those who described successful incorporation of T1DM into their identities also commonly described the following: feeling more mature and responsible than prior to their diagnosis or as compared with peers, having little concern for what others think, being more cautious, having a desire to help others, and experiencing positive changes in self-concept, such as being more confident and feeling stronger:

> "I'm more mature about it because I realize I have to take care of myself and if I don't, it's not like it's going to go away. It's going to be there until there's a cure, so I have to make sure I keep myself healthy."
>
> (14-year-old female)

Containing diabetes within limits.—Adolescents who contained their illness did not fully integrate diabetes into their identities. These adolescents tended to describe T1DM as external to their self-concepts, separate from their identities.

> "A lot of people say I never really accepted it yet though. I feel like I accepted it because I know that I have it, but I never really take care of myself … I don't check as often, I don't inject as often. Mainly because I don't even really want it, I guess."
>
> (18-year-old male)

Often, they described struggles to accept the various aspects of living with diabetes. Participants who attempted to contain the illness commonly described not following self-management plans. Some described problems with self-management as involving a desire to reject T1DM as a part of the self, while noting the self-damaging nature of this battle.

> "I think I almost sabotage myself sometimes because I want to get back at it or rebel. I think it's interesting what the mind does sometimes. I sabotage myself. Like eating too much or not bolusing the way I should. I'm only harming myself, not anyone else. It's just a really bad habit that I formed."
>
> (17-year-old female)

Those who contained their diabetes also tended to keep diabetes a secret and felt as if no one understood them. They described feeling stigmatized by their diabetes in social situations, which often interrupted their self-management plans:

> "I am a lot less likely to be inclusive and wanting everyone else to know about my diabetes and about the way I take care of myself if I'm in a situation where it makes me feel uncomfortable. If everyone else can accept the fact that I have diabetes, I'm great at taking care of my diabetes. If everyone can't really do that, then I'm going to pretend that I don't have diabetes. It's something I'm not proud of, but it's at least something I'll admit to."
>
> (19-year-old female)

Diabetes affecting perceived normalcy.—The majority of participants described ways in which diabetes made them feel different from their peers.

> "I just feel different, and I feel like I have to do more than other people and that frustrates me a lot … So I feel like it's extra weight and extra work and why do I have to do extra work?"
>
> (17-year-old female)

Some specifically acknowledged a current desire to be "normal," suggesting that they felt diabetes made them different, stigmatized, or abnormal.

> "My sugar’s really bad, and I know I can do wrong inside my body. You can say I don’t care, but I do … I just want to be a normal kid. But I can’t."
>
> (16-year-old female)

Perceived over-involvement of family and teachers, especially in the form constant questioning, both at home and in public, was also mentioned in relation to the desire to feel normal. Participants reported sacrificing self-management behaviors to fit in with others.

> "In school, the teachers, they’ll take it easy on me ‘cause they know I got diabetes. I’m not like mad about it, I’m actually kind of glad, but I want to be treated like all the other kids, not just like I have diabetes."
>
> (16-year-old male)

Participants also reported concern over others’ evaluations of them. In some cases, an experience of being bullied or evaluated negatively due to factors related to the illness lead to fear of future stigmatization.

> "In public, I didn’t like checking my blood sugar and taking needles because someone would always ask, “What is that, what’re you doing?” I had an incident before where I was actually made fun of, for having a really old pump. Then I took my pump off and didn’t wear it for almost 2 years because I was insecure about it."
>
> (17-year-old female)

Impact of social support.—Nearly all participants mentioned both positive and negative effects of family and peer involvement in diabetes care. Although T1DM was sometimes described as making adolescents feel different from their peers, the majority of adolescents reported being glad they disclosed their diagnosis to their friends because their friends encouraged their treatment by reminding them to check their blood glucose or take their insulin.

> "They’re all cool with me having diabetes, they’re all super helpful. Like they won’t tell me to do something I don’t want to do like have candy. So yeah, they’ve been really supportive in making me feel normal. Like I don’t even have diabetes."
>
> (15-year-old male)

Some adolescents reported having a friend with diabetes, which helped them adhere better to their treatment and feel more understood. Many also identified their family as a positive form of social support.

> "Of course, my family is 100%. Like if I was to go to a family outing, they make sugar-free cookies, or anything I’m able to eat that doesn’t have a ton of sugar in it."
>
> (15-year-old male)

However, involvement of others in diabetes management could also have a negative impact. Adolescents endorsing this theme primarily expressed annoyance with parents or friends who appeared excessively worried or overprotective. Conflicts with transfer of responsibility for diabetes management from parents to adolescents were commonly described. Female participants were more likely than males to report this negative impact:

> "They’ve always been really overprotective, but since I got diabetes they’re even more protective. And I guess it’s kind of annoying, because I just want to break out and do whatever I want, but they’re always like, 'Are you checking your sugars? Are your sugars ok? If you’re low, come home!' And I’m like, 'No, I got this!'”
>
> (15-year-old female)

Differences by gender.—Finally, based on observations from conducting the interviews and an initial review of the coded material, we examined whether the themes endorsed differed between males and females. Quantitative analysis of code frequency by gender indicated that males and females did not differ in their tendency to describe T1DM as a burden, as the entire sample endorsed this theme. Males were much more likely to describe a containing approach by keeping the illness outside of their identities. More females provided descriptions of successful incorporation of T1DM into their identities. Females were also more likely to share their experience and knowledge about the illness with others. Thus, they also reported more support from friends for diabetes self-care and more family involvement in treatment.

> "My friends are willing to ask, and because they are willing to ask, they find out the information in a really cool, fun way, since that’s how I try and present it. And they are a lot more likely to be involved in my treatment."
>
> (19-year-old female)

Differences in the extent to which diabetes affected perceived normalcy and the impact of social support were more modest at the level of general themes. Females endorsed feeling more stigmatized and negatively changed by diabetes at some point since their diagnosis.

> "At first when I was younger, I felt like there was something wrong with me. Like 'Why do I have this and not them? Why do I have to go through this?'”
>
> (14-year-old female)

Females also reported feeling negative effects of sharing their diabetes status, such as family and friends becoming overprotective and worried. Although boys tended to be more likely to contain diabetes, none described negative expectations or worries about disclosing diabetes to their peers.

> "I swear it’s like I have 3 or 4 mothers, and they are all like, 'Did you test yourself, you can’t eat that, that’s too much sugar.' I’m like, 'Oh my goodness. I left home to hang out with you guys to get away from my mom and you’re acting like her.' So, yeah they’re extremely protective. I can't eat candy in their presence, it’s ridiculous."
>
> (18-year-old female)

Males were generally less likely to endorse difficulties with T1DM, particularly in regard to their social lives. They were also more likely to focus their answers on specific health behavior changes, such as exercise or glucose monitoring, when asked about their life with diabetes. Females, in contrast, described more emotional and social adjustments in life with T1DM, such as negative mood change and restrictions on social life.

> "It hasn't really been that difficult. Just more of a lifestyle adjustment in general, staying away from juices and sodas, and learning how to count carbs. I think once I got the carb-counting aspect of it down, it wasn't really too hard of an adjustment for me."
>
> (19-year-old male)

It should also be noted that females tended to be much more descriptive in their interviews, and thus described more specific details of their difficulties. Males did not endorse as many difficulties as females, but we cannot rule out under-reporting as a gender bias.

Discussion

This study highlights the cognitive, emotional, and interpersonal aspects of growing up with T1DM during adolescence: feeling burdened, wanting to feel normal, and changes in how family and friends treat an adolescent living with T1DM. Results emphasize the importance of personal and social aspects of diabetes self-management in relation to identity development. Most adolescents reported T1DM to be burdensome and socially differentiating, though some also reported a positive, supportive effect of sharing their diagnosis with their friends. Participants in this study unanimously described diabetes as being difficult or burdensome, both in regard to difficulties with daily management as well as negative effects from the responsibilities of self-management on physical wellness and social life. Specifically, diabetes management left visible and potentially stigmatizing “marks” on the body (e.g., insulin pumps, injection site bruises). Self-management requirements also created differences in eating, social, and sports routines that were visible to others and could result in conflict and negative evaluations from family and peers. Thus, T1DM was described as resulting in significant changes in the body, the private self and social self.

The burden of living with diabetes (e.g., self-management behaviors, physical symptoms associated with high and low blood sugars, worry about health) was the only theme described by all members of the sample. This is not surprising given the demands of self-management and the difficulty most adolescents face in meeting treatment targets for glycemic control (Helgeson et al., 2007; Johnson, 1995). It is also important to note that even those identified as incorporating their illness described challenges in integrating T1DM self-management into their daily lives. The coping strategies one uses to manage the demands and stress of self-management may influence emotional and physical health outcomes, a possibility supported by the demonstrated benefits of coping skills training (Grey, Boland, Davidson, Li, & Tamborlane, 2000; Grey et al., 1998). Greater attention to problems with integrating self-management into daily routines and social situations in the care of adolescents with T1DM may facilitate positive identity development. Positive identity development may, in turn, support optimal self-management over time. These hypotheses deserve attention in research and clinical contexts.

The majority of the sample reported that diabetes affected their social selves at some point in their lives; specifically, adolescents reported a desire to feel normal because diabetes and its associated treatment made them feel different from their peers. This is consistent with past literature that adherence is significantly more difficult in social settings (Berlin et al., 2006), particularly when the adolescent fears negative reactions from friends (Hains et al., 2006; Hains et al., 2007). Finally, despite the burdens of life with T1DM and the risk of stigma, the majority of the sample reported positive experiences in sharing their diagnosis with friends. Thus, interventions that focus on peer relationships and social stigma may also be beneficial for adolescents with T1DM.

Themes related to the extent to which the adolescent integrated T1DM into their identities were consistent with the frameworks of identity by Christiansen (1999) and identity development with a chronic illness (Charmaz, 1995, 2000). Christiansen described identity as a construct made up of self-concept, self-efficacy, personal values, relationship roles, and possibilities for the future. These factors are all likely affected by a chronic condition such as T1DM, as the illness will affect how adolescents view themselves, how they believe others to view them, the priorities they assign to managing the illness, and how they perceive the illness to affect their future (Charmaz, 1995, 2000). This is similar to past work by Piana et al. (2010), who suggested that to cope with an illness, the adolescent must understand the experience of being ill by finding and assigning meaning to the condition in regard to their story, world, and life. Our results suggest that by successfully integrating diabetes into a positive self-identity, adolescents may be able to better manage their diabetes in social situations and may be less sensitive to perceived or actual stigma, thus bettering their overall physical health.

Similarly, participants in the current study also endorsed feelings of being different from others and a desire to be “normal.” These feelings may also fall in line with how the adolescents identify with their T1DM. For example, if the adolescent can normalize his or her new lifestyle and view the behaviors involved in diabetes self-management as generally health promoting, something similar to what everyone is recommended to do (such as a healthy diet and regular exercise), as opposed to something just people with T1DM do, he or she can better deal with their new identity with diabetes (Olshansky et al., 2008). Essentially, normalizing suggests T1DM is no longer a differentiating factor in the adolescent’s life. Olshansky et al. (2008) used focus groups to explore how adults with diabetes “normalize” their identity as a person with diabetes. Results suggested that as participants began to view their lifestyle changes as a positive part of their overall health, they moved from describing themselves as “diabetic” to a “person with diabetes.” Diabetes was no longer the defining factor in their identity, but rather, an integrated component. Once successfully normalizing their identities, living with diabetes was actually representative of motivation to live a healthy life with positive lifestyle changes and behaviors. Thus, normalizing the illness may have a significant effect on the role of T1DM in both personal and social settings by allowing the adolescent to become comfortable with their new lives as people with diabetes and the extent to which they share this aspect of their lives with others. The descriptions collected from our sample suggest that this process of normalization is closely linked with the integration of self-management into daily personal and social routines. Normalization and finding meaning in T1DM may be important for providers to keep in mind in working with patients on T1DM self-management.

Normalization of the illness likely is driven by successful coping strategies for dealing with the personal struggle of T1DM in adolescence. For example, adolescents demonstrating successful incorporation may have used different coping strategies than those who described a containing approach to diabetes, though the current study did not assess such strategies in participants. According to Bury (2001), there are two potential coping strategies through which an illness can be normalized: Individuals can either maintain their pre-illness lifestyle and identity by ignoring their illness or they can begin an altered lifestyle in which the illness has a role. A chronic illness such as diabetes could also be interpreted as a “loss of self” (Charmaz, 1983), making the need to analyze a developing identity even more important. Although an abrupt, short-term illness may cause temporary disruptions to the developing self, a chronic condition may cause continued loss of self (Charmaz, 1983) when the adolescent “battles” against their illness in an effort to regain pre-illness control and normalcy. This suggests that perhaps coping strategies related to diabetes self-management are indicative of whether, and how, an adolescent allows T1DM to become part of his or her self-concept. Improving the integration of self-management behaviors into adolescents’ routines in ways that supplement their personal and social goals, needs, and desires may also be helpful in fostering a positive identity with T1DM. Future research should explore the use of coping strategies in identifying with an illness. Similarly, self-efficacy would be another factor of interest to measure in future studies, as adolescents are developing beliefs and attitudes about their abilities to perform self-management tasks during this developmental period.

The final theme reported from nearly the entire sample was the impact of social support on life with diabetes, in both positive and negative ways. Interestingly, far more adolescents indicated that social support from family and friends had a positive effect on how they lived with diabetes, rather than a negative effect. In fact, the majority of the sample reported telling their friends about their diabetes and getting their friends involved in treatment, and were happy that they did so. Past studies have found that adolescents may keep their diabetes a secret from their friends or be reluctant to disclose their diabetes status due to fear of non-acceptance or negative reactions to self-management tasks (Hains et al., 2006; Szydio et al., 2003). However, the current study found it much more common for adolescents to share their diabetes status and treatment with others.

It is possible that these results are due to the demographics of the sample. Recruited from a large hospital in an urban area, diabetes is much more common in this area, making peers more likely to understand and support the adolescent with diabetes. Despite the fear cited about negative peer reactions in previous studies, friends of adolescents with T1DM have been found to provide emotional and companionship support and support for some aspects of the treatment regimen (La Greca, Bearman, & Moore, 2002). It has been said that decisions to avoid treatment adherence because friends do not know of the adolescent’s diabetes status are actually missed opportunities for support (La Greca & Thompson, 1998). Interestingly, the few adolescents who reported a negative effect of sharing their diabetes with others reported support that was intrusive: parents and peers were worrying too much and being overbearing. However, the overwhelming number of adolescents in this sample who reported benefits from social support for diabetes suggests that T1DM may be viewed as a social illness; its treatment and negative effects can be very public. Proper adherence to T1DM treatment can show physical markings on the body from injection sites, fingersticks, and pump sites. Non-adherence to treatment avoids these physical markings but may publicly show symptoms of hyperglycemia, thus drawing attention to the adolescent as “sick.” Thus, both engaging in treatment and avoiding treatment draws attention to the adolescent as unlike their friends and peers, which flies in the face of the typical adolescent goal of fitting in with others. However, with friends and family more involved in care, burden may be lessened, stigma may be diminished, and acceptance of diabetes may become natural.

A developmental perspective is necessary in understanding the process of personal and social identity development. There is a peak in peer pressure in mid-adolescence; as a result, adolescents may be more oriented toward their peers at this time than earlier in their development (Drew, Berg, & Wiebe, 2010). It is possible the results could be different in a larger sample when the age range is broken down into early, middle, and late adolescence.

In regard to gender differences, overall females were more likely to incorporate their illness into their sense of self, while males were more likely to contain the illness outside their identities. Similarly, past research by Williams (2000) found that the majority of girls were able to incorporate their diabetes and its treatment into their social and personal identities, while boys made active attempts to keep the condition as separate from their personal and social identities. The gender differences we observed are consistent with past research, which has found a greater emotional impact on females with T1DM rather than males with T1DM. For instance, depressive symptoms have been found to be higher in females than males in both adolescent and adult populations (Enzlin, Mathieu, & Demyttenaere, 2002; Hood et al., 2006). Previous research also suggests that males are more likely to underestimate or deny problems related to their diabetes (Gåfvels, Lithner, & Börjeson, 1993; Stenström, Wikby, Hörnquist, & Andersson, 1993).

The current study found that despite the higher female endorsement of emotional difficulties, females were still more likely to incorporate their T1DM into their identities. It is possible this finding is related to females being more likely to share their illness and experience with others, which suggests a desire to utilize support from family and friends. A discussion of difficulties with T1DM may be generally more socially acceptable for females. Although males did not describe any concerns with sharing their diabetes status with friends, they were also more likely to ignore their treatment and contain diabetes outside of their identities. It is possible that males may be reluctant to admit to emotional difficulties that make them appear less masculine, and thus less likely to seek and utilize the emotional support that could assist in incorporation of the illness. More intensive investigation of how personal adjustment, disclosure of difficulties, and gaining support are more likely to be socially acceptable to each gender is warranted.

There are some limitations to the current research that should be noted. First, the analysis of interviews leaves room for uncertainty as the major themes and results were subject to potential bias from coders. However, triangulation and use of an audit trail were conducted to minimize interpreter bias in the results. The presence of a parent during the interview may also have affected responses; participants were given the option to conduct the interview in private or with a parent. Finally, the environment in which the study was conducted (waiting for a medical appointment) may have influenced participant responses.

Summary and Conclusion

Although past studies have focused on the helpful and/or negative influence of friends, the current study brought forth a different perspective: How the adolescent views himself or herself may be more important for positive health behaviors and mental health outcomes than how the adolescent is viewed by their peers. Griva, Myers, and Newman (2000) found that perceived identity of oneself with diabetes (i.e., the label of the illness and the symptoms the patient views as being part of the disease), realistic control over diabetes, and belief in oneself to effectively control diabetes were correlated with better adherence. Therefore, the practice of guiding adolescents to incorporate T1DM into their identities may benefit self-management as well as mental health. A measure of incorporation may be useful in clinical practice.

The themes that emerge from the data suggest certain traits and behaviors are closely associated with successful incorporation of T1DM into the self. Given the major themes, the descriptive detail provided by participants on how they viewed their diabetes and its challenges, and previous theoretical work on identity development in a chronic illness (Charmaz, 1995, 2000), we propose several hypotheses regarding some of the necessary conditions for successful incorporation of T1DM into self-identity among adolescents.

Hypothesis 1:

Successful incorporation of T1DM is positively influenced by acceptance of both the illness and its treatment. Regardless of whether T1DM is viewed as a burden, diabetes knowledge and self-care behaviors are viewed as active and necessary parts of daily life. For some participants, these activities were interpreted as positive aspects of their sense of health and identity.

Hypothesis 2:

Our data suggest that when diabetes self-care is successfully integrated into the daily routine in a way that preserves valued activities and relationships, T1DM is more likely to be successfully integrated into self-identity. The directionality and causal nature of this relationship should be tested empirically, and our data may guide intervention development.

Hypothesis 3:

Adolescents who successfully incorporate T1DM may be more willing to share their illness with others. Diabetes can be shared with others by sharing the experience (e.g., accepting reminders for treatment from family and friends) or by sharing knowledge (e.g., educating classmates or extended family on what it means to treat diabetes). Perceptions of self as “normal” and positive evaluations of the impact of T1DM on self-identity were related to viewing minimal to no disruption of peer relationships. In fact, adolescents who were successful in incorporating T1DM into their identities described a positive influence of T1DM on their friendships; by sharing their diabetes status and educating others about diabetes with others, they were able to cultivate valued social support. Helping adolescents navigate social relationships and the sharing of diabetes with peers may facilitate positive identity development and promote successful self-management in social situations. Social competence, social anxiety, and self-efficacy for performance of self-management in social situations may be important constructs to consider in empirical investigations of the relationship between sharing of T1DM with peers and self-management and glycemic control outcomes.

Theoretically, based on suggested requirements for incorporating, illness identity may be viewed as a spectrum consisting of multiple barriers that an adolescent must overcome to reach the end result, incorporation. Those who have been categorized as “containing” may not meet one or more requirements of incorporation, but this may change over time, as each hurdle to incorporation is reached, the individual moves along a path to non-stigmatized acceptance of their diabetes status and treatment.

Finally, these preliminary qualitative results provide a foundation for the quantitative portion of our mixed-methods study (QUAL → quan design; Hanson et al., 2005), in which the interaction of identity, social relationships, and diabetes self-management can be evaluated in a more empirical fashion. Using the hypothesized requirements for incorporation, these criteria can be applied to our full sample size and compared with measures of psychosocial aspects of the self and health outcomes. The relationship between incorporation and validated measures of self-esteem, self-worth, peer orientation, social competency, quality of life, diabetes self-care, and glycemic control will contribute to the literature a possible explanation of the phenomenon of declining glycemic control in adolescence. Given the fact that criteria for incorporation are based on perception of the self with diabetes and the utility of that perception in a social context, measures of self-esteem, self-worth, and peer relationships may further validate the concept of incorporation. Further research on incorporation of diabetes into identity in relation to diabetes health indices, such as glycemic control, may provide empirical information that could inform the development of interventions that could guide adolescents toward incorporation.

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Table 1.

Descriptive Statistics ($N = 40$).

Variable	***n* (%)**	***M* (*SD*)**	**Observed Range**
Sex			
Male	21 (53)		
Female	19 (47)		
Race			
Black or African American	7 (18)		
White or Caucasian	11 (28)		
Asian	1 (2)		
Hispanic or Latino	21 (53)		
Age		16.15 (1.89)	13–20
Duration of illness (in years)		6.87 (3.58)	1–14.6
Insulin method			
Insulin injections	13 (33)		
Insulin pump	27 (68)		
HbA1C (%)		9.68 (1.89)	6.4–13.5