

**Experiences of Adolescents with Type 1 Diabetes as They Transition
From Middle School to High School**

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Abstract

The purpose of this study was to explore the experiences of adolescents with Type 1 Diabetes Mellitus (T1DM) as they transitioned into high school in order to understand the contextual factors that impact diabetic health-related behaviors and self-identity. A qualitative interviewing methodology called consensual qualitative research (CQR) was used. Six high school freshmen with T1DM were interviewed. Adolescents reported both normative as well as diabetes-specific issues (e.g., social challenges of self-care) pertaining to their transition from middle to high school. Implications for school counseling practice are discussed.

Experiences of Adolescents with Type 1 Diabetes as They Transition From Middle School to High School

The transition from middle to high school is significant for many adolescents, frequently resulting in a new, complex school environment and new peers (Graber & Brooks-Gunn, 1996; Newman, Lohman, Newman, Myers, & Smith, 2000). Much is unknown, however, about how adolescents with Type I diabetes mellitus (T1DM) navigate this transition. The developmental tasks likely differ for adolescents living with T1DM because they must also manage their illness and take responsibility for their own health as it relates to their chronic disease (Schur, Gamsu, & Barley, 1999).

Previous research has suggested that some adolescents with T1DM struggle with adherence to the treatment regimen (Thomas, Peterson, & Goldstein, 1997). Adolescents with diabetes need to practice self-care behaviors, such as checking blood sugar, counting carbohydrates, administering insulin, and engaging in regular exercise to maintain glucose levels within normal limits. Adherence to such a regimen, in addition to experiencing the normative structural, social, and interpersonal changes of high school, provides a unique challenge for these adolescents.

Previous quantitative research on adolescents with T1DM has examined issues such as support (Hains et al., 2007; Hanna & Guthrie, 2001; Helgeson, Reynolds, Shestak, & Wei, 2006; La Greca, Bearman, & Moore, 2002) and adjustment (Band & Weisz, 1990; Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007; Smith, Mauseth, Palmer, Pecoraro, & Wenet, 1991), and how these issues relate to adherence and metabolic control. Unfortunately, little is known about how adolescents with T1DM diabetes navigate normal developmental changes involved in the movement from

middle school to high school and how this transition relates to such issues as adherence behavior, peer relationships, support, and disclosure of health status. This transition has the potential to negatively affect self-care behavior in adolescents due to their increasing independence from family (Olsen & Sutton, 1998). One way to examine this issue is to investigate contextual factors of self-care and illness disclosure in order to help adolescents maintain better metabolic control. That is, understanding how an adolescent makes sense of his or her diabetes as it affects new and changing interpersonal relationships is essential to understanding how adolescents integrate diabetes into their self-concept, potentially affecting self-care behavior.

Currently, few quantitative and no qualitative accounts exist regarding the extent to which having diabetes impacts how adolescents experience the transition from middle to high school, including meeting new peers, utilizing support from friends, and self-care behaviors (La Greca et al., 2002). These developmental events can potentially cause stress and influence health-related behaviors for children with chronic disease (La Greca et al., 2002). Consequently, we wanted to explore the experiences of adolescents with T1DM as they transitioned into high school in order to understand the breadth of contextual factors that impact diabetic health-related behaviors and integration of diabetes into their developing self-identity. The acquisition of this knowledge would be beneficial for school counselors. Because of their training and professional role, school counselors would likely be called upon to provide academic and social-emotional support for students making this significant transition (Kaffenberger, 2006). At the same time, many school counselors have not had

adequate training to deal with chronic illness conditions, so this information may identify common issues for these adolescents with T1DM (Hamlet, Gergar, & Schaefer, 2011).

To achieve these ends we used a qualitative interviewing methodology called consensual qualitative research (CQR). Basically, the qualitative CQR interview sought to elicit the experiences of adolescents currently in the ninth grade. Thus, we investigated common themes that arose from adolescents telling their experiences of adherence efforts, peer relationships, support, and disclosure of health status in a new setting.

Method

Participants

Six fourteen- and fifteen-year-old adolescents (5 females, 1 male) with T1DM participated in this study. All participants were European-American. Participants were entering the ninth grade and receiving outpatient diabetes maintenance treatment every three to four months at a pediatric hospital in a large Midwestern city. Participants varied in amount of time living with diabetes.

Participants were recruited through one of two methods. First, members of the treatment team of the Diabetes Clinic gave brief written description of the study to the adolescents, who meet the age criteria and their parents when they came in for their clinic visit. If the adolescent and the parent(s) were interested in hearing more about the study, they signed the form giving permission for the researchers to contact them. The family provided a phone number or an email address on the form for this purpose. Then a doctoral student contacted the family to describe the project in more detail. If the family was still interested at this point, an appointment was arranged to meet with the

family to review and sign the consent form, explain the interview procedure and then interview the youth. The doctoral student making the phone call met with the family and conducted the interview. The researcher offered to meet wherever the family felt comfortable, such as the family home.

The second means of recruiting participants involved contacting by mail a group of adolescents who had recently began the ninth grade and who just completed their participation in another study. Researchers sent a mailing to these 21 youths and their parents which contained a) a short letter asking them to think about participating in another research study and introducing the brief description of the study, b) the brief description of the study described above, and c) a postage paid return envelope. If the families were interested in hearing more about the study, they signed the form permitting researchers to contact them and returned the form in the provided envelope. The family provided a phone number or an email address on the form for this purpose. A doctoral student then contacted the family to describe the project in more detail. If the family was still interested at this point, an appointment was arranged to meet with the family to review and sign the consent form, explain the interview procedure, and interview the youth. The doctoral student who made the phone call met with the family and conducted the interview. The researcher offered to meet wherever the family felt comfortable. Twelve adolescents initially expressed interest in participating in the project; however, only 6 completed the interview.

Researchers

The primary research team consisted of three counseling psychology doctoral students and one counseling master's degree student. The auditor was a counseling

psychology professor familiar with consensual qualitative research (CQR) methodology. All members were trained by two of the counseling psychology doctoral students that had educational experience in the CQR methodology and interviewing. Members read several articles (Hill, Thompson, & Williams, 1997; Hill et al., 2005) and held several discussions on the CQR methodology and qualitative interviewing. Before data collection, the team discussed their expectations and biases. The research team had prior expectations that the data might be congruent with the varied results found in the literature. For instance, one team member was aware of past research which indicated that adolescents with T1DM may be overly concerned with impression management and attribute negative reactions from peers while doing self-care in social situations (Hains et al., 2007; Thomas et al., 1997). With the use of multiple researchers, along with preliminary discussion among the team about prior expectations, the bias of an individual towards finding this type of experience in the reports of the participants could be circumvented (Hill et al., 1997).

Interview Protocol

An interview protocol was developed based on a literature review related to adolescents with T1DM, treatment adherence, self-care, and the transition into high school. The interview guide included demographic data and open-ended topics such as changes experienced from middle to high school, demands associated with living with diabetes, coping with diabetes, the role of support from peers and family, disclosure of diabetes status, and the experiences of performing diabetes self-care.

Interviewers

Interviewers included two advanced counseling psychology doctoral students with training in interviewing. At the initial meeting with the parent and adolescent, the researcher reviewed the consent form, the length of the interview, topics covered (friends and peers, support for diabetes, transition to high school, disclosing of diabetes status, and adherence), and confidentiality and limits thereof. After obtaining consent, the researcher and adolescent met in a quiet area for taping and privacy purposes.

Recorded face-to-face interviews were conducted with adolescents at their homes, each of which lasted 30 to 60 minutes. All questions were asked to each adolescent; furthermore, a list of probe questions was used to gather any additional information or clarification. Additional probes were used to explore issues that emerged in the interview for each participant (Hill et al., 1997). All interviews were taped and transcribed verbatim. Both interviewers recorded their observations and reactions after each interview. The participants were given a \$10 gift certificate to a regional movie theatre chain for their participation.

Data Analysis

This study used a qualitative design based on consensual qualitative research (CQR) (Hill et al., 1997, 2005). Using the CQR method, researchers explored and described in-depth the experiences of adolescents with Type 1 diabetes T1DM as they encounter new social situations by capturing the phenomena as it naturally occurs.

There were several steps in the procedures for analyzing the data. First, domains (i.e., themes) were constructed by dividing up the responses to the open-ended interview questions. Second, core ideas (i.e., summaries) were formed from all the

material from each domain for each adolescent's response. Third, cross-analysis was performed by finding common themes transcending from domains and core ideas. Along the process, the primary team made judgments about each decision until consensus was reached and the best structure developed. At each step, the raw data was continually reviewed making sure the final decisions were based on the data. Lastly, the auditor viewed the judgments during the cross analysis stage to ensure the primary team did not fail to notice any of the essential data (Schlosser, Knox, Hill, & Moskovitz, 2003).

Results

The following six domains were constructed from the interviews: Transition, Identity, Support, Friends and Peers, Disclosure, and Self-Care. Following the procedure described by Hill et al. (2005), categories were developed from core ideas across all adolescents within each domain. Categories were considered "general" in nature when all of the adolescents reported the same issue (6 cases in the current study); "typical" when 4-5 adolescents reported the same issue; and "variant" when 2-3 reported the issue. For this study, only the "General" and "Typical" categories are reported.

Transition

General reports (that is, all adolescents reporting this experience) in this category by adolescents indicated normative, developmental changes to high school; such as engagement in new sports, adjusting to the new class schedule, having new teachers with larger classes, and more homework. Furthermore, adolescents reported having an

easy time making new friends. Adolescents reported meeting new friends through old and new friends, new activities, and classes.

Nevertheless, typical reports (that is, 4-5 adolescents reporting this experience) indicated that adolescents missed their old friends, especially peers from middle school. One adolescent reported she still talks to most of her old friends, but it has been different because she doesn't see them as much as she once did. Throughout this transition, adolescents typically reported exploring their identity or staying congruent to who they were before the transition. Adolescents reported having the same identity, changing their personality attributes (e.g., shy to social), or changing their attire.

Identity

General reports suggested that adolescents self-identified based on their activities (e.g., sports) and interests (e.g., music). In addition, they generally self-identified in reference to their social group and/or affiliation with others, with some adolescents reported using adjectives such as preppy, tomboyish, athletic, and popular; another two adolescents reported fitting in with everybody.

Conversely, typical reports showed adolescents self-identified based on personality traits and mannerisms (e.g., shy, friendly, outgoing). Moreover, adolescents reported multiple components of their identity, including, but not limited to, diabetes. One adolescent described herself as being loud, extroverted, outgoing, and diabetic. Another adolescent also noted diabetes in her identity description. On the other hand, another adolescent reported that she does not consider diabetes as part of her identity when she is around people who do not know she is diabetic.

Support

General reports indicated that adolescents experienced their friends inquiring how they were doing, and understanding and assisting with self-care regime (e.g., reminding to check their sugar level, administering insulin). One adolescent felt that her friends really cared when they ask her to stop what she is doing and take care of her low blood sugar.

Furthermore, additional general reports indicated that family members provided educational and emotional support as well as assistance with self-care. One adolescent stated that she did not worry too much about her self-care given the support of her family. Another adolescent reported she is her older sister's hero because her sister was afraid of needles but now bravely receives shots with ease.

On the other hand, typical reports showed adolescents also feeling annoyed with friends and family members frequently checking in about self-care and emotional status. One adolescent believed that she felt annoyed if her friends checked in about her diabetes self-care because that was all that they would probably talk about. Another adolescent explained if she did not perform her self-care, her friends would ask about it and her parents would argue with her to engage in the behavior.

Another typical report indicated that adolescents experienced support from friends with diabetes-related peer issues (e.g. disclosure, standing up for the adolescent). For example, one adolescent reported that friends helped explain information about diabetes to interested peers because new people can be “weird” about disclosure.

An additional typical report described adolescents as relying more on parents/family than peers for support because of their extended knowledge and availability. One adolescent relied more on her parents than her friends for support because her parents help her with self-care routines that she does not understand.

Adolescents mentioned that others have mistaken beliefs about diabetes or do not know about the disease in a final typical report. One adolescent reported that a kid started teasing her by asking her a lot of questions and claiming that he could catch diabetes by touching her, thus she reported frustration from his misunderstanding and ignorance. In contrast, one adolescent reported that her grandma did not understand and worries a lot about her.

Friends and Peers

Generally, adolescents reported they have close friends. Adolescents described close friends as sharing a reciprocal communication style, thus feeling that they shared a close connection and mutual trust. Furthermore, adolescents generally reported they remained friends with some people they knew before high school. These adolescents continued to be involved with activities with their prior classmates. For example, one adolescent liked to go to movies and bowling with some of her old friends. Moreover, adolescents generally reported meeting new friends with shared interests in high school. One adolescent exclaimed that it has been easy for to find friends and finds that most of the people at school are friendly and accepting.

In terms of typical reports, adolescents said they shared similar interests with their friends; such as sports, leisure activities, and music. Adolescents reported

communicating (e.g., on the telephone, during class, etc.) frequently with their peers. Lastly, adolescents reported spending a lot of time with their friends.

Disclosure

For general reports within this domain, adolescents experienced positive responses from others related to disclosure. Adolescents reported meeting new friends who had diabetes and other peers with medical concerns while engaging in self-care behavior and these peers could relate with their condition. Also, adolescents reported that peers were accepting and supportive during disclosure, often asking many questions. For example, one adolescent reported that her peers did not mind and were very accepting when she disclosed that she has diabetes.

In general, adolescents reported having to answer questions in response to the disclosure. These situations tended to result when identifying diabetes supplies (e.g., pump) or explaining self-care. Adolescents generally reported that they had to provide psychoeducation to peers who did not have an initial understanding of the disease (which could get irritating for some participants). On the other hand, another adolescent stated that other kids understood diabetes from experience of grandparents or adults having Type 2 diabetes, thus she had to briefly clarify the difference.

Additionally, a general report suggested that adolescents engage in passive disclosure. That is, they would wait to disclose until someone asks why they are counting carbohydrates or wearing a medical alert necklace or a pump. In general, adolescents reported that they were not worried or afraid about disclosing their health status. For example, one adolescent reported she does not feel that diabetes is a flaw and therefore is not afraid to disclose.

A typical report stated that adolescents reported feeling annoyed when disclosing. This included situations where they were questioned while busy doing self-care or other activities. The decision to disclose typically depends on contextual factors (e.g., mood, context of conversation, environment, and time). One adolescent explained disclosure has depended upon the person and how good of friend he/she was. Another adolescent stated how she did not tell someone because she did not “want to,” the topic never came up, and she never found a time to tell him.

Typical reports also painted a picture of adolescents who disclosed to others only when necessary, under certain circumstances, or when forced. Adolescents reported this type of disclosure would occur when others did not bring up the topic, during self-care, or when disclosing to select peers. For example, one adolescent discussed how new friends offered him Halloween candy, how he responded that he had diabetes, and how the conversation moved on after disclosure. Typically, adolescents reported taking the initiative disclosing on their own when meeting new teachers, sharing something about themselves with peers, or depending on how well known the other person is.

Additional typical reports described adolescents as being concerned and apprehensive about disclosing to new individuals. Adolescents reported thinking disclosure would be difficult and/or worrying about what others might think. Lastly, adolescents typically reported that disclosure provided an opportunity for someone to help or allowed for closer relationships. For example, one adolescent stated she did not mind if others knew because it can benefit her. If anyone asked, she would tell them what she thinks they should know in case she developed hypoglycemia.

Self-Care

In general, adolescents reported that they were usually able to adhere to their self-care regimen with new friends in a high school environment. Furthermore, adolescents reported that, in general, friends did not mind if the adolescent engaged in self-care in their presence. One adolescent noted that his friends were used to him performing self-care in front of them, and he generally asks for the conversation or activity to continue when he brings out his supplies. In typical reports, adolescents found their friends and peers to be interested in self-care practices by either asking questions or staring. On the other hand, adolescents typically reported that some friends or peers did not like to watch the adolescent performing self-care, in some cases due to a fear of needles.

Typically, adolescents explained that being a ninth grader with diabetes is more difficult than being a ninth grader without diabetes because of the self-care regimen. One adolescent reported previous feelings of jealousy towards friends who could eat candy bars. Other adolescents reported checking their blood sugar during gym class or social gatherings, as opposed to their non-diabetic counterpart peers who do not need to. Despite these challenges, adolescents reported that they typically can participate in activities like sports or social gatherings as long as he or she performed adequate self-care.

Adolescents reported that they typically have been educated on self-care and they perform it in the interest of their long-term health. One adolescent noted that she has been educated about the body in general through learning about proper self-care. Additionally, adolescents typically carried their own supplies, as opposed to the

students in middle school where they engaged in self-care at the nurse's station. Furthermore, adolescents typically performed self-care in public. One adolescent reported that, unlike in middle school, she could now give herself insulin in front of people and does not restrict her eating to avoid taking insulin. Moreover, adolescents typically reported that some people have mistaken beliefs about self-care. One adolescent reported feeling hurt by people's suspicions that she is using drugs when injecting insulin.

Discussion

The purpose of this study was to capture common social, emotional, physical, and logistical components of the transition from middle to high school for adolescents with T1DM. All participants reported normative concerns regarding transitioning into high school, including meeting new peers, missing friends from middle school, and self-identifying through activities and social groups. These results reflect the developmental changes that occur in adolescence, as youth spend increasing amounts of time with peers in the context of school, extracurricular activities, and in the community, as well as the enhanced complexity and intimacy of these relationships (Furman & Robbins, 1985; La Greca & Prinstein, 1999).

Although the majority of participants expressed challenges when developing new friendships, including initial apprehension about meeting people and navigating peer support in relation to self-care, they were able to make friends easily and communicate frequently with their old and new friends. These results makes sense since adolescence is an especially vulnerable time for youth with diabetes, particularly when it comes to difficulties with their diabetes regimen in the context of peers (Berlin et al., 2006; La

Greca & Mackey, 2009; Susman-Stillman, Hyson, Anderson, & Collins, 1997). More specifically, accommodating friends may take precedence over adhering to their medical regimen (Wysocki & Greco, 2006).

As with all adolescents, participants were in the process of developing their identities, a significant part of adolescence that is based on friendships. In other words, they generally self-identified in reference to a social group or affiliation with others, often times revolving around interests such as sports or music, or self-identified based on individual factors such as personality traits and mannerisms. Participants also considered diabetes a facet of their identity, but did not see themselves limited to that identity. On one hand, they do not want it to be neglected or ignored, but they also do not want it to be the sole focus.

Most participants reported waiting to disclose their diabetes status until approached by a peer, which would often occur while performing self-care. At this time, participants would answer people's questions as they disclosed their health status. This result is consistent with studies finding adolescents reporting that it is easier to self-disclose to their peers rather than keeping their disease status hidden. Even though some of the youth felt it was annoying receiving frequent questions regarding their self-care to peers (Carroll & Marrero, 2006), a majority provided an explanation of their illness to others (Cheung, Cureton, & Canham, 2006).

After finding out about participants' health status, friends were emotionally/socially supportive by standing up for participant in social situations. This result is consistent with research showing that peers are a significant factor and provide an important source of emotional support to youth with T1DM (Bearman & La Greca,

2002; La Greca et al., 1995; La Greca & Prinstein, 1999; La Greca & Thompson, 1998; Skinner, Petzing, & Johnston, 1999), making it easier for youths with T1DM to integrate diabetes regimen into their everyday life (Karlsson, Arman, & Wikblad, 2006).

Additionally, the changing roles of parents and friends in adolescents' lives are reflected in this study. Before high school, participants relied on family for emotional/social support and "material" support such as food and shelter, transportation, and medical treatment (e.g., arranging appointments, obtaining supplies). As they entered high school, participants began to seek emotional support from their friends as they are forming their new identities as a high school student with diabetes. It is not uncommon for youth with T1DM to experience a decrease in diabetes support from their parents (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; La Greca & Thompson, 1998) and for peers to become a significant factor of their emotional support (La Greca & Prinstein, 1999). The change from parents to peers reflects the normative separation-individuation phenomenon that occurs as adolescents are developing their independent identities and shifting the nature of relationships with their parents (La Greca & Bearman, 2003; Helgeson, Lopez, & Kamarck, 2009).

In sum, adolescents reported both normative as well as diabetes-specific issues pertaining to their transition from junior high to high school. Diabetes-specific issues consisted of the logistical and social challenges of self-care. A related issue was whether and when to disclose their health status to their peers which often occurred while openly engaging in self-care. There also appeared to be a parallel between diabetes-related issues and other adolescent concerns. That is, adolescents want a balance between parental supports while still maintaining their independence in order to

foster their own identity. Overall, participants appeared to be adjusting in age-appropriate ways: making friends, negotiating the roles of their family and friends' support, and developing the multiple facets of their identities, diabetes-related and otherwise.

Limitations of Study

Hill, Thompson, and Williams (1997) suggest 8-10 participants for studies utilizing CQR methodology. This study, however, only consisted of 6 participants, bringing into question the potential representativeness of these participants.

Furthermore, participants consisted of Caucasian, suburban high school students from both public and parochial schools in a large Midwestern city, thus not representing the experiences of individuals from various cultures and geographic locations. In addition, this study may have a possible participation self-selection bias. The metabolic control readings and the adherence efforts of these participants were generally good.

Adolescents consistent with their self-care and with good metabolic control may be more socially and emotionally mature and have a better level of adjustment to high school compared to those who do not.

Individual characteristics may have created additional limitations for this study. Nisbett and Wilson (1977) explicate that people have varying abilities to recall their internal experiences. Some encounter great difficulty in describing their mental processes when a situation is ambiguous (i.e., when the person is unaware of the stimuli that trigger such responses). The authors attempted to maximize this recall of the middle school to high school transition process by performing interviews during participants' first semester of ninth grade.

Furthermore, interpretation bias is always a concern in qualitative research. The authors tried to address this potential limitation by using four individuals on the primary team as well as an auditor. In addition, the authors tried to stay very close to the data, typically using the clients' own words in developing the core ideas. Overall, given the aforementioned considerations, readers should exercise caution when attempting to generalize these results to other populations.

Implications for School Counselors

This study uncovered the fact that school transitions for adolescents with T1DM appeared similar to adolescents without T1DM, which normalizes the experiences of these teenagers. This information would be useful for school counselors when helping middle school students and their families make the transition to high school. Specifically, school counselors can help adolescents tap into their strengths in preparing for high school and during the first year of high school (Hamlet et al., 2011). For instance, the specific issues uncovered in this study include disclosure of disease status, managing self-care, developing healthy identities, and fostering supportive relationships with family and friends. School counselors are in a good position to initiate academic interventions such as accommodations to facilitate self-care during the school day. Likewise, school counselors can help these adolescents develop self-advocacy skills to decide if or when to disclose disease status with classmates or within the classroom context. Finally, traditional counseling sessions can be used to address the social and emotional needs of developing and maintaining relationships and address self-esteem and self-identity issues (Hamlet et al., 2011).

When school counselors are faced with a student with T1DM, knowledge of the disease would be helpful. Unfortunately, many school counselors do not feel adequately trained for addressing this medical condition, or any other chronic illness for that matter (Hamlet et al., 2011). Some resources do exist, however. For instance, the website for the American Diabetes Association has a section devoted to “Diabetes Care at School,” which would be especially helpful for school counselors who are not familiar with the condition. In addition, regional pediatric hospitals may provide educational opportunities to school personnel to both understand and work with students who have diabetes. Of course, counselors will come face to face with other chronic illness conditions in their students besides diabetes, and comparable resources would be available and helpful for counselors to acquire needed knowledge.

Implications for Future Research

Given that this study consisted of adolescents with good metabolic control, future studies could examine issues related to the transition to high school for adolescents in less than good control. A similar program of research could also examine the transition from high school to young adulthood environments (e.g., college, military, and employment). When the experiences and needs of adolescents with diabetes are better understood, school intervention strategies to support their development and maintenance of health related behaviors can be developed.

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