School-Based Lived Experiences of Adolescents With Type 1 Diabetes: A Preliminary Study

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ABSTRACT

Background: Diabetes self-management is challenging for adolescents with type 1 diabetes mellitus (T1DM). School plays a crucial role in the adolescents’ lives. However, evidence of inadequate quality of school-based diabetes care has been reported in the literature.

Purpose: The purpose of this preliminary study was to obtain an initial understanding of school-based lived experiences of adolescents with T1DM to serve as a foundation of future research.

Methods: The Heideggerian hermeneutic phenomenological approach served as the philosophical underpinning for this study. Two Taiwanese adolescents with T1DM were purposively recruited. Individual, audio-recorded, semistructured interviews were conducted. Verbatim transcripts were analyzed through hermeneutic circle.

Results: Participants described their school-based lived experiences as a dynamic learning process. Four interwoven themes were discovered: (a) learning to be master of their disease, (b) learning to find ways to feel comfortable, (c) learning to not be different, and (d) learning to not let others (especially parents) worry about them.

Conclusions/Implications for Practice: Diabetes care professionals, school nurses, school personnel, and parents should help strengthen resilience of the adolescents to overcome common social obstacles in schools. Creating a supportive learning environment is warranted to help incorporate diabetes management into their daily lives. Future studies should consider specific situational obstacles that the adolescents face to design effective interventions to improve school-based diabetes care.

KEY WORDS:
Heideggerian hermeneutic phenomenology, school, type 1 diabetes mellitus, adolescent, lived experience.

Introduction

Type 1 diabetes mellitus (T1DM), a metabolic disease that relies on exogenous insulin for survival, is mostly diagnosed during childhood and adolescence. According to a worldwide longitudinal research study, the incidence of type 1 diabetes is rising globally at an annual rate of 2.8% (The DIAMOND Project Group, 2006), indicating the importance of addressing the impacts of the disease. To maintain normal growth and development, individuals with T1DM must establish a balance between insulin administration, dietary intake, and physical activity on the basis of glucose self-monitoring results (Evert et al., 2008). These tasks are not easily achieved or maintained by adolescents (Lehmkuhl et al., 2009; Petitti et al., 2009).

Adolescence is a developmental stage of rapid and continuous change intertwined with complex biological, cognitive, emotional, and psychosocial transformations (Sayer, Hauser, Jacobson, Willett, & Cole, 1995). The prefrontal cortex, the area in the brain controlling judgment, reasoning, decision making, and problem solving, is still maturing, which may explain why many adolescents respond inappropriately to complex diabetes self-management situations (Weinberger, Elvevag, & Giedd, 2005). Although adolescents are developing autonomy and independence, their self-identities are formed through experimental behaviors that test their boundaries. They also come to value peer relationships and become more conscious of peer perspectives and peer acceptance (Simpson, 2001). The interplay between these multiple developmental transformations makes adolescence a time of dynamic change. Adolescents are challenged with finding a balance between their developmental needs and diabetes self-management requirements (Sayer et al., 1995).

For most adolescents, school is a powerful influence in their lives. A recent literature review concluded that school connectedness contributed not only to adolescents’ academic outcomes but also to their health and well-being (Waters, Cross, & Runions, 2009). Studies have also found that better...
school-based diabetes care for adolescents was related to better diabetes management and quality of life (Wagner, Heapy, James, & Abbott, 2006); greater satisfaction with diabetes self-management support from their schools was associated with better metabolic levels in adolescents with T1DM (Lehmkuhl & Nabors, 2008). These studies provide evidence that schools play an important role in adolescents’ diabetes management.

Unfortunately, previous studies have also shown that many schools do not provide adequate support for students with T1DM. In many cases, knowledge and training of school personnel were inadequate (Amillategui, Calle, Alvarez, Cardiel, & Barrio, 2007; Hayes-Bohn, Neumark-Sztainer, Mellin, & Patterson, 2004; Nabors, Troillett, Nash, & Masulis, 2005), healthy food options in the school setting were limited (Nabors et al., 2005), adolescents with diabetes felt a stigma or experienced discrimination by school personnel (Amillategui et al., 2007), and school rules interfered with students’ disease self-management (Hayes-Bohn et al., 2004). The earlier findings suggest a need to improve school-based diabetes care.

In the past, many studies have focused on the experiences of adolescents with T1DM and have demonstrated the difficulties they face and the resilience they possess (Burke & Dowling, 2007; Dickinson & O’Reilly, 2004; Lehmkuhl et al., 2009). However, no research has been conducted that focuses solely on adolescents’ diabetes experiences at school, the setting central to their daily lives. The aim of this study was to help close this gap. This preliminary qualitative study began to expand the current body of knowledge on the school-based lived experiences of adolescents with T1DM and was conducted to serve as a preliminary study for later, more comprehensive research.

Methods
The Heideggerian hermeneutical phenomenological approach served as the philosophical underpinning that guided this research and helped researchers understand the hidden and implicit meanings of everyday existence for adolescents with T1DM at school. Because Heidegger’s (1962/2008) hermeneutic phenomenology is ideal for understanding existential issues, it is especially relevant to this topic. In particular, searching for the meaning of being and existence is a common phenomenon during adolescence. By tapping into the personal meanings, these adolescents hold as they experience the daily effects of type 1 diabetes at school, we can understand how they interpret and respond to this phenomenon through their points of view.

Recruitment of Study Participants
Participant inclusion criteria were adolescents between the ages of 12 and 16 years who had been diagnosed with T1DM for at least 1 year, had no other significant health problems, and were studying at either a public or a private junior high school in Taiwan. It is important to note that mandatory education in Taiwan goes through junior high school. A purposive sampling method was used to recruit the adolescents through the solicitation of volunteers in July 2009. Participants were one girl and one boy, aged 14 and 15 years, respectively. The girl had been diagnosed with T1DM for 1 year and received insulin injections three times a day. The boy had been diagnosed for 6 years and used an insulin pump.

Data Collection
Data were collected through individual, audio-recorded interviews by the first author. Interviews took place in quiet corners of two restaurants chosen by the participants and their parents. Average interview time was 75 minutes. A semistructured interview was used to guide the interview process in a flexible manner. The participants were invited to reflect upon their school-based lived experiences of being an adolescent with T1DM. The question “What do you do to manage your diabetes while at school?” was used to start the conversation. Facilitator techniques such as “Could you please describe that further?” and “Do you mean…?” were used to elicit more detailed information.

Data Analysis
The first author transcribed interviews verbatim. Field notes and a memo journal were maintained during the study. The hermeneutic circle (Heidegger, 1962/2008) was implemented for data analysis to understand both parts of the whole as well as to develop a global understanding of the adolescents’ lived experiences. Within the back-and-forth iterative process of the hermeneutic circle, all transcripts were repeatedly read to obtain an overall sense of the data. Meaningful statements and phrases were highlighted to find the thematic phrases and themes within the transcripts. Interpretations emerged from an understanding of the whole in relation to its parts (Mackey, 2005; Packer & Addison, 1989). Themes and interpretations were then checked for fitness against original transcripts. NVivo 8.0 (QSR International, Melbourne, Australia), a qualitative research software program, was used for data management and analysis.

Because both interviews were conducted in Mandarin Chinese, the first author translated the extracted thematic phrases and themes from Chinese into English. Then, those translations were double-checked by a bilingual (Chinese English) assistant. After this, an American graduate student and two other researchers helped to evaluate the comprehensibility and readability of the translations. Any questions were clarified and discussed until agreement was reached.

Methods to Assure Rigor
Quality research is important to knowledge development. The interviewer (the first author) is a registered nurse with 8 years of experience working with children and adolescents,
including 4 years specifically working with those with T1DM. Nevertheless, to promote the rigor and merit of this phenomenological study, the interviewer took specific steps to further enhance her understanding of diabetes by reading related articles, attending conferences, and interacting with T1DM patients and their families. To ensure an understanding of Heidegger’s phenomenological thoughts, the first author made best efforts to adhere to hermeneutical procedure principles. Before this research, she served as a class facilitator for one topic and also presented a class project related to Heidegger’s thoughts in a philosophy class. She also completed a case study using Heidegger’s hermeneutic phenomenological approach in a qualitative research class. Furthermore, she read Heidegger’s seminal work and other exegetical literature in depth and consulted them during this research. Self-reflectivity was also highlighted throughout the research process by examining field notes and a research journal throughout data collection and analysis. Furthermore, peer debriefing with the two coauthors occurred throughout the research to increase study trustworthiness.

**Ethical Considerations**

Approval to conduct this study was granted by the institutional review board of the researchers’ affiliated university. Protection of the participants’ rights and the need for confidentiality and anonymity were ensured as central to the research process. Participants and their parents signed informed consent forms before commencing interviews. Self-reflectivity was also highlighted throughout the research process by examining field notes and a research journal throughout data collection and analysis. Furthermore, peer debriefing with the two coauthors occurred throughout the research to increase study trustworthiness.

**Results**

The aim of this preliminary study was to understand the meaning of being an adolescent with T1DM in a school setting in Taiwan. Four themes were discovered from interviews with the two participants, namely, learning to be master of their disease, learning to find ways to feel comfortable, learning to not be different, and learning not to let others (especially parents) worry about them.

**Learning to Be Master of Their Disease**

Learning to be the master of T1DM is not easy because diabetes self-management is complex and can hinder an adolescent’s sense of freedom and independence. Learning to accept and to take control of diabetes is a learning process. Although school nurses and teachers may provide some assistance, participants were aware that they are responsible for their disease management. Most of time, participants were conscientious about doing what they were supposed to do, although sometimes they were distracted or derailed. Yet, they believed they would not allow their blood glucose to stray extremely of range. The female participant explained it thusly:

> I could never accept it [diabetes]. My mom said she cannot always be with me, so I have to depend on myself…. Sometimes I might indulge and ignore what I should follow…. I know it is wrong … but I will not let myself cross the limit too much. My body belongs to me, so if there is any discomfort, I would be the one suffering.

Parents’ expectations that their children should assume more self-care responsibility may accompany certain milestones in their lives. The male participant described how his mother prepared him for the transition and his understanding of increasing freedom and responsibilities when entering junior high school.

> Before entering junior high school, my mom always reminded me, “You are going to junior high.” Now that I am in junior high, she says, “You are already a junior high school student.” It seems like since I entered junior high, everything is different and I have to take responsibility for myself. It’s good, but also bad because I have more freedom, but I cannot be lazy or indulge myself.

Balancing dietary intake and insulin dosage is an important but challenging task for those with T1DM. Individuals need carbohydrate-counting knowledge and skills and related dietary information, and then they must continue to accumulate experience to adjust insulin dosages successfully. It is a process of experimentation and involves good decision making and judgment. From trial and error, individuals gradually come to understand their bodies’ responses to insulin dosages and food intake and learn to apply this information on a daily basis. The girl participant described her daily balancing act this way:

> Each time before I eat, I try to figure out how much insulin I should inject. Sometimes the number turns out too high and I realize that I underestimated how much I needed. Next time, when I eat the same food, I know how much insulin I should add…. The scary thing is foods without labels. I do not know what to do with them. So I can only guess. Sometimes I win, but sometimes I don’t. So, I just keep trying.

**Learning to Find Ways to Feel Comfortable**

At school, many unwanted situations may occur. Increased sensitivity to peer responses can affect the adolescents’ perceptions of diabetes, their emotional responses, and their diabetes self-management behaviors. They may feel embarrassed or annoyed when people pay attention to them or ask too many or sensitive questions, and they hate being teased. Avoidance was the primary strategy used when faced with these unpleasant situations. For example, the adolescents may want to keep diabetes a secret or try to minimize drawing attention to diabetes self-management–related behaviors. These avoidance behaviors may help them feel comfortable emotionally, but physically, if they do not adhere to their
diabetes self-management, their health could be jeopardized. The boy described how he skipped testing his blood glucose because of social pressure.

When I am home and not feeling well, I will test my sugar without considering anything. If I want to test, I test, but at school I feel some stress. I don’t like my classmates watching.... Testing in the restroom is inconvenient. One time, I accidentally dropped my meter into the toilet.... Sometimes I skip the test.... Now, when I test my sugar in the classroom, I look to make sure no one is watching me, and then I will do a quick test on my thighs. I would never put the meter on my desk.

A similar conflicted situation may also happen when self-administering insulin. The girl participant described her experience as follows:

My mom always told me that since I was not doing a bad thing, I shouldn’t be afraid of other people paying attention. But she is not me. She cannot understand. I would rather go hide in the restroom to inject my insulin. I don’t want people watching or questioning me.

When faced with the need to let others know about their diabetes, they limit their disclosures to people they trust. Both participants recognized the importance and the need to have classmates around them who knew about their diabetes and the emergency management strategies to take. However, because of past unpleasant experiences, they decided selectively to let only “good friends” know about their disease, as a self-protective strategy. The boy said,

At that time [in the elementary school], my parents and I didn’t pay much attention to this issue. Some of my elementary classmates spread rumors and bullied me. They didn’t understand what diabetes is, but continued to speak about it right in front of me.... Diabetes is not a contagious disease, and it is also not because I ate too much candy. Some students said that I might have hypoglycemia, therefore I cannot play with them.... That’s why my parents and I decided to keep it a secret as I entered junior high.... So now, I wait to get to know people and then decide whom and how much I tell them. For those classmates I feel may tease others, I would not answer their questions, or I might say, “If I told you, you wouldn’t understand.”

The girl also spoke of the way that she chose to keep her diabetes a secret:

[Classmates] asked many questions. I tried to explain, but they were unable to understand.

Besides, they don’t have the need to understand so much, because they don’t have diabetes. They are just curious about what’s wrong with me.... Some people in school like to gossip or spread rumors, so I would rather not let them know I have this problem.

Learning to Not Be Different
Feeling differently from peers is stressful for adolescents. They do not want people to treat them differently; they also try not to appear different when they are with others. However, the needs of diabetes self-management force them to do many things differently from their peers. Hence, to fit into the group, adolescents may compromise on their diabetes self-management regimen. The girl described a situation in which she tolerated hyperglycemia discomfort, choosing to postpone taking action to alleviate her symptoms during a required naptime at school.

Sometimes if my sugar is high, I will go to the restroom to give myself a shot to bring it down. Otherwise, I will feel very uncomfortable. One day after lunch [during the required naptime], I knew my sugar was high. I can’t fall sleep. I saw everyone was sleeping and I was just sitting there short of breath. It was very uncomfortable. So, when the bell rang, I rushed to the restroom to give myself a shot.... Because everyone was sleeping, I didn’t want to be seen walking out and through the corridor, because that would be of place.

The boy described his appreciation of the benefits of having an insulin pump. Having the pump made his life at school much easier. His sense of normalcy increased and the attention from his classmates decreased. He considered himself as “normal” as his peers, except that he needed to carry an insulin pump.

I don’t feel I am different from other students. Except that I have it (the pump) with me, I am as normal as others. I can do everything they [classmates] can do and maybe perform better than them. It’s a small machine and is covered by my clothes, so no one would notice it. If I need to give myself insulin, the movement required is small and the other classmates would not easily know what I am doing.

Learning to Not Let Others (Especially Parents) Worry About Them
Both adolescents understood their parents’ genuine love and concern although they occasionally argued with them. Their parents’ love motivated them to pay more attention to and to take responsibility for their diabetes self-management.
The boy described how he learned from his father’s love when he was in elementary school.

[My father] just came to school several times each day because he was worried about me. He came to school to help me test my sugar, inject insulin, and bring my lunch. Sometimes, he just came to make sure I was okay. The record time he came to school in one day was six…. I know they [my father and mother] might get mad when I disobey, but I know they are really, really concerned about me. So, I have tried not to let them worry so much about me.

When discussing the possibility of hypoglycemia, the boy wanted to avoid worrying people around him, so he ate food to increase his blood glucose level. However, overeating might induce the opposite risk—hyperglycemia. He said,

When I was experiencing hypoglycemia, no matter how terrible the food was or how much I disliked eating the food before, the food would become very delicious to me. I would eat a lot and could not stop…. If I am low, my teachers and classmates would worry about me. My teacher would tell my parents what happened at school. I have always asked my teacher not to call my parents because if they know about it, they will worry about me when I am at school.

The girl talked about how she selectively told her mother about her life and diabetes management at school to keep her mother from worrying. However, many problematic behaviors were behind the selective disclosure of information and deceptive behaviors.

When I tell my mother about my day at school, I skip the negative events, because I don’t want to upset her. I skillfully avoid those parts that may be upsetting to her. When I tell her about my sugar levels, I only tell her numbers within or near a normal range…. So every three months, when I go to the hospital, I always feel nervous because the data from the blood tests don’t conceal anything.

Discussion
This was a preliminary study that did not aim to reach data saturation or draw definitive conclusions. Rather, it was designed to provide initial insights to contribute to the literature on the school-based lived experiences of Taiwanese adolescents with T1DM. In addition to serving as a foundation for a larger future study, it also demonstrates the ability of young people to articulate and to interpret their lived experiences. However, certain limitations should be noted. First, the small number of participants in this preliminary study necessitates a future larger-scale study to further enrich understanding of this phenomenon. Second, given the limits of human nature, it is inevitable that researchers were unable to fully transcend into the worlds of the participants. However, issues related to research quality (i.e., research phenomenon and methodology, data contemplation, and interview skills) have been addressed in this study.

Results indicate that teenagers with T1DM undergo different but related learning processes while functioning at school with their disease. The two adolescents’ narratives about their school-based lived experiences were interwoven with positive and negative descriptions. The four themes were (a) learning to be master of their disease, (b) learning to find ways to feel comfortable, (c) learning to not be different, and (d) learning to not let others (especially parents) worry about them.

As in the research of Hema et al. (2009), participants in this study did not report stressors pertaining to their diabetes and its self-management as major issues in their school lives. The topics of their narratives covered past, current events, and future plans. The prevailing themes in their narratives were related to issues of situational stressors and social anxiety that hinder them to make diabetes self-management a priority. Their narratives mainly addressed experiences they had with their peers, reflecting the central role peers play in their lives in the school setting. Similar to the suggestion of Berlin et al. (2006), many adolescents’ diabetes adherence difficulties occur in social and peer contexts. Adolescents’ adherence to diabetes self-management recommendations, diabetes stress, metabolic control, and self-concepts are influenced by their peers (Burke & Dowling, 2007; Karlsson, Arman, & Wikblad, 2008; La Grecia, Bearman, & Moore, 2002; Lehmkuhl et al., 2009). Anticipation of peer pressure and the fear of being singled out by peers may force them to compromise adherence to their diabetes regimen, which may endanger their safety and short- and long-term health (Battista, Hart, Greco, & Gloizer, 2009). It also suggests the importance of educating their peers.

Similar to those in Carroll and Marrero’s (2006) study, participants in this study indicated that they felt like everyone else. Their diabetes had relatively little impact on their school lives, and they believed that they could perform better than many of their peers. However, they still felt stress related to the additional attention received from peers and were afraid of negative peer responses. Thus, they chose to keep their diabetes a secret to be seen and treated like everyone else and avoid negative experiences. This situation has also been highlighted in previous research (Davidson, Penney, Muller, & Grey, 2004; Michaud et al., 2009).

Disclosing their disease is a dilemma for adolescent diabetes sufferers. If they choose to do so, their peers may become more aware of their needs and offer help if needed, but the risk is that naïve and immature peer behaviors may hurt their feelings. Thus, researchers suggest that adolescents and their parents should carefully consider who to tell, what to
tell, when to tell, and how and how much to tell regarding the disease to protect the adolescent’s mental and physical safety (Davidson et al., 2004). There is no definitive answer to this dilemma. In this study, the two participants’ decisions about disease disclosure were made by the participants and their parents. Past negative experiences related to the issue contributed to their decisions. Future studies should investigate further what social situations the adolescents dislike and examine why and how they respond to such to prevent social unease at school. Interventions such as social skill training to handle situational obstacles, social pressures, and disease disclosure should be designed to overcome the potential of intentional health-compromising behaviors. School-based diabetes education should also be implemented to increase peer understanding of adolescent diabetes sufferer conditions and needs.

School is an important context for adolescents with T1DM. Because their diabetes self-management behaviors are reciprocally affected by and affect their development, the support they receive for diabetes self-management from school personnel such as schoolteachers and school nurses should be enhanced. However, as in many other studies, the adolescents in this study revealed that the school environment was not adequately supportive or safe for them to feel comfortable in carrying out their diabetes self-management tasks (Amillategui et al., 2007; Hayes-Bohn et al., 2004; Wilson & Beskine, 2007). Thus, while they were learning to be masters of their disease, the many possible situational obstacles at school represented the main challenge to disease self-management. In the past, studies regarding situational obstacles focused only on participant dietary adherence (Schlundt et al., 1996) and general situational obstacles to diabetes adherence (Schlundt et al., 1994). In future studies, researchers should consider investigating the specific situational obstacles adolescents face in their school settings to design effective interventions to improve school-based diabetes care.

In addition, although one study showed that with each instance of experimentation adolescents’ sense of autonomy and independence increased (Karlsson et al., 2008), parental involvement still played an important role in adolescents’ diabetes self-management. Many studies have identified the benefits of parental monitoring in enhancing the regimen adherence and metabolic control of adolescents with T1DM (Anderson et al., 2002; Ellis et al., 2007). Although parental involvement is not always perceived as supportive by adolescents (Wiebe et al., 2005), this study generated findings similar to those of Dickinson and O’Reilly (2004) in that adolescents revealed an understanding of their parents’ concern and love for them. This understanding motivated them to take responsibility for themselves. In Chinese culture, this demonstrates filial obedience because taking care of one’s own body is a responsibility and duty of children. If children let their parents worry about them, whether because of their physical health or deviating behaviors, it would be perceived as wrong and unbecoming.

Conclusions
Adolescence is an especially challenging time for effective T1DM management because of the difficulties of balancing diabetes self-management and developmental needs. This preliminary hermeneutic phenomenological research is the foundation for a larger future study, aimed to understand the meanings of being an adolescent with T1DM at school in Taiwan. Results revealed that when at school, adolescents went through a multifaceted learning process to master their disease self-management, to identify ways to feel comfortable socially and physically, to not appear different, and to not let other people (especially their parents) worry about them.

Application to Nursing Practice
Adolescents in this study were in the process of learning to take responsibility for their diabetes self-management at school. However, peer-derived and school rule-derived social pressures and situational obstacles compromised their effective diabetes self-management. Participants did not want to be perceived as different from their peer groups. Previous negative experiences with peers also increased their desire to keep their diabetes a secret. On the basis of these findings, effective interventions should be conducted for diabetes care professionals, school nurses, schoolteachers, parents, and even classmates to help strengthen adolescent diabetes sufferers’ resilience to overcome common social obstacles faced at school. Pretraining and on-the-job training for school nurses and schoolteachers related to the biopsychosocial and developmental needs of adolescents with T1DM should be implemented to ensure the safety and well-being of adolescent diabetes sufferers in school environments. Being the sole health professionals at schools, school nurses should proactively build up their professional competencies in diabetes care and demonstrate competence in both caring for diabetic students and educating school colleagues and the student body about T1DM and its management.

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References


第一型糖尿病青少年校園生活經驗：前驅研究

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背景 青少年糖尿病照護是一件具挑戰性的任務。就青少年而言，學校在其生活中扮演重要角色，然而文獻持續告知校園糖尿病照護品質之不足。

目的 本研究目的在瞭解第一型糖尿病青少年校園生活經驗。

方法 Heidegger詮釋現象學為此前驅研究的哲學基礎，目的取樣兩位台灣第一型糖尿病青少年，透過面對面、半結構錄音訪談收集其校園生活經驗。資料分析乃透過詮釋循環。

結果 個案描述其校園生活經驗為一動態的學習過程，他們學習去：(1)當自己疾病的主人；(2)尋找因應之道讓自己感覺舒服；(3)學習不跟別人不一樣；以及(4)不要讓他人生，尤其是父母，擔心他們。

結論／實務應用 糖尿病照護專家、學校護士、學校教職員及家長應齊來協助糖尿病青少年克服在校常見的社交情境障礙，同時為他們創造一個支持性的校園生活環境。未來研究宜探討常見的情境障礙，並設計有效之介入方案，以協助他們在校園生活期間之糖尿病照護。

關鍵詞：Heidegger詮釋現象學，學校，第一型糖尿病，青少年，生活經驗。

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