The School-Based Lived Experiences of Adolescents With Type 1 Diabetes

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ABSTRACT

Background: School plays a critical role in influencing the health, safety, development, and well-being of adolescents with type 1 diabetes mellitus (T1DM). However, scant research has been conducted to understand the lived experiences of these adolescents in school settings.

Purpose: This study investigates the school-based lived experiences of Taiwanese adolescents with T1DM.

Method: A Heidegger’s hermeneutic phenomenological approach was used, and 14 Taiwanese adolescents with T1DM were enrolled through purposive snowball sampling until data saturation was reached. Data were collected using audio-recorded, semistructured interviews and analyzed using the hermeneutic circle supported by qualitative analysis software NVivo 9.0. Reflective journaling, peer debriefing, memo writing, and member checking were performed to enhance the trustworthiness of the findings.

Results: Six interrelated themes were identified: (a) the same yet different, (b) covert and overt, (c) limitations and freedom, (d) independent and dependent, (e) derailing and being on track, and (f) disease identity and denial. Multiple factors, including disease identity, social anxiety and pressure, ignorance of school personnel and classmates, and transition to independent self-management threatened the at-school health and well-being of participants.

Conclusions/Implications for Practice: Much work remains to be done to adequately improve the school-life experiences of adolescents with T1DM. Interventions to facilitate their autonomy, self-efficacy, diabetes knowledge, disease identity, and handling of situational obstacles are suggested as well as improving the understanding of T1DM for teachers and classmates and facilitating more proactive care by school nurses.

Key Words
adolescent, phenomenology, school, type 1 diabetes mellitus.

Introduction

Type 1 diabetes mellitus (T1DM), a complex metabolic disease, is frequently diagnosed among young people. A longitudinal study indicated that the incidence of T1DM is increasing at an annual rate of 2.8% worldwide and 4% in Asia (DIAMOND Project Group, 2006). To prevent diabetes-related emergencies and long-term complications and to achieve optimal learning, growth, and development, individuals with TIDM must regularly balance insulin levels and maintain a proper diet and exercise, based on frequent glucose monitoring (U.S. Department of Health and Human Resources, 2010).

Given the many changes that occur during adolescence, optimal metabolic control may be difficult to achieve. Normative developmental tasks may complicate an adolescent's diabetes self-management (Cameron, 2006). Experimentation with tobacco use, alcohol, recreational drugs, and unprotected sexual intercourse may further compromise their metabolic control (Cameron, 2006; Silverstein et al., 2005). Moreover, girls may skip and/or reduce insulin doses in hopes of controlling body weight, putting their health at further risk (Neumark-Sztainer et al., 2002). The high value that adolescents place on peer relationships may conflict with expected diabetic management behavior (Dickinson & O’Reilly, 2004). Balancing an adolescent’s developmental and diabetes management needs can be difficult.

School exerts a great influence on an adolescent’s academic achievement and also on his or her health and well-being (Waters, Cross, & Runions, 2009). Students with T1DM face significantly greater challenges than their peers to facilitate healthy personal development and effective self-management (U.S. Department of Health and Human Resources, 2010). Previous systematic reviews revealed the potential impact of an individual’s poor metabolic control on neurocognitive outcomes and school achievement (Milton & Whitehead, 2006; Taras & Potts-Datema, 2005). Although several studies have shown the positive effects of support from school personnel for student metabolic control and mental health (Lehmkuhl & Nabors, 2008; Wagner, Heapy, James, & Abbott, 2006), insufficient school-based diabetes care has been extensively documented in the literature (Low, Massa, Lehman, & Olshansky, 2005; Silverstein et al., 2005).
Considering the central role that school plays in adolescent life, it is important to listen to the voices of these adolescents regarding lived school experiences. This qualitative study explores the meaning of being an adolescent with T1DM at school.

**Methods**

**Design**

Heidegger’s interpretive phenomenological approach was chosen as the philosophical underpinning and methodology. Heidegger’s classic work “Being and Time” clearly delves into the central ontological questions on the meaning of “being,” that is, what does it mean to be and what is it to be? (Heidegger, 1962/2008, p. xvi). The nursing profession requires a strong foundational understanding of existential issues and the meanings that people hold to provide substantive assistance. Given the unique psychological development and school living situation during adolescence, it is necessary to explore the school-based lived experiences of adolescents with T1DM. As Heidegger asserted that understanding is interpretive and that all description is derivative of an interpretation (Moran, 2000), Heidegger’s hermeneutic philosophy provides an approach to understand this phenomenon.

**Participants**

Purposive snowball sampling was used to recruit participants for this study. Fourteen adolescents (eight boys and six girls) were enrolled until data saturation was reached. The recruited adolescents had T1DM for at least 1 year, had no other diagnosed health problems, and were students in public junior high schools in Taiwan. The participants’ mean age was 14.20 years (SD = 1.20 years), with an average of 4.64 (SD = 3.02) years since diagnosis. The average self-reported glycolated hemoglobin (HbA1c) was 9.43% (SD = 2.06%), which is higher than the 7.5% level recommended by the American Diabetes Association (2012) for this age group. Eleven participants used pens, and three used pumps to administer their insulin.

**Ethical Considerations**

The university ethics committee approved this study (IRB Protocol # 2009-05-0075). Informed assent and consent forms were obtained from each participant and his or her parent before the interview. Principles of autonomy, participant privacy, and research data confidentiality were strictly adhered to.

**Data Collection**

Because “keeping meaning in the forefront of the study will produce a more phenomenological study” (Munhall, 2007, p. 176), the interviews followed a semistructured interview guideline to direct the dialogue. When needed, probing questions (e.g., “Do you mean…?” “Why…?”) were asked to elicit further details and clarification. The first author conducted each interview between June 2009 and July 2010. In accordance with the preferences of participants and their parents, 10 interviews took place in the participant’s home, and four were held in quiet restaurants. The average interview time was 56.92 minutes (SD = 24.25 minutes).

**Data Analysis**

The first author transcribed verbatim and made proofing, two ways to trigger ideas in data analysis (Sandelowski, 1995), immediately after completing each interview. Hermeneutic circles (Heidegger, 1962/2008) were utilized in data analysis to obtain the structures of experience to better understand the ontological meaning of being. Because understanding is the premise of an interpretation, data were analyzed through repeated circles, moving back and forth between the partial understandings of one transcript and the more complete understanding of the whole transcripts (Mackey, 2005; Packer & Addison, 1989). The process was interactive dialogue between the researcher, each transcript, and the entire transcript body. Meaningful units were extracted, theme clusters were organized, and then, their main components were identified. Finally, emerging themes and interpretations of lived experiences were back-checked to ensure the robustness of each transcript. Qualitative research software NVivo 9.0 (QSR International, Melbourne, Australia) was used to support data management and analysis.

To preserve the original meanings, data were analyzed in Mandarin Chinese, the participants’ first language. Each extracted quotation was translated and then verified by a bilingual expert. Afterward, two American English-major doctoral students and the first author examined each translated quotation line by line.

**Study Trustworthiness**

The researchers scrutinized each step of the process to ensure this study obtained high-quality data and adhered to rigorous methodology. We followed the recommendations in Munhall’s “A Phenomenological Method” (2007) to enhance study trustworthiness. The researchers immersed themselves in the research area, the philosophical underpinnings of the research, and the obtained data and maintained a reflective perspective both during and after the research process. A reflective journal was kept to record the insights and perceptions that arose from personal reflection throughout the research process, which served as a measure of cathartic emotional release and as field notes to track the origin and development of data interpretation. Researcher thoughts, comments, questions, and summaries were also recorded in numerous memoranda. Two participants validated their interview summaries, and one participant provided feedback on the final results. Furthermore, peer debriefing was employed via the first author’s peer classmates, friends, and supervisors, starting from the research design, analysis, and presentation of findings.
School-Based Lived Experiences

Results

The aim of this interpretive phenomenological research was to explore the meaning of being an adolescent with T1DM in a school setting. Six intertwined themes were discovered:

Theme One: The Same yet Different

Lack of insulin is a hidden health problem. Although adolescents with T1DM are externally indistinguishable from their classmates, diabetes symptoms and self-management behaviors revealed the existence of T1DM and set them apart. These adolescents were often confused about their identity and unsure of whether and how much they were similar to or different from their peers. None were comfortable performing diabetes self-management tasks in public because of the accompanying unwanted attention that heightened the sense of being different. Hence, some chose to test their blood glucose and administer insulin in restrooms or health centers. However, leaving the classroom to do so also exposed their difference. As Participant A stated, “When I go to the restroom to give myself insulin, after coming back, usually everybody has already eaten half [their lunch].”

To avoid these problems, participants employed various coping strategies. Some specifically addressed themselves as “normal” or “regular” people. Participant K empowered himself by saying: “I’m the same as others. I can talk. I can eat. I can run. I can do things people do. I just lack insulin.” Some, as Participant I, said, “Although my classmates don’t say anything, I still feel that I’m different from them.” The latter comment was followed by weeping and silence.

Most participants refused to use T1DM as a way to receive “special” treatment and tried not to eat during class. Some strived to perform better than their classmates. In addition, a few negotiated with physicians to eliminate school-time insulin injections. Despite acknowledgment that certain actions might jeopardize their health, some, such as Participant F, stated, “At school I try to avoid anything related to this [disease] because I want to be like others.” In their eyes, appearing normal was more important than physical comfort or possible health risks.

Theme Two: Covert and Overt

Decisions revealing condition, as well as who would be told and how much information would be shared, presented dilemmas for participants that further complicated their desire to fit in with peer groups. Because participants did not want to be considered special or misunderstood, social anxiety and pressure forced to disguise their diabetes or hide their self-management tasks at school. In addition, many described experiencing unforgettable emotional trauma because of classmates’ ignorant or naïve responses. Some also related negative experiences because of schoolteachers’ careless handling of their needs. The teasing, mocking, misunderstanding, and accompanying emotions remained vivid in their memories and prevented them from handling T1DM more openly.

The participants showed varied attitudes, experiences, and processes with regard to disease disclosure at school. Most, such as Participant M, recognized the importance of letting people around them know what symptoms to watch out for: “You have to let your good friends know. The teacher and school nurses should also know. It’s dangerous if no one knows. Because if something happens, they can save you.” However, some worried about possible negative responses that might arise from their classmates or teachers if they disclosed their disease or revealed their discomfort. As Participant B said, “I want people around me to know [that I have T1DM] so they can help me if needed. But I’m afraid some people are too immature and may say something mean to me.” Being accepted and understood by peers was their main concern. Those who had been teased or mocked tried to avoid being put on the spot. For example, Participant J reported, “They all know I have diabetes, but I still don’t want them watching what I’m doing. It makes me uncomfortable.” Some tried to avoid eating sweets in public to treat their hypoglycemia. They did not want their teachers and classmates to know their blood glucose was low because others might panic, worry, or inform their parents or they might label them as a “problem.”

In contrast, some tackled the disclosure issue like an experiment, in which they assessed and observed peers’ responses. They only revealed their condition after they were sure they would be safe from uncomfortable reactions. This was a survival tactic used by many participants at school, typified by take it slow, be low-key, and then come out with safe disclosure. Participant N reported her experience as follows:

It’s very inconvenient and also looks weird to go to the restroom [to check sugar and inject insulin]. So I tried to do these things in the classroom. At first, my classmates were very curious. Gradually, they got used to it and I became more comfortable doing it in the classroom.

Theme Three: Limitations and Freedom

All of the participants acknowledged the importance of normal metabolic control, as they knew that they were vulnerable to long-term complications if they did not care for themselves properly. The physical symptoms of glucose fluctuation constantly reminded the adolescents of their T1DM. As Participant G said, “Even now I can’t accept that I’m sick, but those uncomfortable symptoms continue to remind me.” Many, like Participant N, faced the reality and tried to restore control over their lives:

I know that I am not like others can totally [be] free to eat what they want to eat and to do want they want to do. I need to test my sugar, adjust my insulin, and pay attention to my body carefully. ... Because I don’t want to be limited by this disease, I have been working hard to let others know I’m good and I’m doing well.
In the face of demanding diabetes management tasks and the stress of T1DM, some of the adolescents expressed frustration and fatigue with their diabetes self-management tasks and a desire to forsake all of these requirements. As Participant H mentioned, “I need to be very honest to tell you that I really hate this disease. It’s like a chain that I am trapped by.” These adolescents repeatedly mentioned the many difficulties they had encountered at school, such as limited food choices, the long walk to the health center, and the inconvenience of bringing supplies to school each day, all of which hampered diabetes self-management, although they had developed strategies to confront these difficulties. Many described differences in self-management behaviors between at school and at home, feeling that performing these tasks at school was stressful and inconvenient. As Participant B said:

When I’m home and don’t feel well, I test my sugar immediately. I test whenever I want. My father and mother never watch me like people at school, but my classmates always stare, looking very curious. It seems like I’m special, I’m dressed weird, or I’m doing something very strange.

Participants developed strategies to handle uncomfortable situations, such as “not think about it,” “ignore people’s watching,” or “get used to them.” These thoughts made them more comfortable in stressful situations. Sometimes, they chose to avoid performing required tasks although they knew it was not good for their health and safety. For example, rather than checking blood glucose with a glucose meter, most participants used symptoms as the main or supplemental indicator to judge glucose levels. They thought that they would be fine if they paid attention to their bodies, believing that such sensations were reliable indicators of their glucose levels. It was perceived as a way to earn freedom or gain control. Participant J said:

I haven’t checked my sugar for a long time. I feel it’s enough to sense my body. If my sugar is high, I’ll feel uncomfortable. If it’s low, I’ll feel uncomfortable, too. I’m not so stupid as to be unaware of my discomfort.

Most participants vividly described the hyperglycemic and hypoglycemic episodes that they experienced at school and their responses. Most of these episodes were of a hypoglycemic nature, which could cause an immediate emergency. Many feared hypoglycemia, which was viewed as an invisible stressor limiting their involvement in school activities. Thus, Participant A said, “Sometimes when I forgot to bring candies with me, I worried that my sugar might get too low. So I didn’t dare move much.” Most participants experienced stress while on field trips, especially on overnight trips. Concern that glucose levels might become low prevented them from fully enjoying field trips.

In addition, teachers misunderstood T1DM and lacked confidence in emergency management, limiting student freedom to participate in school activities. For example, teachers asked parents to attend field trips, asked that study participants abstain from races and exercise activities, and even denied their right to serve as class leaders. Participants relayed these experiences with negative emotions.

Theme Four: Dependent and Independent
Participants realized the need to be responsible, independent, and autonomous in managing T1DM. However, they persisted in dependence on parents. For example, as Participant C said, “So far, I haven’t read anything regarding diabetes on my own. My mom will teach me, and I feel that’s enough.” Parents appeared to be the main source of participants’ diabetes self-management knowledge. None were fully confident about having “complete” responsibility for their diabetes.

The increased responsibility for diabetes self-management led participants to quarrel with parents because their behaviors away from home did not meet parental expectations. The adolescents said that learning to be independent and responsible was difficult because they were sometimes rebellious and tempted and occasionally made mistakes. The opportunity for “trial and error” was viewed as necessary to gain skill at choosing the right insulin doses for various situations. Thus, they asked their parents to be more understanding and stop nagging and scolding them when they strayed from the “ideal” regimen.

When asked about school personnel, many participants indicated that the ignorance and misunderstandings of some teachers about T1DM discouraged self-management of diabetes, partly because of inappropriate interference. Most participants also reported that school nurses were not supportive; assistance was limited to calling their parents when they were not well, providing a location to rest and store supplies, and performing necessary tests or injections. Only two students reported that school nurses were ever involved in metabolic control routines.

Theme Five: Derailing and Being on Track
Participants recognized that numerous temptations, especially those related to food, might keep them from following instructions. Their biggest challenges were controlling their “sweet tooth” and the desire for high-calorie fried foods. Thus, they struggled with whether to curb their cravings or submit to them. Participant M described his pain as follows:

When I see my classmates drinking [beverages], I feel unhappy and jealous because I can’t drink like them. I have to suppress my desire…. Feeling everyone can drink but I can’t is very unpleasant. It makes me very upset.

School was the site of many pressure situations. As Participant E mentioned, “I was unable to stop eating when everyone was eating…. Some classmates even purposefully used food to provoke me.” Although participants acknowledged the influence of food on their blood glucose levels, they were afraid that refusal and avoidance would provoke teasing and questions
from classmates. Special occasions were particularly challenging, as Participant N mentioned:

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I lost control sometimes, like at parties at school. That climate made me very relaxed. Everyone ate cookies and I ate, too, and my sugar got high. Or like when I went with classmates to karaoke. The food there was so delicious, so everyone sang and ate. In that situation, although I added extra doses of insulin, my sugar level was still very high.
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Many situations could not be predicted, leading to delays in adjusting insulin dosage. Sometimes, participants just wanted to forget about diabetes and enjoy a happy occasion. Although the adolescents occasionally went off track with respect to following instructions, they confessed that their own or others' diabetic ketoacidosis episodes still scared them. Moreover, they understood that there was love behind their parents' and grandparents' nagging and close supervision and that they had no choice but to stay on track as much as possible.

**Theme Six: Disease Identity and Denial**

Facing a lifelong disease with no cure is like living under dark clouds. Many participants wondered ‘’Why me?’’ and asked themselves why they were so unfortunate as to have this disease. In contrast to their own restricted lives, their classmates’ carefree lives underscored their sense of injustice. This might also explain why negative interactions such as being teased by classmates hindered diabetes self-management at school. In addition, teachers’ lack of knowledge about and responses to T1DM reinforced negative emotions. For example, some teachers publicized participants’ T1DM to classmates despite being asked not to, excluded participants from school activities, or mistook glucose-related problems as misbehavior or as fabricated excuses for school absences. The following example from Participant N reveals his teacher’s lack of T1DM management knowledge:

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I was preparing to eat lunch, had already taken extra doses and my rice fit exactly with my insulin dosage. Still, my teacher said, ‘That’s too much,’ and took some rice away, leaving me just a little… Another time he saw that I was enjoying my Coke Zero and said I couldn’t drink that. He poured out my Coke and instead gave me water.
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However, participants came to believe that, if they maintained metabolic control, there was hope that their condition would not worsen and that advances in medical technology might someday make their lives easier. Many participants believed they were more mature and empathic than their classmates. Indeed, a few of female participants stated a desire to become nurses to help others with diabetes. Many participants compared themselves with those they viewed as less fortunate, partly to comfort themselves. As Participant M said, ‘’Diabetes is better than many diseases. If diabetes is bad, what about polio and other handicaps? You should be thankful you’re diabetic. At least you can still look normal… Those with polio—their problem is so obvious.’’ In addition, support from their classmates and teachers, with positive presence, care, and advocacy, meant a great deal. They especially treasured the care and support of their good friends at school, which helped to ease the burden of having diabetes and motivated them to better adhere to daily care regimens.

**Discussion**

Our findings indicate that adolescents with T1DM face difficulties balancing diabetes self-management tasks at school. Participants’ physical, psychosocial, emotional, and developmental health and well-being were greatly challenged by personal and environmental contexts. Similar to the findings of Dickinson and O’Reilly (2004), adolescents in this study did not always prioritize diabetes self-management. They felt that fitting in with, being accepted by, or avoiding possible trouble from their peers and teachers were often more important than diabetes management. They thus purposely avoided performing diabetes self-management tasks such as blood glucose testing, insulin injection, and diet management in school settings or when they were with peers, thereby putting themselves at greater risk of complications (Di Battista, Hart, Greco, & Gloizer, 2009; Dickinson & O’Reilly, 2004). This phenomenon corresponds with the characteristic of adolescents’ psychosocial development that places high value on social relationships, especially relationships with their peers (Erikson, 1968). There is a need to further investigate obstacles to diabetes self-management at school and help adolescents with diabetes respond to challenging situations properly without compromising diabetes management regimens.

Adolescent glycemic control requires frequent and regular monitoring of blood glucose (Helgeson, Honcharuk, Becker, Escobar, & Siminerio, 2011; Ziegler et al., 2011). Ingerski, Anderson, Dolan, and Hood (2010), however, found that blood glucose monitoring frequency declined during adolescence and that most adolescents experienced increased HbA1c levels. Some study participants were overconfident in their ability to self-monitor physical conditions and neglected to check blood glucose levels. Some insisted they could sense glucose variations accurately. This is dangerous, as previous research has shown that subjective symptom awareness and blood glucose estimation are not closely associated with actual blood glucose levels (O’Connell, Hamera, Schorfheide, & Guthrie, 1990; Weinger, Jacobson, Draelos, Finkelstein, & Simonson, 1995). Interventions to educate adolescents about the importance of blood glucose monitoring and assist in overcoming possible obstacles to testing are needed.

Similar to the findings of other research, disease disclosure was a dilemma for study participants (Dickinson & O’Reilly, 2004). Like the participants in an HIV study conducted by Michaud et al. (2009), participants in the current study struggled with the issue of disclosing their disease to peers, fearing stigmatization, misunderstanding, and rejection. They
wanted to be viewed as normal and believed that, if they avoided performing diabetes self-management tasks in public, classmates would treat them like everyone else. However, hiding the disease was risky.

Participants were fearful in general about sharing because of past traumatic experiences with peers. This further highlights the need to cultivate a safe, supportive school environment. Helping adolescents to weigh the pros and cons of disease disclosure and strengthen corresponding communication skills is an appropriate intervention. Antibullying campaigns should be implemented to encourage students to respect diversity.

Consistent with previous research, participants in the current study struggled with feeling similar to and different from their nondiabetic peers (Dickinson & O’Reilly, 2004; Huus & Enskär, 2007). A sense of ambivalence threatened their sense of normalcy. Starting from the point of diagnosis, “diabetic identity” may overshadow personal identity and self-concept (Tilden, Charman, Sharples, & Fosbury, 2005). Identity development is a vital task during adolescence (Erikson, 1968). The impacts of T1DM might cause a crisis. Interactions with others (Tilden et al., 2005) help diabetic individuals develop a diabetic identity and influence how they cope with both the disease (Luyckx, Vanhalst, Seiffige-Krenke, & Weets, 2010) and integrate diabetes management regimens into their lives (Tilden et al., 2005). Thus, societal and school support to help adolescents cope positively with disease management are important.

Adolescents are expected to become independent and responsible in their diabetes self-management. Parents, peers, healthcare professionals, and school personnel influence the degree of independence and responsibility (Spencer, Cooper, & Milton, 2010). The capacity for competent and responsible diabetes self-management develops in a gradual process (Hanna & Decker, 2010). Although diabetes self-management knowledge and skills are easy to acquire, application within the dynamics of real life may be difficult. For adolescents in this study, proper personal care was a learning process demanding significant time, echoing the finding of a preliminary study conducted by the authors (Wang, Brown, & Horner, 2010). Factual, experiential knowledge and problem-solving skills are necessary to engage in this complex process (Spencer et al., 2010).

Some study participants lacked confidence in their self-management practices; they recognized the need to be independent but trusted and relied on parents as the source of diabetes knowledge. Development of interventions that target adequate self-efficacy to improve the adolescents’ diabetes self-management is needed (Iannotti et al., 2006). A survey conducted on 19 T1DM Taiwanese adolescents found that 42.1% of their parents injected insulin and 26.3% assisted in measuring blood glucose levels on a daily basis (Chien, Larson, Nakamura, & Lin, 2007). This may relate to the parent–child relationship in Chinese culture, in which children are expected to submit to authority and parents tend to be more protective, especially of children experiencing chronic illness. However, these cultural traits may inhibit adolescents from developing autonomy. Parents and healthcare professionals should work together with the adolescents to prepare them for this responsibility. Hence, interventions that teach adolescents to negotiate with their parents about shared responsibility and independence levels in diabetes self-management are needed.

The inadequate support of teachers and nurses was described by the adolescents in this study. On the basis of the adolescents’ high HbA1c, the nature of possible emergencies of T1DM, and the numerous risky diabetes self-management behaviors that they exhibited at school (e.g., missed blood glucose measurement), better support from school personnel, especially nurses, is needed. Evidence has shown a positive correlation between student level of satisfaction with support from school personnel and classmates and glucose levels (Lehmkuhl & Nabor, 2008). Every student with T1DM deserves a competent school nurse able to provide effective care and work with other healthcare professionals, parents (Bobo, Kaup, McCarty, & Carlson, 2011), and other school personnel. However, literature on the subject indicates that school nurses’ inadequate care for students with T1DM (Fisher, 2006; Joshi, Komlodi, & Arora, 2008) leave adolescents exposed to physical and psychosocial risks. In this study, participants reported that school nurses were not a source of support in diabetes management. School nurses’ roles and functions must emphasize effective care for adolescents with T1DM.

Many factors may influence school nurses’ roles and functions, including their visibility; professionalism; marketing strategies; leadership ability; capacity for negotiation and cooperation with school colleagues, administrators, and healthcare providers; case management knowledge; and the ability to overcome the real limitations in school nursing practice (Brandt, 2002; Brousard, 2004, 2007; Simmons, 2002). Previous educational interventions have led to clear, significant improvement in the knowledge and competence of school nurses in caring for students with asthma (Chao et al., 2003). Prior studies have also shown the significant effectiveness of school-nurse case management for students with asthma (Perry & Toole, 2000; Taras & Potts-Datema, 2005). Identifying the significant barriers to school nurse involvement in students’ diabetes self-management is a key question that must be addressed by further research.

Implications for Practice
Our findings identified several implications for professional practice that are pivotal to meet the needs of students’ diabetes management and healthy development at school. It is important for healthcare professionals to understand and recognize the complexity of personal and external (parents, schoolteachers, school peers, school nurses, and healthcare professionals) factors affecting the safety, health, and well-being of adolescents with T1DM. Adolescents with diabetes need adequate and correct knowledge, appropriate attitudes, and skills to become competent at managing diabetes in dynamic environments. Healthcare professionals must provide continuous and accessible support, effective and practical guidance, and reassurance to assist these adolescents in preventing compromises and learning from
experience. Interventions tailored to enable the internal and external parties to competently and effectively fulfill their roles are warranted. In addition, policies and guidelines designed and implemented to support interdisciplinary teamwork among the adolescents, their parents, and education and health professions, especially school nurses and diabetes educators, are necessary.

Limitations of the Study
Findings of this study provide insight into the lived experience of adolescents with T1DM at school. However, there are a few limitations. First, despite the fact that every quotation was rigorously translated and confirmed by Chinese–English bilingual and native speakers, there is the potential for drifts in meaning because of translation issues. Second, further understanding of experiences from different perspectives (e.g., parents, schoolteachers, school nurses, classmates, and other relevant school personnel) may improve our understanding of this important school-based phenomenon. The roles and functions of school nurses in this study were not obvious in the school lives of the participants. Further research is specifically required to explore the school nurse perspectives on adolescents with T1DM in their schools.

Conclusion
Adolescents with T1DM must strike a balance between adhering to diabetes management regimens and fulfilling normative developmental tasks at school. Because health professionals around the world attempt to facilitate this process for adolescents with T1DM, much work remains to provide adequate support and effective strategies to ensure safety, health, and well-being at school. Considering adolescent psychosocial demands (e.g., disease identity, self-efficacy, and social relationships) is necessary when encouraging adolescents to self-manage diabetes in school. In addition, future endeavors of school-based T1DM care should focus not only on adolescents but also on school context, particularly school nurses, schoolteachers, and classmates.

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References


第一型糖尿病青少年校園生活經驗

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背 景

學校在第一型糖尿病青少年的健康、安全、發展與適應上扮演重要角色，然而至今探討糖尿病青少年校園生活經驗的研究卻極少。

目 的

本研究目的在於探討台灣第一型糖尿病青少年之校園生活經驗。

方 法

海德格詮釋現象學為本研究之研究方法與哲學基礎，以滾雪球方式目標取樣14位罹患第一型糖尿病的青少年，以半結構訪談指引為工具，進行錄音深度訪談直到資料達到飽和為止。資料分析乃透過詮釋循環，並佐以質性分析軟體NVivo協助。過程中利用反思日誌、同儕驗證、摘要記錄、與個案檢視增加研究可信度。

結 果

研究發現，第一型糖尿病青少年校園生活經驗中的主要要素有：(1)相同卻也不同、(2)隱瞞及公開、(3)限制及自由、(4)獨立及依賴、(5)守序及脫序、以及(6)疾病認同及否定。許多因素諸如：疾病認同、社交焦慮與壓力、學校工作人員及同學的無知、獨立自我照顧的過渡等，皆威脅著糖尿病青少年在校時的健康與適應。

結 論／實務應用

要協助糖尿病青少年擁有正向校園生活經驗尚有極大發展空間，未來研究宜針對提升這些青少年疾病照護的自主性與自我效能、糖尿病知識、疾病認同、以及情境障礙的因應繼續努力。此外，提升學校老師與同學對於第一型糖尿病的認識，以及學校護理人員的主動參與，也是未來有待加強之處。

關鍵詞：青少年、現象學、學校、第一型糖尿病。

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