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Original Research

# The Lived Experience of Canadian University Students with Type 1 Diabetes Mellitus

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## ABSTRACT

**Objective:** The purpose of this study was to examine the lived experiences of university students with type 1 diabetes mellitus.

**Methods:** University students participated in a 2-part focus group. Transcripts were analyzed thematically using an open-coding approach. Data analysis was guided by a framework analysis method and emergent themes were triangulated between study authors for validity.

**Results:** Three major themes identified in this study were food issues within the university environment, lack of diabetes awareness on campus and internal struggles related to the participants' relationships with their diabetes.

**Conclusions:** Results illustrate some of the unique challenges that interfere with diabetes self-management, academic performance and quality of life among this sample of university students. Findings can provide insight for diabetes educators and other healthcare practitioners regarding the issues that may interfere with optimal diabetes self-care in this population. Findings also can be used to inform university administrators how to make the university environment more diabetes friendly for its students.

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## R É S U M É

**Objectif :** Le but de cette étude était d'examiner les expériences vécues par les étudiants ayant le diabète sucré de type 1.

**Méthodes :** Les étudiants ont participé à un groupe de discussion en 2 parties. Les transcriptions ont été analysées de façon thématique au moyen d'une approche à codage ouvert (*open-coding*). L'analyse des données a été guidée par la méthode de l'analyse du cadre et les thèmes émergents ont été triangulés avec les auteurs de l'étude pour en déterminer la validité.

**Résultats :** Les 3 thèmes majeurs qui ont été relevés dans cette étude étaient les enjeux alimentaires de l'environnement universitaire, le manque de sensibilisation au diabète sur le campus et les luttes internes liés aux rapports qu'entretiennent les participants quant à leur diabète.

**Conclusions :** Les résultats illustrent certains des enjeux particuliers qui interfèrent dans la prise en charge autonome du diabète, la performance scolaire et la qualité de vie de cet échantillon d'étudiants. Les conclusions peuvent donner un aperçu aux éducateurs spécialisés en diabète et aux autres praticiens en soins de santé en matière d'enjeux pouvant interférer dans la prise en charge autonome optimale du diabète dans cette population. Les conclusions peuvent également être utilisées pour informer les administrateurs d'université sur la manière de rendre l'environnement universitaire plus respectueux de la santé des étudiants diabétiques.

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## Introduction

Type 1 diabetes mellitus is a chronic condition that commonly develops in younger individuals and is defined as the primary result of pancreatic beta cell destruction (1), which ultimately results in a lack of insulin production in the body. Current therapy for this condition involves intensive management of blood glucose levels, which includes a rigorous daily routine of insulin injections, blood

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glucose monitoring, and diet and lifestyle modifications (1). Although the recommended treatment for type 1 diabetes mellitus is complex, time consuming and costly, it is critical in reducing the onset and progression of diabetes-related ...complications, such... as blindness, kidney disease, neuropathy and cardiovascular diseases (2,3). Living with and adhering to the complex treatment regimen for type 1 diabetes mellitus often can interfere with various social, emotional and economic lifestyle choices (4,5), which consequently can diminish quality of life. Those patients who have the most trouble managing type 1 diabetes mellitus are adolescents and young adults (6–11). University students are of particular concern because the demands of student life on top of the stressors of living with diabetes put these individuals at greater risk of poor self-management (4,5,12–16).

Certain elements of university life have been identified in the research literature as barriers or challenges to achieving appropriate diabetes self-management in this population. These include the following: (1) social issues, such as peer pressure, alcohol consumption (6,10), smoking, drug abuse (4,6,17–20), dietary constraints (4,5,15) and eating disorders (6); (2) academic barriers, such as irregular schedules and routines, lack of time and financial issues (4,5,19); and (3) emotional and psychological barriers, such as stress (5), insufficient or lack of social support (5,21), loss of parental involvement (4,17), denial and rebellion toward diabetes self-management (5), and emotions of anger, frustration and sadness as a result of feeling isolated from peers (22).

Research to date suggests that the unpredictable nature of type 1 diabetes mellitus can be challenging, especially for young adults who face the stressful demands and routines of university life (4,5,12–16). Given the lack of Canadian data in the current body of literature, the objective of this study was to explore the lived experiences of university students with type 1 diabetes mellitus in a Canadian university to better understand the challenges of living and coping with type 1 diabetes mellitus at this life stage. This study also aimed to identify pertinent issues that may assist practitioners who provide care in similar environments and university administrators on how to make the university environment more diabetes friendly for its students.

## Methods

Phenomenology informed the methodology for this study. The phenomenologic nature of this study's qualitative inquiry led us to focus on understanding the participants lived experiences rather than the ability to generalize the data. Mosselson (23) argued that this type of experiential research allows the researcher to gain a deeper understanding of the phenomenon (university students living with type 1 diabetes mellitus) being explored. A 2-part focus group was used to collect data. The use of focus groups to obtain data helped capture a full spectrum of thoughts and experiences to better understand participants' lived experiences through their own understandings. Rabiee (24) described the strength of focus groups as providing a way to understand the meanings, beliefs and cultures that influence individuals' feelings, attitudes and behaviours.

Ten questions were asked in the focus group sessions. Questions were based on a prior literature review, and were open ended and broad in nature to provoke participants to discuss a range of experiences (Table 1). Each question was discussed until all participants had contributed their relevant thoughts and experiences. Each focus group session was audiotaped and lasted between 1.5 and 2 hours.

Upon receipt of approval from the university-affiliated research ethics board, students were recruited for the study within 1 university in the city of Toronto. Students who were part of a pre-existing support group for university students with type 1

**Table 1**  
Focus group questions

First session
1. Describe your overall experience living with and managing your diabetes since you have been at university?
2. What would you say are your difficulties with having diabetes in university?
3. So now we are going to talk about managing your diabetes, and specifically your ability to do what you think is optimal (whether you do it or not) for good management. Overall, how well do you feel/think you are able to manage your diabetes (in your definition of what is optimal management) considering the situations that university presents?
4. Are there any particular experiences, not including the ones we already have discussed, that you can remember while in any university scenario during which you felt disadvantaged or even discriminated against because you have type 1 diabetes?
Second session
5. Since our last focus group, I am sure that you all have been thinking of what we talked about, so I want to start by asking you if there was anything that you did not get to mention last time, or that you thought of afterward that you wanted to mention.
6. Thinking about why you came to university and the goals and objectives that you have for yourself here, in what ways do you feel diabetes and diabetes self-care affect those goals and objectives? This can be in both positive and negative ways.
7. Stress is a big factor that affects diabetes management. Take a moment to think about how you manage the stress in your current student life; this behaviour can be positive or negative. Now, in what ways do you cope with the stresses of university life, and do you think your coping mechanisms positively or negatively affect your diabetes management? Just before anyone answers, I want to say that because this is a very personal question, please remember no one here is being judged by anyone and we all respect one another's contributions.
8. By a show of hands, how many people in the room had diabetes before starting university? This question is directed to those people: since attending university do you feel your diabetes self-management has changed or been affected in any significant way?
9. How has the university helped or hindered your ability to care for your diabetes?
10. What programs/policies/initiatives, if any, would you like to see in place in a university setting to help you to manage, cope and enjoy student life living with type 1 diabetes?

diabetes mellitus were contacted via e-mail; others were reached through university-wide advertising by the use of posters. Contacting students who were part of the support group was performed to optimize recruitment through directly reaching the target population. Recruitment from both the pre-existing support group and the general student population on campus was important because these 2 groups may have different experiences living with type 1 diabetes mellitus on campus. All participants had to have type 1 diabetes mellitus, be a university student within the past 2 years at the time of data collection and be older than 18 years of age.

A total of 9 students, 3 males and 6 females, participated in the focus groups. Six participants (3 males and 3 females) attended both consecutive focus group sessions. Three other female participants attended only 1 of the sessions, with 2 of these participants taking part in the first session and 1 participant taking part in the second session. Six of the students recruited also attended the diabetes support group on campus. Participants' year of study ranged from their first to fourth year within undergraduate programs; 1 participant was a doctoral student. All of the students were in different programs of study. Four of the students lived away from home, and 5 lived at home. The students had been living with diabetes from 6 to 22 years, and all of them had diabetes before beginning postsecondary education. Participants were given a Can \$20 honorarium for each session attended, as well as dinner during the session. Informed consent was obtained from all recruited participants in this study.

All audio data were transcribed verbatim on completion of the focus group sessions. Transcripts were analyzed thematically using

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