Assessing the Needs and Perceptions of College Students with Type 1 Diabetes: Developing, Piloting, and Refining an Instrument

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Chapter 1: Rationale for an Instrument

In order for college campuses to see if they could better serve the needs and desires of their students with type 1 diabetes (T1D), this researcher concludes that an instrument assessing primarily the social and emotional needs of college students with T1D is warranted and appropriate given the lack of assessment instruments available in the current literature. Various campus personnel could use this instrument to assess the needs and desires of their specific students with T1D, thus gaining valuable insight into what can be improved on their campus in order to better serve the needs and desires of their students with T1D, as well as help to increase their quality of life.

This researcher will describe three quality of life issues that young adults with T1D deal with on a regular basis in the Social Assessment, Chapter 3. First, there is the fear of physical symptoms of T1D interfering with academic performance, and the potential of those fears coming to fruition. Second, there is the difficulty of transitioning to independent diabetes care with the possibility of a change in provider and the encouragement that campus support groups have to offer in regards to this transition. Third, the advocacy and awareness issues students with T1D face when trying to explain T1D to their universities and/or professors add significant stress to their lives.

With these quality of life issues in mind, this researcher aims to create an instrument that addresses four general areas (with specific questions) of the college T1D population:

1) Fear of hypoglycemia
    a. To what degree does fear of hypoglycemia affect their individual academic performance?

    b. To what degree do other symptoms and issues of living with T1D affect their individual academic performance?

2) Campus support
    a. To what degree do university campus personnel encourage and support individuals with T1D?
    b. How available are diabetes support groups on campus?
3) Campus awareness
    a. What is the general level of T1D awareness on campuses?
    b. Does the level of T1D awareness affect people with T1D individually?
    c. What improvements do individuals with T1D think need to be made in raising campus awareness?
4) Transitioning from pediatric to adult endocrinology care
    a. To what degree has the transition out of pediatric care and into adult care affected (positively or negatively) the quality of their academic life?
    b. To what degree has their level of independence in diabetes management influenced the quality of their academic life?

Chapter 2: Epidemiological Assessment

Preface

When following the PRECEDE-PROCEED model to plan a program, the researcher usually begins with a social assessment followed by an epidemiological assessment. This researcher deems it appropriate to instead begin with an epidemiological assessment followed by a social assessment for the following reason: type 1 diabetes (T1D) is a disease that is not caused by lifestyle or social issues, but rather by an autoimmune attack. For this reason, this researcher deems it valid and important to begin with an overview of T1D, its prevalence, as well as its management and complications before discussing the quality of life issues that college students living with the disease face.

Overview of Type I Diabetes

According to the Joslin Diabetes Center (2015), T1D is a lifelong, chronic disease in which the body is unable to appropriately use and store glucose, backing it up into the bloodstream, which causes one's blood glucose (sometimes called blood sugar) to rise too high – a condition called hyperglycemia, which is the chief symptom of T1D ("An Overview of Diabetes, para. 1). It is an autoimmune disorder in which the insulin-producing cells of the pancreas are destroyed, eventually leading to a total loss of insulin production (Hanas, 2007, p. 12). According to the Joslin Diabetes Center (2015), insulin, a hormone produced by beta cells in the pancreas, enables the body to move glucose from food out of the bloodstream and use it for energy ("An Overview of Diabetes, para. 2).

Symptoms of Type I Diabetes and Hyperglycemia

When blood glucose level is high, glucose is passed out of the body in the urine, resulting in an increased urine output. The first symptoms of T1D are likely to be a raging thirst combined with a need to go urinate much more often (Hanas, 2007, p. 26). Other symptoms of high blood glucose, or hyperglycemia, include the following: "dry skin, dry mucous membranes, lack of energy, weight loss, weakness, blurred eyesight, difficulty in concentrating, and irritable behavior" (Hanas, 2007, p. 28).

In people without T1D, insulin levels are normally low only when blood glucose levels are also low. Therefore, in people with T1D, the low insulin levels make the body "think" it must send more energy to the bloodstream. Because of this process, blood glucose levels can increase even without food intake, due to the triggering of hormones adrenaline, cortisol, glucagon and growth hormone to stimulate the production of glucose and ketone (Hanas, 2007, p. 26). Insulin deficiency as represented by hyperglycemia can lead to ketoacidosis and many other diabetic complications. The other diabetic complications will be discussed in detail later on, but first there will be an overview of ketoacidosis and the importance of treatment for a person with T1D.

Ketones are produced when fat is broken down in the body. In normal circumstances, ketones are used by muscles, the heart, the kidney, and the brain as fuel to function. When there is a lack of insulin in the body, as in a person with T1D, ketones are produced in excess, making the blood acidic and causing ketoacidosis (Hanas, 2007, p. 29). The body attempts to rid itself of the extra ketones by excreting them, whether in the urine or in the form of acetone breathed out of the lungs, giving a fruity odor to the breath. Ketoacidosis can rapidly develop into a toxic, life-threatening condition if not treated adequately with fluid intake and increased insulin levels (Hanas, 2007, p. 29). Ketoacidosis can occur if a person with T1D is unable to take their insulin for 12-24 hours, if he or she needs more insulin than usual (as in an infection accompanied by a fever), or even if alcohol intake is involved (Hanas, 2007, p. 29). For a person with T1D, ketoacidosis is an ever-present danger for which one needs to be aware, educated, and prepared.

Hypoglycemia

Low blood sugar, or hypoglycemia, develops fairly easily in people with T1D who are taking insulin. According to the Joslin Diabetes Center, hypoglycemia symptoms typically appear when a person's blood glucose level drops below 70 mg/dL ("Is Low Blood Sugar (Hypoglycemia) Dangerous?", para. 1). The most common symptoms include shaking, sweating, rapid heartbeat (palpitations), headache, hunger, and nervousness, with more severe symptoms including mental confusion, antagonistic behaviors, unconsciousness, and seizures ("Is Low Blood Glucose (Hypoglycemia) Dangerous?", para. 2). Seaquist and Clark (2013) assert that the severity of hypoglycemia can vary from classic symptoms to a loss of consciousness due to inadequate glucose supplies to the brain, depending on a number of different factors (as cited in Peters & Laffel, 2013, p. 341). According to the Joslin Diabetes Center, "The most common reasons for hypoglycemia are too much diabetes medicine [insulin], too little food or a delayed meal, or too much or unplanned activity" ("Is Low Blood Glucose (Hypoglycemia) Dangerous?", para. 2).

Seaquist and Clark (2013) explain that people without T1D respond naturally to hypoglycemia in two ways: their insulin-producing beta cells reduce insulin secretion to maintain normal blood glucose levels and glucagon is released from the alpha cells in the pancreas to raise blood glucose levels. In a person with T1D, neither of these lines of defense are operative, thus immediate identification and treatment of hypoglycemia is essential (as cited in Peters & Laffel, 2013). Low blood glucose should be treated immediately at the first sign or symptom with rapid-acting carbohydrates such as glucose tablets, fruit juice, or candies (Seaquist & Clark, 2013, as cited in Peters & Laffel, 2013, p. 346).

One of the most feared consequences of hypoglycemia is that it will weaken an individual's ability to detect a later episode of hypoglycemia, an occurrence called "hypoglycemia unawareness" (Seaquist & Clark, 2013, as cited in Peters & Laffel, 2013, p. 347). According to Seaquist and Clark (2013), "The occurrence of a single blood glucose level <70mg/dL will shift the glucose level at which the counterregulatory response is triggered to a lower glucose level for many days. As a result, a patient must drop to a lower glucose level before the counterregulatory response is activated" (as cited in Peters & Laffel, 2013, p. 347). This counter-regulatory response is the activation of the sympathetic nervous system to detect a fall in blood glucose level, resulting in neurogenic symptoms such as "pounding heart, trembling, sweating, tingling, nervousness, and anxiety" (Seaquist & Clark, 2013, as cited in Peters & Laffel, 2013, p. 342). If left untreated, hypoglycemia is extremely dangerous for a person with T1D, therefore it is not surprising that fear of hypoglycemia is common among adults and children with T1D (Seaquist & Clark, 2013, as cited in Peters & Laffel, 2013, p. 348).

Treatment and Management of Type I Diabetes

In someone who does not have T1D, the body is able to control its own blood glucose levels within the narrow range of 70-125 mg/dL (Hanas, 2007, p. 31). To mimic the body of someone without T1D, a person with T1D must provide insulin to the bloodstream via injection or insulin pump. Frequent glucose testing and monitoring is also essential for someone with T1D. People with T1D must test their blood glucose levels, give insulin upon eating or a hyperglycemic level, consume fast-acting carbohydrates upon hypoglycemic episodes, count carbs, exercise, and much more. Haller (2013) describes the overwhelming and exhausting management of T1D in the following way:

> Once diagnosed, patients with T1D are subjected to a lifetime of multiple daily insulin injections of continuous subcutaneous insulin infusion (CSII), frequent self-monitoring of blood glucose (SMBG), the unpredictable nature of blood glucose excursions, the potential for microvascular and macrovascular complications, and the incredible economic and psychological burdens associated with managing a disease that requires management 24 hours a day, 365 days a year (p. 2).

Complications of Type I Diabetes

Tight management of blood glucose levels is essential if one wants to avoid the serious complications associated with T1D, including eye disease, kidney disease, heart disease, stroke, delayed healing of wounds, and nerve damage (Wisse, 2014, “Type 1 Diabetes,” Possible Complications section). This researcher will provide a brief overview of the most common complications of T1D.

According to the Centers for Disease Control and Prevention (2013), the leading cause of death in the United States is heart disease, with 611,105 deaths in 2013 (Leading Causes of Death section, para. 1). Washington and Orchard (2013) found, "The three major types of cardiovascular disease (CVD) most often associated with T1D are coronary heart disease (CAD), peripheral vascular disease (PVD), and cerebrovascular disease" (as cited in Peters and Laffel, 2013, p. 413). Young adults with childhood onset of T1D have an estimated 8- to 41-fold increased risk of dying from ischemic heart disease compared to the general population (Washington & Orchard, 2013, as cited in Peters & Laffel, 2013, p. 413).

While heart disease is the leading cause of death in the United States, perhaps the most well-known diabetic complication in the popular press is nerve damage. Perkins (2013) defines diabetic neuropathy as "a polyneuropathy, given the diffuse damage to all peripheral nerve fibers – motor, sensory, and autonomic. Such damage occurs insidiously and progressively, usually beginning as a generalized and asymptomatic symmetrical peripheral nerve dysfunction" (as cited in Peters & Laffel, 2013, p. 433). Perkins (2013) also describes the various manifestations of diabetic neuropathy in the following paragraph:

Sensory manifestations include symptoms, such as numbness, tingling, or pain, and motor symptoms may involve loss of ankle reflexes, include weakness of the foot muscles, and contribute to imbalance. Autonomic neuropathy affects the nerves that regulate the heart, blood pressure, and the adrenergic response to hypoglycemia (as cited in Peters & Laffel, 2013, p. 433).

Chronic kidney disease (CKD) is another significant diabetic complication. CKD in T1D is associated with significant declines in both length and quality of life (Perkins, 2013, as cited in Peters & Laffel, 2013, p. 437). "Diabetic nephropathy has classically been described as a progressive increase in the level of urinary protein excretion in those with longstanding diabetes, followed by declining renal function that eventually can lead to end-stage renal disease (ESRD)" (Perkins, 2013, as cited in Peters & Laffel, 2013, p. 437).

Finally, there is diabetic retinopathy. "The forms of damage referred to as diabetic retinopathy are the most common causes of new cases of legal blindness" (Perkins, 2013, as cited in Peters & Laffel, 2013, p. 443). A crude prevalence rate of retinopathy in the adult diabetic population in the U.S. is estimated in the range of 30-40% (Perkins, 2013, as cited in Peters & Laffel, 2013, p. 443). In addition, within the context of individuals with T1D, limb amputation and visual loss due to diabetic retinopathy are the two clearest individual predictors of early death (Perkins, 2013, as cited in Peters & Laffel, 2013, p. 443).

Incidence and Prevalence of Type I Diabetes in Young Adults

Haller (2013) points out that in the U.S., approximately 5-10% of people with diagnosed diabetes have T1D, with 1-2 million Americans living with the disease (as cited in Peters & Laffel, 2013, p. 1). Over 15,000 new cases of T1D are diagnosed annually in the U.S., and almost 85% of all people living with T1D are adults (Haller, 2013, as cited in Peters & Laffel, 2013, p. 8). Approximately 208,000 Americans under age 20 are estimated to have diagnosed diabetes, approximately 0.25% of that population. According to the Centers for Disease Control and Prevention (2014), in 2008-2009, the annual incidence of diagnosed T1D in youth was estimated at 18,436, equivalent to 50 new cases each day (“National Diabetes Statistics Report: New Cases of Diagnosed Diabetes,” para. 5). Haller (2013) asserts, “Despite the historical focus on children when discussing T1D (formerly known as juvenile diabetes for its prevalence among children), it is important to note that adults make up 20-25% of newly diagnosed patients and represent an overwhelming majority of patients living with T1D” (as cited in Peters & Laffel, 2013, p. 9). There is no known way to prevent or T1D, therefore while a search for such discoveries are underway, public health efforts must also focus attention to caring for and maintaining good quality of life for those living with T1D.

Chapter 3: Social Assessment and Methodology

Preface

The college campus presents a set of unique circumstances where older adolescents and young adults find themselves in a new, independent environment. Those with pre-existing type 1 diabetes (T1D) face enormous responsibility regarding their diabetes management and decision making, without the convenient presence of their parents and/or pediatric diabetes care team. There are also many students who may face a new diagnosis of T1D while in college, leading to an overwhelming lifestyle adjustment. Unfortunately, the unique challenges young adults with T1D face are seldom found in current literature. This section will review specific issues related to diabetes care and quality of life among college students that is found in current literature. The surprising lack of information regarding this population is only further justification that an instrument to assess the needs of college students with T1D is much needed.

First, this researcher will briefly list a number of factors that affect glycemic control in college students. Some of these factors could provide insight into possible quality of life issues college students with T1D face. In one particular study, college students with T1D reported a number of factors that affect glycemic control during college. Commonly reported barriers to diabetes management included “diet, irregular schedules, lack of parental involvement, peer pressure, drugs and alcohol, fear of hypoglycemia, and finances” (Ramchandani et al., 2000, p. 656). Some factors identified as improving diabetes management included “an increased sense of responsibility, increased frequency of blood glucose testing, exercise, contact with healthcare providers, and fear of hyperglycemia” (Ramchandani et al., p. 656). It is clear that transitioning to college is a tumultuous time for young adults with T1D, with a number of factors influencing their health and glycemic control. The following discussion will include four quality of life issues this researcher thinks are important to consider when assessing the needs of college students with T1D: 1) academic performance; 2) availability of institutional support groups; 3) general advocacy and awareness on campus; and 4) the transition from pediatric to adult endocrinology care.

Academic Performance

At the 2013 Students with Diabetes National Conference in Tampa, Florida, Nicole Johnson and her fellow researchers conducted semi-structured interviews with 41 young adults with T1D, aged 18-34. Of those interviews, 59% of the young adults in college feared the physical symptoms of their T1D, for example, "going low during studying or taking tests, forgetting things when low (e.g. classroom location), dropping classes due to poor performance as a result of T1D" (Johnson, Melton, & Wingert, 2013, "Experiences of Young Adults with Type 1 Diabetes…", Major Themes: Academic section). Academic performance has the potential to decline when living with T1D, simply because of the fear of hypoglycemic episodes, as well as those hypoglycemic episodes inhibiting students from performing their best due to decreased fuel to the brain.

Availability of Institutional Support Groups

Another key finding was that 44% of those interviewed had more trouble coping with the transition to college because of the greater responsibility, lack of family support, and likely transitioning out of pediatric care and into adult care (Johnson et al., 2013, "Experiences of Young Adults with Type 1 Diabetes…", Major Themes: Academic section). Adapting to an independent life of diabetes is an enormous challenge for young adults. T1D requires daily diligent management for optimal control and decreased risk of complications, which is often difficult for young adults to navigate during this time period of serious change and transition. Aalto, Uutela, and Aro (1997) state, ”90% [of college students] reported that they would be more satisfied with their health services if [a peer] program were available” (as cited in Johnson, Melton, & Wagner, 2012, “Students with Diabetes…”, Background section). Aalto et al. (1997) also assert that peer support increases “patients’ motivation, self-efficacy, and self-management of their diabetes” (as cited in Johnson et al., 2012, “Students with Diabetes…”, Background section). In addition, Polonsky et al. (2005) and Fisher et al. (2010) found that high levels of perceived social support are tied to “higher levels of social functioning, self-efficacy, more active coping, higher quality of life, and fewer family arguments” (as cited in Johnson et al., 2012, “Students with Diabetes…”, Background section). Johnson founded Students with Diabetes, an organization providing support and professional opportunities for college students with type 1 diabetes. Johnson et al. found that 81% of students with T1D report “feeling more confident managing their diabetes since joining SWD” (2012, “Students with Diabetes…”, Key Findings section). Blood glucose measures such as A1c levels also improved in students that were involved in SWD (Johnson et al., 2012, “Students with Diabetes…”, Key Findings section). From these research findings, it is clear that institutional support is incredibly value in the management of T1D in addition to the quality of life among college students with T1D.

General Advocacy and Awareness on Campus

A third area of concern for college students with T1D is advocacy and awareness on the university’s campus. Institutional personnel can organize support groups for students with T1D, but they can also become more aware of the illness. In the interviews conducted, 22% of the college students reported lack of academic accommodations and awareness as a reason for stress in their lives (Johnson et al., 2013, “Experiences with Young Adults with Type 1 Diabetes…”, Major Themes: Academic section). For example, some students encounter professors who are not fully aware or understanding of needs of students with T1D and believe that T1D is being used as an excuse to miss classes and tests (Johnson et al., 2013, “Experiences with Young Adults with Type 1 Diabetes…”, Major Themes: Academic section). Another cited example is the institutional population not always being very understanding of students with T1D (i.e., denying a request to drop a class due to poor academic performance resulting T1D issues) (Johnson et al., 2013, “Experiences with Young Adults with Type 1 Diabetes…”, Major Themes: Academic section). Dealing with academic accommodations through registering with the disability office as well as the extra step of dealing with professors who may not have an adequate level of awareness of T1D can add significant stress to the life of a college student living with T1D. The College Diabetes Network, JDRF and the American Diabetes Association (ADA) all offer resources to aid college students with T1D in the advocacy process at their university: The College Diabetes Network has a number of documents to help explain T1D to professors and walk students through the process of registering for accommodations (See Appendices A and B); JDRF has an entire section on their website devoted to tips and tricks for college students raising awareness on campus; and the ADA has published an entire guidebook on advocacy for college students with T1D, entitled *Going to College with Diabetes: A Self Advocacy Guide for Students*. Although these resources are offered, the responsibility is still placed on the students to advocate for themselves, which has the potential to add unwanted stress and a decrease in quality of life if their advocacy and promotion for awareness is not well received.

Transition from Pediatric to Adult Endocrinology Care

The fourth quality of life issue that influences college students with T1D and their glycemic control is the transition from pediatric to adult endocrinology services. Adolescents report that they did not receive sufficient information regarding transition issues, and they also worry about leaving their familiar pediatric health care team for a new, unknown, unfamiliar medical provider (Weissberg-Benchell, Wolpert, & Anderson, 2007, p. 2443). Emerging adults, and consequently current college students with T1D, face more complex decisions and situations than do their healthy peers. The daily demands of diabetes management must be considered in all of the normal choices a young adult faces such as relationships, occupations, living arrangements, financial management, and academic performance (Weissberg-Benchell et al., 2007, p. 2442). For a population with such distinct needs and stressors, it is essential that those in this group receive optimal care and undergo as smooth of a transition as possible into adult endocrinology care.

Other Issues

While this researcher chose to focus on four challenges and quality of life issues facing college students with T1D, there are a number of others prevalent in this population. It is important to consider two other major issues facing this population, which are alcohol consumption and risk of having an eating disorder. A brief overview of these issues is provided for the benefit of the reader, although the issues were not covered in the study.

Since alcohol consumption is often pervasive in the lives of college students, it may also exist among college students with T1D. Alcohol may create risk for all college students, but people with T1D have additional concerns related to alcohol consumption. In the long-term, use of alcohol in persons with T1D may cause diabetic complications to worsen or increase. There are also important short-term effects, which have the potential to affect college students and their T1D management (Mellinger, 2003, p. 2677). The most significant and dangerous potential short-term complication is alcohol-related hypoglycemia, which can be either a direct or indirect consequence of drinking (Mellinger, 2003, p. 2677). As a direct consequence of drinking, alcohol-induced hypoglycemia occurs when people are in a fasted state, and is linked to alcohol's ability to block gluconeogenesis, which limits the body's response to low blood glucose levels. Indirectly, alcohol can impair judgment and cause people to forget essential T1D management tasks, such as blood glucose monitoring and eating (Mellinger, 2003, p. 2677). Alcohol's effects on the central nervous system also contribute to hypoglycemia awareness (Mellinger, 2003, p. 2677). Alcohol consumption poses significant issues for college students with T1D. Students with T1D need to be aware of the risks that are involved with alcohol consumption and develop coping and self-management skills to ensure they are safe when drinking.

Eating disorders and weight control practices are not uncommon in today's society, with the pressure to be thin, fit, and beautiful. According to Wade, Keski-Rahkonen, and Hudson (2011), "Up to 30 million people of all ages and genders suffer from an eating disorder (anorexia, bulimia and bing eating disorder)" (as cited in The National Association of Anorexia Nervosa and Associated Disorders (ANAD), "Eating Disorders Statistics", 2015, para. 1). Statistics also indicate the prevalence of eating disorders specifically among college-age women. Shisslak found that "91% of women surveyed on a college campus had attempted to control their weight through dieting" (as cited in ANAD, "Eating Disorders Statistics," 2015, para. 5). According to The Nutritional Journal, "In a survey of 185 female students on a college campus, 58% felt pressure to be a certain weight, and of the 83% that dieted for weight loss, 44% were of normal weight" (as cited in the ANAD). According to Goebel-Fabbri (2015), "Women with type 1 diabetes are more than twice as likely to develop an eating disorder than age-matched women without diabetes" ("Eating Disorders/'Diabulimia' in Type 1 Diabetes", para. 1). Neumark-Sztainer et al. (2002) explains the risk factors for having an eating disorder when being a female with T1D in the following way:

> The presence of type 1 diabetes may heighten attention to dietary restraints, weight gain, and food preoccupation. Being overweight seems to be a risk factor associated with disordered eating among females with type 1 diabetes. Furthermore, the risk for being overweight may be higher among females with type 1 diabetes, as compared with other females (p. 1289-1290).

It is evident that college aged women are at risk for developing eating disorders, and women with T1D are at an elevated risk simply because they live with T1D. Goebel-Fabbri (2015) explains one of the most prevalent eating disorder problems for women with T1D:

Eating disorders in [T1D] such as “diabulimia,” as it is known in the popular press, represent some of the most complex patient problems – both medically and psychologically.

Women with eating disorders and diabetes typically struggle with symptoms similar to those of women with eating disorders who do not have diabetes. However, they exhibit a very dangerous symptom of calorie purging in the form of insulin restriction.

This condition is characterized by weight and body image concerns that lead to the mismanagement of diabetes (“Eating Disorders/’Diabulimia’ in Type 1 Diabetes,” para. 2-4).

Individuals with diabulimia often take just enough insulin to merely function, then feeling dehydrated, fatigued and irritable. Women living with T1D have this unique form of calorie purging called insulin restriction, which leads to hypoglycemia, dehydration, and loss of lean body tissue (Goebel-Fabbri, 2013, as cited in Peters & Laffel, 2013, p. 180). Goebel-Fabbri states, “As many as 31% of women with T1D report intentional insulin restriction with rates of this disturbed eating behavior peaking in late adolescence and early adulthood (40% of women between ages of 15 and 30 years)” (2013, as cited in Peters & Laffel, 2013, p. 180). These women face long-term consequences ranging from blindness and neuropathy to kidney failure and diabetic ketoacidosis (We Are Diabetes, “What Is Diabulimia?”, 2015, para. 2). The cycle of negative feelings about body image, chronically high blood glucose levels, depression, anxiety, shame, poor T1D management, and insulin restriction is difficult to treat and poses a significant challenge and threat to this population.

The two issues of alcohol consumption and eating disorders are important when studying the population of students with T1D, but need to be studied individually. For the purpose of this study, questions related to alcohol consumption and risk of having an eating disorder were not addressed.

The current research indicates that there are many unique challenges faced by the population of college students with T1D. This research chose to focus on four of those challenges and quality of life issues. Based on the research, it is clear that academic performance, availability of institutional support groups, general advocacy and awareness on campus, as well as the transition from pediatric to adult endocrinology care all have significant effects on the quality of life and glycemic control of college students with T1D.

Methodology: Human Research & Students with Diabetes

This researcher obtained permission from the Human Research Committee/Institutional Review Board at Malone University to distribute a 33-question survey under their regulations (See Appendices C and D). Permission was also obtained from Dr. Nicole Johnson, founder and Executive Director of Students with Diabetes (SWD), to distribute the survey via monthly SWD email newsletter (See Appendix E).

Methodology: Sample Selection

Participants were all either members of SWD or subscribers to the SWD email newsletter. The ages ranged from 18-30, and the participants were either undergraduate or graduate students.

Methodology: Instrumentation

A 33-question survey was created in Survey Monkey (See Appendix D). The survey included multiple-choice questions, Likert scales, and short answers. The survey was divided into five sections: Demographics, Academic Performance, Institutional Support, Level of Awareness on Campus, and Transitioning from Pediatric to Adult Care. Each section included at least four questions, with a variety of formats including multiple-choice, Likert scale, and short answer. The survey was determined to have content validity by experts in the fields of endocrinology, public health, and psychology.

The Demographics items were designed to give basic information about the participants, with two items pertaining specifically to T1D demographics. A question regarding how long the participant has lived with T1D was included for the possibility of correlating specific needs with students who have lived with T1D for longer. Similarly, a question regarding method of diabetes management was included for the possibility of correlating specific needs with specific diabetes management methods (for example, a student with a continuous glucose monitor may not fear hypoglycemia as much as a student without one, leading to different needs in terms of level of desire for education about hypoglycemia symptoms and treatment). These correlations may provide valuable insight to an institution distributing this survey.

The Academic Performance items focused primarily on how hypoglycemia affects the participants’ academic performance. Questions focused on the specific ways hypoglycemia affects the participants’ academic performance, how frequently hypoglycemia interferes with their academic performance, how often they feel anxious about hypoglycemia interfering with academic performance, and the specific ways they worry about hypoglycemia interfering with academic performance. This section was designed to give a broad understanding of the common issues college students with T1D face when trying to balance diabetes management and academic performance.

The Institutional Support items dealt with two issues: support groups and educational programs on campus as well as registering with accommodations. Questions regarding the availability of support groups and/or educational programs on campus as well as the desire for these types of programs were included to identify any potential gaps in campus programming for campuses large enough to warrant such programming. One question about the level of satisfaction among participants was asked in order to gain insight about the students' perspective of campus support. Finally, one question was included to identify if participants have registered for accommodations with their university, and why or why not. This question was included to gain insight on participants' desires for recognized support on campus, as well as some insight on desire for awareness on campus in terms of ensuring professors know what to do in a diabetic emergency.

The Level of Awareness on Campus items were designed to gauge how satisfied the participants' are in terms of feeling that T1D is generally understood on campus. Questions were asked regarding the efforts that have been made to raise awareness on campus, what methods would be most effective for raising awareness, what the participants most want their university personnel to understand about T1D, and how the level of awareness affects the participants. These questions may be helpful in identifying what possible types of awareness participants desire: 1) accommodations enabling access and information about possible medical emergencies that can occur in or out of class, 2) awareness/education about T1D in general, 3) possible fundraising efforts for T1D research organizations.

The Transitioning from Pediatric to Adult Care items focused on determining the level of difficulty or stress experienced during transition for those participants who underwent transitioning endocrinologists while also transitioning to college life. Questions regarding how involved participants were in their diabetes care, how strongly they adhered to their endocrinologist's recommendations, difficulty/stress level experienced during transition, and suggestions for making the transition less stressful were all included.

Methodology: Data Collection

The research methodology called for the survey to be sent to a network of approximately 2,000 college students with T1D during the months of May, June, July, and August of 2015. Due to an error in communication, the survey was only sent out via email newsletter during the months of July and August. The survey closed on August 14, 2015.

Methodology: Data Analysis

The analysis of the quantitative data was conducted through Survey Monkey's "Analyze Results" feature. The researcher analyzed short answer responses determining the emerging common themes.

Chapter 4: Results

Demographics

The analysis included 18 participants with one participant not completing any of the survey questions, leaving the survey number at 17 participants of which 13 were female (See Figure 1). Ages ranged from 18-24 (See Figure 2), with the majority (64.71%) (f=11) of the participants ranging from 19-21 years of age. A majority (94.12%) (f=16) of the participants were white, with only 5.88% (f=1) of the participants being Hispanic/Latina (See Figure 3).

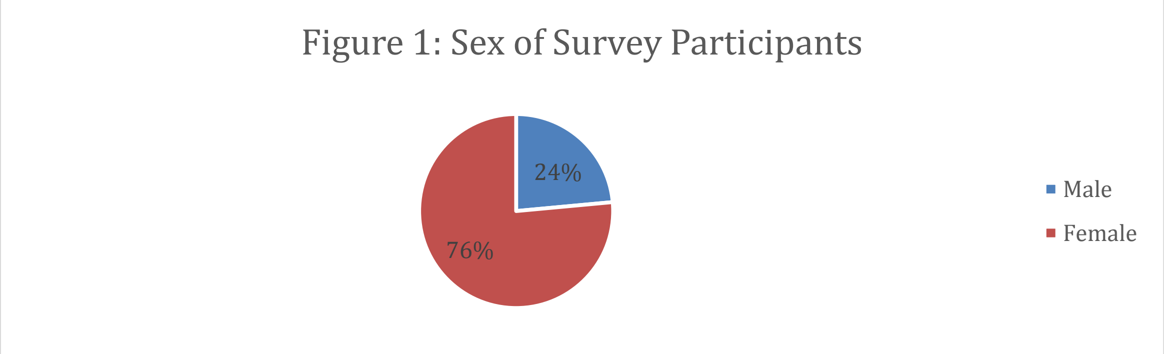


Figure 1: Sex of Survey Participants

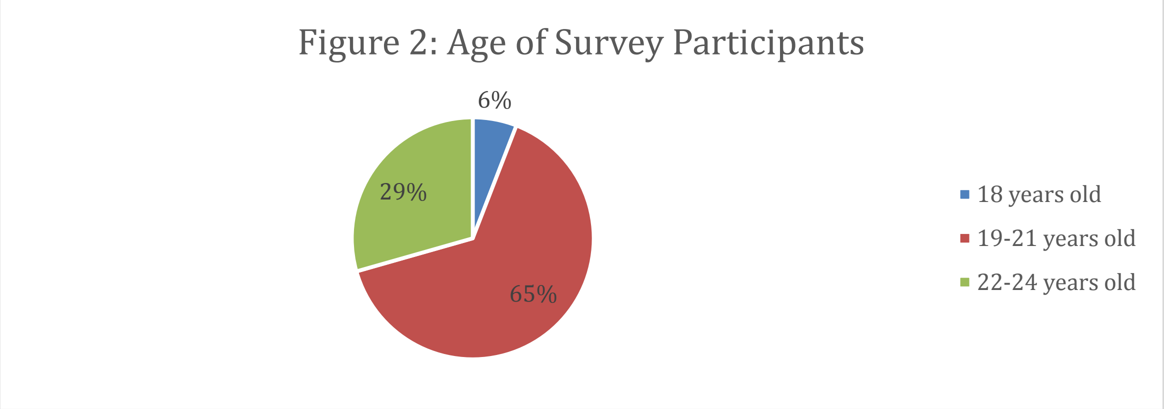


Figure 2: Age of Survey Participants

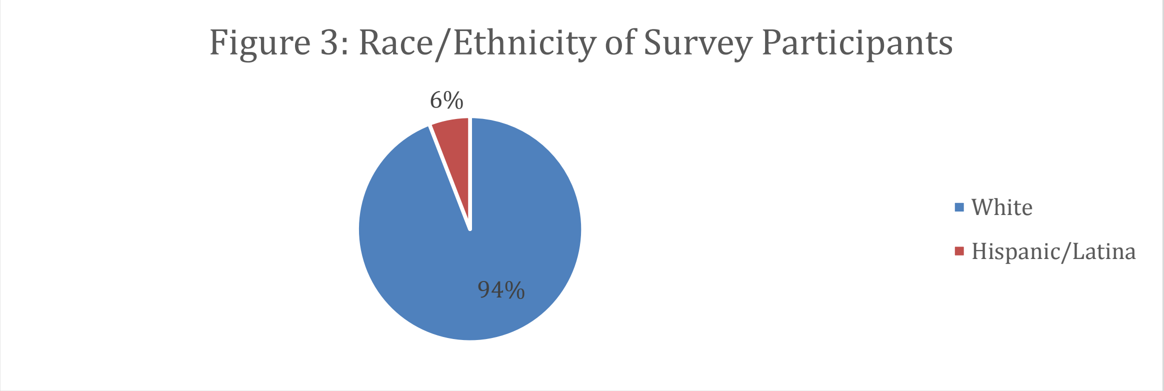


Figure 3: Race/Ethnicity of Survey Participants

None of the participants were freshmen in college, 17.65% (f=3) were sophomores, 35.29% (f=6) were juniors, 41.18% (f=7) were seniors, and 5.88% (f=1) were graduate students (See Figure 4). Approximately 88% (f=15) of the students were full-time, taking a course load of at least 12-credit hours per semester. Approximately 82% (f=14) earned $10,000 or less per year, while 5.88% (f=1) earned $31,000 or more per year (See Figure 5). A majority of students (70.58%) (f=12) lived with a roommate(s) either on- or off-campus, each 35.29% (f=6) respectively. Only 11.76% (f=2) lived on campus alone, 11.76% (f=2) lived off campus with family, and 5.88% (f=1) lived off campus alone (See Figure 6).

Figure 4: Academic Standing of Survey Participants

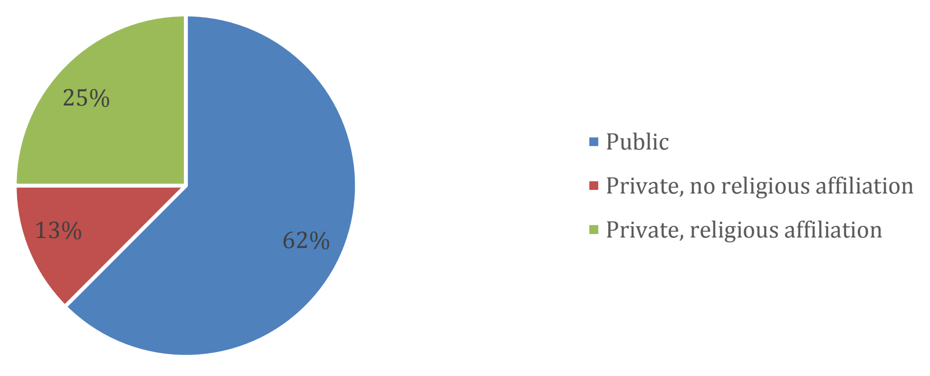
Figure 5: Annual Income of Survey Participants

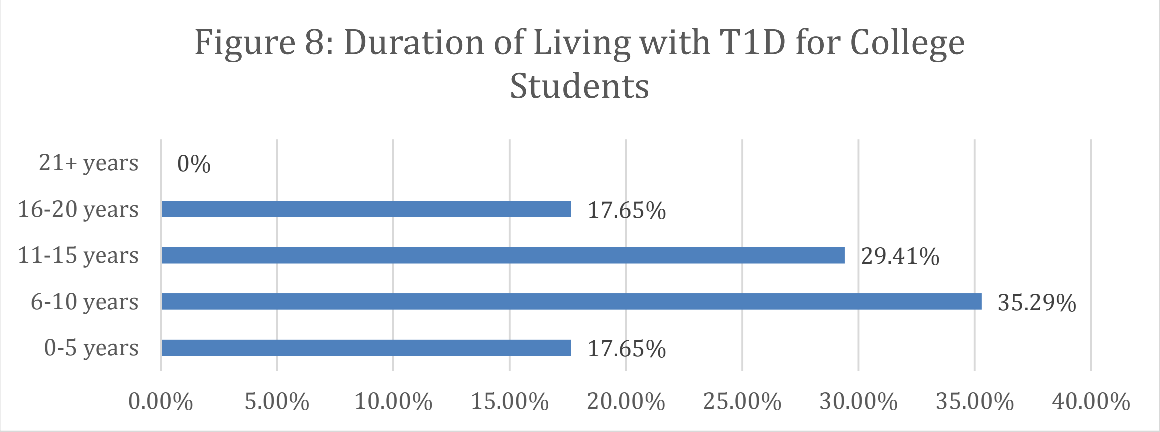
Figure 6: Living Situation of Survey Participants

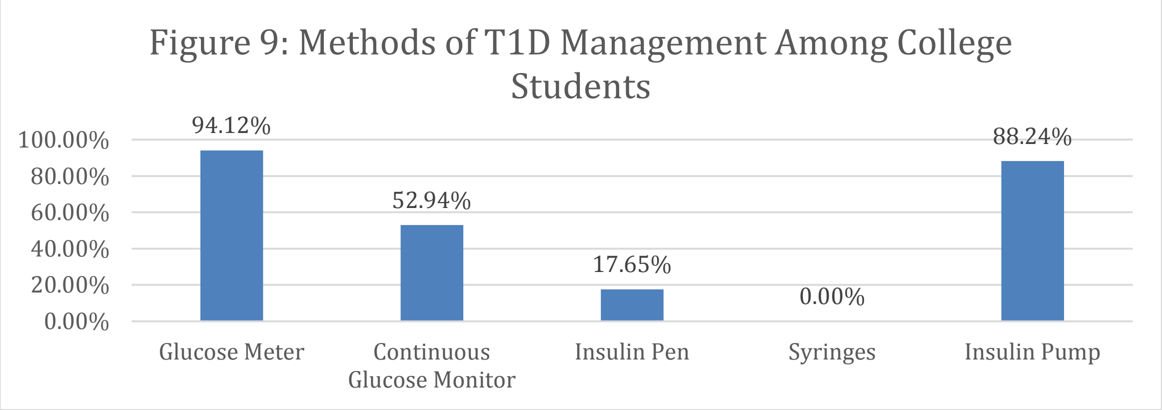
The student population of the participants' universities ranged from 1,300 to 36,000, with an average of 11,477. The variety in types of universities attended was as follows: 62.50% (f=10) attended a public college or university, 25.00% (f=4) attended a private college or university with a religious affiliation, and 12.50% (f=2) attended a private college or university with no religious affiliation (See Figure 7).

In terms of T1D demographics, participants have lived with T1D for a range of 0-20 years (See Figure 8); 17.65% (f=3) have lived with T1D for 0-5 years, 35.29% (f=6) have lived with T1D for 6-10 years, 29.41% (f=5) have lived with T1D for 11-15 years, and 17.65% (f=3) have lived with T1D for 16-20 years. In terms of T1D management (See Figure 9), 94.12% (f=16) of participants reported using a glucose meter for monitoring blood glucose levels. Approximately 88 % (f=15) reported using an insulin pump as their method of insulin delivery, 52.94% (f=9) of participants reported using continuous glucose monitoring for measuring blood glucose levels, and 17.65% (f=3) of participants reported using insulin pens as their method of insulin delivery.

Figure 7: Types of Colleges/Universities Attended by Survey Participants







Academic Performance & Fear of Hypoglycemia

Of the 17 participants, 16 agreed that low blood sugar and the consequential need to treat it has interrupted their attention and focus during class. Approximately 82% (f=14) have had difficulty studying for tests due to low blood sugar, 64.71% (f=11) have had difficulty completing assignments due to low blood sugar, and 47.06% (f=8) have missed class due to low blood sugar (See Figure 10). When asked about frequency of hypoglycemia interfering with academic performance (such as studying, taking exams, giving presentations, or focusing during class), 47.06% (f=8) said that hypoglycemia interferes with their academic performance frequently (once a week), and 35.29% (f=6) said sometimes (once a month) (See Figure 11). When asked about frequency of feeling fear or anxiety about hypoglycemia interfering with academic performance, 35.29% (f=6) said they feel this way frequently (once a week), and 29.41% (f=5) reported feeling this way very often (multiple times a week) (See Figure 12).

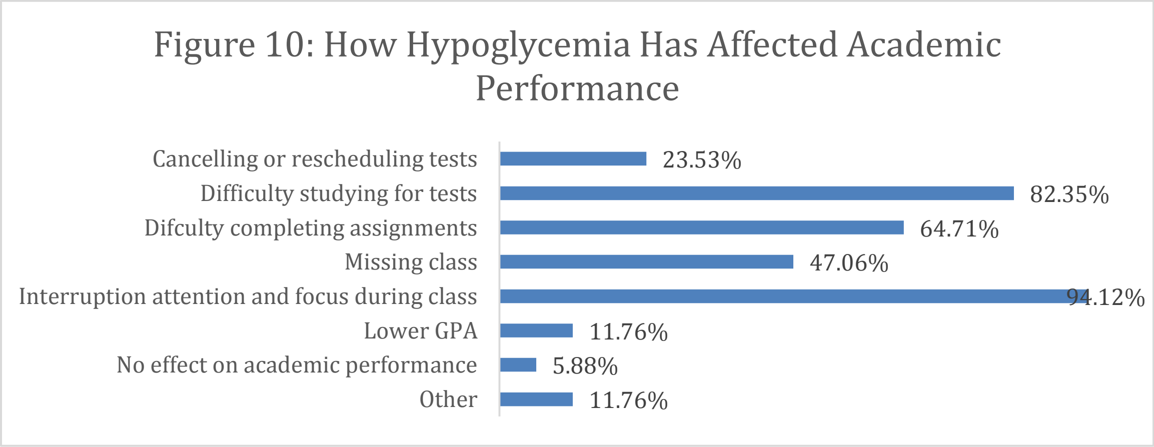


Figure 10: How Hypoglycemia Has Affected Academic Performance

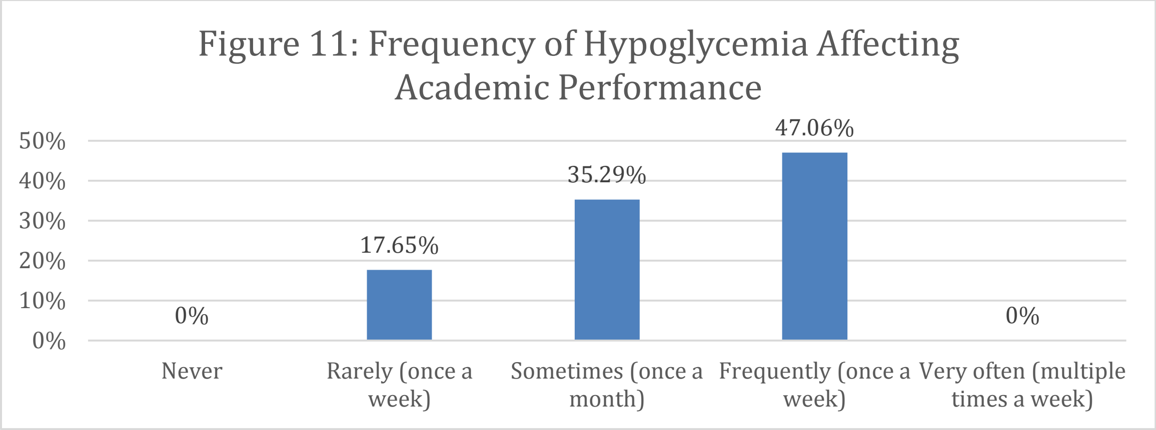


Figure 11: Frequency of Hypoglycemia Affecting Academic Performance

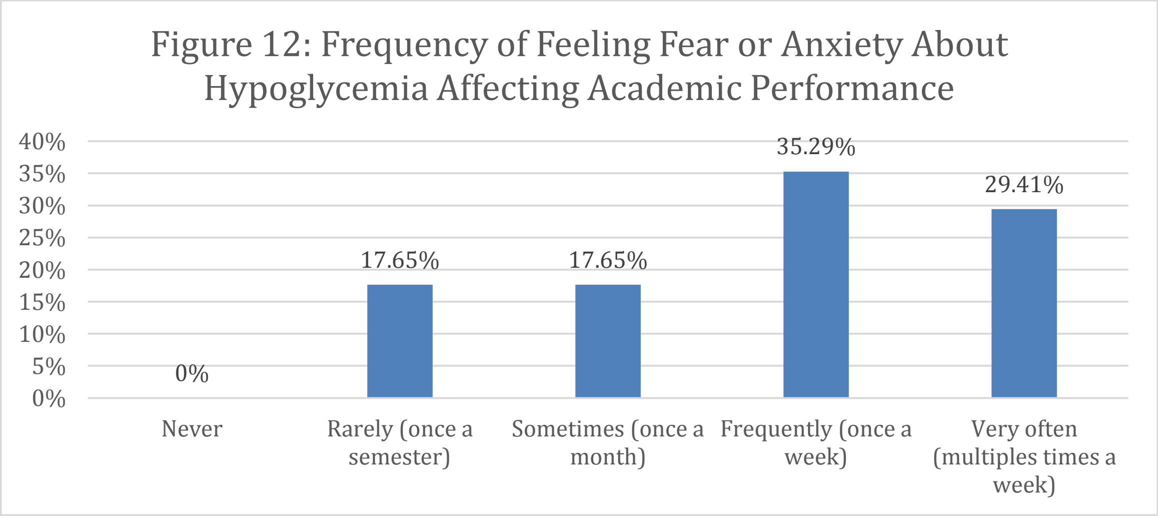
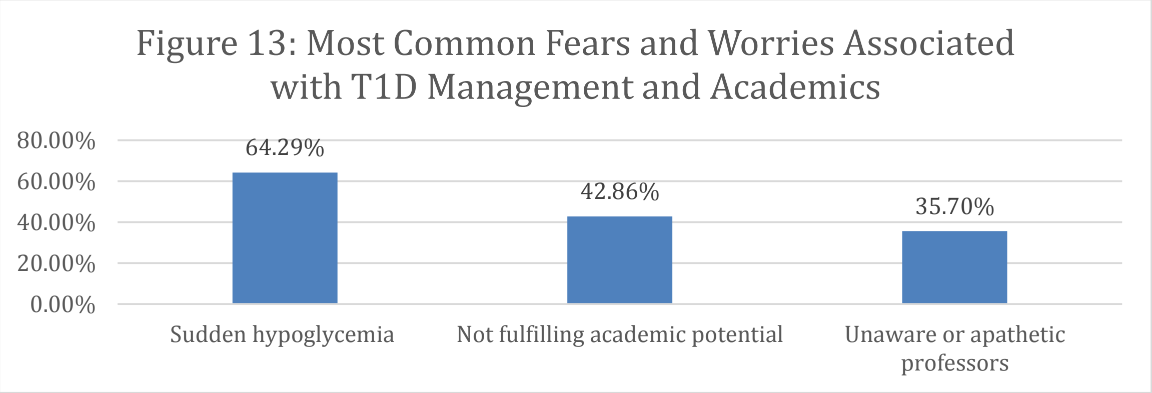


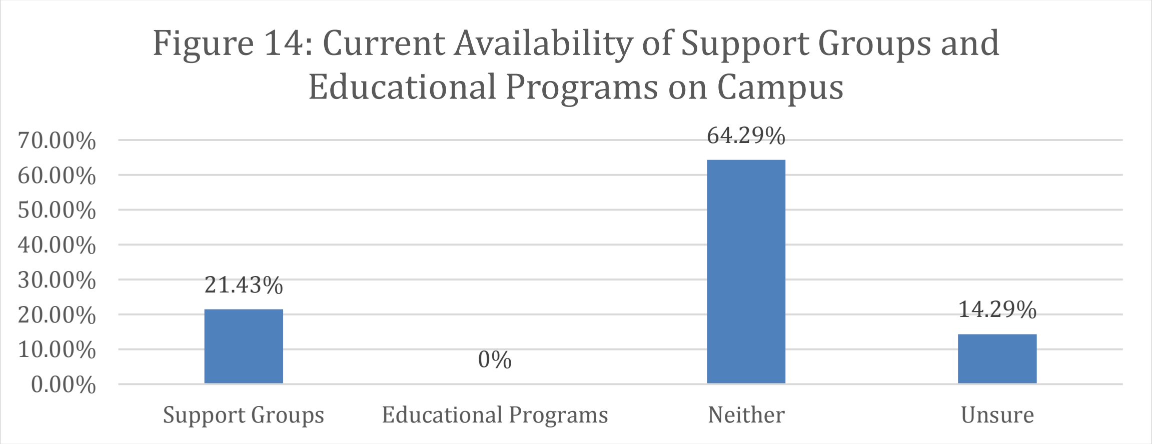
Figure 12: Frequency of Feeling Fear or Anxiety About Hypoglycemia Affecting Academic Performance

In a short answer question, when asked about specific reasons a student might feel afraid about T1D management interfering with academics, some common fears included sudden hypoglycemia occurring during class with no one around them understanding how to help (64.29%) (f=9), not fulfilling their academic potential (42.86%) (f=6), and professors being unaware or apathetic of their condition and its management (35.7%) (f=5) (See Figure 13).

Institutional Support

None of the participants' campuses offered educational programs about T1D. Approximately 21% (f=3) of the participants' campuses offered support groups on campus, 64.29% (f=9) of the campuses did not offer either support groups or educational programs about T1D, and 14.29% (f=2) of the participants did not know what their campus offered in terms of support or education regarding T1D (See Figure 14).





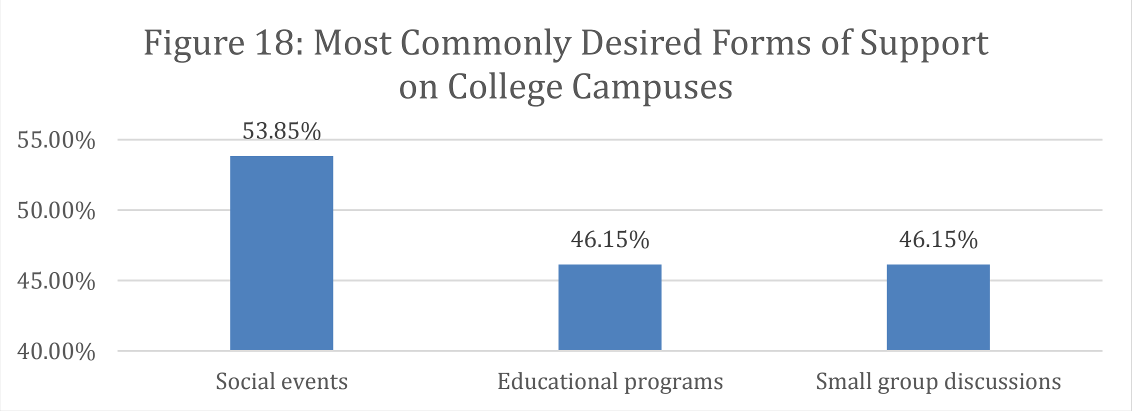
Regarding participants that are on campuses that do not offer such programs (12 in total), 10 responded that they wish their campus offered such programs. The other two did not show concern (See Figure 15). Of 14 participants, 13 said if their campus offered support groups and/or educational programs, they would attend them, with one indicating "maybe" (See Figure 16). When asked to rate their satisfaction with encouragement support on campus, 35.71% (f=5) of the participants reported feeling dissatisfied, 28.57% (f=4) reported feeling satisfied, 21.43% (f=3) were neutral, 7.14% (f=1) were extremely satisfied, and 7.14% (f=1) were extremely dissatisfied (See Figure 17).

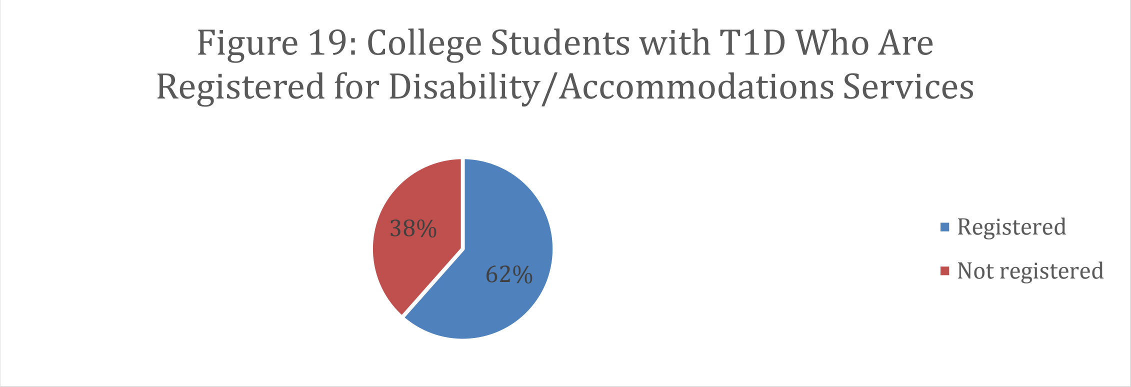
Figure 15: Students Who Desire Campus Programming for Students with T1D

Figure 16: Desire Among Students to Attend Campus Programs about T1D

Figure 17: Level of Satisfaction with Campus Support and Encouragement

When asked in a short answer question what they would like to be offered by university support groups, the most commonly desired forms of support on campus included social events and gatherings for students with T1D (53.85%) (f=7), educational programs (46.15%) (f=6), and small group discussion about self-management and T1D issues (46.15%) (f=6) (See Figure 18). The most prevalent reasons for feeling dissatisfied with the support offered included lack of awareness and understanding (36.36%) (f=4) and issues with professors when eating in class to treat hypoglycemia (18.18%) (f=2). The primary reasons reported for feeling satisfied with the support offered included disability/accommodations services being helpful (18.18%) (f=2) and caring professors who try to understand T1D and its management (9.09%) (f=1). Of the 13 participants who answered the question, 61.54% (f=8) have registered for accommodations (See Figure 19).



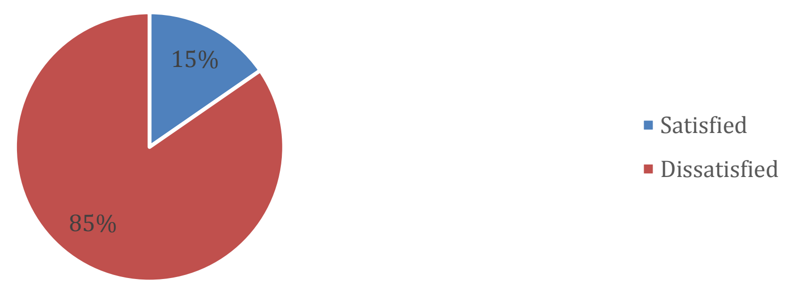


Of those who registered for accommodations, 25% (f=2) of them reported having done so to ensure that professors take T1D seriously. The remaining 38.46% (f=5) of the 13 participants have not registered for accommodations. Forty percent (f=2) of those not registered reported that they have no desire to have others know about their disease and be “judged,” with the other 60% (f=3) of those not registered reported that the accommodations offered, such as extra time on quizzes and tests, are unnecessary for the individual and might be seen as “special treatment.”

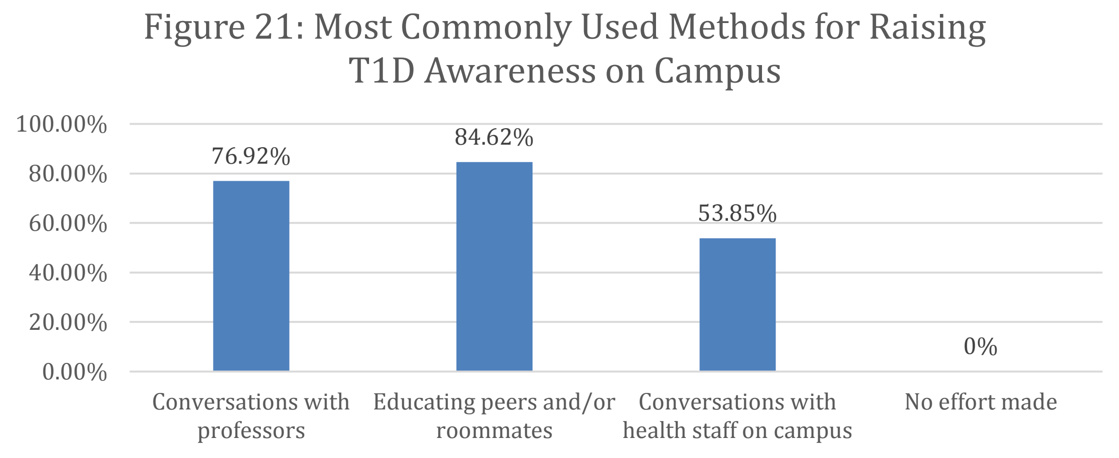
Level of Awareness on Campus

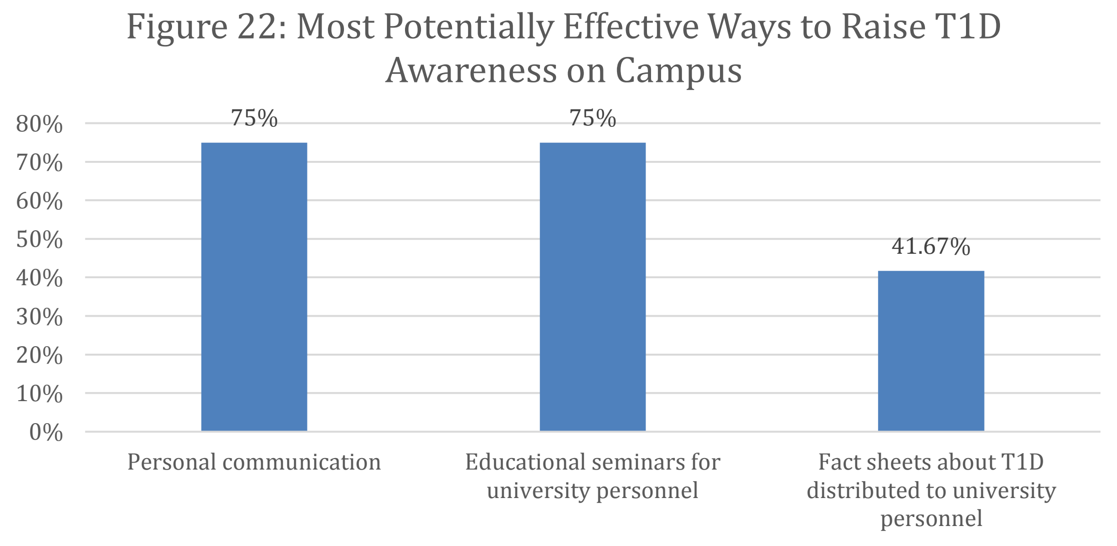
Of the 13 participants who responded, 84.62% (f=11) do not feel satisfied with the level of T1D awareness on their college campus (See Figure 20). In terms of efforts made toward raising awareness on campus, 76.92% (f=10) of the 13 participants have engaged in conversations with professors about T1D, 84.62% (f=11) have engaged in conversation with their peers and/or roommates about T1D, and 53.85% (f=7) have engaged in conversation with the health staff on campus. All participants have made some sort of effort to raise the level of awareness of T1D on their respective campuses (See Figure 21).

Figure 20: Level of Satisfaction with Level of T1D Awareness on Campus



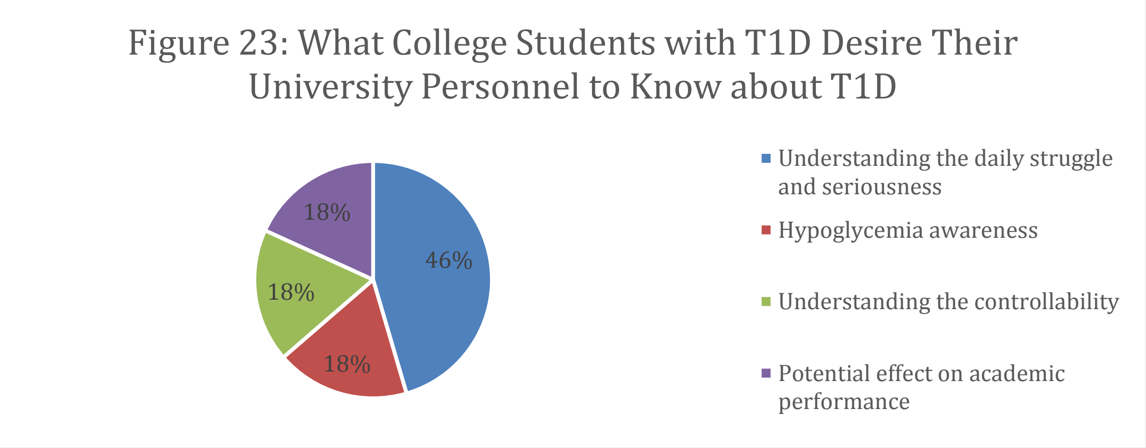
When asked about the most effective ways to raise awareness specifically among campus personnel, of the 12 participants, 75% (f=9) expressed the importance of personal communication with professors and staff members with whom they come in contact most, 75% (f=9) also expressed the potential impact of an in-service training about T1D for university personnel to attend, 41.67% (f=5) suggested fact sheets about T1D be distributed to university personnel through the health system on campus, and 8.33% (f=1) suggested the possibility of a TED talk (for those campuses large enough to offer such an event) (See Figure 22).

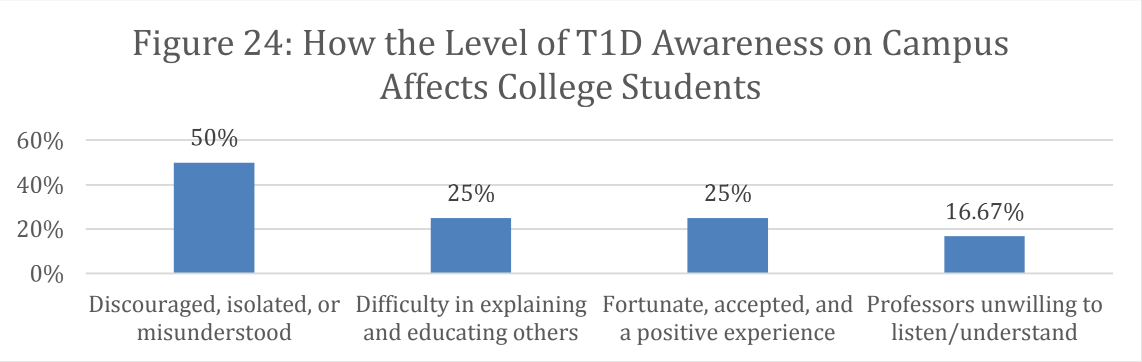




When asked what they most want their campus personnel to know about T1D, of the 11 participants who responded, 45.45% (f=5) expressed the importance of understanding the daily struggle and seriousness of the condition. Approximately 18.18% (f=2) conveyed the desire for hypoglycemia awareness on campus and the subsequent knowledge of how to treat hypoglycemic episodes, stated that an understanding of the relative uncontrollability of the condition would be helpful, and expressed that they want their professors to simply be aware that T1D has the potential to affect a student's academic performance (See Figure 23).

Of the 12 participants that responded to the question about level of awareness on campus affecting them personally, 50% (f=6) reported feeling discouraged, isolated, or misunderstood, 25% (f=3) said they find it difficult to explain/educate others on their own, 25% (f=3) feel fortunate to be accepted by peers and have a positive experience, and 16.67% (f=2) find their professors unwilling to listen or understand (See Figure 24).





Transitioning from Pediatric to Adult Endocrinology Care

Nine out of thirteen respondents (69.23%) reported they have not transitioned out of pediatric and into adult diabetes care. Of the remaining four respondents, three (75%) transitioned while also transitioning to college life (See Figure 25). Nine students responded to the question, "Which of these statements best describes your involvement in your diabetes care? (Please select all that apply)" with:

- 33.33% (f=3) stating they handle all of their prescriptions independently
- 44.44% (f=4) stating their parents handle all of their medical insurance and payments
- 11.11% (F=1) stating they pay for their own medical insurance independently
- 11.11% (f=1) stating their parents handle their prescriptions (See Figure 26).

Figure 25: Survey Participants Who Have Transitioned from Pediatric Diabetes Care to Adult Diabetes Care

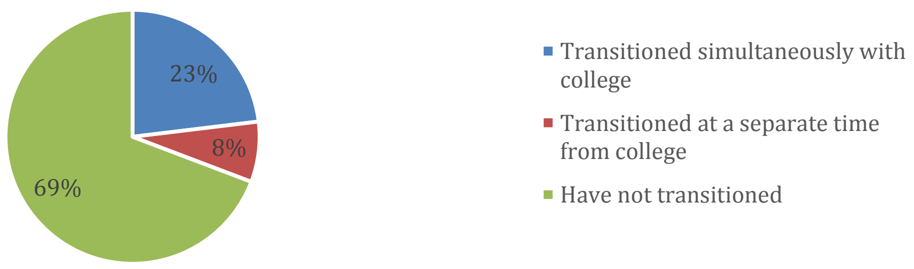


Figure 26: Financial Involvement in Diabetes Care Among Survey Participants

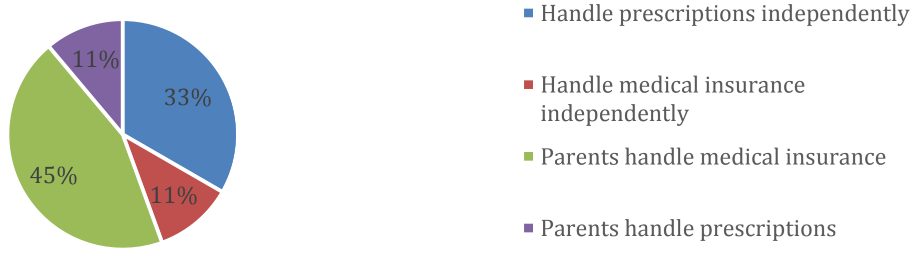


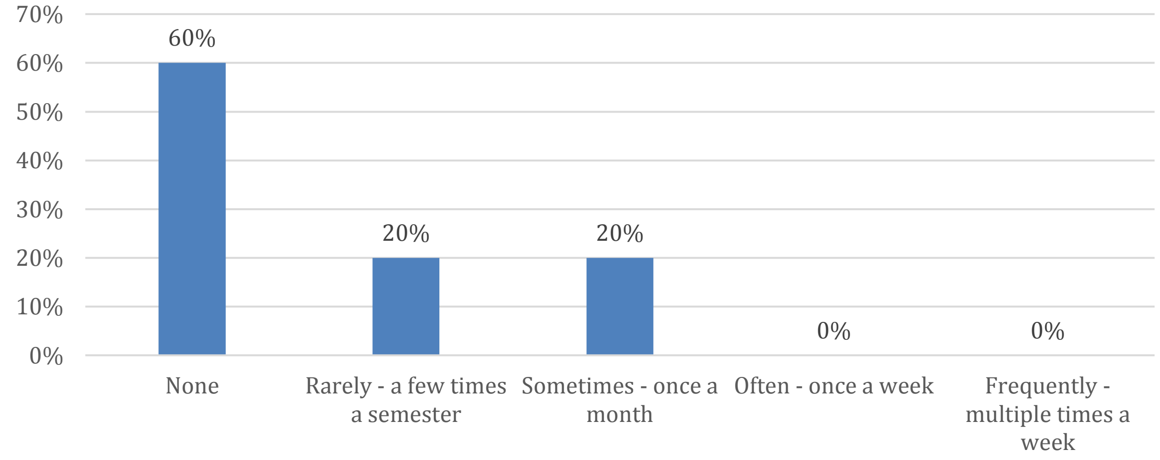
Table 1 shows the responses to question 30, which involves how strictly the respondents adhered to their endocrinologist's recommendations during their time of transition. Nine participants answered this question, though only four participants answered "yes" to having transitioned from pediatric to adult diabetes care. This will be discussed further in Chapter 5.

Of the five respondents that replied to the question, "How difficult/stressful was the transition from pediatric to adult diabetes care for you?" three (60%) stated that they experienced no difficulty/stress during their transition, one (20%) reported difficulty/stress rarely (a few times during the semester, one (20%) reported difficulty/stress sometimes (once a month), and none reported experiencing difficulty/stress any more frequently than once a month (See Figure 27). The most common reasons for stress during the transition included cost of prescriptions, inconvenience of location relative to campus, difficulty in making and attending appointments, and unfriendly office staff at new location, with 25% (f=1) reporting respectively. Possible ways listed to make the transition easier were having recommendations or referrals made for a good adult endocrinologist in the area, having the college campus have endocrinologists on staff, having a doctor the student feels comfortable with, and having friendly support staff, including nurses and office staff, with 25% (f=1) reporting respectively.

Table 1: Adherence to Endocrinologist's Recommendations During Time of Transition

	Strongly agree	Agree	Disagree	Strongly disagree
I checked by blood sugar as often as recommended.	22.22%	33.33%	22.22%	22.22%
I gave insulin as often as recommended.	33.33%	44.44%	22.22%	0.00%
I counted by carbohydrates as often as recommended.	55.56%	44.44%	0.00%	0.00%
I corrected out of range blood sugar levels as soon as I was aware of them.	33.33%	66.67%	0.00%	0.00%

Figure 27: Frequency of Difficulty/Stress Experienced by College Students During Transition to Adult Diabetes Care



Chapter 5: Discussion

Discussion of Data

A majority of participants lived with a roommate, whether on or off campus. In the open-ended questions, some participants noted the need for educating their peers and feeling accepted by peers. This may begin with educating their roommates and other people living closely with them. Issues related to living with a roommate is a topic of interest for college students in general, and perhaps more important for college students living with T1D who need to ensure their roommates are aware of their condition and what to do in emergencies. Stress between roommates may have the potential to affect the college student's T1D management.

Another important theme emerged in the first section of the survey data, indicating that many of the participants were stressed, worried, scared, or anxious about hypoglycemia and its effects on their academic performance. The most prevalent theme regarding hypoglycemia included the factor of unawareness on campus and the fear that professors and peers will not know what to do in the case of an emergency. This issue may be addressed by educating campus personnel about hypoglycemia, its symptoms, and its treatment. Another possibility may be to affirm the students' ability to manage their T1D, instilling self-efficacy, and increasing their ability to confidently feel their hypoglycemic symptoms and take the proper treatment. This increase in self-efficacy and confidence in treating low blood sugar episodes might also positively influence the majority of students who perceive their hypoglycemia as interrupting their attention and focus during class, giving them difficulty when studying for tests, and making it difficult to complete assignments. The frequency of how often hypoglycemia affects a student's academic performance and the fear or anxiety a student may have regarding hypoglycemia are issues that need to be addressed and are topics for further research and programming.

A majority of the participants reported that their campus did not offer support groups or educational programs about T1D. Support may be limited due to the size, budget, and population of students with T1D on campus, but it remains important, particularly since many of the participants desired campus programming and indicated they would attend programs if offered on campus. Many ideas that participants discussed were related to social events and gatherings for students with T1D, including some small group discussion about self-management and miscellaneous T1D issues. On a smaller campus, this would be an easy way to implement a program since social gatherings can be effective, whether small or large. However, a smaller campus will not have a substantial number of students with T1D, and because of FERPA/HIPAA restrictions, identification of students with T1D depends solely on those students' self-disclosure of their condition. It may take the initiative of an individual student to begin an informal social gathering since it would not likely by initiated by the campus health services. It may be intimidating and difficult without the official support of the institution. Students may also need to contact a local clinic or advocacy group for help with implementing any sort of programming on campus.

Another theme that emerged was the perception of helpfulness or not of disability/accommodations services on campus. Some of the participants found it helpful to register for services just in case of emergency. Others, however, did not desire to register for disability/accommodations services for fear of being "singled out." There seemed to be somewhat of a divide among participants who desired awareness from a safety perspective, and those seeking awareness from a social acceptance perspective. There were students who did not want increased awareness for fear of being singled out and isolated. Perhaps students would benefit from a program or discussion on social stigma of T1D and determining what is best for the student regardless of social perceptions of T1D. Although opinions varied on why awareness should or should not exist, the majority of participants reported they were not satisfied with the level of T1D awareness on their college campuses, and many felt discouraged, isolated, or misunderstood, which may indicate that education and awareness campaigns might be worthwhile on a college campus.

A vast majority of the participants reported that their primary way of raising awareness on campus was through individual conversations with their professors, or educating their peers/roommates, yet they were dissatisfied with the level of awareness on campus. Perhaps students felt frustrated with having to personally educate so many others on campus (an area for future research to consider), which may indicate that awareness campaigns would be valuable. Organizations like the College Diabetes Network have helpful information sheets to provide professors when students do not feel capable of personally educating their professors (See Appendix A). Perhaps the student's endocrinologist could actively recommend such organizations and their resources.

The data regarding transitioning from pediatric to adult diabetes care was difficult to interpret. Some technical issues with the survey affected the quality of the results. The question, "Have you transitioned from pediatric to adult diabetes care? If no, please disregard the remaining questions" generated only four participants answering "yes." However, the following three questions had more than four respondents, indicating that some participants did not follow the instructions. The researcher may have considered placing a restriction on this section of the survey, preventing any participant from responding to the subsequent questions if they had answered "no." As a result of not restricting subsequent questions, only two of the questions regarding transition could be interpreted.

There are a few technical changes that will need to be implemented regarding the future design of the survey. To protect against inaccurate data collecting in the future regarding the transition to adult pediatric care, the survey needs to restrict participants from answering subsequent questions if they answered "no" to having transitioned from pediatric to adult diabetes care.

In addition to considering a restriction on questions following the transition from pediatric to adult diabetes care, it might be wise to consider another pilot of this survey where subjects read the questions and provide feedback in order to help refine and clarify the instrument. This would be helpful in other sections of the survey, but particularly in the transition section, as it would give participants an opportunity to clarify why they picked "no" and then responded to the subsequent questions. It is possible that they are at a clinic that incorporates transition in a way that is not specifically implied in the question.

From questions regarding what makes the transition stressful and what would help ease the transition, important issues were identified including the cost of prescriptions (though this factor likely varies dramatically from person to person, as insurance plans vary and many students are still on their parents' plan), an inconvenient location, difficulty in making appointments, and unfriendly staff at a new location. Endocrinologists serving college students with T1D may use data from this question to improve their services to college students. Appointments may need to be scheduled to accommodate the college student's schedule to decrease difficulty in getting to the office. The endocrinologist or other staff members may refer the student to a healthcare seminar that provides information about insurance plans and ways to save money while managing a chronic illness. Ways to make the transition easier included having the pediatric endocrinologist refer the college student to an adult endocrinologist near the campus, having endocrinologists on campus staff, having a doctor they feel comfortable with, and having good support staff. While having an endocrinologist on staff on campus is likely unrealistic for many college campuses, the suggestion of having a referral from a pediatric endocrinologist to an adult endocrinologist near the student's campus is important.

Strengths & Limitations: Areas to Refine

Some important themes emerged from the data that may be very useful for any campus health service personnel interested in serving their students with T1D. One theme included hypoglycemia, the frequency of feeling afraid regarding sudden hypoglycemia, awareness of how to treat it, and the effect it has on students' academic performance. Another theme identified the desire and need for better awareness on campus and decreased social stigma surrounding T1D. Two other themes noted the desire and need for social events on campus, which could be facilitated by the campus health services, and helping students become connected with a local endocrinologist. The survey data indicated that there was a desire for better programming on college campuses regarding T1D.

This research has the potential to aid college campus personnel in providing better care for their students with T1D. College campus personnel that are interested in better serving their students with T1D may use a refined survey to assess those students' needs and use the results to create effective programs and offer useful accommodations on campus. This survey may be refined to use as a tool by many college campuses of any size.

With a sample size of 17 participants, the data is not generalizable to the much larger population of college students living with T1D. The survey was only made available to those who were already either members of Students with Diabetes (SWD) or receive the monthly email newsletter which limited the potential participants to those students that have regular Internet access, check their emails at least semi-regularly, and are the recipient of this particular newsletter. In order to gain a larger pool of participants, the survey could have been distributed to a larger sample size at a SWD conference or perhaps through endocrinology practices with college students.

The small sample size was due to a very low response rate. In hindsight, the researcher could have provided an incentive for completing the survey, such as an opportunity to win a small gift card, to help increase the response rate. Another possible way to increase the response rate is to have the survey available onsite at the SWD conference or other events for college students with T1D, to break down the barrier of inconvenience; students may be more likely to fill out a survey when they are already spending time at a T1D event and have some extra time to spare, as opposed to responding to an email link on their own time.

In addition, many participants skipped questions which may be due to survey length and the number of short answer questions. A survey with 33 items including questions that were not just multiple choice questions may have discouraged participants from completing the entire survey. Efforts to make the survey more concise should be made, while still maintaining adequate coverage of each topic.

With a sample size of 17, there was not much diversity among participants. An overwhelming majority of the participants were white, with only one participant being Latina. The lack of diversity in this sample size limits the ability to generalize the data to the larger population of college students living with T1D. As aforementioned, distributing the survey to a larger population may increase the diversity of the participants, enabling the data to be more generalizable.

The literature review indicated that college students with T1D are stressed and worried about hypoglycemia (low blood glucose level) affecting their academic performance, but there were also indications in the survey responses that they could be equally worried about hyperglycemia (high blood glucose level) affecting their academic performance. Because the researcher lives with T1D and frequently struggles with hypoglycemia affecting academic life, it is possible that the questions unintentionally focused heavily on hypoglycemia alone rather than including hyperglycemia as well.

College campus health service personnel may want to consider size of the campus before distributing this survey. Smaller campuses may not have enough students with

T1D to justify an outreach and education programs or awareness campaigns on campus even though the students with T1D have concerns.

Implications for Future Research

One recommendation for future research includes examining eating disorders, alcohol consumption, and roommate issues. These are aspects of life that college students living with T1D deal with regularly which may also affect their quality of life. These issues may be potential topics of interest for a social gathering or discussion group on campus.

Another area for future research is the effect of increasingly independent financial management of diabetes care for college students. The survey indicated that the majority of participants earned $10,000 or less per year, and that many handled the financial side of their T1D care fairly independently. This survey did not adequately specify the ways in which participants handle their medical expenses, which may be quite varied. Many college students are likely still on their parents' health insurance plans, but they may contribute in some way to paying their medical expenses. These college students may be stressed about budgeting, paying for their current medical expenditures, and finding jobs after graduation that have adequate health insurance for someone living with T1D. Further research on this topic may identify the potential strain or stress placed on college students and what type of financial assistance is needed. The issue of financial strain placed on college students would likely warrant an entire study of its own, as America's healthcare insurance system is very diverse and complicated, with each person's plan warranting different payment options and plans. Further research may also help specify what amount of financial pressure college students feel even when remaining on their parents' plan.

Further research may examine how endocrinologists assist college students with transitioning well to adult endocrinology care. In addition, further research may assess whether or not the transition affects academic performance when starting college and transitioning to adult endocrinology care simultaneously.

Further research may assist campus health services personnel in partnering with local clinics or advocacy groups to develop programming for college students living with T1D since students expressed concerns related to hypoglycemia. Programming may include raising self-efficacy in treating hypoglycemic episodes and the associated worries and fears regarding interference with academic performance or educating peers and professors about the signs of hypoglycemia and how to treat it. Further research may explore ways to decrease the worries and fears associated with hypoglycemia interfering with academic performance.

Due to differences in student population on college campuses, the needs of students living with T1D may differ on each campus. Larger campuses may have more resources (money, people, time, space, etc.) to implement programs and educational seminars. Smaller campuses may have more difficulty with implementing large educational seminars and may choose to focus on small social gatherings so students can feel less isolated on campus. It is possible that smaller campuses have a more supportive culture to begin with, so small social gatherings may be more a better fit for students on such a campus. Further research may identify the best ways for different sized campuses to serve their respective students living with T1D.

It is important to note that even though half of the participants feel discouraged, isolated, and misunderstood, a number of people also feel that they and their university are handling T1D well. Further research may help in understanding why this difference exists. It could be related to personal factors (e.g., some students might be more assertive, confident, or open to discussing diabetes with others) or to university factors (e.g., some institutions may do a better job of educating their faculty about the need for accommodations in general, or some institutions may have a more supportive culture due to size, location, or type of university, etc.).

The survey did not ask students if they were frustrated with having to personally raise awareness on campus. While the survey did identify what methods students used to raise awareness (primarily personal education), the survey results did not identify if this was a problem or frustration for the students. Further research may identify if students are frustrated with having to personally educate everyone they come in contact with on a college campus. If so, the importance of awareness campaigns on college campuses is further solidified, and a need has been identified for the campus health services personnel to aid students in awareness efforts and educating others on campus.

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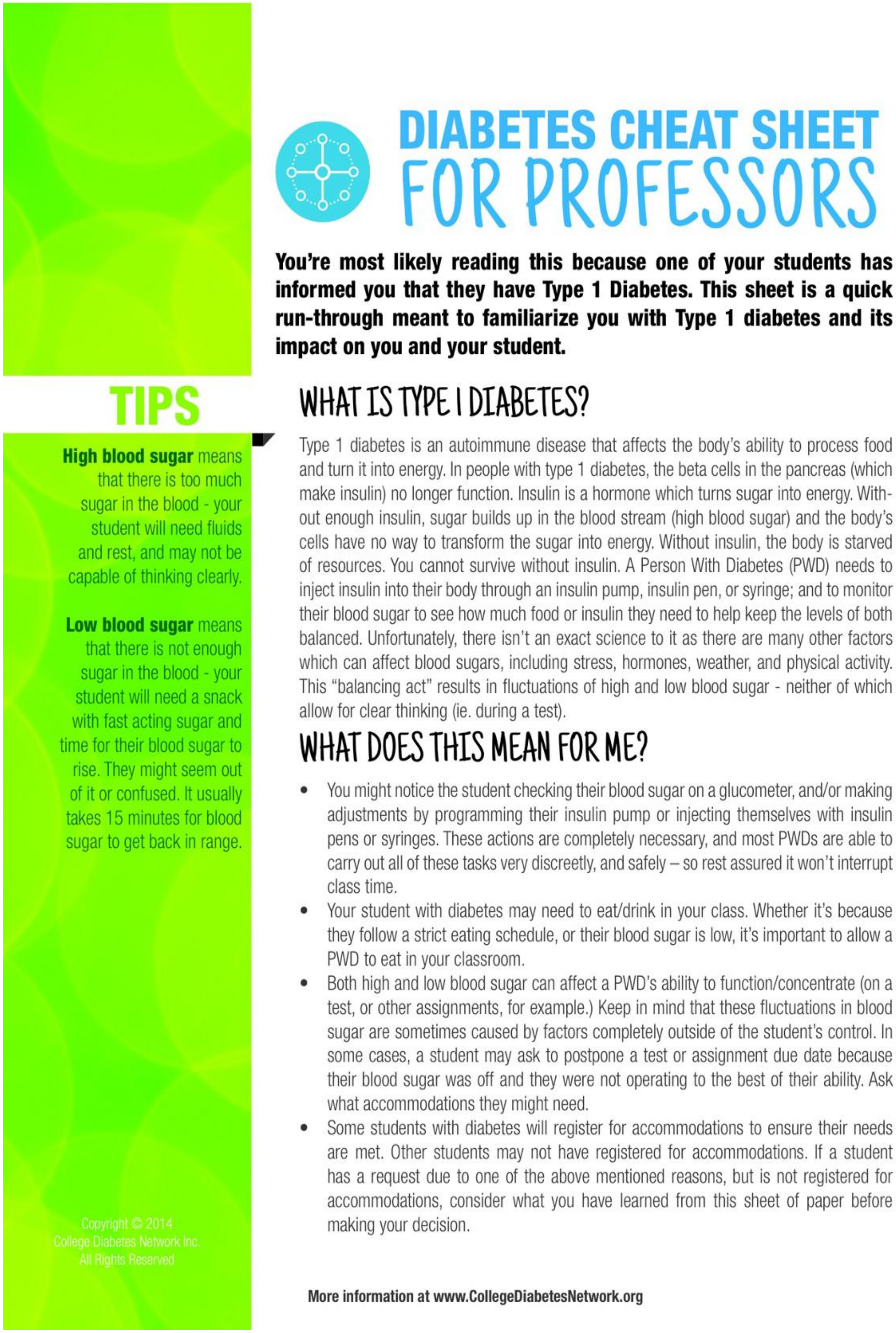
Appendix A



DIABETES CHEAT SHEET FOR PROFESSORS

You're most likely reading this because one of your students has informed you that they have Type 1 Diabetes. This sheet is a quick run-through meant to familiarize you with Type 1 diabetes and its impact on you and your student.

WHAT IS TYPE I DIABETES?

Type 1 diabetes is an autoimmune disease that affects the body's ability to process food and turn it into energy. In people with type 1 diabetes, the beta cells in the pancreas (which make insulin) no longer function. Insulin is a hormone which turns sugar into energy. Without enough insulin, sugar builds up in the blood stream (high blood sugar) and the body's cells have no way to transform the sugar into energy. Without insulin, the body is starved of resources. You cannot survive without insulin. A Person With Diabetes (PWD) needs to inject insulin into their body through an insulin pump, insulin pen, or syringe; and to monitor their blood sugar to see how much food or insulin they need to help keep the levels of both balanced. Unfortunately, there isn't an exact science to it as there are many other factors which can affect blood sugars, including stress, hormones, weather, and physical activity. This "balancing act" results in fluctuations of high and low blood sugar - neither of which allow for clear thinking (ie. during a test).

WHAT DOES THIS MEAN FOR ME?

- You might notice the student checking their blood sugar on a glucometer, and/or making adjustments by programming their insulin pump or injecting themselves with insulin pens or syringes. These actions are completely necessary, and most PWDs are able to carry out all of these tasks very discreetly, and safely – so rest assured it won't interrupt class time.
- Your student with diabetes may need to eat/drink in your class. Whether it's because they follow a strict eating schedule, or their blood sugar is low, it's important to allow a PWD to eat in your classroom.
- Both high and low blood sugar can affect a PWD's ability to function/concentrate (on a test, or other assignments, for example.) Keep in mind that these fluctuations in blood sugar are sometimes caused by factors completely outside of the student's control. In some cases, a student may ask to postpone a test or assignment due date because their blood sugar was off and they were not operating to the best of their ability. Ask what accommodations they might need.
- Some students with diabetes will register for accommodations to ensure their needs are met. Other students may not have registered for accommodations. If a student has a request due to one of the above mentioned reasons, but is not registered for accommodations, consider what you have learned from this sheet of paper before making your decision.

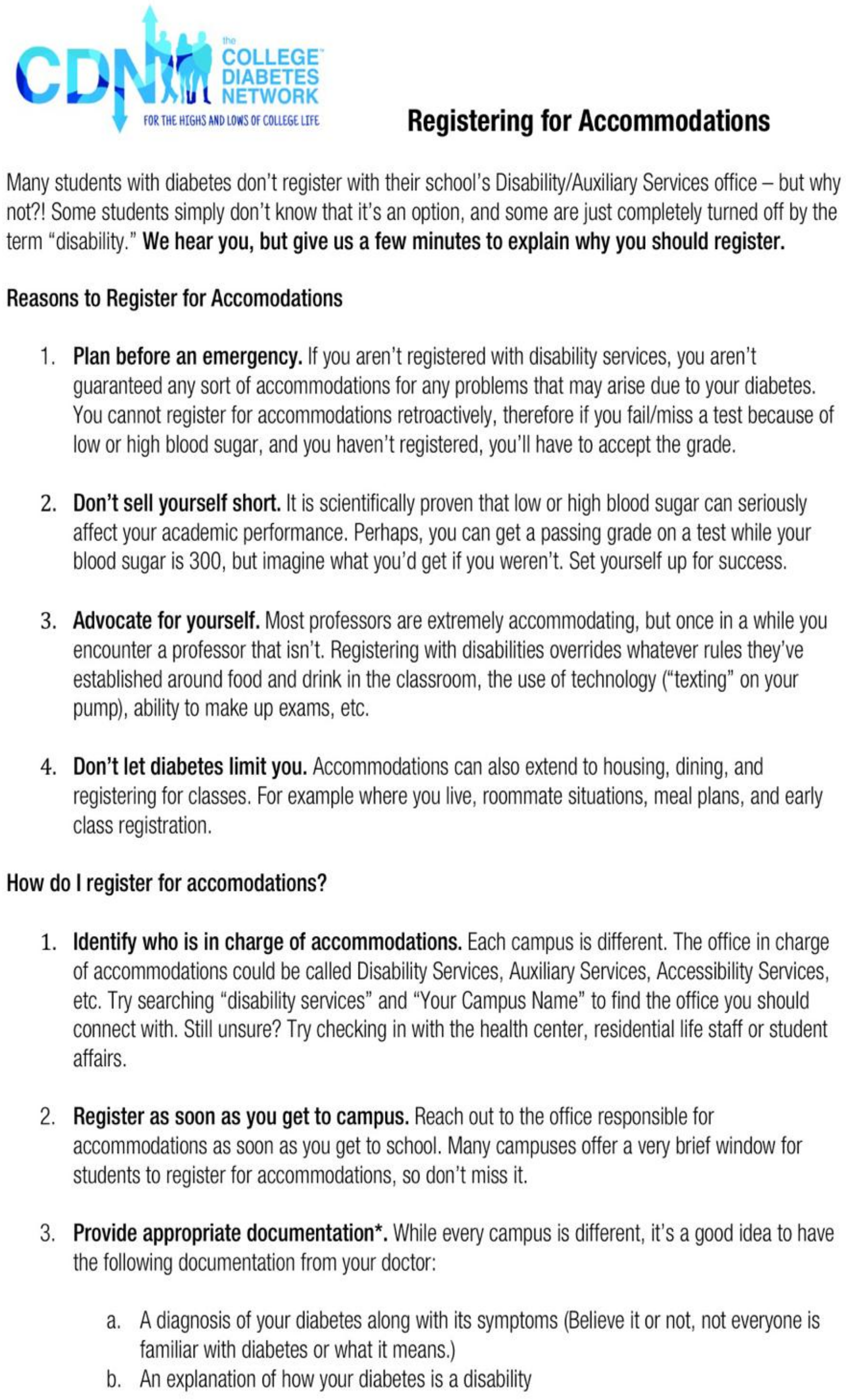
TIPS

High blood sugar means that there is too much sugar in the blood - your student will need fluids and rest, and may not be capable of thinking clearly.

Low blood sugar means that there is not enough sugar in the blood - your student will need a snack with fast acting sugar and time for their blood sugar to rise. They might seem out of it or confused. It usually takes 15 minutes for blood sugar to get back in range.

More information at www.CollegeDiabetesNetwork.org

Appendix B



the COLLEGE DIABETES NETWORK

FOR THE HIGHS AND LOWS OF COLLEGE LIFE

Registering for Accommodations

Many students with diabetes don't register with their school's Disability/Auxiliary Services office – but why not?! Some students simply don't know that it's an option, and some are just completely turned off by the term "disability." **We hear you, but give us a few minutes to explain why you should register.**

Reasons to Register for Accomodations

1. **Plan before an emergency.** If you aren't registered with disability services, you aren't guaranteed any sort of accommodations for any problems that may arise due to your diabetes. You cannot register for accommodations retroactively, therefore if you fail/miss a test because of low or high blood sugar, and you haven't registered, you'll have to accept the grade.

2. **Don't sell yourself short.** It is scientifically proven that low or high blood sugar can seriously affect your academic performance. Perhaps, you can get a passing grade on a test while your blood sugar is 300, but imagine what you'd get if you weren't. Set yourself up for success.

3. **Advocate for yourself.** Most professors are extremely accommodating, but once in a while you encounter a professor that isn't. Registering with disabilities overrides whatever rules they've established around food and drink in the classroom, the use of technology ("texting" on your pump), ability to make up exams, etc.

4. **Don't let diabetes limit you.** Accommodations can also extend to housing, dining, and registering for classes. For example where you live, roommate situations, meal plans, and early class registration.

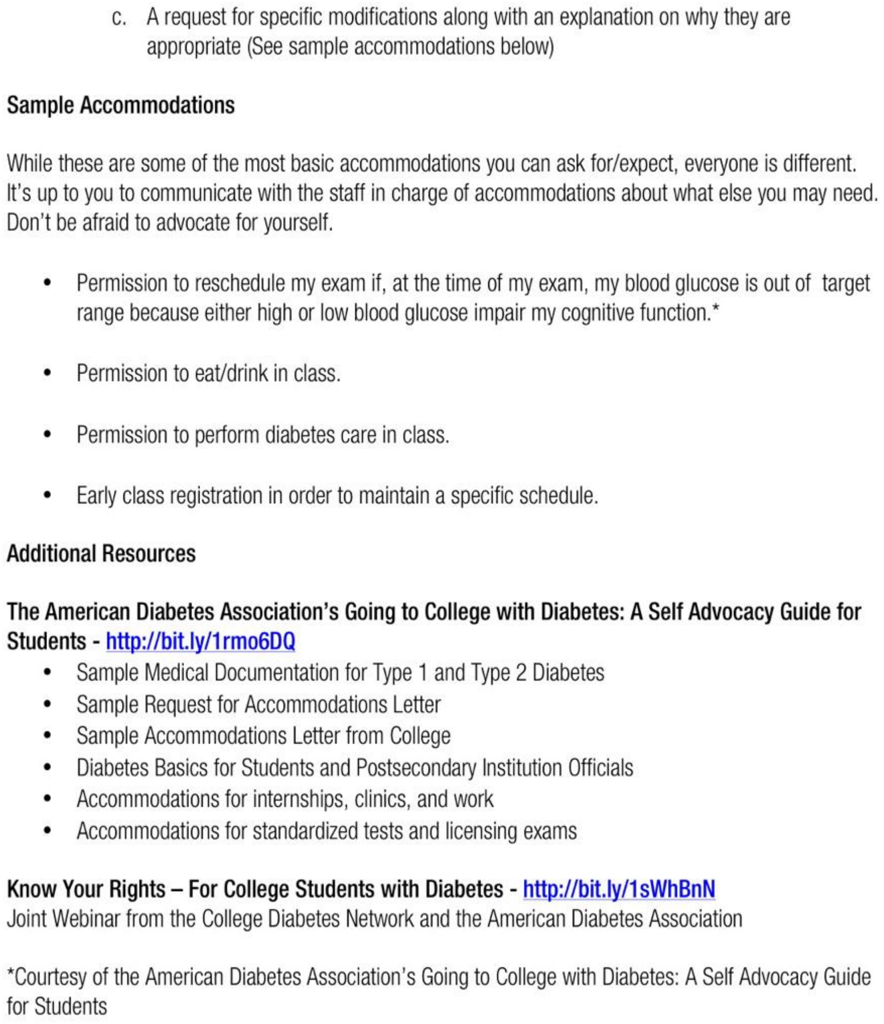
How do I register for accomodations?

1. **Identify who is in charge of accommodations.** Each campus is different. The office in charge of accommodations could be called Disability Services, Auxiliary Services, Accessibility Services, etc. Try searching "disability services" and "Your Campus Name" to find the office you should connect with. Still unsure? Try checking in with the health center, residential life staff or student affairs.

2. **Register as soon as you get to campus.** Reach out to the office responsible for accommodations as soon as you get to school. Many campuses offer a very brief window for students to register for accommodations, so don't miss it.

3. **Provide appropriate documentation*.** While every campus is different, it's a good idea to have the following documentation from your doctor:

    a. A diagnosis of your diabetes along with its symptoms (Believe it or not, not everyone is familiar with diabetes or what it means.)
    b. An explanation of how your diabetes is a disability



c. A request for specific modifications along with an explanation on why they are appropriate (See sample accommodations below)

Sample Accommodations

While these are some of the most basic accommodations you can ask for/expect, everyone is different. It's up to you to communicate with the staff in charge of accommodations about what else you may need. Don't be afraid to advocate for yourself.

- Permission to reschedule my exam if, at the time of my exam, my blood glucose is out of target range because either high or low blood glucose impair my cognitive function.*

- Permission to eat/drink in class.

- Permission to perform diabetes care in class.

- Early class registration in order to maintain a specific schedule.

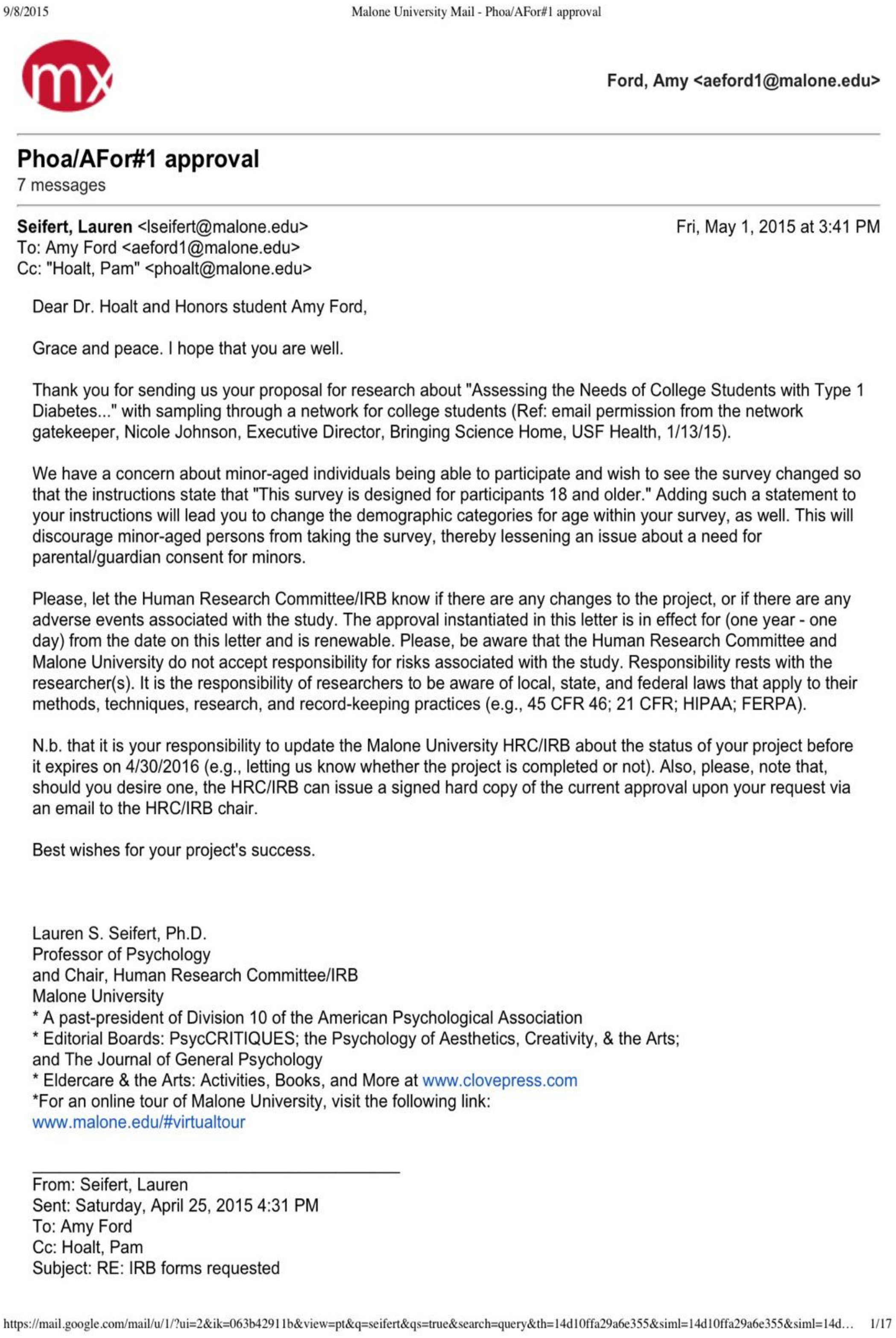
Additional Resources

The American Diabetes Association's Going to College with Diabetes: A Self Advocacy Guide for Students - http://bit.ly/1rmo6DQ
- Sample Medical Documentation for Type 1 and Type 2 Diabetes
- Sample Request for Accommodations Letter
- Sample Accommodations Letter from College
- Diabetes Basics for Students and Postsecondary Institution Officials
- Accommodations for internships, clinics, and work
- Accommodations for standardized tests and licensing exams

Know Your Rights – For College Students with Diabetes - http://bit.ly/1sWhBnN
Joint Webinar from the College Diabetes Network and the American Diabetes Association

*Courtesy of the American Diabetes Association's Going to College with Diabetes: A Self Advocacy Guide for Students

Appendix C



9/8/2015 Malone University Mail - Phoa/AFor#1 approval

Ford, Amy <aeford1@malone.edu>

Phoa/AFor#1 approval

7 messages

Seifert, Lauren <lseifert@malone.edu> Fri, May 1, 2015 at 3:41 PM
To: Amy Ford <aeford1@malone.edu>
Cc: "Hoalt, Pam" <phoalt@malone.edu>

Dear Dr. Hoalt and Honors student Amy Ford,

Grace and peace. I hope that you are well.

Thank you for sending us your proposal for research about "Assessing the Needs of College Students with Type 1 Diabetes..." with sampling through a network for college students (Ref: email permission from the network gatekeeper, Nicole Johnson, Executive Director, Bringing Science Home, USF Health, 1/13/15).

We have a concern about minor-aged individuals being able to participate and wish to see the survey changed so that the instructions state that "This survey is designed for participants 18 and older." Adding such a statement to your instructions will lead you to change the demographic categories for age within your survey, as well. This will discourage minor-aged persons from taking the survey, thereby lessening an issue about a need for parental/guardian consent for minors.

Please, let the Human Research Committee/IRB know if there are any changes to the project, or if there are any adverse events associated with the study. The approval instantiated in this letter is in effect for (one year - one day) from the date on this letter and is renewable. Please, be aware that the Human Research Committee and Malone University do not accept responsibility for risks associated with the study. Responsibility rests with the researcher(s). It is the responsibility of researchers to be aware of local, state, and federal laws that apply to their methods, techniques, research, and record-keeping practices (e.g., 45 CFR 46; 21 CFR; HIPAA; FERPA).

N.b. that it is your responsibility to update the Malone University HRC/IRB about the status of your project before it expires on 4/30/2016 (e.g., letting us know whether the project is completed or not). Also, please, note that, should you desire one, the HRC/IRB can issue a signed hard copy of the current approval upon your request via an email to the HRC/IRB chair.

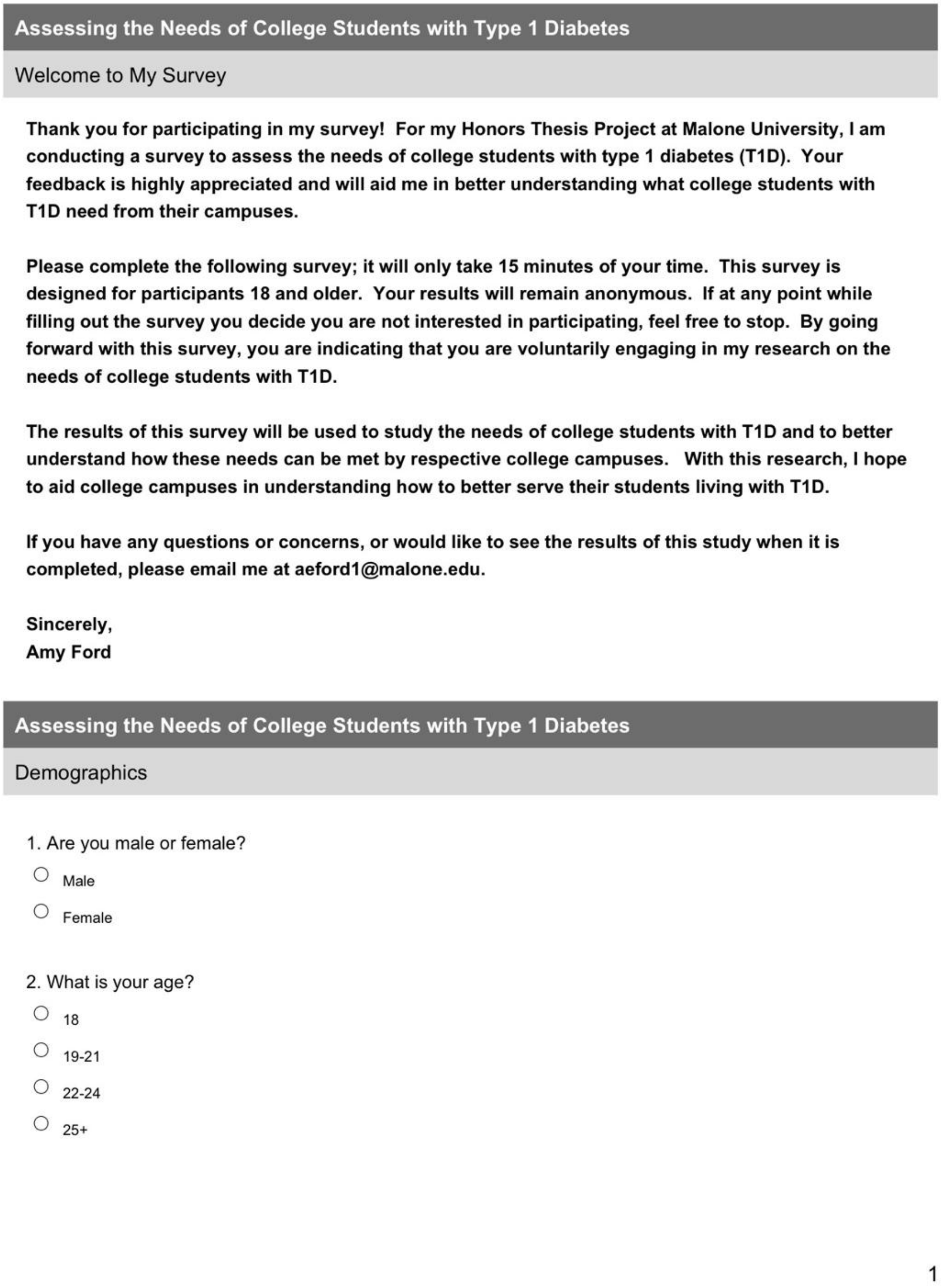
Best wishes for your project's success.

Lauren S. Seifert, Ph.D.
Professor of Psychology
and Chair, Human Research Committee/IRB
Malone University
* A past-president of Division 10 of the American Psychological Association
* Editorial Boards: PsycCRITIQUES; the Psychology of Aesthetics, Creativity, & the Arts;
and The Journal of General Psychology
* Eldercare & the Arts: Activities, Books, and More at www.clovepress.com
*For an online tour of Malone University, visit the following link:
www.malone.edu/#virtualtour

From: Seifert, Lauren
Sent: Saturday, April 25, 2015 4:31 PM
To: Amy Ford
Cc: Hoalt, Pam
Subject: RE: IRB forms requested

https://mail.google.com/mail/u/1/?ui=2&ik=063b42911b&view=pt&q=seifert&qs=true&search=query&th=14d10ffa29a6e355&siml=14d10ffa29a6e355&siml=14d… 1/17

Appendix D



Assessing the Needs of College Students with Type 1 Diabetes

Welcome to My Survey

Thank you for participating in my survey! For my Honors Thesis Project at Malone University, I am conducting a survey to assess the needs of college students with type 1 diabetes (T1D). Your feedback is highly appreciated and will aid me in better understanding what college students with T1D need from their campuses.

Please complete the following survey; it will only take 15 minutes of your time. This survey is designed for participants 18 and older. Your results will remain anonymous. If at any point while filling out the survey you decide you are not interested in participating, feel free to stop. By going forward with this survey, you are indicating that you are voluntarily engaging in my research on the needs of college students with T1D.

The results of this survey will be used to study the needs of college students with T1D and to better understand how these needs can be met by respective college campuses. With this research, I hope to aid college campuses in understanding how to better serve their students living with T1D.

If you have any questions or concerns, or would like to see the results of this study when it is completed, please email me at aeford1@malone.edu.

Sincerely,
Amy Ford

Assessing the Needs of College Students with Type 1 Diabetes

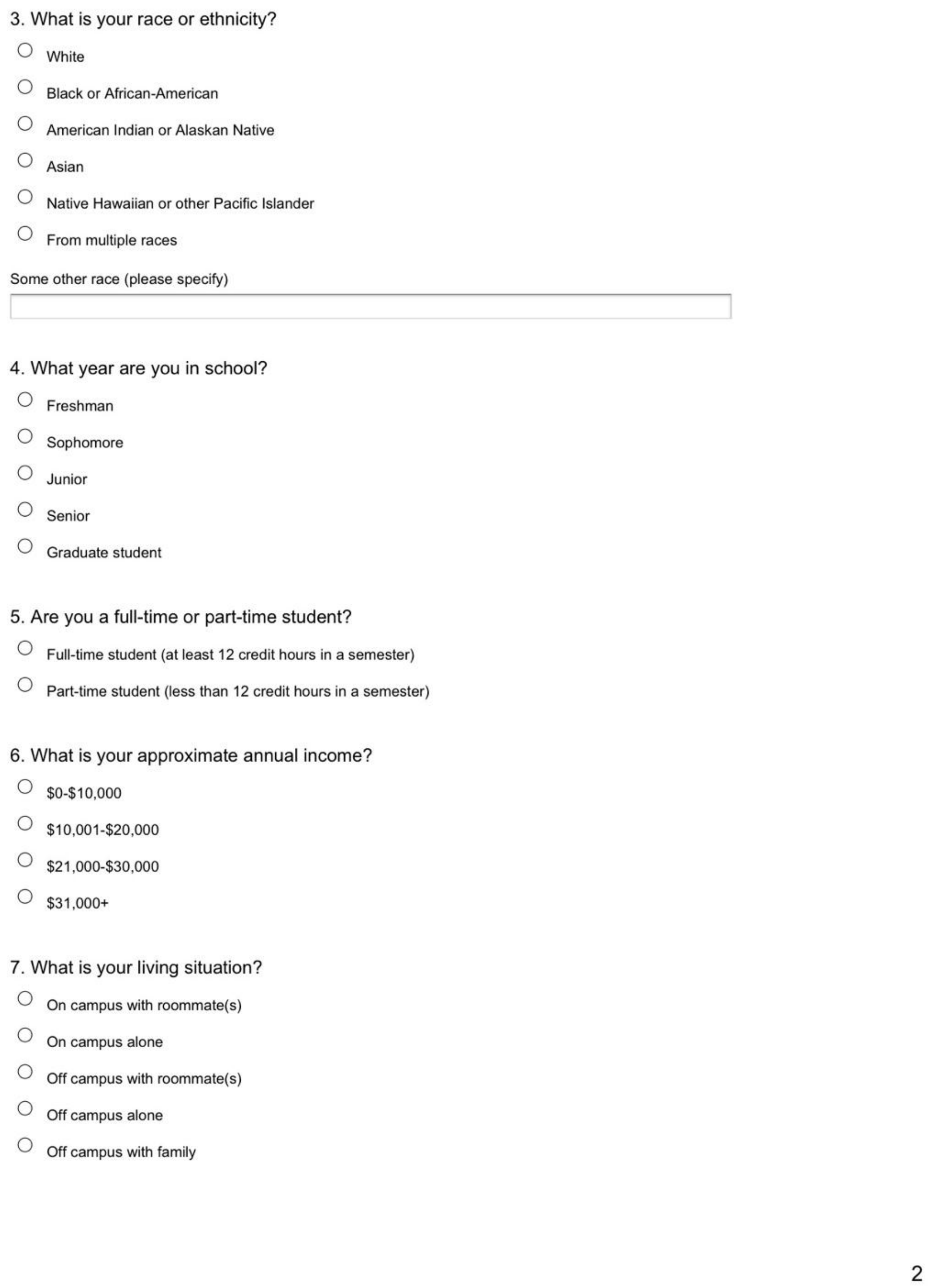
Demographics

1. Are you male or female?

○ Male
○ Female

2. What is your age?

○ 18
○ 19-21
○ 22-24
○ 25+



3. What is your race or ethnicity?

○ White
○ Black or African-American
○ American Indian or Alaskan Native
○ Asian
○ Native Hawaiian or other Pacific Islander
○ From multiple races

Some other race (please specify)

4. What year are you in school?

○ Freshman
○ Sophomore
○ Junior
○ Senior
○ Graduate student

5. Are you a full-time or part-time student?

○ Full-time student (at least 12 credit hours in a semester)
○ Part-time student (less than 12 credit hours in a semester)

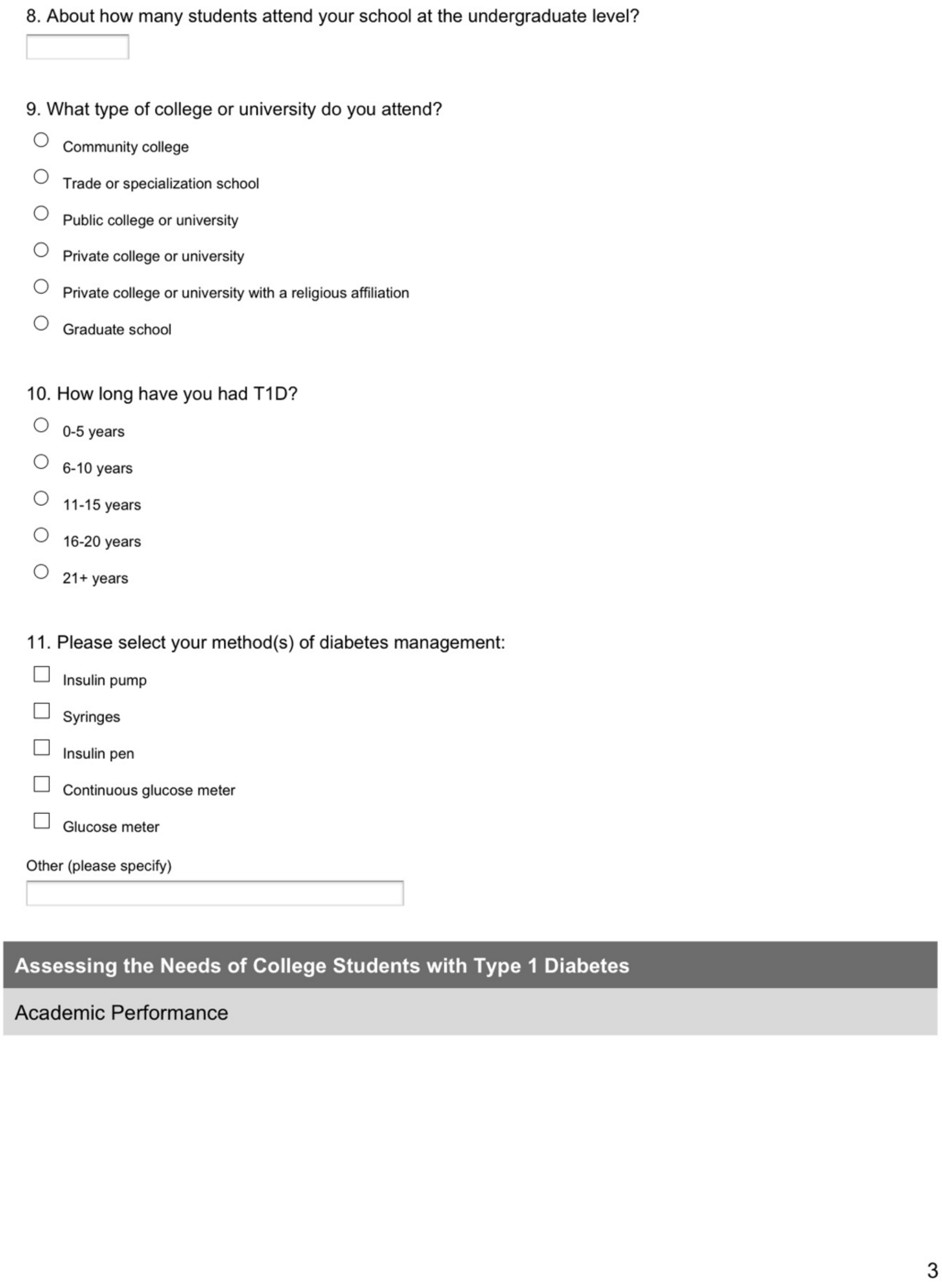
6. What is your approximate annual income?

○ $0-$10,000
○ $10,001-$20,000
○ $21,000-$30,000
○ $31,000+

7. What is your living situation?

○ On campus with roommate(s)
○ On campus alone
○ Off campus with roommate(s)
○ Off campus alone
○ Off campus with family

2



8. About how many students attend your school at the undergraduate level?

9. What type of college or university do you attend?

○ Community college
○ Trade or specialization school
○ Public college or university
○ Private college or university
○ Private college or university with a religious affiliation
○ Graduate school

10. How long have you had T1D?

○ 0-5 years
○ 6-10 years
○ 11-15 years
○ 16-20 years
○ 21+ years

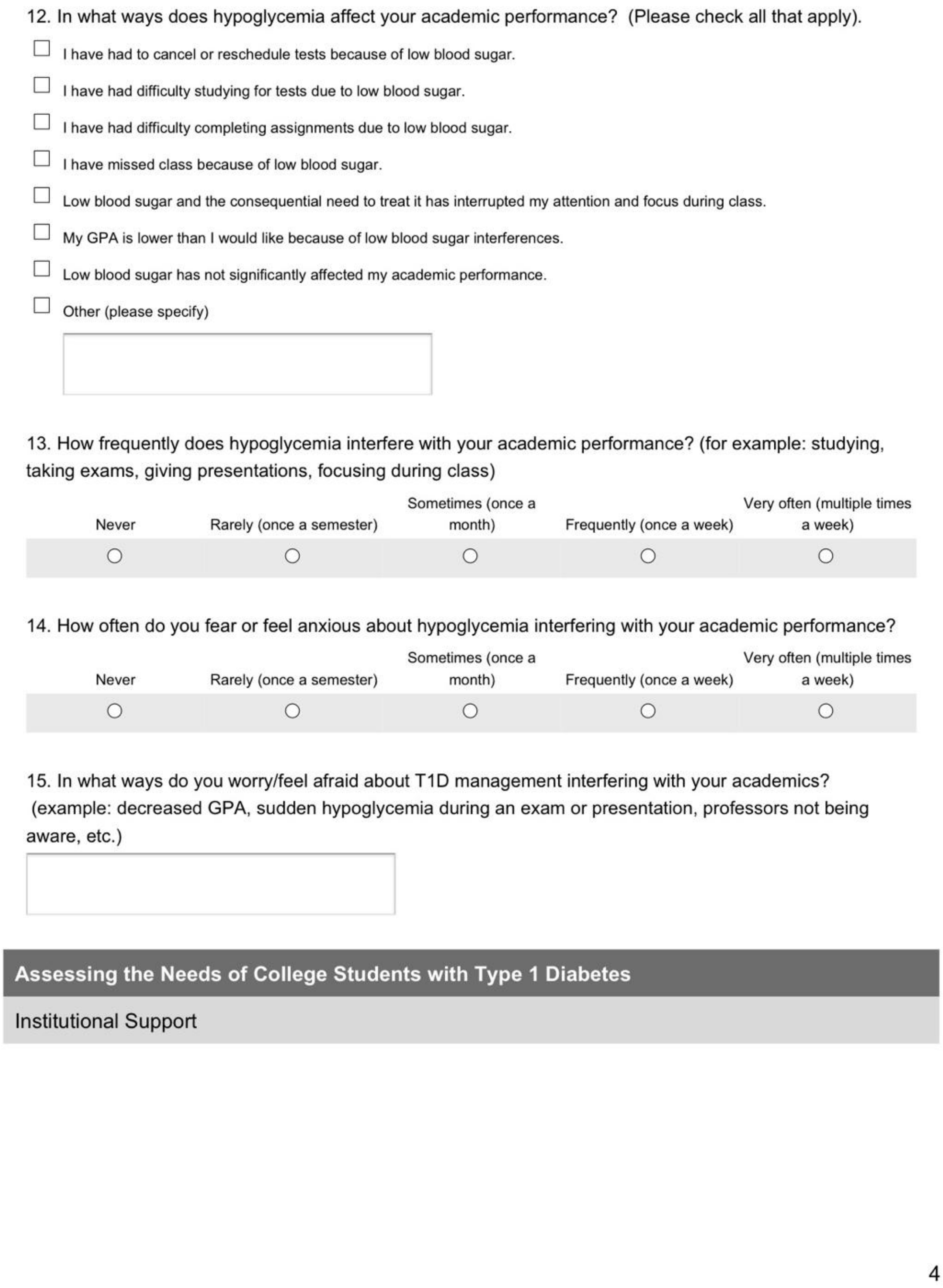
11. Please select your method(s) of diabetes management:

☐ Insulin pump
☐ Syringes
☐ Insulin pen
☐ Continuous glucose meter
☐ Glucose meter

Other (please specify)

Assessing the Needs of College Students with Type 1 Diabetes

Academic Performance



12. In what ways does hypoglycemia affect your academic performance? (Please check all that apply).

☐ I have had to cancel or reschedule tests because of low blood sugar.
☐ I have had difficulty studying for tests due to low blood sugar.
☐ I have had difficulty completing assignments due to low blood sugar.
☐ I have missed class because of low blood sugar.
☐ Low blood sugar and the consequential need to treat it has interrupted my attention and focus during class.
☐ My GPA is lower than I would like because of low blood sugar interferences.
☐ Low blood sugar has not significantly affected my academic performance.
☐ Other (please specify)

13. How frequently does hypoglycemia interfere with your academic performance? (for example: studying, taking exams, giving presentations, focusing during class)

Never	Rarely (once a semester)	Sometimes (once a month)	Frequently (once a week)	Very often (multiple times a week)
○	○	○	○	○

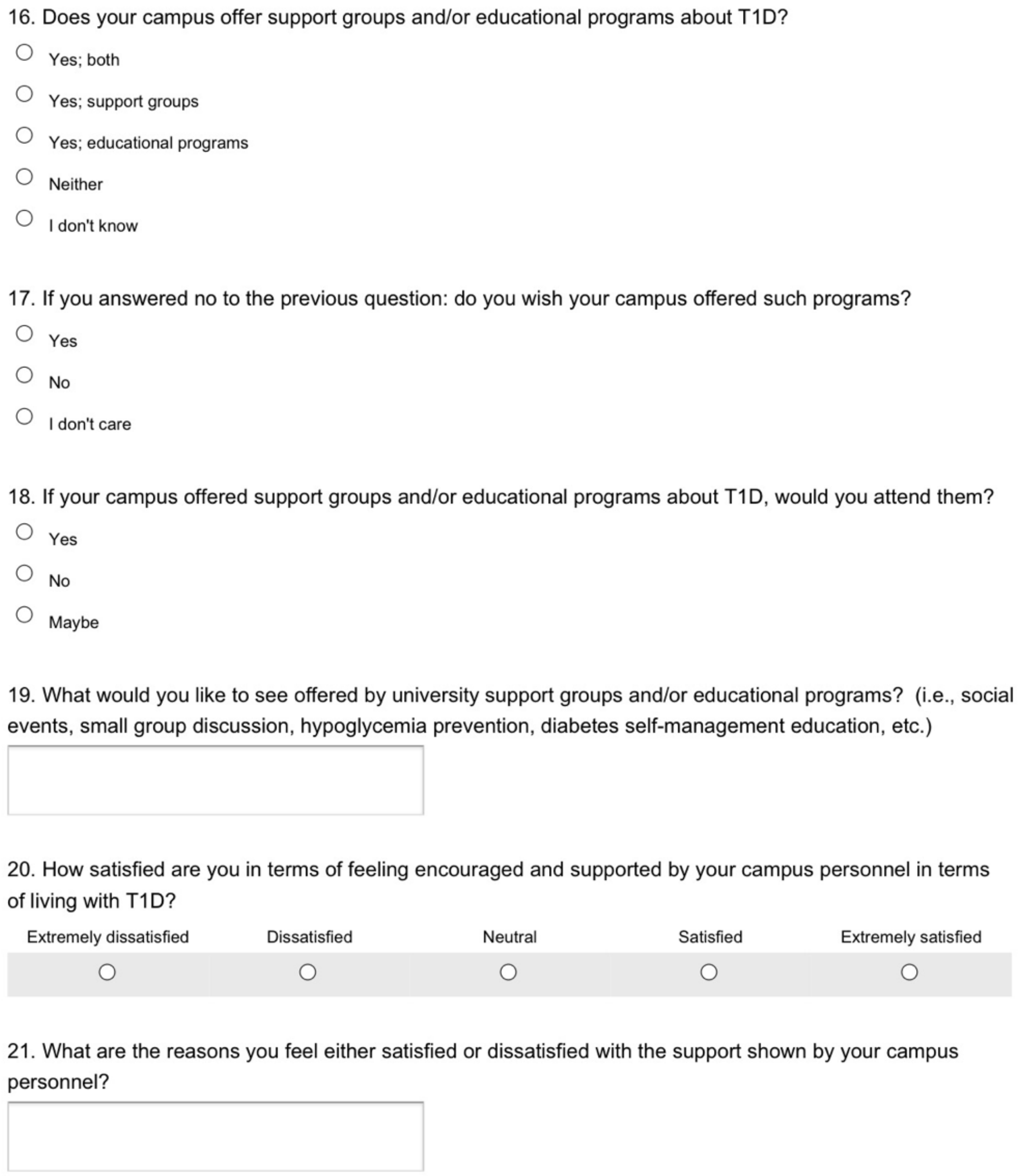
14. How often do you fear or feel anxious about hypoglycemia interfering with your academic performance?

Never	Rarely (once a semester)	Sometimes (once a month)	Frequently (once a week)	Very often (multiple times a week)
○	○	○	○	○

15. In what ways do you worry/feel afraid about T1D management interfering with your academics? (example: decreased GPA, sudden hypoglycemia during an exam or presentation, professors not being aware, etc.)

Assessing the Needs of College Students with Type 1 Diabetes

Institutional Support



16. Does your campus offer support groups and/or educational programs about T1D?

- ○ Yes; both
- ○ Yes; support groups
- ○ Yes; educational programs
- ○ Neither
- ○ I don't know

17. If you answered no to the previous question: do you wish your campus offered such programs?

- ○ Yes
- ○ No
- ○ I don't care

18. If your campus offered support groups and/or educational programs about T1D, would you attend them?

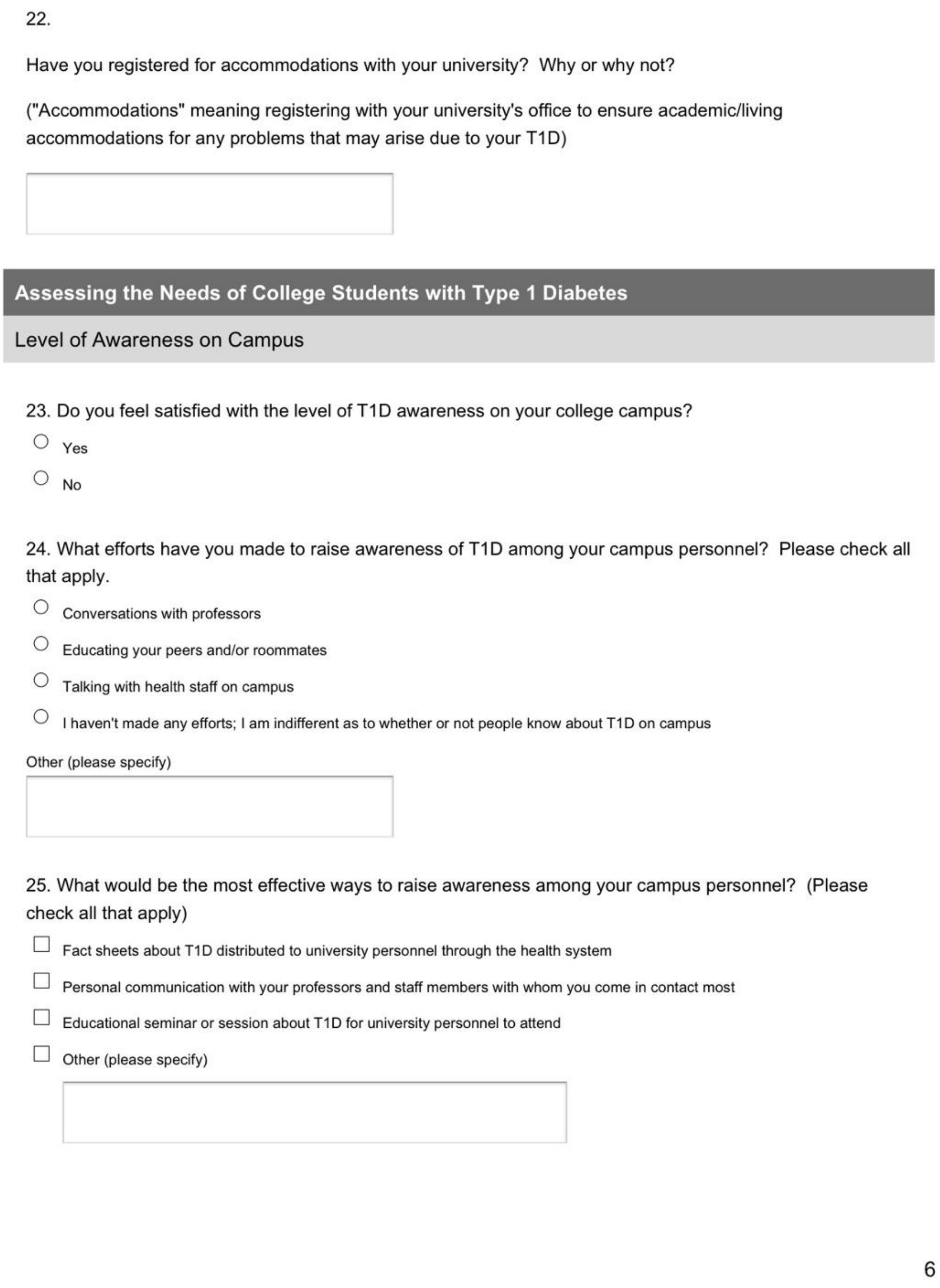
- ○ Yes
- ○ No
- ○ Maybe

19. What would you like to see offered by university support groups and/or educational programs? (i.e., social events, small group discussion, hypoglycemia prevention, diabetes self-management education, etc.)

20. How satisfied are you in terms of feeling encouraged and supported by your campus personnel in terms of living with T1D?

Extremely dissatisfied	Dissatisfied	Neutral	Satisfied	Extremely satisfied
○	○	○	○	○

21. What are the reasons you feel either satisfied or dissatisfied with the support shown by your campus personnel?



22.

Have you registered for accommodations with your university? Why or why not?

("Accommodations" meaning registering with your university's office to ensure academic/living accommodations for any problems that may arise due to your T1D)

Assessing the Needs of College Students with Type 1 Diabetes

Level of Awareness on Campus

23. Do you feel satisfied with the level of T1D awareness on your college campus?

○ Yes

○ No

24. What efforts have you made to raise awareness of T1D among your campus personnel? Please check all that apply.

○ Conversations with professors

○ Educating your peers and/or roommates

○ Talking with health staff on campus

○ I haven't made any efforts; I am indifferent as to whether or not people know about T1D on campus

Other (please specify)

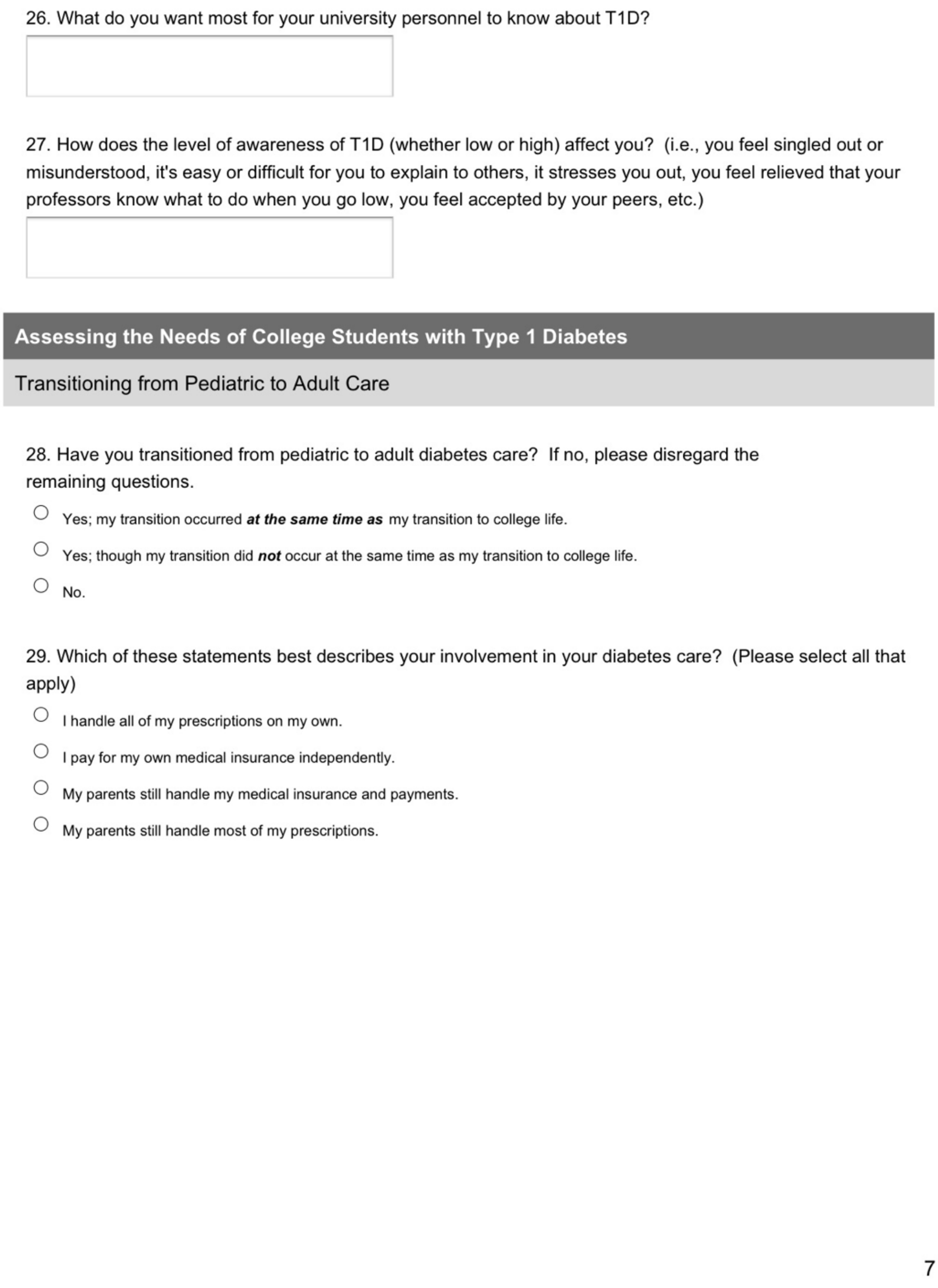
25. What would be the most effective ways to raise awareness among your campus personnel? (Please check all that apply)

☐ Fact sheets about T1D distributed to university personnel through the health system

☐ Personal communication with your professors and staff members with whom you come in contact most

☐ Educational seminar or session about T1D for university personnel to attend

☐ Other (please specify)



26. What do you want most for your university personnel to know about T1D?

27. How does the level of awareness of T1D (whether low or high) affect you? (i.e., you feel singled out or misunderstood, it's easy or difficult for you to explain to others, it stresses you out, you feel relieved that your professors know what to do when you go low, you feel accepted by your peers, etc.)

Assessing the Needs of College Students with Type 1 Diabetes

Transitioning from Pediatric to Adult Care

28. Have you transitioned from pediatric to adult diabetes care? If no, please disregard the remaining questions.

○ Yes; my transition occurred ***at the same time as*** my transition to college life.

○ Yes; though my transition did ***not*** occur at the same time as my transition to college life.

○ No.

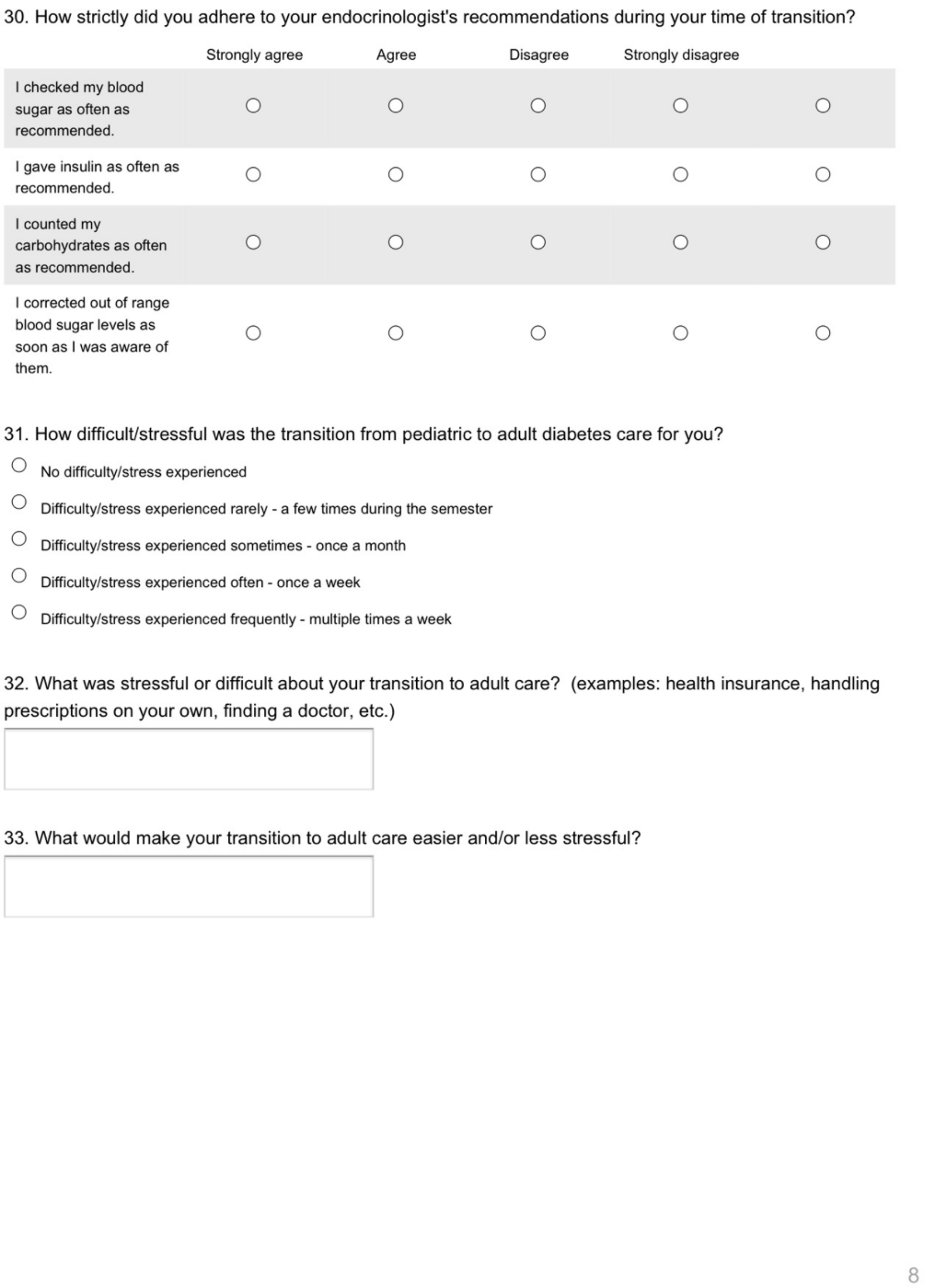
29. Which of these statements best describes your involvement in your diabetes care? (Please select all that apply)

○ I handle all of my prescriptions on my own.

○ I pay for my own medical insurance independently.

○ My parents still handle my medical insurance and payments.

○ My parents still handle most of my prescriptions.



30. How strictly did you adhere to your endocrinologist's recommendations during your time of transition?

	Strongly agree	Agree	Disagree	Strongly disagree	
I checked my blood sugar as often as recommended.	○	○	○	○	○
I gave insulin as often as recommended.	○	○	○	○	○
I counted my carbohydrates as often as recommended.	○	○	○	○	○
I corrected out of range blood sugar levels as soon as I was aware of them.	○	○	○	○	○

31. How difficult/stressful was the transition from pediatric to adult diabetes care for you?

○ No difficulty/stress experienced

○ Difficulty/stress experienced rarely - a few times during the semester

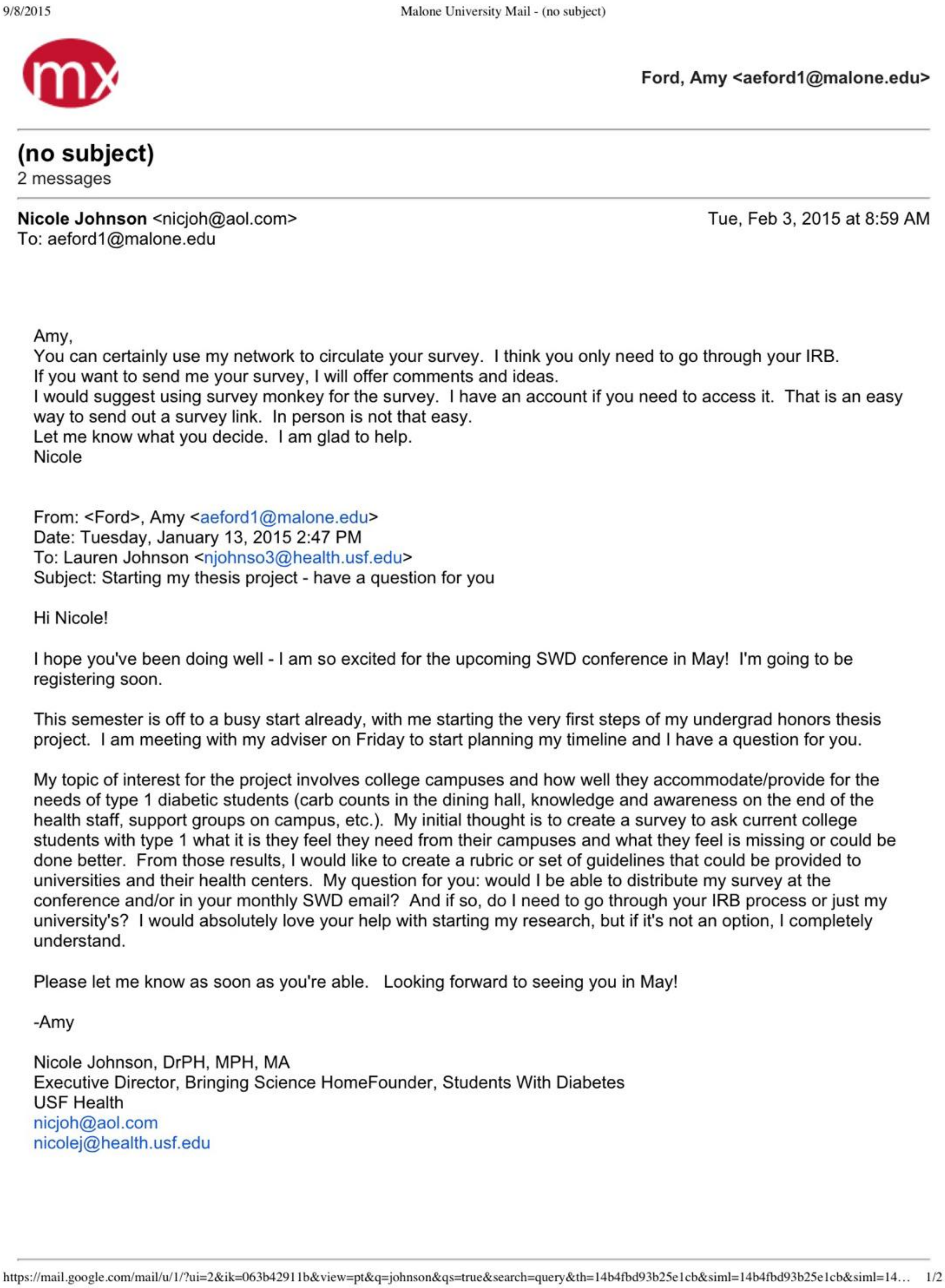
○ Difficulty/stress experienced sometimes - once a month

○ Difficulty/stress experienced often - once a week

○ Difficulty/stress experienced frequently - multiple times a week

32. What was stressful or difficult about your transition to adult care? (examples: health insurance, handling prescriptions on your own, finding a doctor, etc.)

33. What would make your transition to adult care easier and/or less stressful?



Ford, Amy <aeford1@malone.edu>

(no subject)

2 messages

Nicole Johnson <nicjoh@aol.com> Tue, Feb 3, 2015 at 8:59 AM
To: aeford1@malone.edu

Amy,
You can certainly use my network to circulate your survey. I think you only need to go through your IRB.
If you want to send me your survey, I will offer comments and ideas.
I would suggest using survey monkey for the survey. I have an account if you need to access it. That is an easy way to send out a survey link. In person is not that easy.
Let me know what you decide. I am glad to help.
Nicole

From: <Ford>, Amy <aeford1@malone.edu>
Date: Tuesday, January 13, 2015 2:47 PM
To: Lauren Johnson <njohnso3@health.usf.edu>
Subject: Starting my thesis project - have a question for you

Hi Nicole!

I hope you've been doing well - I am so excited for the upcoming SWD conference in May! I'm going to be registering soon.

This semester is off to a busy start already, with me starting the very first steps of my undergrad honors thesis project. I am meeting with my adviser on Friday to start planning my timeline and I have a question for you.

My topic of interest for the project involves college campuses and how well they accommodate/provide for the needs of type 1 diabetic students (carb counts in the dining hall, knowledge and awareness on the end of the health staff, support groups on campus, etc.). My initial thought is to create a survey to ask current college students with type 1 what it is they feel they need from their campuses and what they feel is missing or could be done better. From those results, I would like to create a rubric or set of guidelines that could be provided to universities and their health centers. My question for you: would I be able to distribute my survey at the conference and/or in your monthly SWD email? And if so, do I need to go through your IRB process or just my university's? I would absolutely love your help with starting my research, but if it's not an option, I completely understand.

Please let me know as soon as you're able. Looking forward to seeing you in May!

-Amy

Nicole Johnson, DrPH, MPH, MA
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