

A NEEDS ASSESSMENT FOR ADOLESCENTS WITH TYPE 1 DIABETES

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy

by

Crystal Cartier, Alivia L. Channon, Jamie M. Roddis, and Alyssa N. Sacramento

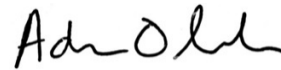
Thesis advisor: Adrianna Olch OTR/L

June 2019

© 2019
Crystal Cartier, Alivia L. Channon, Jamie M. Roddis, and Alyssa N. Sacramento
Thesis Advisor: Adrianna Olch, MS, OTR/L
ALL RIGHTS RESERVED

Certification of Approval


I certify that I have read A Needs Assessment for Adolescents with Type I Diabetes by Crystal Cartier, Alivia L. Channon, Jamie M. Roddis; and Alyssa N. Sacramento, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.



Adrianna Olch, MS, OTR/L

Instructor of Occupational Therapy

ACCEPTED



Vikas Sharma, OTD, OTR/L

Program Director, Master of Science in Occupational Therapy

Abstract

Purpose: The purpose of this study was to conduct a needs assessment for adolescents with type 1 diabetes (T1D) in order to determine a preferred mode of media and educational material currently desired. To assess the education topics and modes of education that will help adolescents stay motivated in adhering to the treatment of their condition.

Methods: An online survey platform called eSurvey Creator® was used to collect information from adolescents with T1D. Participants were informed of the survey through various social media outlets as well as word of mouth. Data was analyzed using summary statistics and SPSS for the quantitative data. Themes were collectively analyzed and determined by the research team for qualitative data.

Results: A total of 10 participants (6 females, 4 males) completed the survey. Adolescents preferred direct verbal education and YouTube as a primary source of education. They needed the most help with weight management and attending social events.

Conclusion: The findings indicate that social media along with direct verbal education are the preferred modes of education for diabetes self-management. This should be considered by the occupational therapist when developing an intervention plan for this population.

Table of Contents

List of Tables.....	vii
List of Figures.....	viii
Statement of the Problem.....	1
Need for Intervention in the Type 1 Diabetes Community.....	1
Role of Occupational Therapy.....	2
Need for Additional Research.....	2
Literature Review.....	3
Type 1 Diabetes Overview.....	3
Type 1 Diabetes in Adolescents.....	4
Self-Regulation Improves Overall Health and Well-Being.....	6
Promising Interventions with Limits to Longevity.....	7
Intrinsic vs Extrinsic Motivators.....	11
Statement of Purpose.....	15
Theoretical Framework.....	16
Model of Human Occupation.....	16
Bandura’s Social Learning Theory.....	18
Methodology.....	19
Method.....	19
Design.....	19
Advantages of Using a Survey.....	20
Target Population.....	21
Data Analysis.....	21

Results.....22

Demographics22

Social Media22

Education23

Most preferred type of education23

Least preferred type of education24

T1D Self-Management.....24

Areas of Self-Care.....25

Areas Education would be Beneficial25

Preferred Platforms of Social Media.....26

Discussion26

Favorable Education Forms26

Unfavorable Education Forms27

Future Education28

Limitations of the Project.....29

Ethical and Legal Considerations30

Conclusion32

References.....35

Appendix A: Research Participant’s Bill of Rights.....42

Appendix B: Permission Form43

Appendix C: Assent Form.....45

Appendix D: Needs Assessment Questionnaire- Adolescents with T1D.....47

List of Tables

Table 1: Demographics of Adolescents with T1D Participating in Survey	40
---	----

List of Figures

Figure 1: Social Media.....41

Figure 2: Education.....41

A Needs Assessment for Adolescents with Type 1 Diabetes

Statement of the Problem

Need for Intervention in the Type 1 Diabetes Community

Diabetes is one of the most common chronic pediatric illnesses in the United States affecting 208,000 people under the age of 20 (Centers for Disease Control and Prevention [CDC], 2017). Type 1 diabetes (T1D) is a lifelong disease, accounting for about 5% of all diagnosed cases of diabetes, affecting approximately 1.5 million people; the incidence rate of those diagnosed has been progressively increasing throughout most regions of the world including Asia, Europe, and North America (DIAMOND Project Group, 2006). In the past 20 years, some regions have increased by over 70% for children under the age of 5, predicting the number of new cases to double by 2020 (Lipman et al., 2013). Diabetes increases the risk of heart attack and death by 1.8 times that of someone without the disease, and is the leading cause of kidney failure, lower limb amputation, and adult-onset blindness (Office of Disease Prevention and Health Promotion, n.d.). Complications from diabetes are typical, and more severe in people who poorly manage their illness (American Diabetes Association, n.d.). Additionally, billions of healthcare dollars are spent treating the disease each year (Diabetes Research Institute Foundation, n.d.). Therefore, it is necessary to improve diabetes control through the practice of better management and prevention in order to improve the health and quality of life of young people with diabetes. Current research recognizes the significant impact the disease has on adolescents as they become more independent in their self-care management; however, studies have not found the best way to educate adolescents about the importance of managing their diabetes.

Role of Occupational Therapy

Adolescents, ages 12-17, living with T1D find that their daily roles and routines are often compromised. While adolescents with T1D have the drive to do something at first, they usually cannot because of the diagnosis, current environment, or the fear of not meeting societal roles (Ye et al., 2017). Through occupational therapy, practitioners can promote healthy lifestyle changes through their understanding of physical and mental health chronic disease management and their sophisticated analysis of performance patterns. As members of a diabetes team, occupational therapy practitioners are skilled in addressing the physical, cognitive, and psychosocial aspects of diabetes-related self-care that support engagement in occupations (Sokol-McKay, 2011). Staying consistent with the AOTA/AOTF research agenda, this project contributes to basic research in terms of examining intrinsic and extrinsic mechanisms in the lives of adolescents with T1D and how they support performance in daily life. By focusing specifically on adolescents with T1D we involve a priority population who is susceptible to future health problems. Learning about the most effective treatments will contribute to promoting positive change and allow occupational therapists to use a client-centered approach to their treatment plans.

Need for Additional Research

Research on successful self-management among adolescents with T1D is mixed. This project contributes to health services research by determining the needs of the adolescents so that information can be utilized to design and implement appropriate education through relevant modes of media. Since diagnosis typically occurs at a young age, parents are given the educational materials and responsibility of managing the

disease, but minimal education is offered to the children. As children develop and become more independent, education varies, and there is no standard regarding the mode, length, or topic given as to how to manage their disease, or how to problem solve when faced with challenges. The purpose of the survey is to gain insights from an occupational therapist's perspective when assisting adolescents living with T1D. This survey will help in developing strategies and a self-guided education plan to benefit teens learning to navigate adolescence while managing their disease and identify social media use and preferences for diabetes education. By doing so, we hope to achieve our goal of gaining a better understanding of what life with T1D is like as an adolescent, and to broaden the scope of occupational therapy in the diabetes community. Practitioners and educators will reach a broader audience through the use of a mode of media younger people prefer.

Literature Review

Type 1 Diabetes Overview

The cause of Type 1 diabetes is different from that of the more commonly known type 2 diabetes. Children are most frequently diagnosed with type 1, accounting for approximately 5-10% of the population with diabetes (American Diabetes Association, 2018). The exact cause of T1D is unknown, but studies suggest a strong genetic component along with environmental factors such as a child's diet, viral infections, and exposure to toxins. The chronic disease is triggered by an autoimmune response in which the body attacks beta cells that produce insulin, thus stopping the body from making insulin. According to the American Diabetes Association, the body's inability to make enough insulin disrupts the balance of blood glucose levels and can be treated with medications, insulin injections, and lifestyle changes. There are several symptoms

associated with diabetes that vary in range and can be life-threatening. The cause of many of the symptoms seen in those with T1D is from hypoglycemia, a condition in which the body does not have enough insulin, which can lead to a diabetic coma and have detrimental damage to the organ systems (Atchison & Dirette, 2017). Although, the life expectancy for someone with diabetes is lower than that of a healthy individual, careful attention to glucose levels and a healthy lifestyle can improve a person's life expectancy and quality of life (Copenhaver & Hoffman, 2017).

Type 1 Diabetes in Adolescents

Adolescence is a critical and challenging time in an individual's life as they begin to discover themselves and how they fit in, all while adjusting to the changes going on within their body. In a study by Hema et al. (2009), adolescents reported having to manage stressors related to self, their parents, and school. They used coping strategies involving persistence and alternative thinking, taking on more personal responsibility in regard to managing their stressors, which varied from the younger children's responses. For the typical adolescent population, during puberty, insulin and insulin-like growth factors increase, stimulating other hormones in the body necessary for healthy cell division and growth (Chisalita & Ludvigsson, 2018). However, for adolescents with T1D, there is a dysregulation of this system related to poor metabolic control which can lead to poor health outcomes, such as end stage renal disease and intestinal problems (Chisalita & Ludvigsson, 2018). Chowdhury (2015) notes that "puberty, at all stages, has the worst insulin resistance" due to an increase in growth hormones (GH) during this stage of development.

Studies show that diabetes management and control tend to decrease during adolescence, leading to an increased risk for complications. Anderson, Auslander, Jung, Miller, and Santiago (1990) found that the child's age, disease duration, sex, and mother and child assumed diabetes management responsibilities are all predictive factors, which contribute to the amount of self-responsibility the child took on in regard to adhering to their regimen, and predictors of their HbA1c levels. As the child or adolescent takes on more responsibility for themselves, and parents decrease their direct involvement in their child's diabetes management care, there is a transitional learning period in which the adolescent struggles to manage the complex tasks of managing their disease.

Additionally, adolescents with T1D face many challenges that affect their adherence to self-management and influence insulin resistance during this developmental stage of their life. These challenges include social pressures, changes in family dynamics, and diabetic burnout (Borus & Laffel, 2010). Compared to that of their peers, teens with T1D have a higher risk of depression and anxiety and struggle with eating disorders as they have to be highly cognizant of their food intake and weight (Borus & Laffel, 2010). During puberty, results from the Diabetes Control and Complications Trial found that the mean HbA1c levels peak as glycemic control declines resulting in the need for more insulin (Chowdhury, 2015). Higher Body Mass Index (BMI) levels are also found to be a factor during adolescence, especially for females, increasing the risk of complications and insulin resistance (Chowdhury, 2015).

During adolescence autonomy increases as they take on more roles and responsibilities (Hilliard et al., 2013). While autonomy increases in terms of taking on more management roles and responsibilities, caregiver involvement, which was a major

source of control and adherence to treatment, decreases (Dashiff & Vance, 2009).

Adolescents establish their autonomy by making their own decisions, known as behavioral autonomy. Behavioral autonomy is a sign of maturity and linked to positive psychological outcomes including the ability to understand the future consequences of their actions; however, studies have shown that along with the development of independence there is a high rate of risky behavior (Helgeson et al., 2014). It is suggested that behavioral autonomy should be encouraged with the support and collaboration of parents so that they may learn to make decisions about their self-care and learn from their mistakes (Helgeson et al., 2014).

Overall, a decrease in the regulation of their disease can ultimately lead to an increased risk for complications. Adolescents can benefit from being involved in their daily insulin regimen as they grow older and become more independent in order to learn how to manage their disease in a way that best suits their ever-evolving daily schedules (Chowdhury, 2015).

Self-Regulation Improves Overall Health and Well-Being

Research shows that diabetes affects both the emotional and physical health of individuals. Adolescents, in particular, are affected by the disease causing an increase in irritability, stress, and behavior problems when they have poor control over their blood sugar levels, often necessitating a psychologist as part of their diabetes care team (Di Battista, Hart, Greco, & Gloizer, 2009). Those with diabetes must learn to manage their health through diet, exercise, and medications to reduce the associated complications. A study by Malipa and Menon (2013) found that the adolescent participants who were part of the intervention group were significantly more likely to comply with insulin

management, eating meals on time, following an exercise schedule, and fewer hypoglycemic episodes. They also found that the intervention group had fewer worries about diabetes and had a higher self-reported quality of life. A teenager's quality of life is a critical factor in their overall health because it is correlated to their HbA1c levels (Anderson et al., 2017). Quality of life is rated higher with optimal glycemic control along with healthy behaviors, which included increased frequency of daily blood glucose monitoring, use of carbohydrate counting, and a higher number of days per week of exercise (Anderson et al., 2017). Adherence to treatment has a positive impact on the lives of those with diabetes; knowledge about the disease and the impact of non-compliance on their long-term health gives adolescents a sense of control over their health.

Greater adherence to treatments and better metabolic control lead to fewer health problems (Berg et al., 2013). In a 10-year follow-up study by the Diabetes Prevention Program Research Group, it was found that those who were part of the lifestyle intervention group and the metformin group were able to lose weight and reduce the incidence rate of diabetes, preventing or delaying it for at least 10 years (Knowler et al., 2009). This extensive study shows that adhering to a healthy lifestyle as well as adherence to prescribed medication can improve a person's health for years to come. Being knowledgeable about the disease and the impact of non-compliance on their long-term health can lead to greater adherence thus a better outcome.

Promising Interventions with Limits to Longevity

Glycemic control tends to decline during adolescence and the transitional period into adulthood for individuals with T1D, utilizing interventions that manage T1D

effectively is crucial in the effort to avoid further complications from diabetes later in life (Wong et al., 2017). Although there have been interventions that showed promise in terms of adherence to treatment, there is still a gap in determining which of them works best in the long run.

According to the American Telemedicine Association, telemedicine involves sharing medical information between one site to another via electronic communications to improve one's health status (American Telemedicine Association, 2012). These services are delivered remotely using technology to determine and diagnose issues, deliver treatments, and for health promotion towards individuals and large-scale communities (Dougherty et al., 2014). Telemedicine and the use of technology have the potential to help in relieving the burden of people having a lack of access to health care and limited financial resources. Adolescents are widely exposed to technology every day. A study performed in 2011 showed that 95% of adolescents in America use the Internet, 70% of them use it daily, and 74% of adolescents own personal computers (Lenhart, 2012). These numbers have only increased in recent years, as the Internet has become more accessible and more affordable. Information and communication technologies (ICT) are technologies which utilize computers and the Internet as primary instruments and should be evaluated as tools for improving processes like health care and education. ICT allows for the advancement of information to reach a broader audience through the use of multimedia resources and allows for the development of interactive processes of education (Souza Pinto et al., 2017). Mobile technology is becoming more and more accessible and a critical component to adolescent culture and daily life (Dougherty et al. 2014). The use of technology can be especially advantageous for providing access to

health care for hard to reach individuals, such as minority and low-income adolescents. Creating interventions that line up with community needs and values is vital for the success of integrating technology and health care.

Doughtery and colleagues (2014) found that telemedicine for adolescents with T1D has not been as extensively studied compared to the data on the use of telemedicine for diabetes management in adults. Studies for adults were shown to be highly positive, with increased rates of patient and provider satisfaction of improved disease management and a decrease in hospitalizations (Harris et al., 2012). The more simple, reliable, relevant, and interactive the technology is for managing T1D in adolescents, the more effective it can be. Through a review of telemedicine interventions in the adolescent population, the study found that several interventions such as social media, websites, Internet and mobile phone applications, remote disease monitoring, text messaging, and phone or video consultations have often been used regarding diabetes (Doughtery et al., 2014). Adolescents revealed their interest in using technology, especially text messaging, and valued the increased communication with health care providers (Mulvaney, Anders, Smith, Pittel, & Johnson, 2012). Visual imagery was also found to be useful for adolescents because it allowed them to learn about and adequately manage their disease using visuals and reminders as opposed to the traditional learning methods of reading or discussion (Frøisland et al., 2012). A particularly valuable use of telemedicine in managing chronic disease lies in the ability for technology to reach underserved and rural areas where access to providers is scarce or even nonexistent (Lehmkuhl et al., 2010). Despite the perceived benefits, the impact of telemedicine interventions is varied. Comparison of interventions is limited due to varying sample sizes, inconsistency in

outcome measures, the type and the duration of the interventions. Although there is significant promise in utilizing telemedicine for diabetes management in adolescents, utilizing telemedicine has yet to demonstrate consistent results (Dougherty et al. 2014).

Souza Pinto et al. (2017) performed an integrative review on information and communication technology (ICT) that have been tailored for adolescents regarding health care. Their findings were similar concerning popular ICTs that can be used in health care for adolescents, such as cellular phone text messages, websites, virtual learning, online courses, online forums, games, blogs and social media. ICTs have made a significant impact on the lives of adolescents today and have been used as a primary method of receiving information (Souza Pinto et al., 2017). With the current generation using the internet more often, social networking technologies have been utilized by health professionals to relay relevant information about health care. Internet browsing for health information has become more straightforward and more accessible, especially for adolescents, than reading published literature or contacting primary health providers. However, it is of great importance for health professionals to read into these resources by ensuring the quality and scientific validity of this content. There is immense potential for ICT to be used as a viable tool in reaching adolescents and influencing their views about positive health behaviors. Despite these strides towards making adherence and intervention more appealing through the use of approaches such as text messaging, online games, and online courses, there are still forms of social media that have yet to be explored, in terms of preferred and impactful modes of education for adolescents with chronic diseases.

Although technology has become a more sought-after method for education due to its ease and convenience, more traditional approaches to diabetes education and management for youth include in-person classes and camps. Diabetes management practices often begin with intensive education at diagnosis, paired with follow-up education as needed. Just like any course of education, it can be argued that everyone could use a refresher course on diabetes management. As adolescents are all in a transition period of changing lifestyles, knowledge, skills, and values, adolescents with T1D may also have changing disease characteristics making follow-up education essential. Diabetes camps for youth have become a common medical practice (Wang et al., 2008). In 2008, Wang et al. investigated whether attending diabetes camp would improve metabolic control, which in turn can improve overall health, wellness and quality of life for adolescents with diabetes. At Camp Sweeney, the specific camp studied, there are numerous planned activities and included daily medical education lectures and discussions. When compared to the group of adolescents that did not attend Camp Sweeney, they found that attendees had slightly better metabolic control levels. Although these lectures and activities were found to be beneficial for attendees, there was no specification as to which modes of education were used (Wang et al., 2008).

Intrinsic vs Extrinsic Motivators

Two main types of motivation can influence a person's behavior. The first form of motivation is intrinsic, characterized by the personal motivation or satisfaction one feels towards accomplishing a goal. The second form of motivation is extrinsic, which is defined as dependent on external feedback, such as physical rewards or verbal affirmation. While research has investigated the effects of extrinsic motivators in the

lives of adolescents with T1D, there is a lack of studies examining the effects of intrinsic motivation on the health of this population.

Various studies have explored the effect of extrinsic motivators on adolescents with T1D. In 2010, Raiff and Dallery conducted a study with four adolescents diagnosed with T1D. The study used an Internet-based contingency management program to improve and increase adherence to blood glucose testing; when the teenagers submitted blood glucose testing videos for a minimum of four times a day, they earned vouchers (Raiff & Dallery, 2010). At baseline, participants were not meeting the minimum of four blood glucose monitoring tests per day. When the intervention was first implemented, an increase in testing frequency occurred leading to monetary vouchers for each participant. However, once the intervention was removed, there was a decrease in testing frequency. Another similar study by Wong et al. performed in 2017, used daily financial incentives on glucose monitoring and glycemic control adherence in adolescents and young adults with T1D. Participants were given a goal of blood glucose monitoring of four glucose level checks each day with at least one of the readings within the target range. Sixty dollars were allotted to each participant in the intervention group at the beginning of each month during the three-month intervention period. While the financial incentives improved glucose monitoring during the incentive period, the adherence did not lead to an improvement of overall glycemic control. Both studies had relatively small sample sizes to the general population, so the results cannot be generalized. These studies focused solely on external motivators for adherence to treatment, however long-term internal motivation and habit formation was not achieved.

There is limited research into intrinsic motivators for the T1D adolescent population; however, in a 2011 study, Selkie, Benson, and Moreno sought to discover adolescents' views about sexual education. They recognized that by giving the adolescents a space to express their personal views regarding sexual education, they might be more intrinsically motivated to practice what they were learning. Facilitators of the focus groups wanted to explore how adolescents currently use and would like to use technology, from social media to text messaging, to receive sexual education. The study found that the participants were interested in and enthusiastic about ways technology could be used to improve sexual health education. The participants were eager to be involved in voicing their opinions about how they would like to see the educational programs (Selkie, Benson & Moreno, 2011). When designing any technological educational program or interventions tailored for adolescents, it is necessary to involve adolescents in the design process. By including adolescents in the development of any intervention, the potential to generate deeper intrinsic motivation in adherence to the management of any chronic condition is increased.

Fostering intrinsic motivation is necessary for adolescents with T1D to be able to better transition into taking on the more complex responsibilities of their disease. Along with this necessity, it is additionally imperative that health professionals are interested in the input of the young respondents, and praise them for autonomous behavior (Almagro, Saenz-Lopez & Moreno, 2010). A study by Almagro, Saenz-Lopez, and Moreno in 2010 focused on the importance of creating an environment of autonomy created by coaches on the motivation and adherence to sports among young athletes. Praise for autonomous behavior revealed a positive prediction of the psychological need for autonomy

(Almagro, Saenz-Lopez, & Moreno, 2010). Simultaneously, perceived autonomy is also a predictor of intrinsic motivation experienced by adolescents. For adolescents with T1D, perceived autonomy and intrinsic motivation are important factors needed to intently adhere and commit to maintaining a healthy lifestyle.

In summary, T1D continues to be one of the most common and prevalent diseases among youth, affecting over 200,000 adolescents in the United States (CDC, 2017). Adolescents with T1D have unique consequences due to a dysregulation of insulin and insulin growth like hormones, which relates to poor metabolic control leading to poor health outcomes like end-stage renal disease and intestinal problems (Chisalita & Ludvigsson, 2018). As children with T1D transition into adolescence, they take on more responsibility for themselves, and parents decrease their direct involvement in their child's diabetes care management (Dashiff & Vance, 2009). Due to the complex and necessary adherence to tasks, adolescents may struggle during this transitional period putting them at risk for future complications. This population may face challenges that affect their adherence to self-management, including social pressures, changes in family dynamics, and diabetic burnout during this developmental stage of their life (Borus & Laffel, 2010). Higher risks of depression, anxiety, and even eating disorders are prevalent as these adolescents must be highly cognizant of their food intake and weight (Borus & Laffel, 2010). Therefore, it is crucial that during this time adolescents recognize the importance of diabetes self-management in order to participate in the everyday occupations of a teenager. Studies have shown that interventions which teach self-regulation improve overall health and well-being (Hilliard, Powell, & Anderson, 2016).

To keep up with current times, researchers have been creating and trialing technological interventions that include education, notifications for medications, encouragement and more. Despite the promise these interventions have shown, there still lacks long term adherence in the lives of adolescents. By conducting this needs assessment, we will be able to identify how information is being received and what is missing from current diabetes education. Adolescents with T1D will have the opportunity to express their opinions, giving them a voice to contribute to the interventions they and their peers will be utilizing in order to live a more healthy and full life.

Statement of Purpose

The purpose of this study was to conduct a needs assessment for adolescents with T1D to determine a preferred mode of media and educational material. The study assesses what education topics and modes of education helps individuals to stay motivated in adhering to the treatment of their condition. The needs assessment allowed us to gather insight from the adolescents themselves in four key ways. First, whether they would prefer receiving educational tools regarding the management of their disease through some form of social media, or some other form of media. Second, this needs assessment enabled us to understand the ways these respondents could be encouraged to develop healthy habits and routines so that they can become more independent. Third, we wanted to find out which platforms of social media are most used by teens living with diabetes. Previous studies have used telemedicine and apps which are outdated as there have been many new forms of social media that have since been developed. And fourth, we wanted to determine what information this demographic feels would be of most benefit to them, which they might not be getting from the other available sources or that

they may not feel comfortable talking to their doctor about. Occupational therapy practitioners can promote healthy lifestyle changes through their understanding of physical and mental health, chronic disease management, and their analysis of performance patterns (Cahill, Polo, Egan, & Marasti, 2016). As members of a diabetes team, occupational therapy practitioners can assist with addressing the physical, cognitive, and psychosocial aspects of diabetes-related self-care that support engagement in occupations (Sokol-McKay, 2011).

Theoretical Framework

Model of Human Occupation

The model of human occupation (MOHO) is a holistic and client-centered approach that conveys the importance of a person's subjective views on life occupations, based off the original works of Mary Reilly, and later Gary Kielhofner (1980). MOHO works to extract the complications that are within each person and how the role of the environment plays a part in shaping one's occupational performance (Kielhofner, 2008). According to Kielhofner (2008), by focusing on a person's internal motivation (volition, habituation, and performance) and changing the way they interact with the environment (externally), occupational therapists can use the MOHO model to help clients engage in occupational behaviors that maintain, restore, reorganize, or develop their capacities, motives, and lifestyles. Similarly, by increasing participation in therapeutic occupations, therapists can help persons transform themselves into more adaptive, functioning, and healthy individuals (Kielhofner, 2008).

More specifically, MOHO was used to develop the needs assessment because of its focus on the concept of the person within the open systems cycle. Before discussing

the opens system cycle further, it is essential to understand how dysfunction is categorized within the model. Dysfunction can be classified when two things happen. The first is when the individual does not experience a basic quality of life, nor can they meet personal and societal expectations. The second is when the inability to perform occupations occurs, an interruption in role performance is experienced, or there is an inability to meet responsibilities (Kielhofner, 2008). Adolescents with T1D usually experience a disruption in their typical routines and occupations (Monaghan, Helgeson, & Wiebe, 2015). The effects of T1D can be experienced in settings such as the school, extracurricular activities, and also at home. While adolescents with T1D have the drive to do something at first, they usually cannot because of the diagnosis, current environment, or the fear of not meeting societal roles.

As mentioned above, the open systems cycle is made up of three parts: habituation, performance capacity, and volition (Kielhofner, 2008). Habituation, otherwise known as roles and routines, refers to the process by which occupation is organized into patterns or routines. Performance capacity is known as skills needed for providing action, including perceptual motor skills, processing skills, and communication skills. Finally, volition refers to the motivation for occupation. It drives the child to act on his or her world, facilitates self-organization, and guides a child's understanding of him- or herself. For this needs assessment, the concept of volition is the main starting point and driving factor. It innately encourages the client to adapt, change, and learn about him or herself as an occupational being. As individuals, before we can achieve something, we need the internal drive and motivation to participate. The concept of volition identifies a child's motivation as being a function of both a child's characteristics and the features of

the environment. Examples of this could include being able to participate in the same activities as their peers, going to school, or “fitting in”. Because of the importance of volition, researchers aim to develop a protocol that can help adolescents become more involved and provide internal motivation for diabetes management guided through their education.

Bandura’s Social Learning Theory

Another theoretical framework used to guide our needs assessment is the psychological theory proposed by Bandura called the Social Learning theory. Adolescents need to learn how to self-regulate and build self-awareness so that they can live successfully and functional with T1D in terms of insulin management, food intake, physical exertions, and mental health. Bandura’s theory provides an understanding of how human behaviors such as these are learned. The theory looks at the interaction of the person, behavior, and their environment. For an adolescent with T1D, it is essential to look at the person and what their personality type is. We can also look at their behaviors, and those that contribute to successful insulin management or behaviors that lead to insulin mismanagement. These behaviors can include checking for insulin before engaging in a preferred activity, such as going out to eat with friends. The individual’s environment, both social and physical, is also essential and often a determinant of success. A strong support system that includes family at home and close friendships can have a positive impact on medication management.

Bandura’s theory focuses on self-regulation and self-efficacy. Self-regulation refers to the ability to direct one’s own life by creating strategies that will help meet the set goals (Cole & Tufano, 2008). This project will allow adolescents with T1D to identify

strategies that will help them set their own goals and achieve glycemic control. The ability to self-regulate without reliance on others is crucial as they transition into adult life. Self-efficacy involves the cognitive ability to foresee the consequences of the behavior (Cole & Tufano, 2008). The project allows for reflection on past experiences and education in order to foresee what the consequences are of glycemic failure. Self-efficacy can be used to help set goals based on using what has not worked in the past, focus on new behaviors, and forecast the effects.

Methodology

Method

The method used to collect information on adolescents with T1D and their preferred methods of education was an online survey platform called eSurvey Creator®. This survey method was chosen due to its ability to reach a large number of respondents, the minimal necessary expenditure, it is quick to administer, it allows instant access to results, and the data can be quickly imported for analysis. The survey consisted of twenty questions. The first five questions consisted of demographic questions that gave some background information to the participant. The next two questions required the participant to say what social media they use and whether they are members of any online social support groups for T1D. The last thirteen questions were related to types of education on T1D management that has been received previously and whether the participant is satisfied with that education.

Design

Participants were recruited via social media sites such as Facebook and through word of mouth from healthcare practitioners. Participants were also acquired through

contacts at the Juvenile Diabetes Research Foundation and the Padre Foundation. A survey was developed using the online platform eSurvey Creator®. By providing an email address, the participant had indicated interest in taking part in the study. Each potential participant was sent an introductory email along with a link to the survey. The participant began the process by logging on to eSurvey Creator® via the link provided. The participants were aged below 17 years, so they needed authorization in order to access the survey. It was at this point where the participant's parent or legally authorized representative was required to complete the Stanbridge University Parent or Legally Authorized Representative Permission Form (Appendix D) and the Stanbridge University Assent Form (Appendix E). Once these forms were completed, eSurvey Creator® opened the survey (Appendix F) for completion. Each participant was able to access the internet-based survey at their own convenience using their own personal electronic device like a computer, tablet, or phone.

Advantages of Using a Survey

Online surveys are used mainly because of the speed in which they can be delivered to the participant, as well as the speed in which the data can be analyzed. By using eSurvey Creator®, there was the option of analyzing the data in real time as each completed survey sends the analysts notification of completion. Notification was also available of all completed surveys that had been completed prior to the date limit. An online survey is available twenty-four hours per day, which enabled the participant the opportunity to give the survey their full attention. Extensive access encouraged the participant to reveal thoughtful and thorough answers and made the results a fair representation. An advantage of using eSurvey Creator® is having the ability to quickly

import the data, using cross tabulation and segmenting the participants and their responses. By using eSurvey Creator®, we were obliged to have enhanced security, which means that participants were able to trust that their results are kept confidential.

Target Population

This project focused on the adolescent population from ages 12 through 17. Adolescence is a pivotal time in which the body begins to go through changes both physically and mentally. During adolescence autonomy increases, but diabetes management and control can deteriorate if the patient's autonomy exceeds their ability to perform all of the necessary components of self-management of their diabetes (Wysocki et al., 1996). The project targeted adolescents with T1D that frequently use social media websites, hence the reason for using Facebook and other social media sites as a primary source for participant recruitment. Along with Facebook, participants were recruited through colleagues from a professional setting such as UCI, as well using word of mouth through healthcare practitioners.

Data Analysis

To analyze data, summary statistics also known as measures of central tendency were used. A measure of central tendency is a single value that attempts to describe a set of data by identifying the central position within that set of data. Using a measure of central tendency involves finding the mean, median, and mode of the data set. The mean represents the average value of a data set and is the most commonly used value. However, for data sets that were skewed or had definitive outliers, the median value was used to analyze the data. The mode was used to ascertain which value was the most commonly entered in the survey.

Results

Demographics

The participants of the survey were based around all regions of the United States, including California, Pennsylvania, North Carolina, Tennessee, Florida, and Illinois. The average age of the participants was 14 years old. Six of the participants were female, and four were male. Nine of the adolescent participants were White/Caucasian and one was Latino. (see Table 1)

Social Media

Predictably, the most well-known social media outlets such as Snapchat, Facebook, YouTube, and Instagram were the most popular modes of media used by the ten participants. The most widely used social media outlet was Snapchat, which is primarily used for “snapping” a photo or short video and sharing it with followers who have instant access. Facebook is a social media outlet, which can be used to post feelings, share videos with friends, and become members of specific interest groups such as Type1Nation. Survey participants who use YouTube have access to millions of videos that have been posted by individuals and companies that are related to T1D. Followers can subscribe to other users and be updated when new videos are posted with the option of posting comments in the reply section regarding the video. Instagram allows members to share photos with followers, whether that be of themselves or things of interest, such as food, motivational quotes, and short video logs. 30% of the survey participants reported they are active with online social support groups, namely Type 1 Mod squad, T1Teens, and Type1Nation. The statistics imply that 70% would prefer not to use online social support for T1D. (see Figure 1)

Education

All adolescents who took part in the survey had received some direct education on T1D management while alongside a legal guardian. According to survey results, participants had received a wide variety of educational resources and as expected, they all stated that they do receive education from doctors and nurses. As indicated in Figure 2, other educational resources utilized were from online resources, videos, pamphlets, diabetes camp, and classes.

Most preferred type of education. The results revealed that the preferred method of education was overwhelmingly through direct verbal communication through members of the healthcare team: 90% of the participants stated this as one of the preferred methods. The reasons provided as to why they preferred this method were based around the fact that they preferred a more direct hands on approach. Statements from the adolescents as to why they preferred the type of education they selected included: “Direct hands on approach. Teach me, let me try it, then have me teach you back” or “my doctor gives me great advice about T1D management, and it’s also super helpful to talk to people online and take advantage of their expertise,” and finally “I can ask questions to the doctors and nurses at my visits every 3 months. I can attend classes anytime I want to through the PADRE Foundation as they are free, and over the years, I have needed refresher courses. At camp, I can share stories and learn tricks from others who are living with Type 1 diabetes every day and make many new friends who understand me.” 30% of the participants preferred method of education was through video, where it was stated that if the participant was feeling overwhelmed, they could stop the video and replay it.

30% of the adolescents also said that they like to use online resources as it provides a platform to speak to experts and take advantage of their expertise.

Least preferred type of education. The least preferred method of education to use was pamphlets, with (66.7%) of the participants placing this as one of their least favorite resources. One participant stated that they do not like to read and pamphlets are too uninteresting and too hard to understand, while another stated the pamphlets are not able to answer any specific questions that they might have. Going to classes was also one of the least favored resources of education. One participant stated that it takes up too much of their time to travel to and from the class and attend the sessions. They also stated that they would prefer to use that time doing something more enjoyable. The other least favored method of education was diabetes camps. The complaints were that the camps were aimed at younger kids, that there are no camps aimed at newly diagnosed teenagers, and that the information centered around pumps and glucose monitoring devices when not everybody uses these devices as a part of their treatment regimen.

T1D Self-Management

Participants were asked to rate how well they feel they are managing their T1D on a scale of 1-10 (1 being very poor and 10 being very well) as well as the reason why they gave that grade. The most popular grades given were 5 and 8 out of 10. A score of 5 was the lowest scoring grade given and this was the grade for 30% of the participants. This score suggested that they felt that they are okay at managing their diagnosis but could do better. One participant stated that they forget to keep on top of their blood-sugar levels and that they need reminding from parents, whereas another stated that things affect them and that is why they struggle to manage their T1D. Another participant stated that they

keep getting told by their healthcare team that the reason that they struggle is that they are going through puberty. The 3 participants who rated themselves an 8 out of 10 for T1D management stated that they pay attention to their A1C levels, do all their shots, and are educated on food intake, in particular, carbohydrates. The one participant who reported that they are 10 out of 10 in management of T1D stated that they were aware of how to manage their diagnosis, and despite not always taking action, they at least know what to do.

Areas of Self-Care

The participants were asked how they managed certain key self-care areas within T1D. Of the self-care areas that participants thought that they managed well, 90% reported that they handled both blood glucose testing and administration of their insulin very well. 80% of the participants reported that they feel that they manage the frequency of which they eat well, and 70% reported that their overall health maintenance was managed well. The participants were also asked which self-care areas they thought that they did not manage well. 44% reported that weight control was difficult to manage, and 33% reported that both eating frequency and attending social events were difficult to manage.

Areas Education would be Beneficial

The areas indicated by participants in which additional education would most beneficial were coping skills, social support, and how to deal with social pressure, and becoming more independent in life and balancing T1D. 60% reported coping skills as an area that required further education, 50% reported wanting more education in social

support and social pressure, and 40% identified a need for more education on how to become more independent.

Preferred Platforms of Social Media.

Participants were asked to select no more than five social media platforms in which they preferred to access educational resources. 60% of the participants reported YouTube as the most preferred social media platform to access educational resources. 50% selected online support groups as an educational resource. 40% reported that Instagram and Facebook were both in their top five social media platforms that they use. Other social media platforms identified were Snapchat (30%) and Twitter (20%), which were identified as top five social media platforms used to access educational material.

Discussion

Completion of the needs assessment further affirmed the need for adolescent input when creating modes of education that would genuinely be appealing for adolescents with T1D to follow and adhere to. The results of the survey had three emerging themes: favorable education forms, unfavorable education forms, and future education. These themes identify forms of education that have previously worked for adolescents with diabetes, forms of education that previously did not work and the type(s) of social media that would be preferred for future education.

Favorable Education Forms

Results from the needs assessment showed that 90% of participants found success in previous educational opportunities when receiving direct verbal education from doctors, nurses, and other healthcare personnel. Data concluded that the reason this previous type of education was favorable was that participants enjoyed the face to face

interaction with their doctors. One participant stated that “direct hands-on approach teaches me, lets me try it, and then has me teach it back”; concluding that another reason direct verbal education was preferred was so that demonstration-return demonstration could be completed. Direct verbal education was also a favorable form of education because the chance to ask questions was available. As one respondent stated, they liked that “I can ask questions to the doctors and nurses at my visits every 3 months.”

Another form of education that was preferred by 30% of the participants were online videos. Participants engaged in this education form because it prevents adolescents from becoming too overwhelmed with information. A participant stated, “I like videos so that if I get overwhelmed, I can stop and come back later.” Videos also allow adolescents to listen to the educational material as well as read it, satisfying at least two types of learning styles for the population studied.

Unfavorable Education Forms

Previous educational forms that were unfavorable to the participants when receiving educational material were pamphlets, classes, and diabetes camps. 60% of participants marked that they did not like pamphlets, whereas 20% marked they did not like classes or camps. As predicted by researchers, pamphlets were challenging to read for those in the targeted age population thus making the material either too difficult to comprehend or not stimulating enough for the adolescents. One participant stated “I don’t like to read information. It gets too boring and too hard to understand.” Another participant stated that they were too young for the information at the time, making the pamphlet confusing. Reaffirming the favorable educational methods, a participant mentioned that “I may read the pamphlets but I learn better from actually doing the

action.” If pamphlets continue to be a primary source of education for adolescents with T1D, information needs to be displayed to meet the specific needs of the target population. Making sure information is easy to understand, bright, and includes pictures, may help make this form of education a success.

Classes and diabetes camps were also another form of education considered to be unfavorable to adolescents with T1D. Data concluded that camps and classes were too far away and interfered with other essential occupations. One participant stated, “It was aggravating because it was too far away. I did not like how it interfered with my swim team meetings.” Another reason these types of education did not work was because of the age restrictions of camps. “I had aged out of the local camps before I was diagnosed. They were all geared towards younger kids and had nothing for newly diagnosed teens.” Although some diabetic camps are specifically aimed for teens, many camps group kids and teens together. This presents a problem as some teens may feel as though the programs are not addressing their needs and feel too childish. This strongly reaffirms the need for an educational platform specifically for adolescents with T1D.

Future Education

Participants indicated several social media platforms as well as forms of media of which they would prefer to receive educational materials and interventions. The social media platform options available for selection were Facebook, YouTube, Twitter, Instagram, Snapchat, Pamphlet, Online, Direct Education, Diabetes Camp, Online social support group and other. The top four social media platforms selected were YouTube, online social support groups, Facebook and Instagram. Beginning with YouTube, 60% of participants chose that they would prefer to receive materials through the form of videos.

As stated earlier, videos would allow users to not only learn in the convenience of their home but allow them to “stop and come back later.” The mode of online support groups was the next highest in favor at 50%. Online support groups could provide a platform for occupational therapy practitioners and adolescents with T1D to connect, exchange information, ask questions and ultimately have a place to support one another. Both Facebook and Instagram were selected by 40% of the participants. These forms of social media have the option of creating a singular profile and then options of posting photos, videos, blurbs and links to websites. Occupational therapists can use these platforms to impart educational materials in appealing and creative ways.

Occupational therapists can use this information as a foundation for future education. By knowing these participants are interested in having information on social media platforms such as YouTube, Facebook, and Instagram, practitioners can move forward and begin relaying evidence-based, stimulating educational content. Taking additional information from the survey, such as “areas of self-care” and “areas education would be beneficial” could be advantageous in catering the information specific to what the participants had marked would be favorable. Using the indicated social media platforms as modes for future education for adolescents with T1D could potentially lead to more exceptional maintenance of their disease, which in turn could lead to an increased quality of life.

Limitations of the Project

There were many limitations of this project including recruitment concerns, participant attention span, willingness to participate, reduced time for data collections and lack of access to a computer. The most extensive limitation of this project, however, was

the small sample size. Because researchers could not reach out individually to recruit participants, the survey was distributed using third-party sources including Facebook, T1D support groups, and other T1D organizational events. The lack of responsiveness from these third-party organizations hindered the potential for a larger sample size. Researchers also experienced incertitude from the type 1 diabetes community as it is close-knit and hesitant of outsiders, making it hard to gain access to their support groups. Since the population of participants were adolescents ages 12-17, willingness to participate and attention span was also a limiting factor affecting the sample size. Four participants were removed from the results of the survey for not completing the survey, or for filling out demographic information incorrectly. The time in which to collect data for the needs assessment was also a limitation. Having a larger time frame for which adolescents could take the survey would have also increased the number of participants. Finally, since the needs assessment was created to be accessed via an online survey, individuals who do not have access to a computer or the Internet, may have been excluded from the survey, further causing the sample size to be impacted.

Ethical and Legal Considerations

Adolescents under the age of 18 are one of the most vulnerable populations because their intellectual and emotional capacities are limited and not fully developed. Adolescents with T1D may be more vulnerable than the average adolescent because of their medical diagnosis. For the study, the research team strived to inquire and meet the needs of the adolescents diagnosed with T1D through the use of a gestated framework. This was done to discover information as to what areas of occupations are affected most by the diagnosis, as well as which method of occupational therapy

(pamphlet, Youtube videos, and phone apps) they would be most responsive to when receiving intervention information. In doing so, the research team conducted a study that embodied integrity by prioritizing the safety and well-being of the participants. Procedures and considerations for security and interviewing strategies were put in place to protect and minimize their exposure to any psychological harm.

For this study, informed assent was required from the adolescent, as well as consent from the parent or legal guardian. After participants met the inclusion criteria, researchers sent a link to the survey. Before the start of the survey questions, detailed descriptions of expectations, researcher contact information, and potential areas of concerns were provided. Mandatory electronic signatures from both the legal guardians and participants were required for these sections before participants could move on to the survey. To retain the confidentiality of records, data was stored anonymously as it is the participants personal experiences and preferences. The survey was completed via e-survey. The research team assessed the exposure of potential risk(s) to our participants during the study. During the survey, emotional distress may arise when participants answer questions about their limitations of occupations and the effect T1D has on their lives. Questions were created with attention and sensitivity to the culture and well-being of the participants to protect the participants from emotional distress. Furthermore, to ensure autonomy, options to omit an answer from any of the survey questions were allowed, including the option to withdraw from the study entirely.

Due to the ages of the participants, they, may have been at risk for answering questions incompletely due to the lack of understanding. Researchers ensured that

questions were stated clearly and matched the participant's level of understanding to eliminate participant emotional stress.

Consent forms, assent forms, and the research participant's bill of rights can all be found in Appendices A-C.

Conclusion

Adolescents with T1D find that their daily occupations are often interrupted by the around the clock care needed to maintain their glucose levels. During this developmental transition, both biological and psychosocial factors affect the management of their disease.

In 2010 the U.S. Department of Health and Human Services developed a nationwide program, aimed at health-promotion and disease prevention, that established goals for reducing controllable health risks called Healthy People 2020. According to Healthy People 2020, the goal was to “reduce the disease burden of diabetes mellitus (DM) and improve the quality of life for all persons who have, or are at risk for, DM” and this can be accomplished through appropriate care and therapy (Office of Disease Prevention and Health Promotion, n.d., para. 1). Occupational therapists can play a vital role as part of an interdisciplinary team, within the community, that helps promote this initiative. Using their expertise in client-centered care, they can help educate adolescents on the significance of managing their disease and help them to develop healthy habits and routines that fit in with their busy schedule by using the social media sites adolescents visit everyday.

The study aimed to fill the gap in research that was found to be outdated and lacking adolescent input. Researchers focused on answering three main questions:

whether adolescents will use social media forums as a tool in learning to manage their diabetes, which social media forums are most used by adolescents currently, and to determine what information adolescents felt would be most beneficial to them that may be lacking in the education they receive from other health care professionals. Of the ten qualifying participants who participated in the survey, all of them reported that they received direct education on managing their diabetes and most reported that they preferred this form of education because they could ask questions. Surprisingly, all participants reported that they felt they were receiving enough support from their healthcare team; however, only 1 participant reported feeling very well on how they managed their disease. As predicted by researchers, social media was used by all but 1 participant and YouTube was found to be the most preferred mode of media for receiving educational material.

Previous research found that adolescents had trouble adhering to treatment regimens and lacked the problem-solving skills necessary to manage their disease. In response to this issue, researchers asked adolescents to identify the areas of self-care which they felt they did well and which areas they felt they could improve on. The top two categories that adolescents felt they had a good handle on were blood glucose testing and administration of their insulin, while weight control and attending social events were ranked as needing the most improvement. One possibility for the reason why adolescents ranked blood glucose testing and administration of insulin as the top two self-care tasks they felt good about is that they are tied together. Also, there have been many advances in technology that keep glucose monitors small and discrete and do not require a great deal of effort from the user. When conducting the needs assessment, it would have been

beneficial to ask whether the adolescent had and/or used a self-administering pump. Adolescents needing help navigating social events and weight management is consistent with the research. Adolescents with diabetes face many psychosocial barriers as they deal with the possibilities of social embarrassment and stigma whenever they have to self-administer an insulin shot.

Future research should include a larger population and additional questions that focus on the self-care areas identified as needing the most improvement. The needs assessment conducted emphasizes the importance of getting direct feedback from this population as technology and social media preferences are constantly changing. From the information gathered, occupational therapists can collaborate with other members of the healthcare team to assist in creating a YouTube channel that can guide and give advice to adolescents on how to develop healthy habits and routines, navigate social events, and provide answers to questions that adolescents have or that may come up as they learn to navigate through this crucial time in their life.

References

- Almagro, B. J., Sáenz-López, P., & Moreno, J. A. (2010). Prediction of sport adherence through the influence of autonomy-supportive coaching among spanish adolescent athletes. *Journal of Sports Science & Medicine*, 9(1), 8-14
- American Diabetes Association. (n.d.). Complications. Retrieved from <http://www.diabetes.org/living-with-diabetes/complications/>
- Anderson, B. J., Auslander, W. F., Jung, K. C., Miller, J. P., Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology*, 15(4), 477-492.
- Anderson, B. J., Laffel, L. M., Domenger, C., Danne, T., Phillip, M., Mazza, C., & ... Mathieu, C. (2017). Factors associated with diabetes-specific health-related quality of life in youth with type 1 diabetes: The global TEENs study. *Diabetes Care*, 40(8), 1002-1009. <https://doi.org/10.2337/dc16-1990>
- Atchison, B. J., & Durette, D. P. (2017). *Conditions in Occupational Therapy: Effect on Occupational Performance*. Philadelphia, PA: Wolters Kluwer
- Berg, C. A., Wiebe, D. J., Suchy, Y., Hughes, A. E., Anderson, J. H., Godbey, E. I., & White, P. C. (2014). Individual differences and day-to-day fluctuations in perceived self-regulation associated with daily adherence in late adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 39(9), 1038-1048. <https://doi.org/10.1093/jpepsy/jsu051>
- Borus, J. S., & Laffel, L. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current Opinion in Pediatrics*, 22(4), 405–411. <http://doi.org/10.1097/MOP.0b013e32833a46a7>

- Cahill, S. M., Polo, K. M., Egan, B. E., & Marasti, N. (2016). Interventions to promote diabetes self-management in children and youth: A scoping review. *The American Journal of Occupational Therapy: Official Publication of The American Occupational Therapy Association*, 70(5), 1-8.
<https://doi.org/10.5014/ajot.2016.021618>
- Center for Disease Control and Prevention [CDC] (2017). Type 1 Diabetes. Retrieved from <https://www.cdc.gov/diabetes/basics/type1.html>
- Chisalita, S. I., & Ludvigsson, J. (2018). Insulin-like growth factor-1 at diagnosis and during subsequent years in adolescents with type 1 diabetes. *Journal of Diabetes Research*, 1-6. <https://doi.org/10.1155/2018/8623560>
- Chowdhury, S. (2015). Puberty and type 1 diabetes. *Indian Journal of Endocrinology and Metabolism*, 19(Suppl 1), S51–S54. <http://doi.org/10.4103/2230-8210.155402>
- Copenhaver, M., & Hoffman, R. P. (2017). Type 1 diabetes: where are we in 2017? *Translational Pediatrics*, 6(4), 359-364.
- Dashiff, C., & Vance, D. (2009). Parenting, autonomy and self-care of adolescents with type 1 diabetes. *Child Care Health Dev.*, 35(1), 79-88.
- Di Battista, A. M., Hart, T. A., Greco, L., & Gloizer, J. (2009). Type 1 diabetes among adolescents: Reduced diabetes self-care caused by social fear and fear of hypoglycemia. *The Diabetes Educator*, 35(3), 465–475.
<https://doi.org/10.1177/0145721709333492>
- Diabetes Research Institute Foundation. (n.d.). What is diabetes? Retrieved from <https://www.diabetesresearch.org/what-is-diabetes>
- DIAMOND Project Group. (2006). Incidence and trends of childhood type 1 diabetes

worldwide 1990–1999. *Diabetic Medicine*, 23(8), 857-866. <https://doi.org/10.1111/j.1464-5491.2006.01925.x>

Dougherty, J. P., Lipman T.H., Hyams, S., & Montgomery K. A. (2014). Telemedicine for adolescents with type 1 diabetes. *Western Journal of Nursing Research*, 36(9). <https://doi.org/10.1177/0193945914528387>

Hema, D. A., Roper, S. O., Nehring, J. W., Call, A., Mandleco, B. L., & Dyches, T. T. (2009). Daily stressors and coping responses of children and adolescents with type 1 diabetes. *Child: Care, Health & Development*, 35(3), 330-339. <https://doi.org/10.1111/j.1365-2214.2009.00937.x>

Hilliard, M. E., Powell, P. W., & Anderson, B. J. (2016). Evidence-based behavioral interventions to promote diabetes management in children, adolescents, and families. *The American Psychologist*, 71(7), 590-601.

Hilliard, M. E., Wessendorf, K. A., Peugh, J. L., & Hood, K. K. (2013). How poorer quality of life in adolescence predicts subsequent type 1 diabetes management and control. *Patient Education and Counseling*, 91(1), 120–125. <http://doi.org/10.1016/j.pec.2012.10.014>

Kielhofner, G. (2008). *Model of human occupation: Theory and application (4th ed.)*. Baltimore MD: Lippincott Williams and Wilkins.

Knowler, W. C., Fowler, S. E., Hamman, R. F., Christophi, C. A., Hoffman, H. J., Brenneman, A. T., ... Nathan, D. M. (2009). 10-year follow-up of diabetes incidence and weight loss in the Diabetes Prevention Program Outcomes Study. *Lancet (London, England)*, 374(9702), 1677–1686. [https://doi.org/10.1016/S0140-6736\(09\)61457-4](https://doi.org/10.1016/S0140-6736(09)61457-4)

- Lipman, T., Levitt Katz, L. E., Ratcliffe, S. J., Murphy, K. M., Aguilar, A., Rezvani, I., . . . Suarez, E. (2013). Increasing incidence of Type 1 diabetes in youth: Twenty years of the Philadelphia pediatric diabetes registry. *Diabetes Care, 36*(6), 1597-1603.
<https://doi.org/10.2337/dc12-0767>
- Malipa, M. N., & Menon, J. A. (2013). The relationship between compliance and quality of life among adolescents with diabetes mellitus type 1. *Medical Journal of Zambia, 40*(3), 93-103
- Monaghan, M., Helgeson, V., & Wiebe, D. (2015). Type 1 diabetes in young adulthood. *Current Diabetes Reviews, 11*(4), 239-50.
- Office of Disease Prevention and Health Promotion (n.d.). Diabetes. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/diabetes>
- Raiff, B. R., & Dallery, J. (2010). Internet-based contingency management to improve adherence with blood glucose testing recommendations for teens with type 1 diabetes. *Journal of Applied Behavior Analysis, 43*(3), 487-491.
- Sokol-McKay, D. A. (2011). *Occupational therapy's role in diabetes self-management*. Retrieved from <http://www.aota.org/-media/Corporate/Files/AboutOT/Professionals/WhatIsOT/HW/Facts/Diabetes%20fact%20sheet.pdf>
- Wang, Y. C., Stewart, S., Tuli, E., & White, P. (2008). Improved glycemic control in adolescents with type 1 diabetes mellitus who attend diabetes camp. *Pediatric Diabetes, 9*, 29–34. <http://dx.doi.org/10.1111/j.1399-5448.2007.00285.x>
- Wong, C. A., Miller, V. A., Murphy, K., Small, D., Ford, C. A., Willi, S. M., & Patel, M.

S. (2017). Effect of financial incentives on glucose monitoring adherence and glycemic control among adolescents and young adults with type 1 diabetes: A randomized clinical trial. *JAMA Pediatrics*, *171*(12), 1176-1183.

<https://doi.org/10.1001/jamapediatrics.2017.3233>

Ye, C. Y., Jeppson, T. C., Kleinmaus, E. M., Kliems, H. M., Schopp, J. M., & Cox, E. D.

(2017). Outcomes that matter to teens with type 1 diabetes. *The Diabetes*

Educator, *43*(3), 251-259.

Table 1

Demographics of Adolescents with T1D Participating in Survey

Characteristic	# of Participants	%
Age		
12	4	40
13	1	10
14	1	10
15	1	10
16	1	10
17	2	20
Ethnicity		
White	9	90
Hispanic/Latino	1	10
Gender		
Male	4	40
Female	6	60

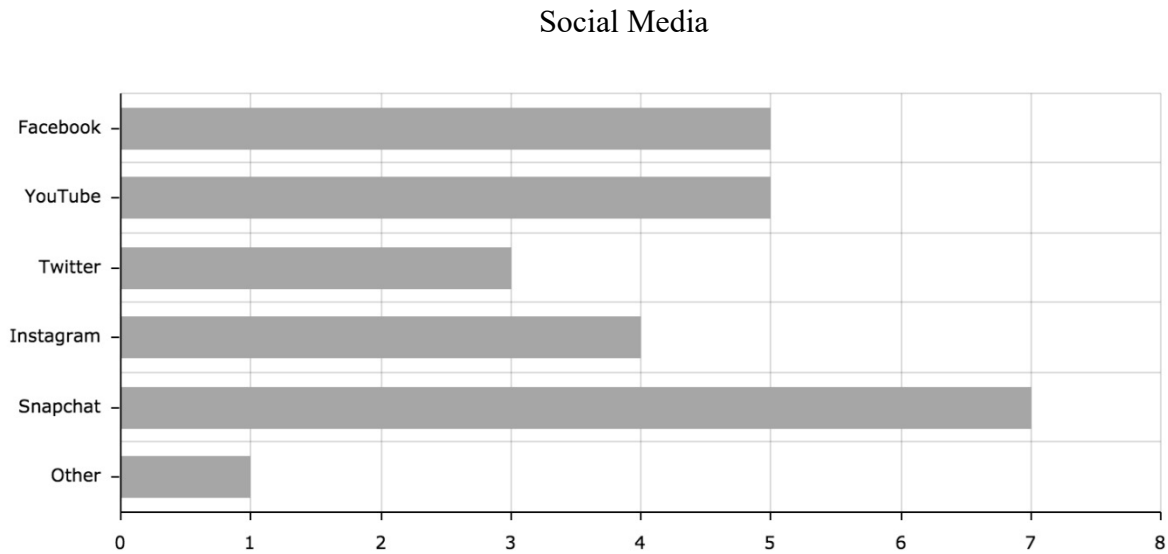


Figure 1. Modes of Social Media used by participants.

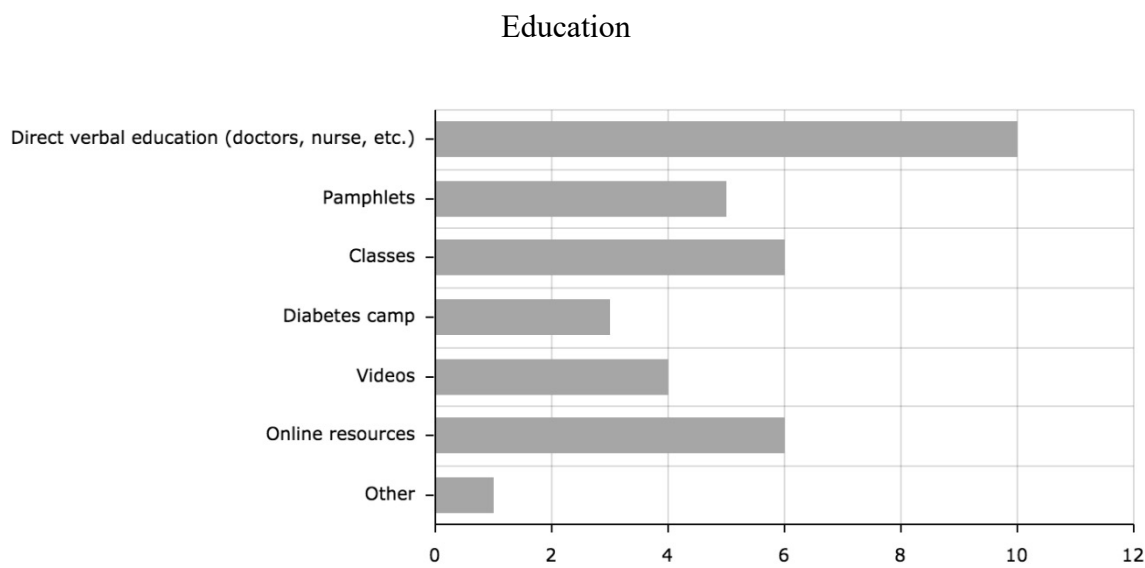


Figure 2. Previous types of diabetes education received by participants.

Appendix A

RESEARCH PARTICIPANT'S BILL OF RIGHTS
STANBRIDGE UNIVERSITY RESEARCH SUBJECT/PARTICIPANT'S
BILL OF RIGHTS

Every person who is asked to be in a research study has the following rights:

1. To be told what the study is about and what will be measured;
2. To be told what will happen in the study and whether any of the procedures, drugs or devices are different from what would be used in standard practice;
3. To be told about important risks, side effects, or discomforts of the things that will happen to her/him;
4. To be told if she/he can expect any benefit from participating and, if so, what the benefits might be;
5. To be told what other choices she/he has and how they may be better or worse than being in the study;
6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study
7. To be told what sort of medical treatment is available if any complications arise;
8. To refuse to participate at all before or after the study is started without any adverse effects. If such a decision is made, it will not affect his/her rights to receive the care or privileges expected if s/he were not in the study.
9. To receive a copy of the signed and dated consent form;
10. To be free of pressure when considering whether s/he wishes to agree to be in the study

Independent Contact: If you are in some way dissatisfied with this research and how it is conducted, you may contact the Stanbridge University Vice President of Instruction.

Appendix B

**PARENT OR LEGALLY AUTHORIZED REPRESENTATIVE
PERMISSION FORM
STANBRIDGE UNIVERSITY PARENT OR LEGALLY AUTHORIZED
REPRESENTATIVE PERMISSION FORM**

(Age 17 or under or Dependent Adults with Disabilities)

Description: Your child or adolescent is invited to participate in a needs assessment to identify how to properly allocate and provide educational resources to help them self-regulate Type 1 Diabetes. This survey will be used to determine whether adolescents will use social media forums or other educational methods as a tool in learning to manage their diabetes and developing healthy habits and routines as they begin to approach their transition into early adulthood. The needs assessment contains questions regarding demographics, preferred form of social media, use of online support groups, type 1 diabetes education history, and preferred methods of education. The needs assessment will be completed online through a secure survey company- esurveycrator®. The participants will not need to disclose any personal information while filling out the survey and all results from the needs assessment will be kept anonymous.

Your Time Involvement: Your participation will take approximately 10-15 minutes, depending on how much time the participant chooses to answer each question. There is no specific time limit in which the survey needs to be completed, but once started, the survey must be completed on that single attempt. You will not be able to save your answers or change answers once the survey has been completed.

Risks and Benefits: The potential risks of completing this survey are very minimal since no physical measures will be performed on your child. Since the survey will be completed online anonymously, participants will not face pressure to answer questions in a certain way to meet the standards of the researcher. If emotional distress occurs, the participant has the option to skip over any question, or withdraw from the study completely. We cannot and do not guarantee or promise any benefits to your child or young adult from this study.

Payment: There will be no payment for participation in this study.

Subject Rights: If you have read and signed this form you are allowing your child or adolescent to participate in this study. Your child or adolescent participation in this study is voluntary and you have the right to withdraw your child or young adult at any point or time without penalty. If you choose not to sign the Stanbridge University Parent or Legally Authorized Representative Permission Form, your child or adolescent will withdraw the option to participate in this study. As stated above, your child or adolescent has the right to refuse to answer specific questions. Your child or adolescent identity will not be

disclosed at any time. The result of this study may be disseminated at professional meetings or published in scientific journals.

Contact Information: If you have any questions, concerns, or complaints about this study you may contact the Faculty Advisor: Adrianna Olch at adriannaolch@gmail.com

Independent Contact: If you are in some way dissatisfied with this research and how it is conducted, you may contact the Stanbridge University Vice President of Instruction.

Please keep a copy of this signed and dated consent form for yourself.

Signature of parent or legally authorized guardian Date

Name of parent or legally authorized guardian (print)

Child's name (print)

Appendix C

Assent Form

Stanbridge University Assent Form (for ages 17 and under)

Study Title: A Needs Assessment for Adolescents with Type 1 Diabetes

1. What will happen to me in this study?

In this survey you will be given the opportunity to tell us about your experiences living with type 1 diabetes. This needs assessment contains questions regarding information about yourself, which types of social media you use, if you use online support groups, what types of education you have received on your type 1 diabetes, your opinion about future methods of education. This study is aimed to give you, the participant, full control over the type of future education you can receive in managing your type 1 diabetes.

2. Can anything bad happen to me?

Nothing bad will happen to you. If at any point you feel uncomfortable answering the questions, you may skip over the question or exit the survey at any time. If you have questions regarding anything you read on the survey, you are allowed to talk it through with your parents. All of your answers will be kept private, and only you and the researchers will know what you answered.

3. Can anything good happen to me?

By filling out this survey, we will get a better understanding of what adolescents, like you, would be most interested in while learning about controlling your Type 1 Diabetes. By giving us your honest answers, we can develop an educational program that was inspired by your specific needs!

4. Do I have any choices during this study?

You are allowed to skip over any question if you want and you can end the survey at any time. However, if you choose to not answer a question or end the survey, you will not be able to retake the survey or change your answers once the survey has been turned in.

5. Will anyone know that I am in this study?

Your participation will be kept secret during this study and the only people that will have the information are the researchers.

6. What if I get hurt, or don't feel right?

If you get hurt or don't feel right at any time your parents should be informed right away. If you feel that the survey is hurting you, you can quit the survey at any time.

7. Who can I talk to about this study?

If you want to talk to someone about this you can talk to your parents or you can contact the research team: Adrianna Olch.

8. If you have questions about the study but want to talk to someone that is not a part of this study, you may call Stanbridge University Institutional Review Board via email at IRB@stanbridge.edu

9. What if I don't want to do this?

If you do not want to participate in this study, you can stop at any time. There will be no bad consequences if you choose to do this.

If you agree to be in this study, please sign here:

Signature of minor

Date

Name of the minor

Appendix D

Needs Assessment Questionnaire- Adolescents with T1D

1. What age were you first diagnosed with diabetes?
2. What is your current age?
3. What is your preferred gender?
 - a. Male
 - b. Female
 - c. Prefer not to answer
 - d. Not listed (please specify)
4. Please specify your ethnicity (Select all that apply)
 - a. White
 - b. Hispanic or Latino
 - c. Black or African American
 - d. Native American or American Indian
 - e. Asian or Pacific Islander
 - f. Prefer not to answer
 - g. Not listed (please specify)
5. In which state do you currently live in?
6. Which form of social media do you use most?
 - a. Facebook
 - b. YouTube
 - c. Twitter
 - d. Instagram

- e. Snapchat
 - f. Other (please state)
7. Do you participate in any social support groups online?
- a. Yes (Please state which ones)
 - b. No
8. Have you received any direct education on management of diabetes?
- a. Yes, they were mostly talking to my legal guardian, but I was in the room
 - b. Yes, they were talking to me and my legal guardian together
 - c. Yes, they were mostly talking to me, but my parents were in the room
 - d. No, I have not received any direct education
9. Which type(s) of education have you received on the management of your disease?
- a. Direct verbal education (doctors, nurse, etc.)
 - b. Pamphlets
 - c. Classes
 - d. Diabetes Camp
 - e. Videos
 - f. Online resources
 - g. Other (please state)
10. Which types of education worked best for you? (Select all that apply)
- a. Direct verbal education (doctors, nurse, etc.)
 - b. Pamphlets
 - c. Classes

- d. Diabetes Camp
- e. Videos
- f. Online resources
- g. Other (please state)

11. Why did that type of education (from previous question) work best for you?

12. Which types of education did NOT work well for you? (Select all that apply)

- a. Direct verbal education (doctors, nurse, etc.)
- b. Pamphlets
- c. Classes
- d. Diabetes Camp
- e. Videos
- f. Online resources
- g. Other (please state)

13. Why did that type of education (from previous question) NOT work well for you?

14. Do you feel like you have or are receiving enough support from your healthcare team?

- a. Yes
- b. No
- c. Some, but not a lot

15. On a scale of 1-10 how do you feel you are managing your disease?

- a. 1- Very Poor
- b. 2
- c. 3

- d. 4
- e. 5- Okay, but could be better
- f. 6
- g. 7
- h. 8
- i. 9
- j. 10- Very Well

16. Why did you give yourself that score? (from previous question)

17. Which area(s) of self-care do you feel you are handling well? (Select all that apply)

- a. Health maintenance
- b. Weight control
- c. Administering insulin
- d. Blood glucose testing
- e. Eating frequency
- f. Emotional well-being (Feelings of depression, anxiety, guilt, stress, and coping methods)
- g. Attending social events
- h. Maintaining/establishing relationships

18. Which area(s) of self-care do you feel you need to improve on? (Select all that apply)

- a. Health maintenance
- b. Weight control

- c. Administering insulin
- d. Blood glucose testing
- e. Eating frequency
- f. Emotional well-being (Feelings of depression, anxiety, guilt, stress, and coping methods)
- g. Attending social events
- h. Maintaining/establishing relationships

19. Do you feel you would benefit from having tips on how to manage diabetes as an adolescent/teen in any of these areas? (Select all that apply)

- a. Coping skills
- b. Becoming more independent
- c. Social support/Social pressure
- d. Creating schedules for timing of meals and insulin doses
- e. Blood glucose monitoring
- f. Being active
- g. Problem solving strategies
- h. Medication management
- i. Suggestions for topics you would find most beneficial (please state)

20. Which platform of social media would you prefer to receive educational material and interventions (please select NO MORE than 5)

- a. Facebook
- b. YouTube
- c. Twitter

- d. Instagram
- e. Snapchat
- f. Pamphlet
- g. Online
- h. Direct Education
- i. Diabetes Camp
- j. Online social support group
- k. Other (please state)