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Type 1 Diabetes Mellitus Self-Management: Combining Research and Technology Within a Singular Facility to Provide T1D with Optimal Self-Management Tool

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Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

SHERIDAN COLLEGE INSTITUTE OF TECHNOLOGY

Type 1 Diabetes Mellitus Self-Management: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

A thesis presented in partial fulfillment of the requirements for the Bachelors Degree of Interior Design, Sheridan College Institute of Technology.

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Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Abstract

Type 1 Diabetes Mellitus is a chronic illness affecting many people around the world and requires a significant amount of knowledge and understanding to properly manage. The lack of general awareness is daunting and impacts Diabetics both physically and mentally. Although there are technological advances and ways to manage it, many fail to realize the difficulty of doing so daily for the rest of their lives as one “cure” does not exist. Many Type 1 Diabetics suffer when faced with hardship that naturally derives from complications with Diabetes and often face secondary illnesses such as anxiety or depression as a result. This study will focus on building essential self-management strategies to ensure T1D’s are receiving the proper information and tools to manage their illness in an optimal fashion. A research questionnaire was conducted to collect data regarding T1D personal experiences and difficulties to better understand which areas of self-management Diabetics struggle with the most. The research found that the areas in which T1D’s struggled the most were time management, mental illnesses due to having Diabetes, funding involved with Diabetes and lack of access to useful technology. Some complications with the study arise due to the personal connection of the researcher to the disease. Another limitation is the sample size of the study which is low and can reduce the accuracy of the study. Through this research, changes to our environments can result in aiding the T1D community. In more depth, Interior Design can benefit a space to support inclusivity and awareness of the Type 1 Diabetes Community to thrive and reduce the amount of work involved with managing the deadly disease.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Introduction

Type 1 Diabetes (T1D) is a disease affecting many children and adults in the world today. Most individuals unaffected by T1D are often ignorant to the many layers of challenges faced daily by T1D patients. One would assume that with the advancement in solutions such as Continuous Glucose Monitors and Continuous Glucose Infusion Pumps self-management has become easier. However, the reality is that while these advancements do assist, they are not one-stop solutions for this difficult to manage disease. There is a lack of understanding of the full process of managing T1D and thus, people are not prepared to deal with the overload of emotional and physical strain it can have on the human body, not only as a patient, but for those in relation to patients. From personal experience, I've learned first-hand the difficulties of self-management when it comes to T1D. Thus, I ask myself if the incorporation of holistic education focused specifically on T1D in a singular facility can help those suffering from proper self-management, until there is an accessible cure. The technology in today's world is remarkable and many steps are being taken towards finding a cure for this chronic illness in the form of auto-immune procedures and the creation of an artificial pancreas. This thesis will not focus on the development of a cure, instead, it will focus on building strategic methods in a singular, mutually accessible environment targeting T1D's to ensure that they can best manage diabetes on their own. It is important to note that self-management is non-binary, and while many patients manage better than others, they still may not be reaching their fullest potential. Helping to build a strong foundation of information and understanding in T1D's will ease this process, which in turn will aid their overall happiness and outlook. This can potentially create a better relationship between the patient and their disease to empower them into establishing a more confident self-

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

management routine. What is currently a vicious cycle of mental anguish, disappointment and sugar lows can be reversed into confidence, pride, and a healthy lifestyle.

Literature Review

The literature supporting the thesis provides extensive research present in support of the variety of factors that affect self-management, however, not an abundance that provides an all-in-one solution. There is a lack of awareness regarding the proven success rate of self-management in Type 1 Diabetic patients and thus solutions are not being presented towards bettering the system of diabetes management. Diabetes is a complicated disease with many ever-changing repercussions that can make the managing phase more difficult than expected. Therefore, it is often known to be a silent deadly disease because it sneaks up on you when you least expect it. It is a silent battle in that people being affected by it are not always aware of the affects/tolls it takes on the human body both short and long term. The communication between T1D patients as well as their caregiver and close friends/family are often lacking due to the inability to control the often-intangible issues. This literature review focused on three distinct themes that all lead back to self-management in T1D patients. The first theme is mental health in diabetic patients and the supportive figures surrounding them such as family and friends. The article by Kaitlyn Rechenberg et al titled “Anxiety and Type 1 diabetes are like cousins’: The experience of anxiety symptoms in youth with Type 1 diabetes” we see a strong correlation between rising anxiety levels in T1D patients. Rechenberg goes on to explain the difficulties of a diagnosis taken in the adolescent stage due to the limitations of self-sufficiency and how critical of a time it is to set healthy habits in line with proper self-management of T1D. The mental ramifications of T1D does not exclude any age and thus the articles by Margaret Power et al

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

provides a more in-depth review of the mental burdens diabetics face including eating disorders, depression and anxiety regarding a wide variety of ages. It gives a further analysis of how the vicious cycle of absent self-care can lead to psychological distress in T1D patients. The other resources by Nicole Johnson and Castensøe-Seidenfaden used in the dissection of this theme talk about the everyday mental struggles that reside with T1D patients such as having a festive meal with your family. A normally happy time for most, can be a stressful time for T1D patients as they face the stresses of not only carb-counting and injection, but social awkwardness of being “different”. It is important for the literature used to collect information beyond the obvious implications of T1D. Expressing the many layers of mental discomfort and challenges presented by both internal and external factors.

The second theme talks about the technological advancements within T1D in modern society. This plays an important role in depicting the different technological innovations created to combat sugar imbalances and regulating the A1C levels. It more importantly discusses the different options available in the medical grade market to create an easier path for T1D patients. The peer-reviewed articles written by Choudhary and colleagues titled “A type 1 diabetes technology pathway: Consensus statement for the use of technology in type 1 diabetes” focuses on two strong pieces of technology at the forefront of T1D treatment in CGMs and CSII. It relies on scientific data to interpret the benefits and disadvantages of the technological advancements mentioned above. Talks of an artificial pancreas emerging in the T1D industry have led Claudio Cobelli and colleagues to research and document findings regarding the technological abilities of the machine and how it will take the role of the pancreas to avoid the current situation placing the burden upon patients. This is crucial to knowing how far the “cure”

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

of T1DM truly is. Kirwan and colleagues also give essential information regarding a free accessible smartphone app directly correlated to T1D patients. The article provides research that proves this app was beneficial to many T1D patients by helping them regulate A1C levels and live a balanced lifestyle. The key thing to note in this article is the importance of accessibility to technology within the T1DM industry, regarding both availability and cost. While not everybody can afford the cost of products like a CGM or CSII, most individuals today do own a smartphone for alternative reasons and can use this as a free tool towards the self-management process. Either way, these articles support that technological availability can absolutely assist in the self-management process. A major difficulty currently targeting the T1D community is the inadequacy in geographic access and affordability of assistance. Hence, it is important to note that any further technological advances created are dampened if it can only be accessed by a small sector of the T1D community. Learning of all the technology currently residing in the market aids in understanding what the general community has access to and what can be done to increase/improve this. This leads into the third and final theme, educational importance, and availability for optimal T1D management. Many Diabetics suffer from hypoglycemic and hyperglycemic episodes throughout their T1D journey. It is a part of the journey to understanding and recognizing the common symptoms and trends that coincide with low and high blood sugars. However, these situations are highly dangerous and require immediate medical attention. They can have ramifications that could injure the patient in both short-term and long-term scenarios, and all it takes is once. Elliott and colleagues discuss how structured educational programs were in direct correlation with reduced instances of ketoacidosis and hyperglycemic episodes as reported in hospitals. This is significant information as hospital costs/reports are the most accurate way of depicting how often T1D patients are crossing into

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

these “danger zones”. The third theme strongly insists that education sits at the core of building a healthy routine in self-management. The articles discussed in the literature review are vital towards reassuring that education does make a significant difference in the bettering of T1D patients who suffer from unbalanced A1C levels. The key, however, is that participation and accessibility is essential. The major players in this literature review are the T1D patients themselves, the “Type 3 Diabetics” (people closely related to/affected by T1D patients), Healthcare systems and organizations, 3rd party support systems and medical device/pharmaceutical manufacturing companies. This literature touches on many major schools of thought that all contribute to the thesis. For one, technology has made great strides in assistive therapy yet not substantial enough to find a “cure”. Another being the mental anguish that can have worse effects on the mind and body than any physical implication. Equally, the school of thought regarding the assistance/knowledge in the T1D community needs to be more readily accessible and affordable with psychosocial considerations. The trends in the literature primarily reside with sincere empathy towards those who suffer from T1D, but do have moments where they challenge those individuals in areas, they simply need to do better themselves. They broaden to explore the extensive qualitative and quantitative research on a variety of topics. These are studies dedicated to mental health, technology, and to various educational methods. The troubling portion of this review was finding literature that concluded a common solution, rather than just available coping mechanisms. This creates a new road of research that can be potentially beneficial towards this thesis. While the advancements in assistive technology are indeed positive (CGMs, CSII) a true “cure” should be the primary objective, and complacency may be at hand. Lastly, the final trend in the literature supports that the public accepts self-management support options are available but they are not being utilized to their fullest potential.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

It is crucial to take into consideration that though options are available, they have not been implemented with the optimal systems to ensure a solid foundation is built in self-management capabilities. The next question to ask is then, does the Healthcare Research and Development Industry truly desire a cure? They make an abundance of money from the medical devices highly beneficial towards helping manage T1D in patients so it can be assumed it is in their best interest to keep the same system. This is a major controversy in the medical world but also heavily present in the literature collected throughout this thesis. Another major controversy that coincides with monetary reward is the capitalization of illnesses and their respective medical equipment. While the economy relies on the money being earned from medical innovations, should an illness triggered without reason be costing a person money despite their inability to be cured or freed from this undesired disease? This is not a disease that is caught by action, it is a genetic lottery. The final controversies revolve around the stigma that sits with T1D patients who struggle to get help at times of need. How can the shame and blame game be put to rest so patients can feel comfortable to admit they are struggling with self-management and need external help? This vicious cycle of lack of self-management resulting in high/low blood sugars often triggers the feelings of failure and disappointment which in turn add to the anxiety and depression many T1D patients are currently suffering from. The key to resolving many issues in the lives of struggling T1D patients lies with the ability to end the shaming of bad self-care and implement educational programs focusing on building a solid foundation. From the literature reviewed, none of the information fully touched base with the entirety of this thesis. Many touched on important themes relating to these, but none covered a combination of all three themes. Thus, I'm hoping this thesis will provide essential information towards helping the T1D

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

community and building a starting line for future researchers to rely on when furthering the concepts summarized through this literature review.

Methods

The research objective in this thesis is to evaluate whether T1D patients who lack control over their illness can benefit from a centralized source of support that offers a wide variety of self-management tools to encourage their T1D journey. This research will be conducted in hopes of analyzing the specific tools T1D patients require to build a healthy relationship with their condition and create healthy routines for optimal management. Both qualitative and quantitative data is critical, as quantitative data will form the foundation to many opinions/views that must be dealt with, but qualitative data is necessary to add context and description to this significantly layered study. I intend to acquire this through a variety of trusted research articles and studies conducted over time. Furthermore, I believe personally conducted anonymous surveys will provide further personal insight to evaluate the validity of my thoughts. Anonymity is key to this survey, as shame and guilt can deviate response from the truth. The test subjects will consist of children and adults ranging from ages 8 years to 60 years of age who have been diagnosed with T1D. While accepting this is a very wide age range, it is critical to compile information from all stages of T1D self-care as the solution I plan to present will be available to all. I intend to sort my findings into age categories to distinguish if there are any disparities. As a 24-year-old Type 1 Diabetic, I can confidently say I struggled greatly with maintaining balanced glucose-levels and thriving health conditions in the beginning. The disappointment can at times feel embarrassing or haunting for failing to flourish given the new technologies in the world. Subsequently, it triggers a lack of care/interest towards bettering the management T1D.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Therefore, if the surveys can remain anonymous, there's a greater chance of subjects signing up. Another measure that can help in attaining subjects for the research is by providing incentives without undermining the intrinsic motivation. To achieve this, attention must be paid to the framing of how the rewards will be given and what reward will entice the subjects to show interest. Lastly, importance will be placed on the structuring of the survey questions and will provide a set of closed-ended questions. This will help the subjects, being of such young age, to express how they are feeling with having to formulate complex thoughts regarding the questions. Ideally, the questions will be presented in an unbiased format yet influenced by previous diabetic experiences from published scholarly journals. The visual appearance of the survey also plays an important role in the outcome of the method. The design of the survey will implement wayfinding strategies regarding the text size, font, and colour as well as the accessibility. At best, the questions create an easy process for the subjects to glide through the survey without hesitation towards their answers. In turn, this will help to ensure their only focus lies with thoughts of familiarity and comfort towards the questions rather than being tainted by the accessibility of the survey. This will be qualitative research to understand the thoughts and experiences of the subjects. If all strategies are implemented correctly, I hypothesize to gather information regarding the everyday struggles (both mental and physical) a T1D patient suffers from. Thus, by learning the most common problems, coping skills and self-management tools can be designed and implemented to improve struggling T1D patients.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Results

The results of the survey showed many outcomes, however, there were 4 evident findings, 1. A lack of funding available to the public regarding specific diabetes supplies 2. The anxiety and depression that derives from diabetes management, 3. Insufficient resources available to the public regarding Type 1 Diabetes management and lastly, 4. The time restriction related with Type 1 Diabetes Management.

Participants were asked to answer questions regarding their daily routine with T1D. The findings showed a commonality between the amount of sugar readings needed to be administered in a single day. 7 out of 8 participants who claimed they maintained a healthy diabetes related routine answered they check their blood sugar levels at an average of 15 times throughout the day. Each glucose reading, according to participants, takes about 5 minutes to both gather the materials and produce a reading. This totals to about 75 minutes per day to properly manage T1D. Participants also reported the time it takes to insulate before meals and once a day for the long-acting insulin dosage. They reported spending about 5 minutes on average in counting carbohydrates and equating the proper dosage depending on their personal ratio. Participants stated in their daily routine they eat 3 main meals and 2 snacks throughout the day totaling to 5 different insulin necessary situations which when translated to minutes per day it totals to about 25 minutes. Thus, according to the data, participants spend about 100 minutes a day tending to typical T1D concerns. Participants described a common problem with the lack of funding revolved around T1D management. When asked “If you could remove/change one thing factor or obstacle from being a T1D, what would it be and why?” 6 out of 8 Participants urged a change in the funding of the insulin and glucose meters supplied to T1Ds all over North America. They

Running Head: *Type 1 Diabetes Mellitus Self-Management: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.*

specified their frustrations regarding the governments support after they turn 25, which in Canada results to zero OHIP coverage for all insulin related products and services. They also exhibited frustration regarding the cost of the products such as the Dexcom 6 (a continuous glucose monitoring system manually inserted into the patient every 10 days that administers blood sugar levels every 5 minutes and digitally transmits this information to a smartphone as well as your registered team of doctors and nurses), insulin pumps, needles, and other forms of sensors. A specific Participant noted, “Free supplies/Insulin because its expensive as buying a car every year.” Which links with another Participant’s answer that stated, “My medical costs are my biggest expenses on a monthly and annual basis.” Overall, Participants largely displayed frustration with the heavy costs incurred from living with T1D such as insulin pump replacements, needles, insulin pens, CGM sensors, GM needles and more. Anxiety and Depression Participants in the study demonstrated a connection between T1D Management and Mental disorders such as Anxiety and Depression. Participants were asked “On a scale of 1-10, 1

being the lowest and 10 being the highest, how much pressure or anxiety do you feel associated with being a type 1 Diabetic?”, 5 out of 8 participants sat in the 6.7-10 range, expressing they felt higher levels of anxiety and pressure to maintain a healthy blood sugar level (refer to table 1). Table 1 depicts the levels of anxiety pertaining to T1D

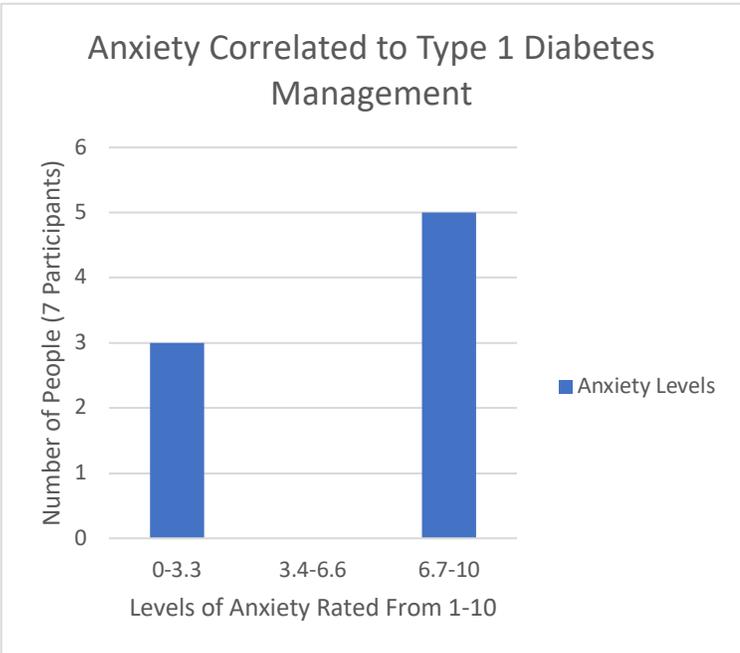


Table 1

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

management and showcases a polarizing outcome. It shows that although some participants don't experience anxiety at a high degree regarding T1D management, the majority experience it at greater levels on the spectrum. Participants also expressed they felt anxiety and depression from having diabetes and be affected by its everyday burdens obligatory to live a healthy, long life. A recently diagnosed participant stated, "I love the new community that I have found from Diabetes, but I hate all the anxiety and depression I have also gained from having diabetes." when asked what they love and hate most about being a Type 1 Diabetic. They also indicated, "I'm always a bit anxious wanting to know how well or bad I have been taking care of my diabetes." When asked how they feel when visiting a Diabetes Clinic or Endocrinologist appointment. Participants also expressed a concern with the lack of mental resources available to the Diabetes Community that helps treat mental anguish such as anxiety and depression. Participants in this study demonstrated a general lack of accessibility to resources that would make Diabetes management simpler. Resources in the study were described as access to endocrinologists, dieticians, diabetic nurses, trainers, psychologist, social workers, new innovate technology such as pumps, CGMs and Insulin. 7 out of 10 Participants reported having a bad or neutral relationship with their caregivers. When asked how they would describe their relationship with their doctors and Diabetic Nurses a participant stated "Terrible. I haven't ever experienced an endocrinologist I like. They treat me like a paycheck and numbers.". Similarly, another participant expressed frustrations with endocrinologists in Canada stating, "My first endocrinologist sent me home with no understanding of my diabetic ratio and carb counting, it wasn't until my mother stepped in and put her foot down that they started treating me more often with better solutions. I have since switched to another doctor, but it seems like a common trend among endocrinologists that they don't have time to answer our (Type 1 Diabetics) questions and

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

concerns. This feels alienating and stressful because they are supposed to be the specialists.” The participant expressed a heavy concern with the Canadian Medical system and how it lacks the necessary support for Type 1 Diabetics to thrive. Other participants had similar responses noting they felt scared and alone while living with Type 1 Diabetes. Particularly, one participant stated “The ADP program in Ontario covers the costs of pump supplies, but not insulin or sensors. Great example of being a disease of the wealthy – if you’re lower SES (Socioeconomic Status), I have no idea how you would manage T1D management well. With higher SES comes knowledge and appreciation for management too.” Claiming the disease relies on wealth to be managed more easily and effectively.

Discussion

The results indicate the major areas that T1D’s face difficulty in managing are a general lack of funding, mental illnesses related to living with T1D such as anxiety and depression, insufficient technological resources available to the public, and time consumed by completing everyday tasks required to properly manage T1D. The results are significant in identifying areas which Interior Design can help simplify the management of T1D. To avoid time staking contingencies access to top-of-the-line technology can help reduce the load of work necessary on an everyday basis as a T1D. This can be implemented in public healthcare settings as well as in corporate spaces to allow T1D patients to thrive in the workplace and in turn feel included. Another large issue related to T1D is the accompaniment of mental disorders such as anxiety and depression. Providing support in a community that promotes inclusivity can create an inviting sensation sure to entice patients into receive forms of therapy essential towards shifting mindsets and reducing anxiety as well as depression. Through open-concept spaces and access to natural

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

light as well as appropriate holistic medical teams, patients can benefit and improve their lifestyle into a healthier practice. Interiors can also heavily impact the knowledge and awareness of the T1D industry using interactive components that can inform users of current trends and most popular and effective products. This technological tool can help bring awareness to the T1D world and in-turn create a more accepting society. Spatial Planning can also help T1D patients if certain factors are implemented to common areas. For example, including needle disposal bins in the washrooms for fast and easy needle disposal. Another example is including diabetic beverages that combat low sugars instantaneously to avoid possible medical complications. If educated about T1D management, the Interior Design industry can create innovative spaces that support the T1D community promote productivity and combat time consumed by proper management as well as create a space that provides technology useful towards bettering their overall health and maintaining good habits. This implementation should help with the mental anguish suffered by T1D's who often feel isolated from society by creating spaces where they feel significant and supported. The results might suggest that there are several areas T1D patients require external support to properly manage their T1D. This could help T1D patients avoid rigorous phases of psychological distress, self-induced disappointment and any damaging physical symptoms related to unmanaged T1D. The data contributes a clearer understanding of the struggles faced by T1Ds on an everyday basis since all participants in the study agreed on how demanding maintaining a consistent routine and healthy mind is. However, there were several limitations due to specific methodological choices. The first being the inability to interview a variety of children in a comfortable space to receive unbiased and honest responses. The participants were asked about previous experiences in their childhood which gave insight into the childhood experience of living with T1D. This information, although contains

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

valuable information which can affect the research study is also unreliable since the participants are no longer in the corresponding age range (8-12) considered children. The second limitation is regarding the 2019 COVID Pandemic currently affecting many civilians across the world. Due to the restrictions passed by governing laws, in-person interviews were heavily discouraged to maintain physical distancing regulations. This made the possibility of creating a personal setting to create a comforting and open environment to receive honest and accurate answers impossible. The reliability of the data is also impacted by the personal connection of the interviewer to the thesis research topic since they share feelings of suffering from T1D. All questions were thoroughly researched and unbiased to ensure the utmost accuracy. The interviews were conducted with composure to avoid unbiased answers from participants.

Annotated Bibliography

Castensøe-Seidenfaden, P., Teilmann, G., Kensing, F., Hommel, E., Olsen, B. S., & Husted, G.

R. (2017). Isolated thoughts and feelings and unsolved concerns: Adolescents' and parents' perspectives on living with type 1 diabetes – a qualitative study using visual storytelling. *Journal of Clinical Nursing*, 26(19-20), 3018-3030. <https://doi.org/10.1111/jocn.13649>

This source is a qualitative study on the experience of not only adolescents with T1D but their parents as well. It speaks specifically on the growth and development of the child's self-management skills, and the concerns it brings from the transition from childhood to adulthood. This information is invaluable to my project as it touches on self-management practices and the struggles faced by not only the patient but by those around them (in this case, their parents).

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Choudhary, P., Campbell, F., Joule, N., Kar, P., Diabetes UK, & on behalf of Diabetes UK.

(2019). A type 1 diabetes technology pathway: Consensus statement for the use of technology in type 1 diabetes. *Diabetic Medicine*, 36(5), 531-538. <https://doi.org/10.1111/dme.13933>

This article provides information into the technology available for T1D patients. This includes two pieces of technology at the forefront of T1D treatment in CGMs and CSIs. Furthermore, it implicates these aids into a designated “pathway” for T1D patients to follow based on their age and difficulties faced, then analyzes their benefits and downfalls. Regarding my project, this is critical information as I am assessing self-management as a whole. This technology and its abilities are key to my research.

Cobelli, Claudio, et al. "Artificial pancreas: past, present, future." *Diabetes*, vol. 60, no. 11, 2011, p. 2672+. Gale Academic OneFile, https://link.gale.com/apps/doc/A273194487/AONE?u=ko_acd_shc&sid=AONE&xid=63463c8

This article provides a highly detailed look into the development of an artificial pancreas, otherwise seen as the “cure” to T1D. It highlights both how far technological advancements have come, and the current obstacles being faced that separates concept from reality. Though I stress in my project that “cure” is not the objective of my research, it is important to understand what

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

separates us from that end goal, so we can better comprehend the task at hand in self-management until we get there.

Elliott, J., Jacques, R. M., Kruger, J., Campbell, M. J., Amiel, S. A., Mansell, P., Speight, J., Brennan, A., & Heller, S. R. (2014). Substantial reductions in the number of diabetic ketoacidosis and severe hypoglycemia episodes requiring emergency treatment lead to reduced costs after structured education in adults with type 1 diabetes. *Diabetic Medicine*, 31(7), 847-853. <https://doi.org/10.1111/dme.12441>

This article is a supporting piece towards the article listed below. It is conducted by the same author with a slightly shifted focus. Our author carries the intent of highlighting the reduction of costs on the healthcare system & its patients with a reduction in the number of ketoacidosis and hypoglycemic episodes. While this is found true, it is not my key takeaway from the article. My value within this article is derived from “how” these severe episodes were reduced. The answer being, a strong educational process, which led to a better self-management system and less of a need for extreme care. Supporting my theory that education is a critical part of effective self-management.

Elliott, J., Rankin, D., Jacques, R. M., Lawton, J., Emery, C. J., Campbell, M. J., Dixon, S., Heller, S. R., NIHR DAFNE Research Study Group, & the NIHR DAFNE Research Study Group. (2015). A cluster randomized controlled non-inferiority trial of 5-day dose adjustment for normal eating (DAFNE) training delivered over 1 week versus 5-day

Running Head: *Type 1 Diabetes Mellitus Self-Management: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.*

DAFNE training delivered over 5 weeks: The DAFNE 5 × 1-day trial. *Diabetic Medicine*, 32(3), 391-398. <https://doi.org/10.1111/dme.12621>

This article is focused on a specific educational programme entitled DAFNE. It compares two variations of this T1D focused education and assesses their effectiveness accordingly. The article concludes that neither option was more beneficial than the other, simply that the existence of structure itself, and participation, being the key to making a difference. This is important to my project as education is one of the key components, I highlight towards an effective self-management process. It shows validity in its role towards a successful routine.

Harris, S., Miller, A., Amiel, S., & Mulnier, H. (2019). Characterization of adults with type 1 diabetes not attending self-management education courses: The barriers to uptake of type 1 diabetes education (BUD1E) study. *Qualitative Health Research*, 29(8), 1174-1185. <https://doi.org/10.1177/1049732318823718>

This article challenges why educational/self-management courses are ineffective, specifically among adults. It not only finds that lack of attendance is a common issue but dives deeper into the “why” lack of attendance exists. It finds that most of these reasons are internalized, rather than physical limitations. As my project focuses on the importance of creating an improved self-management system for T1D patients, it is essential for me to understand the deterring factors within a population that is currently not taking the necessary steps. This information will assist me in creating reasonable solutions to the obstacles it highlights.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Johnson, Nicole. "LIFE WITH DIABETES INTENSE, EMOTIONAL; Type 1 diabetes can be exhausting to families coping with the disease, especially parents. And the continuous holiday food intensifies the struggle. There is a new project to help families." St.

Petersburg Times [St. Petersburg, FL], 18 Dec. 2010, p. 9. Gale OneFile:

News, https://link.gale.com/apps/doc/A244985747/STND?u=ko_acd_shc&sid=STND&xid=0bb7b7b3

This article draws attention to the mental and social burdens of T1D. It uses many real life, everyday examples such as a holiday meal and the stresses it creates on both the patient and the surrounding family and friends. It highlights the concept of Type 3 Diabetes in describing somebody who themselves is not a patient but is suffering vicariously through being in close relation to somebody that is. It is also important to note that it is written by somebody who has T1D herself, adding a layer of validity that is appreciated. Though the word self-management has “self” within it, a strong supporting cast is critical in the life of somebody with T1D. I will use this information to shape auxiliary support programs to further my goal of creating a more sustainable self-management system.

Karlsen, B., Idsoe, T., Dirdal, I., Rokne Hanestad, B., & Bru, E. (2004). Effects of a group-based counselling programme on diabetes-related stress, coping, psychological well-being and metabolic control in adults with type 1 or type 2 diabetes. *Patient Education and Counseling*, 53(3), 299-308. <https://doi.org/10.1016/j.pec.2003.10.008>

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

This research presents an alternative option to an educational platform in the structure of a group-based counselling programme. In hopes that being surrounded by peers, patients will be more willing to attend, participate and grow from the information provided. The research determined that there was a direct correlation in those that attended and their blood glucose levels improving. This evidence is key towards supporting my premise that education and social support are critical components towards a stronger self-management process. Furthermore, it provides an important variability to my research to see an educational avenue aside from a doctor's office, one on one medical meeting, or informative pamphlet.

Kirwan, M., Vandelanotte, C., Fenning, A., & Duncan, M. J. (2013). Diabetes self-management smartphone application for adults with type 1 diabetes: Randomized controlled trial. *Journal of Medical Internet Research*, 15(11), e235. <https://doi.org/10.2196/jmir.2588>

In this article, a different form of assistive technology is explored in a smartphone application which is free and used to assist in the tracking of blood glucose levels. There is no direct medical "plug-in" and the only cost involved in the research is having a smartphone. Though it is not a given that everybody has a smartphone, it is safe to say that this is a more accessible and pre-existing form of technology than a CGM or CSII. The research concluded that users of this free application were better able to self-manage their T1D symptoms, reinforcing that there are alternative forms of technology available to assist patients who are unable to afford more advanced solutions. In importance to my project, this breaks down barriers that could be used to debate the validity of technology being accessible.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Murphy, H. R. (2012). Education, technology, and psycho-technological approaches to type 1 diabetes. *Practical Diabetes* (2011), 29(6), 247-251a. <https://doi.org/10.1002/pdi.1701>

This article is vital to my project, as it directly discusses the gap between the expectations of self-management and the reality of achieving it. It highlights several shortcomings and vulnerable moments (adolescence and pregnancy) that shape any given patient's behaviours. It gives credit to technological and pharmaceutical advances as well as educational programmes but concedes that much more is needed to overcome the “fundamentally disordered pathways” and “additional challenges” as a more personalized approach is deemed necessary for utmost success in self-management.

Pettus, J., Pettus, J., Von Herrath, M., & Von Herrath, M. (2018). The shifting paradigm of a “cure” for type 1 diabetes: Is technology replacing immune-based therapies? *Acta Diabetologica*, 55(2), 117-120. <https://doi.org/10.1007/s00592-017-1069-8>

This article digs deeper into the term “cure” and places realistic expectations in regard to how far away from it we are. It gives credit to what we have accomplished in reducing the burden of T1D but concedes that nothing has yet been successful in true therapy. We are a type of people to suffer in wait, rather than do the extra effort as we wait. This sets the tone for the current state which I claim we are in, at a critical crossroads between cope and cure, with a stronger focus needing to be placed on self-management given the “cure” is in the much distant future.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Powers, M. A., Richter, S. A., Ackard, D. M., & Craft, C. (2017). Diabetes distress among persons with type 1 diabetes: Associations with disordered eating, depression, and other psychological health concerns. *The Diabetes Educator*, 43(1), 105-113. <https://doi.org/10.1177/0145721716680888>

With the physical implications of the disease being apparent, this article provides a more in depth look of the mental ramifications faced by somebody who suffers from T1D. It lists disordered eating, depression, and anxiety as three of many psychological health concerns triggered by T1D. It goes on to explain how this induces a vicious cycle of lack of self-care, which then in turn reforms back into psychological distress. It is important for my project to understand this cycle, as successful self-management would incorporate a means of breaking this negative cycle and creating a positive one.

Rechenberg, K, Grey, M, Sadler, L. (2018)“ Anxiety and Type 1 diabetes are like cousins”: The experience of anxiety symptoms in youth with Type 1 diabetes. *Res Nurs Health*. 2018; 41: 544– 554. <https://doi-org.library.sheridanc.on.ca/10.1002/nur.21913>

Mental health is a focal point of this article, specifically regarding anxiety levels in T1D youth. It expands on how the most difficult age to deal with T1D is in adolescence, which coincidentally happens to be the most common time of diagnosis and furthest reach from self-sufficiency. It also expands on how this is a critical time to lay the foundation of good habits towards self-management and the obstacles that anxiety presents in the ability to do so. In my project, it is equally important to service all ages and stages of the T1D journey. The more age-

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

dedicated obstacles I understand, the more effective I can be in presenting solutions towards a strong self-management process.

Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

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Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

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Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

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Running Head: *Type 1 Diabetes Mellitus Self-Management*: Combining research and technology within a singular facility to provide T1D with optimal self-management tools.

Appendices

Thesis Research Questions: Type 1 Diabetes Management

The following questions are directed to Type 1 Diabetes Patients only. Any information that is obtained in connection with this study and that can lead to your identification will remain confidential. All questionnaire data will be kept strictly confidential.

By accepting, you are confirming that you've read the introduction letter, consent form and informed consent form given by the researcher and agree to have read the explanation provided. All your questions regarding the study have been answered to your satisfaction and you voluntarily agree to participate in this study

1. As a Type 1 Diabetic patient, what do you love and hate most about Type 1 Diabetes?
2. How does it make you feel when visiting diabetes centers or routine check ups at the doctors?
3. How would you describe your relationship with your Doctors and Diabetic Nurses?
4. Over the course of your Type 1 Diabetes journey, do you feel you have received suitable education on how to properly manage it?
5. Do you ever feel lost or confused as to how to deal with a situation regarding Type 1 Diabetes?
6. On a scale of 1-10, 1 being the lowest and 10 being the highest, how often do you struggle talking about the problems you face directly and indirectly regarding Type 1 Diabetes?
7. On a scale of 1-10, 1 being the lowest and 10 being the highest, how much pressure or anxiety do you feel associated with being a Type 1 Diabetic?
8. How does it make you feel when you see high (above 10 mmol/L) or low (below 3 mmol/L) numbers on your glucose readings?
9. Describe your daily routine in relation to Type 1 Diabetes management.
10. On a scale of 1-10, 1 being the lowest and 10 being the highest, how responsible are you in frequently measuring your sugars and insulating?
11. If you could remove/change one factor or obstacle from being a Type 1 Diabetic, what would it be and why?
12. Within practical reason, what would be one thing that you could add to your life, or be offered to you, that would help make managing your Type 1 Diabetes easier?