

Adlerian Art Therapy: Navigating the Chaos and Uncertainty of Type 1 Diabetes

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Abstract

The literature review focuses on Type 1 diabetes (T1DM). T1DM is an autoimmune chronic illness that causes physiological chaos and psychological uncertainty. The self-management of T1DM can interfere with the three life tasks (work, friendship, and love) by creating distress, inferiority feelings, decreased feeling of belonging, and increasing depression and anxiety. Psychological assessment throughout the lifetime of a person with T1DM, no matter what HbA1c levels, would be favorable. There are implications that the navigation of a life with T1DM through the use of Adlerian art therapy can foster hope, motivation, and encouragement. This researcher speculates art therapy can be an effective process for developing coping skills and gaining a sense of control in relation to T1DM. And people with T1DM who attend group art therapy, may immediately feel understood by peers, which generates a feeling of validation and increases their self-care. Which, in turn, improves the level of functioning in the three life tasks.

Keywords: art therapy, Adler, Type 1 diabetes, chronic illness, Three Life Tasks, belonging, inferiority feelings, hope, fear, depression, anxiety

Acknowledgements/Dedication

I wish to express appreciation and great love to my partner, Conor, and our two sons, Dominic and Drake. I am honored to be a part of their lives. They unknowingly give me daily courage and constant motivation to manage my T1DM to the best of my ability. And with gratitude, I would like to thank all the people with T1DM who I have crossed paths with. I have been inspired by their strength and resilience. You do not go unnoticed by this fellow *Type One*.

Table of Contents

Abstract	2
Acknowledgements/Dedication	3
Introduction.....	6
Chaos: Type 1 Diabetes Mellitus (T1DM)	8
What is Type 2 Diabetes?	9
Basic Physiology of Type 1 Diabetes	10
Insulin therapy	10
Nutrition and exercise (input vs. output)	12
Hypoglycemia and hyperglycemia (lows & highs)	13
HbA1c test	14
Diabetic ketoacidosis	15
Technology	17
Additional chaos	17
Self-management	19
Summary.....	21
Uncertainty: Adlerian Conceptualization of Psychological Implications of T1DM	23
Work Task.....	24
Inferiority Feelings.....	27
Stigma & Myths	32
Friendship Task & Belonging.....	36
Online Support Groups	37
Love Task & Encouragement	39
Depression & Anxiety.....	42
Summary.....	44
Navigation: Adlerian Art Therapy and T1DM	46
Coping.....	48
Control	49
Chronicity	50
Importance of Group Therapy	53
Conclusion	56

Areas of Further Research 59

References 62

Appendix A..... 69

Navigating the Chaos and Uncertainty of Type 1 Diabetes

Introduction

People with Type 1 diabetes (T1DM) are at risk of being inflicted with psychological dysfunction. T1DM subjects them to chaos and uncertainty that can be difficult to navigate. The number of people developing T1DM is steadily rising around the world, and it is not known why. Currently every year in the United States 40,000 people are newly diagnosed and 1.25 million American kids and adults deal with the disease every day. Between 2001 and 2009 there was a 21% increase in the prevalence of T1DM in people under the age of 20. Five million people in the U.S. are expected to have T1DM by 2050. Statistics identify that approximately 80 people per day are diagnosed with T1DM in the U.S. (Juvenile Diabetes Research Foundation [JDRF], 2016).

Research reveals there are implications that people with T1DM deal with stigma and face fatigue in relation to the burden of self-management (Engbretson, 2013; Fairchild, 2015). They also experience depression and anxiety at higher rates than those without chronic illness (Pinquart & Shen, 2011; Rassart, Luyckx, Bijttebier, Berg, & Moons, 2015; Shaban, Fosbury, Kerr, & Cavan, 2006). The physical demands and psychological impact are intertwined, meaning the psychological status of a person with T1DM directly affects self-management and vice versa (Due-Christensen, Zoffmann, Hommel, & Lau, 2012). This can become a vicious cycle with real consequences. Therefore finding solutions to aid in the lifelong management of the disease, not only the physiological aspects, but the psychological aspects as well, would be invaluable to the overall well being of those with T1DM.

The focus of this paper will be on the challenges facing a person being diagnosed with T1DM. T1DM is a complex chronic disease and receiving the diagnosis is tragic. Facing the

disease's challenges takes courage and perseverance. The illness impacts every single aspect of a person's life (Due-Christensen et al., 2012; JDRF, 2016). Looking through an Adlerian lens, this paper will discuss the effect T1DM has on Adler's three life tasks, work, friendship, and love (Ansbacher, 2011). Persons diagnosed with T1DM can be overwhelmed to have to cope with feelings of loss, guilt, and fear. Their ability to maintain a sense of control and foster hope can come and go. A diagnosis of T1DM can have a negative effect on a person's sense of belonging and self-worth (Balfe, Doyle, Smith, Sreenan, Brugha, et al., & 2013; Reed, Kennedy, & Wamboldt, 2015). Feelings of inferiority may increase and encouragement becomes an essential part of coping (Due-Christensen et al., 2012). In addition, people with T1DM deal with stigma.

Medical professionals are exceptional at diagnosing chronic illnesses, but research suggests there is a need in continued care for those with chronic illness over the course of their lifetime, not just at time of diagnosis (Swendenman, Ingram, & Rotheram-Borus, 2009). There is additional research supporting art therapy as one solution to aid in the psychological care of those with T1DM. Art Therapy can be used to create a sense of belonging, overcome feelings of inferiority, and foster encouragement in those with T1DM. By learning new ways of coping, identifying what can be controlled, and forming and maintaining new relationships may prove to be beneficial to a person with T1DM's overall psychological welfare (Due-Christensen et al., 2012; Malchiodi, 2003; Reed et al., 2015). Adlerian Art Therapy techniques can be used to successfully treat the psychological implications that occur as a result of navigating a life with Type 1 diabetes.

It should be noted that I, the writer, am a person living with T1DM. I was diagnosed at the age of 19. I have been navigating both the chaos and uncertainty that the illness creates through the use of art making and at times psychotherapy. There have been many ups and downs

in the 13 years living with the disease, from hospital stays (which include near death experiences) to acknowledging my own strength and being proud of my newfound capacity of resilience. Each day is a new beginning and people with T1DM are not “the numbers” that surround and inundate their everyday life. And sometimes doctors are wrong. This author’s firsthand T1DM life experience, along with the presented research support, will provide crucially important information about the complexity of T1DM and how living with the invisible chronic illness impacts interactions and relationships. With my inherent biases in mind, this literature review is intended to advance the profession by bringing a combination of T1DM and psychological research to the attention of others, including those who have T1DM, family members, friends, teachers, nurses, doctors, therapists, and anyone else interested in the multifaceted effects of T1DM.

Chaos: Type 1 Diabetes Mellitus (T1DM)

Chaos is defined as a state of things in which chance is supreme; the inherent unpredictability in the behavior of a complex natural system; a state of utter confusion (Chaos, n.d.)

Type 1 diabetes mellitus (T1DM) is a physical chronic autoimmune illness of the body. Autoimmune, specifically in relation to T1DM, simply means the body’s immune system mistakenly attacks and destroys the insulin-producing beta cells in the pancreas that it believes to be foreign (American Diabetes Association [ADA], 2016). Chronic illness is defined by Compas, Jaser, Dunn and Rodriguez (2012) as “a health problem that is prolonged, rarely cured, and often causes impairment in activities of daily living” (p. 472). It is a disease or illness that lasts indefinitely. It is ceaseless. It is unending. There is no cure for T1DM. Insulin is needed to stay alive; via multiple daily injections or insulin pump, but insulin is not a cure. Insulin is a treatment that will be needed for the rest of the person’s life. The following sections help explain

in more detail a myriad of other tasks that a person with T1DM is subjected to including, but not limited to, knowing the ins and outs of nutrition and exercise, encountering many blood tests, prevention of diabetic ketoacidosis (DKA), continually learning various new technologies, fear of future complications, possibility of co-occurring disorders, and the self-management of it all. In essence, T1DM is a serious chronic illness, with a simple physiological explanation and multiple complex management requirements (see Appendix A for additional definitions of terms related to T1DM).

What is Type 2 Diabetes?

When discussing T1DM it is important to mention Type 2 diabetes (T2D), they often times get confused. There are similarities between the two illnesses, but the differences are quite substantial. T2D is the most common form of diabetes and physiologically is a metabolic disorder. T2D differs from T1DM because the pancreas is still making insulin, but the body is not using it properly, which is called *insulin resistance*. Early on, the pancreas makes extra insulin to make up for it. But, over time the pancreas isn't able to keep up and can't make enough insulin to keep blood glucose levels normal. T2D is treated with lifestyle changes (i.e. diet & exercise), oral medication, and sometimes insulin (ADA, 2016).

The main difference being that T1DM is an autoimmune disorder, while T2D is a metabolic disorder. Most often T1DM is diagnosed in children and young adults, while T2D is more commonly diagnosed in older adults. "Type 2 is still extremely rare in children and adolescents but these rates are increasing rapidly with rising obesity rates" (Compas et al., 2012, p. 456). Insulin is absolutely necessary for those with T1DM and is only sometimes used with T2D patients. T2D receives quite a bit more media attention, which will be discussed later in relation to stigma (Balfe, Doyle, Smith, Sreenan, Brugha et al., 2013). T2D is a serious illness in

its own right. But lumping two different diseases together because they have similar names can be toxic for both parties involved.

Basic Physiology of Type 1 Diabetes

Currently, the cause of T1DM is unknown. Contrary to popular belief, the causes of T1DM are not yet entirely understood. Scientists believe that both genetic factors and environmental triggers are involved. Its onset has nothing to do with diet or lifestyle. There is nothing you can do to prevent T1DM, and—at present—nothing you can do to get rid of it. T1DM seemingly comes out of nowhere. The warning signs consist of extreme thirst, frequent urination, lethargy or drowsiness, increased appetite, sudden weight loss, sudden vision changes, fruity odor on breath, heavy or labored breathing, stupor or unconsciousness (JDRF, 2016). Stated previously, and simply put, T1DM is an autoimmune disorder of pancreas. “The pancreas stops producing insulin, a hormone that enables people to get energy from food. It occurs when the body’s immune system attacks and destroys the insulin-producing cells in the pancreas, called beta cells” (JDRF, 2016). Since the pancreas no longer produces insulin, a person with T1DM has to inject it. Hackworth et al. (2013) state “the management of which requires a strict daily regimen of insulin injections or continuous infusion through a pump, finger-prick blood tests, and dietary monitoring” (p. 360).

Insulin therapy. Insulin became available in 1922, less than 100 years ago. Prior to the development of insulin, ‘starvation’ diets were used in hope to control blood glucose levels. These diets consisted of little to no carbohydrates and in the end only extended life a modest amount, while increasing the risk of infection and poor quality of life. Before insulin the prognosis for people with T1DM was very grim. Death would occur by deterioration and coma

within 2 years following confirmation of a diagnosis (Hilgenfeld, Seipke, Berchtold, & Owens, 2014).

On January 23, 1922, a 14 year old named Leonard Thompson, was the first person to receive insulin injections. The following year, 1923, Frederick Banting and John James Rickard Macleod received the Nobel Prize in Medicine for their discovery of insulin. Charles Best and James Collip played large roles in the development as well (Hilgenfeld et al., 2014).

The development of insulin promised brighter futures for those diagnosed with T1DM, by generating “significant gains in both life expectancy and quality of life” (Hilgenfeld et al., 2014, p. 923). Fairchild (2015) describes how “in 1964, the ‘state-of-the-art’ treatment consisted of one or occasionally two injections a day of animal-sourced, relatively impure insulin. Insulin was administered with a reusable glass syringe and needle. Glucose monitoring consisted of urine testing with tablets or tapes one to four times a day. Families and health professionals had no idea of the true blood glucose levels, but HbA1c would have been greater than 9% in the majority of patients” (p. 122). It wasn’t until the 1980’s that semi-synthetic insulin became clinically available. Previously, insulin was porcine – and/or bovine- based (i.e. pig and/or cow). In addition, it wasn’t until the year 2000, that insulin glargine (24 hour/long-acting/basal insulin therapy) was approved for widespread use (Hilgenfeld et al., 2014).

The development of insulin has come a long way in a very short period of time. Insulin itself has continued to be perfected, resulting in rare skin reactions and allergies. Today there are multiple types of insulin that are available to people with T1DM and T2DM, depending on needs. The mortality rate has fallen significantly over the last 50 years (Fairchild, 2015). Although, T1DM is currently associated with an estimated loss of life-expectancy of up to 13 years (JDRF, 2016).

Nutrition and exercise (input vs. output). The diet of a person with T1DM varies from person to person. Different foods affect each individual differently. A diet consisting of fruits and vegetables, low in complex carbohydrates is the most basic. A carbohydrate is one of the three main nutrients in food. Foods that provide carbohydrates are starches, vegetables, fruits, dairy products, and sugars. Carbohydrate counting is a method of meal planning for people with diabetes based on counting the number of grams of carbohydrates in food (ADA, 2016). When it comes to food and drinks that are put into the body, every single carbohydrate must be accounted for; this determines the amount of insulin that is required to “cover” the food. Measuring everything accurately that is eaten is at times unrealistic, therefore errors in calculation are inevitable.

Buyken et al. (2000) assessed the relation of carbohydrate intake to HbA1c levels in 2084 participants, it was found that people with T1DM may benefit from a higher consumption of vegetable carbohydrates, rather than fruit, potato, and cereal. An increase in fiber was associated with a decrease in HbA1c. This supports the nutritional recommendation for people with T1DM that total carbohydrate intake may vary according to individual preference, but should be provided by carbohydrate sources rich in dietary fiber. In addition, Fleet Michaliszyn, Shaibi, Quinn, Fritschi and Spezia Faulkner (2009) investigated cardiovascular fitness and dietary intake. The main finding being “cardiovascular fitness and daily intake of saturated fat, rather than total fat, play an important role in overall metabolic health” (Fleet Michaliszyn et al., 2009, p. 392).

People with T1DM are sometimes deterred from exercise because managing blood glucose levels can be difficult, this contributes to the fact that less than 40% of people with T1DM are physically active. Another explanation is the fear or experienced exercise-induced

hypoglycemia (Bohn et al., 2015; Kilbride et al., 2011). “In the past, many physicians were reluctant to believe exercise was beneficial for individuals with T1DM; some even surmised that exercise might exaggerate complications” (Loganathan, Searls, Smirnova, & Stehno-Bittler, 2006). Currently there is a limited evidence base to aid people to exercise safely. One study, by Kilbride et al. (2011) explained the necessity for practical guidelines for the control of blood glucose when participating in physical activity, but also acknowledged the difficulty of carrying out such studies because of all the potential variables that may affect blood glucose levels when exercising. They did provide valuable baseline information for people with T1DM who wish to exercise, it was found that 40 minutes of moderate intensity exercise decreases glucose by 3 mmol/l with or without a 30% decrease of insulin before exercise (Kilbride et al., 2011, p. 3428). Exercise is beneficial overall, but it can take some time to understand how a person’s body will respond to particular exercise and duration. The majority of people with T1DM will need less insulin when they are exercising, or will need more while exercising but less an hour or two after. Again, it depends on the amount and kind of exercise, along with what food has been eaten before, during, and after. People with T1DM strive to find the delicate balance of dietary carbohydrate intake, exercise, and insulin needs.

Hypoglycemia and hyperglycemia (lows & highs). People with Type 1 diabetes must be constantly vigilant about episodes of hyperglycemia or hypoglycemia, both of which can be life threatening (Hackworth et al., 2013). Less than one-third of people with T1DM in the U.S. are achieving target blood glucose control levels (JDRF, 2016). *Hypoglycemia* (aka *lows*) can seemingly come out of nowhere and stop a person in their tracks. The participants in Trief, Sandberg, Dimmock, Forken and Weinstock’s 2013 study described hypoglycemia as “the worst feeling” and “life and energy draining” (p. 2485). The symptoms can include shaking,

disorientation, sweating, slurring of speech, or sometimes no symptoms until a coma. There is not enough sugar in the blood. Treatment of lows include eating just about anything with carbohydrates, simple sugars are quicker acting, and therefore they are the go to, such as orange juice, glucose tabs, or candy. A *glucagon kit* is an emergency injectable glucose. It is used to counteract severe hypoglycemia that causes loss of consciousness, or if food cannot be given (ADA, 2016). This life saving tool is only useful if someone besides the person with T1DM knows about it. People with T1DM describe constant vigilance to protect themselves and family from burdens related to lows (Trief et al., 2013, p. 2485).

Hyperglycemia (aka *highs*) is more gradual in onset and can usually be traced back to a reason such as miscalculated carbohydrates (not enough insulin), insulin pump obstruction, forgetting to take insulin all together (this happens), forgetting whether or not insulin has been taken and waiting to see if the numbers rise. Symptoms of hyperglycemia include, but not limited to, extreme thirst and urination, nausea, tiredness, overall unwell feeling. Basically, there is too much sugar in the blood system.

There is a name for a spike in blood glucose after experiencing hypoglycemia it is called *Somogyi effect* or rebound hyperglycemia (ADA, 2016). This can happen when too many carbohydrates are ingested during a low. The blood glucose rises too high and the infamous “rollercoaster” can occur. This experience causes not only physical exhaustion, but may also add to mental exhaustion and self-blame.

HbA1c test. People with T1DM typically receive the HbA1c test at their quarterly endocrinologist appointment. Hare, Shaw, and Zimmet (2012) define hemoglobin A1c (HbA1c) as “a molecule of HbA with glucose bound at the N-terminal valine” (p. 227). Essentially, HbA1c is known to correlate with average blood glucose levels over the preceding 3 months.

HbA1c measurement was introduced into “widespread clinical use during the 1980’s as a marker of glycemic control in people with diabetes” (Hare et al., 2012, p. 227). According to Hare et al. (2012) it was not until “2009 that an international expert committee recommended HbA1c be introduced into diagnostic criteria at a threshold level of >6.5%. This recommendation was adopted by the American Diabetes Association the following year and more recently by the World Health Organization” (p. 231). It has become an integral part of T1DM management.

There are two reasons the HbA1c test is valuable, for both diagnosing diabetes and assessing those who already have T1DM. First it gives an indication of glycemia over a period of time, rather than being a test of glycemia at a single point in time. Secondly, it is relatively convenient for patients since fasting is not required and only a single/simple blood sample is needed, which can be done right in the doctor’s office (Hare et al., 2012). The A1c target rate for most people with T1DM is <7.5% (Fairchild, 2015).

Diabetic ketoacidosis. Wolfsdorf et al. (2009) define *diabetic ketoacidosis* (DKA) as resulting from “absolute or relatively deficiency of circulating insulin and the combined effects of increased levels of the counter-regulatory hormones: catecholamines, glucagons, cortisol and growth hormone” (p 118). DKA is a life-threatening emergency. The body is unable to use glucose as an energy source due to lack of insulin. The body breaks down fatty acids as an alternative energy. This energy release produces toxic, acidic ketones as by-products, which accumulate in the blood resulting in acidosis (Davidson, 2014; Wolfsdorf et al., 2009). DKA occurs in previously undiagnosed people with T1DM and when those on treatment deliberately or inadvertently do not take insulin.

There usually is an important psychosocial reason when insulin is deliberately not taken. Wolfsdorf et al. (2009) give examples as to why insulin would not be taken, they include “an

attempt to lose weight (known as *diabulimia*), a means of escaping an intolerable or abusive home situation, clinical depression, or any other reason for inability to manage T1DM unassisted” (p. 127). Miller et al. (2015) found a correlation that indicated that “the DKA risk was increased in participants with A1c levels >9%, which suggests that poor compliance with their diabetes regimen contributes to the increased risk of DKA” (p. 975).

Inadvertently not receiving insulin may be due to an insulin pump failure; those with a pump can rapidly develop DKA when insulin delivery fails for any reason. Any trauma, sepsis, or gastrointestinal illness with diarrhea and vomiting can also lead to DKA. Sick days for those with T1DM become extremely important to monitor.

The symptoms of DKA include dehydration, rapid/deep sighing (Kussmaul respiration), nausea, vomiting, abdominal pain, progressive obtundation (less than full alertness), or loss of consciousness. DKA is characterized by severe depletion of water and electrolytes. Despite dehydration, Wolfsdorf et al. (2009) declares “patients continue to have considerable urine output until extreme volume depletion and shock occurs”. This then leads to a “critical decrease in renal blood flow and glomerular filtration” (p. 119). It is also stated, “if the cycle of “DKA is not interrupted by exogenous insulin, fluid and electrolyte therapy, fatal dehydration and metabolic acidosis will ensue” (p. 118). There is “extensive evidence that indicates that *low dose* IV insulin administered” (p. 123). Therefore, the treatment of DKA requires a hospital visit (emergency room) and depending on the severity at the time of arrival the stay could be days or weeks. The incidence of DKA has not significantly changed over time. And unfortunately, DKA remains the leading cause of diabetes-related death in children and adolescents (Davidson, 2014; Fairchild, 2014).

Technology. Technological advances are causing people with T1DM to live longer (Compas et al., 2012; Miller et al., 2015; Swendeman et al., 2009). New insulin analogs (rapid- and long-acting insulin) are being developed all the time. Currently there are a few different insulin delivery options for people with T1DM. They include syringe and vial, insulin pens, or insulin infusion pumps (Miller et al., 2015). Insulin pumps are very common among people with T1DM. An insulin pump is an insulin-delivering device about the size of a deck of cards that can be worn on a belt or kept in a pocket. It connects to a thin and flexible plastic tubing that ends with a needle inserted just under the skin. Users set the pump to give a steady trickle or basal amount of insulin continuously throughout the day. Pumps release bolus amounts of insulin (several units at a time) at meals and at times when blood glucose is too high, based on programming done by the user (ADA, 2016). Insulin is the essential requirement for a person with T1DM, whether it comes from a pump or syringe is more of a preference of the person with T1DM than anything else.

Glucose meters are currently widely available and are made to be as convenient as possible. They require a very small amount of blood and have 5-second result times. “Improved insulin pumps and blood glucose meters, insulin pens, continuous glucose monitoring (CGM) devices, and integrated sensory-augmented insulin pump systems with automatic threshold suspend capabilities” are also available (Miller et al., 2015, p. 971). Fairchild (2014) describes how the newest closed-loop system holds the most promise, because the closed-loop system utilizes insulin pumps, glucose sensors, along with various algorithms and controller designs to provide automated insulin delivery (p. 124).

Additional chaos. It should be noted that this writer did not delve into the chaos related to dealing with health insurance companies and pharmacies; it is beyond the scope of this paper.

But it should be considered and at the very least acknowledged that getting insulin and the other necessary medical supplies may at times be a struggle. The process may add to the psychological burden of people with T1DM.

T1DM is associated with serious long-term health complications including heart, vascular, kidney disease, blindness, and neuropathy (Hackworth et al., 2013). Major T1DM complications include *diabetic retinopathy* (adults with T1DM for 30 years, the prevalence increases to an alarming 95%), *diabetic nephropathy* (kidney function/renal failure), *diabetic neuropathy* ('stocking and glove distribution'), *diabetic cardiomyopathy* (can lead to cardiac failure even without coronary artery disease), *coronary artery disease*, *cerbrovascular disease* (stroke), *peripheral arterial disease* (increases risk of limb loss) (Loganathan et al., 2006). In addition to its overall beneficial cardiovascular effects, Loganathan et al. (2006) found exercise for people with T1DM "results in tissue-specific effects that impede diabetic pathology" (p. 86).

People with T1DM, not only have increased risk for long-term health complications, but they also have an increased risk for other autoimmune diseases. The most frequent comorbidities of T1DM include "Hashimoto's thyroiditis and Graves' disease collectively referred to as autoimmune thyroid diseases, celiac disease, autoimmune gastritis/pernicious anemia, Addison's disease, and vitiligo" (Krzewska & Ben-Skowronek, 2016).

The prevalence of celiac disease among people with T1DM is approximately 20 times higher than in the general population (Krzewska & Ben-Skowronek, 2016). Celiac disease is defined as an autoimmune disease characterized by damage to the small intestine, triggered by gluten ingestion from wheat, rye and barley and their derivatives in genetically susceptible individuals. Currently the only treatment for celiac disease is a lifelong adherence to the gluten-free diet (Assor et al., 2015; Krzewska & Ben-Skowronek, 2016).

Diabulimia is a term that is used to describe the deliberate administration of insufficient insulin to maintain glycemic control for the purpose of causing weight loss. Diabulimia has not been formally recognized in the medical arena, has no formal diagnostic criteria, and is often difficult to detect (Balfe, Doyle, Smith, Sreenan, Conroy et al., 2013; Davidson, 2014). “Some clinicians are beginning to adapt the DSM-IV criteria for bulimia nervosa and eating disorders, in particular the ‘inappropriate compensatory purging behaviors’ under misuse of medications for weight loss” (Davidson, 2014, p. 47). Balfe, Doyle, Smith, Sreenan, Conroy et al. (2013) found young women with T1DM would accidentally develop insulin omitting behavior, there was a lack of knowledge about the consequences, and there were positive feelings towards insulin omission in the beginning. One participant stated “I realized that I was getting thinner from doing that and I could manipulate it quite easily. It was like this brilliant trick I had” (p. 2032). Another women said “I thought it was just something that I’d discovered. There couldn’t be any possible long term effects of this, I’ll just do it and it will be grand” (p. 2032). “If there was an event coming up I’d be prone to letting my bloods run high and fit into my dress” (p. 2033). Rates of omitting insulin to lose weight are as high as 30-40% in adolescent and young females with T1DM (Davidson, 2014).

Self-management. The treatment for T1DM has come a long way since the discovery of insulin in 1922, but the burden of self-management has remained unchanged and possibly become more complex. Fairchild (2015) states, “Despite the many changes over the past 50 years, one thing that has not changed is the inherent burden of care and diligence required to maintain optimal diabetes control” (p. 124). “I don’t think people really understand what’s involved. It’s pretty much on my mind the whole time. There’s no day off from it” (Balfe, Doyle, Smith, Sreenan, Brugha et al., 2013, p. 30). “I wouldn’t wish it on anybody. It’s awful. You have

to do this and you have to do that. There's more involved than just doing the finger when you eat" (Balfe, Doyle, Smith, Sreenan, Brugha et al., 2013, p. 30). The self-management of T1DM implies sole responsibility to take care of oneself; wherein fault is own and success is own, the burden is intrinsic.

Swendeman et al. (2009) describe goals for chronic disease self-management programs which include: "adoption of a healthy lifestyle; adherence to treatment protocols, particularly medication; stress, anger, and anger management; and effective communication with health professionals" (p. 1323). Adherence to medication (i.e. insulin) regimen is important for individuals with T1DM. However, van Berkel, Lambooi and Hegger (2015) found in their research "low adherence to prescribed treatment is very common in patients. It is estimated that typical adherence rates for prescribed medicines are as low as 50%. With the increasing call for self-management, it becomes more and more important for patients to gain experience in managing their medicines" (p. 1).

Swendeman et al. (2009) believes "effective treatment of incurable diseases extends life expectancy and causes symptom remission, acute and terminal illness models must be replaced by a chronic care model (CCM) in which patient self-management is a key component" (p. 1321). The criteria for chronic disease includes:

An uncertain course, a prescribed treatment regimen, requirement for self-care, some degree of stigma, changes in roles and relationships, identity changes, and psychological distress. The goal of chronic illness healthcare is to control symptoms and prevent disability rather than cure the disease. Thus, the objectives of chronic disease interventions include managing physical symptoms, improving independence, and increasing quality of life. With chronic illness, in contrast to acute illness, the patient is

the principal caregiver. The majority of illness management takes place outside of formal healthcare with patients engaged in day-to-day *illness work*. Patients are responsible for: using medication properly, changing behavior to improve symptoms or slow disease progression, interpreting and reporting symptoms correctly, adjusting to new social and economic circumstances, coping with emotional consequences, and participating in treatment decisions. Thus, the shift from acute to chronic care brings emphasis to self-management of disease, where patients assume an active and informed role in managing physical, psychological, and social aspects of health. (Swendeman et al., 2009, p. 1322)

Van Berkel et al. (2015) agree that in recent years, “patients with chronic conditions are expected to be more self-sufficient in the management of their disorder; they are expected to take control, take responsibility, and manage their own care process as far as possible. This places high demands on patients, as they need to be aware of what their condition involves, what the consequences are, and which actions they can take to prevent complications” (Background section, para. 1). Problems can arise when working with doctors, such as who has the ultimate power when making decisions. Are there clear expectations? Are people with T1DM capable of making medical decisions, especially when they’ve had the disease for many, many years? All of this will be discussed in later sections.

Summary

The previous section outlined the extensive amount of medical, technical, and procedural jargon that a person living with T1DM needs to comprehend and deal with. In essence, they have to become their own personal medical professional. Technology has created many helpful tools that decrease the chance of physical complications of T1DM, but technology has not cured T1DM. The new technologies are wonderful, but they are not available to everyone (Miller et al.,

2015). It is a huge job to take care of ones self with T1DM in the picture. Always walking the line between feeling well and at any moment feeling sick. Learning about food and its effects, insulin and how sensitive you may or may not be, exercise, stress (good and bad), sometimes restricted, do I eat this and hope for the best? Or do I go without? And hope for the best? There are doctor visits, tests, and etc, but it all comes down to self-management. Mary Vonnegut from Rhode Island reiterates that T1DM “is a 24/7/365 job. We never get to relax and forget about food, whether we’ve exercised too much or too little, insulin injections, blood sugar testing, or the impact of stress, a cold, a sunburn, and on and on. So many things make each day a risky venture when you live with T1DM” (JDRF, 2016).

The burden remains and may lead to uncertainty. How does a person with T1DM process it all? There is a lot of information; do’s and don’ts, seemingly coming from all directions all the time, including wanted and unwanted advice. This chaos of having T1DM, with all of its daily fine-tuning of the physical medical management and unexpected curveballs that can occur, can sometimes lead to negative psychological implications. “The challenges and stressors of serious chronic illnesses, which are often unanticipated, uncontrollable, and functionally impairing... the acute medical events surrounding diagnosis of a serious chronic illness are often the beginning of a long process of treatment and adjustment to a chronic condition” (Compas et al., 2012, p. 457). T1DM can create short-term or long-term uncertainty about life within a person. Uncertainty about work, uncertainty about friendships and feeling understood, and uncertainty in relation to intimate partnerships and feeling loved.

The following section discusses what happens when a person with T1DM is expected to self-manage the disease but may not be completely prepared and supported in all areas of life to handle it all. People with T1DM are inundated with medical information along with the burden

of managing it all; so what happens at work, with friendships, and intimate love relationships with T1DM in the mix? T1DM can have specific implications relating to these different areas of life. The following section highlights work, friendship, and love, and then proceeds to describe the uncertainties that can lead to depression and anxiety and the additional support that may be crucial, such as online peer support groups.

Uncertainty: Adlerian Conceptualization of Psychological Implications of T1DM

Uncertainty is defined as not completely confident or sure of something; almost complete lack of conviction about an outcome or result (Uncertainty, n.d.)

The chaos described in the previous section can become overwhelming and lead to feelings of uncertainty. Friedman (2010) describes how “when a person receives a diagnosis their life is jeopardized. Dependence on others increases, life may feel out of control as feelings of powerlessness suddenly arrive. Roles and goals change. Thoughts that their bodies have betrayed them. Futures are no longer predictable. Isolation and fears of being forgotten and abandoned can creep in” (p. 316). Uncertainty about the past, uncertainty surrounding the present, and uncertainty about the future are real worries for people with T1DM. Fairchild (2014) describes how even with the most optimal resources, people with T1DM, specifically children and adolescents, experience “increased psychological morbidity. There are higher rates of adjustment disorders, major depression, anxiety disorders and eating disorders” (p. 124). The psychological implications can vary from person to person and can come and go over time. People with T1DM are not robotic; therefore, everything may be fine one day, and the next, not so much.

In the following sections it is examined how people with T1DM strive for fulfillment in their work, through friendships, and love relationships just like everyone else. The difference being they have the addition of a chronic illness that at times can cause interference in their

success of life in these three areas. Alfred Adler extensively wrote about these three areas of life and deemed them the *three life tasks*. The *life tasks* are “points of contact between the person and the world” (Mosak & Maniacci, 1999, p. 109). In addition, the prevalence of depression and anxiety amongst people with T1DM will be discussed. Along with the stigma and myths surrounding the disease. Online support groups have become a place where a person with T1DM can find advice, give advice, and receive a sense of understanding and belonging amongst peers. Adler’s concept of *inferiority* will be considered in its relation to the longstanding biomedical model & the newer biopsychosocial model in healthcare. The biopsychosocial model emphasizes the importance of taking all things into consideration, which a person with T1DM is constantly doing in self-management, and is relevant when discussing proper care with their doctor.

Work Task

Ansbacher (2011) describes the work task as “making our living, as we so literally express it, means making our lives possible by supplying ourselves with whatever is necessary for survival” (p. 10). She goes on to say “everyone is responsible for maintaining oneself. Even the very ill must ring their bell when they need help” (p. 10). People with T1DM are not the only people with chronic illness in the workforce. McGonagle and Barnes-Farrell (2013) report 68% of the US working population has a chronic physical or mental health condition or chronic pain. They believe “advances in disease management, coupled with an ageing workforce and trends to delay retirement, are contributing to rising numbers of individuals with chronic illness in the workplace” (p. 310). Making a living is necessary for survival, and so is the self-management of T1DM.

What do you want to be when you grow up? This is a question that many people first encounter in childhood. As Mary Tyler Moore (2016), the JDRF International Chairman states,

“Both children and adults like me who live with Type 1 Diabetes need to be mathematicians, physicians, personal trainers, and dieticians, all rolled into one. We need to be constantly factoring and adjusting, making frequent finger sticks to check blood sugars and giving ourselves multiple daily insulin injections, just to stay alive” (JDRF, What is it like to have T1D, para. 2). Most people with T1DM do not anticipate having to be so many things. But “regardless of what we do, we must do something with our time” (Mosak & Maniaci, 1999, p. 99). And people with T1DM are attempting to self-manage their illness while also participating in the workforce.

Working people with T1DM have work stress, just as their healthy coworkers do. In addition, they can also have T1DM distress, which includes the burden of self-management. While at work, a person with T1DM may feel like they have two jobs. This can lead to work-related T1DM distress. Mosak and Maniaci (1999) state “distress is harmful, unpleasant stress; it places the organism in potential danger. How we deal with that stress, and whether or not it becomes distressful and eventually harmful to survival, is a matter of how cooperatively and efficiently we adapt” (p. 80). Hakkarainen, Moilanen, Hanninen, Keikkinen, and Rasanen (2016) found work-related diabetes distress to be common among those with T1DM. Of the participants in their study, 70% experienced work-related T1DM distress.

Unfortunately, many people with T1DM are making poor decisions while at their place of employment. Hakkarainen et al. (2016) found work-related T1DM distress associated with the blood glucose level being kept at a high level at work. For instance a >40 year old, female with T1DM states “I do everything in my power to avoid the lows” (Trief et al., 2013, p. 2485). Hakkarainen et al. (2016) suggests possible reasons for this. For example, “if the physical load is unpredictable, the risk of hypoglycemia increases. Furthermore, an inability or reluctance to self-monitor blood glucose at work may lead to the blood glucose level being kept high at work.

Therefore, a tendency to keep the blood glucose level high at work as a coping strategy may partly be due to a realistic fear of hypoglycemia and partly due to personal challenges in reaching good control” (p.13). Some of the factors associated with work-related diabetes distress are modifiable, and some are not (Hakkarainen et al, 2016).

Places of employment are required to provide reasonable accommodations for people with T1DM under the *Americans with Disabilities Act*. The *Americans with Disabilities Act* became law in 1990. The most useful part of the *Americans with Disabilities Act* for people with T1DM relates to protection in the work place. It is defined and described as:

A civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. The purpose of the law is to make sure that people with disabilities have the same rights and opportunities as everyone else. The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. (Americans with Disabilities Act National Network, 2016, para. 1)

For people with T1DM, an example of a reasonable accommodation may include unplanned breaks to recover from hypoglycemia or hyperglycemia. Voluntarily keeping blood glucose high at work to avoid unplanned breaks should not be the answer. This choice affects A1c level, overall health, and increases risk for future complications. A person should not have to feel shameful, or inferior, about taking breaks when they really need them.

Inferiority Feelings

“Adler’s initial formulation of organ inferiority clearly reflected the biomedical model. Subsequently, his work on inferiority complex and the lifestyle paralleled development of the psychosocial model. More recently, as Individual Psychology has become even more holistic and integrative, it can rightfully be understood as a biopsychosocial perspective” (Sperry, 2008, p. 371). “Those with chronic illnesses are at greater risk to not fully develop or to diminish their capacity for *Gemeinschaftsgefühl*” (Croake & Myers, 1984, p. 464). Dreikurs (1977) describes *Gemeinschaftsgefühl*.

People can only be understood in their totality. As the Gestalt school of thought demonstrated, the sum of the individual is more than the total parts. The dualistic thinking that characterized nineteenth-century science saw the human as composed of a mind and a body. Even today, common belief holds that the mind influences the body and the body affects the mind. This latter conception is also dualistic and fails to understand the whole person. The mind and the body are simply different views of the same phenomenon. (as cited in Croake & Myers, 1984, p. 464)

Historically the biomedical model has been used to treat patients, wherein disease is viewed as objective with a single cause and single treatment. And conventionally, dissatisfaction from patients is high. Sperry (2008) believes the biopsychosocial model is starting to replace the traditional biomedical model with regard to the conceptualization and treatment of chronic medical conditions. The biopsychosocial model is integrative, comprehensive, and individualized. It includes all the elements that affect the whole person and contribute to shifts in health or mental status (Sperry, 2008). “Illness is viewed in terms of general systems theory or systemic thinking. In systemic thinking, a web of interactions of several factors ‘causes’ an

illness rather than a single factor” (Sperry, 2011, p. 79). The model proposes that a person can only be adequately understood if all levels of an individual’s functioning are considered:

biological, psychological, and social. Sperry (2008) describes them as follows:

Biological functioning refers to all peripheral organ system functions that are subcortical – that is, to all processes that are automatic and outside conscious awareness. The *psychological* functioning refers to the cortical and self-conscious inner world that directs information processing and communication from and with the outside world. It also includes the internal representation of self, the world, and personal goals, which reflects aspirations, ideals, needs, and the cognitions and strategies that govern behavior. The *social* dimension refers to the person’s behavior in relation to family, friends, authorities, peer group, and cultural expectations as well as community institutions which influence and are influenced by the individual. Some might add that a truly holistic approach would include the spiritual or life-meaning dimension of functioning. (p. 370)

Sperry (2008) explains that “chronic illness is the subjective experience of chronic disease, and such diseases tend to have multiple causes and treatments. This means that the experience of chronic illness is quite variable, depending on several biopsychosocial factors, including biomedical, personality, coping, and cultural factors” (p. 369-370). The same illness can be a very different experience in different people, in different families, and in different social/political times. Croake and Myers (1984) agree patients can only be understood within their total situation. “To ignore the total family dynamics and the areas of work, community, and love is as nearsighted as looking only at the dysfunctional organ” (p. 473). There can actually be an increase in disability when the entire context of a patient is not examined.

The feeling of inferiority may be inadvertently triggered or reinforced by insensitive medical professionals. Self-management may be a good thing, but there is research suggesting a battle of power between healthcare professionals and their patients (Hoch & Ferguson, 2005; van Berkel et al., 2015). In the traditional *biomedical model*, the doctor is the decision maker, the one with power, superior; therefore patients are inferior. Dan Hoch, a neurologist, blatantly states that “I’d been trained in the old medical school style: my instructors had insisted that patients could not be trusted to understand or manage complex medical matter” (Hoch & Ferguson, 2005, p. 0728). A problem can arise when T1DM patients are told and taught to self-manage the illness, but then receive contradictory information from the same medical professionals that they are not capable or they are inferior; both overtly and covertly. Trief et al. (2013) found this to be an all too common occurrence among people with T1DM. One participant said “Even as a kid... the doctor would take my blood sugar and if it ran high it was ‘You’ll go blind. What do you think is going to happen?’ I had one doctor... he told me to go make my next appointment at the funeral home” (p. 2486). Paterson (2001) found a central theme as to why participation in healthcare decisions can be problematic between patients and doctors. The research suggests medical professionals position themselves as experts or the sole authority. People with T1DM are being made to feel inferior, when medical professionals assert their superiority. The participants of Paterson (2001) believed that the medical professionals should be the ones taught how to enact empowering practices and behaviors (p. 579)

Having T1DM for over 15 years may lead some to believe that the individual would eventually become an expert about their own disease and their own body. The research suggests that some practitioners disregarded personal, longtime experience with T1DM. A participant from Paterson (2001) stated “So I went to him (the physician) and I explained how using the grid

system for insulin had worked for me. He listened for a second and then said that he didn't believe in that for this and that reason and then he said, 'This is what I use and I think you will find it better.' He was very nice about it. But it was clear that the discussion was over. He was telling me that he didn't want to hear what I thought. He is the doctor and what he says goes. I knew that I needed to shop for another doctor who would be more of a partner with me in this (diabetes management)" (p. 577). "Inferiority feelings encourage us to reexamine our situations and decide what we can do to change them. They allow us to grow, both individually, and as a species" (Mosak & Maniaci, 1999, p. 81). Furthermore, Paterson (2001) found in her study that practitioners do recognize the expertise that their patients with T1DM have, but are failing at actually empowering them. The relationship between a patient and doctor is definitely complicated. Doctors may be compassionate and are striving to give power in decision-making to their T1DM patients, but many are behaving in opposite ways and holding on to their professional dominance. For example, "I tell her about how tired I am, how I just don't have the energy I used to and she says that I am obviously doing well because my HbA1c is so good. I am arguing that the new insulin is not for me because I feel terrible and she is saying it's fine because the numbers say it is" (Paterson, 2001, p. 577). In a more recent study, van Berkel et al. (2015) found patients are indeed capable of understanding complex illnesses. "They are angry and hurt when others blame them yet they feel they are making sincere efforts. Overall, patients described being keenly aware of potential devastating complications and emphasized their need for supportive, non-blaming responses from others" (Trief et al., 2013, p. 2486).

Feelings of inferiority are "experienced as personal deficiencies". These feelings "may come to be felt as so overwhelming that they undermine the courage to move forward with life, to meet and overcome obstacles, and to develop oneself and make a contribution to the

community” (Griffith & Powers, 2007, p. 59). Feeling alienated and isolated in the management and related stressors of T1DM is prevalent. The qualitative outcome of Due-Christensen et al. (2012) study found inferiority feelings to be a common occurrence among those with T1DM. For example, one woman stated, “you have a feeling of not being capable enough. You feel that you are the only one who is not able to manage it; everybody else is capable, for sure. But I do not know anyone else. Therefore, you get more relaxed when you meet others who feel the same way” (p. 253). Those “who feel inferior lack a sense of belonging. They do not see themselves as a part of a family, a group, or community (Abramson, 2015, p. 431).

Since T1DM is life-long there will most likely be a time, or multiple times, when a person with T1DM experiences inferiority feelings and the similar feeling of inadequacy. Often a sense of inadequacy and inferiority can lead to a very uncomfortable feeling that a person strives to reduce and avoid, thus they attempt to overcompensate and this may lead to perfectionism. The goal of perfection induces the inferiority feeling. “Inferiority feelings are not themselves abnormal. They are the cause of all improvements in the position of mankind” “...unattainable ideal perfection, the individual is continuously filled by an inferiority feeling and motivated by it” (Ansbacher & Ansbacher, 1956, p. 117). Ideal perfection is not realistic, but achieving blood glucose levels within ‘normal range’ is possible. A person with T1DM may overcome their feelings of inferiority through perseverance, diligence, and resilience.

Biopsychosocial model is especially important to keep in mind when treating a person with T1DM, since T1DM affects all areas of life. In this respect, “the experience of a chronic illness does not take place in a vacuum, but it is bursting in the patient’s life context” (Karademas, Karamvakalis, & Zarogiannos, 2009, p. 406). Of course, people’s environments change over time and the people they surround themselves with, along with their places of

employment. Therefore, care for those with T1DM should be all encompassing. Taking into consideration the biopsychosocial model, rather than the biomedical model, is one important piece in the care of those with T1DM.

Stigma & Myths

Engebretson (2013) states “social identity is generally based on physical appearance and behavior, professional roles, and concept of self” (p. 546). “It is also possible that perceptions a person holds about illness and the specific ways he/she uses to deal with it are associated with the stress experienced in other domains of life, such as work or family” (Karademas et al., 2009, p. 406). Stigma plays a part in the perceptions about an illness. One piece of stigma that people with T1DM are concerned about is getting grouped together with people with T2DM. A lot of the misconceptions in society stem from the lack of knowledge of the difference between Type 1 and Type 2. It’s nobody’s fault, but couldn’t they have come up with more distinguishing names? Hearing stories about someone’s great grandmother who lost her leg to diabetes doesn’t help anyone. Trief et al. (2013) patients spoke about the ever-looming threat of complications, the “horror stories” about severe complications (e.g. blindness and amputation) and their distress when others share these stories. These stories may come from a place of wanting to connect and acknowledge some sort of understanding, but they often do the opposite.

Social media has made it possible for people to give advice and pass on information (factual or not) really quickly. There always seems to be a new cure for diabetes. This information is ludicrous and does not help to further the knowledge of the general population or support those living with T1DM or T2DM for that matter. If an average person sees an advertisement for “the new diabetes cure”, they may simply glance over it, but retain the information that a cure exists, when this is definitely not the case. Insulin is not a cure. T1DM is

complex and insulin is just a piece of the puzzle. The misinformation is causing harm in the sense that it feeds into the notion that T1DM is really no big deal.

Another myth, T1DM is caused by eating too much sugar, definitely not true. This is a popular joke that floats around social media “eating diabetes” or “I guess I’m getting diabetes tonight” and there’s a photo of a bunch of candy or something similar. Funny? No. In addition, when a person with T1DM is experiencing hypoglycemia (low) they actually need sugar. So the whole, “people with T1DM can’t have sugar”, is false.

Stigma is a term that is frequently found in the literature in conjunction with chronic illness. “*Stigma* comes from a Greek word which describes signs that indicate something out of the ordinary or bad about the person” (Joachim & Acorn, 2000, p.244). In other words, stigma is “a mark of disgrace” associated with a particular circumstance, quality, or person. Engebretson (2013) quotes Erving Goffman’s, 1963, classic work describing stigma as “a process in which one’s normal identity is spoiled by the reaction of others” (p. 546). This leads to the issue of disclosure – to tell or not to tell, and if so, when.

Joachim and Acorn (2000) conducted a meta-study of qualitative research on the lived experience of chronic illness and conditions, which included the relatedness of visibility and invisibility of chronic conditions, stigma, and the consequences of disclosure and non-disclosure. It was found that those with invisible conditions, such as T1DM, had complex decisions to make. Disclosing T1DM may lead to being stigmatized, or at other times, it may lead to increased support with select individuals. The option is to not disclose and attempt to pass for normal, trying to ensure that no one knows about the condition. Passing involves “willful hiding, with the goal of becoming part of the ‘normal’ group” (Joachim & Acorn, 2000, p. 245). For example, a person with T1DM, so as not to appear different from their peers, might eat or drink things they

know they should not, or may not take insulin when necessary. Passing can create stress because of the worry of being found out and the embarrassment of being caught, and in relation to T1DM can be very dangerous.

Beliefs that illness is something private lead people not to disclose, as does guilt and shame about being the focus of care and center of attention (Joachim & Acorn 2000). Joachim and Acorn (2000) state “little is known about how people decide when to disclose and when to be silent as well as how they cope with the results of their decisions” (p. 247). Engebretson (2013) states “the stigmatized individual suffers altered identity, shame, associated blame for the stigma, and often lowered self-esteem” (p. 545).

Balfe, Doyle, Smith, Sreenan, Brugha et al. (2013) qualitative study found about half of T1DM interviewees described feeling angry and frustrated at Type 2 diabetes. The first reason for this anger was that interviewees felt that there is a strong risk that they themselves could be misidentified as having Type 2. Interviewees felt that the “general public had a very prototypical and negative view of diabetes (derived from media reports of Type 2 diabetes that linked the condition to moral laxity, fatness, laziness, eating too much candy, etc.). These participants felt that they constantly had to differentiate between the two conditions to ensure that they were not stigmatized for having Type 2 diabetes” (p. 29). Since Type 2 diabetes is what the media most often focuses on. Another source of the interviewees’ frustration was a feeling that Type 2 diabetes was receiving “disproportionate attention and resources from the media, policy makers, and charities. They felt T1DM was often neglected by these agencies and actors” (p. 29). A 28 yr old interviewee from Balfe, Doyle, Smith, Sreenan, Brugha et al. (2013) study states “I really do think that T1DM gets left behind. Even yesterday was World Diabetes Day and on the news it

was all oh ‘if you improve your lifestyle and if you do this and that’ you improve your risk and I’m there shouting ‘this is Type 2 diabetes!’ (p. 29-30).

Media representations of T1DM are habitually based upon tragic models of illness, usually featuring older people struggling to live with the consequences of complications. Interviewees of the Balfe, Doyle, Smith, Sreenan, Brugha et al. (2013) study were found to be quite “angry about the absence of positive (or even balanced) media representations of T1DM” (p. 37). One interviewee, 30 yr old female, describes the media “people, like articles and news reports, tend to go with worse case scenarios and it’s scary... there was on program and they had some poor guy and he lost half a foot. I was like ‘Jesus Christ’. Then there was some poor woman and while they were filming it she died. I was like ‘holy crap’. It was very extreme. I don’t want to be told that by the time I get to 60 I’m going to have one leg and be blind” (Balfe, Doyle, Smith, Sreenan, Brugha et al., 2013, p. 38). Patients are keenly aware that they need to “save organs” through good management. They reported feeling frustrated when labeled “in poor control”, “brittle”, or “a bad diabetic”, as they feel criticized, guilty, and ashamed (Trief et al., 2013, p. 2486).

Engebretson (2013) concluded “stigma is often a part of the patient experience in chronic health conditions” and “patients often internalize the stereotype” which may “result in separation and isolation, lack of social status, and discrimination” (p. 549). Since T1DM is an invisible disease, it can lead others to believe that the suffering must not be that bad. Sometimes it is forgotten by others that it even exists. This can lead to disruption in relationships with peers, community, close friends, and loved ones.

Friendship Task & Belonging

“The fundamental motivation of human beings is the need to belong” (Ferguson, 2010, p. 1). Stigma, distress, and feelings of inferiority can cause disruption in relationships and decrease sense of belonging with other people, whether it is coworkers, close friends, or even strangers. Ansbacher (2011) describes the second life task as “the all encompassing one of cooperation with one’s fellow humans” (p. 10). When there is a lack of understanding, a person with T1DM, may simply feel misunderstood, may grow tired of explaining the choices they make because of their illness. This fatigue may lead to a reduction in the number of relationships, in which “the loss of intimates, friends, and colleagues is a great source of grief” (Ansbacher, 2011, p. 10).

One of the challenges that contribute to disrupted relationships, which make it hard to connect with others around experiences of illness, is the narrative surrounding an illness. Those who are recruited to listen may also grow tired of witnessing and validating. Weingarten (2003) discusses the stories surrounding illness:

Illnesses are not all alike. One way they are unequal is a way people rarely consider: illnesses themselves generate stories. The narrative one can tell about an illness is inextricably linked to certain parameters associated with the illness itself, and these parameters have real effects on the story that can be told, the storyteller, and the audience. In general, it is easier to recruit witnesses to listen and help with an illness that will improve over time, than it is to recruit witnesses to an illness that will only get worse, perhaps leading to death. (p. 80)

T1DM falls in a strange middle-ground. There is no cure, therefore it will always be there, but it necessarily will not lead to death, in the way some cancers do. Complications occurring sometime in the future are real, but it may take many years. Talking about T1DM with friends

can become precarious, sensitive, and touch-and-go. T1DM has the potential to interfere with peer relationships and alter group relationships. Research about the importance of group therapy will be discussed later, for this very delicate reason.

Shifron (2010) addresses the need to belong and focuses on finding ways to cope with life through increasing social interest and gaining new feelings of acceptance. “While the need to belong is basic for every human being, each individual finds different and unique ways to satisfy this need. The therapist’s role is to unfold the individual’s creative special methods and to encourage the person to use these constructively” (Shifron, 2010, p. 27). People with T1DM can “feel of lesser value compared to other people” (Ferguson, 2010, p. 1).

“Feeling belonging is crucial for the mental health of the individual, and at the societal level it is crucial that all members of the community feel belonging” (Ferguson, 2010, p. 2). Social media has opened doors for those feeling alone with T1DM. Online support groups are available and easily accessible to anyone who is looking for connection and acceptance amongst peers. Feeling belonging increases the chances for people with T1DM to “contribute to the best of her or his abilities to group welfare” (Ferguson, 2010, p. 5).

Online Support Groups

Two doctors, Hoch and Ferguson (2005) admit “I realized that there had always been an unspoken prohibition against groups of patients getting together” (p. 0728). In contrast, Mosak and Maniacci (1999) state that there is a “human need for communal life” (p. 102). The growing online community can be easily accessed and create a sense of belonging for a person with T1DM. Research suggests that there is less judgment and more support and understanding amongst peers with the same illness (Hoch & Ferguson, 2005; van Berkel et al., 2015).

Individuals with T1DM can share similar experiences, ask for advice, and give advice; these interactions become invaluable.

In a recent study, van Berkel et al. (2015) found the three most occurring empowerment processes of patient-to-patient interactions on online discussion boards were providing information, sharing personal experiences, and requesting information. Their study also suggests the dominant view on the discussion boards favored collaboration with medical professionals, with little to no exchange of misinformation.

In further support of this finding, Hoch and Ferguson (2005) observed a “constant outpouring of sympathy and support” amongst the interactions of people participating in online disease-specific networks (p. 0728). They go on to say that the exchanges “among the community members surpassed anything a patient might conceivably expect to receive at a doctor’s office” (p. 0728). About 10% of the members that were part of the Hoch and Ferguson (2005) study spontaneously mentioned that they had been “unable to get the medical information that they needed from their own clinician” (p. 0729). When surveyed directly that percentage rose to 30%. This was a primary reason for participation in the online group. The finding also supports and adds to the previous research about the intricacies of troubled relationships between patients with T1DM and their doctors.

“Many professionals have seriously underestimated the benefits of online health resources for patients, probably because they do not operate within our familiar professionally centered constructs” (Hoch & Ferguson, 2005, p. 0729). This overlaps with the earlier literature about the old biomedical model (i.e. the doctor as sole manager) and move towards a biopsychosocial one (i.e. patient self-manages and doctor is part of the team). “It now seems

quite clear that growing numbers of patients are perfectly capable of empowering themselves, with or without their clinician's blessing" (Hoch & Ferguson, 2005, p. 0729).

The distributed expertise of online support groups is by no means limited to the emotional aspects of the illness and to the practical logistics of living with the disorder. It can also include current reviews of literature, reports from the latest medical meetings, accounts of behind-the-scenes activities at the best treatment centers, sophisticated guidance on dealing with medical professionals, and excellent advice on dealing with complex aspects of medical management. (Hoch & Ferguson, 2005, p. 0730)

"Isolation is one of man's greatest punishments" (Ansbacher, 2011, p. 11). And it seems safe to conclude that a person struggling with T1DM can obtain the feeling of belonging by counteracting the feeling of isolation from people in real life or from peers on online support networks. In addition to colleagues at work and friendships in the community, another source of support could come from a loving partner. A loving partner may be one of the greatest and most treasured sources of encouragement.

Love Task & Encouragement

Ansbacher (2011) describes the third task, love, the greatest possibility for interpersonal appreciation and encouragement. Adler (as cited in Ansbacher & Ansbacher, 1956) describes what is necessary for a fulfilling partnership:

For a full solution of this cooperation of two, each partner must be more interested in the other than in himself. If this is to be, there must be equality. If there is to be so intimate a devotion, neither partner can feel subdued nor overshadowed. Equality is only possible if both partners have this attitude. It should be the effort of each to ease and enrich the life of the other. In this way each will be safe; each will feel that he is worthwhile, and that he

is needed. The fundamental guarantee of marriage, the meaning of marital happiness, is the feeling that you are worthwhile, that you cannot be replaced, that your partner needs you, that you are acting well, and that you are a fellow man and a true friend. (p. 432)

Love relationships, themselves, are unique and it cannot be assumed that everybody's wants or needs are the same and remain the same over time. One person with T1DM may thrive on doing all that is necessary by themselves; while another person with T1DM may need verbal encouragement or actual physical help once in awhile. Trief et al. (2013) suggests a common theme is that of feeling like a burden, which signifies self-blame and feelings of guilt. Alternatively, a small percentage of people with T1DM viewed the illness as bringing them closer.

Partners of those with T1DM may also be experiencing stress out of care and concern. "Both the person with the illness, who needs to have her feelings compassionately witnessed to derive the health benefits of expressing emotion, and family members, who are overwhelmed by passively witnessing the pain of the ill family member and who also need an outlet for what they are experiencing, need a way out of the relational impasse: how to speak without causing the other to suffer; how to listen without suffering" (Weingarten, 2003, p. 80). "Peggy Penn, who has worked with families with chronic illness for over twenty years *'I am afraid that if I do not speak to you and tell you how I am, I will slowly withdraw and leave you; however, if I do speak to you, I am afraid that you will slowly withdraw and leave me'* (Weingarten, 2003, p. 76). For example one patient stated "I would want my partner to understand how scary it is to be the person watching, not the person going through it, because they don't know, the person who's giving the glucagons and thinks you are going to die" (Trief et al., 2013, p. 2486). It is important to recognize the stress loved ones may feel being in a relationship with a person with T1DM.

The love task “requires the greatest amount of intimacy and, therefore, the most skill to fulfill on a consistent basis. It is the hardest task to meet” (Mosak & Maniaci, 1999, p. 104).

Adults with T1DM face unique emotional and interpersonal challenges. But little is known about common psychosocial challenges of adults. Trief et al. (2013) found that although partner involvement varies from very little to significant, “there exists significant anxiety about hypoglycemia and future complications and sources of conflict that may increase relationship stress. Partner support is highly valued, and technology has a positive influence” (p. 2483).

T1DM has varying influences on and plays a different role in each individual love relationship.

For example:

Patient: I think he counts on me taking care of it, which is fine with me because I also don't want to be a burden. (>40-year-old female, married <15 years).

Patient: My wife's pretty helpful and supportive... she kind of makes it... seem like it's no big deal (>40-year-old male, married >15 years).

Patient: I would say there is no positive effect on the relationship at all, for any of us (>40-year-old female, married >15 years).

Patient: I think that if you get through that (the hard times) you share that history and it brings you closer (>40-year-old male, married >15 years). (Trief et al., 2013, p. 2483)

This can be from partners not participating at all to being extremely helpful and supportive, there may even be instances where too much help becomes an issue. In addition, there is ‘feeling like a burden’ to loved ones. Love relationships evolve; therefore involvement from partners can too.

A person with T1DM most often receives encouragement from their partners. The continual encouragement may be necessary for a person living with T1DM, but can cause unwanted stress on relationships. One group in the Trief et al. study (2013) made detailed

comments describing “increased emotional distance, sexual intimacy problems, difficult decisions about if and when to have children, caring for young children with the constant threat of hypoglycemia, and a general increase in relationship stress” (p. 2485). Significant others, family, and close friends play a large role, whether they are aware or not, in the life of a person with T1DM. Subsequently, without encouragement in life, a person with T1DM is at a higher risk for depression and anxiety.

Depression & Anxiety

Research suggests that individuals with T1DM report more psychological disorder as compared to the general population. For instance, individuals with T1DM are approximately twice as likely to meet DSM-IV criteria for major depressive disorder and 20% to 25% of patients report depressive symptoms. In addition, a long-term follow-up study of adolescents with Type 1 diabetes showed that nearly 50% were diagnosed with a psychiatric disorder within 10 years after diagnosis, with depression being the most common diagnosis (Rassart et al., 2015). These findings are alarming given that “depressive symptoms have been linked to poorer diabetes self-care and glycemic control, greater symptom severity, various diabetes complications, and increased health care costs” (Rassart et al., 2015, p. 1059). “Depression in children and adolescents with T1DM has been associated with negative diabetes related health outcomes such as poorer glycemic control and recurrent diabetic ketoacidosis (DKA).” Hood et al. (2006) believe it is “apparent that the chronicity of T1DM and the demands of management provide a fertile environment for adjustment problems” (p. 1389). The level of depressive symptoms in children and adolescents with T1DM was found to be “nearly double that of the highest estimate of depression in youth in general” (Hood et al., 2006, p. 1390).

In a recent, 5 year follow-up study, Rassart et al. (2015) found “perceptions of consequences” and “personal control” to be important predictors of how well individuals managed and adjusted to T1DM. Whereas “some patients might feel as if their treatment impacts on every aspect of their daily life (work, relationships, hobbies), others might consider it just being one of the many daily routines (i.e., high vs. low levels of consequences). Similarly, some patients might feel in control of their diabetes by frequently monitoring their levels of blood glucose, whereas others might feel like their illness is mainly determined by factors beyond their control, such as hormonal changes (i.e., high vs. low levels of personal control)” (Rassart et al., 2015, p. 1059). It was also found that depressive symptoms predicted an increase in social support problems, such as “feeling alone with T1DM and feeling family and friends are not supportive of T1DM management. In turn, a non-supportive social network may interfere with T1DM self-care. “Perceptions of consequences and personal control have been repeatedly shown to relate to diabetes-specific distress, depressive symptoms, and glycemic control in individuals with diabetes. “...constituting a negative vicious cycle. Identifying such pathways over time is of utmost importance for designing prevention and intervention strategies” (Rassart et al., 2015, p. 1059).

Factors associated with elevated levels of depressive symptoms included demographic, diabetes-specific, and family functioning variables. Less frequent blood glucose monitoring, an indicator of suboptimal adherence, and poorer glycemic control were associated with higher levels of depressive symptoms. While these associations can be bi-directional (e.g. more depression causing poorer glycemic control and vice versa) and are connected (e.g. less adherence leads to poorer glycemic control), these findings beg for

longitudinal research to elucidate the link between glycemic control and depression by examining adherence as a mediator between the two. (Hood et al., 2006, p. 1390)

Shaban et al. (2006) found the prevalence of depression to be more elevated amongst males with T1DM and anxiety levels were more elevated in females with T1DM when compared to normative data. Both males and females reported moderate to severe levels.

Pinquart and Shen (2011) define anxiety as “the basic emotion that results from the perception of dangerous stimuli. Anxiety also often comes from a concern over lack of control over one’s circumstances, which means that there are unpredictable or uncontrollable events in one’s life” (p. 1069). An 8 year old, named Jonathan Platt, states “unlike other kids, I have to check my blood sugar 8 to 10 times a day; everything I eat is measured and every carbohydrate counted. My kit goes with me everywhere I go... too much exercises or not eating all my food can be dangerous. I think I’m too young to have to worry about all this stuff” (JDRF, 2016).

Pinquart and Shen (2011) found that anxiety is elevated among those with chronic physical illnesses. Theoretically, being “confronted with dangerous stimuli, such as threatening symptoms of illness or distressing medical procedures, having increased fear of death, chronic illness often reduces one’s ability to control the environment, there would be elevated levels of social anxiety because of increased risk of being rejected by peers” (p. 1070).

Summary

Rassart et al. (2015) supports the idea that medical professionals should find a balance between stressing the importance of self-management activities to people with T1DM and encouraging them to engage in normative development tasks (i.e. building a professional career or starting a family).

Uncertainty in the mind for a person with T1DM looks like work distress, feelings of inferiority stemming from friends, partners, and doctors, stigma from the community and media, trying to belong without wearing on others' emotions about T1DM, finding support via online T1DM group networks, depression and anxiety, nourishment of a love relationship and the amount of support needed from partner, worries and fears about the future. In the event "encounter situations that require more of us than we are currently prepared to offer" (Mosak & Maniaci, 1999, p. 81), like a diagnosis of T1DM, it may cause uncertainties, which can create a disruption in any of the three life tasks. There are emotional implications surrounding T1DM that occur more often than those without the disease and people with T1DM at times feel "insecure, out of control, hopeless, and discouraged" (Friedman, 2010, p. 316). These feelings can stifle growth within the three life tasks and can in turn create physical implications, such as decreased self-care. The uncertainties surrounding a life with T1DM are legitimate.

Friedman (2010) believes people strive for "security, self-reliance, feeling in control, feeling needed, and able to contribute". "The creative self within each of us, using the influence of our surroundings and our own body, determines our health. Heredity and environment provide probabilities. It cannot be assumed that because the child's particular disease is well known, as is the child's premorbid history, that the effects of the disease are predictable for that child. The child's Style of Life will provide the framework within which the objective factors will be synthesized" (Croake & Myers, 1984, p. 464). T1DM is an individualized illness.

"The irony is that it is typically not life that creates our problems; it is our solutions to life that create our problems. That is *the* irony, and what provides writers and artists with the opportunity to portray the human condition as both tragic and, just as significantly, optimistic" (Mosak & Maniaci, 1999, p. 118). Since T1DM is not choice and currently a life-long disease,

the emotional implications surrounding it suggest a need for various screening processes and interventions. Adlerian art therapy is one solution to easing the relationship between a person and their disease. “The outcome depends on the creative power of the individual” (Ansbacher & Ansbacher, 1956, p. 368). And to use Alfred Adler’s (1936) famous quote, as cited in Mosak and Maniaci (1999) through the use of art therapy, “everything can also be different” for people with T1DM (p. 18).

Navigation: Adlerian Art Therapy and T1DM

Navigation is defined as the act or practice of steering, directing the course of, or finding a way through. (Navigation, n.d.)

There is strong evidence that there is a need for an increased emphasis on the assessment of mental health for those living with T1DM (Karademas et al., 2009; Rassart et al., 2015; Trief et al., 2013). People with T1DM can experience multiple stressors including “a sense of powerlessness and lack of control, isolation and separation from family and peers, fears and anxieties related to the illness, and arrested identity formation” (Reed et al., 2015, p. 14). Simply being in the “medical environment itself can feel like a foreign land” and cause stress (Council, 2003, p. 208). In addition, “medical terminology is a new language that must be suddenly mastered” and only adds to the feeling of being completely overwhelmed (Council, 2003, p. 208).

Dreikurs (1977, as cited in Croake & Myers, 1984) states “Holistic treatment means that psychological consultation is begun as soon as an illness is detected. Even with such a concerted effort from all personnel, patients cannot be made well, they can only be stimulated to get well (p. 465). Adlerian art therapy can be used to stimulate people with T1DM. Finding way to navigate the chaos and uncertainties of T1DM is crucial. Art therapy can be used to discover a

route through the day-to-day struggles; it can direct the course toward a positive future, one without fear. Mosak and Maniaci (1999) believe it is “our solutions to life’s challenges that lead us to problems, not the fact that life has challenged us” (p. 110). Art therapy can aid in ignoring the deficits caused by T1DM and stress the assets related to career growth, community and friendships, and intimate love relationships.

The following section focuses on art therapy as an intervention for people struggling with T1DM in any of the three life tasks. Four main themes came up repeatedly in the research. They include *coping* with initial diagnosis and the daily T1DM fine-tuning struggles, the concept of *control*, *chronic* disease and finding hope, and implications for the need of *group therapy* and feeling understood. The American Art Therapy Association (2016) defines *art therapy* as:

A human service profession that uses art media, images, the creative process, and patient/client responses to the created products as reflections of an individual’s development, abilities, personality, interests, concerns, and conflicts. Art therapy practice is based on knowledge of human developmental and psychological theories which are implemented in the full spectrum of models of assessment and treatment including educational, psychodynamic, cognitive, transpersonal, and other therapeutic means of reconciling emotional conflicts, fostering self-awareness, developing social skills, managing behavior, solving problems, reducing anxiety, aiding reality orientation, and increasing self-esteem. (What is Art Therapy, para. 1)

Art therapy is an approachable and an alternative therapy that many people of all ages respond positively to because it is simply not just talking; it’s an active form of therapy. It focuses on both art and relationships. The relationships between art therapist, client, and the artwork, also, when relevant, relationships between group members. Research suggests that art therapy would

be beneficial for the psychological wellbeing of a person with T1DM (Malchiodi, 2003; Reed et al., 2015; Reynolds & Prior, 2003). Art Making is in and of itself empowering. And as the literature suggests, people with T1DM may need to feel empowered from time to time in relation to their T1DM. As a matter of fact, van Berkel et al. (2015) found that “patient empowerment is crucial in the successful self-management of people with chronic diseases” (p. 1).

Balfe, Doyle, Smith, Sreenan, Brugha et al. (2013) found that “knowledge acquired from structured courses seemed to help to empower interviewees, helped them to feel that diabetes management problems were errors that could be fixed rather than the outcomes of personal failings, which in turn ameliorated feelings of guilt and frustration” (p. 38). On the contrary, Main and Boughner (2011) suggest “participants do not thirst so much for information as they thirst for motivation, resolve, or the courage to change” (p. 274). A combination of T1DM information and motivation may be the best solution for those with T1DM. “Medical art therapy is used not only to address trauma associated with illness, surgery, medication, and medical interventions but also as a form of psychosocial treatment and stress reduction” (Malchiodi, 2003, p. 123). Art therapy not only can aid in stress reduction for those with T1DM, but it can also empower people to self-identify as an expert in the management of their T1DM.

Coping

The initial diagnosis of T1DM causes acute stress, followed by a lifetime dealing with T1DM day in and day out, which can create long-term chronic stress (Compas et al., 2012). Coping with the stress can become an issue. Coping is a response to an uncomfortable situation with the goal of reduction of anxiety and fear. Compas, Jaser, Dunn, and Rodriguez (2012) define coping as “the conscious and volitional efforts to regulate oneself and/or the environment in response to stress” (p. 472). Just as sources of stress vary from person to person, so do the

reactions to stressful situations. “There are a wide range of behaviors that individuals use to try to manage their stress” (Compas et al., 2012, p. 459). Some are positive, some are negative. Creating alternative avenues for communication, through art therapy, can reduce stress and relieve some of the fears and anxieties surrounding T1DM.

Coping with a chronic illness not only pertains to the person affected with T1DM, but also those that are closest to them, such as parents, siblings, or partners. Finding ways to deal with new responsibilities and roles is important to explore. Art therapy can open communication about T1DM between family members and/or partners. Authentic communication is a coping skill and also one benefit that art therapy provides.

In an arts program with chronically ill children, Reed et al. (2015) found that through the relationship of artists and students, students are able to access alternative identity possibilities, versus their common association of themselves as sick children. The final exhibition and performance celebration itself can foster the process of reducing stigma and bias. Increased self-esteem and confidence were identified as well. The children described achievements they would never have imagined, allowing perceptions of their own identities to grow in new directions (pp. 20-21). A 15 yr old working with ceramics stated, “I learned that if you do something you like to do, it can help you relax or let go of the hard stuff that has happened or might happen” (Reed et al., 2015, p. 22).

Control

Fears, anxieties, and powerlessness are common feelings amongst those with T1DM. Nicky Hider from New York speaks about T1DM and how “It controls your life in ways that someone without it doesn’t even see. For me, the worst part is living with T1DM is the fear that my three children or their children might develop the disease” (JDRF, 2016, What is It Like to

Have T1D, para. 5). How does a person switch from the feeling of being controlled by T1DM or lacking control to having control over the disease? In addition, people with T1DM may feel like they are responsible for too much, or have too much control, and may need to let go of some things or hand over some responsibility to a friend or partner, if possible.

The past, questions of why me, present, day-to-day challenges, and questioning the future, how much can I do to prevent complications. Accept inability to control the initial diagnosis. Individual holds power to move forward and control most day-to-day needs. Having control is part of the misconception of the general public when it comes to T1DM. There is only so much that a person can control. Overall a person with T1DM will be guessing in the very beginning, but will quickly learn how his or her body reacts to food, insulin, exercise, etc. Unfortunately once a person thinks they have things “under control” a life change could happen (i.e. job loss) or stress or other sickness, which may have them feeling like they are relearning how to “control” T1DM all over again.

Councill (2003) describes a way to navigate the idea of control. She discusses the importance of gaining a sense of control through the use of art therapy and how patients are able to control the materials, intentions, the imagery created and when the product is finished they control whether or not to discard it or keep it. Making choices while creating art encourages power to make choices in life surrounding T1DM. Even with the best A1c numbers (best glucose control) complications are still a high probability of the future. The future is risky and holds uncertainties that are out of anyone’s control.

Chronicity

The word *chronic* was defined in the very beginning of this literature review as *never ending* or *a state of prolonged duration*. When imagining no end to the daily struggles and

realistic fears about what the future holds for a person with T1DM, the idea of *hope* plays an important role. How does a person with T1DM maintain hope with no end in sight?

There are many studies on psychotherapy with medical patients, but few studies address patients' realistic fears, which are very common. Dinkel et al. (2012) describe a realistic fear for physically ill patients as "the fear of disease progression or disease recurrence" (p. 1). Examples of realistic fears for people with T1DM include complications, DKA, coma or death from hypoglycemia or hyperglycemia, and whether or not their children will be diagnosed as well. Dinkel et al. (2012) found high levels of *fear of progression* amongst people with chronic illnesses. These fears can cause intense suffering and reduce quality of life. Such fears are also a common experience in partners. Therefore, art therapy interventions focused on hope would be beneficial.

Hope becomes a necessary tool for navigating the ups and downs of living with T1DM, combating realistic fears. Groopman (2004) defines *hope*:

Hope is one of our central emotions, but we are often at a loss when asked to define it.

Many of us confuse hope with optimism, a prevailing attitude that 'things turn out for the best'. But hope differs from optimism. Hope does not arise from being told to 'think positively,' or from hearing an overly rosy forecast. Although there is no uniform definition of hope, I found one that seemed to capture what my patients had taught me.

Hope is the elevating feeling we experience when we see – in the mind's eye – a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion. (p. xiv)

This definition is extremely fitting for people with T1DM. There are day-to-day obstacles and realistic fears that should be acknowledged, maintaining an *elevated feeling* through it all despite

of what the future holds is truly hopeful. When “action is taken and knowledge put into practice once they are sufficiently inspired to believe or hope that they can change the course of their lives. Family members become courageous through a delicate balance of learning how to act and believing that they can” (Main & Boughner, 2011, p. 274).

Maintaining a belief in personal ability to manage T1DM for the rest of their life can be an overwhelming request. With hope involved, life with T1DM may seem more manageable. Art therapy can foster hope. Groopman (2004) discusses how hope can only arrive when there are sincere choices. And that a person’s choice makes a true difference. Hope therefore becomes a belief that one has some control over circumstances. And a person with T1DM is no longer at the mercy of outside forces. “Clear eyed, hope gives us the courage to confront our circumstances and the capacity to surmount them. For all my patients, hope, true hope, has proved as important as any medication I might prescribe or a procedure I might perform” (Groopman, 2004, p. xiv).

Groopman (2004) mentions fatigue “the body-mind connection should be thought about not only in extreme cases, but in instances where symptoms may be routine and not life-threatening. Among these non life-threatening but significant symptoms is fatigue” (p. 180). Fatigue from T1DM can be equated to the 24/7/365 of it all. There really are no breaks. How can a person with T1DM reenergize themselves, keep up the routine, stay on top of it all? The *life tasks* are happening, *living with NO CURE*, why bother enduring? When fatigue sets in, hope begins to fall.

The vicious cycle of T1DM that can occur needs a jolt to be broken. Breaking the cycle is key and it can be broken by the first spark of hope. “Hope sets off a chain reaction. Hope tempers pain, and as we sense less pain, that feeling of hope expands, which further reduces pain” (Groopman, 2004, p. 179). In art therapy, one simple drawing can spark hope in a person.

Art making fosters genuine hope and courage; courage to continue when a person with T1DM is overcome with fatigue or hopelessness.

Importance of Group Therapy

Dinkmeyer and Sperry (2000) describe the benefits of group therapy. Group process focuses on the “beliefs, feelings, and behavior of the members of the group. Attitudes, values, and purpose are considered. The interpersonal relationships that develop within the group make it possible for the members to become aware of their mistaken and self-defeating beliefs and actions and to feel encouraged to change them” (p. 176). “An effective group offers opportunities to belong and be accepted, receive and give love and to have a therapeutic effect on others, see that one’s problems are not unique but are experienced universally, and develop one’s identity and to try on new approaches to the various social tasks of life” (Dinkmeyer & Sperry, 2000, p. 179). Cohesiveness in group therapy refers to the forces that enable members to experience a feeling of belonging, solidarity, and a common bond. This cohesiveness creates conditions whereby individuals feel not only understood, accepted, and valued, but also free both to reveal themselves and to accept feedback from group members. A cohesive group is one in which members have a high level of mutual understanding and acceptance. Cohesiveness helps supply the feeling of belonging (p. 183). Group therapy allows:

1. Members have their place regardless of deficits or assets.
2. Members’ capacity to reveal themselves honestly and openly is valued
3. Members learn not merely through verbal and cognitive understanding. Expected to put their insights into action inside and outside the group.
4. Lead models attentive listening, caring, congruence, confrontation, and interpretation

5. Members can express their true feelings without fear of permanently disrupting relationships (Dinkmeyer & Sperry, 2000, p. 179)

There are many gains to be attained when it comes to group therapy for people with T1DM. Support from peers, motivation and encouragement to carry on, feeling of belonging to a group, giving and receiving advice, helping/mentoring others are just a few. The single most important feeling, for those with T1DM and psychological stresses that group art therapy provides would be *I am NOT alone*. Bearing witness and validating another person's experience is critical when working with people with T1DM. Weingarten (2003) states, "many art forms perform the function of bearing witness" (p. 188). Group art therapy can foster similar psychosocial benefits as the online support groups that were previously discussed, including a sense of belonging. In addition, it can provide a deeper understanding amongst peers, a deep sense of hope, and the development of long-lasting relationships. "The primary purpose of art therapy is to give people another language to share feelings, ideas, and perceptions about themselves, others, and the world around them. It can also be a catalyst for interaction and exchange between individuals in similar situations. Art therapy deepens the effectiveness of relationships with others, including the therapist" (Malchiodi, 2003, p. 123).

The previously mentioned Dinkel et al. (2012) study about realistic fears amongst chronically ill patients found that the fear of disease progression was reduced with group intervention. Similarly, Due-Christensen et al. (2012) studied whether or not people with T1DM would benefit from a support group, regardless of their HbA1c levels. They found support groups were able to reduce diabetes-related and psychological distress, therefore improving psychosocial functioning. It was concluded that patients with extremely high levels of distress may need more extensive intervention to further reduce their level of distress. Interventions that

target specific self-management problems are needed on an individual basis. Most interestingly, the study also found patients with good HbA1c levels might have an unacknowledged psychosocial burden of living with the illness that healthcare providers overlook. Participants in Reynolds & Prior (2003) study said the artwork they created gave them a positive sense of the future and that creating plans for future art projects instilled hope (p. 791).

Providing a safe environment for sharing stressful experiences is beneficial for the psychological implications of T1DM. The Due-Christensen et al. (2012) study found that the major benefits of sharing experiences amongst a group were feeling less alone and being intuitively understood among peers. The most helpful part of the support group was the newfound feeling of *I am not alone*. Patients evaluated sharing experiences with others as highly important as they felt intuitively understood by their peers and thus were not alone with concerns about T1DM. Some people found the support group to be “more motivating than consultations with healthcare providers in changing their habits with regards to self-management” (Due-Christensen, 2012, p. 253). More than half of the participants continued to meet regularly after completing the support group, which significantly implies the need for ongoing psychosocial support to reduce the burden of living with T1DM (p. 255). Ongoing relationships foster understanding and reduce isolation and the feeling of isolation. An 18-year-old participant in the Reed et al. (2015) study said “it’s not just about art... it’s about connecting with people” (p. 20).

“Social support has consistently been found to have positive effects on adapting to illness, adherence to treatment for illnesses, and even on health outcomes themselves. Social support can reduce morbidity and mortality” (Weingarten, 2003, p. 84). Group dynamics can also create peer leaders amongst the group that provide modeling (i.e. I have lived with this

disease and can teach you how to live with it), which also creates purpose for the leaders themselves, as self-identified experts.

One strategy for managing T1DM distress was present in the Balfe et al. (2013) qualitative research. It was obtaining diabetes-related social support from three main sources: healthcare professionals, family members, and peers with diabetes. Participants felt peers with T1DM provided positive examples of living with T1DM, examples highlighting the difficulties, and that participants were not alone in their suffering. Motivation and practical information for use to improve T1DM control was also exchanged, which helped reduce their feelings of being overwhelmed (Balfe, Doyle, Smith, Sreenan, Brugha et al., 2013). One participant, 28 yr old female, “it’s supportive to hear other people say that they’re not all perfect at managing their diabetes. It’s hard” (Balfe, Doyle, Smith, Sreenan, Brugha et al., 2013, p. 34).

The art therapist can provide the structure, safety, and encouragement that will allow the client to... They may become so hopeful that they now believe they are capable, have some control, and that everything is going to be fine, or maybe joy was found for just a moment, but either way, the client found it for themselves, which is in itself a form of control. The art therapist may share in that joy by validating it. The act of creating can help people with T1DM make sense of their chaotic and uncertain world. Art therapy can provide a path in creating options and offering up choices. This in turn may facilitate a person with T1DM’s sense of control.

Conclusion

“As we mourn the loss of physical well-being, we are increasingly aware of the frailty and brevity of life” (Friedman, 2010, p. 321). This may be the one and only positive aspect of having a chronic illness. Learning to live with T1DM happens based out of necessity, there is no

choice. It is also a learning process that is lifelong; “thus the duration of diabetes is not the ‘point’ in how well a person has been empowered and has accepted his or her diabetes after receiving the diagnosis” (Hakkarainen et al., 2016). Whether a person has had T1DM for 2 years or 25 years, it does not signify their mental status, stress level, knowledge, or self-management capabilities. Each individual has a unique experience that needs to be taken into consideration.

Learning to love one’s self as a person with T1DM only comes when one learns to face imperfections. Adler’s concept of the *Courage to be Imperfect* comes to mind with the daily struggles of calculations that a person with T1DM continuously experiences. “To be human means to be useful, to make contributions-not for oneself, but for others- to take what there is and to make the best of it... We have to realize that we’re good enough as we are; we never will be better, regardless of how much more we may know, how much more skill we may acquire, how much status or money or what-have-you. If we can’t make peace with ourselves as we are, we never will be able to make peace with ourselves” (Griffith & Powers, 2007, p. 19). There are good days and bad days for a person with T1DM, there are frightening moments and moments when the illness can be briefly forgotten. Doctors, friends, and family often focus on what a person is doing wrong in relation to their diabetes management. Switching the focus to what is being done right and acknowledging that we are all imperfect can be validating and give a person drive and courage to do even better. A 27 yr old female with T1DM states, “When you go to the doctor they’re all about the diabetes, looking after your control there’s nobody there to talk to say ‘have you had enough of it?’ That would be something that would really help” (Balfe, Doyle, Smith, Sreenan, Brugha et al., 2013, p. 33).

The ultimate goal for T1DM is a cure; however, that remains an elusive concept. Self-management, insulin, nutrition and exercise are the current practical approach for the chaos.

Adlerian art therapy is a navigation tool that can be utilized to combat the uncertainties of T1DM. People with T1DM are striving to belong like everyone else, “belonging to the family of origin, belonging in a couple relationship, belonging to the world of work” (Shifron, 2010, p.12). The diagnosis of T1DM is an unfortunate, unpreventable, and chronic turn of events. Currently there is a lack of support when it comes to the mental health of those with T1DM. Adlerian Art Therapy techniques can be used to successfully treat the psychological implications that occur as a result of navigating a life with Type 1 Diabetes. Inferiority feelings surrounding the illness can dissipate. Depression and anxiety can be alleviated. Even though T1DM is a chronic illness, learning to cope with a new way of life and gain a sense of control can be achieved. Art therapy can foster *true hope* in people with T1DM. “I thought about true hope versus false hope. False hope does not recognize the risks and dangers that true hope does. False hope can lead to intemperate choices and flawed decision making. True hope takes into account the real threats that exist and seeks to navigate the best path around them” (Groopman, 2004, p. 198). Art therapy aids in the search for the best pathway in navigating a life with T1DM. “Art Therapy can be a bridge from the sad and lonely places of illness to the joy of human connection and understanding” (Councill, 2003, p. 209).

Expression of the self through the visual arts is therapeutic in and of itself. And the use of art as a tool to express feelings of fear and anxiety about T1DM can be beneficial. This writer would encourage group therapy over individual when it comes to T1DM, of course, it would be favorable to participate in both. The group aspect remains so important when working with individuals with T1DM. Belonging to a group of people who instantly understand the burden that is carried is a key component to overcoming some psychological implications. “It is mainly from those people who struggled hard against difficulties, in body as in outer circumstances, that

advances and new contributions have come. The struggle strengthened them, and they went further ahead” (Ansbacher & Ansbacher, 1956, p. 369).

The research findings have various implications for the field of art therapy. To begin with, this research aids in establishing a context of what an individual with T1DM has to deal with medically on a daily basis, wherein the chronicity of T1DM is stressed and can lead to fatigue. Additionally, it has implications for the areas of difficulties or concerns that may arise in relation to Adler’s life tasks (work, friendship, love). This paper can help art therapy professionals to identify problems within specific areas of life. Accordingly, they could develop interventions to cope with the burden of T1DM and reduce its psychological consequence. Interventions may include techniques specifically for stress management, depression and anxiety, communication skills for use with partners/family/doctors, alternative ways to combat stigma, inducing hope, encouragement, and motivation.

Based on the review of research presented, this writer suggests people with T1DM be thoroughly assessed throughout their lifetime to evaluate psychological status and the impact T1DM may have on relationships and feelings about self. Assessment may be necessary no matter what an individual’s HbA1c level is. Psychological implications relating to the chaos and uncertainty of T1DM may come and go throughout a person’s lifetime with T1DM. Therefore interventions to help navigate it all should be made more readily available.

Areas of Further Research

In general, there is a lack of T1DM specific research. There is an abundant amount of research about diabetes in general, where T1DM and T2D are grouped together (with no distinction made), or T2D is the actual focus.

Psychosocial interventions usually ONLY include those with poor T1DM management, therefore, disregard people with well regulated T1DM who may still carry a psychosocial burden of living with the illness.

Since technology has recently and drastically advanced, the effects of living with chronic illness for many years (20+) is a new idea that could use some attention. It will also be interesting to see how far technology goes. A cure is what most people hope for but anything that makes life a little less chaotic and filled with more certainty would be welcomed.

More studies on those diagnosed later in life (18+yrs) and their psychosocial functioning. Interestingly, I was diagnosed “late” for a person with T1DM (although through online social networks I realized this was actually untrue and more common than the general public realizes). T1DM was once referred to as Juvenile Diabetes, therefore, this assumption makes some sense. The majority of people with T1DM that I know actually do not remember a “life without T1DM”. This concept is intriguing to me, especially when compared to my own experience as “remembering life and the freedom before being diagnosed”. It would be interesting to know how much the “age of diagnosis” affects psychological implications for a person with T1DM. And related would be more research on the idea of *fatigue and burnout* surrounding T1DM.

Most research is on children and adolescents with T1DM and the parents of children with T1DM. This is definitely important when it comes to prevention of certain physical complications and psychological disturbances related to T1DM. Young adults transitioning to living on their own and therefore, self-managing T1DM. There is a lack in research surrounding pregnancy and T1DM, both physical and psychological. What about parenting while managing chronic illness? Fears about these things were abundant, but there was little to no research on people with T1DM actually experiencing these things.

A lot of the participants of studies, were treated at centers that focus on care of T1DM, what about those who are uninsured or treated at a primary care clinic? Lower socio-economic situations? How are they surviving?

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Appendix A

Definitions Related to Type 1 Diabetes

Retrieved from the American Diabetes Association Website 2016

<http://www.diabetes.org/diabetes-basics/common-terms/>

A1c – a test that measures a person’s average blood glucose level over the past 2 to 3 months, also called hemoglobin A1c (HbA1c).

Autoimmune disease – disorder of the body’s immune system in which the immune system mistakenly attacks and destroys body tissue that it believes to be foreign.

Basal rate – a steady trickle of low levels of insulin, such as that used in insulin pumps.

Blood glucose (blood sugar) – the main sugar found in the blood and the body’s main source of energy.

Blood glucose level – the amount of glucose in a given amount of blood, noted in milligrams in a deciliter (mg/dL).

Bolus – an extra amount of insulin taken to cover an expected rise in blood glucose, often related to a meal or snack.

Carbohydrate – one of the three main nutrients in food. Foods that provide carbohydrates are starches, vegetables, fruits, dairy products, and sugars.

Carbohydrate counting – a method of meal planning for people with diabetes based on counting the number of grams of carbohydrates in food.

Continuous Glucose Monitor (CGM) – a way to measure glucose levels in real-time. A tiny electrode called a glucose sensor is inserted under the skin to measure glucose levels in tissue fluid. It is connected to a transmitter that sends the information via wireless radio frequency to a

monitoring and display device. The device can detect and notify you if your glucose is reaching a high or low limit.

Coma – a sleep-like state in which a person is not conscious. May be caused by hyperglycemia or hypoglycemia in people with T1DM diabetes.

Dawn phenomenon – the early morning (4am to 8am) rise in blood glucose level.

Diabetic ketoacidosis (DKA) – an emergency condition in which extremely high blood glucose levels, along with a severe lack of insulin, result in the breakdown of body fat for energy and an accumulation of ketones in the blood and urine. Untreated DKA can lead to coma and death.

Diabulimia – an eating disorder which consists of the reduction of insulin intake to lose weight. It is considered a dual diagnosis disorder: where one has diabetes as well as an eating disorder. While diabulimia is generally associated with use of insulin, an individual with diabetes may also suffer from another eating disorder as well.

Endocrinologist – a doctor who treats people who have endocrine gland problems, such as diabetes.

Gestational diabetes mellitus – another type of diabetes mellitus that develops only during pregnancy and usually disappears upon delivery, but increases the risk that the mother will develop diabetes later. It is managed with meal planning, activity, and, in some cases, insulin.

Glucagon – a hormone produced by the alpha cells in the pancreas. It raises blood glucose. An injectable form of glucagons is available by prescription. Used to treat severe hypoglycemia.

Glucose – one of the simplest forms of sugar.

Honeymoon phase – some people with Type 1 diabetes experience a brief remission. During this time their pancreas may still secrete some insulin. Over time, this secretion stops. The honeymoon can last weeks, months, or even up to a year or more.

Hormone – a chemical produced in one part of the body and released into the blood to trigger or regulate particular functions of the body. For example, insulin is a hormone made in the pancreas that tells other cells when to use glucose for energy.

Hyperglycemia – excessive blood glucose.

Hypoglycemia – a condition that occurs when one's blood glucose is lower than normal, usually less than 70 mg/dL. Signs include hunger, nervousness, shakiness, perspiration, dizziness, or light-headedness, sleepiness, and confusion. If left untreated, may lead to unconsciousness.

Hypoglycemia unawareness – a state in which a person does not feel or recognize the symptoms of hypoglycemia.

Insulin – a hormone that helps the body use glucose for energy.

Ketone – a chemical produced when there is a shortage of insulin in the blood and the body breaks down body fat for energy. High levels of ketones can lead to diabetic ketoacidosis and coma.

Ketonuria – a condition occurring when ketones are present in the urine, a warning sign of diabetic ketoacidosis.

Kussmaul breathing – the rapid, deep, and labored breathing of people who have diabetic ketoacidosis.

Pancreas – an organ that makes insulin and enzymes for digestion.

Somogyi effect (rebound hyperglycemia) – when the blood glucose level swings high following hypoglycemia. The somogyi effect may follow an untreated hypoglycemic episode during the night and is caused by the release of stress hormones.

Type 1 diabetes – condition characterized by high blood glucose levels caused by a total lack of insulin. Occurs when the body's immune system attacks the insulin-producing beta cells in the pancreas and destroys them.

Type 2 diabetes – a condition characterized by high blood glucose levels caused by either a lack of insulin or the body's inability to use insulin efficiently.