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The impact of medication unaffordability and community support on complex trauma, post-traumatic growth, and meaning in life in adults with type 1 diabetes

Abstract

The current study sought to examine the extent to which type 1 diabetes is experienced as a complex trauma by adults living with the invisible illness and whether medication unaffordability affects an individual's experience. The study also assessed how connecting with others who share the same illness impacts the development of post-traumatic growth and meaning in life, and whether medication unaffordability could influence the development of both. Adults with type 1 diabetes responded to a series of sociodemographic questions and questions about their experiences with the illness, along with the Post-Traumatic Stress Disorder (PTSD) Checklist for the *DSM-5*,[1] the Post-Traumatic Growth Inventory,[2] and the Meaning in Life Questionnaire.[3] About one-third of individuals with type 1 diabetes experience the autoimmune condition as traumatic. There was a significant negative correlation between PTSD, and socioeconomic status and medication unaffordability. Length of involvement in the type 1 diabetes community impacted their presence of meaning in life, but had no meaningful effect on post-traumatic growth.

Findings revealed interesting relationships between post-traumatic growth and meaning in life, and annual household income, level of education, insulin rationing, and economic sacrifices, respectively. Clinical and social justice implications, limitations, and future research directions are discussed.

Keywords: type 1 diabetes, complex trauma, socioeconomic status and diabetes medication unaffordability, T1D community, post-traumatic growth, meaning in life

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Introduction

According to the 2020 *National Diabetes Statistics Report*, in 2020, about 34.2 million Americans (10.50%) lived with diabetes (Centers for Disease Control and Prevention.[4] In 2018, as many as 1.6 million Americans had been diagnosed with type 1 diabetes (T1D), the unpreventable and incurable form of the illness, which makes up about 5% of individuals with diabetes.[4–6] Results from international studies indicate that the prevalence of T1D has been rising by 2% to 5% internationally, and over 1 in 300 people in the United States are diagnosed with the illness by the age of 18.[7] In recent years, there has been an increase in middle-aged adults and individuals in early adulthood being diagnosed with the illness.[7] This is a noteworthy change to when this illness was typically only diagnosed in children and teenagers.[7] The diagnosis of this chronic health condition and the subsequent physical, emotional, social, and financial changes to one's quality of life can have a traumatic and lasting impact on countless individuals with T1D, leaving them at a significantly increased risk of numerous mental health disorders.[8,9] The resilience of adults with T1D has often been credited to the hardships they experience, which motivate them to improve their situations.[10]

Type 1 diabetes overview

Type 1 diabetes (T1D) is a chronic autoimmune condition that occurs when an individual's own immune system attacks and destroys the beta cells of the pancreas, which produces insulin in the body.[11] Katsarou and colleagues[11] described the nature and course of T1D, noting that the illness is unpreventable and incurable, and, without insulin, individuals diagnosed with T1D will die within a few hours to a few days. Furthermore, the authors indicated that various unpredictable factors, such as stress, illness, medication, lack of food, an abundance or lack of exercise or insulin, menstrual cycle, temperature, and a multitude of other biological, psychological, and environmental factors have the ability to impact blood glucose levels, making the health condition particularly difficult to manage. Hypoglycemia and hyperglycemia can occur at any time. They can trigger physical, as well as emotional symptoms, and can result in death if they are not treated as sensitively as possible.[11]

Individuals with T1D also have an increased probability of developing other autoimmune diseases and chronic illnesses, such as thyroid disorders, celiac disease, Addison's disease, heart disease, and rheumatoid arthritis than the general population.[5,12] Researchers have stated that, due to its wide range of serious complications, diabetes could most likely be the leading cause of medical death worldwide.[5,12,13] Possible medical complications of the illness include damage to the eyes, nerves, brain, feet, kidneys, heart and blood vessels, skin, and mouth.[5,12] Another major complication includes diabetic ketoacidosis, a serious issue in which the body creates too many blood acids, or ketones, resulting in possible hyperglycemia, cerebral edema, hypokalemia, loss of consciousness, or death. Pregnancies with T1D are considered high risk due to the manner in which low and elevated blood glucose levels could affect the fetus.[5,12,13] Due to the various complications that can easily occur, oftentimes individuals with T1D merely become better accustomed to setting other major priorities in their lives aside, as they endure the physical and emotional burdens that accompany dealing with the autoimmune condition.

The current study

This research study was aimed at contributing to existing literature on T1D and mental health, while also providing health psychologists and other mental health professionals working with individuals with T1D with information about the relationship between T1D and trauma.

This information could help them to better understand, empathize with, and treat their patients. This study was designed to provide endocrinologists and other medical professionals, who are typically the first to treat patients with diabetes, with a better understanding of their patients' mental health risks from the illness, their potential need for mental health referrals, and to remain alert for possible insulin rationing. The results of this research study may help mental health professionals, as well as medical professionals, better understand how certain variables, such as social support, socioeconomic status, and medication unaffordability, may impact treatment outcomes. The results may help individuals with diabetes and their loved ones learn about the impact that connecting with others who share this diagnosis and understand it on a similar level could have on their mental health. Furthermore, this research may be beneficial in spreading awareness about T1D and the very real risks due to extreme costs of insulin and other diabetes supplies in the United States, while also helping to minimize the stigma that is often accompanied with diabetes in society. There is a scarcity of mental health research regarding psychological trauma in adults with T1D and the current study sought to provide consideration to a marginalized population.

Social justice applications

Social justice advocates argue that all individuals deserve equal opportunities and rights, including the right to good physical and mental health. Nonetheless, there are avoidable and unjust inequities in healthcare, which result from policies and practices that create an imbalanced distribution of money, power, and resources among individuals based on gender, race, place of residence, and other factors. Achieving social justice in diabetes and mental health suggests that there is a fair and equitable distribution of health benefits and burdens among the population.

However, individuals with T1D who identify with diverse sociodemographic groups do not receive the same levels of care due to access deficiency stemming from health care and medication unaffordability, lack of community resources, societal stigma, discrimination, and lack of trust in healthcare professionals. Even with standard diabetes care, the majority of individuals with T1D have various social vulnerabilities that are not screened for or addressed. This creates significant problems as individuals' diabetes and their mental health are capable of impacting them in life-altering ways. In order to speak to the mental health-related inequities for individuals with T1D, changes in community and system-level interventions and health policies are needed to assure quality diabetes care, mental health promotion and prevention programs, and quality of life for the most at-risk communities. By identifying the needs of these diverse individuals and implementing changes to our health care system, we may improve patient satisfaction, patient follow-up, diabetes management, mental health care outreach, and overall health outcomes. The start of these changes can only occur through the use of peer-reviewed research that can point us in the direction of the most significant mental health issues and their causes.

Literature review type 1 diabetes and mental health

Type 1 diabetes (T1D) includes numerous mental health risks, including depressive disorders, generalized anxiety disorder, panic disorder, post-traumatic stress disorder, obsessive compulsive disorder, and eating disorders.[8,14–16] According to Ducat et al.,[8] Fisher et al.,[14] and Moulton et al.,[15] throughout their lives, individuals with T1D are twice as likely to develop major depressive disorder as individuals without diabetes, and depression is higher among children diagnosed with T1D than those unaffected by the illness. Researchers also suggested that adults, primarily women, suffering from T1D are twice as likely to develop an eating disorder and have double the risk of developing a subthreshold eating disorder compared with those unaffected by the illness.[17] Common emotional issues in which individuals with T1D are susceptible include stress, guilt, hopelessness, mental fatigue, anger, withdrawal from friends and family, difficulty concentrating, and diabetic burnout, which can involve denial and neglect of diabetes management.[8,17] Researchers have found that many individuals with T1D hide or downplay their illness from friends, partners, and family members often due to their fear of being a burden or because of society's inaccurate stigma about diabetes.[18–20] Shaban[16] suggested that individuals suffering from T1D typically cope with the emotional aspects of the illness through avoidance or by hindered disclosure, both of which are frequently related to poor physical and mental health outcomes. Due to the risks to their mental health, as well as the impact that these risks could have on their physical health, it is crucial that individuals with T1D have a support system.

Possible cognitive impacts of type 1 diabetes

Researchers have suggested that both chronic hyperglycemia and the consequent occurrence of diabetes complications, as well as recurrent episodes of severe hypoglycemia, are thought to be associated with cognitive dysfunction in patients with T1D. However, research findings are highly contradictory. Studies on children found that extreme hyperglycemia can slow the growth of a brain as it develops and that the same is true when a child's glucose levels frequently swing up and down.[21] Brain scans show differences between a child with diabetes and one without. Still, most researchers suggest there are no major differences in IQs, mood, behavior, and learning and memory skills in children.

Others propose that diabetes, primarily early-onset diabetes, is associated with diminished neuronal functioning that can ultimately lead to cognitive dysfunction in intelligence, learning, memory, information processing, executive function, visual motor integration/visual perception, psychomotor efficiency, sustained attention, cognitive flexibility, and academic achievement.[21] Some studies have suggested that learning and memory typically are not affected by the disease. However, others have proposed that learning and memory skills, both verbal and visual, are more affected for children with early-onset diabetes than late-onset diabetes, along with attention/executive function skills.[21] Researchers suggest that adults who have had T1D for many years have slower physical and mental reactions. Researchers conclude that the condition does not seem to impact a person's learning and thinking skills, but memory and attention span can be affected. These issues can often affect an individual's work life, schoolwork, and relationships.

The contradictory nature of the research findings on cognitive impacts and the lack of clarity can be frustrating for those medically treating individuals with T1D, but especially for those living with the illness, which causes us to contemplate the affective impact that not having solid answers could have on those experiencing the frustration day to day.

Possible affective impacts of type 1 diabetes

T1D is not only about counting carbohydrates, checking blood sugar levels, and dispensing insulin. Receiving a diagnosis of diabetes adds an emotional weight onto an individual's shoulders which can be challenging to carry day in and day out. Common emotional issues include stress, mental fatigue, denial, anger, diabetes burnout, difficulty concentrating, and withdrawal from friends and family.[8] The emotional impact of not feeling well more days than not and feeling almost as though their body is out to get them can take a toll on the emotional and psychological wellbeing of individuals with T1D. Even if they do everything that their doctors tell them to do, diabetes can be unpredictable and frustrating and, if they are unable to do everything they are "supposed" to do, it can cause feelings of anxiety, guilt, and even hopelessness.

Individuals with T1D face social issues that individuals without chronic conditions often do not understand. Consequently, they sometimes isolate themselves from the rest of the world.[22] They may have to come to terms with people in their lives who treat them differently after their diagnosis. Many individuals without T1D may become uncomfortable with the disease and others will often view them as unhealthy and "weak".[22] Family may become overprotective, and the family environment may become more stressful. Dating and maintaining relationships can be difficult, as those who experience the side effect of extreme fatigue might not have the energy to socialize as much as they used to.[22] While most physicians recognize the challenges patients face in the self-management of diabetes, many fail to recognize the extent of the psychological toll those challenges can take, preventing physicians from taking action. Each day is different; therefore, asking how a patient is feeling one day, when their energy and confidence levels are high, may be significantly different than asking the next day when their blood sugar is unstable, and they feel helpless.

T1D community overview

The T1D community consists of online and in-person subgroups. In the diabetes online community, individuals create personal blogs and social accounts, which focus on their personal experiences and advocacy, on different social media platforms. The community can be found on Instagram, Facebook, Twitter, and TikTok. However, the majority of individuals who join the in- person community first discover it on Instagram.[23] The diabetes online community is the major facilitator of in-person meetups and events in which individuals with T1D gather together, meet other individuals with the illness, share experiences, and develop an empathetic support system.[23] They are able to do all of this online with individuals throughout the world. While some individuals simply prefer to read others' posts, thousands of others become heavily involved by sharing daily or bi-daily blog posts and stories. Bloggers share struggles, as well as humor, hold conferences and meet-ups, and create their own businesses, such as clothing businesses, to help spread awareness. Additionally, many help to provide resources and also help others in need of supplies at no cost.

For many individuals with T1D, the prices of insulin and life-saving medical supplies are extremely costly and, for years, numerous individuals have crossed the Mexican and Canadian borders just to purchase insulin at a small fraction of its cost at United States pharmacies.[24] In 2019, members from the diabetes online community crossed the Mexican border with a videographer to help provide a few individuals in need with insulin and to spread awareness about the significant issue which United States residents with T1D have been facing.[25] That same year, Senator Bernie Sanders joined individuals from the T1D community as they headed on a bus to Canada to highlight the exceedingly high United States prices, which Sanders attributed to corporate greed.[26]

Socioeconomic status and diabetes medication unaffordability

Socioeconomic status, a term which includes elements such as level of education, profession, income, and wealth, has been a major factor in the livelihood of individuals suffering from T1D in the past few years. The American Psychological Association suggested "Examinations of socioeconomic status often reveal inequities in access to resources, plus issues related to privilege, power, and control" (2019, p. 1). For individuals relying on insulin to survive each day, lack of access to medical resources is detrimental. When physician and medical scientist Fredrick Banting discovered insulin in 1923, he felt that it would be unethical to prosper from a medication that would save lives and he sold the patent to the University of Toronto for $1.[27] However, according to the 2018 *Bipartisan Congressional Report*, from 2002 to 2013 the three major insulin-makers increased the price by almost 300% in the United States.[28] As a result, one in four individuals suffering from diabetes is unable to afford insulin, even after making economic sacrifices.[27]

Hirsch[29] noted that patients must now pay full retail price for insulin, unless they have extraordinary healthcare coverage and even the majority of health insurance plans do not cover it completely. Hirsch stated, "One woman on an insulin pump noted, after she went to pick up her insulin and had to pay the full retail price, that her insulin now costs more than her home mortgage" (2016, p. 131). Researchers, such as Chan and Luk,[30] have found that a large number of individuals with T1D underuse insulin because they are unable to find an insurer that will cover the greater amount of the cost. Unfortunately, this has been the cause of many deaths of adults and children in the past few years.[31] The issue with insulin cost and socioeconomic status has become so substantial that one child died after his mother began taking him to an herbalist, rather than providing him with insulin.[32] Shulman et al. found that children and adolescents with T1D who experienced medication unaffordability were at a much more significant risk of diabetic ketoacidosis, which is caused by insulin deficiency, and death than those with higher socioeconomic status, who were able to afford their medication. In this study, medication unaffordability will be determined based on self-reported annual household income, level of education, economic sacrifices made to afford diabetes medication and supplies, and insulin rationing.

The United States' insulin crisis

In order to examine the psychological variables, mental health professionals must be educated about the major issue that has prevented countless individuals with T1D in the United States from being able to acquire their life-saving medication. This issue is insulin's extreme price increase in the past 20 years. In 1921, Sir Frederick Grant Banting, Charles H. Best, and JJR Macleod successfully discovered insulin and sold it to the University of Toronto for $1, stating, "Insulin does not belong to me. It belongs to the world.[33] In 1991, insulin prices began rising exponentially, only decelerating in recent years. Despite using the same formula, "the list price of insulin per milliliter in the United States increased, on average, 2.9% annually from 1991 to 2001, 9.5% per year from 2002 to 2012, 20.7% annually between 2012 and 2016, and 1.5% per year from 2016 to 2018".[34] In 2017, diabetes cost the United States $327 billion and became the most expensive chronic illness in the country.[34] According to the American

Diabetes Association[35] "one in every four United States health care dollars is spent on someone with diabetes, and one in seven dollars is spent directly on diabetes-related expenses." The rising costs of diabetes supplies, which approximately 8.3 million individuals with T1D and numerous individuals with type 2 diabetes require to manage their illness and live, essentially tracks the significant rise in the cost of insulin.[34]

While various patients have been advocating for change for over ten years, our government and the media only began to acknowledge the issue about three years ago. Since then, various medical drama television programs began highlighting the issue, while news channels finally began to report on patients' cries and complaints. Prior to and following trips to purchase insulin in Mexico and Canada, individuals with T1D in the United States, as well as allies in other countries, have advocated for solutions to the injustice on social media and at in- person events. While these efforts have caused thirteen U.S. states to limit monthly copays to be more cost-effective for those with Medicare, Medicaid, and private insurance plans in the past two years, it has yet to create an institutional change regarding the prices that the three major insulin manufacturers, Eli Lilly, Novo Nordisk, and Sanofi, charge for medication that costs roughly five dollars to manufacture.[36]

In past years, some individuals with diabetes have chosen to use outdated insulin from Walmart due to its affordability. According to Shure[37] "one study found that 18,000 vials of past-its-prime insulin are sold daily in the United States". Various deaths have been reported due to the danger in switching between modern and outdated insulin. While countless people must ask for donations, take on additional jobs, and refrain from paying other bills to afford their medication, many adults and children with diabetes are dying due to rationing and their inability to afford insulin. As mental health professionals, we should wonder about the state of mental health that individuals must be in to ration a medication that they need to survive each day. It is in the realm of Counseling Psychology to be concerned with this issue and to determine what we can do to help save the lives of those suffering.

Complex trauma

The term complex trauma refers to trauma which occurs repeatedly and regularly results in direct harm to the individual.[38] Complex trauma involves numerous exposures to adverse occurrences over the course of an individual's life, and often occurs within a specific relationship or setting.[38,39] According to Courtois,[39] "Complex trauma also refers to situations such as acute or chronic illness that requires intensive medical intervention or a single traumatic event that is calamitous" (p. 86). The experiences are connected with an array of mental health outcomes, including a reduced threshold for the development of post-traumatic stress disorder as well as maladjusted behaviors and self-capacity issues.[38,39] According to Briere and Scott,[38,39] mental health interventions which aid in the processing of memories and cognitions, expand emotional regulation, and highlight the therapeutic relationship appear to be the most beneficial for addressing the effects of complex trauma. Briere and Scott[38] also found that medicinal treatments are fairly effective in the management of the post-traumatic stress components of complex trauma, but are typically less effective in decreasing self-related issues and symptoms.[38]

Oftentimes, the literature does not label challenges brought upon by chronic illness as complex trauma. For example, the daily experiences of people with T1D have all of the markings of trauma due the repetitive risk of dying. One small change in the body could cause an individual to experience hyperglycemia or hypoglycemia, which can both lead to life-threatening consequences. The symptoms of hypoglycemia frequently even mimic panic attacks, which in many cases cause those who experience panic attacks to feel as though they are dying.

Characteristic symptoms of hypoglycemia include shaking, sweating, a pounding, rapid heartbeat, loss of energy, dizziness, and, in some cases, an upset stomach and nausea. As professionals, we must contemplate how a repeated risk to one's life could impact psychological and emotional functioning.

Post-traumatic growth and meaning of life in individuals with chronic illnesses

Some individuals who have experienced trauma attempt to understand the traumatic event, redefine their beliefs, and undergo positive changes in relation to how they perceive and value themselves, their relationships, and their lives.[40] Consequently, these individuals have the ability to experience post-traumatic growth.[40] Post- traumatic growth occurs when an individual who experienced trauma not only survives, but grows and surpasses the inner development that he or she had prior to the traumatic event.[41] Much like post-traumatic growth, developing meaning in life is a strength in the way that individuals find satisfaction through the discovery of their life's purpose.[42] While a number of factors affect the potential of developing post-traumatic growth and meaning in life, these developments can still be found in individuals with most chronic illnesses.

For example, researchers have found that individuals with T1D may be able to optimistically transform their philosophies about life and eventually develop post-traumatic growth and meaning in life. Joseph and Butler[41] proposed that 30 to 70% of trauma survivors undergo positive changes and growth. Kremer and colleagues[43] evaluated the development of post-traumatic growth in young adult cancer survivors, individuals with T1D, and physically healthy individuals using the Post-traumatic Growth Inventory (PTGI) German Version,[44] the Hospital Anxiety and Depression Scale (HADS),[45] the HADS-German Version,[46] and the Fear of Disease Progression Questionnaire-Short Form (FoP-Q-SF).[47] Their results suggested that individuals with T1D were more susceptible to anxiety, depression, and fear of progression than physically healthy individuals and cancer survivors who experienced the most spiritual changes.[43] However, individuals with T1D also reported higher PTGI scores of appreciation of life, personal strength, and new possibilities than any other group.[43]

Researchers have also tested the relationship between other chronic health conditions and developing post-traumatic growth and meaning in life. Dirik and Gocek-Yorulmaz[48] used the Multidimensional Scale of Perceived Social Support (MSPSS) Turkish Version,[49] the Perceived Expressed Emotion Scale-Turkish Version,[50] the PTGI-Turkish Version,[51] the Ways of Coping Inventory-Turkish Version,[52] and the Diabetes Management Self-Efficacy Scale-Turkish Version[53] to study the development of post-traumatic growth in individuals with type 2 diabetes. Researchers found that the severity of the disease, as well as the participants personal expressions of criticism and hostility, were negatively correlated with the presence of post-traumatic growth, while the individuals' education levels were positively correlated to the presence of post-traumatic growth.[48] Perceived social support, optimism, and problem-focused coping skills were suggested to be significant predictors of post- traumatic growth.[48]

In their study, Andrykowski and colleagues[54] tested the hypothesis that, since rural cancer survivors report more distress than non-rural survivors, they also have more positive psychological outcomes. The

researchers administered a health-related quality of life survey,[54] the Benefit-Finding Questionnaire (BFQ),[55] HADS,[45] and PTGI,[2] which measures post-traumatic growth through qualities associated with relating to others, new possibilities, personal strength, spiritual change, and appreciation of life. Researchers defined benefit-finding as the process of deriving positive growth from adversity, and suggested that it occurs immediately after diagnosis. Andrykowski et al.,[54] defined post-traumatic growth as an active change in an individual's ability to deal with adverse events and suggested that it may develop even years after the diagnosis. They studied adult lung cancer survivors without any other cancer diagnoses and found that rural cancer survivors reported more post-traumatic growth than non-rural cancer survivors. However, the authors did not find any differences in benefit-finding.[54]

In a cross-cultural study, Baník and Gajdošová[56] used the PTGI-Czech version,[57] the Benefit Finding Scale for Children-Czech version,[56] Distress Tolerance Scale (DTS),[58] the Adult Hope Trait Scale (AHTS),[59] and the Revised Life Orientation Test (LOT-R)[60] to investigate the differences in levels of post-traumatic growth based on cancer type, treatment, and demographic characteristics of adult patients diagnosed with hematological cancer. Their findings suggested that the patients' cancer type, treatment type, and sociodemographic traits did not affect their levels of post-traumatic growth.[56] Nevertheless, unlike the previous study, the results of this research suggested that benefit-finding and distress regulation considerably improved the chances of patients experiencing post-traumatic growth.[56]

The role of rumination

Soo and Sherman[61] used the Medical Outcomes Social Support Survey (MOSSS),[62] the Depression Anxiety and Stress Scales (DASS),[63] the Multidimensional Rumination in Illness Scale (MRIS),[64] and the PTGI[2] to test their hypothesis that, because rumination (i.e., repetitive thoughts) has been linked to both, the development of post-traumatic growth in individuals with chronic illness and psychological distress in medically healthy individuals, various subcomponents of rumination may be related with psychological distress and post-traumatic growth in female breast cancer patients. Soo and Sherman[61] found there was a negative correlation between rumination and the development of post-traumatic growth, and a positive correlation between the development of post-traumatic growth and depression, anxiety, and stress. Soo and Sherman[61] also found that positive rumination was positively correlated with all five domains on the PTGI (e.g., New Possibilities, Personal Strength, Spiritual Change, Appreciation of Life, and Relating to Others).

Social support, self-efficacy, and cognitive processing

Lotfi-Kashani and colleagues[65] studied self-efficacy and perceived social support in patients with stomach cancer using the PTGI,[2] the General Self- Efficacy Scale (GSE),[66] and the Multidimensional Scale of Perceived Social Support (MSPSS).[67] The researchers found that both self- efficacy and perceived social support were positively correlated with the development of post- traumatic growth.[65]

Using the PTGI,[2] the MSPSS,[67] Impact of Event Scale-Revised Form (IES-R),[68] and the Modified Rosenberg Self-Esteem Scale,[69] Senol-Durak[70] studied the development of post-traumatic growth in individuals with type 2 diabetes and expecting mothers with gestational diabetes. Findings suggested that social support dramatically increased levels of post-traumatic growth, and cognitive processing mediated the connection between post-traumatic growth and self-esteem.[70] The results were similar for individuals with type 2 diabetes with or without additional diagnoses.

Adams[70] evaluated women with chronic illnesses, including type 2 diabetes and cancer, using the Life Success Measures Scale,[72] the PTGI,[2] and the participants' narration of chronic illness experiences. The participants, who altered their negative thought processes to be more positive and made significant life changes in order to take better care of themselves, were found to have higher levels of post-traumatic growth.[71]

Social provisions

Zeligman and colleagues[73] studied undergraduate students with different chronic illnesses, including diabetes, asthma, heart disease, sickle cell disease, HIV, epilepsy, fibromyalgia, chronic migraines, arthritis, and dextroscoliosis. Utilizing the PTGI,[2] the Social Provisions Scale (SPS),[74] the Meaning in Life Questionnaire (MLQ),[3] and a demographic questionnaire,[73] the researchers sought to discover how demographic characteristics, social support, life meaning, and type of chronic illness played a role in the development of post-traumatic growth. Life meaning and gender contributed most to the development of post-traumatic growth, as females were over three times as likely to develop post-traumatic growth than males.[73] Meaning and social support together also increased the likelihood of post-traumatic growth. What was highly significant about this research study was that the type of chronic illness the participants had seemed to be a significant predictor in the development of post-traumatic growth. The participants with epilepsy and the participants with heart disease reported experiencing the highest levels of post-traumatic growth.[73]

Loved ones of individuals with chronic health conditions

Children of parents with chronic health conditions

Additionally, researchers have found that loved ones (i.e., those who support chronically ill individuals, witness failures in their family members' health, and experience fears about the results of their family members' chronic illnesses) also have an increased chance of experiencing changes to their perceptions about themselves and the world. If these changes are positive, many loved ones of individuals with chronic illnesses have the opportunity of developing post-traumatic growth. Wei and colleagues[75] administered the Hopefulness About Future Scale,[76] the PTGI for Children (PTGI-C),[77] the Enacted Stigma Index,[78] the Perceived Social Support Measure (PSSM),[79] and the Social Competence Scale (SCS)[80] to study children affected by parental HIV in China. The researchers found that, together, emotional management, hopefulness, and perceived social support helped to lessen the impact of HIV-stigma on post- traumatic growth in children of parents with HIV.[75]

Mothers of children with chronic health conditions

Kim[81] used the PTGI,[2] the MSPSS,[67] the Life Orientation Test-Revised (LFT-R),[82] the Core Beliefs Inventory (CBI),[83] and the Event-Related Rumination Inventory (EVRRI)[83] to determine what factors affect post-traumatic growth in mothers, who had children with cancer. They found that optimism, disruption of core beliefs, and especially, social support and deliberate rumination explained the difference in the mothers' levels of post-traumatic growth.[81]

Caregivers of individuals with chronic health conditions

Hamama & Sharon[84] investigated post-traumatic growth in caregivers, including spouses, adult children, and parents using the PTGI,[2] the Satisfaction with Life Scale (SLS),[85] and the Positive and

negative Affect Schedule.[86] While there was no substantial relationship between post-traumatic growth and negative affect or life satisfaction, positive affect (i.e., optimism) was positively correlated with post-traumatic growth.[84] Additionally, adult children of chronically ill individuals reported a more positive affect and greater life satisfaction than parents and spouses of chronically ill individuals.[84]

Conclusion from the literature

This literature review examined various research articles that supported the connections between chronic health conditions, namely T1D, and mental health. It also examined complex trauma, post-traumatic growth, and meaning in life in individuals living with chronic health conditions, along with other biopsychosocial factors that may contribute to them. Examples provided insight into the potential causes of the development of post-traumatic growth and meaning in life in patients, their children, their parents, and other caregivers. The struggles that the community faces, particularly in regard to economic challenges, were discussed in order to highlight a major issue that denies individuals with T1D from the health and mental health care they deserve—medication unaffordability. The purpose of the current study is to further explore relationships among trauma experience, post-traumatic growth, meaning in life, medication unaffordability, and T1D community support within individuals living with type 1 diabetes.

Statement of the problem

Researchers have found that individuals with T1D are at an increased risk of developing depressive disorders, anxiety disorders, and eating disorders.[8,14–16] However, while various researchers have explored the aforementioned mental health comorbidities of T1D, it remains unknown whether T1D, a chronic condition which involves repetitive threats to one's life, is associated with complex trauma. To date, there is very little research examining the connection between T1D and post-traumatic growth, and the effects of T1D as a trauma in adults. The majority of research on complex trauma is dedicated to children and adolescents who have suffered from domestic violence and abuse. Countless individuals with T1D suffer due to the increased cost of insulin and life-saving medical supplies,[27] yet there is no research to date investigating how these changes influence their mental health.

Although perceived social support has been found to increase positive mental health effects in individuals with T1D in a few studies, social support from those who share the same chronic illness and understand it in the same manner has not been studied. The lack of research available on adults with T1D is problematic. While there is an abundance of research on trauma and post-traumatic growth in individuals with other chronic illnesses, such as coronary heart disease and cancer, as well as parents and caregivers of children with T1D, there is very little research found on the risk of trauma and the possibility of post-traumatic growth in adults with T1D.

The literature suggests that further patient-informed research is needed regarding the presence and level of trauma, post-traumatic growth, and meaning in life in adults with T1D. The aim for this study is to have a better understanding about the relationships among complex trauma, socioeconomic status and medication unaffordability, T1D community support, post- traumatic growth, and meaning in life in adults with T1D. As individuals who must rely on high-priced medication to survive each day, the focus on socioeconomic status and medication unaffordability is integral to examining these psychological variables.

Study hypotheses

The current study was designed to examine the relationship between T1D and trauma symptoms. It was also designed to evaluate how socioeconomic status, medication unaffordability, and relating to other individuals with T1D could influence positive mental health symptoms based on the development of posttraumatic growth and meaning in life. Based on a review of the literature, four hypotheses were tested. It was predicted that adults diagnosed with T1D experience the autoimmune disease as traumatic. In addition, it was predicted that, due to medication unaffordability, T1D is experienced as more traumatic for adults with low socioeconomic status as compared to adults with higher socioeconomic status. It was predicted that connecting with others who share the same illness via the T1D community is associated with higher post-traumatic growth and meaning in life. Finally, it was predicted that medication unaffordability negatively impacts the development of post-traumatic growth and meaning in life in adults with T1D.

Method

Participants

Eligible participants were required to be at least 18 years old and to have a diagnosis of T1D. Eligible participants provided implied consent to participate in the study by beginning and completing the questionnaire after reading the implied consent form. In order to be included in the study, respondents must have answered survey items regarding the key independent variables (i.e., socioeconomic status, cost of diabetes supplies, economic sacrifices, insulin rationing, and length of involvement in the T1D community) and the dependent variables, the three psychological measures (i.e., the PTSD Checklist for *DSM*-5, the Posttraumatic Growth Inventory, the Meaning in Life Questionnaire). Incomplete questionnaires were not used.

Measures

Sociodemographic data

Questions regarding participants' sociodemographic information were included in section one of the online questionnaire. The questions inquired about primary language, gender, race, ethnicity, sexual orientation, relationship status, annual household income, and highest level of education. The sociodemographic questions also included questions pertaining to medical history and involvement in the T1D community. Participants were asked if they had been diagnosed with any other autoimmune conditions or chronic illnesses. They were asked about their length of involvement in the T1D community, the number of days they participate in the diabetic online community each week, and their involvement in in-person T1D meetups and events. Participants were asked if they have ever needed to make economic sacrifices to purchase their prescriptions and if they have ever had to ration their insulin due to unaffordability.

Descriptive data

Additionally, descriptive data questions were included in the survey. The questions inquired about age, state of residence within the United States or country of residence if they resided outside of the United States, monthly cost of insulin, and monthly cost of other diabetes supplies. In order to learn more about the participants' medical history, each participant was asked to state their age at diagnosis of T1D, the names of other autoimmune conditions or chronic illnesses that they have been diagnosed with, and which family members of theirs also have T1D, if any. In order to learn more about their

participation in the T1D community, participants were asked to state the year in which they first attended an in-person meet-up or event with other individuals with T1D and approximately how many events they have attended to date. Finally, participants were asked the types of economic sacrifices they have had to make in order to afford their prescriptions and if they ever experienced a trauma prior to their diagnosis. These inquiries lead into the psychological assessments described below. For the complete set of questions, which were used to determine sociodemographic and descriptive data, see Appendix C.

The PTSD checklist for DSM-5

The Post-traumatic Stress Disorder (PTSD) Checklist for the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (*DSM-5*) (PCL-5) was used to measure the level of complex trauma that the participants may have experienced in relation to their T1D.[87] The PCL-5 is a 20-item standardized self-report scale, which measures symptoms of post-traumatic stress disorder based on the DSM-5.[1,87,88] The *DSM-5* is considered the standard classification of mental health disorders used by the majority of mental health professionals working in the United States.[89] On the PCL-5, each symptom item is assessed according to its rate of occurrence over the past month using a five-point Likert scale, ranging from 1 ("not at all") to 5 ("extremely"). A provisional post-traumatic stress disorder diagnosis can be made by recognizing each item that is rated as 2 ("moderately") or higher as a symptom and, subsequently, using the DSM-5 diagnostic criteria, which requires one reported symptom from cluster B (questions 1-5), one from cluster C (questions 6-7), two from cluster D (questions 8-14), and two from cluster E (questions 15-20). Research suggests that a score between 31 to 33 is optimally efficient for diagnosing post-traumatic stress disorder ($\kappa(0.5) = 0.58$).[1] Participants' full-scale scores were utilized for the purpose of the current study.

Bovin et al.,[1] reported that the PCL-5 has a strong internal consistency ($\alpha = 0.96$), test-retest reliability ($r = 0.84$), and convergent and discriminant validity. Blevins et al.,[87] also reported good convergent ($r = 0.74$ to 0.85) and discriminant ($r = 0.31$ to 0.60) validity, and suggested that PCL-5 scores had strong reliability and validity with reference to symptoms of trauma. These results indicate that the PCL-5 is a psychometrically sound measure of the DSM-5 criteria for post-traumatic stress disorder diagnosis.[1,87,88] The PCL-5 requires approximately five to 10 minutes to complete, and can be scored in approximately five to 10 minutes. Sample items from the PCL-5 include "repeated, disturbing, and unwanted memories of the stressful experience", "trouble experiencing positive feelings (e.g., being unable to feel happiness or have loving feelings for people close to you)", and "feeling jumpy or easily startled".[87] See Appendix D for the PCL-5.

The posttraumatic growth inventory

The Posttraumatic Growth Inventory (PTGI) was used to measure post-traumatic growth.[2] The PTGI is a 21-item self-report scale, which includes five domains (e.g., New Possibilities, Personal Strength, Spiritual Change, Appreciation of Life, and Relating to Others) and two factors (e.g., Self-Perception and Interpersonal Relationships).[2] The personal strength subscale is related to the feeling of self-reliance, feeling stronger than one thought, handling difficulties, and accepting the way things work out. The new possibilities subscale is related to having new interests, new opportunities, and a new path in life, doing better for oneself, and trying to change things. The spiritual change subscale involves understanding spiritual matters and having a stronger religious faith, while the appreciation of life subscale involves the perception of what is important in life, the value of one's own life, and the appreciation of each day. The relating to others subscale is related to how much one relies on people, one's effort in relationships, closeness with and compassion for others, expression of emotions, accepting the need for others, and the perception of how wonderful people are. While the first four domains are categorized into the PTGI's first factor of self-perception, relating to others is categorized into the second factor of interpersonal relationships.[2,9]

Each symptom item is assessed using a six-point Likert scale, ranging from 0 ("I did not experience this change") to 5 ("I experienced this change to a very great degree"). The results of the participants' full-scale score and subscale scores were utilized in the current study. By examining the concurrent and discriminant validity of the PTGI, researchers discovered that the assessment was moderately related to optimism and extraversion.[2] The test-retest reliability of the measure as a whole was 0.71, while the internal consistency of the assessment as a whole was 0.90, with New Possibilities as $\alpha = 0.84$, Relating to Others as $\alpha = 0.85$, Personal Strength as $\alpha = 0.72$, Spiritual Change as $\alpha = 0.85$, and Appreciation of Life as $\alpha = 0.67$.[2] The PTGI requires approximately five to 10 minutes to complete, and can be scored in approximately five to 10 minutes. Sample items from the PTGI include "I have a greater appreciation for the value of my own life", "I put more effort into my relationships", and "I have a stronger religious faith".[2] See Appendix E for the PTGI.

The meaning in life questionnaire

The Meaning in Life Questionnaire (MLQ) was used to measure meaning in life.[3] The MLQ is a 10-item self-report instrument, consisting of two subscales: the presence of meaning and the search for meaning.[3] The presence of meaning subscale evaluates how full examinees feel their lives are of meaning. The search for meaning subscale evaluates how engaged and motivated examinees are in their efforts to find meaning or unearth their understanding of meaning in their lives.

Each symptom item is assessed using a six-point Likert scale, ranging from 1 ("absolutely untrue") to 7 ("absolutely true"). The researcher scored each subscale individually. The MLQ has good reliability, test-retest stability, steady factor structure, and convergence among respondents.[3] According to Steger et al.,[3] the presence subscale positively correlated with life satisfaction, positive emotions, intrinsic religiosity, extraversion, and agreeableness and negatively correlated with depression, negative emotions, and neuroticism. The search subscale was positively correlated with neuroticism, depression, and several negative emotions.[3] The authors reported a good internal consistency for presence of meaning ($\alpha = 0.86$) and search for meaning ($\alpha = 0.88$). The MLQ requires approximately five minutes to complete, and can be scored in approximately five minutes.

Sample items from the MLQ include "I have discovered a satisfying life purpose," "I am always searching for something that makes my life feel significant," and "My life has no clear purpose".[3] See Appendix F for the MLQ.

Design and procedure

The research design used in this study was a quantitative and correlational design. The study was approved by Saint Elizabeth University's Institutional Review Board. The researcher subsequently engaged in online recruitment through snowball sampling methodology. The researcher shared a recruitment flyer with the diabetes online community on Instagram, Facebook, and Twitter, and numerous active community members then shared the flyer with people who they knew to be eligible for participating. The recruitment flyer can be found in Appendix A.

In order to keep the participants' identity anonymous, there was no monetary incentive to participate in the study. Additionally, IP addresses, names, date of birth, and home addresses were not recorded. Following the completion of an online implied consent form (Appendix B), the participants took part in the survey which was in a Google Forms questionnaire. The questionnaire first integrated 28 sociodemographic and descriptive questions, the three psychological measures, and later included questions pertaining to the participants' demographics, as well as descriptive questions about their experiences with T1D and levels of involvement in the T1D community. Participants were free to stop participating in the study at any time per the specific details on the implied consent form. Upon completion of the questionnaires, the participants were provided with a debriefing form with optional referrals for counseling, mental health help lines, and community resources that might assist with costs of diabetic supplies. The debriefing form can be found in Appendix G. The survey used for this study was closed after 1009 responses were received.

Data analysis

Data management

Data management began by examining the extent of missing data. Participants who did not meet study inclusion criteria (i.e., participants that were under the age of 18 and participants who reported not having T1D) were removed, along with participants who were missing data regarding the key independent and dependent study variables (i.e., socioeconomic status, cost of diabetes supplies, PCL-5 responses, PTGI responses, and MLQ responses). Composite scores for the PCL-5, PTGI, and MLQ were computed according to published scoring guidelines.

Descriptive analysis

Descriptive statistics were obtained for the sample sociodemographic characteristics (i.e., gender, primary language, primary race, ethnicity, sexual orientation, relationship status, annual household income, highest level of education, place of residence, and age) and the sample T1D characteristics (i.e., age diagnosed, family history, other autoimmune disease or chronic medical diagnosis, length in the T1D community, weekly participation in T1D community, in-person T1D event involvement, economic sacrifices to afford medication, and insulin rationing).

Frequencies and percentages were reported for the binary and categorical variables, while mean and standard deviations were reported for the continuous variables. Descriptive statistics were also obtained for the key study variables (i.e., PCL-5 composite scores, PTGI composite scores, and MLQ composite scores). Means and standard deviations, along with the minimum and maximum values were obtained. Lastly, Spearman correlation coefficients were computed on the key study variables.

Research question 1

Research question 1 asked whether adults with T1D experience the autoimmune disease as traumatic. The PCL-5 was used to measure complex trauma related to T1D. The PCL-5 was scored by summing the responses to all items in the survey in order to get a total symptom severity score, which could range from 0 to 80. According to the scoring manual, a cut-off raw score of 38 or greater was used to provide a provisional diagnosis of post-traumatic stress disorder (sensitivity = 0.78 and specificity = 0.98). To address this research question, the percentage of subjects meeting the criteria for post-traumatic stress disorder on the PCL-5 was computed.

Research question 2

Research question 2 asked how medication unaffordability impacted the severity of trauma in adults with T1D. It was hypothesized that, due to medication unaffordability, T1D is experienced as more traumatic for adults with low socioeconomic status as compared to adults with higher socioeconomic status. Chi-square tests were used to compare the rate of post- traumatic stress disorder, as measured by the PCL-5, across measures of socioeconomic status (i.e., annual household income, level of education, presence of economic sacrifices to afford diabetes supplies, and insulin rationing). ANOVA and independent samples *t*-tests were used to compare the PCL-5 composite scores across each of the above measures of socioeconomic status. A Tukey test was used to correct for multiple comparisons where appropriate. For all analyses, a p-value <0.05 was used to determine statistical significance.

Research question 3

Research question 3 asked how connecting with others who share the same illness impacted the development of post-traumatic growth and meaning of life. It was hypothesized that connecting with others who share the same illness via the T1D community is associated with higher post-traumatic growth and meaning of life. ANOVAs were used to compare PTGI and MLQ composite scores across categories of years of involvement with the T1D community. A p-value <0.05 was used to determine statistical significance.

Research question 4

Research question 4 asked whether medication unaffordability impacted the development of post-traumatic growth and meaning of life in adults with T1D. It was hypothesized that medication unaffordability was negatively associated with post-traumatic growth and meaning of life. Medication unaffordability was measured using participant's annual household income, economic sacrifices, and insulin rationing. Spearman correlation coefficients and ANOVA tests were used to test the association between annual household income and the PTGI and MLQ composite scores. Post hoc pairwise comparisons between income levels were conducted when a significant ANOVA test was found. A Tukey's test was used to correct for multiple comparisons where appropriate. A p-value <0.05 was used to determine statistical significance.

ANOVA tests were used to measure the relationship between level of education, post- traumatic growth, and meaning in life. Independent samples *t*-tests were used to calculate the differences in post-traumatic growth and meaning in life between adults who rationed insulin and those who did not ration insulin. Independent samples *t*-tests were also used to compute the differences in post-traumatic growth and meaning in life between adults who made economic sacrifices and those who did not. Spearman correlations were used to examine the relationship between medication unaffordability, which included economic sacrifices and insulin rationing, and post-traumatic growth and meaning in life.

Results

This research study was designed to evaluate whether adults with T1D experience the chronic medical condition as a trauma and how socioeconomic status and medication unaffordability could affect their level of experienced trauma. It was also designed to examine how socioeconomic status, medication unaffordability, and relating to other individuals with T1D could impact positive mental health

outcomes, including the development of post-traumatic growth and meaning in life. The study utilized a correlational design and tested the hypotheses using parametric and nonparametric statistical analyses.

Participant sociodemographic variables

Missing data examination

Within approximately one month of the start of data collection, 1,008 participants took part in the online questionnaire. Among those, one did not have T1D (0.10%), one was less than 18 years old (0.10%), and 11 did not provide their age (1.10%). These 13 subjects were excluded from the analysis as they did not meet study inclusion criteria. Among the remaining 995 potential participants, 226 (22.70%) were missing key independent and dependent study variable responses and were excluded from further analysis. Therefore, the final sample consisted of 769 adults with T1D.

Sample sociodemographic characteristics

Table 1 contains the sample sociodemographic characteristics. The final study sample consisted of 769 adults, ages 18 to 68, with T1D. The participants had a mean age of 29.10 years old (*SD* = 8.00). The majority of the study sample was female (86.90%), White (86.60%), non- Hispanic/Latinx (90.80%), heterosexual (80.20%), based in the United States (72.60%), partnered (63.40%), and reported English as their primary language (93.00%). The socioeconomic status of the sample was varied with a roughly equal split across annual household income categories. Most (92.50%) of the participants had an education level beyond a high school diploma or GED. The study included individuals from North America (80.50%, *n* = 619), Europe (13.50%, *n* = 104), Australia (2.70%, *n* = 21), Asia (0.90%, *n* = 7), South America (0.80%, *n* = 6), and Africa (0.70%, *n* = 5).

Table 1 Sample sociodemographic characteristics

Characteristic	n	%
Gender		
Female	668	86.9
Male	96	12.5
Other	5	0.7
Primary Language English	715	93
Other	53	6.9
Missing	1	0.1
Primary race		
American Indian/Alaskan Native	6	0.8
Asian, Native Hawaiian, or other	28	3.6
Pacific		
Biracial or multiracial	41	5.3
Black or African American	28	3.6
White	666	86.6
Hispanic/Latinx		
Yes	71	9.2
No	698	90.8
Sexual orientation Bisexual		
	92	12
Heterosexual	617	80.2
Homosexual	32	4.2
Other	26	3.4
Missing	2	0.3
Relationship status Divorced		
	15	2
In a relationship	148	19.3
Living with a partner	106	13.8
Married	233	30.3
Single	267	34.7
Annual household income		
<$35,000	185	24.1
$35,000-49,999	125	16.3
$50,000-74,999	153	19.9
$75,000-99,999	121	15.7
$100,000-149,999	110	14.3
>$150,000	75	9.8
Education		
Some high school	5	0.7
High school/GED	53	6.9
Some college	178	23.2
Associate degree	47	6.1
Bachelor's degree	319	41.5
Master's degree	134	17.4
Doctoral degree	15	2
Professional degree	18	2.3
Residence Australia		
	21	2.7
Brazil	1	0.1
Canada	61	7.9
Chile	1	0.1
Colombia	1	0.1
Denmark	1	0.1
Ecuador	1	0.1
Finland	2	0.3
France	5	0.7
Germany	10	1.3
Greece	1	0.1
Guatemala	1	0.1
India	3	0.4
Indonesia	1	0.1
Italy	2	0.3
Kuwait	1	0.1
Latvia	1	0.1
Netherlands	4	0.5
New Zealand	8	1
Norway	1	0.1
Peru	1	0.1
Philippines	1	0.1
Portugal	2	0.3
Romania	1	0.1
Russia	1	0.1
Slovenia	1	0.1
South Africa	5	0.7
Spain	1	0.1
Sweden	3	0.4
Syria	1	0.1
United Kingdom	60	7.8
United States	558	72.6
Missing	7	0.9
Age, mean ± SD	29.1	± 8.0

The sample was 86.90% female (n = 668) and 12.50% male (n = 96), with 0.70% (n = 5) identified with other gender identities (e.g., "agender", "gender fluid", "non-binary", "questioning", and "gender nonconforming woman, using both she/her and they/them pronouns"). Ninety-three percent (n = 715) identified English as their primary language, while 6.90% (n = 53) reported having another primary language and 0.10% (n = 1) did not answer this question. A large portion of the sample, identified as White (86.60%, n = 666), while the remainder of the participants identified as biracial or multiracial (5.30%, n = 41), Black or African American (3.60%, n = 28), Asian, Native Hawaiian, or other Pacific Islander (3.60%, n= 28), and American Indian or Alaskan Native (0.80%, n = 6). Of these participants, 9.20% (n = 71) identified as Hispanic or Latinx, while 90.80% (n = 698) identified as non-Hispanic/Latinx. Of the participants, 80.20% (n = 617) identified as heterosexual, while the other participants identified as bisexual (12.00%, n = 92) and homosexual (4.20%, n = 32). Twenty-six (3.40%) participants identified with other sexual orientations (e.g., pansexual, queer, omnisexual, polyamorous, unsure, homoflexible, and asexual aromantic), while two participants did not respond to this question.

About a third of the sample were single (34.70%, n = 267), while others were married (30.30%, n = 233), in a relationship (19.30%, n = 148), living with a partner (13.80%, n = 106), and divorced (2.00%, n = 15). The sample's annual household income included less than $35,000 (24.10%, n = 185), $50,000 to $74,999 (19.90%, n = 153), $35,000 to $49,999 (16.30%, n = 125), $75,000 to $99,999 (15.70%, n = 121), $100,000 to $149,999 (14.30%, n = 110), and $150,000 or more (9.80%, n = 75). Of the participants, 41.50% (n = 319) had a bachelor's degree, 23.20% (n = 178) had some college, 17.40% (n = 134) had a master's degree, 6.90% (n = 53) had a high school diploma or GED, 6.10% (n = 47) had an associate degree, 2.30% (n = 18) had a professional degree, 2.00% (n = 15) had a doctoral degree, and 0.70% (n = 5) had some high school education.

The sample included residents of six different continents, including: North America (United States and Canada), Europe [Denmark, Finland, France, Germany, Greece, Italy, Latvia, Netherlands, New Zealand, Norway, Portugal, Romania, Russia, Slovenia, Spain, Sweden, and the United Kingdom (England, Scotland, Wales)], South America (Brazil, Chile, Columbia, Ecuador, Guatemala, and Peru), Asia (India, Indonesia, Kuwait, Philippines, and Syria), Africa (South Africa), and Australia. Seven individuals (0.90%) did not disclose their place of residence. The sample sociodemographic variables were summarized and can be found in Table 1.

Sample T1D characteristics

Table 2 displays the participant T1D characteristics. About a third of the sample had a family history of T1D (31.50%, n = 242) and 44.10% (n = 339) were diagnosed with an additional autoimmune disease or other chronic medical condition. Some diagnoses that the sample reported were hypothyroidism, polycystic ovary syndrome (PCOS), celiac disease, Graves' disease, Crohn's disease, vitiligo, fibromyalgia, gastroparesis, kidney disorders, diabetic neuropathy, and diabetic retinopathy. Involvement in the T1D online community varied with 29.40% (n = 226) having less than one year involvement with the community and about 71.00% (n = 543) having a year or more. Over half the sample (51.00%, n = 392) attended an in-person event at some point (M = 6.00, SD = 11.40). About 27.10% (n = 208) had over five years of involvement in the T1D online community, while 18.20% (n = 140) had one year of involvement, 17.60% (n = 135) had two to three years, 12.20% (n = 94) had six to twelve months, 11.10% (n = 85) had one to three months, 7.80% (n = 6) had four to five years, and 6.10% (n = 47) had three to six months. The average amount of days a week that participants engaged in the diabetes online community was about 4.4 days (SD = 2.4).

Table 2 Participant T1D characteristics

Characteristic	n	%
Family history	242	31.50
Other autoimmune disease or chronic medical diagnosis	339	44.10
Length in the T1D community		
1-3 months	85	11.10
3-6 months	47	6.10
6-12 months	94	12.20
1 year	140	18.20
2-3 years	135	17.60
4-5 years	60	7.80
Over 5 years	208	27.10
Attended in-person T1D community event	392	51.00
Made an economic sacrifice to purchase diabetes supplies	397	51.60
Insulin rationing	182	23.79
Economic sacrifices	397	51.69
Trauma prior to T1D diagnosis	597	77.63

Approximately one quarter (23.79%, n = 182) had rationed their insulin due to unaffordability at some point. Over half the participants reported making economic sacrifices in order to afford their diabetes supplies (51.69%, n = 397). Some of the participants' economic sacrifices included "credit card debt," "not buying groceries or gas", "moving", "paying rent and bills late", "living with my parents", "having to sell my car", and "food or rent versus medication". Various participants stated that they required "parental help" and "borrowing from friends", while a few others reported "living in my car" and "being homeless for a little while". The amount in which participants paid for a monthly supply of insulin ranged from $0 to $2000 with a mean of $94.41. The monthly total they paid for other diabetes supplies ranged from $0 to $3000 with a mean of $307.65. About 77.63% ($n$ = 597) stated that they experienced trauma prior to their T1D diagnosis.

Additional descriptive information

Table 3 displays the additional description information about the participants. The sample included participants who were diagnosed with T1D any time between 3 months old to 57 years old, with a mean age of diagnosis of 14.70 (SD = 8.70). On average, participants had attended six in-person T1D events (SD = 11.40). They participated in the T1D online community approximately 4.40 days per week (SD = 2.40). The cost of the participants' insulin ranged from $0 to $2,000 per month, averaging to $94.41 ($SD$ = $201.37). The cost of the participants' other diabetes supplies ranged from $0 to $3,000 per month, averaging to $201.59 ($SD$ = $307.65).

Test of research hypotheses

This study was designed to assess the relationship between T1D and complex trauma, as well as the impact of medication unaffordability and socioeconomic status on the presence and severity of trauma symptoms. The study also evaluated how socioeconomic status, medication unaffordability, and relating to other individuals with T1D could impact the development of posttraumatic growth and meaning in life. There were four hypotheses tested in this research study. The Statistical Analysis System (SAS) version 9.4 (SAS Institute Inc., Cary, NC) was used for data analysis. Table 4 displays the descriptive statistics of the study outcome variables.

Table 3 Additional descriptive information

Characteristic	n	Mean	SD	
Age diagnosed	729	14.7	± 8.70	
Number of in-person T1D community events attended	490	6	± 11.40	
Days per week participating in T1D online community	753	4.4	± 2.40	
Cost of insulin	769	$94.41	$201.37 (range: $0 to $2000)	
Median (IQR): $30 ($4.50, $90) Cost of other diabetes supplies				
	769	$201.59	$307.65	(range: $0 to $3000)
Median (IQR): $100 ($30, $250)				

Table 4 Descriptive statistics on the outcome variables

Variable	N	Mean	SD	Min	Max
PCL-5					
Total score	769	30.6	18.3	0	80
Re-experiencing	769	6.7	5.3	0	20
Avoidance	769	2.9	2.5	0	8
Negative alternatives	769	11.4	7.2	0	28
Hyperarousal	769	9.5	5.8	0	24
PTGI Total score	769	50.0	22.4	0	105
Relating to others	769	15.0	8.3	0	35
New possibilities	769	11.5	6.3	0	25
Personal strength	769	12.1	5.2	0	20
Spiritual change	769	2.7	3.1	0	10
Appreciation of life	769	8.7	3.7	0	15
MLQ Presence	769	17.8	6.6	-1	29
Search	769	22.1	6.3	5	30

Hypothesis 1

Research question 1 asked whether adults with T1D experience the autoimmune disease as traumatic. It was hypothesized that adults diagnosed with T1D experience the autoimmune disease as traumatic. Using the PCL-5 scoring manual's cut-off raw score of 38 or greater, the study found that approximately one-third of patients with T1D experience the autoimmune disease as traumatic (35.10*%, n* = 270 of 769). Table 4 displays the PCL-5 total and subscale scores means and standard deviations. These findings support the study's first hypothesis, as a significant portion of the participants fit the criteria for PTSD.

Hypothesis 2

Research question 2 asked how medication unaffordability and socioeconomic status impacted the severity of trauma in adults with T1D. It was hypothesized that, due to medication unaffordability, T1D is experienced as more traumatic for adults with low socioeconomic status as compared to adults with higher socioeconomic status. Chi-square, ANOVA, and independent samples *t*-tests showed that the severity of trauma in adults with T1D varied across socio- economic status as measured by annual household income (Table 5), level of education (Table 6), need to make economic sacrifices to purchase diabetes medications and supplies (Table 7), and need to ration insulin (Table 8).

Annual household income

A Chi-square test was used to analyze the relationship between the rate of post-traumatic stress disorder (according to the PCL-5 criterion total score) and annual household income. The result was significant (x^2 = 17.6, *df* = 5, p<0.01). Pairwise comparisons showed that the PTSD rate was significantly higher among individuals with an annual household income of <$35,000 (47.00%) and $35,000-49,999 (36.00%) compared to individuals with an annual household income of $50,000 -74,999 (30.70%), $75,000-99,999 (33.10%), $100,000-149,999 (28.20%),

and >$150,000 (26.70%). All comparisons were significant at p<0.05. Further, individuals with an annual household income of <$35,000 had a higher rate of meeting PCL-5 criteria for post-traumatic stress disorder than individuals with an annual household income of $35,000-49,999 (47% vs. 36%, p<0.05).

An ANOVA was used to examine the differences in PCL-5 total scores by annual household income groups. The result indicated an overall significant difference among the household income groups (F(5, 763) = 4.81, p<0.001). Post hoc pairwise comparisons showed that, after adjusting for multiple comparisons using Tukey's test, those with an annual household income of <$35,000 had significantly higher PCL-5 total scores (M = 35.00, SD = 18.80) than those who had an annual household income of $50,000-74,999 ($M$ = 29.10, SD = 18.00),$100,000-149,999 ($M$ = 26.6, SD = 17.9), and >$150,000 ($M$ = 25.60, SD = 16.20). All comparisons were significant at p<0.05.

ANOVA tests were run on each of the PCL-5 subscale scores by household income group. The hyper arousal subscale followed the same pattern as was found for PCL-5 total score (F(5, 763) = 4.70, p<0.001). Post hoc pairwise comparisons showed that, after adjusting for multiple comparisons using Tukey's test, those with an annual household income of <$35,000 had significantly higher PCL-5 total scores (M = 11.00, SD = 6.00) than those who had an annual household income of $50,000-74,999 ($M$ = 8.90, SD = 5.80), $100,000-149,999 ($M$ = 8.30, SD =5.30), and >$150,000 ($M$ = 8.50, SD = 5.00). All comparisons were significant at p<0.05.

For the re-experiencing subscale (F(5, 763) = 3.09, p<.01), individuals with an annual household income of <$35,000 had significantly higher scores than those with an annual household income of $75,000-99,999 ($M$ = 7.80, SD = 5.60 vs. M = 7.00, SD = 5.4*; p*<0.05). For the negative alternatives subscale (F(5, 763) = 4.60, p<0.001)), individuals with an annual household income of <$35,000 had significantly higher scores (M = 13.00, SD = 12.0) than those with an annual household income of $100,000-149,999 ($M$ = 9.70, SD = 7.50) and >$150,000 ($M$ = 9.50, SD = 6.60) (all comparisons p<0.05). The difference in avoidance scores (F(5, 763) = 1.74) across annual household income categories was not statistically significant (p>0.05). These findings support the study's second hypothesis that PTSD is experienced more in those with lowest annual household income. The findings can be found in Table 5.

Level of education

A Chi-square test was used to analyze the relationship between the rate of post-traumatic stress disorder (according to the PCL-5 criterion total score) and level of education. The result was significant (x^2 = 28.1, *df* = 3, p<0.0001). Pairwise comparisons showed that the PTSD rate was significantly higher among individuals was significantly higher among individuals with a high school degree or less (44.80%) and post-secondary education (e.g., some college experience, associate degree) (47.60%), compared to those with a bachelor's degree (28.80%) and an advanced degree (e.g., master's degree,

doctoral degree) (27%). All comparisons were significant at p<0.05. The rate of subjects meeting the PCL-5 criteria for PTSD was also significantly lower among those with an advanced degree (16.70%) than those with post- secondary education (39.60%) and a bachelor's degree (34.10%). All comparisons were significant at $p<0.0001$.

An ANOVA was used to examine the differences in PCL-5 total scores by level of education groups. The result indicated an overall significant difference among the level of education groups (F (3, 765) = 17.54, $p < 0.0001$). Post hoc pairwise comparisons showed that, after adjusting for multiple comparisons using Tukey's test, those with a high school degree or less (M = 37.70, SD = 20.10), or post-secondary education (M = 36.30, SD = 19.10), had significantly higher PCL-5 total scores than those with a bachelor's degree (M = 27.20, SD = 16.90) and those with an advanced degree (M = 26.80, SD = 16.30). All comparisons were significant at $p<0.05$.

Table 5 Chi-Square and ANOVA tests of differences in PTSD across annual household income

Household income	N	<$35,000		$35,000-49,999		$50,000-74,999		$75,000-99,999		$100,000-149,999		>$150,000		x^2(df=5)	p
PTSD, %	769	47.0%		36.0%*		30.7%*ŧ		33.1%*ŧ		28.2%*ŧ		26.7%*ŧ		17.6	0.003
PCL-5 scales	**N**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**F(5, 763)**	**p**
Total score	769	35.0	18.8	31.9	18.1	29.1*	18.0	31.0	17.8	26.6*	17.9	25.6*	16.2	4.81	0.0002
Re-experiencing	769	7.8	5.6	6.7	5.3	6.4	5.0	7.0*	5.4	6.0	5.3	5.4	4.6	3.09	0.01
Avoidance	769	3.2	2.6	3.1	2.7	2.9	2.5	3.0	2.6	2.6	2.4	2.4	2.3	1.74	0.12
Negative alternatives	769	13.0	7.2	12.0	7.2	10.9	7.0	11.6	7.1	9.7*	7.5	9.5*	6.6	4.60	0.0004
Hyper arousal	769	11.0	6.0	10.0	6.0	8.9*	5.8	9.4	5.6	8.3*	5.3	8.5*	5.0	4.70	0.0003

* p<0.05 for comparison to <$35,000; ŧ p<0.05 for comparison to $35,000-49,999

This pattern of those with a high school degree or less, or post-secondary education, having significantly higher subscale scores than those with a bachelor's degree and those with an advanced degrees persists for the re-experiencing (F(3, 765) = 11.98), negative alternatives (F(3, 765) = 13.17), and hyper arousal subscales (F(3, 765) = 16.85). All comparisons are significant at $p<0.05$. See Table 6 for the means and standard deviations per education group.

For the avoidance subscale (F(3,765) = 9.03, p<0.0001), those with post-secondary education had significantly higher scores (M = 3.60, SD = 2.70) than those with a bachelor's degree (M = 2.50, SD = 2.40) and those with an advanced degree (M = 2.60, SD = 2.40). All comparisons were significant at $p<0.05$. The scores for those with a high school degree or less (M = 3.40, SD = 2.90) were not significantly different from those with post-secondary education. The finding that those with lower levels of education have higher PCL-5 scores supported the study's second hypothesis. These results can be found in Table 6.

Table 6 Chi-square and ANOVA tests of differences in PTSD across education

Education	N	HS or less		Post-secondary education BA				Advanced degree		x^2(df=3)	p
PTSD, %	769	44.8%		47.6%		28.8%*ŧ		27.0%*		28.1%	<0.0001
PCL-5 Scales	**N**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**F(3, 765)**	**p**
Total score	769	37.7	20.1	36.3	19.1	27.2*ŧ	16.9	26.8*ŧ	16.3	17.54	<0.0001
Re-experiencing	769	8.6	6.1	8.1	5.6	5.8*ŧ	4.8	5.9*ŧ	5.0	11.98	<0.0001
Avoidance	769	3.4	2.9	3.6	2.7	2.5ŧ	2.4	2.6ŧ	2.4	9.03	<0.0001
Negative	769	13.9	7.6	13.4	7.5	10.2*ŧ	6.9	10.1*ŧ	6.5	13.17	<0.0001
alternatives Hyper arousal	769	11.9	6.6	11.3	6.0	8.6*ŧ	5.3	8.1*ŧ	5.3	16.85	<0.0001

* p<0.05 for comparison to HS or less; ŧ p<0.05 for comparison to some college.

Economic sacrifices

Table 7 shows the Chi-square and independent samples t-tests comparing level of trauma in participants who did and did not have to make economic sacrifices to purchase diabetes medications and supplies. The rate of people meeting PCL-5 criteria for PTSD was significantly higher among those who made economic sacrifices (41.80%) than those who did not make economic sacrifices (28%; x^2 = 16.18, df = 1, p<0.0001).

Table 7 Chi-square and independent samples t-tests of differences in PTSD by economic sacrifice

Economic sacrifice	N	No sacrifice		Sacrifice		x^2(df=1)	p
PTSD, %	769	28.0%		41.8%		16.18%	<0.0001
PCL-5 Scales	**N**	**Mean**	**SD**	**Mean**	**SD**	**t(df=1)**	**p**
Total score	769	26.9	17.5	34.0	18.3	-5.47	<0.0001
Re-experiencing	769	5.8	5.0	7.6	5.4	-4.92	<0.0001
Avoidance	769	2.4	2.4	3.5	2.6	-6.22	<0.0001
Negative alternatives	769	10.2	7.2	12.5	7.1	-4.51	<0.0001
Hyperarousal	769	8.6	5.5	10.4	5.8	-4.33	<0.0001

Independent samples t-test were used to analyze the difference in PCL-5 scores by economic sacrifice groups. Those who made economic sacrifices had significantly higher PCL-5 scores than those who did not make economic sacrifices on the PCL-5 total scale (t = -5.47, df = 767, p<0.001), re-experiencing subscale (t = -4.92, df = 767, p<0.001), avoidance subscale (t = - 6.22, df = 767, p<0.001), negative alternative subscale (t = -4.51, df = 767, p<0.001), and hyper arousal subscale (t = -4.33, df = 767, p<0.001). See Table 7 for the means and standard deviations by group for each subscale. These findings support the study's second hypothesis.

Insulin rationing

Table 8 shows the Chi-square and independent samples t-tests comparing severity of trauma in participants who did and did not ration insulin. According to the Chi-square results, the rate of people meeting PCL-5 criteria for PTSD was significantly higher among those who rationed insulin (51.70%) than those who did not ration insulin (30%; x^2 = 28.62, df = 1, p<0.0001).

Table 8 Chi-square and independent samples t-tests of differences in PTSD by insulin rationing

Insulin rationing	**N**	**Do not ration**		**Ration**		**x^2(df=1)**	**p**
PTSD, %	769	30.0%		51.7%		28.62%	<0.0001
PCL-5 Scales	**N**	**Mean**	**SD**	**Mean**	**SD**	**t(df=767)**	**p**
Total score	769	28.3	17.6	37.8	18.5	-6.28	<0.0001
Re-experiencing	769	6.1	5.1	8.6	5.6	-5.67	<0.0001
Avoidance	769	2.6	2.4	4.0	2.6	-6.90	<0.0001
Negative alternatives	769	10.7	7.2	13.6	7.0	-4.84	<0.0001
Hyperarousal	769	8.9	5.6	11.5	5.9	-5.46	<0.0001

Independent samples t-test results showed that those who rationed insulin in comparison to those who did not ration their insulin had significantly higher PCL-5 total scores (t = -6.28, df = 767, p<0.0001), re-experiencing scores (t = -5.67, df = 767, p<0.0001), avoidance scores (t = - 6.90, df = 767, p<0.0001), negative alternative scores (t = -4.84, df = 767, p<0.0001), and hyper arousal scores (t = -5.46, df = 767, p<0.0001). See Table 8 for the mean and standard deviations by rationing group. These findings support the study's second hypothesis.

Together, the results of the annual household income, level of education, economic sacrifices, and insulin rationing analyses support the study's first and second hypotheses.

Hypothesis 3

Research question 3 asked how connecting with others who share the same illness impacted the development of post-traumatic growth and meaning of life. It was hypothesized that connecting with others who share the same illness via the T1D community is associated with higher post-traumatic growth and meaning of life. ANOVA tests were conducted on the PTGI total and subscale scores by length of involvement group and on the MLQ subscale scores by length of involvement group. Results showed that MLQ search subscale score (F(6, 762) = 1.04, p>0.05), PTGI total score (F(6, 762) = 1.73, p>0.05), and the PTGI subscale scores of relating to others (F(6, 762) = 0.98, p>0.05), personal strength (F(6, 762) = 1.82, p>0.05), spiritual change (F(6, 762) = 1.33, p>0.05), and appreciation of life (F(6, 762) = 1.50, p>0.05) did not significantly differ by length of involvement in the T1D community. However, the ANOVA test showed that MLQ presence subscale scores did significantly differ by length of involvement in the T1D community (F(6, 762) = 2.68, p<0.01). Nonetheless, none of the post hoc pairwise comparisons between groups were statistically significant after adjusting for multiple comparisons using Tukey's test. In addition, the ANOVA test showed that PTGI new possibilities subscale scores did significantly differ by length of involvement in the T1D community (F(6, 762) = 2.36, p<0.05). Again, none of the post hoc pairwise comparisons between groups were statistically significant after adjusting for multiple comparisons using Tukey's test. Because the presence of meaning in life and new possibilities subscale scores differed overall, the findings partially support the study's third hypothesis. The results can be found in Table 9.

Table 9 ANOVA tests of differences in post-traumatic growth and meaning in life across involvement in T1D community

Involvement	**N**	**1-3 months**		**3-6 months**		**6-12 months**		**1 year**		**2-3 years**		**4-5 years**		**>5 years**		**F(6,762)**	**p**
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**		
PTGI																	
Total score	769	45.6	24.1	48.5	23.7	46.6	19.6	52.6	22.6	52.8	21.5	52.2	22	49.5	22.8	1.73	0.11
Relating to	769	14.1	9.4	15	8	13.6	7.6	15.8	8.4	15.3	8.1	15.9	7.7	15.1	8.3	0.98	0.44
others		9.8	6.2	11.4	6.9	10.6	5.9	12.2	6.5	12.6	6.2	11.9	6.1	11.4	6.2	2.36	0.03
New possibilities	769																
Personal	769	10.9	5.2	11.4	5.5	11.5	5.1	12.4	5.1	13	5.2	12.3	4.8	12.1	5.3	1.82	0.09
strength		2.5	3.2	2.5	3.2	2.3	2.8	3.1	3.2	2.7	3.1	3.3	3.4	2.4	3.1	1.33	0.24
Spiritual change	769																
Appreciation of	769	8.3	3.8	8.2	3.8	8.6	3.2	9.2	3.7	9.3	3.7	8.8	3.7	8.4	3.8	1.5	0.18
life MLQ																	
Presence	769	17	6.6	15.5	6.9	16.4	6.7	18.4	6.4	18.4	6.8	17.9	6.1	18.5	6.5	2.68	0.01
Search	769	22.2	6.3	23.1	6.6	21.9	7.3	22	5.9	22.9	5.5	21.2	7.3	21.6	6.3	1.04	0.4

Hypothesis 4

Research question 4 asked whether medication unaffordability, as measured by annual household income, economic sacrifices, and insulin rationing, impacted the development of post- traumatic growth and meaning of life in adults with T1D. It was hypothesized that the medication unaffordability was negatively associated with post-traumatic growth and meaning of life. Spearman correlation coefficients, ANOVA, and independent samples *t*-tests were used to test this hypothesis. PTGI and MLQ scores varied across socio-economic status as measured by annual household income (Tables 10&11), level of education (Table 15), need to make economic sacrifices to purchase diabetes medications and supplies (Table 13), and need to ration insulin (Table 12). The relationship between medication unaffordability, based on socioeconomic status, economic sacrifices, and insulin rationing, and post-traumatic growth and meaning in life was examined (Table 14).

Table 10 Spearman correlations between annual household income and the development of post-traumatic growth and meaning in life

	1	2	3	4	5	6	7	8	9
1. Household income 2. PTGI total score	-0.02								
3. Relating to others	-0.03	0.89***							
4. New Possibilities	-0.05	0.90***	0.72***						
5. Personal Strength	0.05	0.83***	0.63***	0.70***					
6. Spiritual change	-0.04	0.62***	0.48***	0.48***	0.43***				
7. Appreciation of life	0.03	0.81***	0.61***	0.70***	0.68***	0.44***			
8. MLQ Presence	0.13***	0.46***	0.38***	0.43***	0.38***	0.30***	0.30***		
9. MLQ Search	-0.09*	0.09*	0.11**	0.07*	0.06	0.09*	0.04	-0.09*	

***** p<0.001; ** p<0.01; * p<0.05 N=769 for all.**

Table 11 ANOVA tests of differences in the development of post-traumatic growth and meaning in life across annual household income

Household income	N	<$35,000	$35,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	>$150,000	F(5,763)	p
		M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)		
PTGI total score	769	49.96 (22.44)	50.19 (23.73)	51.65 (22.66)	48.31 (22.25)	50.34 (22.74)	48.64 (19.14)	0.37	0.87
Relating to others	769	15.26 (8.44)	15.01 (8.62)	15.86 (8.09)	13.94 (8.47)	14.96 (8.46)	14.52 (7.08)	0.81	0.54
New Possibilities	769	11.89 (6.32)	11.65 (6.42)	11.77 (6.50)	10.79 (6.08)	11.38 (6.55)	11.07 (5.54)	0.59	0.71
Personal strength	769	11.57 (5.25)	12.08 (5.58)	12.49 (4.88)	11.90 (5.13)	12.53 (5.43)	12.27 (5.04)	0.75	0.59
Spiritual change	769	2.71 (3.13)	2.63 (3.16)	2.76 (3.16)	3.05 (3.33)	2.55 (3.01)	1.87 (2.77)	1.42	0.22
Appreciation of life	769	8.53 (3.51)	8.82 (3.95)	8.78 (3.79)	8.63 (3.62)	8.92 (4.00)	8.92 (3.17)	0.24	0.94
MLQ presence	769	16.66 (6.83)	16.80 (6.82)	18.23 (6.61)	18.51 (6.35)	18.38 (6.21)	19.55 (5.83)* □	3.38	0.005
MLQ search	769	22.70 (6.30)	22.18 (6.56)	22.36 (6.27)	21.65 (5.94)	21.61 (6.81)	21.12 (6.22)	1.00	0.42

* p<0.05 for comparison to <$35,000; t p<0.05 for comparison to $35,000-49,999.

Table 12 Independent samples t-tests of differences in PTGI and MLQ scores by insulin rationing

Insulin rationing	N	Do not ration		Ration		t(df=767)	p
		Mean	SD	Mean	SD		
PTGI: total score	769	48.86	21.93	53.6	23.5	2.5	0.01
PTGI: relating to others	769	14.76	8.13	15.85	8.76	1.55	0.12
PTGI: new possibilities	769	11.21	6.18	12.41	6.58	2.26	0.02
PTGI: personal strength	769	11.96	5.23	12.54	5.19	1.31	0.19
PTGI: spiritual change	769	2.36	2.96	3.58	3.47	4.66	<0.0001
PTGI: appreciation of life	769	8.58	3.7	9.22	3.62	2.06	0.04
MLQ: presence	769	17.68	6.55	18.16	6.72	0.86	0.39
MLQ: search	769	21.91	6.41	22.49	6.19	1.06	0.29

Table 13 Independent samples t-tests of differences in PTGI and MLQ scores by economic sacrifices

Economic sacrifices	N	No SACRIFICES		Sacrifices		t(df=767)	p
		Mean	SD	Mean	SD		
PTGI: total score	769	49.06	21.82	50.85	22.9	1.1	0.27
PTGI: relating to others	769	14.73	8.05	15.28	8.51	0.93	0.35
PTGI: new possibilities	769	11.31	6.28	11.66	6.31	0.78	0.44
PTGI: personal strength	769	12.05	5.14	12.14	5.3	0.24	0.81
PTGI: spiritual change	769	2.4	2.96	2.88	3.26	2.15	0.03
PTGI: appreciation of life	769	8.58	3.72	8.88	3.66	1.12	0.26
MLQ: presence	769	17.77	6.46	17.85	6.7	0.16	0.87
MLQ: search	769	21.86	6.45	22.27	6.26	0.9	0.37

Table 14 Spearman correlations between medication unaffordability and supplies and the development of post-traumatic growth and meaning of life

1		2	3	4	5	6	7	8	9	10
1. Ration insulin 2. Economic sacrifices	0.42***									
3. PTGI total score	0.09*	0.05								
4. Relating to others	0.05	0.03	0.89***							
5. New Possibilities	0.08*	0.03	0.90***	0.72***						
6. Personal Strength	0.05	0.01	0.83***	0.63***	0.70***					
7. Spiritual change	0.15***	0.07*	0.62***	0.48***	0.48***	0.43***				
8. Appreciation of life	0.08*	0.04	0.81***	0.61***	0.70***	0.68***	0.44***			
9. MLQ Presence	0.04	0.01	0.46***	0.38***	0.43***	0.38***	0.30***	0.41***		
10. MLQ Search	0.04	0.03	0.09**	0.11**	0.07*	0.06	0.09*	0.04	-0.09*	

*** p<0.001; ** p<0.01; * p<0.05 N=769 for all.

Table 15 ANOVA tests of differences in PTGI and MLQ scores by education

Education	*N*	HS or less		Post-secondary Education		BA		Advanced degree		*F*(3, 765)	*p*
		Mean	SD	Mean	SD	Mean	SD	Mean	SD		
PTGI: total score	769	50.4	23.82	50.07	23.3	51.7	21.66	46.53	21.73	1.97	0.12
PTGI: relating to others	769	15.38	9.26	15.21	8.34	15.56	7.97	13.59	8.34	2.2	0.09
PTGI: new possibilities	769	11.43	6.27	11.62	6.28	11.86	6.36	10.67	6.16	1.35	0.26
PTGI: personal strength	769	11.86	4.82	11.55	5.55	12.77	4.88	11.62	5.39	3.15	0.02
PTGI: spiritual change	769	2.97	2.98	3	3.34	2.56	3.06	2.25	2.97	2.15	0.09
PTGI: appreciation of life	769	8.76	3.66	8.68	3.91	8.94	3.47	8.4	3.8	0.81	0.49
MLQ: presence	769	14.86	7.72	16.52	6.67	18.29	6.33	19.68	5.81	12.3	<0.0001
MLQ: search	769	21.31	7.12	22.44	6.49	22.39	6.28	21.23	5.95	1.8	0.15

Annual household income

Spearman correlation coefficients showed that annual household income was not significantly related to PTGI scores (see Table 10). However, annual household income was related to both MLQ presence and search subscale scores. Household income was positively related to MLQ presence ($r = 0.13$, N = 769, $p<0.001$) and negatively related to MLQ search ($r = -0.09$, N = 769, $p<0.05$).

ANOVA tests showed that MLQ presence scores differed by annual household income ($F(5, 763) = 3.38$, $p<0.01$). Post hoc pairwise comparisons between income categories showed that MLQ presence scores were significantly higher in the >$150,000 group than in the <$35,000 group ($p<0.05$) and in the $35,000-49,999 group ($p<0.05$). See Table 11 for these results. These findings partially support the study's fourth hypothesis due to the relationship between annual household income and meaning in life presence and search.

Level of education

ANOVA tests were used to assess the differences in PTGI and MLQ scores between levels of education. Significant results were found for differences in PTGI personal strength ($F(3, 765) = 3.15$, $p<0.05$) and in MLQ presence ($F(3, 765) = 12.30$, $p<0.001$). Individuals with bachelor's degrees ($M = 12.77$, $SD = 4.88$) had higher levels of PTGI personal strength than those with high school or less ($M = 11.86$, $SD = 4.82$), post-secondary education (e.g., some college experience, associate degree) ($M = 11.55$, $SD = 5.55$), and advanced degrees (e.g., master's degree, doctoral degree) ($M = 11.62$, $SD = 5.39$). Individuals with bachelor's degrees ($M = 18.29$, $SD = 6.33$) and advanced degrees ($M = 19.68$, $SD = 5.81$) had higher levels of the presence of meaning in life than individuals with high school or less ($M = 14.86$, $SD = 7.72$) and those with post-secondary education ($M = 16.52$, $SD = 6.67$). All comparisons were significant at $p < 0.05$.

There were no significant differences in the total PTGI scores ($F(3, 765) = 1.97$, $p>0.05$), PTGI subscales of relating to others ($F(3, 765) = 2.20$, $p>0.05$), new possibilities ($F(3, 765) = 1.35$, $p>0.05$), spiritual change ($F(3, 765) = 2.15$, $p>0.05$), and appreciation of life ($F(3, 765) = 0.81$, $p>0.05$), or the MLQ subscale of search of meaning in life ($F(3, 765) = 1.80$, $p>0.05$). See Table 15 for these results. These findings partially support the study's fourth hypothesis due to the relationship between level of education, PTGI personal strength, and MLQ presence of meaning.

Economic sacrifices

Independent samples *t*-tests were used to examine the differences in PTGI and MLQ scores by economic sacrifices. The results showed that adults who made economic sacrifices ($M = 2.88$, $SD = 3.26$) had higher PTGI spiritual change scores than those who did not make economic sacrifices ($M = 2.40$, $SD = 2.96$, $p<0.05$). These tests showed no differences in total PTGI total score and PTGI subscale scores of relating to others, new possibilities, personal strength, and appreciation of life, or MLQ subscale scores of presence and search between adults who did and did not make economic sacrifices ($p>0.05$). See Table 13 for these results.

Spearman correlations found that economic sacrifices had a significant, positive correlation with PTGI spiritual change scores ($r = 0.42$, N = 769, $p<0.001$). Again, there was no evidence of a correlation between economic sacrifices and MLQ scores and PTGI scores for relating to others, new possibilities, personal strength, appreciation for life, presence, and search between those who did and did not make economic sacrifices. See Table 14 for these results. These findings partially support the study's fourth hypothesis due to the relationship between economic sacrifices and spiritual change.

Insulin rationing

Independent samples *t*-tests showed that adults who rationed insulin (M = 53.60, SD = 23.50) had higher total PTGI scores than those who did not ration insulin (M = 48.86, SD = 21.93) (t = 2.50, df = 767, p>0.05). There were no differences in PTGI subscale scores for relating to others (t = 1.55, df = 767, p>0.05) and personal strength (t = 1.31, df = 767, p>0.05), or in MLQ subscale scores of presence (t = 0.86, df = 767, p>0.05) and search (t = 1.06, df = 767, p>0.05) between those who did and did not ration insulin. However, adults who rationed insulin had higher scores on the PTGI new possibilities (p<0.05), spiritual change (p<0.0001), and appreciation for life (p<0.05) sections than those who did not. See Table 12 for these results.

Spearman correlation tests found that rationing insulin had a significant, positive correlation with PTGI total score, new possibilities scores, spiritual change scores, and appreciation of life scores (see Table 14). Again, there was no evidence of a correlation between rationing insulin and PTGI scores for relating to others, personal strength, or MLQ scores of presence and search. The Spearman correlation coefficient findings mimic those of the independent samples t-tests above. The total score and various subscales of post-traumatic growth were found to be connected to whether or not the participants rationed insulin, while meaning in life was not. Therefore, these findings partially support the study's fourth hypothesis. Together, the results of the annual household income, level of education, economic sacrifices, and insulin rationing calculations partly support the fourth hypothesis.

Discussion

The goal of the present study was to evaluate whether adults with T1D experienced the chronic medical condition as traumatic. In an effort to discover how the insulin crisis could impact the mental health of adults with T1D, the study examined how socioeconomic status and medication unaffordability impacted their levels of trauma. The next goal in this study was to determine the degree in which related variables could impact the participants' emotional wellbeing that resulted from their diagnosis. Traumatic experiences could cause negative feelings and symptoms, but they could also cause positive growth and emotional awareness, depending on how the individual coped with their trauma. The study examined whether community support from those who share the same chronic condition impacted the participants' levels of post- traumatic growth and meaning in life. Later, the study investigated whether socioeconomic status and medication unaffordability impacted the participants' levels of post-traumatic growth and meaning in life.

There were significant findings in regard to complex trauma in individuals with T1D, as well as its relationship with socioeconomic status and medication unaffordability. Findings of community support by those who share the same illness, as well as those of socioeconomic status and medication unaffordability, revealed meaningful connections were also established with post-traumatic growth and meaning in life, respectively. Additionally, the investigative analysis revealed interesting trauma-related findings that are discussed for potential future research. The following discussion suggests various conceivable explanations for these findings, clinical implications, limitations of the current study, and several suggestions for future research. The concept of medication unaffordability used in this study is comprised of two parts, economic sacrifices and insulin rationing. Socioeconomic status, which included annual household income and level of education, was also taken into account in order to discover whether the participants had the resources that would allow them to afford insulin and other diabetes supplies. According to the 2020 United States Census, the average annual household income was $67,521.[90] Findings on annual household income suggested that levels of trauma were significantly higher for individuals who earned less than the average annual household income.

Findings suggested that the lower the annual household income, the higher the individual's trauma scores would be. Findings on level of education suggested that those with a high school diploma or less, as well as those with post-secondary education, experienced more trauma than those with a bachelor's degree and those with advanced degrees. In our current society, many high paying positions now require college education. Therefore, for many, lack of education could influence whether or not they could afford their diabetes supplies and, consequently, how severe their trauma symptoms would be. Furthermore, trauma symptoms were significantly higher for those who made economic sacrifices and rationed insulin than for those who did neither, again supporting the idea that the ability to access diabetes medication impacts an individual's level of trauma.

Of the participants in the study, 40.40% reported earning $49,999 or less, and 19.90% reported earning $50,000 to $74,999. While 39.80% of the participants reported earning $75,000 or higher, 51.69% still reported making economic sacrifices and 23.79% reported rationing insulin. Due to these findings, we could conclude that even individuals earning higher than the average United States annual household income were required to make economic sacrifices to afford their diabetes medication and supplies. This sends the message that, in order to afford to live healthily with T1D, patients must earn more than the average United States citizen. Additionally, even after making the smallest sacrifices, such as ordering out less, or the greatest sacrifices, such as living with family or living in cars, almost one fourth of these individuals needed to ration their insulin. While rationing insulin, individuals with T1D might fast or eat less carbohydrates than their bodies require in order to try to maintain stable blood sugar readings or, if they do not have any low-carb food, they might need to allow their blood sugar to elevate. The former option can run the risk of malnutrition or lack of energy due to lack of carbohydrates. The second option not only risks the development of diabetic ketoacidosis and death, it also raises the risk of the participants developing secondary chronic illnesses, such as diabetic retinopathy, diabetic neuropathy, and kidney failure. Both options are dangerous and potentially fatal. The idea that patients must be wealthy or earn high incomes in order to live with a condition that they were unable to prevent supports the unjust notion that financial privilege plays a large role in determining the health of United States citizens. Higher socioeconomic status was also a pertinent determinant of positive mental health.

Findings suggested that the higher an individual's annual household income, the greater the possibility that they have found meaning in their lives. Similarly, individuals with higher education also had higher post-traumatic growth scores of personal strength and were more likely to have found meaning in life than those with post-secondary education, high school, or less. Nonetheless, those who needed to make economic sacrifices and those who needed to ration insulin also experienced some positive mental health outcomes. Those who made economic sacrifices experienced higher levels on the post-traumatic growth subscale of spiritual change, than those who did not, meaning they felt more hopeful and closer to their religion or spirituality. Those who rationed insulin had higher levels of post-traumatic growth through greater spiritual change, were more accepting of new possibilities, and appreciated life more than

those who did not ration insulin. Lastly, the lower the income that participants reported, the greater the possibility that they were in search of meaning in their lives. As they did not experience higher scores on presence of meaning, their search for meaning suggested that the participants had a greater risk of suffering with mental health disorders, such as depression and anxiety.

Nonetheless, due to their willingness to participate in the T1D community, the participants were likely open to discovering what they could do to improve their own lives, while potentially helping others who have also struggled. The findings from this study suggested that socioeconomic status and medication affordability were significant determinants of an individual experiencing trauma with T1D. It could definitely be traumatic for an individual to have a chronic illness that they are unable to afford. Those who reported rationing insulin could feel frightened of dying, becoming severely ill, or developing other chronic health conditions. Those who made economic sacrifices or sought help from friends and family could have exacerbating feelings of guilt, as well as a lack of independence, two issues that could lead to depression, anxiety, and other mental health conditions. Nonetheless, these individuals also had meaningful chances to experience positive changes in their mental health and overall purpose in life. They experienced changes in their spirituality, they became open to new possibilities, and experienced the resilience of post- traumatic growth. All in all, they grew from their financial, medical, and psychological struggles and, in many cases, became hopeful.

Community support from those who share the same diagnosis was also found to be related to positive mental health. While the findings did not suggest a meaningful relationship between this form of community support and post-traumatic growth, they did suggest a significant relationship between the community and presence of meaning of life in the individual participants. The participants who were involved in the T1D community for the longest amount of times were the ones who reported the most feelings of having meaning in their lives. That information is relevant because these individuals were no longer searching for meaning, which in the MLQ is associated with higher levels of depression and other mental health disorders. Being a part of the community appeared to help individuals to find their purpose and feel more passionate about their lives and life goals.

Clinical implications

Through the study, the researcher learned more about the determinants of the negative and positive mental health effects of T1D. This is first time that the determinants, which play a part in the development of trauma in adults with T1D, and their negative and positive outcomes, have been studied. By sharing this research with individuals in the T1D community, which includes parents, doctors, mental health practitioners, and public speakers, there is hope that the information could be used to strengthen the medical and mental health treatment provided to individuals with T1D, as well as strengthen the training of new and existing doctors and psychologists. The findings show that the ability to afford insulin and other diabetes medication is crucial to limiting patient's individual trauma symptoms. This information could be used to advocate for institutional change, as well as change in prices of life-saving medicine and medical devices. Through these findings, we learned that the greatest determinant of negative mental health—unaffordability—was a factor outside of patients' control and that is, in most cases, unavoidable. However, the ability to turn these negative experiences into positive personal growth had nothing to do with doctors, mental health professionals, or medical sales companies, and everything to do with the patients' own resilience.

It is crucial that medical practitioners stay up-to-date on the mental health research concerning individuals with chronic health conditions. In some cases, the presence of continuous high or low blood glucose levels, or significant fluctuations in blood glucose levels, might potentially signify diabetes denial, extreme stress, mental health struggles, or insulin rationing. It is essential that practitioners ask questions about these concerns in a nonjudgmental manner in order for patients to feel trust and support. It is equally essential that medical and mental health practitioners, who do not live with the illness themselves, recall that their patients are human beings with various roles and responsibilities in life, who also happen to live with a diagnosis that will not allow them to always be perfect, and that is okay. In order to help alleviate the mental health concerns that could accompany a chronic health condition, such as T1D, more endocrinologists and primary care physicians could recommend support groups or mental health therapy at the time of diagnosis. Since T1D is a lifelong condition that could lead to burnout, medical practitioners could also ask about the state of their patients' mental health during quarterly check-ups. In order to help ease the financial burden that many patients already experience with chronic health conditions, it may be beneficial to keep on-hand a list of websites and phone numbers of prescription coupons and foundations that might be able to assist individuals who are at risk of rationing, as well as low-cost mental health care referrals. There is currently a mistrust of medical and mental health care professionals by individuals who identify with minority groups related to race and sexuality. Doctors and psychologists must work to build trust with patients of diverse background and encourage them to take part in scholarly research, so that we may learn about their unique struggles and how to better help them as individuals.

Finally, it is essential that patients are not the only individuals advocating for institutional change. As medical providers and mental health providers, it is within our role to support our patients and help them remain or become healthy. In doing so, we must advocate for access to affordable medication for individuals with chronic health conditions.

Limitations

The Covid-19 pandemic

Several limitations of this study must be addressed. First, the sample took part in the current study in August to September of 2020, only five months after the covid-19 pandemic struck our world. The global pandemic caused changes for every individual, whether they realized it or not. People experienced changes in school, work, and relationships, as well as loss of work and financial security. Some people experienced a lack of human contact or social support, physical health declines, increases in anxiety, depression, and substance abuse, and losses of relatives and friends. Individuals with chronic health conditions, specifically those with diabetes, were informed that they had a high level of risk for contracting a critical and potentially fatal case of the virus. However, in some way or another, it can be assumed that everyone experienced moments that caused them to lose the feeling of safety that many had before the pandemic and the sense of stability that their everyday routines had provided them. It is reasonable to assume that results could be influenced in a time when many individuals, especially those with chronic medical conditions, could be experiencing more trauma symptoms than normal due to the Covid-19 pandemic.

Convenience sample

Limitations of the present study also include the use of primarily convenience samples of individuals with T1D who have access to internet and social media. The majority of the participants were White, non-Hispanic/Latinx, heterosexual females who lived in the United States, had a partner, and identified English as their primary language. Additionally, over 90% of the participants had an education level beyond a high school diploma or GED. Due to the homogeneity of the participants' sociodemographic characteristics, the results are not generalizable to all individuals in the T1D community.

The impact of social media

The participants were also individuals who most likely have regular access to social media and researchers have conflicting suggestions about how social media could impact the public's levels of trauma, post-traumatic growth, and meaning in life. Social media is often used in a positive light, as an outlet to unite individuals together, especially in times of great fear and suffering, such as pandemics, wars, and other tragedies. It could help people feel supported, accepted, understood, and even loved. On the other hand, it could have a heavily negative impact on individuals' mental health. Every day, people face judgement from others on social media due to various matters, such as how they look, what demographics they identify with, their political beliefs, and even what health struggles they experience. It is an outlet, which can cause people to compare themselves to others, which can affect self-esteem and how they each experience their emotions.

Order effect

There could have been an order effect because the sociodemographic and descriptive questions appeared in the same sequence and prior to the three psychological measures for all of the participants. After responding to sociodemographic and descriptive questions that cause an individual to think about how much money they spend on their chronic health condition, as well as how much they have had to sacrifice in order to live with this condition, their responses on the psychological measures could have been influenced in that moment. Additionally, the three psychological measures appeared in the same sequence for all of the participants. All of theparticipants responded to the PCL-5 first, then the PTGI, and then the MLQ. By responding to questions about trauma first, the participants' positive feelings about post-traumatic growth and meaning in life could have been influenced.

Education levels

Education levels were combined into groups for the purpose of this study, as some cell sizes were too small (<10) to test and create inferences. The responses of less than high school and high school were combined, while the responses of some college and associate degree were combined as post-secondary education. The results of master's degree, doctoral degree, and professional degree were also collapsed as advanced degrees. Participants may have interpreted professional degree in various ways. For example, a professional degree could be construed as a post-doctoral certification to one individual, while it could be construed as a degree from a technical school (e.g., mechanic, beautician, medical assistant, etc.) to another individual. As the number of individuals who reported earning a professional degree was low (n=18), separated results most likely would not have had a significant impact on the results.

Prior trauma

A large portion of the participants reported experiencing trauma prior to their diagnosis, which could have impacted their results on the PTSD Checklist for *DSM-5*. Although the participants were asked to respond to the questionnaire with only their T1D diagnosis in mind, it is possible that traumas that they experienced prior to their diagnosis could impact the manner in which they feel and experience their T1D. Trauma can cause individuals to internalize their struggles, while also causing many others to externalize and blame others for their negative experiences. Both of these potential symptoms could influence individuals with chronic health conditions to have negative experiences.

Future research

One of the results from this study, and possibly the most meaningful, was the fact that three out of four of the participants (77.63%, n = 597) reported experiencing some sort of trauma prior to diagnosis. This begs the question how, if in any way, psychological and emotional trauma could impact the development of T1D in the body from psychological and medical standpoints. Future psychological research should investigate how prior trauma could impact the experience and management of T1D in individuals who have lived with the illness for years.

Future medical research should investigate if trauma could potentially trigger T1D in the body. During traumatic events, our bodies protect us through fight or flight response, and autoimmune conditions develop when the body mistakenly attacks or fights organs in response to a potential threat. It is pertinent to discover how these responses play a part in the diagnosis of T1D, as well as in the development of other autoimmune conditions.

New technology now allows people to communicate through the use of discussion boards, informative videos, and more pages dedicated to T1D on social media platforms, such as Facebook, Instagram, and YouTube. This sort of community allows individuals with T1D to feel connected, understood, and "normal". However, there is a lack of competence from the mental health community in understanding the complicated struggles and emotions that individuals with T1D face on a daily basis. There are few psychologists who specialize in T1D, and many of them are diagnosed with the illness themselves. Their own diagnoses allow them to truly empathize with clients and understand the significant stressors that their clients face in everyday life. Individuals with chronic health conditions are twice as likely to experience mental health struggles than physically healthy individuals, and for individuals with diabetes, this number can be even higher.[91,92] It could be extremely helpful for the mental health community to have more options for continuing education courses that offer specific knowledge about the ins and outs of various chronic health conditions, patients' daily physical experiences, and their corresponding mental health struggles.

Despite the serious medical and emotional issues that individuals with T1D face, there is great hope for future research. The discovery of biopsychosocial etiological factors could impact future treatment for T1D and, therefore, help alleviate mental health symptoms brought about by the illness. Learning more about how biology and genetics might play a part in the development of the condition has been thought to possibly be the key to finding the cause and a cure for T1D. However, based on the findings of this research study, learning more about how psychological and social factors, such as the experience of a past trauma, could also impact the development of T1D could also help individuals to prevent the disease by attempting to reduce stress and possibly altering their social environment. Due to the uncontrollable factors that contribute to trauma in adults in T1D, the community requires as much help as they can get. This includes improved medical and mental health care, as well as more research for

children with T1D and those who have yet to be diagnosed with chronic illness. While the need for exploration in this area is significant, more and more research foundations and organizations have been created to help speed this process along. Individuals in the T1D Community have been more than willing to contribute as much as they can through advocacy, donations, education, and helping others. The medical and mental health aspects of T1D can take a village to manage. T1D can be isolating and scary, especially when adults feel that they are alone in their chronic illness. It would be helpful to those living with T1D to know that there is a community of support. Through support from family, friends, and the T1D community, there is always someone that is willing to do whatever they can to help.

Dedication

This dissertation is dedicated to the individuals with type 1 diabetes who lost their lives due to medication unaffordability and insulin rationing, and their loved ones This is also dedicated to my daughter, Charlotte Belle, who has experienced her own medical trauma since she was born three and a half months early. You amaze us every day. Keep fighting.

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Conflicts of interest

There are no conflicts of interest.

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