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Heavy is the Arm that Wears the CGM: An Investigation of a Social Support Group of Emerging Adults at a Type 1 Diabetes Camp

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HEAVY IS THE ARM THAT WEARS THE CGM: AN INVESTIGATION OF A SOCIAL SUPPORT GROUP OF EMERGING ADULTS AT A TYPE 1 DIABETES CAMP

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ABSTRACT

Type 1 Diabetes (T1D) is a chronic illness that can be profoundly isolating. T1D often fosters a sense of 'otherness' that is difficult for those without T1D to understand, due to the persistent necessity to monitor blood sugar levels, administer insulin injections, and navigate the ever-present risk of severe health complications if the T1D is mismanaged. For many young adults with T1D, the sense of isolation is magnified amidst the numerous life transitions characteristic of emerging adulthood. Establishing a community of peers with T1D can help mitigate the negative mental and physical consequences. Through semi-structured interviews, this study examines these peer relationships in a medical specialty camp (MSC) context. Study participants (*N* = 12), all of whom are living with T1D, serve as volunteer camp counselors at this MSC. The aim was to identify common experiences among the volunteers and understand how these experiences influence mental and physical health. Key themes constructed from the interviews included a sense of belonging, reduced diabetes-related burnout, a break from the routine challenges of daily life, and a motivational purpose to return and serve at the MSC. The study concluded that a sense of belongingness is crucial for the successful management of T1D.

Keywords: Type 1 Diabetes, social groups, burnout, health stress, emerging adulthood, qualitative study

DEDICATION

This thesis is dedicated to all of those with Type 1 Diabetes who have struggled with finding their place in the world. I hope that everyone can find their circle that helps them cope with the literal and figurative highs and lows of dealing with diabetes. Keep fighting.

ACKNOWLEDGMENTS

To my parents: Thank you for endlessly supporting me throughout my life. Your guidance and support throughout life has allowed me to be comfortable and confident speaking about my illness. You guys had to learn how to handle a misunderstood illness and a stubborn daughter and have never stopped defending me when people tried to put labels and barriers on me. To my brothers, Jacob and Nathan: you are silent supporters that I rely on. Your lightheartedness when it comes to diabetes helped me see it as something that won’t hold me back. You never let me use it as an excuse and I’m eternally grateful for that. To my friends, Ally and Annie: Thank you for helping me find myself. You guys are truly two of my greatest friends in life and I’m so grateful for Clemson bringing us all together. To my research committee: Thank you guys for helping guide me during this process. Research is a challenge, and I’m grateful for y’all handling my questions with kindness and ease and helping me narrow down my research focus. To my Grampy: Thank you for being you. Your light and your jokes always helped ease my stress throughout my life. Love you and miss you forever. To everyone who’s helped me throughout my life: Thank you. You have shaped me into the person I am, and I cherish every conversation and moment with you. ☺

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INTRODUCTION

Adolescents and emerging adults living with chronic illnesses often experience impacts to their biological, mental, and social health beyond those associated with their condition (Denny et al, 2014; Miauton et al., 2003; Wolman et al., 1994). One such chronic illness associated with these negative health impacts is Type 1 Diabetes (T1D). As currently understood, T1D is an autoimmune disease which occurs when the pancreas no longer produces beta cells that are essential in the production of insulin, a blood sugar regulating hormone (Haller et al., 2005: Harrison, 2019). Unregulated blood sugar levels associated with T1D can result in fatigue, nausea, fainting spells, increased hunger and thirst, increased urination, and in some instances, death (Harrison, 2019). To manage these symptoms, those living with T1D must consistently monitor blood sugar levels to prevent other chronic disorders associated with unregulated blood sugar levels, such as kidney disease, liver disease, cardiovascular issues, neuropathy, and retinopathy (Melendez-Ramirez et al., 2010). Managing these symptoms can result in higher feelings of stress and anxiety but increased feelings of belongingness can help reduce these negative impacts (Luycks et al., 2010). Because of the increased challenges those living with T1D face, this study examines how belongingness in a social group consisting of peers with T1D can impact emerging adults' well-being during this transitory period between youth and adulthood.

It is estimated that around 3 million Americans have T1D, with about 47% of these being people between the ages of 18 and 30 (Monaghan et al., 2015; Wagenknecht et al., 2023). Diagnosis of this condition typically occurs at two points during a young person's development: (1) the first age that T1D appears commonly is between the ages of four and seven, and (2) the second spike typically occurs between 10 and 14 years of age (Mayo Clinic, 2023). During these times of diagnosis, individuals are often going through developmental milestones, such as living alone for the first time, can be more difficult to navigate when one is living with a chronic illness than it is for their healthy (Ouzouni et al., 2019). As the individual reaches young adulthood, the transitional stresses can become even more intense when combined with T1D (Lyons et al., 2014). Emerging adults, those between the ages of 18-30 (Arnett, 2000), face transitional challenges during this phase of development that are enhanced even further with the addition of a chronic illness (Lyons et al., 2014). Additionally, the transition from pediatric diabetic (typically under 18 years of age) care to adult diabetic care is often associated with less visits to the endocrinologist, poorer blood sugar control, psychosocial challenges, and a higher risk for T1D associated complications (Peters & Laffel, 2011). While interaction from friends without T1D can help those living with T1D by providing social support, there have been multiple studies indicating those without T1D do not fully understand the T1D experience and, consequently, those with T1D can experience additional negative interactions with peers without T1D (Helgeson et al., 2022; Mattacola, 2020; Raymaekers et al., 2021). While T1D can be managed with daily injections, insulin pump therapies, continuous glucose monitoring, and automated insulin deliveries, there is currently no cure (Chiang et al., 2018).

Individuals with T1D also must adjust to a new style of living that only impacts about 0.55% of people living in the United States, further isolating them from their peers (Bullard et al., 2016). This new lifestyle includes monitoring of carbohydrates, administering daily injections of insulin, close monitoring of blood sugar levels, and learning how to deal with emotional stress of a chronic illness (Smith & Harris, 2018). Furthermore, these changes and additional responsibility can negatively impact the way a person perceives themself and the way in which one interacts with those around them (Alvarado-Martel et al., 2015). Due to the physical and psychological impacts of having T1D, the demands of an illness can be jarring to a person’s psychological health (e.g., increased risks of anxiety, depression, and other socioemotional disorders) (Bernstein et al., 2021).

The impact of T1D affects the mental states of those with the illness, but it also can result in poorer physical health. For example, without proper management of blood sugar, negative physical outcomes such as nerve damage, retinopathy, kidney disease, heart disease, and stroke are increased (Malahi et al., 2021). These ailments, and the risk of developing additional comorbidities, can increase a sense of anxiety and distress within individuals. As noted earlier, young adults are already navigating typical developmental stressors such as an expanded sense of self, broadened their friendships and communities, and escalating levels autonomy (Anderson & Wolpert, 2004). Developing these qualities and relationships are essential for a person to successfully navigate through life (O’Connor et al., 2010). Subsequently, the responsibilities associated with T1D can impair the development of these inter- and intra-personal skills by creating feelings of isolation and ‘otherness’ as they transition to emerging adulthood (Joensen et al., 2017).

Emerging Adulthood

Emerging adulthood is described by Arnett (2004) as a transitionary life stage between adolescence and adults (typically between the ages of 18 and 29). Emerging adulthood has been found to have similar traits across most industrialized countries but is less clear as a life stage in non-industrialized countries (Arnett, 2024; Macek et al., 2007; Nelson et al., 2004; Nelson & Chen, 2007; Rosenberger, 2007). During this life stage, emerging adults often face challenges that are distinct from adolescents and adults such as living alone for the first time, determining a career path, establishing serious relationships, and starting families (Wood et al., 2017). These events can evoke feelings of stress in those living with them. The addition of a chronic illness, such as T1D, can make these anxious feelings more pronounced (Ingersgaard et al., 2019). Support during this period is commonly found through peer relationships (Johnson et al., 2006). Emerging adulthood allows for a more gradual shift from youth to adulthood. The involvement in a social group can provide the support in replace of parents and allow for a smooth shift into the beginnings of adulthood This present study proposes that by relating to other peers who also suffer with T1D, the support of other emerging adults can be more meaningful and result in better overall health outcomes.

The Role of Peer Support

The roles of in groups are important for all individuals to achieve a sense of belongingness. For those within the emerging adulthood range, they allow these individuals to develop alongside others that have similar life experiences (Flamino et al., 2021). In groups are groups that form and allow people to feel a stronger sense of self and a stronger sense of belongingness (Baumeister & Leary, 1995). In groups consist of individuals that have similar life experiences or beliefs, and these vary from group to group. In an examination of the role of in groups among college students, it was found that an in group provides comfort, confidence, and a sense of belonging within individuals (Johnson et al.2006). This dynamic is important to have for those living with chronic illnesses due to the isolation that these diseases can bring on. For instance, in a study performed by Freeborn et al. (2013) that examined adolescents with T1D, one participant said that his friends began treating him differently post diagnosis and these differences made him feel as though he required special treatment from peers. Furthermore, this feeling of being different is often compounded by misunderstandings about the causes of T1D, where many in the “lay public” believe T1D is caused by individual choices (e.g., poor eating and lifestyles) and not an autoimmune disease beyond an individual’s control. In a study of young adults with T1D, Abdoli et al. (2017) suggested peer misunderstandings of what T1D is can increase stress and anxiety in those living with T1D. These stressors often lead to the isolating impact of diabetes and correspondingly enhance other negative outcomes if positive support is not found (Mattacola et al., 2020). One strategy to ameliorate the isolation associated with T1D in emerging adults is to foster a series of factors to enhance their sense of belongingness. These factors include feeling as though they matter, are valued by their interpersonal relationships, and that they can identify with others (Grant, 2022; Kenrick et al., 2010; Marshall, 2002). For those living with T1D, the isolating nature of the disease can make it difficult to feel as though they fully belong with those that do not understand their disease (Browne et al., 2014). Belongingness within a group can help reduce these feelings of isolation among young adults with T1D (Hill et al., 2018; Stuckey et al., 2021).

GUIDING FRAMEWORK

Belongingness Theory

The guiding theory for this research study is the belongingness theory. This theory states that, for positive development, humans must feel as though they belong with others (Baumeister & Leary 1995). There are two primary aspects of belonging that Baumeister & Leary described as

> *People seem to need frequent, affectively pleasant or positive interactions with the same individuals, and they need these interactions to occur in a framework of long-term, stable caring and concern (52)*

These relationships begin at birth and evolve to include peers who share similar qualities, such as race, gender, and beliefs.

The theory of belongingness associates the acceptance of an individual into a group with lower rates of negative self-esteem, how an individual views themselves, and lower feelings of loneliness, a consequence of not belonging with others (Lee & Robbins 1995). Maslow (1943) states that belonging is a desire that every person has and is a person being at home in the world or having a place in the group. He states that negative psychological impacts can occur when one does not feel as though they belong. By reducing feelings of loneliness, psychological and physical health risks, such as development of eating disorders and suicide, can be lowered as well and the overall health of an individual can improve.

Belongingness and chronic illness

There are factors that can inhibit a person from feeling as though they belong within groups. One of these primary factors is a person having a chronic illness (Iovino et al., 2023). Chronic illnesses can cause the individual living with it to feel as though they are not the same as their immediate family members and friends (Symister & Friend, 2003). Because of this, they can become more withdrawn in order to reduce any stigma they might face and any negative reactions from their peers (Gamwell et al., 2018). This withdrawal can result in feelings of loneliness and the development of even more social-isolation habits such as social detachment, self-blame, and alienation from peers (Iovino et al., 2023). Along with this, an increase of suicidal ideation can occur if belongingness is removed from those suffering from a chronic illness (Rogers et al., 2020). IIn these studies (Gamwell et al., 2018; Iovino et al., 2023; Rogers et al., 2020; Symister, 2003), the researchers indicated that having social connections and a greater sense of belonging can help reduce these negative impacts. Other research looking into the relationship between chronic illness and social connection has shown that, in order to be accepted by peers, those living with a chronic illness may hide symptoms and struggles of their illness (Moensted et al., 2023). Ensuring that an individual with chronic illness has a sense of belongingness can increase the likelihood of positive behaviors, as outlined by the theory of belonginess described by Baumeister and Leary (1995), Lee and Robbins (1995), and Maslow (1943).

Research Problem and Questions

Support from peers for those living with T1D has been researched in a diabetic/non-diabetic lens; however, assessing how support from peers with T1D impacts emerging adults has relatively limited data on the benefits and factors of this peer support. Moreover, the support between T1D individuals and non-diabetic individuals has conflicting outcomes in the broader literature. Studies have indicated that diabetes-specific support from those without T1D, such as reminding a person to check their blood sugar or take insulin, can result in negative outcomes for the person with T1D such as ignoring one’s illness even more and having more negative feelings surrounding being a diabetic due to making the person with T1D feel like they are not normal and reminding them that they have an illness that their friends do not (Abdoli et al., 2017;

Bearman & La Greca, 2002; Comissariat et al., 2016; Freeborn et al., 2013; Joenson et al., 2017). Other studies have reported positive influence of peers on diabetes specific support resulting in better overall health and a more positive outlook on life (Joenson et al., 2017; Pendley, 2002). Some research has examined how relationships with others who also have T1D impact overall health and wellbeing (Bisno et al., 2023; Habenicht et al., 2021; Ramfelt et al., 2022; Sabagh et al., 2023) These studies have found that by having the commonality of T1D, individuals living with it are more comfortable sharing their concerns and struggles with the disease and find greater support from those who are also living with the disease. The research within this thesis focuses on the benefits, challenges, and outcomes of belonging within one of these groups and is guided by the following questions based upon contemporary literature.

Research Questions

RQ_1: What are the inclusion factors for a group of emerging adults with T1D? [e.g., Criteria needed for a group to accept new members (Garbutt, 2009; Kovac & Vaala, 2019)]

RQ_2: What does acceptance into the group look like? [e.g., belongingness to a group (Marshall, 2002; Grant, 2022; Kenrick et al., 2010)]

RQ_3: What are the positive biological, psychological, and emotional outcomes of being within a T1D in-group? [e.g., beneficial behaviors to help improve overall health (Begen & Turner-Cobb, 2014; Crawford, 2023; Liu et al., 2020)]

RQ_4: What motivates individuals to return to the group at Camp Kudzu? [e.g., human urge/desire to continue a pattern/habit (Baumeister, 2015)]

LITERATURE REVIEW

What is Type 1 Diabetes: A Brief Primer

Type 1 diabetes (T1D) is a chronic, autoimmune condition that impacts about 3 million Americans, and this number is predicted to rise even more (Monaghan et al., 2015; Wagenknecht et al., 2023). Of this population, about 47% of people with T1D are classified within the emerging adult age range of 18-30 (Green et al., 2021; Imperatore et al., 2021; Monaghan et al., 2015; Tonnies et al., 2022). T1D is identified by the body's inability to produce insulin, which is a hormone that is essential for the body to be able to transport blood glucose, a form of energy, into cells (DiMeglio et al., 2018). If the body cannot naturally produce insulin, then alternative management strategies should be implemented. These management regimens will begin at the onset of diagnosis and continue throughout a person's life, as there is no current cure for T1D.

T1D is typically diagnosed during childhood, and T1D diagnoses typically occur during one of two "peaks," both of which have implications for emerging adults. The first peak of diabetes diagnoses is between the ages of 5-7, and the second typically occurs around the ages of 10-14 (Al-fifi, 2010; Felner et al., 2005; Wagenknecht et al., 2023). According to these authors, the development of T1D at younger ages can put an individual at a higher risk of developing diabetes-related complications in their young adult years. These complications are likely to arise during the transition from childhood to adulthood and are attributed to a variety of factors. As Peters and Laffel (2011) stated in their study:

> *The transition from pediatric to adult diabetes care represents a high-risk period for a person with diabetes, a perfect storm during which interruption of care is likely for multiple reasons. The young person is leaving what has often been a long-term, comfortable relationship with healthcare providers, sometimes without preparation or ready access to a subsequent provider. There are also psychosocial adjustments during the post adolescent period of emerging adulthood that can be confounded by financial stressors. Poor glycemic control, the presence of risk factors for complications (hypertension and dyslipidemia), high risk behaviors (cigarette smoking and drug and/or*

> *alcohol abuse), and emerging complications may further increase the difficulty of this period (p. 2478)*

Consequences and Symptoms of T1D

The leading causes of T1D development include a combination of factors such as genetics, environmental factors, and viral infections that can trigger T1D in the body (Butalia et al., 2016). Symptoms of T1D include increased urination and thirst, increased hunger, fatigue, blurred vision, and extreme weight loss (Lambert & Bingley, 2002). Diagnosis of T1D is made when elevated levels of sugar are found within the blood stream (Akil et al., 2021). Testing for this is typically done when symptoms of T1D are present already or while at a routine physical. For some, the first indication that they have T1D occurs when they enter a state called diabetic ketoacidosis (DKA) that impacts about 40% of newly diagnosed patients (Wherett et al., 2018). This condition typically develops slowly, and early warning signs include constant high blood sugar, increased thirst, and increased urination (Westerberg, 2013). DKA occurs when the body is unable to break down sugar into energy which then causes the body to use the liver to break down fat for an energy source instead (Rosenbloom & Hanas, 1996). This alternative process will then cause acids, called ketones, to form (Adrogué et al., 1984). If too many ketones are produced too quickly, they can reach dangerous levels and result in someone developing DKA (Peters et al., 1933). More severe symptoms of DKA appear suddenly and can include fruity smelling breath, nausea and vomiting, dry skin and mouth, fatigue, and headaches (Rosenbloom & Hanas, 1996). Although serious, the consequences of DKA can be managed and correspondingly prevented by effectively managing diabetes.

Management of T1D

To reduce complications of T1D and reduce the risk of more long-term health impacts, various methods can be used to ensure glycemic control (blood sugar levels). These management strategies for T1D include the use of insulin therapy. Insulin therapy can take different forms, with individuals choosing between pens, syringes, and pumps. When using pens or syringes, there are typically two different insulin types that must be used to manage blood sugar levels (Mathieu et al., 2017). Short-acting insulin begins working about 5-10 minutes after injection and remains active for up to 3 hours after injection, with the effect of the shot lasting up to 8 hours (Malik & Taplin, 2014). Long-acting insulin is used alongside the short-acting and the effects depend on when the insulin is administered. Once injected, long-lasting insulin can last up to 24 hours (Malik & Taplin, 2014).

Insulin pumps are devices that administer a constant stream of insulin to the user (see Figure 1). Insulin is stored within the pump and a small cannula is inserted subcutaneously (Nimri et al., 2019). Insulin delivery can be adjusted to be more precise than it is with injections. This can result in better overall glycemic control for someone using these devices (Berget et al., 2019). There are many different types of pumps, with new ones currently being developed. An individual’s diabetes care team can assist them with choosing an insulin therapy best suited for their needs (Nimri et al., 2020).

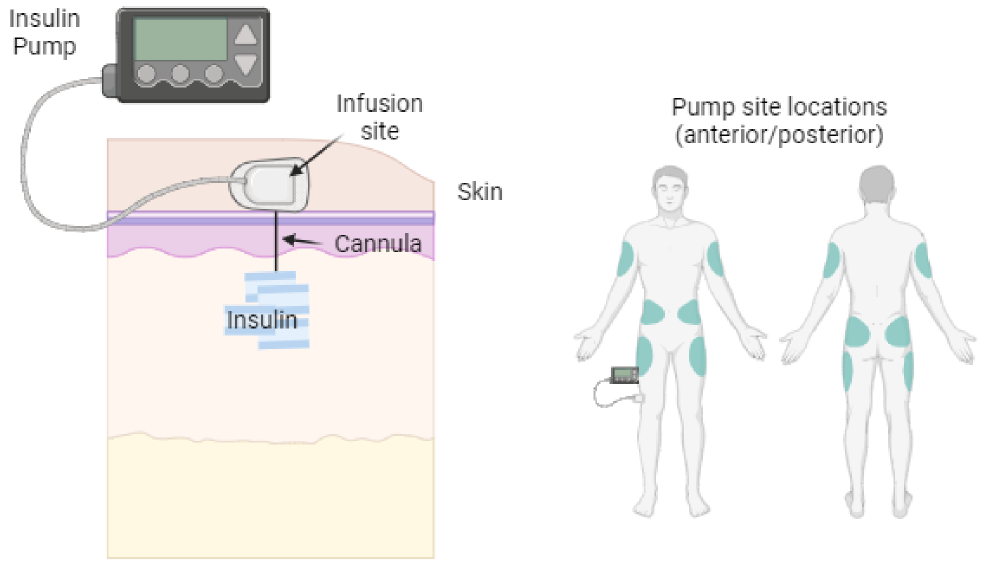

Figure 1: Diagram of tubed insulin pump (Created with BioRender.com)

Along with insulin pumps, those with diabetes can monitor their blood glucose by using a glucose meter, a handheld device that does not provide constant blood sugar monitoring, or a continuous glucose monitor (CGM), a device inserted below the skin that provides constant blood sugar management.

Traditional glucose meters analyze glucose levels in the blood (Vashist, 2013). Those who use these monitoring systems prick their finger using a small lancet device multiple times a day and then place the blood on a test strip, which then is inserted in a meter that provides a glucose level (See Figure 2) (Salacinski et al., 2011). Health care practitioners recommend that those using these devices check their blood sugar at least four times a day to help management decisions (Subramanian & Baidal, 2021).

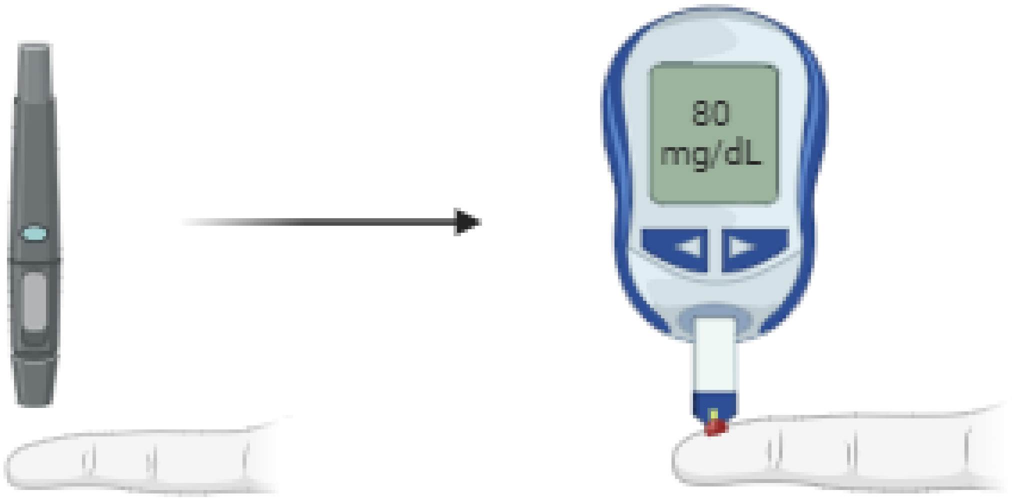

Figure 2: Glucometer with lancets and test strips (Created with BioRender.com)

Continuous glucose monitors (CGM) are devices that are inserted subcutaneously and send blood glucose readings to a receiving device (See Figure 3) (Vashist, 2013). These sensors can take readings every minute and help diabetics monitor their blood glucose levels even more closely (Teymourian et al., 2020). Data from these devices can be shared to help parents care for their children with diabetes, and alarms from these sensors can alert an individual to a high or low blood sugar event, which allows for care to be performed more quickly than with a glucose meter (Subramanian & Baidal, 2021).

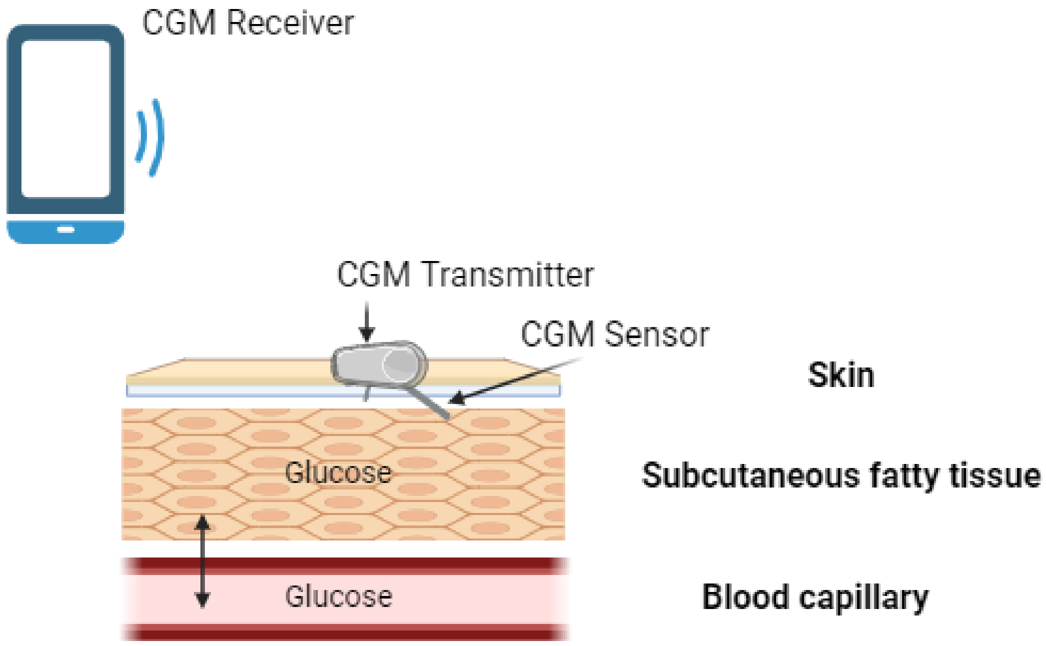

Figure 3: Continuous Glucose Monitoring diagram (Created with BioRender.com)

It is important to use a combination of these devices, such as pump combined with a CGM, a pump combined with glucose meters, or injections combined with either blood glucose monitoring system, to ensure that blood glucose levels stay in an acceptable range. For those living with T1D, the ideal range is between 90-180mg/dL (American Diabetes Association, 2018). One mechanism to track overall glucose levels is by tracking hemoglobin A1C through a glycated hemoglobin test (Peterson et al., 1998). These A1C levels represent average glycemic levels over the course of about three months (Subramanian & Baidal, 2021). For those with T1D, current A1C targets for adults with diabetes is <7%, with a non-diabetic average A1C being around <6%. A1C levels that are above 6% can indicate someone having, or developing, diabetes (Kahanovitz et al., 2017).

If blood sugar is consistently at abnormal levels, adverse health outcomes can occur. Beyond DKA, prolonged hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar) can cause both microvascular issues and macrovascular issues (El Malahi et al., 2021). Diabetes complications are the leading cause of comorbidities, such as cardiovascular diseases, kidney disease, eye-disease, neuropathy, skin complications, oral complications (such as gingivitis and periodontitis), hearing loss, and stroke (Melendez-Ramirez et al., 2010). Conditions such as these can cause significant disruption in an individual's life. The development of kidney failure, a condition that is 20-50% more likely to develop in type 1 diabetics, while managing diabetes can result in the need for dialysis (Raile et al., 2007). Lower life expectancies are common in those with T1D as well, with it being suggested that life expectancy can be shortened by 7-15 years (Tran-Duy et al., 2021). Cardiovascular issues have been linked with T1D through the development of nephropathy (i.e., worsening of kidney function), retinopathy (i.e., damage to the eyes and vision), and poor glucose management practices as indicators (Schofield et al., 2019). These complications can cause anxiety and distress in those living with T1D because the risk of mismanagement for prolonged periods puts one at a higher risk of developing them (Helgeson, 2021).

Emerging Adulthood

Emerging adulthood is characterized by the transitionary period between adolescents and adults (Arnett, 2004). Individuals that fit into this age range between18-30 years old. This concept of emerging adulthood can be found primarily in industrialized countries such as, European countries, China, Japan, Canada, Norway, and Argentina (Arnett, 2024; Macek et al., 2007; Nelson et al., 2004; Nelson & Chen, 2007; Rosenberger, 2007). It is less applicable to non-industrialized countries. During this period, an individual shifts from being taken care of by parents and caregivers to living alone and being the sole carer of oneself (Wood et al., 2017). Those within this period can face challenges such as living alone for the first time, looking for a partner, gaining more independence, working a full-time job, and more (Arnett, 2004). These challenges can create feelings of anxiety within the person (Arnett, 2007). In order to reduce negative feelings, those within this age range typically find a peer group that they can relate to, and, within this group, members can assist each other in navigating through these new stressors.

Emerging Adulthood and T1D

As most studies in the T1D and belonginess space have focused on younger individuals or older populations, there is limited data on how young adults are able to find peer support groups and manage their illness. In this life stage, individuals manage many transitions as they age from childhood into their emerging adult years. Emerging adulthood can be filled with many positive experiences such as a decrease in depression and an increase in self-sufficiency and self-esteem (Arnett, 2004). However, this period in people's lives is also very stressful due to the challenges that are associated with these changes. Emerging adults can frequently feel detached from their life because of the increased stress they have to navigate through (Matud et al., 2020). Living alone for the first time in an emerging adult's life can result in the increase of risk-taking behaviors (i.e., drug use, sexual behaviors, alcohol consumption), and these environmental factors can contribute to the stressful feelings during this period (Nelson & Padilla-Walker, 2013).

Many people who were diagnosed with T1D had the support of their parents at the onset of their diagnosis and throughout their adolescent years (Anderson & Wolpert, 2004; Commissariat et al., 2016; Freeborn et al., 2013). This support is shown through parental involvement in doctors' appointments, insulin administration, and monitoring of blood sugar (Raymaekers et al., 2017). This can be beneficial for adolescents in learning how to manage their diagnosis at first; however, it can also result in a delay of self-sufficiency, autonomy, and competency in the corresponding transition into adulthood (Raymaekers et al., 2017). This shift from childhood to emerging adulthood can be made even more difficult for those suffering with T1D because of the potential over involvement of their parents throughout their youth. Learning how to become self-sufficient is crucial as one shifts to adulthood to ensure that one can be successful in their health, relationships, and careers (Arnett 2004; Serido et al., 2022; van den Toren et al., 2020). Luyckx et al. (2010) examined how emerging adults cope with T1D and found that when emerging adults were able to fully accept their diagnosis of T1D and integrate it into their lives with the help of peers, they were better equipped to deal with the other stressors that come with being an adult. From this study, the researchers found that successful management was heightened the more an individual integrates with their illness. The ability of those emerging adults to discuss and relate to others with T1D allowed this better integration to occur in an individual's life.

Throughout reviewing previous literature, it has been found that there is not much research regarding the effect of T1D on emerging adulthood and how to support those within this transitional group (Helgeson, 2021; Ingersgaard et al., 2019; Peters & Laffel, 2011; Ramchandi et al., 2019; Raymaekers et al., 2017). People within this age group can struggle with the transition from pediatric diabetes care to adult diabetes care. According to previous research (Iversen et al., 2019; Lyons et al., 2013), the transition from pediatric to adult based care can result in less visits to the endocrinologist. This is due to less personability from the doctor in combination with taking on more adult responsibilities such as living on one'sone's own and managing more adult relationships and finances (Peters & Laffel, 2011). Determining strategies to help ease this transition of care, moving from a team of people (e.g., person with T1D, parents, pediatric endocrinologists, nurses) to more individualized care (e.g., only an endocrinologist, nurses, and the individuals with T1D) is important for the mental and physical wellbeing of those living with T1D (Peters & Laffel, 2011).

Development of Peer Support Groups

Because of the beneficial nature of peer support groups in regard to an individual feeling less lonely and a greater sense of belonging, it is necessary to understand how, why, and if these groups are effective at enhancing both diabetic and non-diabetic related dimensions of health. Illness identity, the way an individual perceives themself in relation to their illness, is important to establish for individuals to integrate with their illness (i.e., fully accepting their diagnosis and its impacts) rather than see it as something they can ignore (Raymaeker et al., 2019). For a support group to be effective, this integration of a person and their illness must occur so that the in-group can provide the needed support to everyone in the group. These supportive in-groups can help encourage individuals to have better coping mechanisms and lower overall stress levels (Ellis et al., 2018). This sort of support from social in-groups can help people with chronic illnesses better manage and cope with their illness (Myrick et al.2015). These groups can provide beneficial support and are necessary for individuals to feel as though they are fully integrating into society.

Social Dynamics and Support in T1D

For many people, it can be difficult to find a spot within the world in which they feel as though they belong, and the addition of a chronic illness can make this even more difficult (Nunez-Baila et al., 2021). T1D can create problems for emerging adults to fit in with others (Momani et al., 2022). Because of the addition of needing to consistently worry about blood sugar regulation, diet, and having to use medical devices (such as insulin pumps and continuous glucose monitors), there can be an increased sense of feeling as though they are different from others (Freeborn et al., 2013). Finding social support groups can help counteract these negative feelings of isolation and promote more positive coping skills for those with T1D (Peters & Laffel, 2011).

In multiple studies involving individuals with T1D ranging from the age of 11 to 30, there were common themes surrounding feelings of being different (Abdoli et al., 2017; Freeborn et al., 2013; Joenson et al., 2017). These studies looked specifically into peer-to-peer relationships and support groups that were designed for diabetics and reported similar findings.

In a study of child and youth perspectives living with T1D, Freeborn et al. (2013) suggested respondents were upset when having to take time away from friends to check their blood sugar, and this resulted in them not properly managing their disease, which can potentially lead to long-term health risks. Moreover, study participants indicated feelings of nervousness that properly taking care of diabetes would result in the loss of friendships. Another study reported similar findings to Freeborn et al. (2013), where individuals with T1D struggled to overcome the social stigmas that surround T1D (Abdoli et al., 2017). These stigmas include others thinking that T1D is self-inflicted by dietary or physical habits and abusing disability resources because they do not 'look disabled'. Additional studies which have explored the impact of wearing a pump or a CGM found that these devices can make the wearers feel alone in their day-to-day life because they aren't seeing others who are also impacted with T1D (Joenson et al., 2017). Joenson and colleagues (2017) also reported findings where those with T1D feel as though they are being 'stared at' by those without T1D. These negative feelings reported in these studies can cause those with T1D to feel as though they are not like their peers without T1D and as though they are 'different' or 'other.' Those that participated in these studies often shared how they wish they knew more people living with T1D who could relate to their daily life experiences (Abdoli et al., 2017; Freeborn et al., 2013; Joenson et al., 2017).

Although there are certain anxieties surrounding peer relationships for those living with T1D versus those who do not, these relationships can also help reduce diabetes stressors for those with T1Ds. In one study that was evaluating the effectiveness of a diabetic social support questionnaire, the researchers found peers without diabetes can also be a positive support system for those with T1D (Bearman & La Greca, 2002). This peer support for the person with T1D was typically illustrated as helping them engage in exercise, expressing emotions, and testing blood sugars but was less present when it came to things such administering insulin and managing a proper T1D diet (Bearman & La Greca, 2002). A positive relationship between persons with T1D and their non-diabetic peers was also found in a study performed by Commissariat et al. (2016), with respondents suggesting that they are grateful when their friends without T1D respect their boundaries because it helps them feel more normal and less like an “other.” Additionally, participants in the Commissariat et al. (2016) study reported that their friends often assist them when managing a low blood sugar or by asking questions about their illness, and these actions help them accept their diabetes more. However, if peers or parents begin to ask too frequent questions regarding what their blood sugar numbers are or what A1C was reported, the respondents reported feeling frustrated or annoyed. While it is beneficial to have support to ensure that one is checking blood sugar and exercising enough, the respondents from these studies (Bearman & La Greca, 2002; Comissariat et al., 2016) indicated that support from non-diabetic peers should be within the realm of what the diabetic is comfortable with. This could prevent negative feelings about diabetes from arising.

While negative emotions can occur when someone without diabetes begins to ask about blood sugar levels and insulin administration regimens, other studies have shown that when those with diabetes ask other diabetic related questions, more positive impacts can be realized (Gray et al., 2020; Saylor et al., 2018). T1D/T1D relationships differ from groups that consist of T1D and someone without T1D by allowing those living with the illness to provide more anecdotal evidence and disease specific support that positively impacts individuals living with T1D (Habenicht et al., 2018; Gray et al., 2020; Malik et al., 2014) These positive outcomes were demonstrated in Malik et al. (2014), who explored the role of online peer support groups consisting of individuals all living with T1D. During the study, individuals had to post pictures over the course of three months that demonstrated what it was like to live with T1D. One participant indicated these supportive networks encouraged her to have emergency supplies with her more often, and she felt as though the other participants within the study were the only ones who understood her because of them all having similar life experiences. Being able to discuss similar struggles with others allows T1Ds to feel more positively about their illness and more willing to engage in diabetes-specific discussions (Habenicht et al., 2018).

RESEARCH METHODS

Research Site

The community that was the focus of this study was at a medical specialty camp near Atlanta, Georgia (USA), called Camp Kudzu. Camp Kudzu was founded in 1999 by a team made up of parents, doctors, health professionals, and community leaders (“Camp Kudzu”, 2004). The camp was designed to serve individuals that have been diagnosed with T1D and their families. It is the largest diabetes self-management education program within the state of Georgia. Camp Kudzu focuses on growing individual skills to help youth thrive after leaving camp. Each summer camp session lasts five days and four sessions are held. Outside of summer camp, Camp Kudzu hosts four family camp sessions throughout the year. One occurs during the fall, one during the spring, and two during summer. These camp sessions last from Friday to midafternoon on Sunday and allow for entire families to better understand T1D.

The volunteers for this camp range in age from 18 to over 50, but most volunteers are young adults between the ages of 18 and 30. While some volunteers have T1D themselves, others do not and volunteer to gain college credit or because they have a personal relationship with someone living with T1D. The community of campers and volunteers that attend Camp Kudzu get to participate in classic summer camp activities such as archery, swimming, crafts, skits, horseback riding, ziplining, fishing, and camp games. Along with these activities, Camp Kudzu also hosts sessions to help youth and their families better understand this chronic condition. Sessions include how to manage blood sugar, calculating insulin administration doses, and different ways and strategies to administer medication. Kudzu hosts sessions year-round to fit the needs of the families impacted by T1D. Youth and families can be referred to camp from their endocrinologists, other parents, and from peers. Volunteers can be referred in similar ways, and many volunteers have attended camp as a camper. Those who choose to volunteer can do so as many times as they would like.

Participant Recruitment

Participants included within this study are individuals who have experience working at Camp Kudzu as a volunteer for at least two sessions that are offered (i.e., a combination of Family camp, teen camp, or overnight summer camp). Enrollment into the study took place during Fall 2023 Family Camp. Since the participants within this study have in depth experiences with the study topic, information saturation can be reached with a relatively small number of respondents (Malterud et al., 2016; Robinson, 2013). Information saturation occurs when no new information is found from additional interviews (Saunders et al., 2017). Additionally, given the homogenous characteristics of the study participants (i.e., T1D diagnosis and age group) (Sandelowski, 1995), data saturation was likely to occur between 10 and 20 participants (Vasileiou et al., 2018).

An announcement and overview of the study was given by the researchers at the beginning of the Fall Family Camp session to all volunteers (*for more recruitment information, see Appendix B*). Participants for this study were selected using volunteer-based sampling (Mohsin, 2018). Volunteer-based sampling occurs when participants willingly sign up to participate in a study. This was chosen as the strategy for the study because it ensures that participants will be eager to share their insights and is a convenient sampling procedure (Seetharaman, 2016). While this can result in bias from the participants, data saturation was reached ensuring that the insights were valid and prevalent throughout these participants. By ensuring that this study reached data saturation, the credibility of the study increases because it provides the lived experiences of each individual (Sarfo et al., 2021). Initially, 27 individuals expressed interest in participating in this study and added their names to a signup sheet while at camp. After this, a sign-up link for an interview time was sent to all 27 interested individuals. After sending the link, 12 participants signed up and met with the researcher to participate in the study. (*See figure 4 for a timeline of the process*).

Saturation was reached for each interview question which allows the researcher to infer that there is validity within the study and commonalities that link those living with T1D as young adults (Fusch & Ness, 2015). During the interview process, data saturation was reached at various points for each interview question (*see appendix A for interview questions specific to each topic)*. For questions regarding motivation to return to camp and benefits from the social group, saturation was reached after 6 interviews. Regarding illness identity questions, data saturation was reached after 8 interviews. Saturation was reached for each interview question which allows the researcher to infer that there is validity within the study and commonalities that link those living with T1D as young adults (Fusch & Ness, 2015).

Individuals recruited for this study were within the emerging adulthood range, between the ages of 18 and 29 and were all diagnosed with T1D. Emerging adulthood, as stated previously, is a period of transition (Arnett, 2004)

Following the announcement about the study, potential participants were given two days to sign up for the study while at Camp Kudzu’s Fall Family Camp. This was due to the length of the family camp session (Friday-Sunday). Individuals who participated were then sent a link to sign up for an interview which lasted between 30 and 45 minutes. During the interviews, questions regarding demographics (*see Table 1 for representative quotes and Appendix A for an interview guide*) and their experience volunteering for Camp Kudzu were explored (*see also*

Appendix C for interview guide). In return for being involved in this study, participants received a $20 gift card.

Participants

Participants of this study consisted of 12 individuals. Nine participants identified as female (75%), and three participants identified as male (25%) with 11 identifying as white and 1 as Latina. Participants ranged from 18 years old to 29 years old (*M* = 23.75, *SD* = 2.86). The range of years since diagnosis was 6 to 24 years (*M* = 14.1, *SD* = 4.89). The age of diagnosis for the participants ranged from 5-15 (*M* = 8.9, *SD* = 4.31). All participants that participated in the study were informed of confidentiality prior to starting the interview.

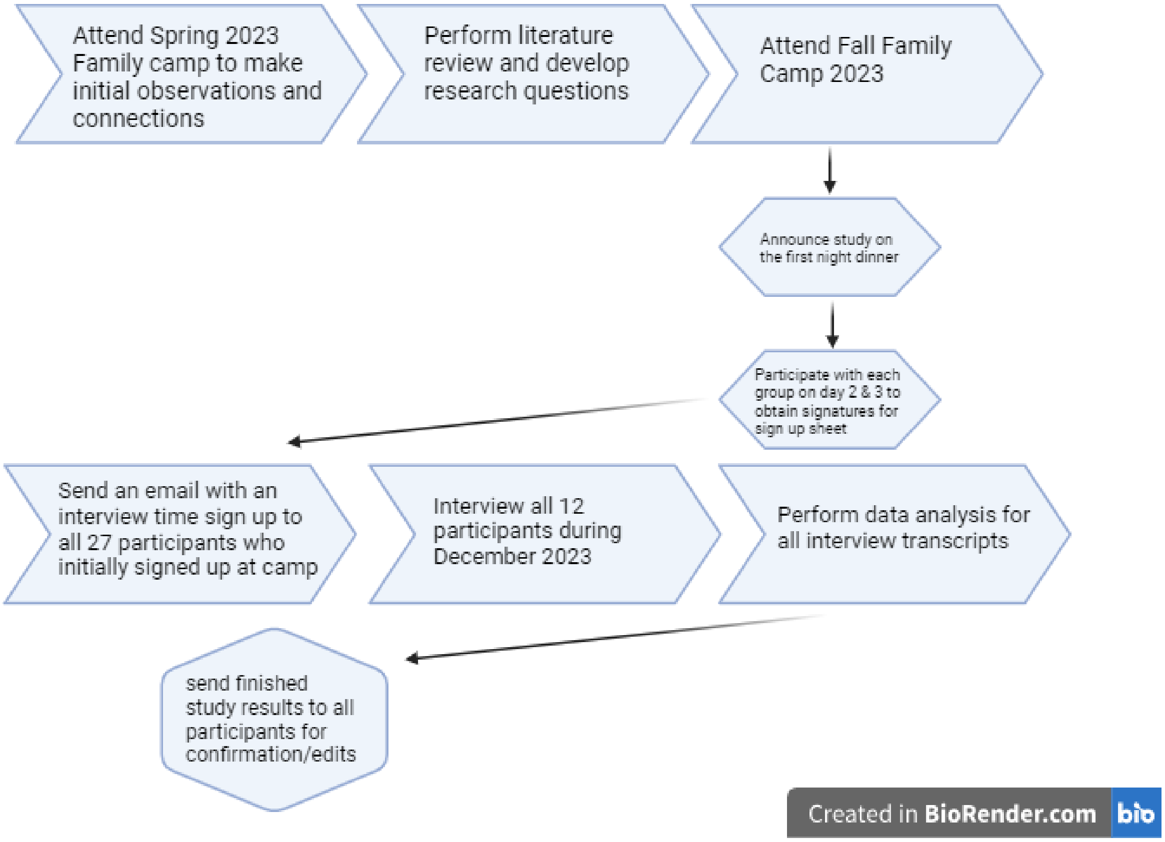

Figure 4: Flow diagram of research process steps

Researcher-Participant Relationship

Prior to beginning this study, I did have existing relationships with the participants. Prior to beginning the study, I attended camp as a counselor to become more familiar with the study site and potential study participants. This was due to the nature of the camp session. While this relationship did exist, steps were taken to ensure that there was minimal bas from my relationship with the participants and the construction of themes. Researcher bias was reduced by ensuring that the interview script was followed, and all questions were asked and answered by the participants (Chenail, 2014). Ensuring the researcher does not stray from the original questions that were created reduces the potential for bias by not allowing participant answers to sway what questions are asked. Along with this, personal biases were addressed by acknowledging the lens in which the researcher views the subject (refer to positionality statement). This acknowledgement, along with including direct quotes from participants and by clearly outlining the reasonings and strategies for the study purpose and design, was also crucial in eliminating researcher bias (Noble & Smith, 2015). In addition to the other methods used to acknowledge and reduce any bias in this study, intercoder reliability and the constructed themes being similar to those that were found in existing research articles that addressed similar topics also helped to ensure that researcher bias was reduced as much as possible and did not significantly impact the results of this study.

Data Collection

All interviews were performed following approval from Clemson University's Institutional Review Board. Verbal and written consent was received from each participant prior to the start of each interview. The interviews for this study were semi structured which allowed participants to fully answer the questions; the interviewer could expand on points that were brought up by the participant.

Interviews were conducted in December of 2023 over Zoom. These sessions were one on one and lasted anywhere from 30-45 minutes. The questions were designed to answer the overarching research questions of the study. Specifically, questions focused on diagnosis identity questions [RQ_3 – the impact of the social group on the overall health of participants](Commissariat et al., 2016; Freeborn et al, 2013) social in groups and out groups [RQ_1 and RQ_2- acceptance and inclusivity of the group](Bearman & La Greca, 2022; Joenson et al., 2017), and motivating factors for participants to continue returning to Camp Kudzu as a volunteer counselor [RQ_4- motivation to return to camp] (*see Appendix B for interview guide)*. Diagnosis identity questions were developed to answer research question 3, regarding the outcomes of how an individual's biological, psychological and emotional outcomes are changed after inclusion within the group. Research questions one and two were answered from the interview questions that focused on social in groups and outgroups. Research question 4 was answered by questions regarding motivating factors to return to camp.

Data Analysis

The conversations that took place were recorded via Zoom, transcribed by Fathom AI, and edited by the researcher after the conclusion of the interviews. Each transcription was read and re-read at least once to ensure proper codes were formed and that the researcher did not miss any topics/themes that were addressed during interviews (Dierckx de Casterle et al., 2012). These rereads allowed for commonalities and themes to be linked between each individual when answering the questions. To reduce bias, names of each participant were removed from the transcription copy and were selected in random order to be read (Smirnova et al., 2022). Each respondent was given a pseudonym to provide anonymity. Interviews followed a semi-structured guideline to allow for in-depth participant responses. Semi-structured interviews were guided by Harrell and Bradley's (2009) outline:

> *The grand tour question is a good type of question to use near the beginning of an interview, because it often encourages a respondent to speak. A grand tour question might be relatively simple, and sometimes includes multiple small questions or repeated phrases.* (pp. 36)

For the present study, the "grand tour" questions included diagnosis timeline in order to warm the participants up to the focus of the study. Following the grand tour questions, mini tour questions were asked (Harrell & Bradley, 2009). Questions that are associated with mini tour, experience (i.e. did diagnosis impact how friends treated you?), and example questions (i.e. how did treatment form peers change after diagnosis?) were structured to gain more insight regarding diagnosis, illness identity, social ingroups, and motivating factors for the participant to return to camp.:

> *Mini tour question asks about a specific element and is often used to follow up after a grand tour question … Example questions ask for a particular example. For instance, if the respondent were to comment that his parents were very strict when he was growing up, the researcher might ask, "can you give me an example of something they would or wouldn't do that made you feel they were strict parents?" Experience questions ask such things as "Can you give me an example of something you did while you were deployed?" Bear in mind that to the extent that certain experiences come readily to mind, they may not be representative* (pp. 37).

When a participant did not initially understand a question, probes were used to provide more clarification and promote a stronger answer from the participant. Probes were also used after specific questions to gain more insight regarding the topic. Example probe questions included "what emotions were present" and "what changes did this bring if any?" These probes were used for clarity and specificity and to gain a more complete answer from participants (Price, 2002).

Themes can be understood as defined by Mishra and Dey (2022), are “perceptions, experiences, feelings, values, and emotions residing in the minds of participants/respondents of a research study” (p. 187). To provide further understanding of what is meant by a theme, Braun and Clarke (2014) stated that themes are discovered across datasets, indicating that multiple respondents will answer similarly to questions resulting in the construction of themes. For this study, a three-step process was used as a framework to prepare for the analyzation of transcripts and construction of codes and themes (Saldana, 2015):

> *(1) To codify is to arrange things in a systematic order, to make something part of a system or classification, to categorize. When codes are applied and reapplied to qualitative data, you are codifying … Coding is thus a method that enables you to organize and group similarly coded data into categories or “families” because they share some characteristics – the beginning of a pattern …(2) Emergent categories might also evolve as conceptual processes rather than descriptive topics … The categories' prepositional statements are then compared with each other to discern possible relationships to create an outcome proposition based on their combination. … (3) Qualitative inquiry demands meticulous attention to language and deep reflection on the emergent patterns and meanings of human experience … Some categories may contain clusters of coded data that merit further refinement into subcategories. And when the major categories are compared with each other and consolidated in various ways, you begin to transcend the “reality” of your data and progress toward the thematic, conceptual, and theoretical (*pp. 8-12*).*

Following this, Braun and Clark’s (2006) thematic analysis steps were followed. After interviews were conducted, the transcriptions were created and edited for clarity and to ensure they matched what was said during the interview. After the transcripts were constructed, they were read and re-read. During these initial readings, prominent ideas were written down, such as better health management after volunteering at camp and T1D/T1D support differing from peers and family without T1D.

After this, initial codes were created from the transcripts. Codes were chosen based on key words and phrases, such as accountability, support, motivates me to take care of myself. After each transcript was coded, all codes were entered into an excel spreadsheet and categorized based on relevancy to each other and potential subthemes, such as burnout from T1D as a subtheme being coded with words and phrases such as overwhelmed, tired of it, and no longer care. Following the formation of subthemes, greater themes were developed, such as reprieve from burnout as the greater theme that was a combination of the subthemes burnout from living with T1D, overcoming burnout from key support, and specific actions at camp that helped to reduce an individual's burnout. This process was followed for each theme constructed from this study. Once all themes and subthemes were formed, key quotes from each interview were chosen as representatives of the themes.

METHODOLOGY

Epistemology and Ontological View

As a methodologist and scientist, the epistemological stance that I took was post-positivism. This is a middle ground between positivism and constructivism and allows for exploration into qualitative research (Clark, 1998; Panhwar et al., 2017). While positivism takes a firm stance based on data driven evidence, post positivism allows for researcher interpretation of the data in relation to biases that are present (Cooper, 1997; Nawrin & Mongkolsirikiet, 2012; Ryan, 2006). This study explores the social dynamics present between emerging adults at a T1D camp. The data collected from the study were analyzed by an individual who also has T1D. Because of these combined factors, the constructed themes from the interviews are informed by both participant and researcher experiences. However, methodological rigor and extensive review into past research can minimize these biases and ensure that conclusions made are empirically sound (Johnson et al., 2020). Methodological rigor within this study is reached by ensuring that the processes performed are systematic by using a stepwise approach and transparent, such as researcher bias being addressed and reasonings behind processes being explained (Johnson et al., 2020). Bias was addressed by acknowledging my unique perspective on the issue and performing extensive literature reviews on relevant topics. Intercoder reliability was used to ensure that the codes and the constructed themes were not significantly influenced by bias from the primary researcher. Along with this, themes found in the current study were compared to themes found in similar studies and the themes constructed in this study did align with previous research. Themes that were present in other studies included feeling less alone (Peters & Laffel, 2011), the ability to provide a higher level of personal care (Malik et al., 2021), and having a more positive relationship with their illness due to the support from others with T1D (Habenicht et al., 2018). These themes were similar to the themes found in this study such as diabetes specific support, improvement of health, and social and emotional challenges described by participants. By utilizing intercoder reliability, all aspects of this study, from the initial planning steps and formation of research questions to the finalization of themes and conclusions, are more reliable (Santos et al., 2020). This provides more credibility and validity to this study when combined with data saturation.

Along with triangulation, following the conclusion of the study, the participants will be sent an analysis of what was found. Upon receiving this, they can either agree, disagree, or have no comment on the researchers' conclusions. To better understand how these groups developed and evolved, I utilized semi-structured interviews (*see appendix A*), interviews that allow in depth responses from interviewees via the asking of open-ended questions (Jamshed, 2014), with individuals and analyzed responses for similar themes.

Positionality

It should be acknowledged that I, the author of this study, am a Type 1 Diabetic and was diagnosed at the age of 14. While I have limited experience working with Camp Kudzu and do not consider myself as part of the ingroup that is present there, I do have lived experiences that allow me to relate to many of the responses that participants gave during the interviews. These relatable experiences include being told and feeling as though I am not 'sick enough' to require certain medical devices or support (e.g., medical alert dog, insulin pumps, or glucose monitors) at the onset of diagnosis from peers and relatives. These feelings of not being "diabetic enough" have followed through my adulthood and to "prove" I was not controlled by my diagnosis, I refused to acknowledge my diabetes for months at a time and refused to join communities and organizations that could have improved my coping abilities. In the Spring of 2023, I participated at Camp Kudzu as a volunteer. During this experience, I was initially made to feel as though I did not belong due to commentary from other volunteers regarding my lack of insulin pump and CGM. These comments emphasized feelings of not being diabetic enough to join a community of other T1D's. However, since then, I have had many more positive interactions with the Camp Kudzu staff and feel as though I do belong at camp as a volunteer. Although the initial introduction to Camp Kudzu was negative, the positive interactions and the research I have conducted to learn more about this community has allowed me to see the positive impact that this community has on the individuals that are a part of it. My experiences provide a bias through which I view the world. This bias has been acknowledged and research processes have been implemented to ensure that my personal bias does not influence the findings through this study.

RESULTS AND DISCUSSION

Saturation

Data saturation was reached for each interview question. Interviews continued after saturation was reached to allow individuals to share their stories and be heard. See appendix D for more information regarding data saturation.

Constructed Themes

From this study, themes were constructed based on the data analysis of the transcripts. Pseudonyms were used to provide anonymity to participants within this study. In total four themes were constructed, and they are (1) social and emotional challenges, (2) benefits of camp and community support, (3) improvement in health monitoring, and (4) motivation to return to camp.

Social and emotional challenges

The first major theme to appear was the social and emotional challenges that those living with T1D experienced throughout their adolescence. This larger theme consisted of three subthemes, isolation and misunderstanding, negative self-image, and acceptance and support.

Isolation and misunderstanding

As one participant stated within this study, “Type one diabetes is a stigmatized illness in the real world” (Lucy). These stigmas were heightened for those living with T1D especially in their early years. Because of these stigmas, those within this study experienced instances of isolation throughout their middle school and high school years. As Margaret stated

> *It made me feel like I wasn't a part of the team as much. Or I felt like I was a burden on the team. That was also kind of how I felt. My friends never made me feel that way, but a lot of times, if I had to stop and take care of myself or I couldn't join in on something, or if there was a panic because of a blood sugar that I was having, whether that be in the high range or the low range. I just felt like I was preventing everyone else from living their life or like it was just burdensome, I feel like. I was bringing the team down*

This mistreatment from her teammates resulted in her feeling as though she was different than peers and caused feelings of alienation.

> *Definitely like a self-conscious, like an alienating feeling. It was a lot of like, why am I... I'm the only one that's dealing with this. I am the only one that's dealing with this because there was no one else in my community or on my teams or in my school that had it at the time. So, it's just felt like I was by myself dealing with it on my own even though I have like a small support system of my family and friends. Even then I still felt like I was kind of just dealing with it by myself and on my own. (Margaret)*

Other participants relayed similar stories of feeling as though they are being treated as though they are different from their peers.

> *They didn't have a meter on me so and they didn't always want to walk me to the nurse because it would be an inconvenience because that's the, another kid from the class to walk me to the nurse because our school was so big that there was a chance I would pass out on the way to my nurse if I was low. (john)*

John went on to describe that while he didn't experience negative emotions from these instances, it was a reminder that he was different from his peers. This was also echoed by Lucy who stated that adults would treat her differently than her peers.

> *there was a lot more of kind of attentiveness almost, but it was more like them constantly stopping whatever we were doing to say, hey, do you need a snack? Hey, are you okay? How do you feel? So, I mean, that was different than before. (lucy)*

April described how when she was diagnosed, her friends saw her as completely different, and she was no longer part of their group.

> *But when I was a kid I my friends definitely sort of iced me out because they didn't really understand it and I Definitely got bullied a lot by classmates that year and a couple years past that so yeah Yeah,*

Being removed or treated differently from peers was a common trend amongst participants with another participant stating.

> *Like I wasn't invited on trips like spring break and stuff like that with my group of friends because of my diabetes. They thought that that was too much of a liability kind of thing.*

> *Which was like, I get it. It’s stressful. But it also made me feel like, oh shoot, they’re not like true friends (Julie)*

Many instances of peers treating them differently stemmed from a lack of understanding of what diabetes was.

> *And everyone kind of questioned, you know, kind of the basic things like, why are you giving yourself a shot? Why do you have to count carbs? Are you eating this? You know, just it was a learning curve for everyone (Tina)*

Overall, many participants described feelings of being a burden on their friends and family because of their diagnosis. Due to the constant management of blood sugar, those living with T1D felt as though they were creating negative experiences in other people’s lives due to the constant need to monitor and manage their illness. *I guess just feeling like dependent on people and like a barrier or like a hardship on my parents (Julie)*

Negative self-image

Participants in the study discussed how the diagnosis of T1D impacted how they saw themselves. While three individuals stated that the diagnosis had little to no impact on self-image, nine individuals reported negative feelings of self, especially during middle and high school.

> *it felt like I was developing faster than my friends were and it was really scary because I thought that they were going to see me as like oh there's the fat diabetic you know what I mean and it was like not something good and so the reason like from that um I definitely had like a pretty bad case of like diabulimia stuff like that where I just wouldn't eat it when I would eat I would throw it up after stuff like um and it just it did cause like a severe spiral of like a lot of stuff (April)*

Navigating through middle and high school with a chronic illness resulted in feelings of self-consciousness and isolation for many participants with one participant stating, “*my confidence level definitely deteriorated when I was like first diagnosed and into middle school, um and a little bit of high school too (Tina)* Feeling as though they were “broken” or “damaged” was discussed throughout the interviews with one participant stating

> *I kind of saw myself as like, why am I broken? Like why are they able to you know, have regular sodas and like Starbucks all the time and like why do I have to like think about what I'm going to eat and try and like plan it throughout my day. Just little things like that added up. I was like, why am I different? Why did I get it? (Maria)*

Other people in the T1D's life could also contribute to these feelings of negative self-image. In school settings, respondents also described instances in which they wanted to do the same things as their peers but couldn't due to having T1D and this caused further negative emotions.

> *When we had that class party, everyone was supposed to bring in something and usually it was like a bunch of stuff that my mom was not comfortable with me having because it was hard to count those carbs because it was a homemade or whatever it was and she wasn't there with me and it was just a big deal so she gave me like two pieces of candy and a Ziplock bag with the carb count on them and how much insulin I was supposed to get and then when I would. When I was at the class party, I felt so sad. was like, I wanted one of those cookies, right? (April)*

Acceptance and non t1d support

Participants within this study discussed how T1D impacted them and while some of the impacts were negative, participants did speak about how their diagnosis gave them a stronger sense of independence later in their life because of the constant need to monitor. *"And then as I grew up, I was pretty independent with it" (Ryan), "I mean it's something like a lot of independence and confidence … so I'm able to do a lot more because of it and because I'm more confident now (Ella).* By having a greater sense of independence from managing their diabetes, those that participated in this study felt as though they were better adjusted to handle other problems that show up during one's life.

All participants that participated within this study were diagnosed with T1D during their childhood or teenage years. Because of this, they initially found support from peers and family who don't live with T1D. Participants described this sort of support as beneficial and a system they rely on.

> *So it definitely used to be a lot more. And they get that. I understand that they do get that they can. can't understand, but they also understand that I can do the things that they're*

> *asking me to do. And so it's kind of, you know, growing up and realizing that they are right, and I should be doing this, and they have a point because they do just care for me and my well-being. They also, you know, in their own, at the same time have grown a little bit more, I don't know, lenient, I guess, just less helicopter-y just been like a lot more understanding, I think, of the difficulties. mean, endo is great about it. Like sometimes it works, sometimes it doesn't. We'll just work through it and work around that. (Ryan)*

While these non T1D support systems don't understand the full scope of living with a T1D diagnosis, participants stated that they were still a positive in their lives.

> *So all of them are made up of people who don't all have diabetes, but it's like my sister and like one or two friends that know kind of all about it and I know if I go to them, they can help me out. (Ella)*

> *And then like for just like ranting and complaining or like needing help with like making decisions or that kind of stuff, then I have my partner that I can kind of just like rant to and I'm like she doesn't understand like exactly what I need in that moment, but she knows that I just need like someone to listen. Yeah. So you don't exactly have to have to have diabetes to be able to help out in general, but I think like definitely my biggest support system has been through camp. (Rachel)*

> *Yeah, so I have my husband at home. He knows so much at this point, even if he didn't want to know it. So after five, six years, you learn a little bit. So I have him, he's for sure one of those people. I have my mom as well. It's been a long time since my mom is dealt with my type 1 herself. So she's just kind of there as a sounding board of me being like, hey, my A1C is this. she's like, oh my god, that's awesome. But I would never be like, hey, mom, can you draw three units of insulin for me? because she probably doesn't remember how or what to do with that (Margaret)*

Participants in this study discussed how support from these individuals is important to them, however, the support that they receive from other T1D allows them to better manage their diabetes.

Disease Specific Support

This was the second major theme that was constructed within this study. This theme consisted of two subthemes, diabetes specific support and community and belonging.

Diabetes specific support

The social group that the T1D’s within this study described as the most important for managing their diabetes was the group found at Camp Kudzu that is made up of others living with T1D. Many participants stated that they had felt alone and isolated prior to attending camp because they were the only one they knew of with T1D. After becoming one of the members of the group at Camp Kudzu, participants stated that, because of their shared experiences, they were more comfortable opening up about T1D specific difficulties with others at Camp Kudzu.

> *I think that the way that I interact with people from Kudzu is more honest. Um, like I think that I have an easier time letting go and being honest with the things that I'm actually feeling or the things that I'm doing I think that it also helps that, you know, they're not going to have as much of an air of judgment about them because they go through it as well. And so they can put themselves in that position more easily be like, okay, I get it. (Kennedy)*

This sense of belonging allowed participants to feel as though they better understand themselves and their disease because they were no longer alone in managing their diabetes. Those who have lived with T1D are able to provide more disease specific support to others and coach them through hardships that they themselves have experienced.

> *A camp friend, I could call them up like and be like, I don't want to change my pod right now. My blood sugar is 500, whatever. And they'd say, you need to change your pot. And then we can talk about this after. Like, they'd force me to do it. Which is a good thing. Because it's more about, like, with support. And you're in the camp community (April)*

Most participants within this study expressed how ranting with other T1Ds about disease specific challenges allowed them to not live within that challenging moment but to get past it.

> *A lot of times it's even just like ranting or like asking each other like stupid questions. But yeah, I think a lot of times it's really just like, look at this like stupid thing that happened to me. Or like, wow, I pulled my pump side out on a doorknob three times in a row today. Just like the kind of stuff that they understand that non-diabetics wouldn't understand like the struggle or the frustration (Rachel)*

Along with the emotional support provided within this group, group members are also able to share information on their management strategy which allows other individuals to explore more management options.

> *I definitely learned like little tips and tricks like from friends that were in my cabins um from counselors that had it um being able to you know draw up insulin out of a uh insulin pen versus a vial. I had no clue that you could do that because they don't tell you that in the hospital. They're like here's your vial, here's your syringe. That's how you're gonna draw up insulin so I had no idea that you could just pull from a pen if you only have pens or um that like changing your lancet at every time like yes you should but like are you gonna you know the end of the day? (Margaret)*
>
> *Being around the people they showed me new things to do with the pump because again I've never had a pump up until college … So when I started volunteering with camp, I learned a lot about how to like finagle the pump and how to like cheat the system a couple times from the other counselors and volunteers, which was really, really cool. (john)*
>
> *Um so obviously there's the I guess the real deep understanding of diabetes that is pushed at camp. Um just through the like the educational sessions that we hold for the campers. And in general, I know a lot of people learn things from that that they hadn't thought of or hadn't heard before, just, you know, because it never comes up (Ryan)*

Being around the community and learning these tips and tricks and being able to more freely express struggles surrounding diabetes and different management strategies was shown to help the mental aspect of dealing with T1D. In a setting that is designed to cater to T1D, those living with the illness are able to worry less about their T1D since carb counts are provided and glucose checks are normalized.

> *…it was kind of like a reset button as well. Every single time I would volunteer at camp, was like, OK, reset, you're going to do it this way, this time. Don't be lazy with it. Like everyone can get lazy with it. So it was always a nice refresher coming to camp as a volunteer to just hear tidbits on new things coming out, especially, and just talking to other people about it. (Tina)*

By having this normalization of T1D issues, those within the camp are able to focus more on building strong relationships that will last outside of the camp session.

> *That was a big deal, and we lean on each other all the time. I was a CIT when I was a CIT, she was the cabin counselor that I was assigned to. [name redacted] is literally always there when I need to rant about having a bad day with my blood sugar. It's a big part of being in the camp community, being able to text a friend, even now to have diabetic friends. (April)*

Community and belonging

T1D can reduce a person's sense of belongingness because of its profoundly isolating nature. Many participants within this study stated that they were the only people they knew from their hometowns or schools that actually live with the disease. Attending camp was the first time that many participants met others living with T1D.

> *Yeah, I saw that I wasn't alone. In my high school, there was just one other kid with type one that I knew of, but I knew there was more, but they weren't in my grade … my first year, the people I was partnered up with and in my cabin, they were super, super sweet and opening like open arms and we're like, oh my gosh, we're so happy you're here. And like I still think back on the one volunteer that's still volunteers with us and I bring it up every year I see her. like, you were my first friend here. Like you made me feel welcome. I think that's a part of how I've come back. (Julie)*

Participants stated how it was exciting to finally feel as though they are able to meet with people that understand the struggles, both mentally and physically, of managing T1D. By having this support, respondents felt a greater sense of belonging and placed high value on the relationships that they have formed at Camp Kudzu.

> *I mean nobody looks at you weird for pulling out a second phone or administering insulin and some needles when you're at camp or around camp people I mean you go out to dinner with them and everybody's out there counting their carbs. It's so much it's so much fun too, and it's kind of like a secret club, which is the hilarious to think about (Lucy)*

Because of the impact that the group has had on each individual member, those who are active within the group try to ensure that it is welcoming to new members.

> *So we really try to make sure that everyone's included like we talk like especially with my friend group will go up to random people and be like hey is this your first year at camp you know or like I did camp little shot this summer. (maria)*

This inclusive nature of the group allows new members to feel as though they do belong, and this can help improve even more T1D's sense of belongingness and self.

Improvement of health

Ensuring that one living with T1D is managing their health properly can help to prevent any future consequences of T1D. Those that participated in this study stated that their health after attending camp and belonging in this group led to the development of the third theme, improvement of health monitoring. This theme consists of two subthemes, improved glucose monitoring and a reprieve from diabetes burnout.

Improved glucose monitoring

Proper glucose monitoring is essential for the longevity of a person living with T1D. Due to external factors such as moving, work, school, etc., it can become less important for a person to check their blood sugar and properly manage it when they're doing something else. Those that participated in this study stated that they have experienced other factors taking precedent in their life and not monitoring their blood sugar or managing their diabetes the way that they should. However, after attending camp sessions and being immersed in the world of T1D, participants stated that they left camp feeling more prepared to manage their diabetes.

> *100% every time I go to camp, my numbers get much better for at least a period of time. It might wear off as, you know, the excitement of being at camp and seeing all these people who are putting forth all the effort and getting the results wears off. But yes, it has a very tangible benefit on my sugar levels. (Ryan)*

> *But every time I come back from a summer session or a weekend program, I'm like okay this is great. I loved having that time. There's a little bit of depression afterwards because I'm sad because I'm not there anymore. But it's like, I'm like okay. I'm ready to go schedule that endocrinology disappointment or oh man that reminds me that I need to get my eyes checked because I haven't done my yearly exam or that kind of thing. It's motivating to get my life together, to make diabetes easier for my life at home (Margaret)*

Having T1D as the sole focus for a weekend family camp or multiple weeklong summer sessions helps these volunteers better manage their diabetes and multiple participants associated lower A1C numbers with the encouragement and advice they have received from camp sessions and other volunteers at camp.

> *But like, Because of those mental health restarts or those like blood sugar restart weeks or whatever it was, like I got it [A1C] down because of that. I know it was because of that, and also because I got a new pump, but other than that like it was definitely like, just the aspect of like although it feels impossible now, it could happen is the biggest*

> *thing. You can do it and it's like that's pretty important because my A1C was like 8.3 for I feel like the longest time. It was 8.3 for like 5 years and I couldn't get it down. Then because of camp, they helped me through my burnout stage and then when I got out of that I just felt so much relief and I was able to take care of myself in the way that I hadn't been able to before so that was pretty important. (April)*

> *I think the way that I've had a lower A1C in college has been from the encouragement and from the stuff I've learned at camp. Because we do, especially with the teens, we talk a lot about that transition from high school where you're around your parents all the time to college where you're literally not around them at all. I'm maintaining that level of care. So I think Kudzu definitely helped with that. (Rachel)*

Finding ways to ensure that blood sugar levels are being monitored and managed appropriately is essential for those living with T1D. From the participants within this study, they have shared that the social connectedness with other T1D's and the information they receive from camp contributes to their management strategies.

Reprieve from diabetes burnout.

Diabetes burnout can occur when an individual living with T1D becomes overwhelmed with the management needed for this disease and the knowledge that this disease is lifelong and does not have a cure. Participants in this study discussed their experience with burnout and how camp helped them overcome their burnout phases.

> *Um, and I definitely just had those, you know, frustrations of like, I'm so sick of this, like this is, you know, not fair and I'm over it and, um, well a lot of people call it diabetes burnout where you just like don't do anything like you just don't take care of yourself and, um, I think I probably did that maybe often on like every few months, like I would have those faces of up and downs of I don't want to do this. I'm not going to do this. I, it really wasn't like a conscious thing. It was kind of something that was unconscious that I did that was, well, I know that I have to do this for my body, but I just don't think about it. (Kennedy)*

Burnout phases are frequently associated with teenage and early adult years and those within this study discussed how they experienced burnout within this range as well. *I guess like going into high school, there was a little bit of burnout, and I would just kind of get sick of doing the same thing over and over* (John). When an individual enters a burnout phase, they are less likely to take care of themselves and tend to start ignoring their illness entirely. It can be difficult for someone to get out of one of these episodes. However, those who were members of the volunteer group at camp Kudzu discussed how talking with others who have experienced and gone through similar events were able to provide advice and support on how to get out of a burnout session.

> *I feel like I had diabetes burnout like a couple of years ago and I had heard from people from camp back to take an insulin pump break so I did that for a week and then I came back and I was because I heard about that idea at camp I was able to do it in my life and when I came back after that week I was a lot better and I was perfectly fine with the insulin pump. (Ella)*

Being around others with T1D can help someone going through burnout focus more on T1D and see that others are going through similar events. By being immersed in this group, those in a burnout phase can find support more easily than if they had no peers that live with T1D.

> *Yes, it definitely lessens the burnout phase because you know, you get so caught up with your life and just going, going, going, and then you can finally just like relax. Relax in a way but you're focusing on diabetes like the whole time… So it definitely tunes your brain like back in like, okay, you really need to get a handle on this. (tina)*

Aside from the emotional and verbal support that those in this group offer each other, they also provide physical support to those experiencing burnout. For those who wear pumps, the knowledge and the steps of what has to be done to put a new pump site on can be overwhelming for those in burnout. Taking off the old pump, cleaning the site, opening a new pump, drawing up insulin, putting insulin in the pump, prepping the pump, cleaning the new site, putting the new pump on the clean site, and finally administering the cannula under the skin can be a lot for a T1D in burnout to do. Within this group, one participant stated how when her and her T1D friends are in burnout, they will assist with site changes, along with providing emotional support, and this helps them feel less overwhelmed with changing a pump site and allows them to get out of the burnout phase quicker.

> *Honestly, it's motivating from like a friend perspective to like, if I have both my Dexcom and my pump site need to be changed, and that's like the worst thing ever when you're in burnout because you're like I could just lay here and just not do it but like the physical*

> *action of having to get up and do all the site changing and all the drawing up insulin and the changing off the sensor. Having a friend at camper volunteer at camp be like, hey Margaret have you done that yet? It's I'm almost held like accountable in that way too. So it's nice to have that support during the burnout so that I can be like okay I'll do it. Or like we've done it before where like a volunteer will draw up the insulin and put it in the cartridge and hand them the cartridge full of insulin and be like here I did this step for you that way it's you can get over that one hurdle of having to do that and then it makes it easier to do all the rest of the site change or the rest of whatever you need to do to get through that burnout so. (Margaret)*

These emotional and physical support strategies can be implemented to reduce burnout for those living with T1D. It is important to identify these strategies to best support individuals living with this illness.

Motivation to return to camp

The last theme that was constructed from this study was the motivation to return to camp. From this theme, two subthemes were identified as key motivators. One of these was the positive experiences at camp as a camper and the second was helping kids living with T1D.

Positive experience at camp as a camper

The first motivating factor for those participants who return year after year to volunteer was reflecting on their own experiences they had as campers. One participant described the camp as a safe place from his everyday struggles in life.

> *So I loved camp so much as a camper. It was such a safe space for me because I had like my parents had this horrendous divorce and it was the one week every year where I was like, I do not need to communicate with like my parents. It was like just a place where the adults were just so fun and like loving and just friendly and it was just so happy (Ben)*

This refuge from normal life stressors was also applied to diabetes. Participants in this study described how it was fun and they got to learn from their counselors and fellow campers about diabetes and see the positives that can be associated with this illness.

> *I think definitely just like the community and like the level of support that I feel when I'm there and that I know that like my campers will feel because like as a as a camper, I always felt like so supported by my counselors and by my fellow campers. (Rachel)*

> *Looking back on you know experiences that have had with other counselors that I can think of like well they impacted me you know positively in this way that they you know promoted good habits and they um provided a safe space for me to connect with people that were like me and to open up and to be, you know, vulnerable in those situations. (Kennedy)*

Having these experiences as a camper motivated individuals to continue to come back and provide these safe and positive experiences to future campers.

Helping kids living with T1D

The volunteers in this study understand what it's like to be a kid diagnosed with a chronic illness. All the stress that is associated with it and the unknown that they have to navigate. Their goal as volunteers is to help kids navigate through these same experiences and feel confident managing their diabetes while living a fulfilling life.

> *Um, I think it really solidifies what I was talking about earlier with being a counselor just remembering that my place and my goal as a counselor is to be, um, you know, a support system for younger kids. (Kennedy)*

> *So I go back to camp to give back to that. Like so there will be a kid that will have a week of like safety and security and freedom. Like it just I want to give back and give the experience that I got. (ben)*

The volunteers have seen the positive impacts of camp and want to ensure that future kids with T1D can experience the same positive environment that the volunteers had as children.

> *I want to make sure that camp can keep happening so the kids can keep experiencing this and meeting people and growing up and becoming volunteers and continuing to come back and just perpetuate the cycle and just the connections that I get to build with the kids in that process (Ryan)*

While there might be other factors that motivate volunteers on a more individual level, all volunteers within this study stated that helping the children is the key motivating factor to keep returning. *Being able to be a resource and then being able to provide the experience for the campers, that's my biggest motivator for sure. (Margaret)*

Table 1: Representative quotes of themes and subthemes

Themes	Subthemes	Representative Quotes
Social and emotional challenges	Isolation and misunderstanding	Um, yeah, definitely. It made me feel like I wasn't a part of the team as much. Or I felt like I was a burden on the team. That was also kind of how I felt. My friends never made me feel that way, but a lot of times, if I had to stop and take care of myself or I couldn't join in on something, or if there was a panic because of a blood sugar that I was having, whether that be in the high range or the low range. I just felt like I was preventing everyone else from living their life or like it was just burdensome, I feel like. I was bringing the team down. (Margaret)
		I guess just feeling like dependent on people and like a barrier or like a hardship on my parents (Julie)
		But when I was a kid I my friends definitely sort of iced me out because they didn't really understand it and I Definitely got bullied a lot by classmates that year and a couple years past that so yeah Yeah, (April)
		Definitely like a self-conscious, like an alienating feeling. It was a lot of like, why am I... I'm only one that's dealing with this. I am the only one that's dealing with this because there was no one else in my community or on my teams or in my school that had it at the time. So it's just felt like I was by myself dealing with it on my own even though I have like a small support system of my family and friends. Even then I still felt like I was kind of just dealing with it by myself and on my own. (Margaret)
		They didn't have a meter on me so and they didn't always want to walk me to the nurse because it would be an inconvenience because that's the, another kid from the class to walk me to the nurse because our school was so big that there was a chance I would pass out on the way to my nurse if I was low. (john)

This table consists of all quotes that were used to describe each subtheme.

Table 1 (contd.): Representative quotes of themes and subthemes

Theme	Subtheme	Representative quotes
Social and emotional challenges	Isolation and misunderstanding	there was a lot more of kind of attentiveness almost, but it was more like them constantly stopping whatever we were doing to say, Hey, do you need a snack? Hey, are you okay? How do you feel? So I mean, that was different than before. (lucy)
		Like I wasn't invited on trips like spring break and stuff like that with my group of friends because of my diabetes. They thought that that was too much of a liability kind of thing. Which was like, I get it. Its stressful. But it also made me feel like, oh shoot, they're not like true friends (Julie)
		And everyone kind of questioned, you know, kind of the basic things like, why are you giving yourself a shot? Why do you have to count carbs? Are you eating this? You know, just it was a learning curve for everyone (tina)
	Negative self image	When we had that class party, everyone was supposed to bring in something and usually it was like a bunch of stuff that my mom was not comfortable with me having because it was hard to count those carbs because it was a homemade or whatever it was and she wasn't there with me and it was just a big deal so she gave me like two pieces of candy and a ziplock bag with the carb count on them and how much insulin I was supposed to get and then when I would. When I was at the class party, I felt so sad. was like, I wanted that one of those cookies, right? (April)

Table 1 (contd.): Representative quotes of themes and subthemes

Themes	Subthemes	Representative quotes
Social and emotional challenges	Negative self image	it felt like I was developing faster than my friends were and it was really scary because I thought that they were going to see me as like oh there's the fat diabetic you know what I mean and it was like not something good and so the reason like from that um I definitely had like a pretty bad case of like diabulimia stuff like that where I just wouldn't eat it when I would eat I would throw it up after stuff like um and it just it did cause like a severe spiral of like a lot of stuff (April)
		I kind of saw myself as like, why am I broken? Like why are they able to you know, have regular sodas and like Starbucks all the time and like why do I have to like think about what I'm going to eat and try and like plan it throughout my day. Just little things like that added up. I was like, why am I different? Why did I get it? (Maria)
		my confidence level definitely deteriorated when I was like first diagnosed and into middle school, um and a little bit of high school too (Tina)
	Acceptance and support	So it definitely used to be a lot more. And they get that. I understand that they do get that they can. can't understand, but they also understand that I can do the things that they're asking me to do. And so it's kind of, you know, growing up and realizing that they are right and I should be doing this and they have a point because they do just care for me and my well-being. they also, you know, in their own, at the same time have grown a little bit more, I don't know, lenient, I guess, just less helicopter-y.Just been like a lot more understanding, I think, of the difficulties. mean, endo is great about it. Like sometimes it works, sometimes it doesn't.We'll just work through it and work around that. (ryan)
		So all of them are made up of peoplee who don't all have diabetes, but it's like my sister and like one or two friends that know kind of all about it and I know if I go to them they can help me out. (ella)
		And then like for just like ranting and complaining or like needing help with like making decisions or that kind of stuff, then I have my partner that I can kind of just like rant to and I'm like she doesn't understand like exactly what I need in that moment, but she knows that I just need like someone to listen. Yeah. So you don't exactly have to have to have diabetes to be able to help out in general, but I think like definitely my biggest support system has been through camp. (Rachel)

Table 1 (contd.): Representative quotes of themes and subthemes

Themes	Subthemes	Representative quotes
Social and emotional challenges	Negative self image	Yeah, so I have my husband at home. He knows so much at this point, even if he didn't want to know it. So after five, six years, you learn a little bit. So I have him, he's for sure one of those people. I have my mom as well. It's been a long time since my mom is dealt with my type 1 herself. So she's just kind of there as a sounding board of me being like, hey, my A1C is this. she's like, oh my god, that's awesome. But I would never be like, hey, mom, can you draw three units of insulin for me? because she probably doesn't remember how or what to do with that (Margaret)
		And then as I grew up, I was pretty independent with it. (ryan)
		I mean it's something like a lot of like independence and confidence … So I'm able to do a lot more because of it and because I'm more confident now. (ella)
Benefits of camp and community support	Disease specific support	I think that the way that I interact with people from Kudzu is more honest. Um, like I think that I have an easier time letting go and being honest with the things that I'm actually feeling or the things that I'm doing I think that it also helps that, you know, they're not going to have as much of an air of judgment about them because they go through it as well. And so they can put themselves in that position more easily be like, okay, I get it. (kennedy)
		Um so obviously there's the I guess the real deep understanding of diabetes that is pushed at camp. Um just through the like the educational sessions that we hold for the campers. And in general, I know a lot of people learn things from that that they hadn't thought of or hadn't heard before, just, you know, because it never comes up (ryan)
		A camp friend, I could call them up like and be like, I don't want to change my pod right now. My blood sugar is 500, whatever. And they'd say, you need to change your pot. And then we can talk about this after. Like, they'd force me to do it. Which is a good thing. Because it's more about, like, with support. And you're in the camp community (April)
		being around the people they showed me New things to do with the pump because again I've never had a pump up until college … So when I started volunteering with camp, I learned a lot about how to like finagle the pump and how to like cheat the system a couple times from the other counselors and volunteers, which was really, really cool. (john)

Table 1 (contd.): Representative quotes of themes and subthemes

Themes	Subthemes	Representative quotes
Benefits of camp and community support	Disease specific support	I definitely learned like little tips and tricks like from friends that were in my cabins um from counselors that had it um being able to you know draw up insulin out of a uh insulin pen versus a vial. I had no clue that you could do that because they don't tell you that in the hospital. They're like here's your vial, here's your syringe. That's how you're gonna draw a insulin so I had no idea that you could just pull from a pen if you only have pens or um that like changing your lancet at every time like yes you should but like are you gonna you know the end of the day? (Margaret)
		That was a big deal, and we lean on each other all the time. I was a CIT when I was a CIT, she was the cabin counselor that I was assigned to.[name redacted] is literally always there when I need to rant about having a bad day with my blood sugars. It's a big part of being in the camp community, being able to text a friend, even now to have diabetic friends. (April)
		it was kind of like a reset button as well. Every single time I would volunteer at camp, was like, OK, reset, you're going to do it this way, this time. Don't be lazy with it. Like everyone can get lazy with it. So it was always a nice refresher coming to camp as a volunteer to just hear tidbits on new things coming out, especially, and just talking to other people about it. (Tina)
	Community and belonging	I mean nobody looks at you weird for pulling out a second phone or administering insulin and some needles when you're at camp or around camp people I mean you go out to dinner with them and everybody's out there counting their carbs. It's so much it's so much fun too, and it's kind of like a secret club, which is the hilarious to think about (Lucy)
		Yeah, I saw that I wasn't alone. In my high school, there was just one other kid with type one that I knew of, but I knew there was more, but they weren't in my grade … my first year, the people I was partnered up with and in my cabin, they were super, super sweet and opening like open arms and we're like, oh my gosh, we're so happy you're here. And like I still think back on the one volunteer that's still volunteers with us and I bring it up every year I see her. like, you were my first friend here. Like you made me feel welcome. I think that's a part of how I've come back. (Julie)

Table 1 (contd.): Representative quotes of themes and subthemes

Themes	Subthemes	Representative quotes
Benefit of camp and community support	Community and belonging	So we really try to make sure that everyone's included like we talk like especially with my friend group will go up to random people and be like hey is this your first year at camp you know or like I did camp little shot this summer. (maria)
		we're all pretty accepting and like open and welcoming to new people. (ben)
Improvement of health monitoring	Improved glucose monitoring	100% every time I go to camp, my numbers get much better for at least a period of time. It might wear off as, you know, excitement of being at camp and seeing all these people who are putting forth all the effort and getting the results wears off. But yes, it has a very tangible benefit on my sugar levels. (ryan
		But like, Because of those mental health restarts or those like blood sugar restart weeks or whatever it was, like I got it [A1C] down because of that. I know it was because of that, and also because I got a new pump, but other than that like it was definitely like, just the aspect of like although it feels impossible now, it could happen is the biggest thing. You can do it and it's like that's pretty important because my A1C was like 8.3 for I feel like the longest time. It was 8.3 for like 5 years and I couldn't get it down. Then because of camp, they helped me through my burnout stage and then when I got out of that I just felt so much relief and I was able to take care of myself in the way that I hadn't been able to before so that was pretty important. (April)
		I think the way that I've had a lower A1C in college has been from the encouragement and from the stuff I've learned at camp. Because we do, especially with the teens, we talk a lot about that transition from high school where you're around your parents all the time to college where you're literally not around them at all. I'm maintaining that level of care. So I think Kudzu definitely helped with that. (Rachel)
		But every time I come back from a summer session or a weekend program I'm like okay this is great.I loved having that time. There's a little bit of depression afterwards because I'm sad because I'm not there anymore. But it's like, I'm like okay. I'm ready to go schedule that endocrinology disappointment or oh man that reminds me that I need to get my eyes checked because I haven't done my yearly exam or that kind of thing. It's motivating to get my life together, to make diabetes easier for my life at home (Margaret)

Table 1 (contd.): Representative quotes of themes and subthemes

Themes	Subthemes	Representative quotes
Improvement of health monitoring	Reprieve from burnout	Um, and I definitely just had those, you know, frustrations of like, I'm so sick of this, like this is, you know, not fair and I'm over it and, um, well a lot of people call it diabetes burnout where you just like don't do anything like you just don't take care of yourself and, um, I think I probably did that maybe often on like every few months, like I would have those faces of up and downs of I don't want to do this.I'm not going to do this. I, it really wasn't like a conscious thing. It was kind of something that was unconscious that I did that was, well, I know that I have to do this for my body, but I just don't think about it. (kennedy)
		I guess like going into high school, there was a little bit of burnout and I would just kind of get sick of doing the same thing over and over (John)
		I feel like I had diabetes burnout like a couple of years ago and I had heard from people from camp back to take an insulin pump break so I did that for a week and then I came back and I was because I heard about that idea at camp I was able to do it in my life and when I came back after that week I was a lot better and I was perfectly fine with the insulin pump. (ella)
		Yes, it definitely lessens the burnout phase because you know, you get so caught up with your life and just going, going, going, and then you can finally just like relax. Relax in a way but you're focusing on diabetes like the whole time… So it definitely tunes your brain like back in like, okay, you really need to get a handle on this.(tina)
		Honestly, it's motivating from like a friend perspective to like, if I have both my Dexcom and my pump site need to be changed, and that's like the worst thing ever when you're in burnout because you're like I could just lay here and just not do it but like the physical action of having to get up and do all the site changing and all the drawing up insulin and the changing off the sensor. Having a friend at camper volunteer at camp be like, hey Margaret have you done that yet? It's I'm almost held like accountable in that way too. So it's nice to have that support during the burnout so that I can be like okay I'll do it. Or like we've done it before where like a volunteer will draw up the insulin and put it in the cartridge and hand them the cartridge full of insulin and be like here I did this step for you that way it's you can get over that one hurdle of having to do that and then it makes it easier to do all the rest of the site change or the rest of whatever you need to do to get through that burnout so. (Margaret)

Table 1 (contd.): Representative quotes of themes and subthemes

Themes	Subthemes	Representative quotes
Motivation to return to camp	Positive experience of camp as a camper	So I loved camp so much as a camper. It was such a safe space for because I had like my parents had this horrendous divorce and it was the one week every year where I was like, I do not need to communicate with like my parents. It was like just a place where the adults were just so fun and like loving and just friendly and it was just so happy (Ben)
		I think definitely just like the community and like the level of support that I feel when I'm there and that I know that like my campers will feel because like as a as a camper, I always felt like so supported by my counselors and by my fellow campers. (Rachel)
		looking back on you know experiences that have had with other counselors that I can think of like well they impacted me you know positively in this way that they you know promoted good habits and they um provided a safe space for me to connect with people that were like me and to open up and to be, you know, vulnerable in those situations. (Kennedy)
	Helping kids living with T1D	Um, I think it really solidifies what I was talking about earlier with being a counselor just remembering that my place and my goal as a counselor is to be, um, you know, a support system for younger kids. (kennedy)
		I want to make sure that camp can keep happening so the kids can keep experiencing this and meeting people and growing up and becoming volunteers and continuing to come back and just perpetuate the cycle.And just the connections that I get to build with the kids in that process (ryan)
		So I go back to camp to give back to that. Like so there will be a kid that will have a week of like safety and security and freedom. Like it just I want to give back and give the experience that I got. (ben)
		being able to be a resource and then being able to provide the experience for the campers, that's my biggest motivator for sure. (Margaret)

STUDY LIMITATIONS

Limitations to this study were minimized as much as possible by following the research methods as they were originally planned,; however, some were still present. One limiting factor for this study was the lack of respondents who were not currently active in the social group (Patton, 1999). Only volunteers who were currently working at the camp were asked to participate in the study. Due to the nature of how participants were recruited for this study, those who were not able to attend the Fall Family Camp session were not included. Previous literature has cited that reasons for not returning as a seasonal worker include compensation rates, other opportunities, and a poor fit for the person (Richmond et al., 2020). The present study did not address these reasons for not returning. Because of this, information regarding potential negative aspects of the social group were not addressed. This could result in the social group being somewhat misrepresented (Chowdhury, 2022).

Another limiting factor for this study is that the study population was comprised of individuals who had been long term volunteers and some who even attended camp as campers. This could create bias within the population and could also leave out more negative implications of the social group (Abbink & Harris, 2019). If new volunteers experience social support differently, in a more negative way, then input on how their experiences impacted them would be essential in providing a full evaluation of how social support groups impact members (Everett et al., 2015).

Regarding the makeup of the study population, all but one of the participants were white. This does not accurately represent the racial makeup of those who are impacted by T1D. Recent estimates of the racial breakdown of T1D include 72% as white, 15.7% as Hispanic, 9.3% as non-Hispanic Black, and 2.4 % as Asian (Akturk et al., 2021). By not having a diverse population within this study discussing in group perceptions, there could be racial bias in how welcoming and inclusive this group is (Chowdhury, 2022).

Along with racial bias, the difference of gender was also a limiting factor that does not accurately represent the diagnosis of T1D in adult male and female populations. T1D has a higher rate of occurrence in males. It’s been found that, in men, the rate of diagnosed T1D is about 16.4/100,000 people compared to only 8.9/100,000 in women (Diaz-Valencia et al., 2015; Ostman et al., 2008). This study consisted of more female respondents than male respondents. Having a more diverse population and one that is more accurate to the rate of T1D in the world could provide new insights into how belonging in a social group impact those living with T1D.

Time of the study was also found to be a limiting factor. Time in this regard is referring to only attending the Fall Family Camp for participant recruitment. By only attending one of the family camp sessions at Camp Kudzu, the entire breadth of volunteers was not able to participate within this study. If this study was performed during summer sessions of Camp Kudzu, more data could have been collected and more respondents interviewed. This constraint would have allowed for greater data saturation and potentially differing responses had the respondents been more diverse (Sargeant, 2021). Performing this same study during the summer months, where more potential participants are present, could provide more and different insights into the study questions.

While steps were taken to reduce researcher bias, there is still a limitation associated with completely removing it. This research topic was close to my own lived experiences, and there was likely some confirmation and researcher bias that influenced parts of the study. However, by following the steps outlined in above sections regarding researcher bias, such as following the script, member checking, and triangulating with another researcher, this limitation was minimized as much as possible.

While this study can likely generalize some that live with T1D, the lack of diversity from respondents makes it unclear how generalizable this study is across the entire population of emerging adults with T1D.

These limiting factors could be reduced in future studies which would further improve the understanding of how belongingness in a social group impact those living with T1D. The current study reduced limiting factors as much as possible, yet these limitations need to be addressed and considered when analyzing data.

CONCLUSION

The role of social support groups on emerging adults with diabetes was explored in this study, and the themes that were constructed following the interviews provide more insight on how to better support those with diabetes. There have been limited studies on how an environment such as Camp Kudzu can impact emerging adults living with T1D. Based on the findings, certain conclusions can be made to further improve diabetes management for this population.

First, being involved in a support system specific to their illness allows them to receive support that cannot be found in their typical day to day lives. With diabetes being associated with higher levels of mental health concerns, processes and strategies to help those living with the illness should be identified. Those that are in the emerging adulthood age range have stated that there are limited resources and groups that they are able to join (Balfe et al., 2013). Many support groups are online, and this type of interaction does not work for every person. Creating and funding groups creates time and resources and can be a difficult task. By using current groups, such as the social group present at Kudzu as a model, more support groups can be established for this age.

Diabetes burnout occurs frequently within individuals with diabetes. This phenomenon has detrimental impacts on those experiencing it if they remain stuck in it for too long. Recovery from burnout is understudied in multiple areas, including both the workplace and from diabetes. One possible solution that was found during this study to help those in burnout is to provide a group in which support is offered by those in similar situations. Recovering from burnout can be difficult when no one understands what caused it. Findings from this study indicate that many people with T1D can relate to burnout experiences and can provide support and advice to others struggling.

This study promotes further research by strengthening themes that are currently associated with T1D care and providing more insight to how the disease impacts those living with it. The day-to-day stress that each participant spoke of in this study is prevalent in a diabetic’s daily life. However, there are few reported ways for an individual to combat these negative feelings and help young adults transition through this stage. Endocrinologists tend to provide feedback on how a person’s A1C and overall glucose management is and will only sometimes provide resources or advice to those struggling (Balfe et al., 2013; Lehmkuhl et al., 2009; Ramchandani et al., 2019). A common feeling is that of only being a number, and not a person. To improve care processes for those with diabetes, research should be done more intensively on how best to address concerns with these adults so that they are receptive to medical advice.

FUTURE DIRECTIONS

The future of research regarding T1D, and social groups has many different factors that can be studied. This current research study provides a more robust understanding of how social groups can impact those living with T1D. To go deeper into belongingness and T1D, one future direction should focus on device empathy (Moudatsou et al., 2020). This refers to how those who live with the diabetes devices (e.g. pumps or CGM) perceive others with the same devices (i.e. is it more favorable, less favorable, or no impact)

Another future direction should determine how attending a T1D camp as a non T1D impacts that individual (Beverly et al., 2021; Speight et al., 2024). Does empathy increase or remain the same? Looking into this can provide insight on how to make T1D less stigmatized and more accepted by those who don't live with the disease. Along with this, the exploration of how camp impacts career goals of those that attend. One participant in this study stated how it altered her career path. Determining the connection between camp and career paths can allow professionals to better tailor their programs to participants and their life goals.

Determining how emerging adults attending camp reduces T1D specific hospital visits is also a future direction that should be explored (Joish et al., 2020). Hospitals are expensive and can create feelings of stress for those living with T1D. By finding strategies to reduce the rate of hospitalization, T1D management and treatment plans can be improved.

Another future direction for T1D management stressors and the improvement of care would be to look into how diabetes specific devices, such as CGM's, being available to the general public impacts T1D's accessibility to these devices (Burnside et al., 2023; Mariani et al., 2020). As these devices become more accessible to those without T1D, there could be an impact on how likely it is for insurance to cover the cost of these devices. The impact of insurance reducing the rate of coverage on T1D mental and physical health should be examined to provide T1D’s and their care team better strategies of T1D management.

AUTHORS REFLECTION

This was not the initial study that was planned for my thesis. Upon being accepted to Clemson University, initially I was interested in how female recreation guides fit into the guide world and what primary factors made them leave the industry sooner than their male counterparts. However, during the first semester of the program, I was introduced to Dr. Ryan J Gagnon. While sitting in his first class, he mentioned that he did research that focuses on T1D summer camps. I was not aware that T1D and PRTM were able to be blended. While talking to him, we initially decided to work together on a project that looked into a T1D specific eating disorder. However, after attending the first Family Camp (Spring 2023 Family Camp) there was more information and focus on the social group impact on the emerging adults working at camp. After leaving the family camp, we returned to Clemson and discussed together and with the committee about switching focus to the social group of emerging adults that is present at Camp Kudzu. Prior to beginning this study, the primary researcher had a preconception that belongingness to a T1D specific support group is not essential for T1D success. This was based on her lived experience and how she has managed her own T1D throughout her life. However, after attending camp sessions and speaking with those in the community, through casual conversations and through these interviews, she found a better sense of self and her ability to manage her own diabetes improved. This was due to the support and strategies discussed regarding reducing burnout, monitoring blood sugars, discussions regarding potential future complications associated with T1D, and the knowledge that reaching out to this group is normalized and people within the group are welcoming and want to help. Along with these factors, she began trying CGM’s and insulin pumps again after seeing the beneficial outcome that these devices have on those who use them regularly. .

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APPENDIX

Appendix A: Interview Guide

Introductory Questions	What's your name		
	Age		
	Gender		
Diagnosis Questions Illness Identity	When were you diagnosed with type 1 diabetes?	Probe: How old were you upon diagnosis?	Commissariat et al., 2016
	Did diagnosis impact how friends treated you?		Commissariat et al., 2016
	How did this impact how you saw yourself?	Probe: What emotions were present?	Commissariat et al., 2016
Social Group: In and Outgroups	When did you first start going to Camp Kudzu?		Bearman & La Greca 2002
	Did this impact how you saw yourself and your illness?	Probe: What changes did this bring if any?	Bearman & La Greca 2002
	How long have you been a counselor at Camp Kudzu?		Bearman & La Greca 2002
	Do you feel as though you're able find support from other counselors when not at camp?		
	What does this support look like?		Joenson et al., 2022
	Has there ever been a moment in which you feel as though you don't belong in this group? (not 'diabetic' enough ideology?)	Probe: Expand if yes	
	Overall, is this group welcoming and inclusive from what you've seen	Probe: Examples	
	Outside of camp, do you have support systems in place for diabetes?		Joenson et al., 2022
	Have you experienced diabetes burnout?	Probe: What does this look like and how to overcome it?	
Motivation to return as a counselor	What’s the biggest motivator for you to return as a volunteer counselor?		Joenson et al., 2022
	What benefits, aside from the social aspects, does Kudzu provide?		Joenson et al., 2022
	Do you receive any medical equipment after camp?		Joenson et al., 2022
	Does this encourage you more/less to return to camp?		

Appendix B: Recruitment Guidelines

In order to gather participants for this study, the researchers will attend the Fall Family camp in the fall of 2023 at Camp Kudzu, a long-term partner with Clemson University. An announcement will be made at the beginning of the camp session by the researcher to make volunteers aware of the study. The announcement provided details of what the topic of the study was and who qualifying characteristics of participants. This information included when the interviews would occur, the focus on social support from Camp Kudzu volunteers, age of participants, and diagnosis criterion. Following this, individuals who have volunteered for at least two sessions with Camp Kudzu (i.e.. Family camp, teen camp, overnight summer camp), have type 1 diabetes, and are between the ages of 18-29 will be approached and asked to take part in the study. Individuals will be given an overview of the study and will be informed that a $20 gift card will be given to all who participate within the study. If individuals decide to participate, they will provide their name and contact information to the researcher and a follow up email will be sent for participants to sign up for an interview time.

Appendix C: Interview Script

Informed Consent Verbal Script

Hello, my name is Mackenzie Dawes, and I am a master's student within the Parks, Recreation, and Tourism Management program at Clemson University. I am conducting this research study to better understand the role of in-groups' impact on overall health of individuals with type one diabetes. This study will focus on those who have been volunteering at Camp Kudzu, a medical specialty camp for Type 1 Diabetics, and the experience they have being involved as a volunteer.

Your participation in this study will involve one interview that will last between 45 minutes to an hour. There are no known risks to this research study. This research will benefit the academic community by helping us to better understand how belonging in a social support group can impact individuals with chronic medical conditions.

I will do everything I can to protect your privacy. Your identity or personal information will not be disclosed in any publication that may result from the study. Audio and visual recordings that are taken during the interview will be stored in a secure location with only researcher access.

After completion of the interviews for this study, participants will receive a $20 gift card that will be mailed to them.

Do you have any questions before we begin?

During this session, I will ask questions about your diagnosis, involvement at camp, and how this has all impacted you.

Questions Begin

Introduction

To start, what is your name, age, and gender identification?

Diagnosis Questions and Illness Identity

Thank you. Now moving on to your journey as a Type 1 Diabetic, when were you diagnosed and how old were you upon diagnosis?

How did this diagnosis impact how your friends treated you?

Did this diagnosis impact how you saw yourself?

- What emotions were present?

Social Support Groups: In-groups and Out-groups

After diagnosis, when did you first hear about Camp Kudzu and when did you start attending this camp?

Did attending camp impact how you saw yourself and your illness? How so?

- What changes did this bring, if any?

How long have you been volunteering for Camp Kudzu?

Outside of camp, do you feel as though you're able to find support from other Kudzu volunteers?

What does this support look like?

Have you always felt as though you belong within the social group at Camp Kudzu?

Have you ever felt as though you don't belong?

Overall, is the group at Camp Kudzu welcoming and inclusive from what you've seen?

Outside of camp, do you have support systems in place for diabetes?

Motivation to return as a volunteer

What's the biggest motivator for you to return as a volunteer counselor?

Apart from social aspects, what benefits does Kudzu provide for you?

Do you receive any medical equipment after camp sessions?

Does receiving this medical equipment encourage you more or less to return to camp?

End of questions

Thank you ____ for sharing your insights with me today. I appreciate your time and thought you put into the answers you provided. You'll receive the gift card soon. Once again, thank you.

Appendix D: Data Saturation

Data saturation for this study was reached after eight interviews regarding illness identity questions. During the interviews, two common responses were said regarding adverse treatment from peers. Interviewee responses were a variation of "*Not really*" (John, 23) or "*It definitely did impact how I was treated by people"* (Ben, 28). Participants in this study stated that they experienced no adverse treatment from peers after diagnosis (33.3%) or they experienced adverse effects from diabetes diagnosis such as different treatment from peers and adults (66.7%). Regarding how T1D caused self-perception to change, most participants stated that they initially had negative experiences with this disease. As Julie stated, and other participants echoed, *"Yeah. I felt like I was kind of like a … burden. I became more dependent on my parents."* This shift included questioning why they are the ones dealing with this rather than siblings or peers, burnout symptoms, feelings of being a burden, and negative feelings such as shame and anger (66.7%). Others reported that they had no change of self-perception due to diagnosis being at a younger age and having other family members with T1D as well (33.3%). Those who responded that there was little to no change in self-perception responded similarly to the following quote from Lucy:

> *I really became more health conscious. It's not…there wasn't like a necessarily positive or negative view of myself, but I mean life changed overnight. So, it was definitely kind of jarring, but I don't really think it changed my self-view.*

Participants said that now, in their emerging adulthood years, they feel more confident and comfortable living with T1D because of their experiences through childhood and meeting others with T1D through camp (75%).

For questions regarding the social in group made up of others living with T1D, data saturation was reached after 6 interviews. Regarding how attending camp impacts how participants viewed themselves after attendance, all participants stated that it made them feel less alone. Ella stated:

> *I hadn't met anybody else with it before, so it was more isolating and then after camp I saw like 200 kids or something with the same thing. And we all had the same experiences, so I saw myself as not alone anymore.*

These feelings were due to being surrounded by others living with T1D after not having many, if any, people in their lives with the illness. Along with this, all participants stated that support outside of camp can be found within this group via social media (i.e., snapchat, Instagram, texting) and by meeting up for dinners, concerts, or just general hangouts. All participants stated that the T1D group at Kudzu is welcoming and inclusive, however, 6 participants (50%) said that the group can be cliquey and less welcoming to those who volunteer and don't have T1D.

Motivation to return to camp questions reached saturation after 5 interviews. All participants in this study stated that their biggest motivation to keep returning to camp included helping kids and those who are newer to T1D adjust to the new life. Tina stated: *A lot of it is just being there for the newcomers, like the new diagnosis's kind of, and just showing them that it's nothing, there's nothing that you can't do, like there's just not.* Multiple respondents stated that helping the children and peers see that a diagnosis of T1D doesn't mean that they have to stop living their life, it just takes a little extra work to ensure they are safe. All participants also said that attending camp and being able to talk to others impacted by T1D provides them with better motivation to care for their T1D. This includes lower A1C numbers after camp sessions, reduced burnout symptoms and better overall glycemic control. In response to these questions, Margaret stated:

I definitely come back feeling renewed, feeling refreshed and ready to deal with anything that comes my way as far as the diabetes.

Participants stated that they have received the free medical equipment and supplies (i.e., insulin pumps sites, insulin, needles) after camp but receiving these supplies is not the prime motivator for returning to camp and they would still return to help the children if these supplies were no longer offered.