# Focus on the Positive: A Qualitative Study of Positive Experiences living with Type 1 and Type 2 Diabetes

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A Thesis

Presented to

The Honors Tutorial College

Ohio University

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In Partial Fulfillment

of the Requirements for Graduation

from the Honors Tutorial College

with the degree of

Bachelor of Science in Translational Health – Exercise Physiology/Pre-medicine

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by

Molly A. Carrier

April 2020

# Positive Experiences of living with Diabetes

This thesis has been approved by

The Honors Tutorial College and the Heritage College of Osteopathic Medicine

Department of Primary Care

Dr. Elizabeth Beverly

Professor, HCOM Primary Care

Thesis Adviser

Dr. Cheryl Howe

Director of Studies, Translational Health

Dr. Donal Skinner

Dean, Honors Tutorial College

## ABSTRACT

**OBJECTIVE:** The purpose of this study was to identify positive experiences associated with diabetes from the perspective of adults diagnosed with type 1 (T1D) or type 2 diabetes (T2D).

**METHODS:** We conducted in-depth face-to-face interviews with adults with T1D or T2D. Interviews were transcribed, coded, and analyzed using content and thematic analysis using NVivo 12 software.

**RESULTS:** Sixteen adults completed interviews (mean±SD; age=36.4±10.6 years, Hemoglobin $A_{1c}$=7.2±1.9%, 62.5% T1D, duration=11.6±9.8 years, 43.8% female, 100% white). Qualitative analysis revealed four themes: 1) Positive and Supportive Community: Participants described positive experiences with family, friends, classmates, coworkers, and the online diabetes community. Their support systems helped them manage and cope with the many challenges of diabetes; 2) Improved Health Behaviors: Participants reported positive changes in their self-care behaviors, mainly diet and exercise improvements; 3) Positive Outlook and Personal Growth: Participants attributed increased empathy, compassion, maturity, and confidence to their diabetes. 4) Advocacy for People with Diabetes: Participants took on the role of advocates for diabetes policy changes and educating peers about diabetes.

**DISCUSSION:** Communicating positive experiences about type 1 and T2D may help clinicians and educators reframe the negative messages commonly shared with people with diabetes.

# PREFACE

Chapter 4 of this thesis document is a prepublication manuscript for the Journal of Chronic Illness. This manuscript has been formatted to SAGE Vancouver Style to meet the guidelines of the Journal of Chronic Illness.

## ACKNOWLEDGEMENTS

I would like to extend my deepest gratitude to those who assisted me in writing and research for my thesis. A special thank you to the participants who participated in this study and took the time to share their experiences with me. Without your help, this would not have been possible.

To Dr. Elizabeth Beverly, my thesis advisor, thank you is not enough. You taught me everything you know about qualitative research from the initial IRB submission through writing and submitting a paper for publication. You helped me create a manuscript that I am beyond proud to publish. You always reminded me throughout the process to keep the best attitude and that we would finish this, even through a pandemic.

To Dr. Cheryl Howe, my director of studies, I am thankful to have had you as a mentor. You've been here since the start of undergrad and helped me become a better scientist, researcher, and exercise physiologist. You were always there to push me when I needed it most.

To all of my other mentors throughout undergrad, you helped me build an amazing network that I know I will always have and for that I am forever grateful. You taught me things from my first insulin ELISA to my first diabetes community group presentation. I learned in different environments from Athens, Ohio to Lima, Peru to Rochester, Minnesota including both qualitative and quantitative research methods. These experiences will last a lifetime. Thank you.

To the Honors Tutorial College, thank you for all of these unique undergraduate opportunities.

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# CHAPTER 1: INTRODUCTION

Diabetes is one of the most significant health problems in the United States (US). An estimated 34.2 million people of all ages—or 10.5% of the population—have diabetes, the vast majority being type 2 diabetes (T2D).[1] Diabetes is a group of diseases characterized by high blood glucose levels resulting from the body's inability to produce and/or use insulin.[2] The two most common types are type 1 (T1D) and T2D.[2] T1D is marked by the body’s inability produce insulin, and T2D is marked by the body’s inability to produce insulin as well as the body’s inability to effectively use the insulin it produces. While T1D is most commonly diagnosed in childhood or adolescence, it can occur at any age. Comparably, T2D is most commonly diagnosed during middle-age, but it can be diagnosed in childhood or adolescence. Recent trends in incidence show increases in T1D and T2D, especially in children and adolescents.[1] According to the CDC National Diabetes Statistics Report (2020), the median county level prevalence of diagnosed diabetes among adults 20 years and older increased from 7.8% in 2004 to 13.1% in 2016 (**Figure 1**).[1]

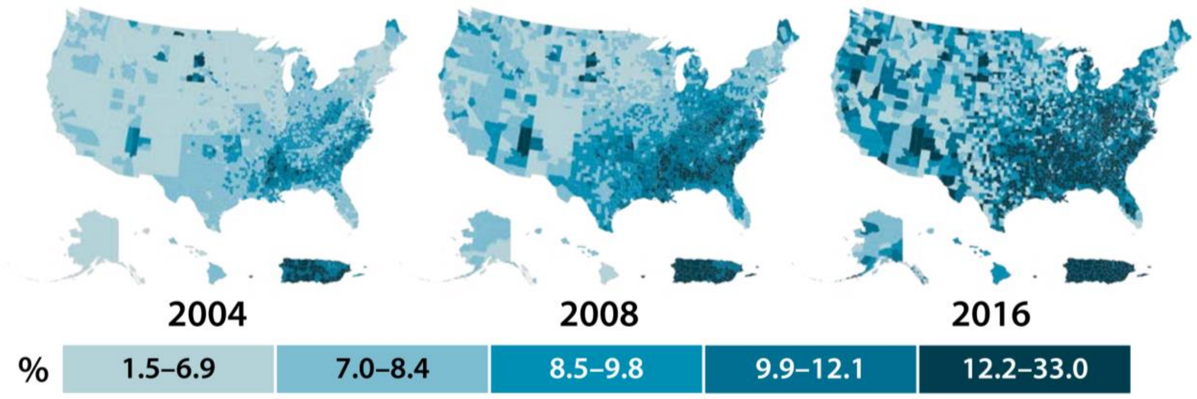

**Figure 1.** Age adjusted, county-level prevalence of diagnosed diabetes among adults aged 20 years or older in the United States.

As prevalence of diabetes continues to rise, it is important to remember that diabetes requires continuing medical care and self-management education to reduce the risk of acute and long-term complications. Recent data from the Centers for Disease Control and Prevention (CDC) show half (50.0%) of US adults with diagnosed diabetes have a Hemoglobin $A_{1c}$ (A1C), a measure of a person's average blood glucose values over 2-3 months, value at or below target (<7.0%).[1] Of these, 19.2% met their ABC goals of an **A**1C value <7.0%, **b**lood pressure <140/90 mmHg, non-HDL (high density lipoprotein) **c**holesterol <130 mg/dL, and being a nonsmoker.[1] Reaching ABC goals decreases the risk of macrovascular (e.g., cardiovascular disease) and microvascular (e.g., retinopathy, neuropathy, nephropathy) complications.[3-7] Behaviors that promote ABC goal achievement, and in turn reduce the risk for complications, include smoking cessation,[8] following a healthy diet,[9] weight management,[10] engaging in regular physical activity,[11, 12] monitoring blood glucose levels,[13, 14] taking medications as prescribed,[15] maintaining proper foot health,[16] and attending clinical appointments.[17, 18] Reaching and maintaining these behaviors is encouraged in Diabetes Self-Management Education and Support (DSMES).[19, 20]

DSMES is an important component of diabetes care for all people with diabetes.[20, 21] DSMES should be person-centered and facilitate learning about knowledge, decision-making, and skills for self-care.[20] Further, providers who deliver DSMES should incorporate positive, strengths-based language to reduce stigma and feelings of shame and guilt related to this disease.[22, 23] Historically, diabetes care and DSMES have focused on behavioral and clinical targets, which may explain the short-term benefits (reaching A1C levels <7.0%) but limited long-term outcomes (maintaining A1C levels <7.0%).[24-26] Emphasis on personal stories and positive experiences may help adults with diabetes sustain these A1C benefits.[27-30] However, minimal research has explored positive stories and experiences living with T1D or T2D. Thus, the purpose of this study was to identify positive experiences with diabetes from the perspective of adults diagnosed with T1D or T2D. Findings from this study may be incorporated in clinical care and DSMES to promote active engagement in diabetes self-care, thus, reducing risk of complications.

## CHAPTER 2: REVIEW OF THE LITERATURE

This literature review will cover general diabetes information regarding diabetes prevalence, financial burden, types of diabetes, diabetes self-care behaviors and diabetes treatment. The role of DSMES will also be discussed. Additionally, the importance of optimism and social support for people with diabetes and the role that optimism and social support play in reaching diabetes management goals (specifically ABC goals) will be reviewed.

### *Diabetes*

**Diabetes Prevalence.** In 1999-2002, the CDC reported that diabetes prevalence in the United States was 9.5%. This prevalence had significantly increased by 2013-2016 to 12.0%.[1] The CDC estimates that as of 2018, 32.4 million Americans are living with diabetes. Astonishingly, only 26.9 million of these 32.4 million cases are diagnosed diabetes, meaning that ~17% of diabetes cases go undiagnosed.[1] In the United States, diabetes is most commonly diagnosed in American Indians/Alaskan Natives (14.7%), people of Hispanic origin (12.5%), and those who are non-Hispanic Black (11.7%).[1] Prevalence is also known to vary with socioeconomic status. Among adults with less than a high school education, an indicator of socioeconomic status, 13.3% had diagnosed diabetes compared to 9.7% of people with a high school education and 7.5% of those with more than a high school education.[1] Furthermore, in 2018, it was estimated that there were 1.5 million new cases of diagnosed diabetes among US adults 18 years and older. That is 6.9 cases per 1,000 people. With these alarmingly high numbers of diagnosed diabetes, it is important to consider diabetes, its related complications, and the day to day lives of those living with the chronic illness.

**Financial Burden.** According to the CDC, the total direct and indirect costs of diabetes in the US in 2017 was $327 billion.[1] This is a marked increase from $188 billion in 2012.[1] Direct costs include cost of care and clinical appointments and medications. Indirect costs can include things like sick time from work. The rising prevalence as well as the serious complications, including retinopathy, neuropathy, and nephropathy, add to the cost of the disease.

**Diabetes Definitions and Treatment Options.** Diabetes is a group of diseases characterized by high blood glucose levels resulting from the body's inability to produce and/or use insulin.[2] The two most common forms of diabetes that will be discussed in this review are T1D and T2D.[2] T1D is marked by the body’s inability to produce insulin due to autoimmune destruction of pancreatic insulin producing beta cells.[2] The CDC estimates that nearly 1.4 million Americans including 187,000 children and adolescents younger than 20 years have T1D.[1] Although T1D is commonly diagnosed in youth and adolescents, it can occur in people of any age. T1D requires insulin therapy as treatment. This can be through insulin injections, insulin pens, or an insulin pump.[2]

T2D is the most common type of diabetes.[2] According to the CDC, approximately 25.5 million of diagnosed cases of diabetes are people with T2D.[1] T2D is marked by the bodies inability to properly utilize the insulin it makes which leads to increased insulin resistance and can lead to decreased or no insulin production.[2] Some people are able to manage T2D with diet and exercise alone, but many require the use of oral medications and some require insulin therapy in order to properly manage their diabetes.[2] Regardless of the treatment regimen, diet and regular physical activity are critical components of proper blood glucose management in patients with T2D.[2]

**Diabetes ABC goals.** Recent data from the CDC shows that half (50.0%) of US adults with diagnosed diabetes have a Hemoglobin $A_{1c}$ (A1C), a measure of a person's average blood glucose values over 2-3 months, value at or below target (<7.0%).[1] Of these, 19.2% met their ABC goals of an **A**1C value <7.0%, **b**lood pressure <140/90 mmHg, non-HDL(high density lipoprotein) **c**holesterol <130 mg/dL, and being a nonsmoker.[1] When using less stringent ABC goals of **A**1C value <8.0%, **b**lood pressure <140/90 mmHg, and non-HDL **c**holesterol <160 mg/dL, 36.4% of adults 18 years or older with diagnosed diabetes were able to meet these goals.[1] Reaching ABC goals decreases the risk of macrovascular complications such as cardiovascular disease (CVD) and microvascular complications such as retinopathy, neuropathy, and nephropathy.[3-7]

Mortality rates from CVD are two to four times greater in people living with diabetes compared to those without.[3] Large clinical trials have revealed that meeting ABC goals leads to risk reduction for a cardiac event.[3] In a study conducted by Varma and Piatt (2013), patients who improved their A1C value to <7.0% had a 47% reduction in incident CVD. Furthermore, participants who achieved all ABC goals at least once throughout the 10-year study were 2.5 times more likely to not develop incident CVD.[3]

In a 6-year study including 652 people with T1D, only 6% of participants reached all ABC goals, however, ABC achievement was a strong predictor for development of microvascular complications including diabetic nephropathy and diabetic retinopathy.[4] Those who met no ABC goals at baseline compared to those meeting all goals were at increased odds of developing microvascular complications.[4] The study did not find an association between ABC goals and macrovascular complications such as cardiovascular disease.[4]

Beyond macrovascular and microvascular complications, diabetes can be associated with depression and diminished mental-health.[6] In a study performed by Shah et al. (2015), 808 non-pregnant patients with T2D were examined for ABC goals ( A1C <7.0%, BP<130/80 mmHg, non-HDL cholesterol < 100 mg/dL), depression, and quality of life.[6] Overall, the study found that severe depression was significantly associated with lower rates of ABC goal attainment (5.0%) compared to those with no depression (25.4%).[6] While there exists a complex relationship between diabetes, quality of life, depression, and ABC goal attainment, patients who are unable to achieve ABC goals may benefit from increased contact with healthcare providers.[6] This increased healthcare provider contact can include things such as DSMES, cognitive behavioral approaches, and helpful discussions around diabetes self-care behaviors.

Behaviors that promote ABC goal achievement, in turn reduce the risk for complications. One behavior that promotes ABC goal achievement is following a healthy diet.[9] Pi-Sunyer et al. (1999) found that after implementing diet regimens that follow American Diabetes Association guidelines in patients who have T2D, glycemic control and cardiovascular risk factors improved.[9] By improving glycemic control patients may be able to achieve an A1C <7.0%, and by improving lipid panels patients may be able to reach a non-HDL cholesterol <130mg/dL. Weight management, in particular weight loss, also promotes ABC goals.[10] A study by Shantha et al. (2012) compared the relationship between magnitude of weight loss and improvements in A1C.[10] The study revealed that weight loss of 10% of an individual's body mass can potentially decrease A1C by 0.81% in patients with T2D.[10] By decreasing A1C patients may get closer to reaching the target A1C value of below 7.0%. Additionally, by engaging in regular physical activity participants may be able to reduce cholesterol levels, reduce weight and in turn A1C values, and decrease BP. In a study by Maiorana et al. (2002), sixteen people with T2D participated in an 8-week circuit training program.[11] The results showed that after 8 weeks muscular strength increased while skinfolds, % body fat, and waist to hip ratio significantly decreased. Fasting blood glucose also decreased after the training protocol.[10] Further, interventions that implement regular physical activity will improve metabolic control,[11] thus helping patients reach their cholesterol and BP goals. Through maintaining a healthy diet, weight loss, and increased physical activity people living with diabetes may be able to reach their ABC goals, thus, reducing their risk for diabetes-related complications.

**Diabetes Self-Care Behaviors.** In addition to weight loss, healthy diet, and regular physical activity, diabetes self-care behaviors including monitoring blood glucose levels,[13, 14] taking medications as prescribed,[15] maintaining proper foot health,[16] and attending clinical appointments[17, 18] can help patients reach their ABC goals. A study with 24,312 adult patients with diabetes reviewed the relationship between self-monitoring frequency (using blood glucose meter) and first measured A1C.[13] Self-monitoring among patients with T1D and pharmacologically treated T2D was associated with lower A1C values (1.0% in T1D and 0.6% in T2D).[13] In patients using non-insulin diabetes medication, those who practiced self-monitoring had greater reductions in A1C than those who did not.[14] Increasing frequency of self-monitoring blood glucose can result in greater reductions in A1C.[14] A1C values can be further decreased by adhering to medication prescription.[14] Good medication adherence is associated with lower BMI, lower A1C, and longer diabetes duration[15]. Patients with good adherence to diabetes self-care in general (≥5 days practicing each self-care behavior including medication adherence, foot care, blood glucose monitoring, diet, and exercise) exhibited lower BMI and lower serum lipid profile,[15] thus allowing them to be closer to achieving lower cholesterol. Maintaining proper foot health is an important self-care behavior to monitor for development of microvascular complications such as diabetic neuropathy which is commonly observed in the feet. Clinical intervention in diabetes patients with a prior foot ulcer is associated with improved foot care.[16] Lastly, attending clinical appointments is critical for patients with diabetes. People who infrequently attend clinical appointments are more likely to higher A1C values and are at a greater risk for diabetes complications due to higher A1C values.[17] Non-attenders of clinic appointments had a significantly higher mean A1C (8.1%) than those who did attend clinic appointments (7.6%).[18] Engaging patients in regularly supervised treatment has important health implications in diabetes patients.[17] Reaching and maintaining these self-care behaviors is vital to patients short- and long-term well-being and is encouraged in Diabetes Self-Management Education and Support (DSMES).[19, 20]

### *DSMES*

**Description of DSMES.** In 2011, the American Association of Diabetes Educators convened an invitational Reducing Risks Symposium.[19] During the symposium a panel of eleven interdisciplinary individuals examined current information on reduction and prevention of diabetes associated complications.[19] This evidence was translated into DSMES.[19] One goal of the symposium was to develop practical advice for diabetes educators and other members of the diabetes care team to provide patients, thus, DSMES.[19] Through DSMES, the diabetes care team can help the patient understand diabetes, its progression, possible complications, but also to be a source of encouragement to achieve self-care behaviors to reduce their risk for complications.[19] According to the American Diabetes Association Standards of Medical Care, DSMES should be patient-centered and facilitate learning about knowledge, decision-making, and skills necessary for optimal self-care.[20] DSMES is based on evidence of its benefit to patient outcomes.[20] DSMES specifically helps patients with coping at four critical times in their life (diagnosis, annually, when new complicating factors arise, and when transitions in care occur).[20]

An important consideration for professionals administering DSMES is the language that is being used. The stigma that has historically been attached to a diabetes diagnosis can cause individuals to feel shame, guilt, and judgement.[22] A person’s health care team can help mitigate these feelings by incorporating person-centered strengths-based, positive and empowering language in their communication with patients.[22] It is crucial to put the person first and the disease second. By using person centered language such as saying “a person with diabetes” rather than “diabetic” or “living with diabetes” rather than “suffering from diabetes” a care team may be able to improve ABC goal achievement and self-care practices amongst patients.[23]

**Benefits of DSMES.** Studies have found that DSMES is associated with improved diabetes knowledge and self-care behaviors, lower weight, lower A1C, and healthy coping skills.[20] Theory and model based diabetes interventions such as DSMES have positive effects on A1C. DSMES has shown short-term A1C benefits by a reduction of 0.29%[24] to 5.35%[25] but limited long-term outcomes (sustained A1C benefits).[24] Several studies have looked at the impact of “story-sharing” on diabetes outcomes.[27-30] The talking circle technique amongst American Indian Tribes proved to be effective in providing information on diabetes and revealed many themes.[27] Some relevant themes included sharing personal stories and exchanging emotions and feelings.[27] In a story sharing intervention among minority ethnic groups, patient enablement score improved significantly in the story-sharing arm compared to the control arm.[28] Another study of eight adults with T2D implemented two eight session story-telling interventions.[29] The study analysis suggests that storytelling facilitates knowledge exchange, reflection, and collaborative learning.[29] Storytelling could potentially result in peer support, empowerment, increased disease awareness and engagement in self-care behaviors.[29] Emphasis on personal stories and positive experiences may help adults with diabetes sustain the A1C benefits initially seen as a result of DSMES.[27-30]

### *Optimism and Diabetes*

"*Optimism is an individual difference variable that reflects the extent to which people hold generalized favorable expectancies for their future*." [56] Optimism has been linked to higher levels of engagement coping, or taking an active role in one's health, and lower levels of avoidance coping.[56] There is also evidence that optimism can be associated with proactive steps to improves one's health while pessimism can be associated with health-damaging behaviors.[56] Research in non-diabetes populations shows optimism is associated with better mental[48] and physical well-being.[56-58] A cross-sectional study by Zhao and colleagues (2019) found diabetes self-care behaviors, specifically following a healthy diet, physical activity, taking medication as prescribed, blood glucose self-monitoring, and foot care, were associated with optimism.[59] These initial findings may motivate people with diabetes to improve diabetes self-care behaviors in order to improve subjective well-being.[59] A study of 87 adults with depression and uncontrolled T2D found that those individuals in the intervention arm who received cognitive behavioral therapy for adherence and depression were significantly more adherent to medication regimens and to self-monitoring blood glucose compared to those in the control arm.[60] With these findings in mind, clinicians should encourage cognitive restructuring techniques that challenge negative thoughts and reframe them so they are more positive.[60]

### ***Social Support and Diabetes***

Support for people with diabetes comes from many different people including peers, family, friends, classmates, coworkers, and the online diabetes community. Social support is well-documented in the diabetes literature. In a four-year longitudinal study, depressive symptoms and social support were shown to have a reciprocal relationship in patients with diabetes.[44] Furthermore, a larger support network is shown to improve physical well-being among patients with diabetes.[45] Greater support system satisfaction among a group of adults with T2D was significantly associated with lower diabetes distress levels, thus supporting the stress-buffering hypothesis.[46] Additionally support from important family members and friends was associated with lower A1C values, better adherence to self-care regimens, and showed a buffering effect on diabetes distress.[47]

Peer support is defined as support from an individual who has experiential knowledge in the specific behaviors and/or practices of the target population.[48] After an eight-week study implementing peer coaching, participants reported that coaching was useful in disease management including behavior changes in diet, exercise, and blood glucose monitoring.[49] The effectiveness of peer support is attributed to the reciprocal relationship formed between people sharing similar life experiences.[48, 51] Communicating the importance of community and peer support to people with diabetes should be emphasized during clinical appointments and DSMES.

Some participants lack social or family support and children living with diabetes may experience “miscarried helping.”[54] Participant reports of family members non-supportive behaviors were associated with being less adherent to medication regimens.[52] Importantly, “miscarried helping” is a pattern of frustration and conflict surrounding diabetes management between caregivers and their children.[54] For individuals who experience sabotaging behaviors and/or miscarried helping from family members,[52-54] clinicians and educators should engage family members in discussions about the negative influence of non-supportive behaviors on diabetes self-care and A1C values.[55] Family members should be included in DSMES to be able to communicate productively about diabetes care and management.[55]

## CHAPTER 3: METHODOLOGY

### *Study Aim*

The aim of this study is to identify positive experiences of living with diabetes from the perspective of people with diabetes. Participants living with T1D or T2D were recruited to participate in in-person interviews. Participants were asked a series of questions about positive experiences they have encountered in their time living with diabetes. Some categories with potential positive encounters include the social setting, health, and well-being (**Table 1**).

**Table 1**. Interview Guide

| Questions |
|---|
| 1. Can you please share any positive experiences you have as a result of living with diabetes? |
| 2. Have you experienced anything positive with your health behaviors? |
| 3. Have you experienced anything positive with your social network? |
| 4. Have you experienced anything positive with your personal growth? |
| 5. Have you experienced anything positive with your career aspirations? |
| 6. Have you experienced anything positive in your community? |
| Probe: In your diabetes community? |
| Probe: In your home community? |
| 7. Can you foresee any positives in the future with your diabetes? |
| 8. Are there any positive messages you would like to share with newly diagnosed individuals with diabetes? |

### ***Recruitment of Participants***

We used maximum variation sampling[32] to recruit a total of sixteen participants (N=16) living with type 1 or type 2 diabetes age 18 years and older. Participants must be able to read and speak English. Exclusion criteria included individuals whose diabetes diagnosis could not be clearly identified as T1D or T2D, individuals with maturity onset diabetes in the young (MODY; related to genetic mutations), individuals with gestational diabetes, and/or individuals under the age of 18 years.

Participants were recruited via flyers, email, advertising on social media, University owned and maintained listservs, and word of mouth. Individuals interested in participating contacted the study team and left their information (via email or phone) to be contacted. One team member (MAC) contacted them to ask if they wished to participate and explained what participation would entail. If the individual agreed to participate and they met the inclusion and exclusion criteria, MAC scheduled an in-person interview with the participant based on the individual's preference. All participants provided written informed consent prior to participation (see Appendix A). Participants were explicitly informed that there were no "right" or "wrong" responses to the interview questions, and that their responses provided no bearing on their diabetes care. They were also informed that they could decline to participate at any time in the study process without explanation. MAC and EAB then conducted individual interviews. MAC conducted fifteen interviews and EAB conducted one interview. Participants were compensated for their time with a $10 gift card or cash using funds from Dr. Beverly's grant funding.

### *Interview Methods*

Interviews were conducted at Ohio University using Dr. Beverly's office and took approximately 20 to 60 minutes to complete. Prior to the interview participants completed a short demographic form to provide such information as anthropometric data (height, weight, age), hemoglobin A1C, medication regimen, race/ethnicity, marital status, education, occupation, income level, and county of residence (see Appendix B). All interviews were digitally audio-recorded and transcribed verbatim using Verbalink© (transcription service). Quality checks of the transcribed files were performed by listening to the recordings to validate the transcriptions. Names and identifiers were removed to protect participant confidentiality. Data was collected until saturation was reached; that is until no new information was generated from the interviews.[32]

### *Data Analysis*

Data analysis in qualitative research is an iterative process, in which data collection and data analysis occur concurrently. The multidisciplinary research team, consisting of a health behaviorist/qualitative methodologist (EAB) and pre-medical/translational health (exercise physiology) student (MAC) performed content analysis by independently marking and categorizing key words, phrases, and texts to characterize the overarching themes.[34-36] Discrepancies were resolved through group consensus.[36] The Cohen's kappa coefficient for inter-rater agreement between coders was calculated to indicate the amount of agreement between coders.[37,38] The Cohen's kappa coefficient between the two coders was $\varkappa = 0.918$, indicating very good agreement.[37,38] We analyzed each interview separately and then MAC input the data to NVivo 12 (QSR International, Victoria, Australia) in order to compare common themes across interviews. Themes were selected that characterized participants' positive experiences that occurred multiple times, both within and across transcripts.

### ***Scientific Rigor***

Qualitative research is different from statistically driven research, which relies on randomness to generalize findings from a small sample to a larger population.[40] The logic of qualitative sampling rests not on generalizability or representativeness, but on the notion of saturation, that is, the point at which no new information is obtained.[32] Thus, sample size and statistical analyses are not criteria for evaluating the rigor of qualitative research, but rather, for evaluating the adequacy and the comprehensiveness of the study findings.[40]

To support credibility (validity), the investigators were triangulated with expertise from different disciplines including health behavior, qualitative methodology, pre-medicine, translational health and exercise physiology. Analyst triangulation provided a check on selective perceptions as well as a means to identify blind spots in the analysis.[41] Further, three participants reviewed the findings to achieve participant corroboration.[42] Transferability (external validity) was supported by rich descriptions and verbatim quotations from the transcripts. To support dependability (reliability) of the data, a researcher not involved with the study conducted an external audit to examine both the process of the research study and to evaluate whether or not the findings, interpretations and conclusions were supported by the data.[39] Finally, confirmability (objectivity) of the data was supported through tracking the decision-making process with an audit trail, which is a detailed description of the research steps conducted from the development of the project to the presentation of findings.[41, 43]

# CHAPTER 4: Focus on the Positive: A Qualitative Study of Positive Experiences living with Type 1 and Type 2 Diabetes

## ABSTRACT

**OBJECTIVE:** The purpose of this study was to identify positive experiences associated with diabetes from the perspective of adults diagnosed with type 1 (T1D) or type 2 diabetes (T2D).

**METHODS:** We conducted in-depth face-to-face interviews with adults with T1D or T2D. Interviews were transcribed, coded, and analyzed using content and thematic analysis using NVivo 12 software.

**RESULTS:** Sixteen adults completed interviews (mean age=36.4±10.6 years, Hemoglobin $A_{1c}$=7.2±1.9%, 62.5% T1D, duration=11.6±9.8 years, 43.8% female, 100% white). Qualitative analysis revealed four themes: 1) Positive and Supportive Community: Participants described positive experiences with family, friends, classmates, coworkers, and the online diabetes community. Their support systems helped them manage and cope with the many challenges of diabetes; 2) Improved Health Behaviors: Participants reported positive changes in their self-care behaviors, mainly diet and exercise improvements; 3) Positive Outlook and Personal Growth: Participants attributed increased empathy, compassion, maturity, and confidence to their diabetes. 4) Advocacy for People with Diabetes: Participants took on the role of advocates for diabetes policy changes and educating peers about diabetes.

**DISCUSSION:** Communicating positive experiences about type 1 and T2D may help clinicians and educators reframe the negative messages commonly shared with people with diabetes.

## INTRODUCTION

Diabetes is one of the most significant health problems in the United States (US). An estimated 34.2 million people of all ages—or 10.5% of the population—have diabetes, the vast majority being type 2 diabetes (T2D).[1] Diabetes is a group of diseases characterized by high blood glucose levels resulting from the body's inability to produce and/or use insulin.[2] The two most common types are type 1 (T1D) and T2D.[2] T1D is marked by the body's inability produce insulin, and T2D is marked by the body's inability to produce insulin as well as the body's inability to effectively use the insulin it produces While T1D is most commonly diagnosed in childhood or adolescence, it can occur at any age. Comparably, T2D is most commonly diagnosed during middle-age, but it can be diagnosed in childhood or adolescence. Recent trends in incidence show increases in T1D and T2D, especially in children and adolescents.[1]

Diabetes requires continuing medical care and self-management education to reduce the risk of acute and long-term complications. Recent data from the Centers for Disease Control and Prevention (CDC) show half (50.0%) of US adults with diagnosed diabetes have a Hemoglobin $A_{1c}$ (A1C), a measure of a person's average blood glucose values over 2-3 months, value at or below target (<7.0%)[1]. Of these, 19.2% met their ABC goals of an A1C value <7.0%, blood pressure <140/90 mmHg, non-HDL(high density lipoprotein) cholesterol <130 mg/dL, and being a nonsmoker.[1] Reaching ABC goals decreases the risk of macrovascular (e.g., cardiovascular disease) and microvascular (e.g., retinopathy, neuropathy, nephropathy) complications.[3-7] Behaviors that promote

ABC goal achievement, and in turn reduce the risk for complications, include smoking cessation[8], following a healthy diet[9], weight management[10], engaging in regular physical activity[11, 12], monitoring blood glucose levels[13, 14], taking medications as prescribed[15], maintaining proper foot health[16], and attending clinical appointments.[17, 18] Reaching and maintaining these behaviors is encouraged in Diabetes Self-Management Education and Support (DSMES).[19, 20]

DSMES is an important component of diabetes care for all people with diabetes.[20, 21] DSMES should be person-centered and facilitate learning about knowledge, decision-making, and skills for self-care.[20] Further, providers who deliver DSMES should incorporate positive, strengths-based language to reduce stigma and feelings of shame and guilt related to this disease.[22, 23] Historically, diabetes care and DSMES have focused on behavioral and clinical targets, which may explain the short-term benefits (reaching A1C levels <7.0%) but limited long-term outcomes (maintaining A1C levels <7.0%).[24-26] Emphasis on personal stories and experiences may help adults with diabetes sustain these A1C benefits.[27-30] However, minimal research has explored positive stories and experiences living with T1D or T2D. Thus, the purpose of this study was to identify positive experiences with diabetes from the perspective of adults diagnosed with T1D or T2D. Findings from this study may be incorporated in clinical care and DSMES to promote active engagement in diabetes self-care.

## METHODS

### Research Design

This qualitative descriptive study explored positive experiences of living with T1D or T2D. We employed qualitative descriptive methods to obtain rich data and achieve a thorough understanding of positive feelings, behaviors, and/or experiences from living with diabetes.[31] The University Office of Research Compliance approved the protocol and all recruitment procedures and materials (18-X-346).

### Sample

We used maximum variation sampling[32], a form of purposive sampling, to recruit adults aged 18 years and older who were able to read and speak English, and diagnosed with T1D or T2D. Exclusion criteria included individuals whose diabetes diagnosis could not be clearly identified as T1D or T2D, individuals with maturity onset diabetes in the young (MODY; related to genetic mutations), and/or individuals under the age of 18 years.

Participants were recruited via flyers, email, advertising on social media, University owned and maintained listservs, and word of mouth. Individuals interested in participating contacted the study investigators (MAC, EAB) and left their information (via email or phone) to be contacted. Individuals who met all inclusion and exclusion criteria were included in the study. All participants provided written informed consent prior to participation. Participants were explicitly informed that there were no "right" or "wrong" responses to the interview questions, and that they could decline to participate at any time in the study process without explanation. Participants received a $10.00 gift card or cash as compensation.

### Data Collection

We devised and field-tested a semi-structured interview guide with two participants (see Table 1). Two trained interviewers (MAC, EAB) conducted all interviews, asking participants broad, open-ended questions about diabetes self-care behaviors, healthcare experiences, social networks, career aspirations or achievements, community involvement, and messages for newly diagnosed individuals with diabetes. All interviews were conducted in conference rooms and University offices. Interviews lasted 20 to 60 minutes. Data was collected until saturation was reached; that is until no new information was generated from the interviews.[32] Interviews were digitally audio-recorded and transcribed verbatim. Quality checks were performed on the transcribed files by listening to the recordings to validate the transcriptions. Names and identifiers were removed to protect participant confidentiality.

### Qualitative Analysis

The multidisciplinary research team, consisting of a health behaviorist/qualitative methodologist (EAB) and pre-medical/translational health (exercise physiology) student (MAC), analyzed data using content and thematic analyses.[33] Specifically, we performed content analysis by independently marking and categorizing key words, phrases, and texts to identify themes.[34-36] The team coded the data, and reviewed, discussed, and resolved all discrepancies via consensus to establish inter-coder reliability.[36] The Cohen's kappa coefficient between the two coders was $\varkappa = 0.918$, indicating very good agreement.[37, 38] No negative or deviant cases were excluded from the analysis.[39] After the transcripts were coded and reviewed, one member of the research team (MAC) entered the coded transcripts in NVivo 12 software (QSR International, Victoria Australia) to organize the coded data. Themes were selected that characterized participants' positive experiences that occurred multiple times, both within and across transcripts.

## Scientific Rigor

Qualitative research is different from statistically driven research, which relies on randomness to generalize findings from a small sample to a larger population.[40] The logic of qualitative sampling rests not on generalizability or representativeness, but on the notion of saturation, that is, the point at which no new information is obtained.[32] Thus, sample size and statistical analyses are not criteria for evaluating the rigor of qualitative research, but rather, for evaluating the adequacy and the comprehensiveness of the study findings.[40]

To support credibility (validity), the investigators were triangulated with expertise from different disciplines including health behavior, qualitative methodology, pre-medicine, translational health and exercise physiology. Analyst triangulation provided a check on selective perceptions as well as a means to identify blind spots in the analysis.[41] Further, three participants reviewed the findings to achieve participant corroboration.[42] Transferability (external validity) was supported by rich descriptions and verbatim quotations from the transcripts. To support dependability (reliability) of the data, a researcher not involved with the study conducted an external audit to examine both the process of the research study and to evaluate whether or not the findings, interpretations and conclusions were supported by the data.[39] Finally, confirmability (objectivity) of the data was supported through tracking the decision-making process with an audit trail, which is a detailed description of the research steps conducted from the development of the project to the presentation of findings.[41, 43]

## RESULTS

Sixteen adults (age=36.4±17.4 years, A1C=7.2±1.9%, diabetes duration=11.6±9.8 years, , 43.8% female, 100% White; see Table 2) participated in the study. Transcript identifiers are used with quotations indicating participant number and type of diabetes (T1D or T2D). The following themes emerged from the data analysis:

### 1. *Positive and Supportive Community*

All participants described positive experiences with their support system and community (100%, N=16). Many expressed gratitude for people who checked in on them during episodes of hyper- and hypoglycemia. They valued the support and sense of community received from different sources, including their families, friends, roommates, classmates or coworkers, and the online diabetes community. One participant described the help they received from their family: *“I have a family of – I have two sons, and my husband are all – all three of them are extremely supportive.”* (ID 109, T1D) Another participant shared appreciation for their roommates’ involvement in their care and willingness to learn about diabetes: *“Also, I’ve made my friends and my roommates more aware because I genuinely don’t think [they] would know really what diabetes was if I didn’t have it…Educating my friends about it has definitely been a positive outcome.”* (ID 101, T1D) Additionally, some participants spoke about the formation of new friendships because of their diabetes: *“I’ve had some kind of friendly interactions with other people with diabetes, especially people who wear pumps…I would say that diabetes is a means of connection that allowed us to introduce each other.”* (ID 108, T1D)

Participants also talked about the unique support they received from the online diabetes community. The online diabetes community consists of thousands of people with diabetes sharing information, advice, and encouragement to each other across many different platforms including social media:

> *“I find the whole diabetes community like a family. Everyone is willing to help each other out...Something a little small, but whenever I like have something or even if it’s not diabetes-related, half of my [online] comments are people from the diabetes community saying, ‘Oh, this is great!’ ‘Yeah, we love you.’ ‘Miss you, or something like that.’ So, it’s a very tightknit group”* (ID 100, T1D).
>
> *“Also, being part of this online community, it’s definitely been rewarding. It’s given me a real feel of practicing medicine, too. We’re giving each other advice”* (ID 102, T1D).

Several of the student and faculty participants referred to the support they received from the University’s diabetes community. Specifically, they mentioned College Diabetes Network© (CDN) in addition to the University’s student organization dedicated to supporting students on campus with diabetes. The following quotations exemplified the positive and supportive community at the university:

> *“I definitely think joining DOSES [University student group] has been helpful because it’s easy to see that other people who go here are living with the same thing.”* (ID 101, T1D)
>
> *“I’m getting involved with things like College Diabetes Network, meeting new people. I’m continuously meeting people who have T1D as well and it’s just – it’s nice to be able to talk with other people and share similar experiences we might have…If you have a problem with your supplies or anything, you always know who to go to. You can always talk to someone. You’re not alone with it and it’s nice to have that.”* (ID 106, T1D)
>
> *“What was surprising to me was the response of how many people are living with this…I had a group of five or six people in the university community that said that I was helping them. They were getting out to exercise because they could see what I was doing”* (ID 107, T2D).

Finally, multiple participants discussed the importance of mentorship as well as mentoring others with diabetes. They described the role mentors played in encouraging positive self-care behaviors and everyday life advice:

> *"The person that told me about CDN was one of my biggest mentors even to this day. I'll call her and she gives me advice about how I'm running my group, and what – and it's just kind of nice, like she's always a source of encouragement for whenever I'm doing something especially in the diabetes community…She's doing things that I hope I can do in the future."* (ID 100, T1D).

Some participants, inspired by the positive role models in their life, felt it was necessary to give back to the diabetes community. They described volunteering to speak at local schools, serving as diabetes camp counselors, and/or traveling to other countries to provide diabetes education. For example, this participant spent time in local elementary and high schools mentoring children with diabetes: *"Being able to help other people who are recently diagnosed or are also living with it would definitely be a positive thing…Having a conversation with them and just talking to them about – it doesn't even have to be about diabetes, but just knowing that there's someone else there who has diabetes"* (ID 101, T1D).

### 2. Improved Health Behaviors

Nearly all of the participants (n=14) reported positive changes in their health behaviors as a result of living with diabetes. Participants cited improvements in their eating habits and awareness of the carbohydrate content in foods. In their opinion, diabetes made them more aware of how certain foods affected their blood glucose values and overall well-being. As these participants explained:

> *"It's made me more conscious of how I treat my body. What I eat. Also, I know what's in my food from counting carbs…I'm careful to look at my body, how I'm feeling. It makes me more aware of what's going on."* (ID 100, T1D)
>
> *"I'd say now I'm very conscious about what I eat. I like to say I have a pretty healthy diet. It's really helped me to manage that and I need to keep a healthy diet in order to keep my blood sugar in check. It's really an encouragement to eat better and also to exercise a lot to keep blood sugar in range."* (ID 106, T1D)

Some participants shared examples of how small swaps in the foods they ate helped them improve their blood glucose values while still enjoying some of their favorite foods:

> *"And you don't want to have the roll or avoid the corn and swap that out for green beans or something like that."* (ID 112, T2D)
>
> *"If I do get pizza, it's thin crust, but I do still have pizza."* (ID 113, T2D)
>
> *"I stay pretty strict about diet and just substitute turnips for potatoes... I've had conversations with friends that know I'm perhaps more diet conscious than they are about, like using the potatoes and turnips thing. I guess fewer carbs, I think in my mind is better for everybody."* (ID 115, T2D)

Participants attributed engaging in regular physical activity to lowering and maintaining blood glucose values within their target range. Many participants used a combination of healthy diet and exercise while others used exercise alone to manage their diabetes.

> *"I found come spring I had lost enough weight that I could run, so I started doing that. Got to where I did a 5K, and then eventually a 10K."* (ID 107, T2D).
>
> *"I have better management of my health overall than I did before. I was diagnosed really recently, October of this past year. And, so, after that, I've been paying more attention to what I ingest. And I've been noticing that I'm more conscious of my fitness and all that, just to make sure my sugar levels are good… Ever since I've been more regulated, I've been more on the healthy side and I've been getting more fitness goals reached because of that."* (ID 110, T1D)
>
> *"I do make a very concerted effort to try to walk at least two to three miles at least three or four times a week."* (ID 111, T2D)

For many of the participants, healthier eating and exercise helped them lose weight*: "I guess finding the diagnosis gave me what I needed to do something about it. So for the last year, I've dropped 80 pounds and [my] energy level has skyrocketed."* (ID 107, T2D). These behavioral changes improved their emotional well-being, energy levels, and overall health status: *"That is something that I factor in when I try to eat healthy and exercise regularly, I know that it also helps me to have better control, and so I feel better when I have better control"* (ID 108, T1D). One participant also shared the benefit of healthy diet and exercise on mental health and how it helped them improve their depression:

> *“Mental wellbeing is tied to a lot of things and a good diet is part of it. When I was in my late 30s into my 40s [I] was medicated for depression and anxiety….Definitely affected my wellbeing and I think we get into that, okay, did the diabetes cause that or is it a factor. You get into that tailspin and then, you're going to eat more Snickers bars, you're going to tailspin into it and for me, it was alcohol. And it was beer, high carb kind of stuff and I'm certain that exacerbated the diabetes, I'm sure. And didn't exercise… It's [diabetes] kind of a blessing in disguise, because I am doing more for myself because I've got something to keep track of. So, yeah, I would say definitely it's helped, and I got to think it's helped with emotional outlook, too, because it's all one body.”* (ID 115, T2D).

### 3. *Positive Outlook and Personal Growth*

Most participants credited their personal growth and a positive outlook to living with diabetes. All but one participant (n=15) felt that their diabetes helped them grow as a person. For some, living with diabetes increased their empathy and compassion towards others:

> *“Growing up with this disease I found out that I really, really, really care for people. I like to make sure that people are always in the best physical state of health and mind and psych.”* (ID 103, T1D)
>
> *“Having empathy for others, too. I know that it’s not just other people who have diabetes, but other people who may have other chronic illnesses or something going on in their life.”* (ID 106, T1D).

For others, especially participants with T1D, diabetes forced them to mature at an earlier age. They had more responsibilities (e.g., monitoring blood glucose levels, taking medications, treating hypoglycemia) compared to their same-age peers:

> *"It made me mature faster. My parents never really would ask me – they weren't hovering me about my blood sugars. They were like, 'If you have a problem, I know you'll say something.' I was in sixth grade and it just helped me to take care of myself better. It made me be more conscious and aware of my surroundings. Taking care of myself was the main point."* (ID 101, T1D)
>
> *"Yeah, the positive one was just growing up, it taught you self-discipline. I was diagnosed going into sixth grade. Throughout middle school and high school, I just found myself way more mature than all my friends. They were still goofing off and stuff, which is fine because you're young. I felt like I had a huge responsibility with my health and that made me grown up way, way quicker than others."* (ID 103, T1D)
>
> *"I was older when I was diagnosed. I was 13. I feel like that made me grow up in a sense. I had to be more responsible than other teenagers. I felt like it was the end of the world when it happened, but I feel like I have a more positive outlook on things now. Everyone can have it worse. It's not a competition. In that way, it made me grow up, too."* (ID 104, T1D)

Still others believed that diabetes gave them the confidence to take care of themselves now and in the future:

> *"So, I think I just feel better or have more confidence that I'm doing something that's going to benefit [me] when I'm 70 and 80… it's just a kind of a relaxed confidence that, oh, I'm doing the right thing and it's the best thing I can do for myself and that will pay dividends down the road."* (ID 115, T2D)

The majority of participants (n=11) held a positive outlook about their diabetes. Diabetes was not viewed as a hindrance but rather as an advantage. Diabetes improved their health, self-care behaviors, relationships, work and/or school, and personal disposition. Participants explained that they could do everything a person without diabetes could do, and in some instances, better:

> *"It's not something bad to live with. People are like, "Oh, I'm so sorry." It's not a big deal. I still make the most out of my life. Everything I want to do, I can do. People like to think that you shouldn't eat this or something, but I can do whatever I want with an insulin pump or even if you're on the shots. Nothing holds me back from doing anything and it's actually made me a better student. It's made me better with my diet and better getting me to go to the gym."* (ID 106, T1D)

Moreover, participants recognized that diabetes was a part of their lives, but it did not define who they were or what they could accomplish in life:

> *“Diabetes is definitely a part of my life. It is literally impossible for me to separate it. But I don’t think it’s what defines who I am as a person. It’s just this thing I have to deal with.”* (ID 108, T1D).
>
> *“It took me a while to realize this is the rest of my life, but now looking back, I'm happy this is what's happened. It's part of who I am. The things that I've been doing with it have made a positive impact in general on my own life.”* (ID 101, T1D)

Lastly, several participants expressed optimism for their future. They recognized that successful diabetes management helped them feel better and cope with uncertainty:

> *“So, there’s a sense of optimism, of figuring out, okay, I don’t know what the future is, but it’s going to be good. I said that’s the main lesson I’ve taken away from the diabetes thing right now…I feel so much better.”* (ID 107, T2D)
>
> *“I have a very positive life, so is my life positive because of diabetes? Maybe in some ways, because it’s made me adaptable and it makes me a good planner and maybe more compassionate to others… Everything is positive to me. I don't know how to really explain that. I don't know what's in store for me, but I know whatever it is, it's going to be a blessing.”* (ID 109, T1D)

### ***4. Advocacy for People with Diabetes***

Half (n=8) of the participants shared stories of advocacy about themselves and others with diabetes. For example, one participant used their voice to discuss policy issues on Capitol Hill:

> *"I think through working with the diabetes community I have been able to be an advocate, not only for myself…but I also advocate for others and can help others navigate whatever system they're going through. Or even I talk to representatives about issues going on…I advocate on a political level. Through the Diabetes Patient Advocacy Coalition I have [had] the opportunity to go to Washington D.C. and actually get training and experience on how to be an advocate, which I definitely would never have that experience if I wasn't diagnosed and have this passion. So, it's really awesome to kind of learn about what issues are not only affecting me, but so many other Americans and people with diabetes."* (ID 100, T1D)

Participants took on the role of advocating for key policy issues, such as lowering the cost of insulin and providing insurance coverage for pre-existing conditions. In addition, participants recognized that education and increasing awareness about diabetes was something within their power:

> *"There's such a generalization of diabetes, whether it be Type 1 or 2. I like being able to teach them about what it means to be a Type 1 diabetic and stuff."* (ID 104, T1D)

> *"We talk about different events we could set up for getting diabetes awareness out and doing fun things together [in student organization]."* (ID 106, T1D)
>
> *"People judge me a lot for having fruit snacks at the gym. So, I posted something like 'Hey, if you see somebody with juice or snacks, maybe they have diabetes and they're trying to raise their sugars.' And I find it helpful because people are like, 'Oh, thank you. I didn't know that.'"* (ID 110, T1D)

Beyond advocacy, all 16 participants offered advice for people newly diagnosed with diabetes. One common sentiment was reassurance that a person's life was not over because of this diagnosis:

> *"Their life isn't over. When I was diagnosed, [I thought] my life was over. It's definitely not at all. It's [diabetes] helped me with so many opportunities."* (ID 101, T1D)
>
> *"It is not the end of the world…It keeps you aware of your body and your food intake and your habits and it kind of makes you more whole as a person I feel."* (ID 110, T1D)

If people newly diagnosed felt overwhelmed, participants stressed the basics of diabetes self-management. For example, one person remembered the 15-15 rule when experiencing hypoglycemia:

> *"This is such a little thing, but it goes such a long way and it's one of the fundamentals of when you're going low. They always tell you the 15/15 rule. You eat 15 carbs, wait 15 minutes."* (ID 103, T1D).

Others emphasized the habitual nature of diabetes self-management. They explained that diabetes could be managed by forming positive diet, physical activity, and blood glucose monitoring behaviors:

> *"I think with diabetes it's a habitual disease. It's about getting into good habits."* (ID 108, T1D)
>
> *"Try to make the effort to exercise and change your diet and avoid having to go on the medication."* (ID 111, T2D)

Finally, participants emphasized that diabetes was a manageable condition. With the support of the diabetes community and a positive outlook, people with diabetes had a promising future:

> *"There's more to come and there's a great community out there willing to support you."* (ID 100, T1D).
>
> *"I feel like you have all the control in the world…the good news is that you've got pretty much total control in managing this thing and it's not that hard."* (ID 115, T2D)

## DISCUSSION

In this qualitative study, positive experiences were explored from people living with T1D and T2D. These findings highlight the importance of a positive, supportive network of family, friends, and community. Participants recounted story after story of positive experiences with people exemplifying support, encouragement, advice, and mentorship. In addition, participants believed diabetes improved their health, self-care behaviors, and outlook on life. Further, many participants recognized that diabetes contributed to their personal growth. They attributed increases in empathy, compassion, confidence, and maturity to living with diabetes. Finally, many participants assumed the role of advocate, educating people about diabetes and recommending policy change for diabetes coverage.

All participants commented on the value of community and peer support from many sources in their lives, including family, friends, classmates, coworkers, and the online diabetes community. Participants' support systems helped them manage hypo- and hyperglycemia, as well as cope with the many challenges of diabetes. Social support is well-documented in the diabetes literature. It is associated with better physical and mental health,[44, 45] and may have a buffering effect on diabetes distress, self-care, and A1C values.[46, 47] Additionally, several participants referred to the supportive diabetes community at the University, as well as the online community. Both the University and online communities offered peer support, which is defined as support from an individual who has experiential knowledge in the specific behaviors and/or practices of the target population.[48] Peer support has been shown to improve diet, physical activity, blood glucose monitoring, and medication adherence in adults with diabetes.[49, 50] The effectiveness of peer support is attributed to the reciprocal relationship formed between people sharing similar life experiences,[48, 51] like the student organization on campus and the online diabetes community. This community provides advice, tips, tricks, and encouragement about all aspects of diabetes management. Thus, communicating the importance of community and peer support to people with diabetes should be emphasized during clinical appointments and DSMES. For individuals who experience sabotaging behaviors and/or miscarried helping from family members,[52-54] clinicians and educators should engage family members in discussions about the negative influence of non-supportive behaviors on diabetes self-care and A1C values.[55]

The majority of participants held a positive outlook about their diabetes. They viewed their diabetes as a benefit rather than a detriment to their personal lives and health. These participants felt optimistic about their future. Optimism has been linked to higher levels of engagement coping, or taking an active role in one's health, and lower levels of avoidance coping.[56] Research in non-diabetes populations shows optimism is associated with better mental[48] and physical well-being.[56-58] A cross-sectional study by Zhao and colleagues (2019) found diabetes self-care behaviors, specifically following a healthy diet, physical activity, taking medication as prescribed, blood glucose self-monitoring, and foot care, were associated with optimism.[59] While more research is needed to determine the cause-effect relationship between diabetes self-care and optimism, these initial findings may motivate people with diabetes to improve diabetes self-care behaviors in order to improve subjective well-being.[59] With these findings in mind, clinicians should encourage cognitive restructuring techniques that challenge negative thoughts and reframe them so they are more positive.[60]

## Limitations

Study limitations include homogeneity of the study with regards to race/ethnicity, small sample size, participant self-selection, and self-reported data. The all-white study sample is reflective of the racial and ethnic distribution of southeastern Ohio (95.0% white[61]); however, we included students and employees from the university who may be from outside of the region. The small sample size and participant self-selection limit the generalizability of the findings. Individuals who volunteered to participate may have had more positive experiences with diabetes compared to people who did not participate. Next, self-reported data are vulnerable to social desirability bias.[62] To minimize bias, the researchers informed participants that their responses were confidential and could not be linked back to their personal identity. Further, the investigators emphasized the voluntary nature of participation and explicitly informed the participants that their responses had no bearing on their diabetes care. Future research with a larger, more heterogeneous sample should involve the collection of mixed method data from adults with positive experiences and adults without positive experiences. This research should include measures of diabetes self-care behaviors, A1C values, and psychosocial factors; these measures can be compared in adults with and without positive experiences. Finally, research is needed to assess positive experiences over time to assess whether experiences change at different stages in the lifespan.

## Conclusion

In conclusion, research that recognizes and understands the positive experiences of living with T1D and T2D presents a unique opportunity for clinicians and educators to reframe the negative messages commonly shared with people with diabetes. Our participants focused on positive and supportive experiences with their peers and community, improved health behaviors, personal growth, and engagement in diabetes advocacy. Communicating positive experiences with people with diabetes, especially newly diagnosed, may promote optimism, and in turn, improve self-care, emotional well-being, and physical health. Additional research is needed to examine these associations among social support, optimism, diabetes self-care, and physical and mental health in adults with T1D and T2D.

**Table 1**. Interview Guide

| Questions |
|---|
| 1. Can you please share any positive experiences you have as a result of living with diabetes? |
| 2. Have you experienced anything positive with your health behaviors? |
| 3. Have you experienced anything positive with your social network? |
| 4. Have you experienced anything positive with your personal growth? |
| 5. Have you experienced anything positive with your career aspirations? |
| 6. Have you experienced anything positive in your community? |
| Probe: In your diabetes community? |
| Probe: In your home community? |
| 7. Can you foresee any positives in the future with your diabetes? |
| 8. Are there any positive messages you would like to share with newly diagnosed individuals with diabetes? |

**Table 2**. Demographic and Health Characteristics of Participants (n=16)

| | Mean (%) | Range |
|---|---|---|
| Hemoglobin $A_{1c}$ (%) | 7.2±1.9 | 5.5-13.0 |
| Body Mass Index (kg/m$^2$) | 29.4±9.2 | 21.1-59.7 |
| Age (years) | 36.4±10.6 | 50-83 |
| Diabetes duration (years) | 11.6±9.8 | 1-42 |
| Education | | |
| Current undergraduate student | 6 (37.5) | |
| Four-year college degree / B.A. / B.S. | 3 (19.8) | |
| Current graduate or professional student | 2 (12.5) | |
| Some graduate work | 1 (6.3) | |
| Completed Masters or professional degree | 2 (12.5) | |
| Advanced Graduate work or Ph.D | 2 (12.5) | |
| Prescribed Diabetes Medication(s) | | |
| No medication, managed by diet and exercise | 1 (6.3) | |
| Oral diabetes medication(s) | 5 (31.3) | |
| Insulin | 10 (62.5) | |
| Gender | | |
| Female | 7 (43.8) | |
| Male | 9 (56.3) | |
| Race | | |
| White | 16 (100.0) | |
| Relationship Status | | |

| | |
|---|---|
| Single/Never Married | 11 (68.8) |
| Married | 4 (25.0) |
| Divorced | 1 (6.3) |
| Occupational Status | |
| Working Full-Time | 5 (31.3) |
| Working Part-Time | 1 (6.3) |
| Student | 8 (50.0) |
| Retired | 2 (12.5) |

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# CHAPTER 5: CONCLUSION

Results from this qualitative study revealed that people living with diabetes have positive experiences as a result of living with diabetes. These findings highlight the importance of a positive, supportive network of family, friends, and community. Participants recounted story after story of positive experiences with people exemplifying support, encouragement, advice, and mentorship. Several participants went on to educate others and/or be a mentor to others living with diabetes. In addition, participants believed diabetes improved their health, self-care behaviors, and outlook on life. Participants expressed satisfaction with weight loss, increased awareness of carbohydrate content, healthier overall diet, making “swaps” for lower carbohydrate options, and gratification with setting physical activity goals and meeting them each week. Self-care behaviors such as blood glucose monitoring, attending clinical appointments and foot care are a few examples among many that participants engaged in. Through these lifestyle modifications participants were able to recognize the overall effect diabetes had on their physical and mental well-being.

Further, many participants recognized that diabetes contributed to their personal growth. They attributed increases in empathy, compassion, confidence, and maturity to living with diabetes. Finally, many participants assumed the role of advocate, educating people about diabetes and recommending policy change for diabetes coverage. Participants shared that the most important policy change to them was the astonishing price of insulin and that fact than many Americans must ration insulin to be able to afford their medical costs. Furthermore, many participants shared that they enjoyed educating people both on diabetes in general but also more specifically on the difference between T1D and T2D as they are commonly confused and/or misunderstood.

In conclusion, research that recognizes and understands the positive experiences of living with T1D and T2D presents a unique opportunity for clinicians and educators to reframe the negative messages commonly shared with people with diabetes. Our participants focused on positive and supportive experiences with their peers and community, improved health behaviors, personal growth, and engagement in diabetes advocacy. Communicating positive experiences with people with diabetes, especially newly diagnosed, may promote optimism, and in turn, improve self-care, emotional well-being, and physical health. Additional research is needed to examine these associations among social support, optimism, diabetes self-care, and physical and mental health in adults with T1D and T2D.

We would like to continue the work of this study with a future mixed methods study that measures values including A1C, self-care behaviors, and psychosocial factors associated with diabetes. This study would include two groups, one group with positive experiences, and one group without positive experiences. This may be accomplished through an optimism scale and grouping individuals based on “more negative” and “more positive.”

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## APPENDIX A: INFORMED CONSENT

### Ohio University Adult Consent Form With Signature

Title of Research: Patients' Experiences of Living with Diabetes Distress

Researchers: Molly Carrier, Elizabeth A. Beverly, PhD

IRB Number: 18-X-346

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

### <u>Summary of Study</u>

Diabetes is one of the biggest health problems in the United States, affecting 9.4% of the national population and 19.9% of southeastern Ohio. Uncontrolled diabetes is associated with serious complications, including retinopathy, neuropathy, and nephropathy. Medicine and education have focused on the negative consequences of uncontrolled diabetes. While it is important to increase knowledge and awareness about diabetes and its related complications, it is also important to highlight positive outcomes associated with living with the disease. Thus, the purpose of this study is to identify positive experiences from living with diabetes from the perspective of people with diabetes. Participation will involve completion of a brief demographic form and an interview or focus group. Findings from this study may lead to the development of a program to help people lower their diabetes distress.

## **Explanation of Study**

This study is being done because we are trying to identify positive experiences of living with diabetes. While diabetes is associated with complications and psychosocial issues, it can be associated with increased health behaviors and social support.

If you agree to participate, you will be asked to complete a brief demographic form and an individual interview or focus group. The demographic from will take approximately 5 minutes to complete and the interview or focus group will take approximately 30 to 45 minutes. We will ask you questions about your positive experiences of living with diabetes. The interview will be audiotaped.

You may be eligible to participate if you can read and speak English, are age 18 years and older, have been diagnosed with type 1 or type 2 diabetes.

## **Risks and Discomforts**

Risks or discomforts that you might experience are that the audiotaping may cause some discomfort and distraction. The research team is trained in the interview process and will use their expertise to minimize any discomfort that may arise. You may withdraw from the study at any time for any reason. Such a decision will not affect you in any way.

## Benefits

This study is important to society because the information may be integrated into education programs to improve the psychosocial well-being of people with diabetes.

You may not benefit personally from participating in this study.

## Confidentiality and Records

Records relating to your participation as a research subject will remain private. All of the information given by you will be labeled with a code number and not your name. The list linking your code number to your name, and all audio recordings, will be destroyed one year after all of the study information is collected (November 2021). Also, your name will never appear on surveys, audio recordings or any information produced from this study. You will receive a copy of this consent form for your reference.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with the representatives of the Ohio University Institutional Review Board as part of their responsibility to oversee research.

## Compensation

As compensation for your time/effort, you will receive a $10 gift card or cash after the completion of the interview. In order to receive this compensation, you will need to provide your name and address. The study team keeps track of the compensation that was provided for the Ohio University Finance division's records. Because the $10 gift card or cash are paid through University funds, the names and addresses will be shared with the Office of Finance, but Finance will not know your individual responses.

## Future Use Statement

Data collected as part of this research will not be used for future research studies.

## Contact Information

If you have any questions regarding this study, please contact Elizabeth Beverly at 740-593-4616 or beverle1@ohio.edu.

If you have any questions regarding your rights as a research participant, please contact Dr. Chris Hayhow, Director of Research Compliance, Ohio University, (740)593-0664 or hayhow@ohio.edu.

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By signing below, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered
- you have been informed of potential risks and they have been explained to

your satisfaction.

- you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study
- you are 18 years of age or older
- your participation in this research is completely voluntary
- you may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Signature_______________________________________________ Date______

Printed Name__________________________________________

Version Date: [11/1/2018]

## APPENDIX B: DEMOGRAPHIC FORM

ID: _______ Date: ______________

### Demographic Form

1. Gender: ☐ Male ☐ Female ☐ Another term is better, specify:____________

2. Age: ______

3. Type of diabetes: ☐ Type 1 ☐ Type 2

4. Year of diabetes diagnosis: ________

5. What was your most recent Hemoglobin A1c level? ____________

6. What is your height? ____________________

7. What is your current weight? ______________________

8. What diabetes medication(s) are you on? Please check all that apply

☐ No medication, managed by diet and exercise alone

☐ Oral diabetes medication(s)

☐ Injectable diabetes medication

☐ Insulin

☐ Insulin and oral diabetes medication (s)

9. Are you Hispanic or Latino? ☐ Yes ☐ No

10. Race: (please mark all that apply)

☐ Asian ☐ American Indian ☐ Pacific Islander

☐ Black/African American ☐ White/Caucasian

☐ Mixed ☐ Other: ______________________

11. What is your current marital status?

☐ Married

☐ Widowed

☐ Divorced

☐ Separated

☐ Single/Never Married

12. What is the highest level of education you completed?

☐ Elementary school only

☐ Some high school, but did not finish

☐ Completed high school

☐ Current undergraduate student

☐ Some college, but did not finish

☐ Two-year college degree / A.A / A.S.

☐ Four-year college degree / B.A. / B.S.

☐ Current graduate or professional student

☐ Some graduate work

☐ Completed Masters or professional degree

☐ Advanced Graduate work or Ph.D

13. What is your occupation type?

☐ Working full-time (35 or more hours per week)

☐ Working part-time (fewer than 35 hours per week)

☐ Unemployed

☐ Student (either full or part-time)

☐ Social Security Disability

☐ Applying for Social Security

☐ Retired

☐ Other (Please explain): ________________________________________

14. What figure is closest to your current annual income?

☐ Under $25,000

☐ $25,000 - $39,999

☐ $40,000 - $49,999

☐ $50,000 - $74,999

☐ $75,000 - $99,999

☐ $100,000 - $124,999

☐ $125,000 - $149,999

☐ Over $150,000

☐ Prefer not to say

15. Do you currently have health insurance?

☐ No coverage/ self-pay

☐ Medicaid or Medicare only

☐ Private insurance only (job/ school/ purchased)

16. Do you live in the Appalachian region of Ohio? ☐ Yes ☐ No

**If yes, which county?** ______________________________

(Athens, Hocking, Meigs, Monroe, Morgan, Perry, Vinton, or Washington)