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Addressing the Limitations of the Medical Model: An Examination of Stigma, Challenges and
Social Support for College-Age Women Living with Type One Diabetes

By

Karson MacKenzie Saunders

Senior Thesis

Submitted in partial fulfillment
of the requirements for Honors
in the Department of Sociology

UNION COLLEGE

Schenectady, New York

March 2023

ABSTRACT

SAUNDERS, KARSON. Addressing the Limitations of the Medical Model: An Examination of Stigma, Challenges and Social Support for College-Age Women Living with Type One Diabetes

Department of Sociology, March 2023

ADVISOR: Melinda Goldner

Prior scholarship examining chronic illness experience within the United States is limited and fails to capture the experiences of college-age women living with type one diabetes (T1D). This study attempts to explore perceived stigma and social support available to college-age women with T1D in hopes to highlight the pressing need to utilize the sociological model to understand the emotional labor produced by the tensions existing between expectations and reality for the chronically ill within our ableist society. To do so, I performed a systematic review of existing research and cross-referenced this review with qualitative interviews of twelve present and former college-age women with type one diabetes. The twelve women interviewed reported that stigma was pervasive throughout their lives as a result of their identities as individuals *and* women with T1D. Stigma was reported to manifest in reactions of ignorance and pity. While physicians were knowledgeable about the disease, these women found they ignored the social and emotional impacts of type one diabetes, which led to these women internalizing unrealistic expectations for disease management. The qualitative interviews shed light on the taxing nature of living with T1D and echoed themes of emotional labor in the form of feelings of uncertainty and social isolation reflected by the existing literature. The results of this study support the need to stray from application of the medical model to better combat stigma's amplification of the already enormous tolls of navigating life with type one diabetes.

ACKNOWLEDGEMENTS

I offer my sincerest gratitude to the following individuals with whom this thesis would not have been possible.

To the twelve women who so generously and enthusiastically contributed their time and voices to this thesis. Your transparency and strength serve as an inspiration for all, and especially fellow women with type one diabetes.

To Professor Melinda Goldner for her unwavering support throughout my thesis, for her patience and continued sparking of my sociological and public health passions, and perhaps most importantly, for welcoming me so warmly to Union my sophomore year.

To Professor Rosemary Patterson for her encouragement and support, and for the many academic conversations on social work, illness experience, mental health and aging that motivated this thesis.

To the members of the Department of Sociology for all that you have contributed to my education and time on this campus.

To my mother for her constant love and encouragement in all my endeavors.

To my pediatric endocrinologist, Kristine Wolfhart, for breaking the medical model mold – not many patients are gifted the ability to text professionals like yourself when our health and emotions get the best of us.

To my dearest friends for their laughter, lovingly enforced breaks, embraces, and open ears over the past twenty-six weeks.

Thank you.

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INTRODUCTION

The purpose of this thesis is to explore the shortcomings of the medical model via examination of challenges pervasive and social support available to college-age women living with type one diabetes (T1D). Such will be done through a simultaneous examination of the impact of stigma on the women's ongoing decisions to pass or disclose within US society. As a result of our society's dependence on the medical model of illness and inattention to the importance of the sociological, existing literature is devoid of portrayals of first-hand accounts of chronic illness experience (generally and especially those) with T1D. According to the CDC (2021), chronic illness is an ever increasing and pressing reality and approximately 1.45 million youth and adults within the United States live with T1D. It is compelling to look at the actual and perceived experiences of college-age women with this disease as their identities function to highlight the ways in which illness, life-stage, and gender interact and impact their realities and resulting ability to remain in alignment with ableist expectations for the chronically ill.

This thesis will be a qualitative study providing an in-depth study of existing literature relevant to chronic illness experience in the United States. Chapter One will examine existing literature's coverage of the medical and sociological models of illness, logistics relevant to T1D, as well as what it looks like to live with a chronic illness in the United States. Chapter Two will provide an overview of the methods of this study, which included the conduction of twelve in-depth interviews with present and former college-age women with T1D in the Northeastern United States. Chapter Three will present the results as well as discussion of the significance and connections present between existing literature and the completed interviews. Chapter Four provides a summary, suggestions, and recommendations for the future.

CHAPTER 1: LITERATURE REVIEW

With life expectancy increasing in the United States thanks to advancements in medicine and technology, chronic illness and disability have become ever more present in our social world. Prior scholarship has examined chronic disease generally in the US. This general examination has included actual/perceived social expectations of the chronically ill, and what it looks like to live with chronic illness through the lens of the medical model. Overwhelmingly and concerningly absent from the literature surrounding chronic illness are the lived experiences, provided by the sociological model, of college age women with Type One Diabetes (T1D).

There are two primary models for examining illness and its experience: the medical and sociological. Under the medical model, illness is understood as bodily impairments which denote difference and result in the expectation to seek treatment and cure. Past and present research, under the guidance of the medical model, has increased the scientific understanding of type one diabetes reflected in the earlier sections of this literature review. Missing from the medical model is attention paid to relevant social forces and our wider, social world – gaps able to be addressed by the sociological model. Therefore, in comparison, the sociological model places emphasis on the ways in which society produces and contributes to health at the micro and macro level (Weitz 2010). When it comes to solutions to health issues, the sociological model examines changes to be made at the micro/individual and macro/societal level to benefit the entire population (Weitz 2010).

Like the work of sociologists such as Peter Conrad (1987), this thesis desires to contribute to and expand the presently existing literature's discussion of illness experience. To do so, this thesis works to understand the chronic illness experience subjectively, rather than through the objective lens focusing on disease and its treatment imposed by the medical model

(Barker 2005). Like Conrad and others, the central questions utilized to guide the review of illness experience within the existing literature were:

“How do the chronically ill understand and make sense of their illness? How do they adapt to, and cope with, the biological and social restrictions of chronic illness? And, how do they deflect self-erosion in the face of those biological and social restrictions?” (Barker 2005:69).

Within the first chapter of this thesis, the medical and sociological models of illness are foundational to the examination of the existing scholarship’s coverage of: the expectations posed by the medical model’s sick role upon those who are chronically ill; what it looks like to live with a chronic illness; strategies commonly employed to manage stigma; and the emotional tolls resulting from the tensions between expectations and reality. All examinations are conducted in relation to how lived experience is impacted by stigma, gender theory, and age to address the gaps which deprive the literature of the ability to directly speak to the lived experiences of stigmatization faced by college-age women, with type one diabetes.

Chronic Illness and Disease in the United States

Illness and medical conditions can be acute or chronic (NCOA 2022). Acute illnesses “develop suddenly and last a short time, often only a few days or weeks” (NCOA 2022). Chronic “develop slowly and may worsen over an extended period of time – months to years” and “make(s) it difficult to perform one or more activities generally considered appropriate for persons of a given age” (NOCA 2022; National Center for Health Statistics 2008a). For this thesis surrounding type one diabetes (T1D) within college-aged women, chronic illness is of focus and interest.

According to the American Action Forum, “chronic disease in the United States, [is] already highly prevalent” (Hayes O'Neill, Tara, and Serena Gillian 2020). Presently, 6 out of every 10 American adults are diagnosed with a single chronic condition and 4 out of 10 possess two or more (CDC 2022b). These percentages are “expected to worsen over the next several decades among all age groups” as medical and technological advancements continue to increase life expectancy (Hayes O'Neill et al. 2020; Weitz 2010:137). Therefore, an unintended consequence of such advancements is that chronic illness has become an ultimately unavoidable identity category, given that one lives long enough (Samuels 2003). Because women live longer, on average, than men, the prevalence of chronic illness is greatest among American women (Weitz 2010:137). Such is important to note as the illness experience of college-age women are of concern for this thesis project.

The products of the worsening issue of chronic disease in the US most heavily recognized by the existing literature are increased “burden[s] of (the) associated physical and economic costs” (Hayes O'Neill et al. 2020). Physical costs associated with chronic disease are multifaceted (Weitz 2010). Great physical and bodily tolls correspond with the decline in one's health brought on by chronic illness. These take most tangible form in the comorbidities those with chronic illness are at increased likelihood of suffering from.

The economic costs of chronic illnesses are enormous at the individual and global level (Hayes O'Neill et al. 2020). At the individual level, “health care costs of individuals with chronic disease...dwarf those of individuals without” (Hayes O'Neill et al. 2020). In 2020, the average cost for those living with chronic conditions averaged “\$6,032, approximately 5 times that of a person without a chronic disease,” with higher costs stemming from more frequent emergency and routine medical visits, and “greater prescription drug use” (Hayes O'Neill et al. 2020). The

\$6,032 however, only refers to direct costs – or those pertaining to *required*, or care deemed ‘medically necessary’ (Hayes O’Neill et al. 2020). Indirect costs also plague those who are chronically ill. Such costs are those less easily quantified and “far beyond [those within the realm of] medical care” (Hayes O’Neill et al. 2020). These costs can include hits taken to education, employment, social life, and other aspects of general wellbeing which ultimately have a negative impact on financial standing.

At the global level, “an estimated 84 percent of health care costs” result from treatment of chronic disease (Hayes O’Neill et al. 2020). According to the Centers for Disease Control and Prevention (CDC), “chronic diseases such as heart disease, cancer, and diabetes are...leading drivers of the nation’s \$4.1 trillion in annual health care costs” (CDC 2022a). Of the most prominent chronic diseases recognized by the CDC – heart disease, cancer, chronic lung disease, stroke, Alzheimer’s disease, diabetes, and chronic kidney disease – diabetes, heart disease, stroke, and cancer are categorized as “Major Chronic Diseases” (CDC 2022a). For this thesis project examining related experiences with stigma for college-aged type one diabetic women, it is necessary to relate the economic burden associated with diabetes. The Juvenile Diabetes Research Foundation (JDRF) – the leading nonprofit in the funding of type one diabetes research – reports that annually, “there are \$16 billion in T1D-associated healthcare expenditures” (JDRFa). With the number of Americans 65 years and older expected to “more than double” by 2060 the financial, and therefore physical and emotional, costs of living with T1D continue to steadily increase (Hayes O’Neill et al. 2020).

Closely tied to the physical and financial costs of chronic illness, but largely underrepresented and absent within the existing literature, are the emotional costs stemming from the toll taken on one’s emotional state as they grapple with the permanence of changes

coinciding with a chronic illness diagnosis (Weitz 2010:138-9). The limited presence and concerning overall absence of the emotional costs are of specific and increased focus for this thesis project. To best attempt at understanding these costs, it is necessary to relate the understanding of type one diabetes – the illness of focus – derived from existing scholarship.

Type One versus Type 2 Diabetes

Of the many chronic diseases recognized by the CDC, the one relevant to this thesis project is type one diabetes (T1D). There are two types of Diabetes: Type 1 and Type 2. Type One Diabetes is a chronic, autoimmune disease that occurs when the body suffers an autoimmune response resulting in an attack of itself. In this attack, the body kills all beta cells responsible for producing insulin – the hormone which allows the body's cells to absorb blood sugar and create energy – within the pancreas (JDRFa). Type 2 Diabetes (T2D) is a long-term, and sometimes chronic condition (CDC 2021). In T2D, the body is still able to produce insulin but lacks the ability to utilize it correctly, resulting in insulin resistance (JDRFa).

The key to distinguishing between the two types is to determine whether the body produces insulin. When one has T1D their body does not. When one has T2D their body does, but their cells “don’t respond normally” (CDC 2021). In T2D, the “pancreas makes more insulin to try to get cells to respond by reducing rising blood sugar levels” (CDC 2021). Because one’s body still produces insulin, management of T2D is much less involved than T1D. Unlike those with T1D, individuals with T2D “may be able to manage [and reverse their Type 2] diabetes with healthy eating and being active” (CDC 2021). T2D can be easily managed and even reversed if these healthier lifestyle choices are adhered to (CDC 2021). For those with T1D, there is no reversal which can be secured once onset occurs. While the progression of T1D can

be delayed through medical treatments and therapies which “prevent[ing]... further damage of [beta] cells in people who are newly diagnosed,” onset cannot be reversed nor prevented from occurring once the body has begun to attack itself and kill its beta cells (Mayo Clinic 2022).

The causes of Type One and Type Two Diabetes differ immensely. Contrary to common belief, type one diabetes does not result from poor dietary or lifestyle choices (JDRFa). It is a chronic illness which develops completely outside and beyond the control of the individual. The same statement cannot be made for type 2 diabetes. Factors such as poor lifestyle and dietary choices are proven causes of T2D (JDRFa). Hereditary factors, viral infections and environmental factors have been identified as potential causes for both types (JDRFa). For type one diabetic, those with relatives with the condition are fifteen times more likely to develop it – but a family history can and is often absent for many newly diagnosed T1Ds (JDRFb). For T2D, family history is both a proven cause. Family history doubles as an example of an environmental factor contributing to onset of T2D as one reared in an environment promoting engagement with unhealthy lifestyle choices is placed at a greater chance of being diagnosed with T2D (JDRFa). For T1D, no specific connections can be drawn as the exact cause(s) remain unknown (JDRFa).

A Basic Understanding of Type One Diabetes

Symptoms and Onset of T1D

According to the CDC, individuals of any age can develop type one diabetes (2022c). T1D has historically been, and is still inaccurately, referred to as “Juvenile Diabetes” due to the original understanding that onset was isolated to childhood and adolescence. Presently, approximately 1.45 million youth and adult Americans live with T1D, and that number is expected to more than triple by 2050 (JDRFa). Each year, approximately 64,000 Americans are

diagnosed with T1D, with the majority – but not all – of onset taking place during childhood and early adolescence. Presently 200,000 of the approximate 1.45 million Americans with type one diabetes are under the age of 20 (JDRFa; Beyond Type 1 2018).

According to the Juvenile Diabetes Research Foundation (JDRFa), symptoms of Type 1 Diabetes include: frequent urination, extreme thirst, dry mouth, fatigue and weakness, increased appetite, unexplained weight loss, slow-healing cuts/sores, and yeast infections. Other symptoms include feeling abnormally tired or lethargic; limb pain; changes in vision; fruity-smelling breath; and nausea or vomiting.

When an individual presents with these symptoms and is suspected to have T1D, a test is performed to measure their current blood glucose level. If found to be elevated and outside of the advised range, a Glycated Hemoglobin (HbA1c) test will be conducted to determine the individual's average blood-glucose level over the past 3 months. If that is also found to be elevated, a diagnosis of type one diabetes will follow (JDRFa). After diagnosis, it (typically) takes time for the body to kill off all remaining beta cells producing insulin (JDRFa). This period post diagnosis, and prior to elimination of all insulin production, is recognized as the “Honeymoon Phase” (JDRFa). This period receives this bliss-associated title from the lower doses of prescribed insulin needed to manage blood glucose levels. As a result, proper management, and control of blood sugar levels during this period is temporarily, but notably easier to attain. During the honeymoon phase, the individual's body functions minimally, until the disease deprives it of the ability to produce all insulin (JDRFa).

Management and Treatment of Type One Diabetes

Although a cure is yet to be discovered, type one diabetes is no longer the fatal diagnosis it once was before insulin was invented in 1921 (JDRFa). Thanks to advancements in medicine and technology – such as the creation of differing types of insulin, insulin pump systems, and now artificial pancreas systems – the prognosis is increasingly less bleak. Still, the management of T1D is heavily involved, and a sentence in and of itself. Day to day life with T1D consists of managing not only blood sugar levels but carrying the pressure of maintaining one's present and future quality of life (Weitz 2010). Depending on access and personal choice, blood sugar levels can be checked manually with traditional meters and pricking of fingers using a lancet needle device; with the more advanced technologies of continuous glucose monitors; or via CGMs which involve the placement of a wire-like needle under the skin, capable of tracking the levels and movements of one's blood sugar levels for 2 weeks' time. To better keep blood glucose levels within advised ranges, carbohydrates must be accurately measured to properly calculate required insulin dosages (JDRFa). Insulin must be administered continuously throughout the day, as needed to treat all carbs consumed, and to treat hyperglycemic blood glucose levels, or those which are too high. Insulin can be delivered via syringes, pens, insulin pumps, and/or newly developed artificial pancreas technologies. Under the knowledge of their practitioner (typically an Endocrinologist or Medical Professional specializing in the field), everyone is given a personalized insulin-to-carb ratio which informs them of how many carbs are covered by 1 unit of insulin. This ratio can and often varies with the time of the day, so time of meals must be accounted for as well (JDRFa). The many demands of this illness result in the need to be extremely conscientious of things consumed and executed by one's body. Immense benefits and increases in success of management have been proven to be linked to engagement in practices

such as eating a well-balanced diet –consisting of ideally conscientious carb in-take–, regimented exercise, and regular sleep have continuously proven to assist in securing increased time in which blood sugar levels are in ideal range. Therefore, engagement in practices like these have been proven to be advantageous to securing a better present and future quality of life.

Complications of Type One Diabetes

As a result of the chronic nature of Type One Diabetes, there are many side effects and health conditions likely to develop over time (JDRFa). While “proper maintenance [of blood sugar levels] and routine checkups” can help to mitigate complications, they are difficult to prevent as it is ultimately impossible to ensure that one’s blood sugar levels remain within advised ranges at all times as it is immensely challenging to balance insulin levels with varying food intake, exercise, sleep levels, etc. presented by the volatile nature of everyday life. Thus, ‘perfect’ management is impossible to achieve, and results in the existence of many complications and comorbidities for those with T1D (JDRFa).

Per the Mayo Clinic (2022), complications of T1D include: heart and blood vessel disease, nerve damage, kidney damage, eye damage, foot damage, skin and mouth conditions, and pregnancy complications. Therefore, due to the close relationship T1D shares with other comorbidities, it is necessary that those with T1D have regular check up with many medical professionals such as: endocrinologists, retina specialists, dietitians, and dentists to best ensure preservation of their health and quality of life.

Living with Type One Diabetes

The Medical Model of Illness

This thesis focuses on college-aged women's lived experiences with Type One Diabetes, a concept that sociologists call illness. Unfortunately, much of the literature telling the story of type one diabetes in the United States is conducted through a medicalized lens, which focuses on the physical aspects of the disease and medical treatment of it, rather than the lived experience. The medical and sociological models are vastly different in their approach to understanding and considering illness. Under the medical model, illnesses are expected to be addressed and cured by treatments, even when the illness may be chronic and therefore, incurable. The medical model focuses on what is 'wrong' with the ill individual, grounding its labeling as ill and/or disabled based on their bodily dysfunctions. The sociological model of illness exists in opposition to the medical model. This model examines and recognizes the way illness and disabilities are produced by society by considering social, cultural, and political factors which contribute to the individual's bodily malfunctioning (Weitz 2010).

The existing literature's understanding of acute versus chronic, chronic illness in the US, and the specific example of type one diabetes are all products of the medical model of illness (Weitz 2010). This model describes and portrays illness in terms of the ways it strays away from normal biological functioning (Weitz 2010). This model views illness as an "objective, scientific process," detached from personal feelings and opinions and dependent heavily upon the concept of medicalization (Weitz 2010:113). Explored and defined by Peter Conrad (1992), medicalization refers to the "process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders" (209). As a result of its role in determining what is and is not a 'medical problem,' medicalization impacts the extent to which

ill individuals are able to receive medical treatment. On the one hand, medical diagnoses can destigmatize the experiences of the chronically ill as their existence reflects acknowledgment of the legitimacy of the ill person's experiences. This de-stigmatization is challenged however, by the fact that physicians retain authority over the ill individual in their own experiences as patients within the power dynamic perpetuated by the medical model. This authority granted to the medical field and its workers has resulted in the defining of "deviance...as particular forms of illness, sickness, or disease" reflects "the rise of medical social control" that has come to define the history of the United States (Schneider and Conrad as quoted in Roth 1980:3).

US society's dependence on the medical model and submission to medical social control has resulted in critical gaps in the existing literature's representation of illness experience at the micro and macro level. Through its production of a "lack of fit between healthcare environments," the chronically ill are frequently put in the position of having to "educate their physician[s] about the fundamental [and everyday] aspects of their disabilit[ies]" (Dillaway et al. 2022:64-65). Physicians treat physical symptoms, so patients are taught to think that they must appear and present as ill to be seen as deserving of time and treatment. Such a mentality imposed by the medical model reflects a critical failure on society's behalf to fulfill the basic needs of the chronically ill (Dillaway et al. 2022:59). This need to look ill is explored within "The Body and Self: Adapting to Impairment" (2022). Here, Kathy Charmaz explores the disruption of "unity between body and self" resulting from identity changes imposed upon individuals by a chronic illness diagnosis (1995:657). Through a completion of 115 interviews of chronically ill people, Charmaz sheds light on how one of the most concerning products of the medical model's ableist foundations is the created need and dependence upon the ill needing to discernibly present as such to ensure "credibility with health care practitioners" (Charmaz 1995:665). Lack of

alignment with these presentation expectations is raised by individuals like those of focus in this thesis project: Type One Diabetics. Not only a chronic, but an invisible illness, type one diabetes challenges the medical model's dependence upon one's adherence to the ideals of the 'sick role,' as developed by Talcott Parsons (1975) and therefore falls into a noticeable gap within the existing literature's ability to speak to the experiences of those existing outside the bounds of this role.

The Sick Role

The sick role dictates "how sick people should behave," and work to treat and overcome their illness, thus revealing its alignment with acute rather than chronic illness (Weitz 2010:125). The sick role, like the medical model from which it stems, notably fails to recognize chronic illness as beyond individual control and out of alignment with the desire to "get well" (Weitz 2010:125). Chronic illnesses like type one diabetes challenge this role as these conditions can only be managed, not cured. The sick role and the medical model fail to take note of this and impose unrealistic expectations upon those who are chronically ill. What results from the relentless expectation to adhere to the ideals of the sick role: visibly presenting as sick and possessing the desire to get well, is the erasure of the experiences of those who stray from this norm imposed by the medical model.

Not only does this model have dangerous consequences for the chronically ill, but for women as well. Derived from the medical model, the sick role carries with it roots of gender discrimination and sexism stemming from the historical delegitimization of women's health experiences through over dependence on hormonal factors (Weitz 2010; Cahill 2001). Therefore, as Weitz (2010) explains, being a woman correlates with significant barriers to securing the

medical treatment socially expected of one to seek out and secure. So even though women are more likely than men to seek help, they are less likely to have their symptoms taken seriously, therefore hindering their ability to secure medical attention and remain in alignment with the ideals of the role (Weitz 2010).

The Sociological Model of Illness:

The shortcomings of the medical model of illness and its sick role highlight the overall failure of existing literature to foster an understanding of what it means to live with a chronic illness (such as Type One Diabetes) within, rather than isolated from, the context of US society.

The sociological model of illness presents an “opposing” way to examine the meaning of illness within our society (Weitz 2010:108). This model “summarizes critical sociologists’ retort to the medical model of illness,” revealing how the world, rather than ideally, constructs illness (Weitz 2010:110). Under the sociological model, illness is recognized as a *subjective* label and a social construction (Weitz 2010). Diagnosis is recognized as a “subjective process” which carries enormous consequences and negative connotations: “when we define... [something such as] diabetes as illness, we judge the bod[il]y changes these conditions produce to be both abnormal and undesirable, rather than [as] simply normal variations in functioning, abilities, and life expectancies” (Weitz 2010:112-3). This model exposes how within our society, an ill individual is synonymous with “one whose actions, abilities, or appearance do not meet social norms, or expectations within a given culture regarding proper behavior[s] or appearance[s]” (Weitz 2010:112). Such demonstrates how illness triggers individuals to violate norms and social expectations, and therefore becomes a “moral status,” telling of one’s “goodness or badness, [and] worthiness or unworthiness” (Weitz 2010:112).

The lens of the sociological model of illness sheds light on the many social constructions and negative consequences produced by the dominating, medical model (Weitz 2010). Medicalization hinders the social statuses of those diagnosed due to the ties it creates between illness and deviance (Parsons 1951). These ties make it so that the labels ‘chronically ill’ and ‘disabled’ are tied not only to one's bodily malfunctioning, but to their supposed lacking moral and interpersonal qualities (Weitz 2010). Under medicalization, “medical treatment [frequently] become[s] the only logical response to” one’s illness, and such is reflected by the existing literature’s overall inability to engage the holistic approach called for by the sociological model. This model emphasizes the need to examine illness at not just the micro, but macro level (Conrad 1992 within Weitz 2010:119). Medicine functions “as an institution of social control by pressuring individuals to *abandon* sickness,” and code illness as deviance for the way it bars individuals from engaging in expected social tasks and scripts (Parsons 1951 within Weitz 2010:124).

The glaring gap in the existing literature is an absent sociological lens, focusing on the lived, everyday micro-level experiences within the macro-level context of US society as pertains to illness. Considering this thesis on college-aged women’s lived experiences with Type One Diabetes, an application of this lens is necessary to understand what it means to live with a chronic illness, and how the misalignment between societal expectations and realities results in significant tensions and consequences for these individuals.

Living with Chronic Illness

The term ‘chronic’ only partly communicates the inevitable permanence of an altered life one must live post chronic illness diagnosis (Weitz 2010). In US society, the chronically ill are

expected to accept their location within the bounds of the sick role and therefore, all behaviors that come with it – such as the need to engage in attempts to get better. Under the medical model, individuals are expected to “com[e] to terms with a body that does not meet social expectations for behavior or appearance” while simultaneously “nurturing social relationships despite a contrary body, and constructing a viable life-sustaining sense of self” (Weitz 2010:131). An account provided by Nancy Mairs, a woman living with multiple sclerosis (MS) powerfully captures the distress resulting from pressure faced by the chronically ill (and disabled) to adhere to able-bodily driven expectations:

I don't like having MS. I hate it. My life holds realities – harsh ones, some of them – that no right-minded human being ought to accept... My life often seems a series of small failures to do as I ought... [Over time], I [have] learned that one never finishes adjusting to MS. I don't know now why I thought one would. One does not, after all, finish adjusting to life, and MS is simply a fact of my life... It may at any time get worse, but no amount of worry or anticipation can prepare me for a new loss. My life is a lesson of losses. I learn one at a time. (Mairs 1986 as quoted in Weitz 2010:131)

The failures and losses Nancy references support chronic illness onset and diagnosis as events producing significant changes to the perception of oneself and body. These changes result from the tensions which exist between perceived social expectations and realities for the chronically ill. Thus, the chronically ill's “image of self” predating their diagnosis and/or that which they are expected to have, must be either modified or altogether abandoned “to accommodate disability and impairment” (Dillaway et al. 2022:66). The reconstruction of one's self-image in response to chronic illness diagnosis possesses no end. This process too is chronic in nature as individuals, like Nancy Mairs, “are forced to adapt repeatedly as they experience new losses” (Charmaz

1995:657). These emotional tolls present within Nancy Mairs's account are critical to this thesis project seeking to extend beyond the physical and financial tolls focused on, at the expense of emotional tolls, by the medical model. To attempt to understand the experiences of college-age, type one diabetic women's stigma-related experiences, gaps in existing literature's discussion of this tension and its production of emotional tolls must be addressed to incorporate the sociological understanding that chronic illness is more than a diagnosis or physical experience. Rather, it is a never ending, mental, emotional, and psychological process fueled by failures to act as society expects (Weitz 2010).

Perceived Social Expectations: What do the chronically ill think they are supposed to do?

Social expectations, or social norms, enforce "proper behavior or appearance" within the context of a given culture, group, or society (Weitz 2010:112). In response to one's adherence to or divergence from social expectations, positive or negative social sanctions result (Weitz 2010:112). Positive social sanctions include reactions such as celebration, promotion, and approval while negative include those such as embarrassment, shame, and criticism (Weitz 2010). Chronic illness, the identity and experience relevant to this thesis, is an identity which causes the individual to violate social expectations and be negatively, socially sanctioned.

US society is an ableist society led by the expectation and assumption that all 'normal' bodies function to their fullest capacities. Chronic illness, disease, and disability therefore produce tensions between expectations and realities within our social world. The cumulation of existing literature on varying chronic illnesses and disabilities demonstrates how illness's "abnormal state...[is] constructed as negative and stigmatized" by the medical model (Dillaway et al. 2022:6; Royer 2004).

From the research has appeared three overarching and simultaneously occurring expectations for the chronically ill. These expectations are the expectation to return as things were pre-diagnosis/onset, to ignore bodily discomforts, and to maintain adherence to prescribed gender roles respective to one's given age.

The Expectation to Return to as Things Were

The first key expectation of the chronically ill reflected by existing literature is the ability to return to the life and person they were pre-onset and diagnosis. Studies such as Kathy Charmaz's (1995) "The Body Identity and Self: Adapting to Impairment" expose the unattainability of this expectation, for those who are chronically ill, by shedding light on the permanent and constantly evolving changes diagnosis imposes upon one's self-conceptualization and image. Inherent of the medical model's acknowledgment of the burdens of illness is the failure to possess proper awareness of "the temporary and/or permanent impairments [likely to] result from treatment or progression of these diseases and the disabilities" (Dillaway et al. 2022:62). The absence of this understanding reflects not only the model's, but US society's inability to recognize the impossibility and ableism inherent of their belief that one with a chronic illness can ever return exactly to the person and life they once took part in (Dillaway et al., 2022:62). Such is impossible because chronic illness disturbs the "sense of wholeness of body and self [and intrudes upon a person's daily life] and undermines self identity" (Charmaz 1995:657). So, how can one ever be expected to act as though nothing has changed and return to life as 'normal' - when their ability to partake in society's normal has been ripped from them (Royer 2004; Weitz 2010)? They should not be, yet they are, and with that comes the second

pervasive expectation prevalent within the existing literature: the expectation to ignore bodily discomforts.

The Expectation to Ignore Bodily Discomforts

Closely tied to the expectation to return to as things were pre-diagnosis/onset is the widespread expectation to ignore bodily discomforts (Charmaz 1995). When an individual is ill, they are expected to take on the medical model's 'Sick Role' (Parsons 1975). Within this role, individuals are expected to visibly present as ill and seek treatment/cures necessary to foster alignment with institutionalized, able-bodied, social expectations. When one is chronically ill, it is management, not treatment and cures, that are and can be sought out. This relentless pressure prescribed by the sick role to seek out treatment and cures to be deserving of positive social sanctions is exhausting financially, physically, and emotionally for the chronically ill. The physical and emotional exhaustion, as well as dangers imposed by the pressures to succumb to this expectation are effectively and poignantly captured by Christine Miserandino's (2003) "The Spoon Theory."

The Spoon Theory

The Spoon Theory functions to combat the medicalization of all illness experiences imposed by the medical model and its sick role through its provision of an easily accessible metaphor for living with illness (Miserandino 2003). It is a critical tool for this thesis project examining college-age women's experiences with stigma resulting from their identities as type one diabetics. Miserandino's theory is derived from her identity and experiences as a woman with Lupus – a chronic illness also qualifying of disability. The Spoon Theory sheds light on the

ableism inherent within and therefore inappropriateness of the imposition of the expectation to ignore bodily discomforts upon those with chronic illnesses. Engagement in the decision to ignore bodily discomforts is a choice disabled bodies are not privileged to have if they wish to make it through one's day, let alone one's life. Utilizing spoons as a metaphor for one's energy, Miserandino created the metaphor of the Spoon Theory to shed light on how "the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to (Miserandino 2003:1). Within the Spoon Theory, those who are healthy are gifted a "never-ending supply of spoons" (Miserandino 2003:1). The same cannot be said for those who are chronically ill. They must meticulously and strategically plan their day around their starting number of spoons, or the total energy they possess. Unlike medicine and its model are claimed to be, chronic illness resides in the territory of being inherently imperfect. Despite all planning and strategizing executed, there is no "guarantee that you might not lose some [spoons] along the way, but at least it helps to know where you are starting" (Miserandino 2003:1). The Spoon Theory is explained by Miserandino (to a friend) as follows:

I asked her to list off the tasks of her day, including the most simple. As she rattled off daily chores, or just fun things to do; I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said 'No! You don't just get up. You have to crack open your eyes...You didn't sleep well...You have to crawl out of bed... you have to make yourself something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too.' I

quickly took away a spoon and she realized she hasn't even gotten dressed yet.

(Miserandino 2003:2).

Before arriving at work, Miserandino's friend was left with just 6 spoons and was repeatedly reminded to proceed strategically with caution because not only are spoons gone when they are gone, overuse of one's energy provides a harsh reminder and reality check of how "how hard tomorrow will be with less" (Miserandino 2003:2).

Christine Miserandino's Lupus is especially relevant to this thesis project's focus on the lived experiences of women with type one diabetes – another invisible illness. Invisible illnesses (and disabilities) are those for which symptoms and impairments are not always discernible to the naked eye, but still limiting of engagement in day-to-day life activities (Invisible Disabilities Association). Discussion of the literature's interaction with invisible, illnesses is especially important to this thesis project because this illness category further highlight the shortcomings of the medical model and its sick role:

Much of our understanding and treatment of disability and chronic illness comes from our knowledge of the 'sick role'. Unfortunately, healthcare institutions remain staunchly committed to ideologies and practices that reinforce that one must look 'sick' to receive care (Dillaway et al. 2022:65)

The expectation and reinforcement of the need to "look 'sick' to receive care" is incredibly problematic for the chronically, but more especially the invisibly, chronically ill (Dillaway et al. 2022:65). This blind spot of the medical model's Sick Role contributes to the erasure and delegitimization invisible illnesses suffer within American society. Through its overall disregard for this population, it delegitimizes the volatile nature of many illnesses and impairments such as type one diabetes and Lupus (Dillaway 2022). When individuals are invisibly and visibly,

chronically ill they are expected to ignore bodily discomforts to remain in alignment with the sick role's treatment and cure-centered mindset. The existing scholarship takes the construction of this phenomenon within the chronic illness experience one step further, reflecting how adherence to the sick role is further complicated by the issue of gender discrimination in US society. Discriminated against in our sexist society for their gender and potential failures to align with expectations of their given age, women and their illness experience face increased delegitimization and erasure at the hands of the medical model.

The Expectation to Maintain Adherence to Gender Roles and Expectations of a Given Age

Those who are chronically ill are not exempt from social expectations and discrimination resulting from societally enforced gender and age roles. While there are differing expectations for chronically ill men and women prevalent in the literature, those relevant to this thesis surround women.

Social expectations are gendered. An examination of West and Zimmerman's (1987) concept of "doing gender" serves useful as it is centered around the concept of gender as something performative in nature, accomplished through action, and therefore able to be discredited. Recognizing gender as a social construct rather than a biological trait, West and Zimmerman explore and defend how gender is created, coded, and performed "routine[ly], methodical[ly] and [as a] recurring accomplishment" through social interaction (1987:126). Individuals are taught to adhere to social expectations to avoid negative sanctions and discrediting inflicted when one violates notions of their respective gender: "if we fail to do gender appropriately, we as individuals– not the institutional arrangements – may be called to account" (1987:146). West and Zimmerman (1987) recognize that gender expectations are not

universal. The pressures faced by men and women vary according to the differing requirements for proper social embodiment of masculinity and femininity. Within the context of this thesis project, isolation of the experiences resulting from gendered expectations faced by women are of primary concern to better understand the nuanced experiences of chronically ill, college-age women, living with Type One Diabetes.

The medical model and its healthcare institutions “reinforce social constructions of... structural inequalities for specific groups [such as women] in society” (Dillaway et al. 2022:64). Gender discrimination foundational to the medical model contributes to the additional stigma suffered by women at the hands of the medical model and its professionals (Nathanson 1975; Gabe et al. 2004 within Dillaway et al. 2022). Existing literature reports that disbelief and delegitimization of women’s health-related experiences stems largely from society’s portrayal as of women “poster[s] of health” (Cahill 2001). Thus, women’s higher engagement in help and health-seeking behaviors results from the gendered social expectation that women must constantly work to meet all their healthcare needs to remain in alignment with their poster-child identity (Charmaz 1995). Such alignment is challenged by the emotional and physical fragility associated with femininity, expecting women to prioritize balancing the emotions of others, especially their male partners or husbands, before and in addition to their own (Charmaz 1995). As a result, the literature reflected increased “stigma [brought] to women, especially if their symptoms are invisible or contested,” making them “predisposed” to face additional forms of stigma and erasure, by the medical model, in comparison to chronically ill men (Dillaway et al. 2022:63).

Within the context of this thesis looking at college-age women’s experiences with stigma stemming from their Type One Diabetes, existing literature widely suggests that expectations

and ideals of “youth and beauty render an invisible illness even more invisible” for chronically ill women than men (Charmaz 1995:666). Thus, closely tied to gendered expectations are those pertaining to age. This notion of “youth” highlights one of the foundational gaps in the existing literature this thesis is working to address: an absence of representation of *college-age* women’s experiences with chronic illness. When it comes to existing literature on those with type one diabetes, there is a significant gap in overall representation and coverage of college-aged individuals (typically aged 18-22). Instead, the extensive scholarship is situated on the front and back end of age. At the front end, there is much literature present and examining youth, and therefore parental, experiences with type one diabetes (JDRFa). At the back, there is broader literature of how chronic illness and disability play out in working and professional scenes of adulthood (Clair et al. 2005). While the front and back ends are necessary to traverse the gap in literature surrounding college-aged individuals, and more specifically women, neither accurately capture the threshold between childhood and adulthood, or dependence and independence defining this demographic’s stigma-related experiences.

The shortcomings of literature representative of childhood experiences are encapsulated by studies such as Allen’s (2013) study on the concept of ‘normal adolescence’ and the experiences of young people and their parents with T1D. In their examination of this age demographic, it is unavoidable that studies like Allen’s delegate greater attention to the examination of experiences of parents and guardians, rather than those chronically ill children who are not independently managing/executing their care and stigma-related experiences (Williams 2000). Thus, while there are gendered findings relevant with the literature on adolescence, such as girls’ increased likelihood of integrating illness into their social identities than boys, this literature cannot speak properly to the experiences of the individuals with chronic

illness themselves because they are children (Williams 2000). This is where literature representative of professional/adult women's experiences with managing chronic illness and stigma comes into useful discussion.

Overall, this literature, situated at the back end, highlights the workplace as an important site of negotiation between differing interested and interacting parties. As highlighted by the work of Margaret Vickers, the workplace is just another setting within which the three overarching expectations examined above are rampantly present (1992 and 2001). Exploring testimonials of workers with invisible illness such as cancer, MS, and endometriosis, Vickers (2001) explores the marginalization resulting from the way their illness “disrupt[s] the taken-for-granted ways in which we strive to create order and predictability in our lives,” especially in institutions such as the workplace (Pinder 1995:607). For those with chronic illness such as diabetes, “the consequence[s] of stigma” resulting from their health differences are pervasive and take many overarching forms such as “job loss” and “social isolation” within the workplace (Clair et al. 2005:79). Social isolation is critical to this thesis project and will be explored in the section: “Results of the Tensions Between Social Expectations and Reality for the Chronically Ill: Emotional Labor.”

The literature which currently exists speaks to the front and back-end age experiences for a wide slew of illnesses and disabilities present in the literature. For this thesis project, I am interested in a specific age and illness. I am interested in college-aged women with T1D and the stigma resulting from the social expectations plaguing these age, gender, and illness demographic (Dillaway et al. 2022). Situated at the threshold between dependence and independence, childhood and adulthood, college-age women's experiences with T1D are left under theorized and unrepresented in existing literature. Transitions inherent in this age include

living on one's own, in communal settings, and away from parents/guardians and other established support networks. Such results in an increased responsibility in their management which may serve crucial in determining/explaining their long-term care for this disease (Ramchandani et al. 2000). Yet even though these shifts have occurred and moved them away from childhood, college-aged women are largely not yet in the workforce nor their desired professional role, revealing the opportunity to utilize this project to address that gap.

What it Looks Like to Live with Chronic Illness: The Reality of Living with Chronic Illness

From the expectations faced by the chronically ill results a reality defined by management of stigma. The need to engage in this practice results in the engagement of the strategies of passing and/or disclosure. Overall, when it comes to the discussion of what chronically ill individuals actually do, the existing literature depicts a concerning hole in its depiction of the everyday experiences of those with chronic illness within the US.

Managing Stigma

Stigma is inevitable for those who are chronically ill due to the medicalization of deviance making negative social sanctions a natural consequence of chronic illness onset and diagnosis (Goffman 1963). Stigma, first defined by Erving Goffman, is an “attribute that is deeply discrediting” (1963:3). Stigma can exist at the micro and macro level. Thus, it is widespread, making it so that most individuals have or will experience stigmatization “at least in some connections and in some phases of [their] life” (1963:138). Contemporary studies have also contributed significantly to our continued understanding of stigma within the context of chronic illness. Stigma results because “we are taught to think negatively of those who go against, or break, the prescribed norms of society” (Dillaway et al. 2022:67). Therefore, to avoid negative

sanctions and combat negative thoughts directed their way, chronically ill and disabled individuals are socialized to “compensate in varied ways to manage the potential or actual stigma that they confront in public [and private] space[s]” (Dillaway et al. 2022:67). Two specific strategies of compensation and management pervasive in the existing literature are passing and disclosure.

Strategy #1: Passing

Passing is a technique which permits individuals to traverse identity boundaries and avoid being regarded as a member of one typically less desired (or safe) group to be identified as the part of a more advantageous other (Goffman 1963). Passing speaks to the assimilationist mindset which dominates the US’s able-bodied society, socializing individuals to engage in passing to escape stigmatized identities (Samuels 2003).

Within the context of this thesis project, passing can protect one from “having to come out to be recognized as disabled” or chronically ill (Samuels 2003:239). Invisible chronic illnesses like type one diabetes can privilege one to possess better ability to successfully engage in passing (Samuels 2003). With that acknowledgement of privilege, although those with invisible illnesses may, at times, face less barriers to passing, engagement does not come without its tolls and consequences (Samuels 2003). Chronically ill who engaged in passing through acts such as avoiding public treatment of their illness, reported a “profound sense of misrecognition and internal dissonance” or “self-betrayal” (Samuels 2003:230 & 40). Within the existing literature, studies, and testimonials of the chronically ill expressed sentiments of discomfort, exhaustion, guilt, “self abasement,” and shame in response to the fact that their body’s “failure to meet [ableist] standards” triggered their engagement in passing (Royer 2004; Charmaz 1995:663; Glassner 1988). These negative sanctions, as well as tolls on their physical and mental wellbeing

overwhelmingly outweighed the potential protection from “being stigmatized and isolated” passing was initially thought to promise (Royer 2004:8). Due to this, passing is painted as exhausting, difficult to maintain, and undesired by existing literature (Samuels 2003). Thus, when one never or no longer desires to pass, the strategy of disclosure may be selected (Samuels 2003).

Strategy #2: Disclosure

Like passing, disclosure is not “a static [nor] singular event” (Samuels 2003:237). Unlike passing, disclosure can be best understood through its resonation with the idea of “coming out” and making unknown/unclear information known (Samuels 2003:237). As a result of its expository nature, existing literature paints disclosure overall as an anxiety inducing concept and experience for the chronically ill (Royer 2004). Disclosure can be an autonomous act or one inflicted upon an individual if they were to be ‘outed’ against their desires (Samuels 2003). The “worry that their disability will ‘overshadow’ the rest of their identity, at least in others’ minds” was pervasive in the literature (Dillaway et al. 2022:67). This anxiety resulted in widespread concern “about whether others would understand and be considerate of their disabilities” (Dillaway et al. 2022). Plagued by the need to manage stigma, the strategies of passing and disclosure are relevant in the context of this thesis focusing on the experiences of chronically ill, college-aged women with type one diabetes as they highlight gaps in the literature’s portrayal of the way in which these practices manifest and impact individuals of the desired age, disease, and gender.

Results of the Tensions Between Social Expectations and Reality for the Chronically Ill: Emotional Labor

Emotional Labor, coined by Dillaway et al. (2022), best articulates the many unseen costs associated with chronic illness reflected by the literature. Through its primary focus on visible physical and financial costs chronically ill bodies face, such as comorbidities one is at increased risk/predisposed to experience because of their diagnosis, the medical model turns a blind eye to emotional tolls suffered by the chronically ill. Thus results an absence of comprehensive coverage of the less visible, emotional costs for the chronically ill who reside in the tense space between expectations and reality. Emotional labor involves the “reconciling perceived and real versions of self and negotiating societal expectations of what someone ‘should’ be like in public” (Dillaway et al. 2022:67). This labor captures a significant part of “the daily living experience” for the chronically ill that remains concerningly unseen by existing scholarship as a result of its failure to move beyond Goffman's concept and theory of stigma to capture interactions at the micro-level (Dillaway et al. 2022:67). Within the literature that exists, the emotional tolls suffered by the chronically ill are best reflected by widespread feelings of uncertainty and high levels of social isolation.

Feelings of Uncertainty

As a result of “the uneven course of acute episodes [or flare ups] of many chronic illnesses” such as type one diabetes, anxiety of the unknown is at the center of chronic illness experience (Royer 2004:10). Threatening the individual’s ability to be spontaneous, chronic illness limits and hinders their ability to adhere to social expectations such as ‘normal’ participation in social engagements like school and work (Royer 2004). To secure positive social

sanctions, “these feelings [of uncertainty] must be managed, so that more mundane tasks of learning to deal with these demands can be undertaken” (Royer 2004:12). To manage these feelings of uncertainty and worries and anxieties about the future, the chronically ill and disabled individuals interviewed in the literature share being taught to “learn how to preserve a reasonable emotional balance by controlling upsetting and negative feelings aroused by the illness” to ensure alignment with social expectations – ultimately not for the sake and best interests of others, not themselves (Royer 2004:12).

Social Isolation

Since December of 2020, approximately 40% of US adults with chronic illness have “report[ed] feelings of loneliness and being socially isolated” (CHRT 2020). As put by Royer (2004) in “Social Isolation: The Most Distressing Consequence of Chronic Illness,” life with chronic illness is a “no-win” situation when it comes to the fight against “alienation and stigma to prevent social isolation” within the US’s able-bodied society (15). Both a trigger and product of stigmatization, social isolation is pervasive and self-perpetuating in the chronic illness experience constructed by the accumulation of existing literature: “when [chronically] ill persons feel(ing) negatively identified, they... experience emotional isolation and remain unresponsive in the presence of others which contributes to further difficulties [and increases in isolation] in future periods of interaction” (Royer 2004:8). Within the literature, social isolation faced by the chronically ill resulted for two primary reasons: first as a consequence of time spent seeking treatment and medical care, and second from abandonment and avoidance of others (Royer 2004). The prevalence of social isolation, so closely tied to the feelings of uncertainty, experienced by the chronically ill was most blatantly expressed through losses suffered in one’s

ability to participate in everyday activities such as “fishing and camping with friends” that once contributed to the health and bolstering of their social networks (Royer 2004:6).

The feelings of uncertainty and social isolation which result from the tensions between expectations and realities for the chronically ill highlights how physical, financial, and emotional costs and tolls are not separate entities: “the social isolation resulting from their financial situation, as well as the stressful psychological burdens it creates, make the physical effects of their chronic illnesses all the worse” (Royer 2004:6). While the literature’s portrayal of the tensions lack specificity to the gender, age, and illness demographics of my thesis project: college-aged women with type one diabetes, there are components which may prove applicable and in alignment with the way in which my subjects of desired focus report navigation of stigma.

Conclusion

From the cumulation of existing scholarship examined above, chronic illness experience is primarily conducted through the medical model of illness. As a result, we can come to understand that there is something important about illness and management in light of stigma. Unfortunately, however, the literature’s portrayal of management reflects the social, cultural, and emotional barriers put in place by the medical model, thus preventing comprehensive understanding of lived experiences. Within the context of the desired chronic illness of focus: type one diabetes, there is literature present on the scientific underpinnings and experiences of individuals at the front and back end: adolescence and adulthood. Thus, the literature on type one diabetes reflects the over-medicalization and lack of use of the sociological model of illness within US society. As a result, the scholarship is deprived of focus on the desired gender and age and illness demographic of this study: college-age women with type one diabetes. Such led me to

wonder, can recent findings and the gaps they highlight allow us to think differently? Where can gaps in understanding be filled in to address the issues of stigma faced by college-age women suffering from T1D? Methods have thus developed to address this research problem.

To combat the barriers to understanding imposed by the medical model as reflected in existing scholarship, this thesis will attempt to pinpoint and feature the experiences of US college-age women living with T1D and their experiences with stigma. Methods developed will incorporate the conduction of interviews and analysis of public/social media figures of the demographic of focus of this study: college-age women with type one diabetes. Development of interview questions and analyses of public figures living with type one diabetes will allow for a sociological examination of the lived experiences of this population required to hone better understanding and articulation of the stigma-related experiences of type one diabetic, college-age women presently overlooked by the medical model foundation to the existing literature.

CHAPTER 2: METHODOLOGY

Methods

The purpose of this study was to address the limitations of the medical model via exploration of potential stigmatization faced by college-age women with type one diabetes (T1D) as well as relevant impacts, challenges, and forms of social. To do so, themes of public navigation and passing, disease management, disclosure, gender, and stigma were also examined. This study specifically explored how gender and expectations surrounding alignment with ideals of femininity may influence stigma-related experiences as well as the specific impacts of type one diabetes on their adjustment to college. To capture these experiences, analyses of the women's self-evaluations of present and former experiences with disease management and social support were conducted via in-depth interviews. This work sought to understand how college-age women with type one diabetes navigate life generally, as well specifically within the context of the academic and social settings relevant to college.

In alignment with the literature review conducted over the course of the fall term, the methods for this study surrounded an interest in whether or not the chronically ill individuals interviewed would similarly highlight the social expectations, realities, and emotional tolls present within examined, existing scholarship.

In this study I interviewed twelve current or former college-age women with type one diabetes in the Northeastern United States. Half were currently in college, and the other half had graduated at most eighteen years ago. In interviewing these women, I was interested in disease management, engagement in passing and disclosure, gendered experiences, as well as most preferred and (if unable to be secured) desired social supports. All themes were examined in relation to the women's perceptions of stigma.

Population and Sampling

The original intention reflected was to interview individuals within the Northeastern United States who fell into two different “client” categories. The first subject type intended to be studied was healthcare practitioners and/or professional support persons for those with type one diabetes. The second were current and former college-age women with T1D. The first subject type was selected with the hope of gaining greater understanding of the medical model’s perspective on challenges faced by this demographic, how such experiences may or may not be related to stigma, as well as formal support offered to this demographic. The women themselves were subjects of interest to provide a sociological perspective, grounded in first-hand experiences concerning absent within existing scholarship. The hope was that interviewing these women would shed light and provide insight into concepts ignored by the medical’s focus on disease rather than illness experience.

Interviewing the first subject type: healthcare practitioners and professional support persons for those with T1D proved unsuccessful. Thus, the subjects for this study were twelve present and former college-age women with type one diabetes. After contacting potential participants, snowball sampling techniques were utilized. Potential subjects were informed that participation in this study was voluntary and confidential, and that there would be no repercussions if they declined to participate. No deception of any kind was used. Zoom appointments were made with those who agreed to participate.

Informed Consent and Confidentiality

Research methods for this study involved interviews with present and former college-age women with type one diabetes to gain better understanding of their illness experience. Informed

consent was obtained by explaining to all participants the purpose of the study, how interviews would be conducted, and that all data collected would be kept confidential. Participants were not told which other women were also being interviewed. Participants were reminded before beginning that they could decline to answer any questions, ask clarifying questions, or end the interview if they wished to do so. The face-to-face interviews lasted between approximately thirty and 75 minutes and were held via Zoom. Permission was obtained to record the interviews and participants were informed they could ask to pause the recording feature at any point. The interviewees' names were not included nor stated within the recordings and transcriptions. All participants were identified by their reported graduation year. If there was more than one participant of that respective year, they were also denoted with a letter of the alphabet, starting with the letter "a". Access to the transcriptions of the interviews was limited to the researcher and advisor. All interview recordings, transcripts, notes, consents, and any other materials collected during the course of research were maintained in a secure location.

Participants were asked to sign the electronic interview consent form (see Appendix A), emphasizing the voluntary nature of this study before the interview was conducted. Interviews were conducted through use of the complete interview guides (see Appendix B) pre-approved by the Human Subjects Review Board at Union College. No deception of any kind was used in this study. At the end of the interview, the participants were debriefed with a more detailed explanation of the purposes of the study. Any identifiable characteristics of the participants, including colleges attended, were suppressed in the written and oral reports of this study.

Interview Guide

The open-ended interview questions were approved by the Human Subjects Review Committee at Union College (see Appendix B). The first two questions covered the topics of diagnosis and general impact of type one diabetes upon the women's lives by collecting data as to how old they were when diagnosed and the year they graduated or intended to graduate with their undergraduate degree.

The next set of questions were crafted with the intent of shedding light on the concepts of public navigation and passing. These questions asked the women to explain the role played by T1D in their adjustment to college as well as strategies employed to navigate this invisible, chronic illness at this transitional life stage and within the specific setting of college. In attempts to have women more explicitly address the extent to which type one diabetes is (or is not) pervasive in their lives, they were asked when they found themselves most aware of their illness, as well as how often they actively think about managing it.

The questions that followed dealt with support available to, sought out by, and most favored by the women. They asked who they turn to for support, whether any of those individuals also have T1D, as well as what types of support they find most helpful and why.

Finally, the women were asked to reflect on how their experiences of living with type one diabetes are impacted by being a woman as well as their experiences with stigma. Such was asked in hopes to address gender, femininity, and Goffman's sociological concept of stigma (1963). The women were asked to first define stigma generally becoming commenting on whether or not they ever perceive stigma because of T1D. If they answered "yes" to the latter, they were asked how stigma impacts their life as an individual with T1D and how, if at all, they respond. If they answered "no," they were asked why not. Overall, these questions took a step

away from the medical model by seeking to elicit primarily qualitative data of first-hand experiences with illness experience for college-age women with type one diabetes.

Analyzing Data

The data collected in the interviews were qualitatively and quantitatively analyzed for common themes and unique experiences among the participants. The results were then analyzed for alignment with concepts, themes, and ideas presented in the literature review. The data was examined to understand the women's' self-evaluations and reflections on their current experiences as college-age women with type one diabetes and resulting perceptions of stigma and gendered experiences. In particular, the results were evaluated for insights into the influences of gender, stigma, and the impact of the medical model of illness on the lives of these women. The next chapter presents the key themes produced by interview data.

CHAPTER 3: RESULTS AND DISCUSSION

Demographics

In-depth, face-to-face interviews were conducted with twelve college-age women with type one diabetes. Half of the women (n=6) reported they were presently in college. The other half had graduated within, at most, eighteen years. Eleven of the 12 women graduated or were graduating between the years 2020 and 2026. The women all were diagnosed with type one diabetes prior to their first year of college. The women were asked to self-report their date of diagnosis and year of undergraduate graduation. The average age of diagnosis was eight (7.88 years exactly) and the (rounded) average graduation year was 2022.

Interview Results

The insights gathered from the interviews with these twelve women provide a framework for understanding the experiences of college-age women with type one diabetes as well as limitations of the medical model. The interviews were analyzed to determine whether the results confirmed, contradicted, extended, or shed light on present, but especially absent, depictions of this demographic within current literature.

Impact and Management of Type One Diabetes

Introductory questions were aimed at gaining an understanding of the women's views of the general impact of type one diabetes on their lives. In response, the women reflected their internalization of the pressures of toxic positivity by either asking the interviewer (myself) if they should attempt to balance their responses with "the positives with negatives," or by making a clear effort to do so (2024b). Their expressions of this pressure to strike a balance and bring up

these “positives” fell in alignment with the existing literature’s findings regarding perceived social expectations of chronically ill – to return to as things were, ignore bodily discomforts, as well as adhere to expectations associated with gender and their given age (Charmaz 1995, Parsons 1975, Weitz 2010). In response to the expression of this pressure to strike a balance imposed by these social expectations, the women were informed there were no guidelines for sharing and to answer to the best of their ability, as well as they saw fit. The effects of the relation of this information were notable, as the women were noted to engage in physical displays of relief from assumed expectations (implied by body language – discernible through the Zoom camera – such as laughing, exhaling, and the dropping of their shoulders). They proceeded willingly and rapidly into discussions of the “negatives,” or the harsh, taxing realities presented by their diagnoses and lives with type one diabetes.

A Daily, Relentless Toll: Awareness and management

The women’s descriptions of the impacts of T1D on their lives reflects the disease’s identity as “chronic” (CDC 2021) and resulting imposition of significant tolls upon those afflicted (JDRFa). For the women interviewed, the average age of diagnosis was eight. Five out of 12 (42%) participants expressed a lack of knowledge of life without type one diabetes. Ten out of 12 (83%) women spoke to the enormity of the impact of diagnosis, and more than half (58%) described it in terms contributing to an overall definition of T1D as a daily, relentless toll. The daily and relentless nature of T1D was captured and confirmed by the women’s repeatedly frank and transparent responses with regards to the “extremely taxing” (2024b) nature and enormous extent to which type one diabetes plagues their minds and everyday lives: “The back of my head is always, ‘oh my diabetes’” (2022). For these women, it was matter-of-fact that T1D

was a constant presence in their minds not only in terms of the immediate effects and worries it presents, but in terms of those which are long-term, as this disease poses enormous power to threaten and diminish one's quality of life (in the form of health complications) if, as explained by the Mayo Clinic (2022), they are not conscious and consistent in their management.

The responses of 83% of the women highlighted the never-ending nature, presence, and pressures imposed on their person and lives by T1D. Such discussions transitioned into those of the “seen and unseen” impacts, and therefore into larger conversation of the invisible and visible nature of type one diabetes (2025b). Such was notable for it functioned to add another reinforcing layer to the depiction of this disease as something relentless and extremely taxing in nature. In her response to the question of the impact of T1D on her life, one of the women explained how the tolls produced by this disease is so much more profound than the finger sticks, insulin pump changes, and other medical activities one becomes responsible for managing: “It’s the external physical aspect and the internal aspects as well. You can’t not be thinking about it, and when you may not be, you may be feeling it. You can’t escape it” (2021b).

The legitimacy of these less visible, or “unseen” challenges (2025b) faced by the women were justified by discussions of increases in self-awareness produced by the reality of life with type one diabetes: “I think it (type one diabetes) has definitely shaped who I am and how self-aware I am of what I eat, what I do” (2024a). Four out of 12 (33%) women used the term “awareness” in their interviews. This awareness was most frequently discussed in terms of what one puts into their body, such as food and drink. Within the context of the college setting, discussions of food and drink (primarily alcohol) were especially high due to the large roles the two play in the dominant social scenes of college life: dining halls and parties (the “going-out” scene as multiple respondents put it). Women’s discussion of increases in self-awareness brought

on by T1D extended beyond the topics of food and drink, as well as beyond the social scene, and into everyday activities of their college-age lives such as exercising, driving, and taking tests. Overall, in alignment with the expression: “The back of my head is always, ‘oh my diabetes’” (2022), T1D clearly possesses a guiding role in the wide range of activities and realms of the social world (specifically college) these women report engaging in.

Speaking to the everyday activity example of exercise, one woman explained how “frustrating” the seemingly simple task can be “because of the planning that goes into it” as a result of T1D (2024a). In her explanation of the typical steps taken to prepare for a run (picking out an outfit, shoes, and potentially eating a snack) she dramatically interrupted her listing of these steps, exclaiming: “Oh wait, I have diabetes, I have to do that!” (2024a). To make her point about the enormous and interruptive nature of this disease in her life, she continued on, relating how frustrating and time consuming such a simple task quickly becomes with type one diabetes. She explained how if she makes the choice to drink a glass of milk or too big of a banana, her blood sugar will go too high. Even if she is not hungry, or not feeling as though food will make her feel at her best to run, she must eat something if her blood sugar is at a low enough level to run safely and effectively. If she wants to go for a longer run, she must eat regardless to avoid a dangerous low blood sugar. She must have a good bag to carry snacks and her devices with her in case of emergency. Once the run is done, T1D’s presence in her head and its management does not cease. In the hours after, she has to be especially cognizant of her blood sugar levels and be sure to eat a carb-dense meal to avoid dangerous low blood sugars. Thus, she reflected, runs are best for her when completed as early in the day as possible so that she does not suffer from a low blood sugar, and potentially fall into a coma, while she is asleep.

This woman’s depiction of how much goes into engaging in the simple, everyday task of

going for a run so powerfully captures what it is like to live among the daily, relentless pushes and pulls (both physical and mental) of living with type one diabetes. In attempts to gain a more complete understanding of the nature of the impacts of T1D on the lives of these women, questions were curated to examine whether, and if so when, increased awareness of their need to manage T1D was heightened or reinforced. While questions five and 6 (see Appendix B) targeting disease management primarily functioned to further establish the need to recognize type one diabetes and its management as something daily and relentless, they ended up highlighting specific situations within which women experienced increases in awareness. These situations reported by the women were dominated by references to moments when their blood sugars fell outside of advised ranges (both too low and too high) as those would leave them feeling poorly (JDRFa). A situation especially triggering erratic blood sugar levels and (therefore) increased awareness for these women was their menstrual cycles. This will be further discussed and analyzed in the section on gender. References were also made to interactions with medical professionals perceived to be inflicting stigma in the form of unrealistic pressures and expectations for securing ideal management (for the sake of their general and future health).

The frequency to which the women reported actively thinking about managing T1D was not quantifiable, for such was reported as too great and too frequent to put into numeric terms. In response to the sixth question: “In relation to management of your T1D, how frequently would you say you actively think about managing your T1D?” (Appendix B), one woman stated: “I think about [it] A lot. It’s a 24/7 thing. It’s attached to my hip and it’s always there. It’s annoying” (2020a). Another shared, “It’s always just a pain to have it” (2005) and “Subconsciously I am thinking about it 24/7. It’s an alarm showing up on my phone. I am eating something and need to bolus. My blood sugar has been annoying me that day” (2025b). Thus,

responses could not be quantified in terms of how many times they think about it each day. The women expressed a general consensus that the number of times T1D crossed their minds was far too large and constant to be spoken of numerically, thus bolstering T1D as something daily and relentless in nature.

While ten out of 12 of the women's accounts supported a negative characterization and connotation of T1D, two responses were greatly different in nature. In contradiction with repeated references to the immensely taxing presence of T1D on their lives and mind, these two women described diagnosis and life with T1D as rather untaxing in nature: "It has been pretty straightforward. I do not feel as though I had as hard a time as some of my friends" (2021a). The main reasoning behind their easier transition to life with type one diabetes was cited by the two women to result from their "older" ages of diagnosis (2021a). Diagnosed at thirteen and 14, compared to the average age of 8, these two women felt that their greater maturity as well as naturally "independent" characters functioned as protective factors to the difficulties of daily tolls related by the other 10 women (2021a).

Charmaz (1995) detailed the social expectations for people with chronic illness in terms of the pressures to return to as things were pre-diagnosis and to ignore bodily discomforts. The information collected from these interviews functioned to extend existing studies like this by providing accounts of the women's overall inability to adhere to ableist expectations. Overall, the findings from these interviews in relation to the impact of T1D on these college-age women's lives confirmed that T1D is best characterized as daily and relentless in nature. Furthermore, they function to highlight the highly problematic application of the Sick Role's (Parsons 1975) expectation to visibly present as ill and seek treatment/cures imposed upon the chronically ill by our ableist society. As related by the women, expectations for their adherence to this role

highlights its inapplicability, for T1D is far too inescapable and relentless to ignore bodily discomforts without placing oneself in grave danger, let alone return to the way things were pre-diagnosis. Therefore, the ten women's responses affirming T1D's identity as a daily, relentless toll are significant for they confirm the need to utilize sociologically grounded theories such as The Spoon Theory (2003) to better understand what it means to actually live with an illness. By depending upon theories such as Christine Miserandino's, we can shed light on how "the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to" (Miserandino 2003:1). Such is important for it highlights the inappropriate and irrelevant application of the Sick Role's (Parsons 1975) to those who are chronically, and especially invisibly ill, with conditions such as type one diabetes within US society.

Enforced Maturation and Responsibility

Shifts in conversation to early maturation and early independence naturally stemmed from the women's detailing of the daily tolls and nature of type one diabetes. Five out of 12 (42%) of women reflected that T1D expedited their maturation. As one woman so powerfully stated in reflection of the moment of her diagnosis, "The adulting starts then and there. As soon as you are in that room" growing up "fast" was paired with the imposition of the type one diabetic identity (2025b). To bolster this response, another woman elaborated further, saying: "Maturing was something that had to be done very quickly. [You must begin] thinking of such a tough thing at such a young age" (2025a). Interestingly, reverting back to their initial inclinations, the women's discussions of being forced to grow up quickly reflected that previously stated desire to balance the positives with the negatives. Even though T1D was

painted as something robbing these women of their peace of mind and innocence, this loss was generally coded as something producing positives such as increased independence and responsibility – two characteristics highly valued by US society.

In their discussions of enforced maturation resulting from their diagnoses with T1D, the words “independence” and “responsibility” were utilized by a third of participants. Such references not only bolstered T1D’s identity as something relentless in nature, but also highlighted two societally valued qualities that were coded as a gift hidden in all the negatives and consequences of life with T1D. Those two qualities were independence and responsibility. Responsibilities for these women centered not only around the logistics of managing their disease (checking blood sugar, counting carbs, remembering to bolus for meals, etc.) but also the responsibility of maintaining their health for the sake of preventing complications associated with (poor management of) T1D (JDRFa). Interestingly, despite their harsh portrayals of the onset of such maturation, independence, and responsibility, participants repeatedly made sure to mention the positives, or “blessings” which come from the expediting of their growing up processes: “If I didn’t have diabetes, I would probably say ‘Agh! I’m not feeling too good, but I’m going to do it anyway. But no, I need to take care of myself’ (2024a). As this woman’s response shows, she codes the increased self-awareness and sense of responsibility resulting from her T1D as something positive and which makes her better off (than those around her). Another woman reflected this mindset as she too considered how things may differ if she did not have T1D:

I think in general; it has made me responsible in some ways that I may have not been otherwise. It’s always just a pain to have it, you know. I can never go anywhere without a purse. I can’t go anywhere without this mom bag. It’s a blessing and curse. (2005)

This response reflects the respondent's internalization of expectations imposed upon chronically ill individuals to engage in demonstrations of positivity that can be toxic to the legitimate, everyday tolls taken on their lives (Parsons 1975). Such notions of positivity are reflected by Parsons's (1975) Sick Role within which the ill person is expected to visibly present as ill and seek curative treatment – or in other, positively skewed terms: to present as one striving 'to win the fight' – to align with institutionalized, able-bodied, social expectations. As reflected by this respondent's discussion of her inability to go anywhere without the mental, physical, and material baggage of T1D, chronic illness functions as an immense barrier to one's ability to engage in the Sick Role as no cure nor relief is ultimately available. What is available to the chronically ill is daily, relentless management.

Overall, the women's positive coding of the independence and responsibility brought on by and required of those living with T1D functions to highlight the need to explicitly examine the reasoning, motivations, and influences behind as well as the consequences of their embodiment of this toxic positivity so heavily promoted and enforced by our society. As the questions developed for this interview guide intentionally examined micro-level impacts of diagnosis and management of T1D, they asked the women to reflect more generally and organically on pressures compelling them to engage in this mentality.

Adjustment to and navigation of college: A stressful endeavor

The next two interview questions prompted the women to discuss their adjustment to and navigation of college. Adjustment was portrayed by the twelve women, like management of their chronic illness, as something constant, never ending, and (therefore) unable to be perfectly mastered. In the words of one of the women, adjustment "was terrible. Absolutely terrible" and

something that will “always be a learning curve” (2024a). The lifestyle adjustment called for by the transition to college was for these women, highly stressful and amplifying the tolls already taken on them by T1D. Amplification was reported to result from the addition of “new challenges” (2020b) to their already overwhelmed plates. Generally, the women’s discussions of adjustment were devoid of references to new challenges stereotypically presented by the transition to college – such as academic or roommate struggles – but rather populated by discussions of college-triggered stressors increasing the difficulty of securing successful management of T1D.

The list of new challenges and stressors presented by the college setting according to these women were numerous. Examples included (but were not limited to): unpredictable schedules, difficulties accessing healthy food options, the dominant role of eating and drinking to excess within the social scene, limited access to medical supplies and resources, living away from social supports of home, sedentary lifestyle, and increased stress overall. While these challenges varied and were numerous, all ultimately are best encompassed under the last item on the list: “increased stress.”

Increases in general stress levels as a result of their entry into and navigation of the college scene were reflected by ten of the twelve (83%) women interviewed. The two most pervasive manifestations of this were stress stemming from the unpredictable and erratic nature of one’s schedule and day-to-day life in college and that produced by food and drink. The stress of food and drink took two primary forms: that related to the limited nutritionally dense options within the college setting of dining halls as well as the dominant role consuming both to excess (drink in the form of alcohol especially) plays in the social scene of college.

Unpredictable Schedules

The typical college “day” depicted by the accounts of these women was a day inherently unpredictable and therefore, highly stressful in nature. In their descriptions of the constant nature of adjustment to college, it was challenges associated with scheduling which most frequently threatened the ease and success of their management of type one diabetes. As explained in the literature review, T1D is a disease requiring immense planning, preparation, and rigidity (JDRFa). Thus, the erraticism of the college setting makes establishing routines difficult, therefore amplifying challenges associated with handling the logistics of managing T1D. Routines are highly beneficial to management and examples of such which positively impact ease of blood sugar level management and can be difficult to secure in college are eating at scheduled times throughout the day, regularly exercising, as well as getting consistent sleep. As captured by one of the women, many aspects characteristic of a typical college day cannot be predicted, planned, nor taken into consideration before one is swept up by them:

Even if you are able to account for your insulin, you know when your insulin is going to hit your bloodstream, you never know when you are going to get a bad grade, when you are going to forget an assignment. Like, I’m not a bad student, but there is a lot of different stress that you have to manage in college. (2024a)

The words of this woman function to highlight the toll stress takes explicitly on the body, and on the management of their disease as a direct result. More specifically, such remarks highlight how stress in the form of the unpredictable schedule is not isolated to one scene of college life, but transverses the bounds of the many components of the college setting– as is shown by references made to the social and academic scenes above. For these college-age women with type one diabetes, stress in the form of unpredictable schedules is taxing for it forces them to spread

themselves even thinner, furthering compromising their ability to account for all that chronically resides on their plates as individuals living with illness within US society.

Food and Drink

The second major source of stress within the college setting is food and drink. This stress manifested in two forms dominant throughout interviews: stress resulting from lack of healthy, well-rounded options and that from the excessive consumption of both characterizing the social scenes of college. Eight out of 12 (67%) women spoke to the difficulties posed by the limited food options in college dining halls. Most frequently noted as desired options by the women were those low in carbohydrate value and sensitive to other dietary needs often paired with this chronic, autoimmune disease (such as the inability to eat dairy and gluten). As a result of these limited options, the women expressed generalized frustration with the need to take higher levels of insulin (required by these unhealthy, high-carb foods) which left them feeling ill and run-down. While the women did acknowledge that they could purchase options more suitable for ideal management and requiring less insulin, such foods are much more expensive and require extra time and resources (such as access to a car) to incorporate.

The second discussion that was prevalent in relation to the stress associated with food and drink was that produced by the consumption of them to excess pervasive to the social scene of college. Socializing for college students centers around social settings involving food and drink such as the dining hall and parties. In both, food and drink play not only a leading role on their own, but so does the associated pressure to manage the freedom to “eat [and drink] whatever” that others (without T1D) appear to possess (2020b). For these women (and type one diabetics in general) succumbing to this pressure is dangerous and unadvisable as it increases the chances

they will suffer from cases of hyperglycemia (high blood sugar) and associated complications (JDRFa and Mayo Clinic 2022). In addition to unregulated consumption of food, alcohol places them at increased risk of suffering from hypoglycemic (low) blood sugars and, if serious enough, falling into a coma. Thus, this culture of drinking and eating to excess promoted by the social scenes of college (dining halls and parties) was a significant manifestation and source of the generalized increase in stress experienced by this population as a result of their continuous adjustment to and navigation of college.

For these women, it was important to discuss the harsh realities and negative experiences produced by the reality of adjusting to and navigating college as an individual living with type one diabetes. Such conversations were glaringly absent from the existing literature of what it is like to live with chronic illness, let alone T1D. Such limitations stem from the literature's heavy dependence on the medical model, which limitedly focuses on the physical aspects of a disease as well its respective medical treatment, rather than the lived, first-hand experiences resulting from onset and diagnosis (Weitz 2010). Therefore, as was shown through the account of Nancy Mairs, a woman living with MS (Weitz 2010), diagnosis with chronic illnesses like MS and T1D carries enormous consequences and imposition of negative connotations which make their lives increasingly porous to high levels of stress – as demonstrated by the accounts of the women explored above. Findings in relation to the stress produced by adjustment to and navigation of college for these women are significant for they function to support the primary purpose of this thesis to shed light on the experiences of *college-age* women with T1D.

Questions targeting the impact of type one diabetes on adjustment to, and navigation were curated with the intention of addressing a critical gap within existing literature: isolated study and attention paid to the experiences of this specific age (18-22). Thus, the findings above

detailing the stress pervasive among college-age women are significant for they shed light on all that has been neglected as a result of the situation of the existing literature at the front (childhood) and back end (adulthood and workplace) of life. Studies at the front end, such as Allen's (2013) and Williams (2000), highlighting the experiences of children with T1D and their caretakers are useful, but not directly applicable to college-age individual individuals as children are not as likely to manage independently. Those at the back end, such as Vickers (2001) and Clair et. al (2005), examining management of chronic illness by adults in the workplace definitely possesses more applicability to the experiences of college-age T1Ds, but are lacking in coverage of the transition to independence promoted by the college setting. Therefore, the increased stressed produced by these women's identities a type one diabetic in college call for the need to extend studies such as Allen (2013), Williams (2000), Vickers (2001), and Clair et al (2005), to provide more specific representation for the for the chronically ill generally, as well as those specifically with T1D.

Support

In an attempt to understand what resources are most frequently available to and selected by these women, the seventh and eighth questions of the interview guide were interested in not only who these women turn to for support, but also what types of support are found to be most helpful and why. In questioning who they turn to for support, the women were also asked if any of these selected or sought out individuals have type one diabetes themselves. This was asked to gain a better sense of the role this specific community may play in the support of and desired by this demographic.

For these women, the people who primarily made up their support systems were equally

split (50%) between close friends and parents, with college bringing on a notable shift from parents to friends being named first as a source of support. When it came to types of support, responses could be classified into two major categories: acts of service and that provided by the T1D community, or fellow type one diabetics.

Acts of Service

Prevalent throughout the interviews in response to the question of what types of support are most helpful was a sense of appreciation for what one woman referred to as “the little discrete things” (2024a). When asked to, the woman defined these things as: “taking into consideration the little things I could need and planning without telling me, so I don’t feel a certain way” (2024a). For the purpose of conveying the findings of this study, these little discrete things are best summarized as acts of service, or actions which make activities and life easier and/or more easily enjoyable for college-age women with type one diabetes. The acts of service held in positive, high regard were actions of others within their support network – primarily close friends – which assist the women in securing more seamless management of their diabetes, without an increased need to draw further attention to themselves for the way in which they differ from the so-called ‘normal.’ Examples of these acts shared by the women included: offering snacks when going out in the social drinking scene of college (to help prevent low blood sugar typically brought on by the consumption of alcohol); keeping these same snacks in places such as their car so that the women do not have to interrupt a trip by announcing their needs; as well as asking to be taught/independently seeking out classes to be taught how to use glucagon (an emergency medication for low blood sugar events). Although these acts of service were not described as having to always be discrete, many of them were warmly regarded for being so as

they provided the women with a feeling of being seen and safe, without drawing extra attention to their chronic illness.

For these women, acts of service were not always tangible nor visible. Acts of this type took the form of “a deep interest in learning about type one (diabetes),” (2024b) as well as “an ear to talk to” (2025c). Across the board, the women expressed sincere appreciation towards those who asked questions reflective of genuine interest in their care, experiences, and safety. Such sentiments were also extended to those who allow them to complain, vent, and “say anything” without making them feel badly for doing so (2025c). For these women, being an ear to talk to not only means providing space to vent, something reflected as a positive for multiple women at the conclusion of their interviews, but also being someone to laugh with and forget momentarily about the weight of type one diabetes by supporting them as an individual, apart from the disease they feel so frequently defined by in the eyes of other: “I see this as acting as a form of social support for people who *have* diabetes, not as diabetics” (2025c). While many women do acknowledge feeling that only fellow type one diabetics could ever truly understand their complaints and frustrations, they still express immense gratitude towards those without T1D who try their best to understand and reflect this attempt through a willingness to listen without inflicting judgment and bolstering expectations to adhere to ableist expectations.

Community: Fellow type one diabetics

Three out of 12, or a quarter of the women, reported that individuals within their support systems had type one diabetes. For these women, these communities of fellow type one diabetics took various forms. Some groups took the form of one-on-one, in-person relationships while others were virtual, with connections taking place via group chats with other type one diabetics

at their respective colleges, via platforms such as Facebook, or even more distantly via the following of public figures with T1D such as social media influencers. Overall, these groups were also held in positive regard by these three women, as this sense of community functioned to combat the loneliness they often feel: “it’s just nice to know we have others and can relate to in the hardest moments when we feel alone” (2022). As was found in the women’s discussions of the daily relentless toll of living with type one diabetes (generally and specifically in relation to college) much anxiety and mental space is taken up by the ways in managing type one diabetes threatens to and makes their experiences greatly differ from the ‘normal’ of those around them. Thus, the women’s description of the significance of having access to this form of social support reflects the positives resulting from being connected to individuals who can not only relate emotionally, but to those who can support them logistically by doing things such as providing medical supplies when they experience a shortage or emergency, if in close enough proximity.

Overall, the women’s discussion of support provided insight into the individuals and characteristics which help them combat the “small things that add up” as a result of the intricacies and complexities of managing type one diabetes while being a college student (2025b). For these twelve women, the most helpful practices were acts and service and access to support provided by the type one diabetic community. Most notable findings in relation to support for this demographic was an overall and sincere appreciation held for those who, as one woman stated, “care a lot and would do anything for me in a [T1D-related] situation” (2025b). Although the acts of service took differing forms, the term speaks to an overall appreciation for those who participate in making management easier by providing support which mitigates the chances that something unpredictable such as low blood sugar will completely upend the women’s day-to-day lives. Such practices such as serving as an ear to talk to were also observed

to combat the pressures of toxic positivity imposed upon the chronically ill. Like an ear to listen to, access and connections to others with T1D functioned to combat and highlight the impossibility and unrealistic character of pressures demanding these chronically ill women to adhere to the rigid guidelines of the medical model's sick role. What was even more compelling about conversations of community for these women was the centering of discussions and reflections not only around existing community ties, but those which they desired so strongly and imagined would be helpful to have. One woman in particular reflected in her discussion of the isolating experience of living with type one diabetes how she wished she had not succumbed to the pressures of desiring to be "normal" and like everyone else:

I felt overcome with this feeling of not wanting to be defined by it. I didn't want to go to diabetes camp. I wanted to go to gymnastics camp with the normal kids. But it probably would have been nice because no one can understand the constant presence. (2005)

This woman was not alone in craving this community she reflects overlooking the importance of years ago out of fear for being seen as different than others around her. Other's shared yearnings for connections with those who could understand the relentless nature of T1D. Therefore, finding only a quarter of women interviewed to possess this support reinforces the need to explore why these connections are so sparse and what can be done to better promote the fostering and provision of these community connections.

Findings related to support functioned to provide insight into how these women seek out assistance in managing the emotional labor produced by T1D (Dillaway et al. 2022). Confirming and providing extension to Dillaway et al.'s (2022) study examining the unseen costs associated with life with a chronic illness, the women's classification of support positively regarded functioned to further shed light on this labor ignored by the medical model's inattention to

emotional tolls suffered by the chronically ill.

The women's discussions of their admiration for assistance provided through practices under the categories of Acts of Service and Community highlight support taken advantage of to manage "the uneven course of acute [T1D] episodes" defining these women's lives and therefore threatening their abilities to adhere to social expectations of typical participation in the varying scenes of college life (Royer 2004:10). Such findings function to extend Royer's findings of the feelings of uncertainty needed to be managed by the chronically ill within US society. Royer's study acknowledges that the chronically ill must "learn how to preserve a reasonable emotional balance by controlling upsetting and negative feelings aroused by the illness," but fails to provide a means by which they can or actually do so (2004:12). The findings above in relation to forms of support sought out by and leaned upon by college-age women with T1D are therefore significant as they provide specific examples of ways in which the chronically ill work to manage feelings of uncertainty and anxiety produced by their illnesses.

In addition to confirming the legitimacy of Royer's observation and extending his study through provision of a means by which the chronically ill navigate emotional labor produced by tensions between social expectations and reality, conversations surrounding Acts of Service and Community highlight resources utilized by the chronically ill to combat and address consequences of social isolation. As found by CHRT (2020), approximately 40% of US adults with chronic illness report feeling lonely and socially isolated. Therefore, these women's fond regard for others willing to engage in acts of service to assist them with everyday management as well as the comfort provided by knowing "[they] have others and can relate to in the hardest moments when [they] feel alone" (2022) provides two responses to Ross's (2004) unanswered question of the ways in which the chronically ill cope with feelings of uncertainty and social

isolation.

Impacts of Stigma on Navigation Strategies: Passing and Disclosure

Experiences with stigma significantly impacted the women's willingness to disclose their T1D. Defining "stigma" generally (isolated from T1D), the women reported stigma to stem from: perceived violations of definitions of "normal," being uneducated or ignorant in one's formation of an opinion or statement, as well as the formation of reactions grounded in stereotypes and assumptions. Stigma was also defined as a practice no one can be seen as exempt from partaking in the perpetuation of. Eleven out of 12 women perceived stigma as a result of their T1D. Responses and discussion prompted by this affirmation fell in alignment with expectation that stigma has a legitimate and heavy presence in the lives of college-age women with type one diabetes.

As discussed within the Literature Review's discussion of existing literature surrounding living with chronic illness, the strategy of disclosure is closely related to and utilized as a strategy to combat stigma (Goffman 1963). These interviews extended the work of Goffman, revealing that the relationship between disclosure and stigma was multi-directional. Disclosure was not only utilized as a strategy to manage stigma, but something the women were at increased chances of facing as a result of their decision to "come out," as highlighted by Samuel's (2003) study examining intersections between Queer and Disability Theory.

Passing

As explained within the Literature Review, strategies of passing directly oppose those of disclosure. Interestingly, within the twelve interviews, discussions of engagement in passing were far less prevalent than those surrounding disclosure. Unsurprisingly, strategies for passing contradicted the prevalent disclosure strategy of “laying it all out” (2025b). Under this mindset, choices such as wearing their devices so they were not visible and managing in private as much as possible were made to take advantage of T1D’s invisibility. The choice made to wear devices less visibly related to the more informal social scenes of college such as parties. Those made to “do it (manage their diabetes by testing blood sugar, delivering insulin, etc.) under the table or go to the bathroom” spoke to practices engaged in within both informal and formal social scenes such as the dining hall and classroom (2025c). Women interested in passing did not express the same sense of relief which came from having their disease “revealed” for them as the women who participated in disclosure and were relieved to be outed and therefore freed from the pressures of initiating the “I have diabetes” conversation. Rather, these women expressed immense anxiety over having their disease revealed by any visible and audible evidence: “I do not want to gross other people out by taking care of myself at the table or in class because some people do not like blood” (2025c). Like many of the women interviewed, this woman’s response reflects an internalization of stigma to be discussed in the coming section. As described here by the decision to manage invisibly under the table of her classroom or dining hall, the decision of passing for this woman (and others) is tied to an assumption of responsibility of managing the needs of others in addition to the extremely pressing medical ones of her own. Such is important to note in the discussions of passing present throughout these interviews as reasoning behind passing was often framed as politely or thoughtfully placing the needs of others above their own

– an expectation also placed upon this population when faced with reactions out of places of pity.

Reasons to Disclose

The women's shared reasonings and motivations behind disclosure primarily surrounded two desires: to be their true selves and to ensure their own safety. Across the board, the women's willingness to disclose their T1D in relation to the desire of wanting to be their truest selves around others was explained as a natural product of the enormous role it plays in their lives: "I like to tell people as early on as possible. It is the first thing someone is going to know because it is such a big part of who I am and it's a constant, living thing" (2024a). What naturally resulted from discussions of this desire was that of *who* the women felt most compelled to disclose their illness identity to. Explanations were grounded in the strength of trust and bonds as increased closeness with others was directly correlated with an increased willingness to disclose. Until this closeness was achieved however, the women reflected anxiety over the matter of how to work the "I have type one diabetes" statement of disclosure into introductory conversations. The three women who spoke directly to this disclosure-related anxiety is captured well by one respondent's statement: "It is definitely not the first thing I tell people because it is a part of me, and it is not everything" (2024b). For these women, "coming out" (Samuels 2003: 237) as a type one diabetic – especially within the early stages of relationships – was anxiety producing as they did not want to be seen only for their illness, and therefore for the ways in which they differ from "normal," and other stereotypical (healthy) college-age women. Despite such anxieties however, the women overall felt compelled to disclose because of the enormity of the disease's role in their lives and the immense health risks, such as low blood sugar that could result and threaten their safety if no one in their proximity were to know they were diabetic.

To understand and discuss what it looks like when these women would participate in disclosure, it was important to examine motivations behind their participation in this tactic. By examining the way in which the desire to be their true selves and protect their safety directly correlate to an increased willingness to disclose, it can be better understood what factors likely underlie these college-age women's choice to stray from passing and lean towards disclosure, or the choice to, as one woman put it: "lay it all out" (2025b).

Making the Choice to Disclose and "Lay it all out" (2025b)

Engagement in disclosure was described by these women as something quite similar in nature to the process of ripping off a band aid: "Alright if we are going to do it, we are going to go all in and lay it all out" (2025b). Choices made by these women to engage in this disclosure mindset were predominantly those which would render their T1D visible such as wearing their devices (such as insulin pumps and/or continuous blood glucose monitors) visibly. The choice to do so was primarily motivated by overall anxiety surrounding initiation of the "I have (type one) diabetes" conversation. Across the board, the women preferred to be prompted to disclose their illness via the visual and audio aids of their devices than have to call attention to or reveal their T1D themselves. Therefore, participation in this method was engaged in by these women to combat and avoid the (previously discussed) anxiety discussed previously of navigating the difficulty of inserting their illness into, primarily introductory, conversations.

The strategy of "laying it all out" is all the more compelling for it is fueled by both reasons for engaging in disclosure discussed above. As one woman shared, she made the intimidating decision to wear her devices visibly to elicit the questions of others, and thus remove the pressure to always be the one enacting her engagement in disclosure: "This is really,

really scary. I don't want to wear my CGM out to this frat where people can see me” (2025b). For her, and other women, making the decision to be “out” with their type one diabetes by making the decision to do things such as wearing their CGM (continuous blood glucose monitor) visibly were grounded in both their desire to navigate the social scene more easily and protect their safety. Therefore, for these women, feeling momentarily embarrassed by the visible (or audible) outing provided by their devices and other visible aspects of their management outweighed not only the anxiety associated with working “I have diabetes” into conversation, but the fear of falling into an emergency situation without anyone knowing they were diabetic.

This strategy of “laying it out” speaks to the multi-directional relationship between disclosure and stigma. In contradiction to what is suggested by existing data, disclosure is not only a strategy used to combat stigma, but a process from which engagement is producing experiences with stigma (Dillaway et al. 2022). For these women, these experiences with stigma in response disclosure took the form of reactions commonly experienced and those most feared by the women. Common reactions were those founded in ignorance and pity. Reactions most feared by the women were described in terms of the person executing them, rather than content of the reactions itself as those most dreaded and feared were the negative reactions of those they shared interpersonal relationships with. This reaction type will be discussed within the section: “Impacts of Being a Woman on T1D.”

Reactions grounded in ignorance

Reactions grounded in ignorance primarily took the form of questions and statements revealing misunderstandings of the differences between type one and type two diabetes. Repeatedly cited examples of such statements were those pertaining to the women’s

consumption of sugar; comments about grandparents or pets with diabetes in an attempt to relate; as well as “unwanted suggestions” regarding management of this illness (2021b). In relation to discussions of stigma, reactions grounded in ignorance fell in alignment with the women’s understanding of the term as something produced by lack of education and blind dependence on stereotypes most frequently associated with T2D.

Also, heavily pervasive and reflective of widespread misunderstandings of the differences between type one and type two diabetes were references made (by others to the women) to family members – specifically grandparents – and pets with what they do not actually understand is actually T2D diabetes. Shocking to see was the identical sharing of the comment of either: “oh my grandparent [whether father or mother]” or “my cat” has or had diabetes in seven of the 12 women interviewed. Once again, such comments supported the foundational role that misunderstandings of the differences between T1D and T2D played in the ignorance repeatedly faced by these women.

References to questions and comments surrounding their ability to consume sugar and food (especially carbohydrates) were discussed by ten of 12 (83%) of women interviewed. Their general interpretation of the source of such ignorance was the common misunderstanding that T1D, unlike T2D (see “Type One versus Type 2 Diabetes: Differences in Causes” within the literature review), does not result from unhealthy eating habits such as the overconsumption of sugar. A repeated scene within which inappropriate understandings of food consumption shined through was that of the women’s memories of childhood birthday parties - a scene within which cake and other sweet and carb-filled treats such as pizza are staples. One woman shared with me the memory of an elementary school birthday party. As a kind gesture, one of her friends had brought her a sugar-free blueberry muffin to have in place of the “giant cupcakes” brought for

the other students (2024b). While acknowledging the kind intentions behind this gesture, this woman reflected that in the moment and now, “it was very frustrating because it resulted from the stigma that you cannot eat or do what you want because of type one [diabetes]” (2024b). Like this woman, many of the other eleven responses confirming the weighty presence of stigma in their lives shared frustration with the idea that they “cannot do the same things as everyone else” (2025b). These women countered this ignorance by affirming that despite all the hardships and logistics involved in ensuring they can actively participate, they are successful overall in their attempts to participate in life to the extents which align with their personal desires: “I’ve never been unable to do or eat something because of type one, I have had to do extra steps, but I have never had to sit out” (2024b).

Another type of reactions stemming from ignorance most heavily commented on by these women can be described, as one woman stated, as “unwanted suggestions” (2021b). These unwanted suggestions were reported from those who do not have T1D and felt entitled to offer their opinions when it came to achieving successful management. In their explanations of such suggestions, the women expressed immense frustration and resentment towards the ignorance and innocence of the imperfect nature of T1D management possessed by those living life free of this disease. According to these women, those responsible for imposing these suggestions were not just limited to others around them in the social scene of college. Physicians and medical professionals were also cited as a significant source. The unwanted suggestions and comments made by this population, as well as the role they play in the fostering of self-stigmatization observed and reflected on by the women, will be specifically addressed within the section: “Impacts of being a Woman with T1D.”

Reactions grounded in pity

In their discussion of the aftermath of laying it all out, many of the women reflected on discomfort produced by reactions grounded in pity. Reactions of pity focused on the assumed sufferings and misfortunes experienced by these women. These reactions took the form of statements such as: “I don’t know how you do it” (2020a) or “Wow, that must be awful. I couldn’t do that if I were you” (2021a). In their sharing and recall of these statements, the women were visibly uncomfortable. They would pause and share that they often had no idea how to react or address such statements due to the great discomfort they were triggering off. The women reflected that while yes, statements like these are acknowledging and potentially validating of the harsh realities of T1D, they are ultimately coming from a place of ignorance. The women possess no choice when it comes to “doing” all that a diagnosis with T1D calls for. If they do not “do it,” they die. Furthermore, such comments were discomforting for they place the additional toll of having to manage the emotions and reassurance of others (without T1D) upon these women who are already spread so thin: “I did have a lot of reactions where people were acting more sad for me than I did for my own diagnosis. I had to kind of reassure them when I was the one sick in the hospital” (2021a). To combat the discomfort produced by these comments grounded in pity, the women overwhelmingly acknowledged that they would respond with something along the lines of “it’s okay” or “not that big of a deal” (2021a) to terminate the existence of conversations surrounding “the one negative they are honing in on” (2024a). As was discussed in the explanation of their motivations behind participating in disclosure, these women repeatedly attempt to strike a delicate balance between sharing an important and large part of their identity, and a fear of being seen for only that. Reactions of pity are stigmatizing for they not only promote dwelling on the hardships of their illness, but also impose a responsibility upon

the women to comfort others about the harsh realities of their own struggles.

For these women, the most common reactions to strategies of disclosure, such as laying it all out, were overwhelmingly coded as negative and associated with expressions of ignorance and pity which left the women frustrated and less willing to take on the role of an educator, which is discussed further below. Classification of these reactions into these two categories is significant for it demonstrates the widespread power and potency of misunderstandings between T1D and T2D. Thus, it calls attention to the need to better educate the public on such differences to mitigate the consequences of these reactions upon those living with T1D. Also compelling about the women's discussion of reactions to disclosure was their mentioning of reactions that had not necessarily occurred but were most feared and dreaded. Analysis of such reactions proved them to be most connected to the participants gender and will thus be discussed within the section on the "Impacts of being a woman with T1D."

Addressing Stigma: Acting as an Educator

When the opposing choice to pass was made, and the women chose to disclose their identity as a college student with type one diabetes, they were faced primarily with reactions of ignorance and pity. To address this stigma, the most common tactic employed by the twelve women interviewed was taking on the role of an educator.

The women's passions and positive feelings towards the opportunity to act as an educator were abundant throughout the twelve interviews. For these women, the main reward of disclosing their identity as a diabetic was the opportunity and platform granted for them to educate and inform others about the truths and realities of living with type one diabetes. Fifty percent of respondents possessed a warm regard towards the asking of questions and the

opportunity provided to take on the role of an educator in response. While the general inability of (most) audience members to truly understand the lessons and information being shared was acknowledged by the women, half of them still exhibited this “love” for teaching others about T1D (2020b & 2026). As one respondent stated: “I love teaching people about it” (2020b). Another claimed: “I love answering questions when people seem really interested asking questions. It’s my favorite thing to do” (2026). For these women, this love for teaching others about T1D functioned as a protective factor for the challenges of navigating the college social scene as a woman with T1D as it was important for them to have the opportunity to inform others of the “hard and different” truths and aspects of their reality resulting from their diagnosis with T1D (2025b).

An admirable quality within their respective audience members noted to increase the women’s willingness to take up this favored role was a “willingness to learn” (2020b). According to these women, this willingness was emulated by those who seemed “really” (genuinely) interested and participated in active listening when the women took the opportunity to shed light on the truths of life with type one diabetes. Comments and questions looked upon fondly by these women and increasing of their willingness to serve as educators were those such as that asked by a coworker of one of the women interviewed: “Oh, really, what’s it’s like to have diabetes? If you don’t feel comfortable, you don’t have to talk about it” (2020a). In sharing this memory with me, this woman reflected how “nice” it was to be asked this question because it so strongly and notably countered the nature of stigmatizing, ignorant, and pitiful questions typically asked of the chronically ill (2020a).

Unfortunately, the women’s propensity to take up the role of an educator was not always bolstered by the reactions of those around them. Unlike reactions displaying this willingness to

learn, reactions of ignorance and pity were referenced as diminishing of the women's willingness to act as an educator in an attempt to combat stigma. In the explanations of reasonings behind the responses resulting in a disinterest in educating others about T1D and the reality of being chronically ill, the women expressed aversion to addressing stigma perpetuated by those who seemed disinterested in listening and therefore working to change and combat stigmatizing perceptions and attitudes surround T1D:

You can preach it for the rest of your life, people will not tell the difference between type 1 and type 2. Unless people start to do the research, they are not going to care. Unless they are personally impacted, they have no reason to want to care, so why am I going to worry about that when I can focus my energy more so on myself, and bettering myself, so people can see that rather than the negative. (2024a)

As is captured by the powerful commentary of this woman interviewed, the willingness to educate others was severely undermined and mitigated by expressions which fell in alignment with general and T1D-specific understandings of stigma. Furthermore, this statement functions to highlight an overall acceptance of the presence of such expressions reflective and revealing of stigma pervasive throughout US Society. As another woman stated: "I wouldn't expect others to be knowledgeable" (2026). Therefore, it became clear from discussion of barriers to a willingness to engage in this stigma-addressing and combatting technique that although these women have not yet become desensitized to stigma, their experiences are frequent enough that they feel dwarfed when it comes to their ability to tackle the dismantling of such a system on their own. Instead, they make the decision, as demonstrated by the above statement from 2024a, to recognize – but not accept – the legitimate existence of stigma and combat it by prioritizing directing their energy to their own needs. Such is disheartening, yet important to recognize as it

functions to highlight how pervasive and potent the issue of stigma is generally, but specifically in the lives of college-age women living with type one diabetes.

Findings in relation to stigma support widespread findings from existing literature that expectations faced by the chronically ill result in a reality defined by the need to manage stigma. The interplay between stigma and navigation strategies for college-age women with T1D function to first confirm the legitimate existence of stigma in the lives of the chronically ill as defined and explained by Goffman (1963) and Dillaway et al. (2022). To avoid the negative sanctions and “deeply discrediting” attributes associated with stigma per Goffman (1963), Dillaway et al. (2022) explains how chronically ill and disabled individuals are socialized to “compensate in varied ways to manage the potential or actual stigma that they confront in public [and private] space[s]” (Dillaway et al. 2022:67).

Thus, these findings function to extend existing literature’s portrayal and understanding of passing and disclosure as strategies utilized primarily to address stigma. As discussions of passing were far less prevalent than those of disclosure, future research should be focused on asking the women to more directly reflect on the moments within which they choose to pass. The women’s discussions of disclosure, however, were pervasive and challenging Royer’s (2004) and Samuels’ (2003) characterizations of the strategy as one only producing immense anxiety for the chronically ill. Specifically, for the women interviewed and in direct contrast with the existing literature, anxiety associated with and produced by the act of disclosure did not stem from being outed against their desires (Samuels 2003), but rather from the moments within which they had to initiate the “I have diabetes conversation” – especially in the introductory stages of relationships. The twelve women interviewed challenged the existing literature’s negative and anxiety-inducing portal of disclosure inflicted upon an individual through repeated reference to

choices intentionally made – such as wearing devices visibly – to engage in “laying it all out” so that others would be primed to ask about T1D.

By inviting others to “out” them by making the choice to lay it all out, these women highlighted the legitimacy of a stigma management strategy absent within existing literature, the practice of acting as an educator. Overall, the literature’s acknowledged methods utilized by the chronically ill to address and manage stigma only very generally: “[the chronically ill and disabled individuals compensate in varied ways to manage the potential or actual stigma that they confront in public [and private] space[s]]” (Dillaway et al. 2022:67). Thus, responses to questions surrounding themes of passing, disclosure, and stigma are significant for they shed light on the way in which college-age women with T1D strategically make the choice to engage in the strategy of acting as an educator to combat differing types of stigmas faced in response to disclosure. Unlike the existing literature attempting to speak to the reality of living with chronic illness through the limited, medical lens the findings from these sociologically grounded interviews shed light not only on the extent to which reactions of ignorance and pity pervade this population’s lives, but how these women calculate whether serving as an educator is worth their very precious time. As indicated by their responses, these women are not only overwhelmingly aware of the large presence stigma possesses in their lives as a result of T1D, but calculating and intentional in their addressing of resulting stigma. If their efforts and the reward associated with acting as an educator will be spent in vain, they choose not to participate as such is not seen to be worth the emotional labor associated with acknowledging the permanence and power of stigma within US society.

Impacts of being a Woman with T1D

The tenth question of the interview guide produced some of the most noteworthy reactions and responses. As implied through repeated moments of silence upon being asked about the impacts of being a woman on their experiences with type one diabetes, this question challenged original predictions that women would be readily and easily able to dive into reflective conversation of the interplay between gender and illness. Responses elicited by this question are best categorized under these three themes: Fluctuating Hormones During Menstruation, Interactions with the Medical Realm and its Professionals, and concerns pertaining to Appearance and Body Image.

Fluctuating Hormones During Menstruation

Five out of 12, or 42%, of the women discussed and expressed visible frustration towards increased challenges faced as a woman due to fluctuating hormones brought on by menstruation. Conversations surrounded increased difficulties in maintaining stable blood sugar levels as a result of menstruation. Many women utilized such discussions of the increased difficulty of being a T1D during menstruation as an opportunity to return back to, and flesh out, their previous responses to the fifth question (Appendix B) examining times and factors resulting in a heightened awareness of having T1D. Discussions of menstruation expanded upon and provided a specific example of a situation producing the “like WHAT?” feeling discussed in the section: *A Daily, Relentless Toll: Awareness and management of type one diabetes* (2020a) that was triggered by blood sugars uncontrollable for no discernible reason. This time period was also described by the women as a period of increased exhaustion. As one woman stated, her menstrual cycle is “definitely a little extra something I have to think about. My body is all

drained from my numbers going all over the place” (2025b). Thus, the women admitted to trying their best, and awareness of times in which the tolls taken on them by their menstrual cycle force them to succumb to the extra challenges posed to ideal management to preserve their physical and emotional wellbeing.

Pressures faced from the medical realm: motherhood and resulting self-stigmatization

As mentioned within the discussion of reactions grounded in ignorance, medical professionals were repeatedly cited by the twelve women interviewed as sources of unwanted suggestions and unrealistic expectations triggering suffered self-stigmatization.

Throughout the twelve interviews, the women repeatedly shared feelings of frustration in response to pressures placed upon them by the medical realm and its practitioners. As a result of menstruation, the women report being facing exacerbated tolls taken on management that could not ultimately be lessened by the knowledge or assistance of medical professionals. Despite physicians’ (often acknowledged in their interactions with the women) lack of the knowledge necessary to assist women with securing better management during menstruation, the women reflected feeling overwhelmed and frustrated by pressures to uphold ideal management. Such expectations in relation to ideal management from physicians were especially taxing and emotionally charged for these women as they surrounded expectations to maintain management for the sake of preserving their fertility and health to partake in motherhood.

A potential complication of poor management of one's blood sugar levels is increased difficulty in getting pregnant. Specifically, higher blood sugars over long periods of time resulting in elevated A1C values (the 3 month average of blood glucose levels) have been proven to correlate to not only complications for vital organs such as the eyes, but for one’s fertility and

ability to conceive naturally. Medical professionals were repeatedly identified as enforcers of this societal expectation placed upon women. As a result of their combined identity as a woman and an individual with type one diabetes, three women spoke directly about the increased pressure felt to secure this example of a gendered expectation, and how their identity as a type one diabetic creates additional barriers to achieving such that is bestowed upon women by US society.

Pressures associated with management imposed upon these women by medical professionals most clearly manifested in their reflections of self-stigmatization. While not all remarks or interactions with medical professionals were negative, and some were certainly noted as sources of support, it was most often expectations set in place by this population which resulted in their experiences with self-stigmatization and assumption of responsibility for perfect control of an uncontrollable disease – something, as one woman stated: “that’s easier said than done” (2025b)

So often, when I am struggling, I have to tell myself: You know what, I work hard, or harder than any other human being so I should treat myself the same. So having a little conversation with myself sometimes helps me. If not then addressing it, if no that, then letting it go and trying not to fixate on it. That is definitely what I have found to help me, but it is definitely easier said than done, I think. (2025b)

Here, this woman’s reflection reveals not only the existence of self-stigmatizing practices explicitly present among a quarter of the women interviewed but also the self-awareness possessed by these women allowing them to acknowledge the contributing role they play in the stigma faced by this population. Such is significant for it validates the women’s shared understanding of stigma as something no individual is exempt from contributing to the

perpetuation of, as well as something able to be inflicted upon oneself.

Appearance and Body Image

As predicted in the creation of the interview guide, discussions of the increased difficulty to maintain alignment with stereotypical notions of femininity so heavily enforced by US society upon women were prevalent throughout the interviews.

These women had numerous, detailed responses and examples capturing the increased pressure placed on women in relation to their body image and displays of ideal femininity. This pressure was noted to be especially present in the social (specifically the “going out” or party) scene of college:

In some very superficial ways, it’s just planning where you are going to put your site versus what you’re going to wear when it’s the weekend (college going out scene).

Trying to keep it hidden and kind of being self-conscious about how it looks because if you have like large random lumps around your body, it’s hard to really keep that separated, like what your body looks like versus what the pump looks like. (2021b)

Thus, it was such pressures that resulted in the women’s efforts and contemplations to engage in passing strategies such as concealing their devices with their clothes. Specifically, the women expressed anxiety over the pressure to align with the expectation that women must dress in a revealing, provocative manner in the college social scene. While many women noted they had overcome pressures by making the decision to wear what they want, regardless of how their devices may show, others personally desired to remain less visible as such was more comfortable for them.

Closely tied to discussions of pressure surrounding physical presentation were those of

associated with body weight:

As a girl it makes me feel, not less feminine, not less attractive, but in my eyes like when I first started wearing something, I look damaged, not clean, not put together, not bumps and bruises. Both mentally and physically I got a little something there. I think it has affected the way I view my body and my relationship with food – I know that doesn't happen for just females – but I think there is a big weight and stigma on females on how they look, and in their clothes when I'm going out. (2025b)

Discussions of weight were present among five of the 12 (42%) interviews conducted. The women were confident in their analyses that society expects women to be thin and inflicts stigma and judgment upon those who do not meet this “ideal female body type” (2021b). When one has type one diabetes, losing weight comes with additional challenges due to the dangers associated with adherence to extremely rigid eating and exercise habits. Physicians were frequently cited by the women as perpetrators of these expectations. As a result, frustration towards their providers' inability to understand how challenging the, already very difficult, task of losing weight becomes when you have type one diabetes was repeatedly expressed by the women.

Another prevalent manifestation of concerns in relation to appearance and body image are best defined as reactions not necessarily or always experienced personally by these women, but reactions most feared or dreaded. Reactions most feared by these women were most dominantly negative reactions from romantic interests or established partners. Thus, the social scene, and more specifically the hookup and dating scenes presented additional anxieties for these women. This overall fear and anxiety stemming from dating was discussed by five out of 12 women interviewed for this study: “When I go out, I always have to be aware someone is going to see it or feel it in a relationship. This has raised anxieties I didn't have pre-diagnosis”

(2025b). In relation to this section on appearance, the anxieties repeatedly expressed by the women overwhelmingly surrounded fear of facing judgment for the devices worn on their body and being thought of as “weird” and less romantically and sexually desirable (2024a). The women shared that facing judgment in response to the visual presence of their devices (such as insulin pumps and CGMs) was an example of a situation within which they were most scared of being seen only for their diagnosis. Their devices played an active role in the reinforcement of this fear. They worried about them logistically, for the ways in which their physical presence functions to remind them and their partner of T1D every time they choose to do something intimate such as cuddle. For these women, it was the fear of stigmatizing reactions grounded in ignorance by those they are romantically interested and involved with that were most dreaded, feared, and producing of anxiety.

The responses of these women pertaining to the impacts of being a woman with type one diabetes functioned to confirm the gendered nature of social expectations examined by West and Zimmerman (1987) and the existence of the expectation to maintain those of a given age imposed upon the chronically ill within US Society (Dillaway et al. 2022). Here, the women’s accounts of frustration and stigma inflicted upon them – especially by medical professionals – in relation to their blood sugar management during their periods and weight function to confirm how gender is created, coded, and performed “routine[ly], methodical[ly] and [as a] recurring accomplishment” through social interaction (West and Zimmerman 1987:126). The resulting self-stigmatization experienced by these women thus sheds light on how violations of notions of one’s respective gender is paired with the imposition of negative sanctions: “if we fail to do gender appropriately, we as individuals– not the institutional arrangements – may be called to account” (West and Zimmerman 1987:146). For these women, medical professionals were noted

as a population specifically responsible for calling them out for these failures. Their assigning of this responsibility is an important extension and specification of the findings of West and Zimmerman's (1987) study. It highlights of the need to pair such work with that of studies like that performed by Dillaway et al. (2022) to better recognize the medical model's active role in reinforcing inequalities for certain groups within US society. One of the key results of such reinforcement unaddressed by the literature are experiences with self-stigmatization reported by the women interviewed. Such is significant for it highlights how conversations of gender cannot be expanded upon through dependence on the medical model. If we wish to better understand and address the interplay between gender, illness, and stigma within US society, we must employ the sociological model of illness and utilize first-hand, micro level accounts to examine how social constructions and structural inequalities actually manifest and therefore impact the lives of college-age women with type one diabetes.

Summary of Results and Discussion

The results of this study have shown interviews targeting how the lived experiences of chronic illness are impacted by stigma, gender theory, and age through highlighting the many gaps in the existing literature's ability to speak to the lived experiences of college-age women, with type one diabetes. For these women, life with type one diabetes is relentless in nature and produces many consequences and daily tolls to their overall wellbeing. The adjustment to and navigation of college is a significant source of stress for these women, as entry into it is associated with the pressures to succumb to behaviors contradicting those advisable and best for securing ideal management of T1D. Stigma is pervasive throughout these women's lives as a result of their diagnosis with type one diabetes and experiences with stigma can vary based on

whether one makes the decision to pass or disclose. The women expressed a preference in being outed by others or disclosed by visual and audio cues of their T1D than initiating ‘coming out’ dialogue as well as an immense passion for taking on the role of an educator to address stigmatizing reactions faced to such disclosure. Surprisingly, despite their love for this role, the women acknowledged that there were times in which the power of stigma in US society squashed their beliefs in their individual abilities and underlying desires to address this oppressive system. For these women, gender significantly impacts their experiences with T1D, and they were not hopeful that such (or any other impacts explored) was likely be recognized by wider society and therefore changed in the near future.

CHAPTER 4: CONCLUSIONS

Significance of Results

The purpose of this study was to explore the shortcomings of the medical model through an examination of perceived stigmatization faced by college-age women with type one diabetes (T1D). This study was conducted through a pairing of a systematic review qualitative with in-depth interviews. Methods for the systematic review included selecting articles examining chronic illness prevalence in the United States, basic understandings of T1D, and illness experience for the chronically ill in this nation. Articles were then compared to determine prevailing themes. Methods for the qualitative interviews included interviewing twelve present and former college-age women with type one diabetes from the Northeastern US. The questionnaire was inspired by and derived from the foundations of the sociological model, which function to shed light on the ways in which society and our social world produces, contributes, and therefore constructs illness experiences at the microlevel. In other words, the interview guide was created to attempt to address the shortcomings of the medical model, which focuses on disease, rather than calling attention to illness experience for chronic conditions such as T1D.

The methods of this study consisted of twelve in-depth interviews with present and former college-age women with type one diabetes. The interviews and their findings served as the beginnings of much needed and to-be-conducted research on this demographic of chronically ill women with T1D. Ultimately, these interviews functioned to support the original argument against such heavy, isolated dependence on the medical model of illness and that advocating for better implementation of the sociological model of illness. Results concluded that awareness and management of type one diabetes for this demographic is universally recognized as something daily and that which relentlessly imposes tolls upon their daily lives. Such functioned to

legitimize both the unseen and seen challenges associated with this invisible illness as well as transition seamlessly into support for the need to push back against society's ableist enforcement of the medical model's Sick Role upon chronically ill populations (Parsons 1975). Within the Sick Role, one is expected to not only visibly present as ill, but to possess a toxically positive mindset. The women were seen to reflect their succumbing to pressures to be toxically positive through discussions positively coding the enforced maturity and responsibility as admirable qualities gifted to them by their diagnosis and resulting experiences with type one diabetes.

When it came to the results of responses to questions pertaining to adjustment and navigation of college, the women unanimously painted the picture of this life-stage and experience as one defined by stress. As a result of their diagnosis with T1D, the two dominant sources of stress surrounded the unpredictable schedule and food and drink characteristic this setting and life stage. Overall adjustment and navigation were painted as feats unable to ever be truly mastered, further amplifying this life stage as one highly stressful in nature.

Discussions of support available to and most heavily sought out by these women were filled with references of close friends and family. Few shared supportive relations with those who were also type one diabetics. The two types of support the women noted to be most helpful were acts of service: support making daily life with and management of their T1D easier and support provided by communities of fellow type one diabetics. Overall, the findings revealed an unanimously strong desire for better access to support provided by fellow T1Ds. The women were frustrated by lack of access and connections as they felt fellow T1Ds would be providers of support and connections most mitigating of emotional labor inflicted upon them by the medical model and resulting stigma.

Stigma was abundant throughout the twelve interviews. It was present within the

women's conversations of the women's discussions of reasons to pass, reasons to disclose, results of disclosure, as well as in their discussions of the interaction between gender and illness within the medical and social scenes of US society. Interestingly, these women preferred to be disclosed by others and worked to ensure such responsibility would be taken off their shoulders by rendering their illness visible, or "lay[ing] it all out" (2025b). This "laying it all out" was accomplished by wearing their devices visibly to increase the chances that they would be called out, "outed," or questioned by others (Samuels 2003). Laying it all out resulted in experiences with stigma best categorized as reactions of ignorance and pity. Such findings were significant for they bolster the need to call attention to the immense misunderstanding of type one versus two diabetes plaguing of US society. This lack of understanding of what it truly means to live with T1D is not isolated to general members of society. As a result of their combined identities as women *and* type one diabetics, these women reflected engaging in self-stigmatization as a result of pressures imposed upon them by the medical model and its professionals. Within the social setting of college, interactions between gender and illness took the form of expressed concerns in relation to appearance and body image as well as an immense fear of stigmatizing reactions from romantic interests and established partners. Such results are significant for they confirm the legitimate existence of interplay between illness and US society's expectation of rigid adherence to gender roles (West and Zimmerman 1987).

Recommendations

One of the first recommendations elicited by the results of this study is to create greater recognition, awareness, and education surrounding the shortcomings of the medical model of illness. As a result of the blind eye turned by the medical model to relevant social forces of our

wider, social world this model and its professionals (physicians, specialists, etc.) fail to pick up on experiences captured by these in-depth, sociologically grounded, interviews. This blind eye is problematic for it not only reveals the ignorance of the medical model, but the harm in the form of additional barriers, such as stigma and ideals of toxic positivity, which are afflicted upon the chronically ill. Therefore, to address and combat the blind eye, stigma, and toxic positivity perpetuated and enforced by the medical model of illness, it is essential that physicians and other formal support persons in the lives of these college-age women, such as providers in college wellness centers, are taught how to ask sociologically grounded questions – questions which seek to get at and provide space for chronically ill individuals (like the twelve women interviewed for this study) to discuss the ways in which the world around them contributes to the construction, characterization, and therefore effects of illness on their lives. Education on this type of question asking should be sourced from sociological research as well as the informal expertise provided by the voices of the patients themselves. Exposure and completion of such curriculum should be a key component of mandated medical training for all medical professionals, regardless of specialty.

To combat the highly problematic Sick Role (Parsons 1975) – dictating that ill individuals should work to treat and overcome their illness(es) – and pervasive misunderstandings between type one and type two diabetes, it is essential that better public health education is created. Such education could take the form of Public Service Announcements (PSAs) as well as health education in schools and differ from the stereotypical format defined by the medical model. Learning about stigma, toxic positivity, and the differences between T1D and T2D must start early and be ongoing so that individuals are better able to talk about such topics and recognize burdens afflicting this populations. By providing

them with this education, individuals will become familiar with stigma imposed upon the chronically ill from young ages – whether they themselves are chronically ill or not. For PSAs, we need to have similar education and public portrayal of type one diabetes as we do for type two. By ensuring they have these qualities, PSAs can better and effectively provide information necessary to foster awareness of the way in which stigma begins with and is continuously perpetuated by our social world.

Like PSAs, health education in schools surrounding illness experience generally and specific examples such as T1D must begin young and be ongoing. As was calculated from the data collected by the twelve interviews conducted, the average age of diagnosis for these women was 8. Such is important for it confirms the need to not only continue conversations and education, but to ensure they begin at young ages. To divert from the health education courses typically subscribing to the medical model, such education must prioritize building empathy and awareness of many different conditions and illnesses. Schools are an effective and strategic choice for there is no better place to ensure a diverse group of youth, young adults, as well as adults are reached on a repeated basis. In its diversion from the medical model, sociologically grounded education could do things such as bring in speakers with T1D to (like the guiding purpose of this thesis project) repeatedly expose individuals from young ages to voices silenced by the medical model blind focus on treatment and cure. By promoting these voices and doing other things such as utilizing the month of November type one diabetes awareness month – as a means by which to especially welcome the telling of these first-hand experiences, we would increase the chances of providing children with the tools necessary to hone strong, interpersonal skills needed to interact with chronically ill individuals in a non-stigmatizing manner. Such education should be holistic and comprehensive. It cannot be teacher (or in this potentially case,

provider) led, nor a top-down in lecture style. At its core, this public health education needs to be founded in the purpose and goal of this study: to shed light on the voices of those who live day in and day out with chronic illnesses like T1D and are currently ignored by existing literature. This education cannot be a mindlessly checked box by school administration, it must be consistent and intentional in its efforts to build empathy and combat the perpetuation of stigma pervasive in the lives of individuals like the twelve women interviewed.

As was seen throughout the interviews, ignorance surrounding the differences between T1D and T2D was one of the most pervasive sources of stigma faced. Additionally, the enormous presence of ignorance surrounding T1D and the differences between acute and chronic illness was highlighted by the women's discussions of emotional labor and stigma resulting from their expected ability to adhere to the Sick Role. Within the sick role, individuals are expected to visibly present as ill and reflect a desire to get well – something unavailable to those who are chronically ill and prescribed a life not set on securing a cure but persevering through relentlessly harsh and imperfect management. Thus, providing such education would be a means by which to begin addressing such ignorance perpetuating the stigma further increasing the already immense emotional labor associated with life with T1D.

Furthermore, and perhaps most importantly, provision of such PSAs and public health education will result in a trickling down of positive effects as individuals (and therefore greater society) will be more likely to and capable of asking questions of these women that are rewarding and displaying of the warmly regarded and highly desired willingness to learn, rather than stigmatizing ignorance and pity. As shown by the responses of the women interviewed, increased displays of this willingness to learn by audience members resulted in their increased desires and willingness to serve as an educator. Such correlation is something to take note of it

comes with its own consequences upon this population. While I could recommend that we tell the women to keep educating others on the ground, that is neither a fair nor sociologically derived approach. Such is why we need mandated medical training on how to ask sociologically grounded questions, which tap into micro-level, first-hand experiences. What we must do is combat stigma and deprive these women of this enormous responsibility and burden of educating the ableist world around them chronically residing on their shoulders.

Finally, these women reflected an overall lack and resulting desire for support provided by a community of fellow type one diabetics. To better support this demographic, those with connections to other T1Ds (such as providers) must find appropriate means by which they promote the development of better patient organizations that focus on building community for individuals like these women. For example, this could be something such as the provision of the opportunity to join a support group available to all patients of a particular hospital or medical practice. Physicians and other specialists would be responsible for promoting awareness and the benefits which stem from taking advantage of this resource. The running of the support group itself could then be organized by a diverse team of medical professionals (doctors, nurses, diabetic educators, etc.) and professional support persons (such as social workers and mental health counselors). Some women were hesitant to disclose more than necessary within the college setting, or some would be in the situation where they have no other diabetes, so having access to an ongoing form of social support that exists outside of this setting may serve most useful to address this ongoing and lifelong need.

Building off of this desire for support, the interviews of the women demonstrated that supportive connections to other human beings do not always have to take place in-person, or face-to-face to be effective and combative of the consequences and toles produced by life with

T1D. Furthermore, such is not always what is most comfortable and therefore effective for each individual with T1D. To best ensure the creation of T1D communities that are accessible and diverse in their provision of support to this demographic, medical professionals and other individuals capable of organizing must make use of not only in-person connections, but those that can be fostered online as well.

Limitations

There are several limitations present in this study to be addressed, both for the systematic review as well as the qualitative interviews. For the systematic review, the sample of articles available to be selected for review was limited. This could not have been mitigated on the part of study design, because as explained previously, there is an extremely limited volume of literature utilizing a sociological approach to address the experiences of type one diabetics, let alone college-age women with type one diabetes. Given the limited quantity of articles available to be included in the systematic review, observed conclusions may or may not be representative of true experiences with stigma and social support and their contributing factors. Despite this, proposed recommendations are a helpful start towards future research and the development of interventions to better promote the wellbeing of this population.

For the qualitative interviews, while the interviews conducted were in-depth, this study only conducted interviews with twelve women from the Northeastern United States. Because of the limited number of interviews, the results of this study cannot be generalized to the larger population. Interview results are predicated on the assumption that all participants are answering honestly. Lack of honesty, or not discussing disclosure practices, impacts of gender, and experiences with stigma to their full extent, could potentially skew results. If any of the

women perceived discussing themselves as negatively impacted by T1D, despite the interview being confidential, their response could be censored to not contain the full extent of their experiences out of reasoning such as unwillingness to share or lack of comfort sharing in an interview/discussion-based format.

Time was another limitation when it came to the qualitative interviews. Had more been permitted to complete this project and run interviews, it is possible that more women's voices could have been heard and other limitations such as diversity in terms of race, ethnicity, socioeconomic status, type of college attended, sexuality, and geography could have been addressed.

Finally, the original intent was to interview not only present and former college-age women with T1D, but also healthcare practitioners and/or professional support persons for those with T1D. While contact was attempted to be made with such individuals, such efforts did not result in the conducting of any interviews. While the interviews with the twelve women provided significant information on the use and findings elicited by the sociological model of illness, we need more first-hand accounts to characterize and identify human sources and perpetuations of the problematic ideals of the medical model. Such limitations are important to identify for they highlight future work and research required to better accomplish the goals of the present study.

Future Research

Future research on the experiences of college-age women with type one diabetes should address the limitations presented in this study. To address those stemming from the limited number of interviews able to be conducted, future research should replicate this study on a

larger scale so that not only a significantly increased number of women can be interviewed, but a more diverse sample can be obtained. Such is important because it will allow for more diverse findings in relation to key factors such as experiences with stigma, social support, and gender which can then be better generalized to the larger population of college-age women with type one diabetes in the Northeastern US.

This study functions as a starting point for general and sociological research performed on the experiences of college-age women with type one diabetes. Thus, to further the original intentions of this project, future research should focus on ensuring interviews are conducted with physicians and professional support personnel who routinely interact with members of this population. Such is necessary to better characterize and analyze the impact of the limited medical model upon these college-age women's experiences as individuals with chronic illness. By gaining the voices of individuals a part of the population responsible not only for this population's medical care, but for the resulting self-stigmatization they report suffering, a better understanding of the issues and practices needed to address them can then be derived.

Another way in which these interviews can be utilized to better achieve the original goal of capturing and characterizing the medical model of illness would be through the conduction of focused research on the Sick Role in relation to these women's experiences. By curating more specific questions pertaining to how these women attempt to "do" the Sick Role when their disease is daily and chronic, research would be better able to understand the impact of this mindset and notions of toxic positivity. Such questions would then allow them greater, much needed, and presently absent space to reflect on the negatives stemming from their illness. As noted earlier, this study's ability to collect genuine reflections of harsh matters such as the immediate and resulting realities of living with T1D may be challenged by the existence of

responses lacking honesty or absence of those withheld out of discomfort. Such limitations call attention to the need to conduct future interviews via alternative platforms other than face-to-face. Therefore, future research should also provide these women with interview formats removing of pressures associated with talking face to face, and in a more formal setting. Options should include and range from interviews that are over the phone without video recording, to the choice of completing a written survey that is confidential.

This study of the experiences of present and former college-age women with type one diabetes in the Northeastern United States is just the beginning of research needed to address the limitations of the medical model. To better provide holistic support to these women and move beyond the limitations and consequences of this clinical perspective of illness experience, we must employ the sociological model and create space for the voices of this setting, demographic, and disease.

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APPENDIX A: CONSENT FORM

Consent Form

I consent to participate in this interview about the experiences of college-age women with type one diabetes and relevant impacts, challenges and forms of social support. This research is part of my, Karson Saunders', senior thesis in Sociology, under the direction of Professor Melinda Goldner at Union College in Schenectady, New York. Involvement in the study is voluntary. There are no repercussions if you choose not to participate.

Karson Saunders, the project researcher, has explained the purpose of the study, how the interviews will be conducted, analyzed and reported on, and the expected duration of my participation. I have had the opportunity to ask any questions that I may have regarding the study, and I have received answers that meet my satisfaction. I understand that I am free to skip any questions that make me uncomfortable and to discontinue participation in this interview, without penalty,, without penalty, at any time. I understand that I can choose whether or not the interview is recorded and that I can have the project researcher turn off the recording device at any point. I understand that my participation will be kept confidential.

If you have any questions about the research, please contact Karson Saunders (saunderk@union.edu) and Professor Melinda Goldner (goldnerm@union.edu). If you have any concerns or unanswered questions related to your rights as a participant, you may contact Joshua Hart (hartj@union.edu), the Union College Human Subjects Review Committee Chair, or the Office for Human Research Protections (<https://www.hhs.gov/ohrp/>).

I have read and fully understand this consent form. By signing below, I indicate that I wish to participate in this research study. I sign it freely and voluntarily.

Date: _____

Signed: _____ (Participant)

Signed: _____ (Principal Investigator)

APPENDIX B: INTERVIEW GUIDE

Participants: Present and Former, College-Age Women with T1D

Diagnosis

1. How old were you when you were diagnosed? When did you graduate from college?

General Impact

2. How would you describe the impact of T1D on your life? Please explain.

Public Navigation/Passing

3. What, if any, role has T1D played in your adjustment to college? Please explain.
4. How do you navigate T1D in college? Please explain.

Disease Management

5. When are you most aware of your diabetes? Please explain.
6. In relation to management of your T1D, how frequently...
...would you say you actively think about managing your T1D?

Support

7. Who do you turn to for support?
 - a) Do they have T1D?
8. What types of support are most helpful and why?

Disclosure

9. Do you tell people about your diabetes? Why or why not?
 - a) Who do you tell?
 - b) How do you decide whether to tell them or not?
 - c) What are their reactions?

Gender/Femininity

10. How are your experiences of living with T1D impacted by being a woman, if at all? Why or why not?

Stigma

11. How would you define stigma? What does it look like? Please explain.

12. Do you ever perceive stigma because of T1D?

If no:

Why not?

If yes:

How does stigma impact your life as a T1D? How do you respond, if at all?

Is there anything else you would like to add?