The Diabetic Self, Embodied:
Illness Narratives of Women with Type 2 Diabetes in Rural Tennessee

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Abstract

Type 2 diabetes is a chronic illness requiring those affected to integrate illness management into their everyday life. Healthcare providers expect patients to adhere to consistent and regimented clinical treatments, which are difficult for patients to meet when balancing the other responsibilities and commitments that make up their life-world. This leads to stigmatizing labels of "noncompliance." Academic scholarship focused on illness narratives of patients with type 2 diabetes reveal that patients deemed "noncompliant" often have well-thought-out self-management routines that fit into the context of their lives. Patients define their illness in terms of their life-world, seeking a balance of a good life with a long life. In this study, I interviewed five women with type 2 diabetes about their experiences and what constituted a "good life" while living with type 2 diabetes. I explore concepts of the sense of self, embodied experience, and moral imaginaries to evaluate how patients view themselves, their relationship with their diabetes, and their relationship with the world. I argue that there is a need to focus on the moral component of living with diabetes and to understand how patients deal with this to understand what a good life means in this regard. Attending to the patient's language as it is used in terms of their own experience and values enables us to understand relationships between the self and moral worth in the context of American society. A patient-centered approach allows healthcare providers to understand how a type 2 diabetes diagnosis is both embraced and resisted in daily life. These approaches are critical to understand what it means to live with a chronic illness based in bodily denial and how a good life is both part of and separate from it.

Introduction

Across the United States, over 37 million people have diabetes—approximately 90–95% of them have type 2 diabetes (*Centers for Disease Control and Prevention*, 2023). Type 2 diabetes is a chronic illness caused by the body's inability to make enough insulin, use insulin properly, or both, resulting in hyperglycemia, or persistently high blood sugar levels. (*Cleveland Clinic*). Type 2 diabetes is characterized by insulin resistance and β-cell dysfunction. β-cells are insulin producing cells in the pancreas; in early stages of type 2 diabetes, "decreased insulin sensitivity triggers β-cells hyperfunction" to combat high blood glucose levels, leading to hyperinsulinemia (Banday, et. al 2020). Symptoms of hyperinsulinemia include weight gain, cravings for sugary food, and fatigue; however, the increased insulin secretion eventually is not enough to compensate for insulin resistance, leading to hyperglycemia (Banday, et. al 2020). Classic symptoms of severe hyperglycemia, often present at diagnosis of type 2 diabetes, include weight loss, blurred vision, polyuria (excessive urination), and polydipsia (excessive thirst) (Banday, et. al 2020).

The hemoglobin A1C (HbA1C) test is a blood test that specifically measures the percentage of red blood cells with attached glucose. It is a way to measure one's average blood sugar levels over the past three months (*Centers for Disease Control and Prevention*, 2023). HbA1C levels below 5.7% are considered normal; a range of 5.7%-6.4% indicates prediabetes, those at a greater risk of developing diabetes, and above 6.4% indicates diabetes. A normal blood sugar level is 70-99 mg/dL, and for someone with type 2 diabetes, that level is 137 mg/dl or higher (*Centers for Disease Control and Prevention*, 2023).

In 2022, the economic cost of diagnosed diabetes in the U.S. was $412.9 billion, an increase of 7% from 2017 (Parker, et. al 2022). Three quarters of these costs were associated with direct medical costs from diabetes, including diabetes-related complications such as peripheral vascular disease, diabetic neuropathy, foot problems, diabetic retinopathy, and nephropathy (Bailes 2002). This includes excess costs associated with medication, constituting "44% of the total direct medical burden" (Parker, et. al 2022). Out of this, over a quarter of the economic burden of diabetes was from indirect costs associated with the disease, rather than diabetes itself. These include reduced employment, reduced productivity at work, and premature mortality (Parker, et. al 2022).

Primary care has become the central point for diabetes management—primary care providers deliver 90% of the clinical care to individuals with type 2 diabetes (Shrivastav et. al 2018). Providers' goals center around achieving sustained glycemic control, specifically maintaining hemoglobin A1C (HbA1C) < 7%, which is associated with reduced risk of diabetes-related complications (Boye, et. al 2022). Yet, primary care providers face time constraints, having limited time to cover various topics; in 2017, primary care providers spent an average of 18 minutes per exam (Shrivastav et. al 2018). As a result, there is a need to find ways to balance time limitations with effective care that meaningfully supports patients.

Every year, the American Diabetes Association releases the "Standards of Care in Diabetes," a comprehensive review of guidelines for managing diabetes. In 2024, these standards for providers included setting and modifying glycemic goals to create individualized treatment plans to optimize self-efficacy and engagement (American Diabetes Association). Further, the guidelines emphasize considering if "life expectancy is sufficient to reap the benefits of stringent goals" of managing blood sugar. This brings into focus the quality of life for patients and suggests that following clinical goals is more complex than simply striving for the "ideal" HbA1C of 7-8% for a person with type 2 diabetes (American Diabetes Association).

Current recommendations for type 2 diabetes management include physical activity, healthy eating, blood sugar monitoring, insulin injections, and diabetes medications (Mayo Clinic, 2023). While type 2 diabetes affects all populations, rates differ among different ethnic and racial groups and are often linked to socioeconomic status. Diabetes rates are highest among American Indian and non-Hispanic Black people, and people with less than a high school diploma are more likely to be diagnosed with diabetes compared to people with a college degree ("National and State Diabetes Trends").

Geographically, rural populations, defined as people living in areas with a population less than 50,000 people, have a 16% higher prevalence of type 2 diabetes and a 20% higher type 2 diabetes-related hospital mortality. (Dugani, 2021). Living in a rural area presents a wide set of barriers to care, including reduced access to providers, healthy foods, and physical activity (Dugani, 2021). As of 2020, in Tennessee, 13.8% of the population has been diagnosed with diabetes (United States 2021). In rural areas of Tennessee, these rates are even higher due to factors such as isolation, distance to medical facilities, and lack of resources (Dugani 2021). Because of its chronic nature, type 2 diabetes involves both clinical intervention and self-management, or activities and behaviors individuals take to treat their condition.

Common academic scholarship on type 2 diabetes management and treatment centers the clinical perspective focused on lowering HbA1C counts (Brown and Prather 2020). Extensive research has been conducted on topics such as clinical outcomes, social science, history, patient provider interactions, public health interventions and more; this research has yielded a great deal of knowledge but only modest gains in clinical outcomes. As shown in Figure 1 below, the age-adjusted incidence of diagnosed diabetes has decreased by 2.6% since 2008; yet this is only a 0.4% decrease since 2000. Further, an additional 1.2 million Americans are diagnosed with diabetes every year (*Centers for Disease Control and Prevention*, 2023). Current scholarship cites low education and literacy rates as factors that impede self-management of type 2 diabetes, specifically in rural areas (Ross 2015). This research expresses how patients are expected to adhere to the treatment regimens proposed by their healthcare providers, creating a binary of compliance versus noncompliance. However, this research does little to show how expectations are hard to meet for patients balancing the other responsibilities and commitments their lives demand.

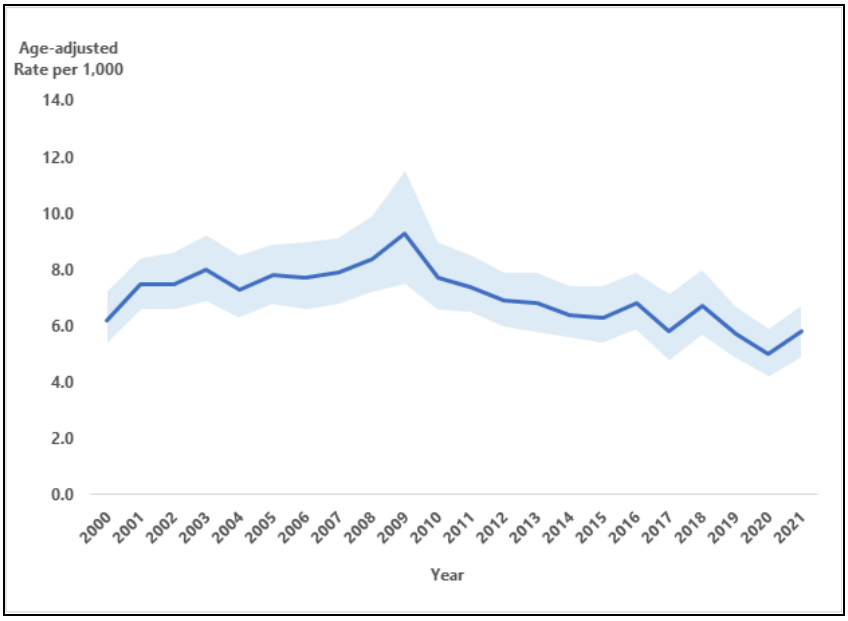

Figure 1. Trends in age-adjusted incidence of diagnosed diabetes among adults aged 18 years or older, United States, 2000–2021 (*Centers for Disease Control and Prevention*, 2023)

To move beyond the clinical focus, I concentrate on the patient side of type 2 diabetes. For a chronic illness such as type 2 diabetes, management and care fall largely on the patient outside of the clinical setting, to make changes in both mindset and actions that shape everyday life. Yet, evaluating and researching this management requires an understanding of patient lives and values. Thus, this thesis employs illness narratives to understand the patient experience. Illness narratives are a form of autobiographical storytelling that patients use to make sense of their symptoms and experience. (Kleinman 1988). Often obtained through qualitative interviews and ethnographic studies, these narratives center the patient voice and delve into the lived experience of patients. Scholarship focused on illness narratives of patients with type 2 diabetes examines how patients with type 2 diabetes make sense of their condition. Illness narratives capture the diverse realities of people with type 2 diabetes, demonstrating how they create agency in their lives and seek a new normal.

Ideas of noncompliance, morals and productivity, control, chronicity, and suffering appear frequently in scholarship on these narratives—these topics characterize the lived experience of patients with type 2 diabetes. As a result, much research implicitly suggests that there is a discrepancy between what patients consider a "good life" and what clinicians consider a "good life" for someone living with type 2 diabetes, as emphasized both in illness narratives and the ADA Standards of Care guidelines. In a broad sense, a better understanding of patient values could not only improve how type 2 diabetes is approached and managed, but also help to create a more empathetic response to this disease, one that takes into account the complexity of patient lives.

Comprehending the patient perspective of living with type 2 diabetes requires studying the internal conflicts patients face—conflicts between what should be done and what produces

positive bodily experiences—and how these are reconciled. I argue that there is a need to focus on this moral component of living with diabetes to understand what it means to live a good life. To achieve a good life, women living with type 2 diabetes must balance their embodied experience with what they view as an ideal diabetes patient, thus remodeling their sense of self.

In order to approach this issue and better understand how lived experiences shape patient realities, I first explored key scholarship surrounding patient values for type 2 diabetes and chronic illnesses more generally. I investigated the major concepts that arose through the lens of the self, embodied experience, and moral imaginaries. Second, I conducted semi-structured interviews with women with type 2 diabetes living in Jackson, Tennessee, focusing on patient value and experiences.

I then interpreted this data by assessing how the self shaped patients' diabetes experiences, examining the differences between the embodied experience of diabetes and the moral imaginaries that shaped how patients viewed the world. I concluded that implicit within the journey toward a good life, there is a sense of inner resistance felt by patients—conceptions of what "should be done" associated with bodily denial conflict with what patients desire to do or what produces positive bodily sensations. To reconcile these tensions and make diabetes management more holistic, there should be attention on the moral interpretations of the patient's sense of self and how this drives decision-making processes in the pursuit of a good life.

Literature Review

The concept of the self in crafting patient perceptions

Academic scholarship centered on the patient experience with type 2 diabetes highlights the idea of the "self" as a driving factor in patient decision-making. To understand how patients manage their diabetes, it is crucial to consider the idea of the self in the patient identity.

I use Martin Edwardes' concept of the self to examine literature on themes of noncompliance and suffering for patients with type 2 diabetes. The social self is the self that "others believe me to be" (Edwardes 2019, pp 166). This self stems from social relationships with others; it is both opinion and offered "about me to me". This view of the self ultimately is defined by how one is seen by others.

The various social selves from the relationships in our lives come together to form a self-model, the "self I believe me to be" (167). This self is "like an amoeba, it constantly changes its form." The social self sometimes is in line with the self-model but sometimes conflicts with it.

Finally, the cultural self is the "self I should be" and is an ideal. Like the social self, it is offered to the individual by others but as an ideal of what a person should be, not as they are perceived. (174). Patient narratives often express sentiments of what they "should be" doing in regards to their diabetes. This forms the basis of the cultural self that defines how diabetics view an ideal patient.

Labels of noncompliance divide versions of the self

When evaluating patient outcomes from the clinical side, noncompliance frequently appears as a patient-oriented label of blame. Noncompliance is the lack of adherence by a patient to the medical regimen or treatment plan proposed by a healthcare provider (Barasa and Mmusi-Phetoe, 2021). Clinicians typically label patients as noncompliant due to disobedience or a lack of education. However, there is a wide range of barriers and factors that influence a patient's perceived "noncompliance." While the cultural self is linked to management plans proposed by providers, illness narratives reveal that the self-model is linked to how these plans manifest in patient lives. These divided versions of the self demonstrate the ways in which patient experiences are complicated by reality and can lead to "noncompliance."

For older women in the rural South, illness narratives showed "erratic self-management" as well as eating patterns that differed from their providers' recommendations (George and Thomas 2010). Through interviews, the patients discussed how providers seemed unwilling to listen and were not helpful in adapting self-management routines to the reality of daily life. This created a struggle between doctor recommendations and patient self-management, ultimately leading to the patients being labeled as "noncompliant." These patients were further labeled as difficult to work with and unwilling or unable to change, constructing a cycle of dismissal by providers.

Patients, when asked, emphasized their unique diabetic condition and how they adjusted their routine to match how they feel, which can differ from doctor recommendations (Ferzacca 2000). Ultimately, the same value of self-discipline that informs doctor recommendations also informs patient self-management tactics. Each patient had their own version of what self-management looked like, and through their illness narratives, patients that on the surface are deemed "noncompliant" actually had well-thought-out self-management routines that they felt worked for them based on their bodily experience.

Noncompliance places the blame solely on the patient, and it fails to account for the differences in the "life-world" of the patient and the "clinical world" of the provider (Hunt and Arar 2008). Not only do patients and providers sometimes have different goals, different subsets of patients have different goals of what they want their diabetes management to look like. For example, one patient noted that she felt sick when her doctor took off insulin because her blood glucose levels were within a normal range, explaining "They say it's fine. But I don't know, because I feel sick. And they still don't believe me" (Hunt and Arar 2008, p. 361). In their narratives, patients also cite how their familial obligations restrict their abilities to follow management routines and how patients do what they can within the context of their daily lives. They develop treatment strategies that are necessary to fit into their lives. Further, patients often prioritize bodily experiences, leading them to treat their diabetes only when they feel sick, which differs from the consistent regimen that providers give.

Using the concept of the self, it becomes apparent that clinicians create an ideal model of a patient—one that is compliant. However, the self-model of the patient centers lived realities and barriers to management that ultimately result in the label of noncompliance. Further, illness narratives provide insight into the thought that goes into patient self-management of type 2 diabetes. These narratives show that often, patients deemed "noncompliant" actually have well-thought-out strategies that have been adjusted to fit into the context of their daily lives. The illness narrative reveals a disconnect between the physician's recommendations and the patient's lived experience, as well as the cultural self and self-model, especially when the patient finds the recommendations impractical given barriers like familial obligations and geographic isolation. Finally, the label of noncompliance centers the clinicians view of a "good life" and disregards the patient's point of view.

Chronic illnesses lead patients to redefine the self

Illness narratives lend themselves well to making sense of the reality of living with a chronic illness like type 2 diabetes. Patients relay their frustrations about losing control over what they considered essential aspects of their life (Kaufman 1998). Unlike short term illnesses, chronic illnesses present a new daily life that require patients to reevaluate their life-worlds. Transformations occur within patients, forcing them to change their goals and incorporate their illness into their new sense of self, or the self-model.

Patients with chronic illnesses must find a way to cope with their illness and the suffering it brings. Illness narratives reveal how patients with chronic illnesses confront American moral

values and find ways to either incorporate or reject them into their disease experience. For a life-long illness, patients must change their viewpoint on what productivity means in the context of their daily life. They must find a new normal because their new self feels unrecognizable (Hay 2010). Chronic illnesses force patients to find new ways to gain control over their illness and to define their sense of self.

Illness narratives are a form of meaning-making for patients with chronic illnesses and show how patients make sense of their lives with diabetes. Patients with chronic illnesses described feeling different from the person they used to be and used illness narratives to "get their thoughts straight" (Gomersall, et. al 2012). In this process of putting meaning to their lived experiences, patients faced a tension between official and unofficial voices, or between physicians and the patient, friends, and family. This tension led these patients with chronic illnesses to use illness narratives to address the question of "What kind of life is worth living?"

To further complicate the question of what constitutes a good life, illness narratives for patients with comorbidities of two or more chronic illnesses showed how their realities and social contexts shaped their experiences. Chronic illnesses were both caused and worsened by a stressful life. Patients all had unique experiences based on their social context that could not be generalized across different cultures. Various factors caused social suffering for patients with chronic illnesses, and comorbidities were more likely to occur for patients with chronic illnesses.

Ultimately, illness narratives are the way in which patients with chronic illnesses search to define their sense of self. For a chronic illness, the patient's goal is to return to a sense of normalcy, rather than to "get better" in a clinical sense. Illness narratives allow patients to weigh what they value in their lives and determine for themselves what they feel constitutes a good life.

Suffering responses for part of self-model to help some patients make meaning of their illness

Much scholarship in critical disability studies rightly critiques the cultural belief that living with a disability means that one is suffering and that one should, therefore, be pitied and "cured" (Reynolds 2017, Gill 2001, de Wolfe 2010). Linking suffering and disability strips away agency from patients and places the perception of disease on everyone other than the individual actually affected. For example, one patient noted, "My disability is how people respond to my disability" (Gill 2001, p. 353). The stigma around living with a disability causes patients to be viewed as living in a state of tragic suffering, regardless of their actual experience.

Through the lens of the self, a suffering response forms part of the self-model. In terms of what constitutes a good life and who decides that, the suffering scholarship on type 2 diabetes implies that this life is not a good life. A critical disability lens would suggest a deeper inquiry is needed into how people with type 2 diabetes examine and explain their own lives when given the chance to speak about more than the suffering the researchers assume is there. Still, to fully understand the lived experience of people with type 2 diabetes, it is important to understand how patients narrate suffering from, coping with, and ultimately living with diabetes.

Through patient narratives, diabetes appears to be both a cause and product of social suffering (Mendenhall et. al 2010). Structural inequalities and barriers to care both cause and

worsen suffering, while making diabetes management more difficult. Patients expressed that stress from various forms of suffering such as anger or lack of resources was the cause of their diabetes. Patient narratives illustrate how stressful situations that are both a result and cause of their diabetes lead to more suffering which in turn worsens their condition. These narratives give more insight into the comorbidities with type 2 diabetes, specifically depression. These illness narratives ultimately show diabetes not just as a product of suffering, but also as a factor that worsens their suffering, magnifying the intense personal struggles that come with this disease.

Patient narratives also emphasize how a lack of agency increases their suffering and impacts their view of themselves—patients turn to either a heroic response to dominate their illness or a suffering response to cope. (Hay 2010). These responses help patients make sense of chronic illnesses to fit them into their everyday lives. To cope with their suffering, patients must find a way to take control and gain agency, whether by taking on a sick role or trying to overcome their illness. These narratives reveal that patients with chronic illnesses do indeed face forms of suffering every day and must find a way to cope with it.

Lived experience and patient narratives demonstrate the way local realities shape social suffering. The comorbidities of diabetes and depression worsened the suffering, but for different social groups, context was important. Sociality was important for shaping patient suffering, as each reality presented a different set of barriers. The narratives offered the conclusion that suffering should be understood as a holistic experience grounded in a specific social context. The social context is important for how people understand and experience their illness (Mendenhall 2016). While there is overlap between some barriers and daily life factors, ultimately patient narratives illustrate that social realities greatly vary across cultures which impacts the way suffering is experienced.

Patients with chronic illnesses face a great deal of social suffering, which stems from sociopolitical, economic, and institutional factors. This type of suffering is viewed as something that both worsens and causes chronic illness, and there are often comorbidities that worsen this suffering. Patients struggle to find a way to incorporate their suffering into their daily life and take various approaches to cope with this suffering. Ultimately, by solely focusing on suffering, clinicians miss the complexity of the lived experience with type 2 diabetes. However, an examination of suffering illustrates the different ways that type 2 diabetes can be experienced and how patients have different values and obstacles in their pursuit of a good life.

In my own data collection, ideas of suffering were not explicitly brought up by the women interviewed, despite holding minority identities such as being women and living in rural areas. I argue that due to the agency embedded in their language, suffering was not a key part of what they decided to share in our conversations. While the trauma and existential processes of pain and death could certainly be part of these women's experiences, their approach to managing their illness was not to adopt a suffering response. Words like "frustrated" or "tired" appeared in conversations, but this does not relate to the structural barriers and passive resignation that accompanies the suffering response. The women interviewed took on the responsibility of managing their illness and thus suffering was not a state that came up. While ideas of suffering

are important to this area of study, this work prioritizes other aspects of living with type 2 diabetes that shape patients' lived experiences.

Embodied experience of living with type 2 diabetes

Embodied experience, a term used by anthropologist Thomas Csordas, refers to the ways in which our experiences are not just products of our minds but are also influenced by our bodily sensations and environmental interactions. To understand how we perceive and engage with the world around us, embodied experience centers the body as an integral part of understanding emotion and behavior (Musolino et al., 2020).

In rejecting the mind/body dichotomy, Csordas argues that "the body is not an object to be studied in relation to culture, but is to be considered as the subject of culture, or in other words, as the existential ground of culture" (Musolino et al., 2020). The body is thus not an empirical "thing" that stands in as a backdrop to cultural life, but it is an "experiencing agent that is intersubjective, relational, dynamic, sentient, and indeterminate in nature" (24). By giving agency to the body, embodied experience centers bodily sensations and perceptions. For type 2 diabetes, exploring patient narratives through the lens of embodied experience provides insight into why patients choose to make decisions that differ from clinical recommendations and illuminates the impact of their illness on their body and in their life as a whole.

Embodied experience changes perceptions of blood sugar levels

Illness narratives describe how patients adjust their diabetes routines to match how they feel, which can differ from doctor recommendations (Ferzacca 2000). One patient noted about his blood glucose levels, "They [the clinic] want me between 200 and 100. If I got below 200 I would be in big trouble…If I ever got to 80 [a normal level] I'd be dead" (Ferzacca 2000, p. 39). Patients noted the difference between a happy and healthy life, emphasizing that strictly following the regimens proposed by their healthcare provider would not let them live a life they were content with. Embodied experience brings the focus of the illness to patients' bodies, emphasizing how the body's experiences can differ from what clinicians recommend. In the excerpt above, the patient's embodied experience magnified the fact that clinically "normal" blood sugar levels were not what felt "normal" in his body, challenging cultural beliefs about where expertise lies. In the quote above, the expertise is from the embodied experience of the patient, rather than from the physician, complicating biomedical epistemology which defines the physician as the expert surrounding health decisions.

Embodied experience draws attention to the difference in the "life-world" of the patient and the "clinical world" of the provider' (Hunt and Arar 2008). Not only do patients and providers have different goals, different subsets of patients have different goals of what they want their diabetes management to look like. For example, one patient noted that she felt sick when her doctor took her off of insulin because her blood glucose levels were within a normal range, mentioning "I brought her all the count of the blood I was checking at home, and to me it

was really high. It was way over normal, but she said that's fine…But I don't think so, because I know how it was when I was on insulin. And I feel worse" (Hunt and Arar 2008, p. 361).

Ultimately, patients often prioritize bodily experiences—they treat their diabetes when they feel sick, which is not the constant regimen providers prescribe. Thus, embodied experience both explains how labels of noncompliance can come from prioritizing the body and how the life-world of the patient is centered on bodily experience rather than adherence to orders.

Embodied experience impacts definitions of control for patients

Beyond just bodily sensations, embodied experience encompasses how patients view recovery from their illness. For a chronic illness like type 2 diabetes, ideas of "control" are complicated because a full recovery is unlikely and sometimes impossible due to the lifelong nature of the illness. Embodied experience demonstrates how the definition of control itself is different for patients and providers based on the goals of the two groups.

Interviews with both patients and physicians make evident that there is a difference in what is considered "control" over type 2 diabetes. While physicians base type 2 diabetes control on objective clinical indicators such as blood glucose levels, patients evaluate their success and control of type 2 diabetes on how they are feeling and if that feeling is "normal" (Hunt 2001, Gomersall, et. al 2012, Gammeltoft 2021). Many patients expressed feeling tired and weak with low blood sugar—what providers wanted patients to achieve actually led to the patients feeling worse. There is a difference in clinical versus bodily indicators. As such, there is a difference in what is considered a "good life" depending on how control is characterized.

Control of type 2 diabetes from the patient's perspective involves the patient feeling able to control their illness to the extent that they can live their life in a way that makes them happy. Control for clinicians comes from achieving acceptable blood glucose levels (Hunt 2001). While providers cite a lack of education or understanding as a reason that patients are unable to control their blood glucose levels, narratives show that patients have different obligations and barriers that impact how they are able to control their diabetes. In this manner, a good life for the patient from the patient's view is based on embodied experience while a good life for the patient from the clinician's view is based on numeric evidence.

When managing a chronic illness, patients view control over their illness as the ability to return to a sense of normalcy in their lives (Hunt 2001, Becker and Kaufman 1995, Hay 2010, Gomersall, et. al 2012, Kaufman 1998). Stroke patients express similar values about their chronic illness as those with type 2 diabetes. Illness narratives from stroke patients were shaped by patients' sense of self; their values were implicit in their hopes for recovery. Returning to things they could do before their stroke were oftentimes their goals for recovery—the ability to "ride the bus or drive again" (Becker and Kaufman 1995, p. 177). Rehabilitation, and more broadly control of their illness, was motivated by the hope of returning to normalcy. However, providers looked for different signs of recovery. In the case of stroke patients, provider goals materialized as "tiny incremental, physical gains" to gain reuse of limbs (Becker and Kaufman 177). While patients and providers both desire to "control" chronic illnesses, this materializes as

vastly different realities, indicating that different goals underlie the quest for a good life for these two groups.

Illness narratives showed that patients changed their eating habits and daily lifestyles to control their diabetes (Sherman, et. al. 2014). Patients also relied on social support. Control was viewed as something achievable, but barriers such as sticking to their diet or their age lowered levels of patient "compliance." Ultimately, these narratives show that patients aimed to control their diabetes by following recommendations from providers but adjusted treatment plans based on what was manageable for their daily lives.

The illness narrative of one woman in Thailand illustrated how she was able to take control over her illness by changing her lifestyle and controlling her diet. The patient put personal meaning to her illness and looked beyond the self, specifically to spirituality. She referenced learning from a Buddhist monk who helped her to think more existentially about her illness and how it affected those around her (Oakley, et. al 2011). This form of thinking allowed her to put meaning to her illness beyond just herself and ultimately led her to make changes to achieve a healthy lifestyle. The illness narrative was told through a lens of what the patient valued, and her control over her illness came from her being able to find meaning in her treatment, health, and illness (Oakley, et. al 2011).

Illness narratives exhibit a focus on how, in some cases, control of the body and autonomy can be stripped away by different treatments, preventing patients from choosing what constitutes a good life. Patients are expected to passively cooperate with the treatment plans proposed by clinicians, leading to a loss of agency over their illness. Thus, there is an expectation that patients should fully comply with what the healthcare provider views as a "good life." Yet, patients sometimes choose to ignore clinical recommendations for treatment in favor of feeling like themselves (Gomersall, et. al 2012). One patient noted, "[insulin] will make you healthy, but not necessarily happy" (Ferzacca 2000, p. 42). Physicians, patients, family, and friends all hold different perspectives and voices, and as a result, patients must prioritize different truths about their illness and what kind of management works best for them to achieve a good life.

Ultimately, there are differences between what patients and providers consider control over type 2 diabetes. In illness narratives from key scholarship, patients expressed two main desires in controlling their illness—feeling good in their body and returning to normalcy in things they could do before their diagnosis. However, these desires often contradicted the provider's goal of controlling numeric evidence. Control is context dependent, and patients face different barriers and daily struggles that inhibit their ability to control their illness, instead creating their own self-management routines to feel content with their lives.

Moral imaginaries frame the pursuit of the good life

As evidenced from illness narratives above, there is a discrepancy in the life-world of the patient and the clinical world of the provider. The underlying quest for a good life for these

groups stems from their definitions of control, based on concepts of embodied experience and definitions of the self. Control for patients entails centering the body and what feels "normal," while for providers, this control is directly linked to blood sugar levels. (Hunt 2001, Gomersall, et. al 2012, Gammeltoft 2021). Still, there is a moral component grounded in the experiences of these two groups that determines how things should be: what a good life "should be", what an ideal type two diabetes patient "should be", and how recommendations "should be" followed.

The ideas of what "should be" surrounding type 2 diabetes management and a "good life" more broadly, tie into the concept of moral imaginaries. With moral imaginaries, I refer to Elana Buch's use of the term in her book *Inequalities of Aging*, described as the lens through which individuals evaluate their decisions and what "should be" done. Moral imaginaries are the wide range of "imaginings, practices, processes, and relations" that shape our view of everyday life. (Buch 2018, p. 6). I advance the idea of a "good life" with diabetes as a concept that brings together components of moral imaginings surrounding eating habits, social support, and bodily sensations.

Moral imaginaries demonstrate ideas of "which kinds of persons and social relations exist and should be supported" (Buch 2018, p. 15). Our moral imaginaries provide the basis upon which we make decisions about what to eat, do, and how to act, rooted in how we think the world, and what we think our role in it, "should be." In terms of a good life, moral imaginaries define what is the "good" and "right" life for a diabetic. Our imagined idea of the good life delineates what actions we take.

Moral imaginaries influence self-management routines

Illness narratives display how self-management approaches are informed by American capitalist moral values such as hard work, productivity, and autonomy. Conceptions of U.S. citizenship are grounded in values of happiness, with the Declaration of Independence itself stating life, liberty, and the pursuit of happiness as the unalienable rights of every U.S. citizen. These values, both capitalist moral values and happiness, are incorporated into both patients' sense of self and treatment plans when living with chronic illnesses. Patients strive to achieve control over their illness by embodying these values (Becker and Kaufman 1995, Hay 2010, Ferzacca 2000).

The same values that motivated clinical approaches formed the basis of patient self-management plans. Yet, because the actual approach was different, patients were labeled as noncompliant. The patients made sense of clinical advice through their lived experience, and each patient had their own version of what compliance was, based on how they could feel in control of their illness. Further, patients prioritized competency in their own lives and measured success in terms of how they felt day to day, rather than strictly on blood glucose readings (Ferzacca 2000).

Illness narratives depict the pressure patients with type 2 diabetes face when American moral values of optimism and productivity conflict with managing their illness (Reichenbach and Maish 2006). Patients internalized labels of "lazy" in their disease and felt pressure to conform to

what is valued in a society that places an individual's worth in their productivity. Illness narratives revealed that patients felt that their illness was an individual shortcoming; they felt it was their personal responsibility and thus sought to be productive and work hard to manage it. Ultimately, American morals influenced patients' views of themselves and characterized how they felt about their experience with type 2 diabetes.

A meritocratic model of productivity and agency informed narratives of patients with chronic illnesses. While some patients tried to dominate their illness and completely overcome it, others turned to a passive, suffering response (Hay 2010). Agency was important for patients to maintain autonomy and productivity in their lives. Specifically, autonomy materialized as the ability to "overcome" the illness. Productivity was important for self-management routines and having hope in their recovery to achieve a sense of normalcy in their lives. Patients frequently mentioned that they could gain control over their illness by working hard and being motivated.

For patients in rehabilitation for strokes, American moral values informed the recovery process. Patients perceived motivation as the most important factor in determining outcomes post stroke (Becker and Kaufman 1995). Illness narratives shed light on the patient's belief that a full recovery could be achieved by working hard in rehabilitation and maintaining productivity, both in the rehabilitation process and in their daily life. Gaining control over their recovery as well as finding a new normal were important keys in the illness narratives. Patients felt that the more they embodied values of hard work and productivity, the quicker they could achieve their goals. Further, patients looked for a sense of fulfillment by embodying these values, but expressed unhappiness with their recovery if they failed to do so. In this way, there was a pressure to embody American moral values to achieve a good life.

Conclusion

Through a review of the common themes that emerge from illness narratives of patients with type 2 diabetes or other chronic illnesses, it is evident that the life-world of the patient differs from the clinical world of the provider. Yet, there are nuances within these differences—patients and providers both sought to create individualized treatment plans, but the reality of these led to patients being labeled as "noncompliant." Further, moral imaginaries shape both patient and provider views of the world. The cultural self, or ideal diabetic, is the same for patients and providers—someone who follows clinical guidelines. Still, the manifestation of these selves becomes more complicated when considering the embodied experience of patients. Many patients cite the importance of maintaining normalcy in their lives or looking for a way to make sense of their experiences. To delve further into patient narratives, literature must focus on the patients' bodily experience to gain a deeper understanding of how type 2 diabetes shapes the self, affecting the patient on both a physical and mental level. By centering embodied experience, the self becomes the priority in the life-world of the patient; the embodied experience alters the ability and norms of how one interacts with the social world, thus extending the diabetes experience beyond the individual body.

Concepts of the self, embodied experience, and moral imaginings all shape the way patients view themselves and their interactions with the world. Through this review of academic scholarship, I position my research in the center of these three concepts, focusing on how they overlap and determine patient values in pursuit of a good life.

Methods

Participants

This research examines the experiences of five women from Jackson, Tennessee. The purpose of the study was to explore the lived experiences of women with type 2 diabetes among women in Jackson with the aim of understanding their life values and what made a good life for them. Women were specifically chosen for this study to examine if gender-coded family roles, body standards, or social relationships affected their experiences. The study focused on participants from Jackson, Tennessee to explore ways in which barriers or lifestyles associated with living in a rural area impacted patient experiences. Data collection occurred over two weeks and involved women ages 36 to 87. As the project was interested in a wide range of experiences, the only criteria for recruitment were women who were both aged 18 or older and diagnosed with type 2 diabetes. Additionally, the study sought to highlight varied mindsets surrounding the embodied experience, so patients with a range of years (8 to 30) since diagnosis were included.

Recruitment

I selected participants from patients who met with a practicing family physician at The Jackson Clinic in Jackson, Tennessee. I met with each participant at the clinic.

The study received approval from the Vanderbilt University Institutional Review Board. Prior to giving consent, all participants were fully informed about the study, what the interview would consist of, and their right to withdraw from the study at any time. In agreeing to participate in the study, participants were informed that the transcript and any written notes would use a pseudonym in place of the patient's name, and data would be reported in a de-identifying way.

Illness Narratives and Grounded Theory

The interviews were used to generate illness narratives of the women. These narratives paint a picture of the patients' life-world in relation to type 2 diabetes and center patient values within the context of their disease. By using illness narratives, I could accurately and precisely represent the illness experience of the women using their own words.

Grounded theory, developed by Barney Glaser and Anselm Strauss in their 1967 text *The Discovery of Grounded Theory*, is an inductive approach to analysis that is used to explain human behavior "within social context" (Munhall and Boyd 2010, pp. 226). Rather than imposing preconceived ideas into research, grounded theory aims to generate theory grounded in data (Chun, et. al 2019). I utilize grounded theory to form the illness narratives of the women interviewed, using their quotes and perspectives to form my interpretations about the self and embodied experience.

After the interviews were completed, the following questions guided the analysis: How do patients characterize their experience with type 2 diabetes? What values emerge in illness narratives of these patients? In what ways does embodied experience shape patient narratives? How do these values align and conflict with clinical recommendations and why? What are the moral underpinnings of these values? What makes a "good life" for a woman with type 2 diabetes and how is that influenced by her sense of self?

Results

I conducted semi-structured interviews at The Jackson Clinic with 5 women. Due to the exploratory nature of qualitative research, the interviews varied in length but were each approximately one hour long. I recorded the interviews in order to focus on the conversation with the patient. After completing each interview, I transcribed the recording. Participants were given a $20 VISA gift card upon completion of the interview.

The five women interviewed were Cynthia, Martha, Janet, Lauren, and Gail (all pseudonyms).

Table 1. Participant characteristics

Participant	**Age**	**Years since diagnosis**
Cynthia	59	24
Martha	78	30
Janet	62	16
Lauren	36	8
Gail	87	22

The women varied in age and in years since diagnosis, and all offered different perspectives on what their embodied experience with diabetes was. While Lauren and Janet, for example, were very adamant about overcoming diabetes in the future, Gail displayed a sense of acceptance that she was going to live with diabetes for the rest of her life. Despite the age range, all of the women discussed how their family, friends, and various support systems were important in their diabetes experience. Through the use of illness narratives, I interpreted how the embodied experience of living with diabetes affected the sense of self as well and tied into their moral values. This manifested as differences in management routines, eating habits, and bodily sensations associated with diabetes.

Discussion

Specific themes emerged throughout the interviews that I analyzed through the lens of three different concepts—the idea of the self, embodied experience, and moral imaginaries. First, in order to discuss their experiences with type 2 diabetes, many patients noted a way of incorporating type 2 diabetes into their view of themselves. This self-view of the patient with diabetes was important in determining their mindset as well as how their values aligned or did not align with their illness. Next, there was a clear tension between the patient and the provider. While patients valued their relationship with the physician, they simultaneously mentioned feelings of discontent or frustration surrounding their diabetes, specifically around bodily sensations such as low blood sugar or eating food they enjoyed. Finally, the values that encompassed a good life emerged. For many of the patients interviewed, a good life was tied to family, friends and support. These values determined how they viewed their diabetes, both on its own and in relation to themselves.

I first examine the concept of the self, as defined by Martin Edwardes, including the self-model, "the self I believe me to be," the social self, "the self others believe me to be," and the cultural self, "the self I should be" (Edwardes 2019, pp. 166-174). These selves intertwine in some aspects of diabetes but are disparate in other ways, magnifying how a chronic illness like diabetes asks patients to redefine their sense of self. Specifically, I examine the idea of becoming "used to" diabetes and how that intersects with the self. I then analyze how the "expert" for diabetes differs when prioritizing the self-model versus the cultural self depending on embodied experience with blood sugar. I look at how support systems and the social self influence the diabetes experience as well as how mindsets align with the cultural self for some women but conflict with it for others.

Next, I explore embodied experience, the way in which the body shapes the life-world of the patient, through analysis of Janet's interview. I illustrate the ways in which embodied experience and Janet's reliance on her body both exacerbated disordered eating habits and satisfied her cravings for unhealthy food and drink such as sweet tea. I connect the embodied experience to the good life by linking Janet's focus on her family and desire to see her grandchildren grow up to the active denial of positive bodily sensations.

Finally, I use the concept of moral imaginaries, or patients' view of what the world "should be" and what an ideal type 2 diabetic "should do" to discuss how values of self worth influence the diabetes experience. I analyze the language the women use to define a "good" diabetic, someone who follows clinical guidelines exactly. I consider how years since diagnosis impacts moral imaginaries and more broadly, acceptance of the illness. I then consider how women will both actively choose to eat things that deviate from this idea to prioritize the embodied experience while simultaneously feeling negative emotions for doing so.

Chapter 1: The view of the self in shaping patient experiences

To properly evaluate what a good life means from the patient perspective, it is important to first understand how patients view themselves. Within my interviews, it became apparent that there were various ways diabetes was incorporated into the view of the self. I use Martin Edwardes' concept of the social self, the self-model, and the cultural self to understand how women internally view their relationship with diabetes, both as a part of their self-model and separate from it. Through our conversations, I saw how women had social selves defined by experiences with providers and family members, which often conflicted with each other. All of the women interviewed gave insight into bodily sensations and experiences that formed their self-model. This model was moldable based on their experiences with family and providers (who offered social selves). The social self sometimes was in line with the self-model but sometimes conflicted with it. Patients interviewed expressed sentiments of what they "should be" doing in regards to their diabetes. This forms the basis of the cultural self that defines how the women viewed an ideal patient based on experiences in clinical settings.

I argue that within the pursuit of a good life is the reconciliation of these three selves. The women had to find ways to have their self-model align with the cultural self, but sometimes this did not happen. Nevertheless, their pursuit of a good life included the pursuit of a content self—the feeling of peace with their diagnosis and decisions.

<u>"Who I believe me to be" — The self model is determined by bodily experiences</u>

"You just learn to live with it… that's your life… you don't know anything else"

The quote above comes from the interview with Cynthia, whose mindset surrounding diabetes had become incorporated into her self-model. Cynthia is a 59 year old woman who has been living with diabetes for 24 years. In our interview, Cynthia heavily focused on the importance of family in her life as well as her view on life with diabetes.

For Cynthia, diabetes becomes a part of you and how you view yourself. She says, "I guess I've lived with it so long that I'm just used to it." Rather than diabetes being something extra to account for in her routine, it has become integrated into her perspective of how she views herself. Her embodied experience was intertwined with her diabetes experience, and thus, by becoming "used to it," she incorporated diabetes into her view of life. Her self-model was shaped by the fact that she had been diagnosed for many years. For Cynthia, diabetes was not something to fight against—a sentiment expressed by other women—but instead something that she was "used to." Cynthia's view of herself changed because she had lived with diabetes for "so long." Through this lens, understanding a good life for Cynthia meant understanding that her self-view incorporated her diagnosis.

For Martha, another woman interviewed, to learn to live with diabetes meant to adjust her disposition and outlook towards management. Martha is a 78 year old woman who has been living with diabetes for 30 years. Our interview was characterized by her emphasis on the importance of family and support systems in her life. Martha described herself as "sedentary"

and noted how her relationships with her husband, kids, and God were the most important parts of her life. In regards to her blood sugar, she noted, “But I run pretty high, over 200 most times. I can't eat anything, I can’t drink water, anything. I can remember one of my teacher friends who had cancer and diabetes and she said water even made her sugar go up and I thought, well, ok, I'll just learn to live with this.” For Martha, to “learn to live with this” meant that her diabetes could not be managed very simply. It would require the same fluid self-model that Cynthia expressed. Cynthia’s friends and her own bodily experiences influenced her view of herself, so her self-model also incorporated her diabetes. “Learning to live with it” meant that the view of the self changed to include diabetes.

In interviews with Cynthia and Martha, the theme of “learning to live with it” and “dealing with diabetes” frequently appeared. I use Edwardes’ concept of the self-model to evaluate these interviews. For these two women, living with diabetes was incorporating it into their daily routines and finding ways for it to become part of their views of themselves. Thus, to “learn to live with it” means to be able to modify routines so that “it”—diabetes— can become part of your life.

Using the self-model, the self “I believe me to be,” Martha and Cynthia were influenced by their diagnosis and the chronicity of it. Rather than something to fight against, their diabetes had become an accepted part of their lives—it was a part of how they approached everyday life. Various social selves, including that before diagnosis and after, formed a fluid self-model. Thus, through the lens of the constantly changing self-model, Martha and Cynthia had modified the view of themselves to incorporate diabetes.

“Just living with diabetes” was a change in the self-model based on the longevity of their diabetes rather than a slight modification made to daily routines. For these women, “learning to live with it” was how diabetes had to be incorporated into the fluid self-model. Living with diabetes was more than just a change in diet or exercise, it was something that became a part of the patient and affected multiple aspects of everyday life.

“I can always tell if it drops too low. There is a feeling inside. There is a weak, nervous feeling inside and you know that sugar is low but I don't always know when it gets high”

The quote above comes from Gail, who like two of the other women interviewed, was most aware of her diabetes when her blood sugar was low. Gail is an 87 year old widowed woman who has been living with diabetes for 22 years. Gail credited her age as part of the reason she did not feel extremely compelled to follow clinical recommendations regarding food. As evidenced by the quote above, her bodily sensations contrasted with clinical guidelines that imply a lower blood sugar results in feeling healthier, and therefore better. Gail emphasized the importance of religion in her life and mentioned the ways her age impacted her life—she could no longer drive on her own and relied on her son and his wife. Ultimately, Gail felt that prioritizing things that made her happy (such as food) was worthwhile at her age.

While the clinical goal in diabetes management is to lower blood sugar levels, these women felt sicker when their levels dropped to lower levels. Gail explained she often did not even know when her blood sugar was too high. For patients to adjust their self-view to incorporate their diabetes, they had to learn to rely on bodily signals. The negative physical feelings associated with low blood sugar clashed with the providers' aims of lowering blood sugar. Thus, the self-model of patients with type 2 diabetes involved feeling dissatisfied in their bodies.

The comments from Gail evoke the Edwardes concept of the self-model or "the way I believe me to be." Gail feels weak and nervous when her blood sugar is low, which represents a departure from the social self, as clinicians assumed Gail would feel better, not worse, with low blood sugar. In this way, for Gail to live with her diabetes meant to live with a discrepancy between how she viewed herself and the social self that clinicians expected: someone who would feel better with low blood sugar.

The sentiments that Gail expressed were shared by Lauren, who was also most aware of her diabetes when her blood sugar was low. Lauren, the youngest woman interviewed, was a 36 year old woman who had been living with diabetes for 8 years. As the woman with the most recent diagnosis, Lauren most vividly recounted the story of her diagnosis, emphasizing her diet in the past. At the time of her diagnosis, she described feeling scared and noted that her vision had become blurry. Now, Lauren was working on improving her relationship with food, citing the emotional and psychological effects of eating that had greatly impacted her both in the past and present.

In regards to her blood sugar, Lauren explained, "if I don't eat something, I get really low blood sugar and then it gets to the point where I will start slurring my words and getting really faint." Again, Lauren's feelings of sickness with low blood sugar represent clinical goals that differ from patient realities, a difference which in turn impacts the pursuit of a good life. There were two different Laurens. First there was the social self, or the Lauren seen by providers who prioritized lower blood sugar. There was also the self-model, the Lauren who felt faint when her blood sugar was low. These different selves represent the inner conflict that Lauren had to grapple with. Lauren went on to note that she felt "almost out of control of [her] body." When Lauren's sugar was too low, she felt less bodily agency. Thus, feeling "out of control" stemmed from prioritizing the cultural and social self her providers saw and the internal conflict to reconcile these selves with her self-model.

Finally, Cynthia also felt that she was most aware of her diabetes when her blood sugar was low. She reported that "I operate better on high sugar, but when it gets low, I guess I just feel real sick… nauseated...headaches." All of the women interviewed described feeling "weak" when their blood sugar was low, contrasted with higher energy levels and strength when blood sugar was higher. Correspondingly, Cynthia, operating "better" on high sugar meant that her management of diabetes directly contradicted what clinical goals predicted. Again, the difference between Cynthia's self-model—feeling sick and nauseated with low blood sugar—contradicted with the social self that providers expected.

Ultimately, to live a good life for these women incorporated a feeling of control over their diabetes. Their view of themselves involved being able to read these signals, such as “slurring words” or relying on “feelings inside.” Yet, these women felt better when their blood sugar was high, and felt sick, weak, or nauseated when their blood sugar was low. For them, managing their diabetes did not mean having their blood sugar as low as clinical standards would suggest. For patients, living a good life meant finding ways to reconcile the self-model and the social self and considering the differences in patient and provider goals. Their reliance on bodily signals was both crucial for the management of their diabetes as well as a reminder of their illness.

<u>“Who I should be” — The cultural self and morally charged language surrounding self worth</u>

So I'll still eat, you know, something sweet like a dessert here and there, but I try to not overdo it... But as far as that, I don't check my blood sugar as often as I probably should.

The quote above comes from Lauren in regards to her daily diabetes routine. Using the word “should” indicates a right versus wrong mindset surrounding diabetes management. When asked what words came to mind when thinking about her diabetes, Lauren said “frustration, disappointment, shame.” For some of the women interviewed, diabetes management encompassed a moral level of right and wrong and should versus should not, typically surrounding eating. These ideas of right and wrong manifested as feelings of shame and guilt for the women, as they grappled with what they knew they “should do” versus what they actually did.

Using Edwardes’ concept of the cultural self, or the ideal self, the women interviewed faced a discrepancy between what they felt like the ideal diabetic did and what they did. While feelings and sensations surrounding eating determined self-model, the cultural self was someone who followed clinical guidelines exactly. Using words like “should” and feeling negative emotions when they did not follow these guidelines exemplify this tension.

This awareness of what should be done, or the cultural self, influenced the patients’ view of themselves, often leading to negative emotions. When Martha reflected on her diagnosis, she described feeling “just disgusted with myself that I didn't try to keep it in check. I thought I did, but I didn't.” The use of the word “disgust” again refers back to a moral understanding. Further, when Martha said she thought she was keeping her diabetes in check but actually was not, she implied feeling a sense of failure.

Janet, a 62 year old woman who had been living with diabetes for 16 years, had complicated feelings surrounding her diabetes. The longest interview, my conversation with Janet was characterized by a contradiction between what she did and what she thought. Janet brought up sweet tea numerous times, discussing how much she enjoyed it. At the same time she acknowledged that health was the most important part of her life, despite knowing that a clinical understanding of health would position sweet tea as unhealthy specifically for a diabetic, because it contains high amounts of sugar. Janet began our conversation by explaining how many of her

family members had been impacted by diabetes and how for her, being with her children and grandchildren was the most important part of her life. Janet has a complicated relationship with food, both greatly enjoying desserts while also eating extremely small portions when she went out to eat.

When describing her eating habits and approach to management, Janet said "I shouldn't even be at 10.8. I should be at 5.5 or 6, because I know what to do. I just have to do it." While her view is optimistic, it still implies a sense of struggle because actually making the changes is something she has yet to do. Further, there is a sense of an imagined ideal— Janet associates being at a 5.5 or 6 with success. Yet, her use of the word "should" again refers back to a moral right and wrong surrounding eating habits. Janet's cultural self was more in line with her self-model because she viewed herself as someone capable of achieving her ideals.

Overall, the word choices of the women interviewed revealed an implicit sense of right versus wrong. This sense tied into the feelings they had surrounding their diabetes, such as shame, as they knew what they "should" do, but were not doing it in some capacity or another. For the women to pursue a good life, they had to reconcile the cultural self with their self-model.

<u>"Who others believe me to be" — The social self and relationships shape patient experiences</u>

"So I think my friends and my son and daughter, they support me, even though they give me the wrong things sometimes if I ask for it."

The quote above comes from Gail, who described her family as her support system. She noted how in addition to being important sources of support for her diabetes management, they would also give her foods she knew were "bad" for her. In this way, Gail's support system, along with a few of the other women interviewed, was complicated—the family offered support but simultaneously allowed them to fulfill their food cravings. In this way, the family acted to prioritize physical health in terms of diabetes management but to also give the women things that they felt they "shouldn't" have.

Support and enablement from family members built the social self of the women, which influenced their self-model. Family members offered foods that were not in line with clinical recommendations, creating a social self that involved maintaining relationships through food. This also differs from the cultural self, as this social self puts the cultural self below positive bodily sensations in order of importance.

Janet shared this same sentiment, citing her husband as her biggest supporter while also acknowledging how he gave her food that was bad for her. She said, "He'll bring a whole 12 pack, a whole 12 dozen of donuts home…But I can't pass those donuts on that counter and they're the best donuts in town. You know what I'm saying? I said, so don't put that in front of me. I can't handle that. But every now and then he'll bring a dozen home and I may have a couple." For Janet, her husband both supported her and put her in positions where she ate things deemed "bad" for the diabetic. Her support system, like Gail's, enabled her to have things she

knew would make her feel good but also raise her blood sugar. Again, the social self was one that pursued these cravings, creating a tension between the self-model (the way I see myself) and the cultural self (the way I should be).

Martha expressed a similar story about her support system. She named her husband as someone who supported her and said, “Well, more or less, my husband gets involved every once in a while, but then he'll bring me a piece of fudge, because he knows I love chocolate.” For these women, their family gave them food that they knew they would enjoy, despite the risk of raising their blood sugar. The support system in this way prioritized the embodied self and positive bodily sensations over the cultural self centered by the provider. This created a social self that did not necessarily subscribe to the clinical recommendations.

In the pursuit of a good life, this social self was disparate from the self that clinical guidelines create. By giving the women things that they knew they liked, the support systems did not follow the same sense of moral right and wrongs surrounding food. These family ties impacted the ways in which the women interviewed were willing to accept food they knew the cultural self deemed “bad” for them. Using the concepts of the social self and cultural self, there seems to be a prioritization of positive experiences from food over a consistent following of clinical recommendations when support systems are involved. This begs the question—what is the purpose of this support? I argue that this support was not necessarily to follow doctors’ orders; rather, it was support to fit diabetes into the self-model and find ways to live a good life and obtain positive bodily sensations while living with diabetes.

> *“We just kind of laugh about it. I have several friends who deal with this and they just go on. Why complain? I see no point. I've never been a complainer. I always have to count my blessings and think, well, I have this lovely chair to sit in, that bed over there, my husband's here, I can get up and go somewhere if I want to. It's just a lot. This is a beautiful day. Thank you, lord, for everything. I'm just very happy. Thank you.”*

The quote above comes from Martha. Nearly all of the women interviewed mentioned ways that they remain positive about their diabetes management, despite the ups and downs. Martha described remaining positive by thinking about what she was grateful for. Her mindset ties into the way that emotions surrounding diabetes are largely negative; to maintain a positive outlook, people often look to other parts of their lives. Instead of finding positives within her illnesses, Martha looked elsewhere. This allowed her to maintain a good life because she separated her self-model from diabetes by focusing on the parts of her life that made her feel positivity. For her, a good life did not come from trying to match her self-model to the cultural self. Rather, it was formed from the social self, the one formed by the relationships with her husband and friends.

Janet, on the other hand, maintained a positive outlook by thinking about where her diabetes could be. She said, “A lot of people say, oh, once a diabetic, always a diabetic. But I don't believe that. I believe you can switch the numbers. I do believe you can switch the

numbers, no matter what my numbers are." Despite her high HbA1C, Janet spoke positively about her future with diabetes. This contrast between her goals and the present reality of her illness represents how Janet's positive mindset came from forming an ideal of what she wanted. For Janet, the cultural self drove her mindset and obtaining what she considered "ideal" numbers was what she associated with a positive outlook. Thus, Janet's goal overlapped with the clinical, numbers-oriented conception of diabetes. She prioritized the cultural self, constantly working towards what her diabetes could be and incorporating that into her self-model.

Similarly, Lauren had a goal of being "in remission" from her diabetes, meaning that she would strive to lower her blood sugar. Like Janet, Lauren kept a positive mindset by setting goals for her future diabetes. These two women formed an ideal model of what their diabetes management could be, and for Lauren that came from examples of people who had been able to achieve this. In addition to mentioning her faith and support system, Lauren centered control of her diabetes as a marker for positivity. Again, Lauren used the cultural model as a goal and incorporated this into her self model.

The women interviewed offered different ways that they maintained a positive mindset surrounding their diabetes. For Martha, that meant looking at things she was grateful for outside of her diabetes. Yet, for Janet and Lauren, they centered their diabetes and found ways to maintain a positive outlook by creating an ideal. All these women centered the body and set a goal that tied diabetes to their happiness. In this way, positive emotion was linked to illness and the cultural self influenced the self-model.

> *I value my husband and children and my relationship with Jesus, and that's it… Well, without them I'd just be a very unhappy person. I wouldn't feel like I had any worth, or that was no reason to hang around. I'd just wait and see what happens next, which I'm doing anyway. I just have somebody to do it with.*

The quote above comes from Martha, as she spoke about what constitutes a good life for her. All of the women interviewed, in some way or another, emphasized the importance of their family, friends, and support systems as part of what made a good life. In some ways, the value of these relationships overcame the positive bodily sensations that came from external sources like food.

Janet, a woman who heavily focused on the positive and negative emotions that came from food, ultimately tied her pursuit of a good life back to being with her family. She said, "So it's important for me to want to live and to be in the best health, so I want to be here to see my grandkids grow up." Cynthia noted in her interview, "Whenever I finally got children, they were just...everything." For these women, their family was one of, if not *the*, most important part of their lives. Their diabetes experience was secondary to that.

Lauren noted, "Anytime I kind of struggle with something, I kind of keep it to myself and internalize, but my mom is definitely my rock and my sisters, I have three sisters, but I'm close, close with two of them…Before, when I was like going through certain things or just really

frustrated with my diabetes, I just wouldn't really talk about it, especially if I had a couple setbacks and… I would just really internalize it. But now I try to talk it out with them." For her, family served the role of support system by lessening the struggles of living with diabetes. Further, Gail said, "Well, I guess you feel like if you've got friends and family, the things that's on your mind and the problems that you think you have, it helps to talk to somebody about them and that helps me cope with whatever, you know." For these women, family relationships were inextricably tied to the diabetes experience.

Overall, whether family was primary to diabetes or a part of the diabetes experience, a good life was intertwined with support systems. Every woman mentioned family and the importance of having people in their lives, and their relationships with family and friends made their diabetes more manageable.

Through the lens of the various selves, I found that the women had to reconcile the cultural and social selves with the self-model to be able to pursue a good life. While certain foods or desserts provided positive sensations, there was also a sense of moral wrongdoing associated because of the framework of the cultural self, or an ideal diabetic. The women's embodied experience of themselves was constantly changing, sometimes prioritizing positive bodily experiences when with family members, sometimes serving as a model for positivity to maintain an optimistic outlook. These various selves came together to form the self-model which also led the women to grapple with what they should do versus what they actually did. In the next chapter, I analyze a specific patient, Janet, in how her bodily sensations and embodied experience framed her experience with diabetes.

Chapter 2: Embodied experience

Through the concept of embodied experience, I analyze Janet's experience with type 2 diabetes. This concept highlights the active role the body plays in life experience and how bodily sensations alert Janet to her being-in-the-world. The category of embodied experience highlights two contradicting ideas for women living with type 2 diabetes: patients are asked to not feel satisfied in their bodies, prioritizing low blood sugar even if they feel better when their blood sugar is high. At the same time, patients are forced to rely on bodily signals to monitor their health and keep track of blood sugar levels to avoid more severe symptoms. Embodied experience draws attention to the ways in which the mind and body are not disparate entities but intricately connected and how the body itself actively shapes the life-world of the patient.

Janet's embodied experience was crucial for her to live with diabetes—she gave her body an active role in her diabetes experience. Yet, contradictions of what she considered a good life characterized her interview. She heavily described a good life as one with good health and strove to reach the numbers or clinical markers associated with good health, relying on her bodily signals to do so. Simultaneously, she was consciously aware of doing things, like drinking sweet tea, that did not correspond with these clinical goals. She concluded that for her, it was

worthwhile to deny herself positive bodily sensations and instead pursue the clinical markers of health so she could be with her family.

Janet described her body as being equally involved in the decision making process surrounding her diabetes; by giving her body agency, she faced a tension between what she wanted versus what her body needed. Her body "spoke" to her and would tell her that her desires, drinks and foods she found satisfying, were not necessary. Janet's experience was characterized by three conflicting voices: that of her body, her diabetes, and her desires. By analyzing the language Janet uses surrounding her body, I argue that Janet's embodied experience allowed her to reason with herself surrounding her eating habits. Her embodied experience both hindered her pursuit of good health by allowing sensations of satisfaction and aided her pursuit by telling her what she should or should not put in her body. In this way, a good life, through the lens of embodied experience, was one that balanced positive bodily sensations with long term happiness and family values.

> *The body talks to you and you just about know when something is off. I can tell you right now if my blood pressure just went up. I can tell you right here, in this moment my blood pressure's up. The body will begin to talk and send signals or feeling like my face feels cool, I may have some pressure goin' on right here, even with my diabetes. It can let me know that your sugar's up…So I was like, oh, let me just check my sugar and so. But that's how I knew.*

Janet gave her body an active role in her health maintenance, and the passage above illustrates Janet's embodied experience. Her body is a figure that "talks" to her and sends her signals surrounding her health. Through the lens of embodied experience, Janet's body alerts her to whether "something is off" and assists her in the pursuit of good health. Yet, throughout the interview, what Janet said her body "told" her to do did not always align with what she did. The language Janet used indicated signs of disordered eating, which played a role in how she listened to her body. This led to a tension between what she did and what her body told her, revealing the ways in which her pursuit of a good life was both hindered and helped by her embodied experience.

Janet frequently alluded to disordered eating behaviors; her previous diet was strictly monitored six days out of the week and then disregarded one day a week where she would eat anything she wanted. Through the lens of embodied experience, Janet's comments exemplify how ignoring cravings for what she wanted allowed her to achieve an ideal weight. Her use of the word "trouble" indicates a negative view of herself when her sugar is high; for her to avoid that, she denied herself of things she wanted for six days of the week. Thus, Janet rejected her bodily sensations in order to pursue what she deemed a "healthy" body. Her cravings represented her bodily desires, yet to fulfill the ideal of what she deemed healthy—which was also what she considered a good life—she decided to disregard them. As a result, her embodied experience required her to ignore cravings that she knew would result in positive bodily sensations.

So it has had a major impact upon my life and how I feel about it and how we know what is right. But you still have the craving for what you want. So you know you have to try to find something else to substitute that out. You know, and I guess when I went on my most major weight loss ventures I stuck to six ounces of chicken or fish, all veggies I wanted to eat…no bread, no sweets, no sodas, no tea unless it was unsweet tea.

And I had one day a week that…I could choose any day of the week. One day I can eat anything I want to eat and I stayed out of trouble and my sugar was good. So that's where I am and I told my doctor today that when I come back in three months I hope to come back with a bang and be where I need to be, because I know that diabetes just basically breaks the body down. It breaks your organs down and once it starts affecting one thing then it could go somewhere else and you know you can have many, many factors that could contribute to different things.

The positive senses associated with eating what Janet deemed satisfying were challenged by the body, as outlined in the excerpt below. Janet creates a tension between what her "system" wants versus what her body needs. Her body communicates with her and shuts down these desires, fulfilling a clinical voice of reason. She says below that sweet tea is "something that's satisfying to my system, that I want, but my body has already said you don't need that." Here, her embodied experience centers a tension between what the body wants and needs. The excerpt demonstrates the conflicting senses Janet felt—satisfaction from drinking sweet tea and eating "delicious ribs" and guilt surrounding what she should or should not do. This demonstrates the ways in which her illness requires her to not feel satisfied in her body.

Interestingly, Janet frequently mentioned her positive outlook, which appeared to be tied to her embodied experience. She said, "I'm going to turn it back around because I know that I can do it," reflecting her reliance on her body's voice of reason to tell her what she needs. Her body's agency created a trusting relationship between Janet's mind and body and gave her the confidence to feel that she could "turn it back around." Janet's embodied experience was tied to her positive outlook, as she felt that her body knew what was right; by following these signs, she would achieve good health, which she associated with a good life.

I get up and…where I was starving myself and eating one meal a day, and that was dinner. One meal a day was good enough for me, but I turned that around and now I'm eating three meals a day and I'm eating my little…I eat like a baby. I don't eat a lot.

When I went out yesterday I had a half a rack of ribs. I had two servings of broccoli and a sweet potato. I ate two bones off the rib and they were tender and delicious. I ate one serving of broccoli and I did have just a little bitty piece of the bread at LongHorn. But the tea. I had two glasses of that tea, that Arnold Palmer and that's what kicked me off base. And I had a spike. I went up to 350 even though I'd taken my insulin. I had a spike.

> *So I know what I'm supposed to be doing and what I'm not supposed to be doing. And at 62, I got more time behind me than I have in front of me and I don't want any of that time to be spent hospitalized, loss of limbs or anything like that. I want to be able to enjoy my family, enjoy my children and my grandchildren and my great-grandchildren. So I'm going to turn it back around because I know that I can do it, but sometimes I just get into what I want, what I want. It's something satisfying about the sweet tea with the lemon in it. It's something that's satisfying to my system, that I want, but my body has already said you don't need that and you really can't tolerate that. You shouldn't put this in your body.*

As shown above, the body talks to Janet and tells her what it does or does not need. These "needs" contrasted with her desires and connected to the disordered eating sentiments exemplified by her comments of eating "like a baby." Again, to listen to her body meant to reject positive bodily sensations—"You shouldn't put this in your body." In this way, the body served to center the clinical world of the provider rather than Janet's life-world, keeping her on the clinical diet that would lower her blood sugar. Janet's cravings and desires did not align with what her body told her to have, yet she acknowledged that she would still eat and drink these things. This illustrates how her embodied experience of type 2 diabetes creates a tension by both alerting her to her well-being and asking her to deny herself of food and drink that are associated with positive sensations.

> *But at least I fed myself and my diabetes has something to eat on while it's functioning. So with my medicine and with the food, everybody's happy. But then, when I was having the one meal a day, really, I was starving myself and so my diabetes is saying where is our food? We need something to work with. But I would rather sleep because I was so sluggish. It's not that I wanted to, it's just what my body said because of how I felt.*

The passage above exemplifies the agency that Janet gives to her body and how her diabetes contrasted her embodied experience. She says, "It's not that I wanted to, it's just what my body said because of how I felt." Her embodied experience controls both how she manages her diabetes and her sleeping schedule, telling her when to eat or when to sleep. Further, her body's needs contrast her diabetes' needs. She personifies her diabetes, and the needs of her illness contrast with what her body tells her. In this way, her diabetes aligns with her cravings—both are associated with positive bodily sensations. Her diabetes was something that needed to be fed while it was "functioning" indicating that Janet viewed her diabetes as a living being. To some extent, Janet's diabetes was an antagonist inhibiting her pursuit of health. Rather than something to live with, as other women mentioned, Janet viewed living with diabetes as an active fight. Janet maintained that her body knew what the "right" thing was, yet this also came with a denial of what she herself described as "satisfying." Ultimately, the excerpt represents a contradiction in Janet's reliance on her bodily signals. While earlier she maintained that her body

would push her to make healthy choices, here it told her to sleep rather than eat, which would have stabilized her body. Thus, Janet's embodied experience and reliance on her bodily signals contradicted her diabetes management.

In regards to a good life, Janet emphasizes that she wants to be able to "enjoy my children and my grandchildren and my great-grandchildren." Giving up foods that she wanted meant obtaining good health, which by Janet's standards would allow her to achieve a good life. Consequently, Janet's embodied experience here helped her achieve a good life. The short term satisfaction in her "system" from things she knew she shouldn't have ultimately hindered the long term good life that she sought.

> *Yes, you can have a great life and do anything that you want to do, but it's just about the numbers. At the end of the day, it's about the numbers, keeping the numbers where they should be. When the numbers are where they should be, you automatically have more energy, you're in a better place and you're happy to...You're even happier just knowing where those numbers are, which changes your whole attitude. But you know you say, oh, you're at a 10.8. Oh Lord. Oh, I can't go any higher than that…I want to be happy because the numbers make you happy. You know, when you say I'm at a 6.5 or a 7, you're happy. You're happy, you say, okay, I'm where I should be, and so this means there's no damage going on inside my body*

I argue that Janet's embodied experience allowed her to make sense of her diabetes. Like all of the other women interviewed, Janet's struggle in her diabetes experience was finding how to balance her cravings with her knowledge of things that would raise her blood sugar. However, through this case study, it becomes evident that for Janet to find this balance, she chose to feel dissatisfied in her body in order to pursue good health, which was intertwined with her relationship with her family and desire to be with them.

As shown above, a good life, in Janet's words, centered around numbers. In regards to her current HbA1C level, she says, "I can't go any higher than that" and then goes on to say "I want to be happy because the numbers make you happy." Her discontentment, exemplified by negative words such as "can't" or "damage" indicate that a good life for Janet was not fulfilled by positive bodily sensations gained by food or drink. Her embodied experience both promoted a healthy ideal, a diet solely based on necessities rather than cravings, and denied her of experiences she knew would result in positive bodily sensations, such as sweet tea. Therefore, her embodied experience is one that centers a tension between what the body wants and needs in order to pursue good health for her to be with her family. The body created tensions, but this displeasure allowed Janet to stay positive and pursue a good life by leading her to decisions that would improve her health.

By giving ownership to the body, Janet finds a way to balance her cravings with her view of a good life. The embodied experience served as a clinical voice, telling Janet what she "needed" and to deny herself of what she associated with satisfaction. In relation to scholarship

that creates a tension between the clinical world of the provider and the life-world of the patient, and as a result a good life from these two points of views, Janet's embodied experience provided both perspectives. She valued clinical health and what made her feel good but chose to deny herself of these things. In Janet's words, this denial would lead to positive clinical outcomes and in turn, to happiness and a good life.

Ultimately, I believe that the power of Janet's relationships with her family led her to choose bodily dissatisfaction and denial of what she enjoyed. By fulfilling the clinical sense of a good life, one that prioritized numbers, she had the ability to center her family and her relationships with them. Living a good life with diabetes for Janet was characterized by denials and big changes rather than sentiments of "learning to live with it" which appeared in other interviews. Through the perspective of embodied experience, this came from a reliance on bodily signals that told her what to do in order to reinforce the important role her family played in her life.

Chapter 3: Moral imaginaries

Janet's experience in the case study above illustrates the value of bodily sensations and embodied experience for women with type 2 diabetes. The cravings that existed before diagnosis existed after, and she, along with the other women interviewed, discussed the emotions surrounding fulfilling these bodily desires. Now, through the lens of moral imaginaries, I argue that the pursuit of a good life for women with type 2 diabetes is shaped by their moral view of themselves as well as the management of their illness.

> *You have to eat healthy and you really do have to say no to some things, because there are times that I'll buy a Milky Way and I'll keep it in my pocketbook and maybe in there for a long, long time. And then one night, in the middle of the night, I'm having a craving for that Milky Way. I'm digging in my pocket after I find that Milky Way, and when I find it and I get my first bite of it, it's like mmm, it's like heaven. But then, on the other side of the coin, I know that I'm not supposed to eat that candy bar. After I took my long acting insulin for the night. I'm not supposed to add anything else to that…water, maybe…but nothing else, because I've already taken my medicine for tonight and I know that if I put anything else on top of that it's going to cause my medicine to be…my sugar numbers are going to be higher in the morning, because I ate that candy bar.*

Centered around moments like Janet's experience with the Milky Way bar but also within the larger moral and social contexts that shape people's lives, I explore how moral imaginaries, ideas of what "should be" done, sculpt the embodied experiences of women. I focus on the morally charged language embedded in narratives surrounding eating habits and how that affects what constitutes a good life in illness narratives of women with type 2 diabetes.

By focusing on the role of morality in type 2 diabetes experiences, this thesis explores the contradictions that underlie illness narratives of women with type 2 diabetes. On one hand, women describe positive emotions and bodily sensations associated with eating "unhealthy" foods that should be restricted for diabetics. At the same time, they experience feelings of shame, guilt, and frustration when eating these foods. As Buch explains in her book, moral imaginaries include "the ways in which bodily practices produce moral understandings" (15). The feelings of satisfaction or happiness that come from food contrast with negative feelings that come from the moral imaginaries of what the experience of a diabetic and the attitude towards food "should be."

Moral imaginaries determine what kind of people and patients "should" exist and be supported. Further, moral imaginaries provide the basis upon which providers and patients themselves evaluate type 2 diabetes management. This concept highlights both the discrepancy in the patient and provider view of a good life as well as the importance of bodily sensations for patients. Diabetes is implicitly associated with denial of positive bodily sensations. This draws attention to the ways in which women with type 2 diabetes are asked to deny themselves positive bodily sensations that they associate with happiness and a good life. In this sense, moral imaginaries determine how patients view both themselves and their relation to others. They draw attention to the "good" and "bad" dynamic as well as the layered emotions surrounding eating habits. By analyzing patient language surrounding eating habits, what "should" or "should not" be done, and emotions around eating, it would appear that a good life produces positive emotions. Yet, these emotions are complicated by moral guilt that is exacerbated by the diagnosis of type 2 diabetes and encounters with providers.

The excerpt from Janet above exemplifies the moral imaginary surrounding what should or should not be eaten by a person with type 2 diabetes through the experience of buying and consuming a Milky Way. Her experience with the candy bar is drawn out, indicating the internal battle to follow the moral ideal of what a "good" diabetic is (someone who follows the exact diet prescribed by a physician). Yet, when Janet consumes the candy bar, her moral imaginary of what should be done leads to feelings of "guilt" as she says, "I know that I'm not supposed to eat that candy bar." However, she also feels positive emotions and describes the candy bar "like heaven." Janet draws a direct correlation between eating the candy bar and her "sugar numbers" being higher in the morning, indicating that for her, she simultaneously has positive feelings associated with eating the candy bar and negative feelings surrounding the outcome.

Janet's use of phrases such as "supposed to" and "say no" indicate the moral framework surrounding her decision making processes. Despite her cravings and desires for the candy bar, she feels that to be a "good" diabetic she should say no. The implication that denial is an inherent moral good for a person with diabetes obscures the fact that the desires do not simply fade away with a diagnosis of diabetes. Further, the emotions associated with eating are amplified for a person with diabetes who must be consciously aware of the decisions they are making surrounding eating habits. The ideas of "should" and "should not" display that the moral imaginaries for women with type 2 diabetes affect their view of a good life. A good life is both

associated with the positive feelings from food as well as the "heroic" moral capabilities to deny those foods and have lower HbA1C levels (Hay 2010).

> *So I feel like a lot of people when they think about food, it's like they eat for survival, they eat for, you know, the nutrients. But I notice with me it's like if I want to eat something, it's because I want that particular food, it's not because, oh, I know I need to eat, like, of course, you know, yeah, you need to eat. But like if I'm thinking about food for the day or what I'm gonna eat for dinner, it's like, oh, you know, I really kind of want some Texas RoadHouse or I really want this. Like it's not like the main thing, which it should just be eating for nutritional benefit. So I feel like it's.. I don't know… it's…I think it's like an emotional thing, like a feel good thing.*

The quote above comes from Lauren, a 36 year old woman with diabetes. Her quote illustrates the moral imaginary surrounding what purpose food "should" serve versus what her own relationship with it is. The description of food as "emotional" or "feel good" magnifies the value of relationships with food as well as the awareness of her own relationship with it. Further, Lauren says the purpose of food "should just be eating for nutritional benefit" indicating her moral view of her own relationship with food. For her, the positive senses and emotional layers that she associated with food is something diabetics should not feel.

Because Lauren felt that she "should not" associate food with emotions or feeling good, this enjoyment was often coupled with feelings of guilt or an acknowledgement that she was not supposed to be eating those things. For Lauren, food was "emotional" in the sense that there were positive and negative feelings associated with food. In the past, Lauren had used food as a comfort or coping mechanism, but now with her diabetes she had to be more aware of her food intake. Lauren expressed negative emotions surrounding her diabetes—the words that came to mind when thinking about diabetes were "frustration, disappointment, shame." These morally charged words indicate that in Lauren's view, enjoying food is coupled with an awareness of what "should be" done.

> *I'll just remember like I'll say oh well, you know I had a rough day, so I'll get a milkshake because you know that'll make me feel better. And I was justifying that a lot years ago, definitely when my diabetes was… you know my A1C was way higher at times, but I'm trying to get away from that mindset. Sometimes it doesn't always, you know, work, but you know I'm trying to just do better.*

The excerpt above from Lauren's interview describes the complex mindset surrounding her relationship with food as well as the awareness of positive emotions associated with her A1C count. For Lauren, milkshakes "make [her] feel better" indicating that the satisfaction from food improved her mood. Yet, she also said that this enjoyment was coupled with her A1C levels being "way higher." As a result, Lauren creates a negative correlation between the positive

sensations associated with foods that "should not" be eaten and the clinical outcome. This link refers back to the moral imaginaries surrounding eating habits for diabetics as well as the type of patients that diabetics "should be." Lauren's decision of "trying to do better" indicates she strives to fulfill this moral imaginary even if it impedes the positive emotions that food brings.

In the pursuit of a good life, morally charged language illustrated the complex relationships the women interviewed had with food. Ideas of what "should be" eaten as well as sensations when eating something "unhealthy" and the emotions felt afterward display a clear link between self worth and following the "ideal" diet for a diabetic. Based on these excerpts, it seems that a good life is both achieving a healthy ideal by denying oneself "unhealthy food" and having positive bodily sensations from what one eats. These contradicting sensations also bring forward layers of morality, complicating what a good life is for women with type 2 diabetes.

Gail, an 87 year old woman who has had diabetes for 22 years expressed the same ideas of wanting foods that she knew she "shouldn't have." Yet, contrastingly, she felt no guilt or remorse for her eating habits. As shown in the excerpt below, Gail's relationship with food was characterized by a sense of acceptance—rather than feeling morally wrong for eating unhealthy foods, Gail acknowledged the purpose of enjoying her food.

> *My approach, I think, is to deal with it as best I can and keep check on everything with the doctor's visits and things that I can to keep check on. But at my age I think I'm going to enjoy something that I eat…I don't want to just eat collard greens and broccoli the rest of my life. So I am going to enjoy some things, even though I know I don't need to eat it.*

Interestingly, Gail's use of the word "need" rather than "should" displays that she does not use the same morally charged language. Rather than feeling guilty because she thinks she "should be" eating "collard greens and broccoli," Gail simply recognizes the difference between what she wants and what she needs; even if the foods that obey these two do not match, Gail does not use any language that indicates negative emotions. Gail also references the importance of her age saying, "But at my age I think I'm going to enjoy something that I eat." Gail seemed to be more at peace with her decision to eat things she knew would raise her blood sugar because she prioritized enjoying food at her age. Gail expressed a sense of acceptance surrounding her eating habits and enjoyed the food she ate.

> *So the things that I really need to eat, diabetic wise, I don't want on a regular basis… I don't eat what I need to eat as often as I should. I eat carbs…I like baked potatoes, grained potatoes, any kind of potatoes, but potatoes will just about run my sugar higher than a piece of pie will. So I do know what I need to do, but I don't always do it and that's the reason I have the medicine that I do and the Dexcom on my arm.*

The excerpt above gives more insight into Gail's mindset surrounding her diabetes. For Gail, the moral framework that characterizes her illness is not one of the "heroic" denial of foods

she enjoys. Rather, she accepts that she knows what she "needs" to do but also that she actively makes choices that do not align with the clinical recommendations. She uses the word "should" but unlike the other women, Gail did not use the same negative language around her emotions. Further, while other women interviewed mentioned ideas of overcoming diabetes such as being "in remission" or "changing the numbers", Gail appeared content with the medications she was on. She said, "So I do know what I need to do, but I don't always do it and that's the reason I have the medicine that I do and the Dexcom on my arm." Gail provided a sense of acceptance—the medicine and Dexcom was simply a fact of life, something that could help her, rather than something to try and change.

In Gail's case, the moral imaginary framing her eating habits was less impacted by what an ideal diabetic ate. Rather, her moral framework was separate from the foods she ate. This allowed her to feel happy from foods that provided enjoyment without coupling this with negative emotions afterwards. For Gail, a good life was characterized by willful choices to enjoy food, likely due to her age.

Overall, the women at different ages expressed different sentiments surrounding the emotions felt while enjoying food. While the act of eating itself evokes positive emotions, the two younger women simultaneously felt feelings of remorse due to ideas of what they "should be" eating. Yet, for the older patient interviewed, she acknowledged that she knew what she should do, but explained that she willfully chose to enjoy what she ate.

The contradictions and entanglements created by the morally charged language that patients used draw attention to the ways in which diabetes impacted their relationships with food. Patients simultaneously enjoy the food they eat while feeling negative emotions surrounding their decisions to eat the food in the first place.

The concept of moral imaginaries highlights how relations to the self and food are impacted by type 2 diabetes. It opens analytic possibilities for recognizing the immense emotional impact of type 2 diabetes in all aspects of life and the ways in which emotions impact management and on a deeper level, values of self worth. Considering moral imaginaries as dynamic and ever-changing based on patients' ages and views of diabetes can make care more holistic and address patients' emotional needs. From this perspective, the fact that moral imaginaries are so deeply entrenched in patients' life-views illustrates the need to directly address their impacts in a clinical setting. It also exemplifies the need to dismantle the belief that enjoying bodily sensations is less worthy than achieving ideal health.

Within the pursuit of a good life, the idea of satisfaction in both bodily experiences and with decisions frequently appeared. While all of the women whose experiences were detailed expressed satisfaction from food, only Gail, the oldest woman interviewed, felt satisfaction with the decisions she made. This points to the fact that a good life both encompasses satisfaction with and repression from food. More broadly, this indicates that living with type 2 diabetes means both holding on to previous aspects of enjoyment while learning to reframe what it means to feel like you "should" or "should not" do things.

Conclusion

Much of the patient's response to the demands of living with a chronic illness like type 2 diabetes involves changing what is morally acceptable to do and eat. Ideas of what should be done permeate the self-view of the women interviewed and also determine how they interact with the world around them. Profound dilemmas regarding disruption of bodily satisfaction and change that individuals face following diagnosis are rooted in moral understandings of diabetes. For patients I interviewed, frustration, shame, and disappointment characterize these understandings. What impedes their pursuit of a good life is not the disease alone, as it is medically conceptualized, but rather the moral implications of having an illness that requires denial of positive bodily sensations in the pursuit of health.

In regards to the model of the self, I have ascertained that implicit within the pursuit of a good life is an attempt to both reconcile and separate the different senses of self held by the patients. The cultural or ideal self ties closely to the moral aspect of patient experience and influences the self-model. While patients in some ways acknowledged the influence of the cultural self in their management of diabetes, their self-model often conflicted with this. The self-model prioritized their desires, demonstrated by active decisions to choose experiences that produced positive bodily sensations over strictly following clinical guidelines.

In talking with type 2 diabetes patients and in attempting to represent their voices, I have found two competing but coexisting essentials. First, women attempt to fulfill the ideals of "good" patients, denying themselves of things they know make them feel good. Simultaneously, they still value and eat or drink these things. It is equally important for these patients to fulfill these cravings as it is for them to deny them. Moral imaginaries may, this suggests, involve inner resistance; where conceptions of what "should be" done are challenged and changed with diagnosis, people may hold onto what was before, resisting desires while also embracing them. Connecting to the model of the self, the moral imaginaries associated with the cultural self are acknowledged and sometimes fulfilled; in spite of this, the self-model prioritizes these desires.

In regards to what makes a good life for someone living with diabetes, values of friends and family consistently emerged and were emphasized throughout the interviews. The individual experience was important, but the women interviewed put extra emphasis on the value of their social relations and support systems in their lives. As Martha put it, her family was important because "well, without them I'd just be a very unhappy person. I wouldn't feel like I had any worth, or that was no reason to hang around. I'd just wait and see what happens next, which I'm doing anyway. I just have somebody to do it with." For her as well as the other women, having someone "to do it with" was what made a good life.

What are the implications of a moral exploration of the illness experience for a broader understanding of the emotional and psychological response to diabetes for women? Attending to the patient's language as it is used in terms of their own experience and values enables us to understand relationships between the self and moral worth in the context of American society.

For further investigation into how to better address patient needs in regards to type 2 diabetes, group health visits, psychosocial and emotional counseling, and sensitivity training for providers are potential areas of exploration. Group health visits are shared patient appointments in which patients receive diabetes education and medical care while learning from peers. Shown to increase social support, decrease dissatisfaction with diabetes, and lower HbA1C counts, group health visits could be a method of helping patients to address conflicts between their concepts of self while simultaneously fulfilling clinical ideals (The University of Chicago and Baig, et. al 2022).

Psychosocial and emotional counseling could be beneficial for helping patients to reconcile the complex moral layers that type 2 diabetes asks them to address, specifically surrounding the differences between the embodied experience, where the body is the expert, and the biomedical epistemology model that positions the provider as the expert. By increasing support for patients, this counseling could help patients build skills to find overlap between the self-model and cultural self.

Sensitivity and professional training in how to support patients emotionally could be advantageous from the provider side for type 2 diabetes. One study found that "regular assessment of well-being by a diabetes nurse specialist and discussing the results, increased the emotional well-being of people with diabetes and satisfaction with the care provided by the diabetes nurse specialist" (Stoop, et. al 2019, pp. 1710). By working to build a deeper understanding of the emotional and moral conflicts felt by patients with type 2 diabetes, providers can present a more empathetic approach to care that can help patients create their self-model.

These interviews have illustrated how concepts of the self, embodied experience, and moral imaginaries shape the illness experience of women with type 2 diabetes. A patient-centered approach allows us to understand the embodied experience of a chronic illness such as type 2 diabetes and the ways in which the diagnosis is both embraced and resisted in daily life. These approaches are critical to understand what it means to live with a chronic illness based in bodily denial and how a good life is both part of and separate from it.

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Appendices

Appendix A:
Information Sheet

Vanderbilt University
Anika Mahajan, Undergraduate Student
Department of Medicine, Health, and Society
300 Calhoun Hall, PMB #358507, 2301 Vanderbilt Place, Nashville, TN 37235
Illness Narratives of Women in Tennessee with Type 2 Diabetes

Introductory Section: You are invited to take part in a research study conducted by Anika Mahajan from the department of Medicine, Health, and Society at Vanderbilt University. Before you decide whether or not to participate in the study, you should read this form and ask questions if there is anything you do not understand.

Description of the project: The purpose of the study is to explore the lived experiences of women with type 2 diabetes in the Jackson area and how values, needs, and desires impact management.

What you will do in the study: The researcher will interview you about your experience of living with type 2 diabetes. The interview will be conducted at a location of your choosing or over the phone if you are unable to meet in-person. If you do not have a preferred location, the interview will take place in a room in the North Clinic. The researcher would like to audio record the interview. The researcher will ask a series of open-ended questions, and you may decline to answer any question. You may also request for the recorder to be turned off at any time.

Time required: The interview will take approximately one hour

Risks or discomfort: There are no direct risks to you as a participant in this study. If at any point during the interview, you feel uncomfortable, you may take a break or terminate the interview.

Benefits of this study: You will receive a $20 Visa gift card for participating in this study. In addition, the researcher may learn more about the patient experience of living with type 2 diabetes.

Confidentiality: The information that you give in the study will be handled confidentially. Your name will not be used in any report.

With your permission, I would like to tape this interview so that I can make an accurate transcript. Interviews will be recorded on a Zoom H2next handy digital audio recorder obtained from Vanderbilt Central Library. The audio files will be uploaded and stored on a double password protected website directly after each interview; then the audio will be permanently removed from the audio recorder. Only the researcher and Principal Investigator will have access to the interview audio file. Once I have made the transcript, I will erase the file. The transcript and any written notes will use a pseudonym in place of your name and be kept in a locked file cabinet that only the researcher and PI have access to. The file cabinet will be kept in the Principal Investigator's locked office on Vanderbilt campus. Interviews and notes will only be discussed with the PI, and identifying information, including your name, will be avoided.
The information that you give in the study will be kept confidential. Your name will not be collected or linked to your answers. Because of the nature of the data, it may be possible to deduce your identity; however, there will be no attempt to do so and your data will be reported in a way that will not identify you.

Decision to withdraw at any time: The decision to take part in this study is completely voluntary. You do not have to participate. Even if you decide to take part, you are free to change your mind at any time and quit the study. Your decision will in no way penalize you.

Rights and Complaints: If you have questions about this research, please contact Anika Mahajan, anika.mahajan@vanderbilt.edu; 731-345-7141 or Dr. Celina Callahan-Kapoor, celina.callahan.kapoor@vanderbilt.edu; 615-875-0289. If you have any questions regarding your rights as a research participant, please contact the Office of Compliance at Vanderbilt University at 844-814-5935 or https://www.vanderbilt.edu/compliance/helpline.php .

Appendix B:
Interview Questions

Before you decide whether or not to participate in the study, you should read the consent form and ask questions if there is anything you do not understand. With your permission, I would like to record this interview on this audio recording device so that I can make an accurate transcript. Is that okay? If at any time you want me to stop recording the interview please let me know. If at any point during the interview, you feel uncomfortable, you may take a break or end the interview. The transcript and any written notes will use a pseudonym in place of your name, and your data will be reported in a way that will not identify you.

Thank you very much for your willingness to meet with me and discuss your experiences living with type 2 diabetes. I am hoping to learn more about your daily life with diabetes and what comes to mind when you think about your experience. (Then I will briefly explain how I became interested in this topic)

Categories covered by questions:

- Bodily experience and feeling with type 2 diabetes
- Daily life and self-management
- Values and their relation to type 2 diabetes

Can you tell me about a typical day?
How does your daily life affect your diabetes routine?
At the doctor's office, who do you meet with to discuss dealing with diabetes?
What does your doctor recommend?
What would you describe as your biggest challenge in managing your diabetes?
What does it feel like, in your body, to have diabetes?
When are you most aware of your diabetes?
What words come to mind when you think of having diabetes and dealing with it everyday?
Do you feel like type 2 diabetes is a disease you can overcome? Why or why not?
What do you remember about your diagnosis?
How do you feel like you cope with your diabetes?
What do you value? What kind of life is worth living for you?

Is there anything else you would like to share that I have not asked about? If you think of anything later, feel free to reach out to me through email (anika.mahajan@vanderbilt.edu) or phone (7313457141). I will transcribe the interview within the next two weeks and offer you the chance to read over the transcription and request changes. Once the study is complete, the audio files and notes from your interview will be destroyed.