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Picturing Health; Picturing Life: Visual Illness Narratives of Women with Type 2 Diabetes

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Graduate School of Education

Lesley University

Ph.D. Educational Studies

Individually Designed Specialization

In partial fulfillment of the degree of Ph.D.

Picturing Health; Picturing Life: Visual Illness Narratives of Women with Type 2 Diabetes

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Approvals

In the judgment of the following signatories, this dissertation meets the academic standards that have been established for the Doctor of Philosophy degree.

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Abstract

The prevalence of diabetes in the U.S. reached 23 million people between 2012 and 2017 and consumed one-quarter of the overall healthcare dollars. Remembering the suffering and pain of individuals behind these numbers becomes difficult and incalculable. Black American women are the most affected by type 2 diabetes (T2D), compared to their white counterparts, as well as twice as likely to be diagnosed with T2D and 2.5 times more likely to die from T2D. Therefore, understanding the problem requires the fundamental consideration of how these women cope daily with this complex illness while often struggling with complex lives. This narrative study provides a framework for 14 women of color to reveal their illness narratives using participant-generated photography, photo-elicitation interviews, and relational map making (relational interviewing tool), which resulted in six findings. These methodologies combine to allow an unframed participant expression of their own experiences. According to Finding One, T2D experience can exacerbate stress in the lives of participants, while others find mastery over the management. In Finding Two, T2D experience influences generalized feelings of control in life or the lack thereof. Finding Three indicates that T2D concern fluctuates in the hierarchy of importance in the lives of participants. Finding Four shows all participants use a variety of stress relievers, (including pets, social activities, exercises) some of which conflict with T2D management which they consider as necessary in their lives. In Finding Five, significant childhood trauma plays a role in coping with T2D experience. Finding Six shows religious beliefs and rituals were invoked by all participants but played varied roles. These findings show the complexity of the lived experience of these women within their social contexts.

Keywords: type 2 diabetes, women, illness narratives, health inequality, visual narratives, photo-elicitation.

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Chapter 1: Narratives of Illness

During the Dust Bowl in the United States, Dorothea Lange was employed by the federal government to photograph and document the suffering of America's poor and dispossessed. At a migrant labor camp in California in 1936, Lange photographed a mother and her children. In the photograph, the children are dirty and bedraggled as they climb on and cling to their mother. She sits seemingly stoic and impassive with her gaze considering the distance. It has since become an iconic symbol of the Dust Bowl and the Great Depression. I recall gazing at this image and wondering if that was the photograph that the mother herself would have chosen. I further speculated what photographs she might have taken had the camera been given to her instead of being focused upon her. I believe that the story would have been starkly different than what Lange had documented through the six photographs of this subject. While Lange's narrative is valuable and provides an enduring symbol of the oppressed, I question if the story of the experience of this mother and her children was authentic. Decades later, after the mother was identified as Florence Owens Thompson, she and her children complained that Lange had not paid them for the appropriation of the image, nor had she correctly document Thompson's story in the text accompanying the photographs.

As a patient advocate, I listen to stories of illness from the patient and the physician, which are often very far apart, seemingly about different experiences altogether. Therefore, recalling my desire to hear the migrant mother's story in Lange's photograph from her own perspective, I embarked on the search to hear authentic stories of illnesses. I studied illness narratives including the poetry of Emily Dickinson (1999), the essays of Audre Lorde (1997), and the works of Anatole Broyard (1993) among others. Moreover, I wrote several articles and book chapters attempting to express the patient's perspective (Gurley-Green, 2001; 2003; 2010)

and spoke about it at many physician as well as patient learning conferences both in Europe and the United States. In addition, I studied narrative medicine with Rita Charon at Columbia University and took classes with Arthur Kleinman of Harvard University, the originator of illness narrative study. Accordingly, while Kleinman listened to the voices of patients and told their stories, Charon taught physicians to listen to patients' stories through the study of literature and writing. Although both are ethical and empathetic approaches, they rely on the physician to hear patient stories rather than directly listening to patient stories.

Problem Statement and Background

Encounters from my past experience include extensive research confirming the role of bias and discrimination in healthcare and the toll of poverty on the health of our most vulnerable citizens. My work has been concentrated on chronic illnesses, particularly, chronic pain. Furthermore, a unique form of illness narrative arises from the experience of chronic illness, which tells the story of quotidian experience: the daily lived life and the illness are intertwined. It is both personal and social as well as specific and generalizable. Subsequently, it not only gives voice to the individual body but contributes to the social body of experience. Therefore, my personal medical experience with chronic pain, as well as my work with chronically ill patients, has clarified the devastating effect of chronic illness on one's daily life and life prospects. Moreover, structural racism, low socioeconomic status (SES), and health-related stigma act synergistically to exacerbate negative outcomes for some populations.

The American health story of inequality is documented in the divergent experiences and patient outcomes with type 2 diabetes (T2D). Accordingly, Tables 1 and 2 detail the racial and gender discrepancies in T2D prevalence and deaths respectively. As such, Black women are strikingly twice as likely to be diagnosed with and more than twice as likely to die from diabetes

than white women. More than 12% of Black women are diagnosed with T2D, a higher prevalence than white women and white and Black men. Further, while Black men are more likely to die from T2D than Black women, the death rate for Black women is still higher compared to white men or women. Despite the alarming societal implications of these statistics, few studies examine these women’s own illness experiences. While there are many important studies that endeavor to determine the patients’ explanatory understanding of the etiology of T2D (Skelly et al., 2006) and other studies examining the diet of these women (Montague, 2016), they are grounded in an understanding of patient individual responsibility as a cause for their illness, while not attempting to understand the contextual experience of these women in their own words (Hotz, 2015; Pierre-Louis, Akoh, White, & Pharris, 2011). I address this less populated area in the literature.

Table 1
Age-adjusted Percentage of Adults with Diabetes (2017)

	All races	Non-Hispanic White	Non-Hispanic Black	Ratio: Black to White
Male	9.9	9.0	10.6	1.2
Female	7.8	6.1	12.1	2.0
Total	8.8	7.5	11.5	1.5

Adapted from the Centers of Disease Control and Prevention National Health Interview Survey. Retrieved from <https://www.cdc.gov/nchs/nhis/index.htm>

Table 2
Age-adjusted Diabetes Deaths per 100,000 Individuals (2017)

	All races	Non-Hispanic White	Non-Hispanic Black	Ratio: Black to White
Male	26.8	24	46.6	1.9
Female	17.1	14.6	32.8	2.2
Total	21.5	18.8	38.7	2.1

Adapted from Centers for Disease and Control National Center for Health Statistics. Retrieved from <https://www.cdc.gov/nchs/nvss/deaths.htm>

The surveyed literature for this study falls into four broad categories, which are explored thoroughly in the literature review chapter. The first area of study asks in what ways the biomedical system serves or disserves patients with chronic illness and how the physician-patient dyad problematizes the experience of the patient, especially considering the movement from a dominant physician model to the active patient model (Dubbin, Chang, & Shim, 2013; Huizinga, Cooper, Bleich, Clark, & Beach, 2009). The second area of the literature review explores scholars' examinations of how social determinants of health such as low SES, race/ethnicity, and gender have created health inequalities (Pinxten & Lievens, 2014; Walker, Gebregziabher, Martin-Harris, & Egede, 2014a, 2014b, 2015a; Walker, Smalls, & Egede, 2015b). Some scholars believe that health inequalities are caused by poverty (Levesque, Harris, & Russell, 2013), while others determine race/ethnicity as a cause (Paradies et al., 2015). Moreover, the third area of study explores the increasing incidence of T2D and poor health outcomes in the Black American population compared to other population groups. Lastly, the fourth area of my literature review describes how the use of narrative inquiry in health studies may determine the best means of answering my research questions.

Statement of Purpose

People with T2D have vast divergence of outcomes. I know people who have fought against T2D treatment and felt stigmatized and controlled by their medical regimes, as opposed to others who accepted their chronic illnesses as manageable tasks, to accommodate which, they altered their lifestyles. Moreover, my desire to understand why this divergence might occur drew me to look at the experience of T2D as a subject of study, but the incidence and prevalence of T2D in the U.S. also drew my attention. The Centers for Disease Control National Diabetes Statistics Report (2017b) estimated that 30.3 million people (9.4% of the population) in the U.S.

have T2D . These statistics are overwhelming since each represents an individual coping with a chronic and life-threatening disease, potentially living in despair, shame, and fear about their future. Moreover, constantly coping with a chronic disease is challenging since one must interact with the world while coping with these illness experiences. T2D, as a chronic illness, is especially intrusive in daily life because it requires a high level of monitoring of food intake and exercise alongside an understanding of how the aforementioned alter blood sugar. In addition, without understanding an individual's contextual experience, there is a propensity to believe that this disease is caused by poor choices. Apart from being unsubstantiated, T2D has the detrimental effect of pointing blame at the individual sufferers. Thus, the statistics, while monumental in size, are of little or no use in helping the individuals or their healthcare providers improve the situations of those who suffer with T2D. In this study, I attempt to closely listen to the illness experiences of 14 of the 30.3 million Americans with T2D.

The chosen population for drawing my sample included T2D education groups in the study catchment area (a relatively large Northeastern city). Furthermore, I was fortunate to be welcomed into several neighborhood centers. Consequently, the location of these T2D education groups allowed my study to include a majority of Black women and Latinas, although I did not set out to recruit any specific race or ethnicity. The experiences of T2D among the women in this population varied, but I observed several commonalities. Accordingly, money and stress were the greatest concerns, in that individuals often expressed understanding how they should manage their T2D within the medical guidelines but equally expressed that they had limited financial resources and energy available to allocate to the task. The population I observed involved women between the ages of 50 and 70, many of whom had disability and mobility issues. Moreover, some had adult children, while others bore responsibility as guardians for

their grandchildren. They relied on each other for support, mostly through humor and experience commonalities. Further, some had side jobs of baking, sewing, or volunteering in churches, schools, and retirement communities. Consequently, after giving their lives to the service of others, these women did not have the same energy to devote to coping with a serious chronic illness in a challenging social context.

Research Question

My research question is grounded in the attempt to phenomenologically understand the lived experiences of these women and the desire to explore whether and how this chronic illness changed their experiences of what Heidegger (1962) being-in-the-world: *how do these women make meaning of their experiences with T2D?*

Based on my research question, I determined that hermeneutical phenomenology would be the best conceptual framework for my study and the best approach to understand lived experiences and achieve the goal of obtaining meaningful (Smith, 2003) data directly from the participants. Hermeneutical phenomenology studies how individuals experience and understand phenomena and engage with their world. My expectations about what I would find in my research, originating in my own researcher identity, were formed in my doctoral studies on chronic illness and identity in addition to being influenced both by my experience as a patient advocate and a person with a different but equally life-altering chronic illness. As such, I expected to find the following: (i) T2D is ubiquitous in the lives and the consciousness of those suffering from it; (ii) there is some disconnect between how medical practitioners expect these patients to live and how they actually live; (iii) the people in my study experience the intersection of racial discrimination, gender, and financial pressure impacting their experiences;

(iv) I would see the incidence of diabetes-related stigma shown by recent studies (Browne, Ventura, Mosely, & Speight, 2013; Schabert, Browne, Mosely, & Speight, 2013).

Overview of Methodology

Researcher identity. In “White Privilege: Unpacking the Invisible Knapsack,” McIntosh (2004) provides a useful metaphor of the “invisible knapsack of unearned assets”: invisible to whites and interwoven enough in our society to be unseen by those benefiting from it. This invisible knapsack is equally applicable to institutions such as medicine that have been formed and dominated by a patriarchal white system. As an affluent, well-educated, white person who has spent decades navigating healthcare systems, I am confronted by my own frustration and anger when dealing with the healthcare system in the U.S. Moreover, I know that the inequities of the system are multiplied for those who do not have my advantages of whiteness, affluence, and access to education. My history of being both patient and patient advocate may help with my understanding of other patients; however, my standpoint, personal history, and cultural context can act as both positive and potentially negative influences. Furthermore, Minnich (2004) discusses her choice to use the term “Black” over “African-American,” reasoning that this equates being Black with other “hyphenated Americans” who chose to come to the U.S. voluntarily rather than being brought as slaves. Moreover, she chooses to capitalize “Black” and not capitalize “white” to distinguish them as being members of an oppressed group due to race. When the participants in my study referred to their perceived identity, they identified themselves as Black women belonging to a particular ethnic group. As an outsider in terms of ethnicity and experience of racism, I determined to use the term “Black women” while understanding that the preference is personal.

While reflecting on the difficulties of my positionality as a white researcher with Black women as participants, I read widely on the subject. I considered that being an “ethnically matched” researcher has advantages and disadvantages (Gibson & Abrams, 2003). Accordingly, the notion that one would automatically be an insider due to skin color seems simplistic (Buford May, 2014). However, a white person immersed in white culture is unable to fully understand the experience of being identified as Black. Additionally, to be identified as Black does not automatically mean for one’s experiences to match with someone else who identifies the same way. Therefore, rather than labeling oneself as an insider or outsider due to ethnicity, one should be clear about one’s standpoint as a researcher. Further, instead of the insider/outsider status, some researchers account for multiple identities yielding “insider moments” (Buford May, 2014, p. 124).

In addition, it is vital to point out that my affluence, whiteness, and education makes my experience of illness vastly different than that of the participants in this study, as these advantages all positively impact health outcomes and how the healthcare system views me. The social determinants of health—ethnicity, relative affluence, and education—establish that the experience of healthcare and the likely health outcomes are worse for my participants than for me, which may be particularly true for T2D. In Gaskin et al. (2014)—a study examining the National Health and Nutrition Examination Survey (NHNES), a program of studies assessing the health and nutrition of adults using both interviews and physical examination—data from 1999–2004 and the 2000 U.S. Census found a race-poverty-place relationship for inequalities in T2D outcome and prevalence thereof in Black Americans (Gaskin et al., 2014). This increased the odds of having T2D through concentrated poverty in residentially segregated areas.

Subsequently, the social determinants of health create a chasm of experience between me and my participants in terms of health outcomes.

Methodology. “Whether I shall turn out to be the hero of my own life, or whether that station will be held by anybody else, these pages must show” (Dickens, 1917, p. 1). The first sentence of *David Copperfield* illuminates the narrative dilemma for patients with chronic illnesses, where the hero, faced with a life dominated by illness, often becomes the illness itself rather than the individual. Since we communicate through storytelling, we make our lives meaningful by sharing different types of experiences. In discussing the difference between narrative and non-narrative knowledge, Charon (2006) stressed that the non-narrative focuses on the universal experience and not the individual; the narrative looks at the individual experience to deeply understand the individual, which hopes to illuminate the universal experience. Although Chapter 3 will present the study methodology in detail, the range of considerations regarding the selection of the methodology deserves the reader’s understanding. My enthusiasm for narrative exploration and writing may not have the same appeal or purpose for people of different cultural and educational backgrounds. Consequently, a belief that change can be achieved through one’s efforts is an important element in the value of narrative exploration. For example, many patients may associate reading and writing with school; however, a negative experience with school may influence how open they would be to a modality that includes writing. This can be exacerbated by a form of institutionalism where an ill person has to trust physicians to the extent that they feel a lack of belief in their own agency (Frank, 1995). In addition, Krumer-Nevo and Sidi (2012) suggest that people of low income may not have the energy or time to commit to a program of narrative writing because living within these contexts may require more time expenditure on the daily life routines.

My goal in examining an effective methodology was to reframe the creation of narratives in a way that would be accessible and effective for diverse populations. Some means of overcoming these problems would include utilizing forms of narrative expression other than writing, such as storytelling and the visual arts. Furthermore, employing diverse artistic modalities is a necessary step in aiding the creation of illness narratives with diverse populations (Villigran, 2011). Moreover, when defining narrative creation and narrative competence more broadly, programs have been developed using a range of artistic modalities including the creation of music and visual arts with patients and vulnerable populations (Carnegie Hall Corporation, 2017). This has significant implications for successful narrative inquiry and practice with patient groups.

Furthermore, issues of rapport are important in researching sensitive topics such as health and illness within the contexts of inequality and discrimination. The two goals of rapport and participant illness reflection were central in my thinking: how I could establish the necessary rapport to work with these participants became an additional focus of my methodology. It was important that the ownership of the knowledge and narrative remain with the participants, the of which purpose was twofold: (i) to encourage the creation of the narratives and the reflection necessary to create them; (ii) to foster empowerment through the process to make the experience positive rather than negative.

In light of the above, I established a relationship with the participants through the research process and group meetings, but I was careful not to use self-disclosure as I feel that it would have significantly altered the findings. However, power is always imbalanced in any research situation favoring the researcher. Therefore, although I established a relationship, my methodology was designed to counter that balance. Moreover, since narrative interviewing is

interactive, it divests the researcher from the typical power relationship found in other forms of stimuli and response interviews (Kvale, 2006). A key aspect of this is my repeated emphasis that the participants were experts in their own narratives and that I was interested in and valued their stories.

Furthermore, I realized that I needed an approach that increased the participants' reflection upon their illness, thereby allowing data to flow directly from the participants and avoid framing and defining the narratives by my own experience and biases. Additionally, accepting that there would likely be a mixture of participant comfort with expressing their thoughts and ideas through writing, I explored using photography in the methodology, involving a form of visual methodology: participant-generated photo-elicitation interview. The participant's choice of photograph subject was both a way to gather data directly from the participant as well as to increase introspection about the illness experience of the participant. In the interview, the participant would decide which photographs would go into her story and organize them in an order that made sense to her. As such, I used relational narrative interview techniques (Josselson, 2013) to elicit the story of illness and, inevitably, the stories of their lives. Moreover, I transcribed the interview and created a printed visual health and illness narrative using both the participant-generated photographs and their own words. Consequently, I wrote participant portraits using the verbatim interview transcript and the participant-generated photographs, an approach that led to unintended consequences of benefit for the participants by articulating their stories of illness experience with T2D to their medical practitioners, family, and community. As the researcher in this methodology, I am also part of the narrative; thus, the narrative truth shared with me in the interviews is grounded in photographs taken by the

participants, and the story elicited by those photographs are, in a real sense, influenced by their understanding of me as the listener.

Definitions of Terms

Illness. Illness is the individual experience of disease, including understanding, feelings, and interpretation thereof. In contrast, disease is the object of biomedicine (Mol, 2002); the patient also becomes the object of biomedicine after diagnosis. In general, biomedicine is devised to focus on disease and not the individual experience of it.

T2D. T2D is classified into two types: type 1 T2D mellitus, formerly juvenile T2D; type 2 T2D mellitus, formerly adult onset T2D. The health consequences of T2D are serious and include heart disease, stroke, blindness, organ system failure, and amputation. T2D is characterized by hyperglycemia (high levels of glucose in the blood) and defects in insulin production and action (Gillibrand & Stevenson, 2006).

Stressor. A stressor is anything that causes the release of stress hormones, which can include physical stress or psychological stress. In addition, it can be actual or perceived as negative or threatening. There are absolute stressors, such as trauma as in a natural disaster or relative stressors, which someone's life experience may cause them to perceive as stressful or not. Moreover, how a stressor will impact an individual will be ameliorated by several social mediators.

Social determinants of health. The Centers for Disease Control and Prevention defines social determinants of health as the complex and integrated overlapping social structures and economic systems responsible for health inequalities or health disparity. Health disparity is a difference of health and health outcomes occurring to a group of people closely linked with

social and economic injustice attributed to race/ethnicity, religion, SES, gender, mental health, sexual orientation or geographic location (Centers for Disease Control, 2015).

Narrative. In this study, narrative refers to a story told by one person from her perspective, which relates an experience but may include many events as part of that experience. Narrative truth is situated, which means that it is true in the time it is told from the perspective of the present and as told to a person.

Narrative illness identity. The voicing of one's illness narrative in the larger context of life is necessary and gains agency over illness, which is achieved through narrative re-storying of the self with the consequences of illness, personal expectations and limitations, and the changed perceptions of others. This task is made more difficult for certain ethnic and socioeconomic groups by a web of causation of social factors and historical structural inequalities, thereby causing further disparities of outcomes in the experience of health and illness. Thus, through the cognitive process of narrative "emplotment" or placing oneself within a story or plot, one can construct a dynamic self-concept, important in helping one cope with the vicissitudes of chronic illness.

Chapter 2: Literature Review

In 1890, psychologist William James wrote, “the breach from one mind to another is perhaps the greatest breach in nature” (James, 1890/1950, p. 237). I believe he meant that it is impossible to know the understanding held within another’s mind. Of course, such knowledge can never be fully achieved; it can only be endeavored through the ability to articulate thoughts, feelings, and experiences and simultaneous listening with openness regarding someone’s story. Moreover, William James’s only sister Alice wrote about her struggle through chronic illness and finally terminal breast cancer during her final years. Alice’s illness narrative articulated the journey of one individual while simultaneously expressing the universality of her story, which is still relevant 125 years later. Furthermore, Clifford Geertz said, “one of the significant mysteries of man’s life in culture [is] how . . . other people’s creations can be so utterly their own and so deeply part of us” (Geertz, 1983, p. 54). The genre of the illness narrative is a quintessential example of this mystery. As such, reading another’s illness narrative and sharing their mind in the extremes of a crisis of life and health bridges the “greatest breach” of which William James spoke. The process of telling and of receiving another’s story of illness is the sharing of self with another, a hermeneutical bridging between minds.

The burden of health has been placed on the individual in chronic illnesses, such as obesity and T2D, where the individual responsibility is exacerbated with the perception of the above being lifestyle-related illnesses. This literature review first examines the difficulties of the illness experience of chronic illness within the context of the biomedical model. Second, it examines how social determinants of health cause health inequalities in terms of prevalence and experience of illness. Third, it explores T2D specifically and in the context of the intersection of ethnicity, gender, and low income, followed by finally investigating the use of narrative in health

and how narrative theory can help create the hermeneutical bridge necessary to share illness experiences. Moreover, medical education has begun to realize the necessity of thinking narratively, but its benefits have thus far not helped the patient find her voice in the medical dyad between physician and patient.

Chronic Illness: An Epidemiological Shift

Abdel R. Omran (1971) described an epidemiological shift in developed societies over the last century, including the movement from the age of receding pandemics marked by acute illness and infectious disease to the age of degenerative and man-made diseases marked by chronic illness. Due to this epidemiological shift, we are currently less familiar with death as part of our daily lives. As such, people are living longer while being sicker. Moreover, life expectancy has increased along with morbidity, resulting in a more nuanced measurement of “healthy” life expectancy. The vastness of the problem is outlined in the statistics from the Centers for Disease Control and Prevention, in that seven out of ten deaths among Americans are caused by chronic disease. During the past century, chronic disease has become the leading cause of death in the U.S. (Remington & Brownson, 2011).

Furthermore, a divide exists between how people with chronic illness can successfully negotiate life with illness and how physicians are traditionally trained to treat disease. This disconnect is rooted in how such patients make meaning and approach the successful management of illness ontologically juxtaposed to the biomedical model that still dominates western medical education and delivery systems of healthcare. Additionally, Moss and Dyck (2002) discuss the contested space of the body labeled ill by the medical world and the embodiment of the lived body of the everyday. Moreover, the biomedical model is rooted in epistemological dominance over patient embodied knowledge (Frank, 1995), creating a conflict

and power dynamic making the treatment of chronic illness difficult. The next section examines the doctor-patient relationship in the context of chronic illness.

Chronic Illness and the Contested Body

The names and labels attached to illness as well as how we create its categories and assign its causation define power relationships and normative concepts. Accordingly, Mol (2002) describes the two ontologies of the patient and biomedicine, beginning with the definitions of disease and illness, which in the Western world, we accept as natural rather than representing a specific epistemology. As we grapple with statistics, we must first pause to consider the meaning of the words used for categorization. The Centers for Disease Control and Prevention does not use the term “chronic illness” since their terminology is “chronic disease.” This choice alone reveals the ontological divide between biomedical epistemology and that of the embodied experience of illness. Moreover, disease is the biological problem in an organism, while illness is the social and lived experience of individuals who have diseases. Accordingly, statistics are often misused to blame those with chronic illnesses and promote fear. For example, in 1998, the National Institutes of Health (NIH) redefined the measure of overweight from a body mass index (BMI) of 27.5 to one of 25 (Rothblum & Solovay, 2009). As a result, 30 million Americans were moved instantly from a healthy category to that of risk, thereby redefining the bodies of these individuals from well to unwell. This normative definition of who is healthy and who is not has social and relational consequences in the patient-doctor dynamic as well as the relationship that everyone has with their bodies. Consequently, one’s identity and embodied experience are greatly affected by how society—whether a school, physician, or the Centers for Disease Control and Prevention—categorizes you.

The World Health Organization (WHO) and the Centers for Disease Control and Prevention continue to identify the causes of chronic diseases as being lifestyle related. According to the Centers For Disease Control And Prevention, the four most common causes of chronic illness are lack of physical activity, poor nutrition, tobacco use, and excessive alcohol consumption (Centers for Disease Control and Prevention, 2017a). Furthermore, sociologists would suggest that a web of causation should be favored for the aforementioned, which includes issues such as ethnicity (the effects of racism), stress, low income, and gender. These biopsychosocial factors significantly account for the disparities in health seen in the United States (Pinxten & Lievens, 2014; Walker et al., 2014a; 2014b; 2015a; Walker et al., 2015b). As such, a sociological perspective would also suggest that the use of epidemiological statistics could undermine the awareness of the complexity of the causation of disease and the individual and cultural experience of illness.

Social Determinants of Health: Intersection of Ethnicity, Gender, and Low Income

According to mounting evidence, the intersection of race/ethnicity, low income, and gender creates a complex picture of the outcomes and prevalence of disease. The Centers for Disease Control and Prevention defines social determinants of health as the complex, integrated, and overlapping social structures and economic systems responsible for health inequalities or health disparity. Moreover, health disparity is a difference in health and health outcomes occurring to a group of people closely linked with social and economic injustice. These injustices are historically attributed to race/ethnicity, religion, SES, gender, mental health, sexual orientation or geographic location (Centers for Disease Control, 2015). The role of racism as a social determinant of health is diversely demonstrated across the U.S. Further, interpersonal and structural racism has been linked directly with poor health outcomes (Berger & Sarnyai, 2015;

Paradies et al., 2015; Williams, Priest, & Anderson, 2016). Consequently, racial discrimination indirectly increases poor outcomes for disease through limits in access to care, quality of care, and bias of the healthcare provider. In addition, racism may be responsible for a direct increase in risk because of the stress response causing a biological challenge to the individual's regulatory system (Wagner et al., 2011). Thus, the stressor of racism can lead to harmful mechanisms for coping such as internalization of negative emotions. Structural racism is defined as discrimination based on the mutually reinforcing systems in a society that reinforces racist beliefs. As such, whether the experience of discrimination is interpersonal, micro-aggressions (daily, small discriminations or racial slights or insults) or structural racism, the biological effects are significant (Bailey et al., 2017; Berger & Sarnyai, 2015; Krieger, 2014; Paradies et al., 2015; Williams & Sternthal, 2010).

One example of structural racism is the segregation of Black Americans in geographical areas. For example, in the catchment area where my study takes place, gentrification is well underway; however, the major public housing developments initiated in the 1960s of low income and elder housing create isolated areas of low-income housing.

Additionally, environmental, and occupational health are social forces causing structural racism and influencing health outcomes by geographic neighborhood. Moreover, racial residential segregation adversely affects health outcomes in various ways (Williams & Collins, 2001). Furthermore, the fast food industry has long targeted marginalized neighborhoods with restaurants supplying cheap and fatty foods. Unequal and inadequate healthcare in these areas has been documented, in the case of T2D, leading to an increase in lower leg amputations in poorer areas (Stevens et al., 2014) caused, in part, by a systematic underfunding of public health hospitals and elimination of hospitals through the acquisition of hospitals by healthcare

conglomerates. This leads to a drain of specialists, such as vascular surgeons who might be able to save limbs, from poorer areas.

Black women persistently have poorer health and health outcomes than white women in the U.S. (Williams & Sternthal, 2010). In a study of 204 Black American women of low SES, Perry, Harp, and Oser (2013) found that these women were vulnerable to higher levels of personal stress and at the risk of higher mental health issues. Moreover, low income Black American women experience worse mental and physical health due to the intersection of gender, race, and class. Perry et al. (2013) also found that those who experienced adult victimization and financial stressors had a greatest risk. Further, women who had been victimized in childhood showed outcomes of the highest level of anxiety.

A study of 125 overweight Black and white American women found a racial bias that led to delays in cancer screening and perceptions that the bias of the healthcare provider is a barrier to proper healthcare (Amy, Aalborg, Lyons, & Keranen, 2006). The study found that as the participants' BMI increased, the delay in attending cancer screening increased significantly. The reported barriers to healthcare were disrespectful treatment by medical staff, embarrassment at being weighed, unsolicited suggestions to lose weight, negative attitudes of healthcare providers, and undersized medical equipment. Consequently, one can extrapolate that the same results would be found for overweight people with T2D. The combination of racial and weight bias is a regular experience for many Black Americans (Puhl, Andreyeva, & Brownell, 2008). Furthermore, many studies confirm the racial bias of healthcare physicians and the impact on the treatment of Black Americans (Green et al., 2007; Johnson, Roter, Powe, & Cooper, 2004). In addition, the perception of racial bias influences the lower usage of health services by Black

Americans, including preventative care and screenings (Musa, Schultz, Harris, Silverman, & Thomas, 2009; Nicolaidis et al., 2010; Rahim-Williams, 2011).

In the United States, a higher proportion of Black women live in poverty, which is defined as earning less than 100% of the federal poverty line: 24% for Black women compared to 10% for white women ('U.S. Census Bureau Current Population Survey', 2018). Low income directly affects the outcomes of T2D patients. Accordingly, a study of geographic distributions of the frequency of adverse outcomes for those with T2D found a strong association between lower-extremity amputations due to uncontrolled T2D and a higher density of low income in neighborhoods (Stevens et al., 2014). Thus, the rate of people with lower extremity amputations due to T2D is double the rate for people living in high-income neighborhoods. Similar results were found in a study conducted in Finland which has universal healthcare; it found a significant association between diabetic lower-extremity amputation and low SES (Venermo et al., 2013). Further, possible explanations for the results in both studies are lower quality hospitals in poorer areas, fewer vascular surgeons, and a mindset that accepts amputations for those in a lower SES neighborhood (Stevens et al., 2014).

Diabetes

The etiology of T2D is complicated, scientifically disputed (Hardy, Czech, & Corvera, 2012; Pouwer et al., 2003; Pouwer, Kupper, & Adriaanse, 2010; Roman, Parlee, & Sinal, 2012; Surwit & Schneider, 1993), and beyond the scope of this paper. Diabetes is classified into two types: type 1 diabetes (T1D), formerly juvenile diabetes; type 2 diabetes (T2D), formerly adult onset diabetes. The health consequences of both types of diabetes are serious and include heart disease, strokes, blindness, organ system failure, and amputation. Moreover, T2D is characterized by hypoglycemia (high levels of glucose in the blood or blood sugar) and defects

in insulin production and action (Gillibrand & Stevenson, 2006). Once one has T2D, weight loss and exercise can lessen blood glucose levels, which can help prevent the worsening of some comorbidities. However, a large federal study of over 5,000 overweight people with T2D—who were put on a regimen of diet and exercise to prevent hypertension, heart attacks, and strokes—had to be abandoned after 11 years as the intensive program did not help prevent these comorbidities (Kolata, 2012).

In light of the above, T2D is increasing in prevalence: 9.4% of the U.S. population has T2D, estimated at around 30.3 million people (Centers for Disease Control and Prevention, 2017b), of whom 9.7 million are women, and 1.9 million or 12.1% are Black women (Centers for Disease Control and Prevention, 2017c). The temporal relationship of large weight gain and insulin resistance is yet unknown (Gard & Wright, 2005). According to one theory, T2D and weight may share the same genetic inheritance; thus, weight may be a precursor of the expression of this inheritance (Muennig, 2008). Moreover, the stress caused by the stigma of excess weight is likely a greater contributing factor for ill health than fat itself (Puhl & Heuer, 2010). Therefore, an increase in morbidity may be caused in part by the stigma that often prevents good healthcare and by the socioeconomic penalties of weight that generate health disparities (Puhl & Heuer, 2010).

African American Women, T2D, and Social Determinants of Health

T2D was the seventh leading cause of death in the United States in 2010 (Centers for Disease Control and Prevention, 2017b). Research has found that racial and gender disparities are prevalent in terms of T2D, access to T2D care, and diabetes-related complications and mortality rates. The rate of T2D was 77% higher among Black Americans than among non-Hispanic whites; Black Americans were 2.2 times as likely to die from T2D (Health and Human

Services Office of Minority Health, 2016). Studies determining why these health disparities occur have had conflicting results, two prevailing theories of which are that income is accountable due to the larger numbers of Black Americans who live in poverty (Levesque et al., 2013; Link & McKinlay, 2009); the second theory is that race/ethnicity is the primary factor (Chow, Foster, Gonzalez, & McIver, 2012; Harris, Eastman, Cowie, Flegal, & Eberhardt, 1999; Kirk et al., 2006; Paradies et al., 2015). Additionally, Campbell, Walker, Smalls, and Egede (2012) conducted an online search in Medline with race/ethnicity and glycemic control as criteria and found significant racial differences in health outcomes. Accordingly, Black American women with T2D had poorer health outcomes and glycemic control than Caucasians. In a study that complicates these findings, Walker, Gebregziabher, Martin-Harris, and Egede (2015a) conducted focus groups of 615 adults with T2D, finding that subjective social status, psychosocial determinants (psychosocial distress, self-efficacy, and social support), and self-care are important factors of glycemic control. Moreover, there was a direct relationship between psychosocial determinants of health (psychosocial distress, self-efficacy, and social support) and outcomes in these T2D patients. They add that social status alone did not have a significant effect; rather, it was social stress effects, including physiological responses such as elevated blood pressure and heart rate, in response to social and environmental stress, which influence health over time (Walker et al., 2015). Thus, social determinants of health have a great impact on the prevalence and outcomes of T2D for Black American women.

Relatively few studies look at the lived experiences of Black American women with T2D. For example, a selection of studies found with a search for Black women with T2D includes an examination of the health beliefs and health literacy of Black Americans (men and women) with T2D (Al Sayah, Majumdar, Egede, & Johnson, 2015); beliefs about the racial influences and

health of Black women (Wagner et al., 2011); and eating practices among Black women with T2D (Willig, Richardson, Agne & Cherrington, 2014). Most of the aforementioned tend to focus on T2D self-management behaviors (Ciechanowski & Katon, 2006; Denig, Schuling, Haaijer-Ruskamp, & Voorham, 2014; Rosenbek Minet, Lonvig, Henriksen, & Wagner, 2011). All the above studies focus on T2D as a lifestyle disease, a term used for diseases associated with how a person or group of people live and is thus thought to be preventable.

A study by Pierre-Louis, Akoh, White, and Pharris (2011) focuses on Black women with T2D in social and cultural contexts, the central question of which is as follows: how do Black American women handle the challenges of supporting their families while dealing with T2D? This question was situated within the history of Black American women in the context of their collective past and present, including the cultural experience of slavery and the struggle for civil rights, as well as the women's primary financial, emotional, and educational roles in raising families. A "spoken word narrative" using the seven participants' words was co-created by the researchers and participants. They found eight themes involving the presence of major trauma or life stressor, in addition to blood sugar rising and falling with stress. As such, all the women suffered from depression, usually suffered on their own; there was a lack of mentorship and sister friends. Moreover, food was both a source of comfort and stress for the women because, in the past, they had gained pride and accomplishment in making food that they could no longer eat. Many of these women had spent their lives caring for others and were now realizing that no one cared for them. Furthermore, many found God to be a source of strength as well as infallible. This belief system could also lead to conflicts in self-management (Pierre-Louis et al., 2011).

In addition, Hotz (2015) interviewed 21 Black American women in a church-based T2D program. As Pierre-Louis et al. (2011), Hotz was interested in the experience of T2D in these

women's lives. Therefore, she explored the concepts of medical fatalism and hope from the religious perspective and found three themes: (1) the idea that if one does not claim a disease, it cannot enter one's body based on the religious practice of denial of negative pressure, which is common in Black Southern churches; (2) the role of church-based clinics in creating trust with Black American communities around health; (3) the importance of social location of patients by health practitioners to re-frame our understanding of patient compliance (Hotz, 2015).

The role of gender in T2D experience for Black Americans was explored by Chlebowy, Hood, and Lajoie (2013) in a study utilizing single-sex focus groups, where they examined facilitators and barriers to self-management. Moreover, they found that family support and religious beliefs were facilitators for both men and women. Further, the facilitator to self-management was described as the acceptance of one's T2D diagnosis specifically for women. The study also identified many barriers to acceptance for both men and women: financial burden, fatalism and negative outlook, perceived lack of control of the disease, and health-related stigma focused on the testing of glucose and insulin injection. These studies, which explore the illness experiences of individual lives, show the effect of the juxtaposition of lived experience with the biomedical view of T2D as a lifestyle disease.

The Study of Narratives

Anthropologists, linguists, philosophers, and psychologists have studied narrative from the perspectives of their own epistemologies. The word "narrative" is generally used in every concept, yet it has a different meaning and connotation in each. The frequency of its use is likely ascribed to the narrative being ubiquitous and the primary means by which humans communicate, creating meaning from events and making sense of lived experiences. As such, the simplest and agreed upon definition is that narrative is a story conveying a series of events.

The increase in the use of narrative theory in social science can be traced to a “narrative turn” in social science research beginning in the late 1960s and 1970s (Abbott, 2008). Since then, there has been great interest in the narrative as a focus and means of research in social science.

Narrative inquiry in health studies. Narrative inquiry in health studies has largely been used in the field of medical anthropology and sociology. Accordingly, sociologists, notably Arthur Frank (1995) and Kathy Charmaz (1995), and anthropologists, such as Arthur Kleinman (1988) and Bryon Good (1994), have explored medical and illness narratives. Therefore, for the purposes of studying narrative in health, the definition of narrative is a story of illness or health crisis told by an individual speaker who interprets a series of events from their own point of view. The hierarchical ordering of events helps indicate the importance and meaning for the storyteller to the audience. The dominant view in medical anthropology and sociology is that humans use narrative to make sense and order life events.

Several questions have been raised by the study of the narrative theory, which have application in the study of illness experience, the first of which involves understanding that there is a human desire for causality. Further, narrative linearity tends to imply causality: this happened before that, so this was the cause of that. This is similar to the erroneous conclusion that correlation and causation is consecution and consequence (Abbott, 2008), which is significant for illness narratives, as the patient may view their actions prior to illness as causative to illness. Many plots are recurrent in different cultures and therefore have certain expectations in their closure (Garden, 2010), which can influence the reading and telling of narratives. As such, the above is relevant to patient narratives, as patients may feel compelled to tell their stories in a way that is accepted or familiar to the audience.

The societal pressure to tell a certain story may cause a disconnect between the perceived narrator and the author of an illness narrative (Shapiro, 2011). Moreover, the pressures on marginalized or stigmatized individuals can have a profound influence on how they tell their narratives. Additionally, the members of a stigmatized group may not feel free to express their own stories. The dominant societal narrative about what defines this individual may prevent them from expressing true stories of self or voicing those stories to individuals from a dominant group or more powerful group member. Therefore, in order to study the narratives of health and illness, one must explore how other disciplines understand and approach the narrative.

Narratives of Chronic Illness

Chronically ill patients, especially those suffering chronic pain, tell their stories in the present tense, where events occur without order or purpose, creating a recurring negative experience between the patient's body and their social experience. Frank (2005) suggests that chronic illness is linked with a negative narrative feedback loop, which can be reduced by temporality, thus creating a distance from the story of pain and illness. Moreover, chronically ill patients may have increased difficulty in maintaining self-concept and strong self-efficacy; therefore, creating a narrative is critical. Over time, patients faced with chronic illness often lose the voice necessary to advocate and speak for themselves.

Furthermore, agency in relation to illness is the belief that one will be able to change the course of their illness by changing their behavior, which is lessened over time due to the vicissitudinous nature of the chronic illness. Additionally, their illness has no resolution and makes the creation of a comprehensible narrative difficult. The chronically ill often cannot conceptualize a resolution; therefore, they are perpetually in the middle of their stories, thereby becoming victims of the seemingly arbitrary condition of their illness.

Cultural, Class, and Racial Issues of Narrative

The effectiveness of an individual's voice is even more critical for populations with low income. These individuals may be more challenged in advocating for themselves than others of a more advantaged socioeconomic position (Wilson, 2015). In addition to issues of personal health management, the current healthcare system increases body-self disassociation (Frank, 1995) and general patient voicelessness. As such, narrative studies are often highly academic and, in many cases, inaccessible to the wider population. Individuals with low income may be overloaded and may not have the time or energy to devote to writing narratives (Krumer-Nevo & Sidi, 2012). The use of the written narrative may be more or less accessible to different populations. More specifically, in the context of racism and sexism, populations may have negative experiences with the academic pursuit and may be affected by negative stereotyping in relation to writing and language in general (Steele, 2003). This threat of being viewed through a negative stereotype lens can have an especially powerful effect on silencing the voices of some individuals. Therefore, years of discrimination are especially threatening in situations such as hospitals where such feelings of powerlessness may have serious health consequences for oneself or one's children, which is compounded by the medicalization of language that all patients face in the healthcare system; the language used by healthcare professionals becomes linguistically hierarchical, specialized and inaccessible to many. For people who must negotiate health and healthcare as a part of daily living and thrive as a medically monitored chronically ill person, one often must adopt a biomedical way of knowing (Mol, 2002), by which Mol refers to the set of knowledge and practices through which biomedicine understands illness. The prioritizing of these set of knowledge over the individual's own way of knowing can affect the experience of illness and possibly change the individual's self-concept.

Conclusion

The prevalence of T2D in the Black American population is often explored with quantitative methods. However, the voices of those with an intersection of race/ethnicity, gender, and low income are still not well heard. Moreover, methodological issues are present in hearing these experiences without the framing of the researcher; indeed, the effects of oppression may make it difficult for many women to believe that anyone wants to hear their stories. The pressures and stresses of daily life often make time and space for reflection seem a luxury that many feel they cannot afford. Therefore, a methodology that can aid in reflection about illness experience while simultaneously hearing authentic stories of illness is required.

Chapter 3: Methodology

During my related work experience, I learned that people living with chronic illnesses wanted to tell their health stories and needed them to be heard. Moreover, the stories of illness experiences are usually filtered by physicians who often hear only people with social and cultural capital and privilege. Hence, I wanted to learn the participants' own stories and, if possible, in their own words. My research question is as follows: how do these women with T2D make meaning of their experience with T2D? In other words, the central goal of my methodology was to understand the viewpoint of women living with the intrusive daily illness as well as what happens in their lives in the process of living with this complex disease. Further, how do these women make sense of their illness within their daily lives, create meaning, and accommodate T2D? In the medical sociology vocabulary, I wished to understand any biographical disruption, its manifestation, and whether and how it was accommodated. Finally, it was important for the data to be derived as directly as possible from the participants themselves.

A theoretical grounding in hermeneutical phenomenology was central to this narrative inquiry (Heidegger, 1962). Phenomenology is the study of how a phenomenon or experience holds meaning for an individual or group of individuals (Heidegger, 1962; Husserl, 1913/1998). The goal of phenomenological philosophy and research methodology is to uncover social and individual experience; it seeks to uncover the nature and meaning of phenomena through deep and substantial description. In other words, phenomenology is the study of an individual's consciousness of their experiences. As a research methodology, it provides direct data from the participants, all of which informs my understanding of illness experience and the meaning individuals find from that experience. Ideally, it comes as close as one can to understanding and uncovering the meaning of another person's lived experience without influencing the data with

the knowledge and experience of the researcher. Accordingly, thematic content analysis was utilized with both inductive meta-themes and deductive novel thematic insights from the narrative interviews (Riessman, 2008).

The rest of this chapter begins with a description of, and rationale for using, the methodology of participant-generated photo elicitation to understand the illness narratives of the participants. Further, it discusses visual methodologies and how they are used, followed by a section on narrative inquiry. Subsequently, the chapter describes the study design, including an overview of the process, the research setting, the methods for recruitment, and the sample of participants. The research process is then discussed in detail, beginning with a group orientation to narrative thinking about illness, use of situational photography, and describing data collection. The chapter concludes with a description of the thematic narrative analysis developed by Riessman (2008), which was used to analyze the interview data.

Methodologies

Several key goals defined my methodological choices: accessing a depth of knowledge to be gained about the lived experience of participants; participant-created data with as little researcher framing as possible; sensitivity to participants with life-long exposure to racism and sexism; a moral duty to do no harm in the research; and a preference for positive outcomes of participants. I believe that the chosen mix of methodologies allowed me the best opportunity to deeply understand how these women exist in the world with their illness. Furthermore, rapport was an important issue because people are often hesitant to discuss troubling issues of health as well as discrimination (Antin & Hunt, 2013). Thus, in order to gain rapport, interviewers often mobilize what is called category membership: sharing personal details of the researcher to indicate membership or partial membership in a group (Roulston, 2013); however, I was

concerned that doing so would not be effective and may alter the participants' responses. As such, participant-centric methodologies change the dynamic in the research process and increase rapport without self-disclosure. In addition to further rapport, I oriented the participants over two group sessions to be reflective about their illness experiences and share with others who have had similar experiences.

Participant-centric methodologies. The sources of my methodological approaches include the following: Community-Based Participatory Research (CBPR) and visual and narrative methodologies. Moreover, participatory methodologies such as Photovoice (Wang & Burris, 1997) address the criticism about many health-related strategies that have pathologized people's experiences and contributed to individual-oriented—rather than community-based or societal-based—etiology and solutions to health problems. Further, Wang and Burris (1997) developed Photovoice as a research method to learn about people who may otherwise be overlooked by traditional research methodologies. Others have found participatory methodologies useful for a varied population. Villagran (2011) examined methodologies for patient samples from marginalized populations and found that alternative methodologies such as Photovoice and narrative inquiry have potential benefits to gather data from populations across the whole literacy and educational spectrum. Additionally, Olshansky (2016) promoted the centering of the participant in research: “CBPR aims to assist the vulnerable in attaining and maintaining a voice, to recognize those who are vulnerable as the true experts about issues they are experiencing” (Olshansky, 2016, p. 274). Thus, through visual participatory methods, participants can identify and present their individual and collective issues via photography. Consequently, authentic voices of the participants are shared since they choose the subject, select the photos to be shared, and tell stories of why they chose the subject to be photographed.

Visual methodologies. I chose to use participant-generated photographic elicitation, a methodology in which the participant takes photographs which are used as foci of the interview: why they took those photos and the significance thereof. Accordingly, photo-elicitation relies on participant data creation and addresses the unequal power relationship between the researcher and the researched (Rose, 2012). I wanted participants to create knowledge as in Photovoice through the artifact of the photograph, as well as be the analyst of the photograph, which is a departure from some other visual methodologies. The meaning of the individual artifacts is best left to their creator, rather than to guesswork or hypothesis of its meaning by the researcher (Guillemin & Drew, 2010). Moreover, Drew, Duncan, and Sawyer (2010) used visual storytelling (their term for interviews elicited through participant photography) with 68 children with chronic health issues. Their intent was to shift away from a “top-down” approach to data collection, as they had determined that many established methods such as one-on-one interviews are adult driven (p. 1677). As such, they found that this method increased participants’ control over their storytelling, enabling more authentic voices and participant influence during the interview. In addition, the authors demonstrated their concern to dismantle the typical power relationship in a stimulus and response interview dynamic, a relationship described by Kvale (2006). The participants stated that this method aided them in approaching difficult concepts, expressing themselves, and helping them recall their own thoughts and issues during the interview.

Participant-generated photography-elicited interview has been described as a combination of Photovoice and non-participant created photo-elicitation interview (Rose, 2012). The participant has a determining role in choosing which photographs to take and which to discard as well as sorting them into a storyline and interpreting them with the researcher.

Moreover, participant-generated photography-elicited interview can have other advantages, such as conveying difficult experiences through image metaphors (Affleck, Glass, & Macdonald, 2013), which may help improve the visibility of the previously invisible (Guillemin & Drew, 2010). Furthermore, a participant can discover the meaning of a photograph often through exploring unconscious framing of a photograph subsequently explored with someone else. It is the “reflexivity between image and verbalization that produces the data for the investigator” (Harrison, 2004). The use of visual images as a means of expression is useful in several other ways. Moreover, photography is a valid means of showing culturally defined ideas to a researcher who does not share the culture. The use of visual methodologies may broaden and deepen the scope of research data and allow participants to “frame” issues, literally and figuratively. Finally, it is accessible to participants of all levels of education and literacy. Furthermore, methodological considerations of studying a population with the intersecting burdens of racial discrimination and chronic illness (which may include individuals who live well below the poverty line) present challenging issues of research. This necessitates a concentration on being sensitive to the narratives in context.

Narrative inquiry. Narrative creation is a valuable means to understand self and make meaning from experience. Further, narrative inquiry often rests on a “phenomenological assumption that experience can, through stories, become part of consciousness. It also takes a hermeneutic approach to analyzing stories aiming at understanding” (Squire, 2013, p. 65). Oral narrative storytelling is social, in that it uses a social form of communication and is socially subjective as it tells a story from one individual within her social context. Moreover, photographic narration can move beyond imagery and normative narratives when it triggers a story. In the clinical and educational settings, narrative methodologies have been used

successfully in medical schools and hospitals. Additionally, Columbia Medical School uses narrative medicine in their schools and clinics through a close reading of selective literature and journaling (Charon, 2006). Although attempts have been made to offer narrative medicine to patients, translating the program has been unsuccessful; a significant problem involves devising a narrative methodology effective for all patients, regardless of their literacy skills (Charon, personal communication, June 2012). As such, I could not assume that my sample would be comfortable with these skills and did not want them to feel uncomfortable. Therefore, by adding the visual methods, I hoped to provide another avenue of narrative creation available to all.

Participatory visual narrative methods can be empowering and therapeutic through contemplation and time taken to explore thoughts and feelings about illness experience. Hence, asking participants to create something that has both meaning to them and value to the researcher creates a different kind of data, thereby allowing the research to delve deeper into the rich experiences of individuals. Participatory visual methodologies can be used for realizing and reflecting on day-to-day experiences that can otherwise be taken for granted by the individual who lives them. Asking a participant to document their day through photography allows for a pause to reflect on experiences and meanings of those experiences of living with chronic illness. A series of photographs can provide a narrative without the use of text, but the viewer will interpret and understand them instead of the photographer doing so. I felt that the content and meaning must come from the participant-photographer for me to best understand their images. Thus, a degree of power relations equality exists as a fundamental reflexive practice in conducting any kind of research with populations not similar to the researcher or research into sensitive health topics (Affleck et al., 2013). Visual storytelling, or participant-generated visual research, is geared toward a close relationship between the researcher and the researched and

commitment to creating a conduit for the direct input from the participant (Bergold & Thomas, 2012). Moreover, I felt that this was an important aspect of the methodology as I am a white researcher interested in understanding the participant stories of women with different ethnicities as honestly and as directly as possible. Participant-generated photography can also provide a good method for counter-narratives, “allowing for the probability that what people themselves regard as important in their lives in social or cultural worlds may be different to how others may have viewed them” (Harrison, 2004). In addition, counter-narratives are stories told by people in a non-dominant group, often upending or challenging the accepted story. Therefore, according to the accepted dominant story about T2D, it is a lifestyle and choice-based disease, thereby leaving the responsibility of health with the individual. Thus, I wanted my participants to tell their own stories.

Study Design

Overview. This health study used narrative participant-generated photo-elicitation to gain an in-depth understanding of their experiences. I worked with two groups of women participants with T2D. Participant Group One had seven participants, one of whom did not complete the research in full, resulting in a sample of six. Participant Group Two had eight participants, all of whom completed the study. The resulting combined sample comprised 14 women ranging in age from 50 to 79. Both participant groups met for four meetings, each of which lasted for two hours. Moreover, both groups were given the same materials and the same protocol was followed. Participants were loaned cellphones with cameras, and over a two-week period, each participant took photographs of their experiences with T2D. Subsequently, they returned the cameras, and the photographs for each participant were printed. Each participant was individually interviewed, which consisted of relational map making, the participant sorting her

photographs, and arranging photographs into a story format. Accordingly, the story of the illness experience could be described through viewing and discussing the photographs in story form in an order set by the participant. The text of the interview was matched with the photographs and printed in a visual narrative book given to the participants.

Sample population. I chose this area of study because Northeast is a relatively large and prosperous city with the availability of good health services. Further, it has a great reputation for healthcare and hospitals; I was interested in the experience of low-income women who might not have the financial resources to access such world-quality care. While race was not a criterion for the sample recruitment, the 14 participants who finished the study self-identified as Black women. The participants ranged in age from 50 to 79 years: four participants were in their 50s, six in their 60s, and four in their 70s. The number of years since diagnosis of T2D ranged from three to 30 years. Ten people reported a family history of T2D, three did not report this information, and one had a negative family history.

Neighborhoods and housing context. The context of participants' lives cannot be stripped away or separated from questions of meaning-making (Andrews, Squire, & Tamboukou, 2013). The neighborhoods and communities the participants live in or come from are important parts of the context of their stories. However, narrative inquiry is designed to hear what the participants choose to say; therefore, my methodology places the emphasis on data offered by participants while not directly asking for demographic information. Consequently, much of the context of the participants' environment must be gleaned from publicly available or observed data of their catchment area. While this is imperfect, it does give some general context. Moreover, although I do not have specific demographics about the sample due to the method used, I have a clear understanding from the interviews and group meetings that all of the

participants spoke of struggling financially. In addition, I recruited from health centers whose clients are primarily low income. In lieu of data from participants, I provide a brief sketch of the environment from which the sample was drawn to give some context, including the sketch the neighborhoods the participants came from, which does not make assumptions about the participants, but in combination with the narratives which spoke of financial struggles and using food pantries, it can serve to provide some background. The healthcare services with which I worked to help recruit participants serve medically underserved patients from several relatively lower-income neighborhoods in the catchment area. The medically underserved population is defined by the federal Health Resources Service Administration as people who face economic, cultural or linguistic barriers to healthcare (Health Resources Service Administration, 2016). Participants currently residing in elder housing or housing in whiter and wealthier neighborhoods reported in their narratives that they had spent most of their lives in neighborhoods that are largely low income and majority non-white.

Recruitment. Recruiting for health-related research can be difficult and fraught with ethical issues and conflicts of interest. My work as a healthcare advocate provided me access to health fairs and outreach opportunities around the catchment area. In addition, my acquaintance with community health workers in the geographic area enabled them to serve as gatekeepers to help with my sampling and provided a relationship with the participants. These health workers have close working relationships with individuals who attend their clinics and are aware of people who would meet the research criteria. Furthermore, pragmatic and ethical considerations are important for the sampling of some populations such as those with chronic illness or health-related stigma:

With sensitive research topics, it can be hard to recruit a sample for qualitative interviewing. The resultant small number of participants may, as a research concern to learn as much as possible from this group, be asked to participate in more intensive research. (Squire, 2005).

As an incentive for participation and addressing these issues, I offered each participant three forms of incentives: \$100 at the end of the project provided she attended all the meetings and completed the photography and interview; a group session with a dietitian; a printed and bound copy of the visual health and illness narrative she would create during the research. This visual narrative consists of their photographs and verbatim text from the interview referring to each photograph.

Accordingly, I recruited via leaflet and posted on many community announcement and information boards. Further, I stipulated on the posters that the study was open to any women who have been diagnosed with T2D. I stated that they would be lent an iPhone to take photographs of their everyday life experiences living with T2D. Moreover, the leaflet stated my information and that I would utilize the research for my doctoral thesis for Lesley University (see Appendix A for the sample leaflet). The posters had my telephone number for contact, or in some cases, the outreach worker gave me the telephone numbers of people who had seen the leaflet and expressed interest. Additionally, I recorded the contact details of each person who called me (or who had contacted the outreach worker), including their date of birth and address, and confirmed that they had T2D. This convenience sampling stipulated for the participants to be women with T2D. In addition, snowball sampling was involved as some people joined by hearing about the project from other participants. After I had compiled a spreadsheet of possible recruits for the study, I contacted each person and offered several times and days of the week that

might be convenient to meet. In many cases, either the common time was not available to them or the participant dropped out for other reasons. These included losses of interest, feeling too overwhelmed by their life circumstances at the time, or scheduling of medical appointments or procedures and work conflicts. In Participant Group One, although people expressed excitement, their complex lives intervened, and I had a rate of 50% cancellation, implying that I had to recruit for a second participant group and recruit twice as many as I required.

Meeting Protocols and Data Collection

While the group sessions contributed to the participants' understanding of the narrative process and aided in reflective and situational photography, they also provided me with an understanding of the context and background of the participants and afforded an opportunity to greater rapport; however, the interviews provided the data to be analyzed in the study.

Accordingly, Participant Group One met over a span of six weeks from June and July of 2016, for a total of four two-hour group meetings, while Participant Group Two met at the end of October and in November of 2016 for a total of four two-hour group meetings (see Table 3 Timetable for Data Collection). There was a break after two meetings to allow participants to take photographs. Both Participant Group One and Participant Group Two were held in the community resource outreach office of a public housing development; meetings were conducted following a written protocol to keep the experience as similar as possible.

Table 3
Timetable for Data Collection

Meeting	Protocol
Group Meeting #1	<ol style="list-style-type: none"> 1. Introduce myself 2. Read aloud consent forms and sign 3. Pass out folders 4. Discuss ethics of photography 5. Go over outline of research 6. Practice taking selfies 7. Discuss participant photography and situational photography
Group Meeting #2	<ol style="list-style-type: none"> 1. Share situated selfies 2. Read postcard stories 3. Brainstorm about what they might take pictures of 4. Introduce idea of relational map (to be completed in individual interviews)
<i>Two-week break with no meetings to allow participants to take photographs</i>	
Group Meeting #3	<ol style="list-style-type: none"> 1. Turn in iPhones 2. Share experience of the photography project 3. Organize thoughts on what to ask dietitian 4. Schedule individual interviews
Group Meeting #4	<ol style="list-style-type: none"> 1. Visit from dietitian 2. Provide water flavored with lemons, mint, and cucumber
Individual Interviews	<ol style="list-style-type: none"> 1. Scheduled individually and recorded with audio and video 2. Option to mail or meet up to distribute Visual Narrative Books

Orientation to reflection. During the first two meetings, I worked with the participants to become more comfortable with narrative creation through various exercises orienting participants toward reflection on illness experience. The goal of this reflective process was to encourage participants to gain perspective and create their illness narrative through participant-generated photography and photo-elicitation interview (see Appendix B for Researcher outline). As such, they gained distance from their own experience, thus being both inside and outside of their stories and creating new knowledge. In addition, the participants’ motivations for attending

the research varied: Barbara and Geneva were motivated to share their strategies for managing T2D successfully; Lela, Ruth, Gabrielle, Cecilia, and Sylvia were troubled by their T2D illness experience and sought help; Gabrielle, when looking at a selfie taken on the first day, said, “[I’m] skeptical, but I’m happy I joined. They’ve been helping me out. They help me a lot.” I believe she was speaking of both taking the photographs and sharing her experiences with the group.

Meeting one. I gave the participants a printed outline of what to expect over the course of the research (see Appendix C for Participant outlines). I introduced myself as a student and a patient advocate, explaining that this project aimed to use photographs to tell the real story about living with T2D. My instructions were as follows: You will express through photographs and describe why you took the photograph, what it meant to you, and why it is important. Each person will take photographs of her life with T2D and write or record description to recall why the picture was taken. Further, there are no wrong answers as each person is the expert of her own experience. At the end of the research, each person will receive a printed, bound book of her visual narrative with her own words and pictures.

Moreover, participants who attended all sessions received \$100 and a group session with a dietitian. Further, I explained that I would use the interviews conducted for my dissertation research and read the consent form aloud and obtained participant signatures (see Appendix D for Consent form). After my introduction, I asked that they introduce themselves to the group, although I suggested that if they were uncomfortable, they could refuse. In addition, I provided each participant with a colored plastic folder which contained an iPhone and a small notebook, a pen, a larger notebook, an outline of each day’s activities, a reference guide for using the iPhone consisting of photographs, and my contact details. We discussed how photographs can be

ethically taken and used, as outlined in other forms of participatory visual research (Wang & Redwood-Jones, 2001).

Further, I discussed the role of telling one's story: we create bonds with each other and help order the importance of key episodes in one's life, and some people can find stories healing. I explained that they would be using the iPhones to take photographs of their lives with T2D, beginning by taking selfies. At this point, they took out the iPhones and turned them on. The rest of the first session involved practicing with the iPhone. Moreover, I showed them how to take photographs, record voice memos, and reverse the camera to take selfies. This was an effective means for them of establishing comfort with me and amongst themselves.

Moreover, I felt that it was important to use digital photography as I wanted participants to be able to experiment, try photography, and review what they had taken in real time to ensure the photograph matched their intentions. I chose a smartphone for the participants to use recording apps and add oral memos about the context of photographs in addition to them being reminders of why they were taking photographs. In case anyone was not familiar with a smartphone, I provided them with a photographic step-by-step guide to using the iPhone. While some owned or were very familiar with smartphones, others had either never used a mobile device or were intimidated by the technology. I clarified that the goal was to take photos of their experiences of T2D and record any necessary explanation about the photography either via the recording app on the iPhone or the small notebook. As such, giving them a large notebook to use in our sessions and write about their experiences outside of the sessions created both a visual and written method of reflection.

I introduced the concept of participant photography (Findholt, Michael, & Davis, 2011; Guillemin & Drew, 2010; Valera, Gallin, Schuk, & Davis, 2009; Wang & Burris, 1997) and

suggested that their images and discussion in the interview with me about the images would be the basis of their stories, both of which I would use for my dissertation as data. Further, I would provide a bound copy of the visual health and illness narratives to each participant, which could be shared with their families, friends, medical providers, or anyone they felt would better understand their illness experiences. Moreover, I explained that I would be recording the interview to provide a transcript for data for my research, as well as make the visual narratives using the verbatim text of the interview and associated photographs.

Situational photography. I introduced to the participants the importance of situating themselves in their photography by asking them to take “situated selfies” where the background to the selfies meant something significant and individual for them, effectively a visual reflection to be shared through storying. Practically, this helped them by reviewing the use of the camera on the iPhone and alerted me to any individuals who might be struggling with the technology. We practiced taking a selfie in the first meeting, where I asked if the situated selfie could be completed before the next meeting. Any photographic visual methodology risks that only a few photographs of people can be taken, as asking ask people’s permission before photographing can be onerous, but some participants felt that this was an important part of the process of gaining confidence and empowerment in creating visual narratives. Moreover, creating a “situated selfie” was the first stage of orienting toward reflexivity, as they must identify what background or artifact is important to themselves and how they will tell a story to help others understand their lives.

Meeting two. The participants shared their situated selfies as a means of understanding situatedness in photography and encouraging reflective thinking and storying to others. We brainstormed about what they might take pictures of, including common aspects of their

experiences with T2D or individual struggles. Further, I briefly introduced the idea of a relational map (Josselson, 1996), which would be completed in the interview. In this case, the relational map would not be between people they knew, but between themselves and T2D.

Meeting three. No meetings were conducted for two weeks in order to allow the participants to take photographs. I provided my telephone contact details for them to call me in case of any questions; one participant asked for a broken iPhone replacement. Following this, the participants could return their iPhones in the third session; I downloaded the photographs to my computer and made a file for each participant. We discussed what questions they might ask the dietitian; they shared some of their experiences from the photography process. Some reported that they had gained confidence in taking pictures while others felt that their self-images had improved. Moreover, some people reported feeling frustrated while working the camera initially, and one said that taking the photographs made her think about her health issues and reflect on her experiences with her medicine and her doctors. Some said that they had a new focus on their health and had learned about themselves as well as others. Finally, one person said that she had learned that she did not have to let her disease control her; she could control it.

Meeting four. In our last meeting, we were joined by a trained and certified dietitian who was available for questions about T2D.

Relational narrative interviews. For both participant groups, the individual interviews were held in the community outreach office of an affordable housing complex, which I accessed through the outreach coordinator at a health center who was a member of the task force for the aforementioned. It was a good location, being a one-bedroom apartment repurposed as an office. It consisted of a kitchen, bathroom, an outer room, and a closed-door inner room where I conducted the interviews. I brought a sheet to each interview as a reminder of my goals (see

Appendix E for Interview plan). Accordingly, I started with an orientation statement, which said, “You are participating in this study because you are a woman with T2D. I am interested in your experiences living with T2D in your own life. There are no wrong answers; you are the expert. You will do several things today to help me to understand your experiences.” This was followed by relational map making.

Interview methodology. I chose an amalgam method of participant photographic interview and narrative interviewing (Josselson, 2013), which is a hybrid of narrative inquiry, Photovoice, and photo-elicitation interview. At the beginning of the interview, I asked each interviewee to make a relational map. The relational mapping in these interviews is based on Josselson’s relational map making (Josselson, 1996), a tool she employs in qualitative interviews; she asks interviewees to create a map (indicating importance by size and distance from self in the middle) of their important relationships at a time which Josselson is interested in exploring in the interview.

How has diabetes changed your life and relationships over time?

How does it influence each aspect of your life?

Show me by coloring in the amount it has affected you in:

1. Day to day living
2. Your family
3. Food
4. Cooking
5. Drinking
6. Exercise
7. Understanding about yourself, including:
 - i. Self-image
 - ii. Confidence
 - iii. Self-identity
8. Work life
9. Social life
10. Religion
11. Emotions
12. Money
13. Any other areas of your life

Figure 1. Relational map making script adapted from Josselson (1996)

Combining methods is a technique recommended by other health scholars: “using a variety of methods, especially from other qualitative data sources, is important for increasing the robustness and rigor of the research design and, subsequently, for achieving deeper insight into the phenomenon under study” (Affleck et al., 2013, p. 160).

Relational map making. Unlike the traditional relational mapping (Josselson, 1996), in my interviewing process, the individual was focused on and the social factors altered by illness were arranged in relational order by size and coloring in describing the strength of the effect. Accordingly, I wrote an interview plan that I kept with me during the interviews; it had a topic list to check off for any issues not being answered by the relational map. In most cases, all the questions were answered sufficiently using the relational map, including origin family, others in the family with T2D, experience with diagnosis, blood sugar testing, satisfaction with medical

care, feelings about others knowing about their T2D, and T2D changing the way they felt about themselves. Further, I listed the suggested subjects for their relational maps (see Figure 1). However, the participants knew that the list was only a guideline, and most of the items were added to the list as the map was created.

Two participants in the interview were already carrying their individual relational maps in their large notebooks. All participants used the word “me” in the middle of the map to represent that they were at the center of their illness experiences. Moreover, they made circles around themselves (represented by the circle with “me” in it), with other circles containing relevant social elements. Participants chose a colored pencil to fill in how much they felt this social element was affected by their T2D. This was a useful method for re-orienting the thinking about T2D experience and how it influenced their lives.

However, it must be noted that some of the participants did not wish to make a relational map; they asked me to draw their maps while they dictated, and others changed the subject or otherwise made it clear that it was not a useful method for them. As such, with these participants I did moved on with the interview, but many others enjoyed the process of the relational map making greatly and found it useful.

Participant-generated photo-elicitation interview. The number of photographs taken varied widely among participants from single to triple digits. I printed all the participant-generated photos before interviews, numbering each photograph to allow me to read out the number of the artifact for the audiovisual recording. Subsequently, I asked the participants to look at their photographs, which each of them was eager to do. Moreover, I asked them to discard the ones she did not wish to include and put the photographs into a story order that made sense to her. I then re-numbered them. The interview prompt for each photo was: “What is

happening here?” or “What is this about?” Occasionally, I would follow up with clarifying questions, such as, “Can you tell me a bit more about that?”

Therefore, inevitably and purposively, the story of each photo collectively generated the narrative of each participant’s life.

Visual health and illness narrative books. The printed and bound visual health and illness narrative books were commitment acts (Glesne, 2006), showing my level of commitment to their own stories and fostering rapport. They consisted of the photographs taken by participants and the verbatim text of the discussion of each photograph. Additionally, the narrative books were in the participants’ own words, reinforcing the understanding that each was the expert on her own experience. In addition to providing a commitment act and fostering rapport, giving them their visual narratives allowed them to use the narratives as a means of communication with their communities, including health professionals and family. The visual health narrative book was also an incentive at the end of the research process, along with questions and answer by a dietitian, and \$100.

Data Analysis Methods

While a narrative interview is not as clearly defined a strategy as some other methods, such as grounded theory, it can result in in depth research (Andrews et al., 2013). Accordingly, small stories obtained from everyday experience can compare to a “snapshot” from life and can indicate meaning to the individual, as in the participant photograph story. In addition, the big story may be revealed only when the snapshots are arranged. An analogy for this type of analysis would be a flip book, where many photographs of daily life are placed next to each other, but the whole story emerges only by running through the snapshots. Moreover, some evidence suggests that the use of small stories strips away the dominant cultural narratives and

allows for alternative narratives to gain importance (Sools, 2013). Although most visual methods rely on the researcher being the analyst of the photographs (Rose, 2012), I am interested in how the photographer-participants analyze and reflect upon the photographs they have taken to tell their own stories.

My interview method is based on relational narrative interviewing (Josselson, 2013), the goal of which is to understand the interviewee holistically and experientially. This requires an intersubjective perspective on the process:

We understand that people construct their own social reality. . . We are aware that we as researchers are the authors of our interpretations; yet we aim through interviewing, to learn something about what is beyond ourselves and our pre-existing assumptions (Josselson, 2013, p. 2).

Heidegger (1962) and Gadamer (1977) describe a hermeneutic circle, defined as a process of understanding, which is increased through an intersubjective relationship with a text, speech, artifact, or person. Furthermore, the relational narrative interview can be understood as a hermeneutic circle with the interviewee, which is not necessarily a historical fact but narrative truth because it is influenced by the interviewer and thus it is not *the* story of the participant but *one* story. In transforming the other's narrative into data, Wiklund-Gustin (2010) details the researcher's role: "Instead of being the means of the participant's self-understanding, it turns into research data as text that should be interpreted to promote a more general understanding of human experiences" (Wiklund-Gustin, 2010, p. 35). Once the interview is completed, the interpretive authority of the data is the researcher's responsibility alone (Chase, 1996). However, one must be concerned with separating the interview from the interviewee; the analysis is of the data and not the participant (Josselson, 2013).

Thematic analysis is used as the narrative analysis method in this study. It concentrates on the content of the narrative: the told rather than the telling. Furthermore, it is often used in health studies, including those such as the present, which are influenced by phenomenology and hermeneutics. The goal is to uncover and categorize the health experiences of the participants. Moreover, there are no clear sets of rules of narrative thematic analysis, other than the influences and preferences mentioned above: “Data are interpreted in light of thematics developed by the investigator (influenced by prior and emergent theory, the concrete purpose of the investigation or the data themselves . . .)” (Riessman, 2008, p.54). As such, my job as a researcher is to interpret the individual stories on a larger and theoretical basis. The text and photographs belong to the participant, while the “interpretive authority” belongs to me as the researcher (Josselson, 2007, p.179).

This hermeneutic circle requires a greater focus on the researcher’s situated positionality and a recognition of the relational aspect of the co-constructed interview. Additionally, it is important to recognize the ethics regarding the analysis, including issues of relations of power between the researcher and the participant. Therefore, giving the production of the data over to the participant reduces the power differential between researcher and participant. In addition, there is a greater responsibility to be conscious of othering in the process of the analysis. In this case, othering refers to the process of replacing an individual by a category or believing an individual is knowable by an understanding of the social category to which she belongs. While the transcript is verbatim, I was concerned that certain parts of the narrative interview might be traumatic, in which case, I asked if the content should be amended for the visual narrative book for it to be could be freely shared. In one case, the youngest child of a participant did not know

about her mother's cocaine abuse, which was excluded from the visual narrative book, but the participant specified that she wanted it included in my research.

Thematic coding. While I originally decided to create the visual narrative books of the participant images and interview to present as a tangible manifestation of the interview that we shared, I also found it a valuable tool in my analysis. Consequently, when I made the initial transcript of the interviews, I did the aforementioned to provide a verbatim discussion of photographs by the participants in the preparation of the visual narrative books that I would give to the participants. However, it was valuable in precoding the data (Saldana, 2010), engaging in close reading (Charon, 2006) and using a traditional means of color highlighting for qualitative coding. Further, I used the Dedoose software to code the narratives, analyze the frequency of concepts, and engage more closely with the material. Using the coded excerpts of the narratives, I simultaneously worked on narrative portraits of each participant and analyzed the narratives thematically. In addition to using the qualitative elements of Dedoose, I found that some of the mixed method aspects of the software, such as the use of "descriptors" of each individual participant, helped me explore the data. Additionally, making spreadsheets was valuable for comparing descriptor data with codes. While the assignment of the codes was largely subjective and the data I gleaned were in no way causal, it did alert me to interesting findings that I might otherwise have missed in a purely qualitative software program.

Portraits. Portraiture is a method of analysis relying on a hermeneutical bridge between the researcher and the participant. In this dialogue with the participant's words and photographs in the creation of the portraits, I embarked on a "complex, provocative, and inviting [process] that attempts to be holistic, revealing the dynamic interaction of values, personality, structure, and history" (Lawrence-Lightfoot, 2005, p. 11). Further, Lawrence-Lightfoot and Davis (1997)

defined portraiture as an art and a science. I kept a running database of key elements of the participant narratives from their interviews and their visual narratives throughout the process of visual narrative creation, analysis, and synthesis. I read through the interview transcripts and visual narrative books for each participant underlining text that I thought might illustrate the contexts, qualities, and essence of each participant. As regards the art, I tried to write each portrait with a deep appreciation of the individual and her own contexts. Moreover, I tried to write a portrait that was both authentic and individual but with the knowledge that there is never a single story and that the portraits are my own understanding of another person. Consequently, in thinking of the process as a whole, I tried to keep in mind the purpose of the project and understand the lived experience of T2D but with a rich context of the individual story. “Looking for points of thematic convergence is like searching for the patterns of texture and color in a weaving” (Lawrence-Lightfoot & Davis, 1997, p. 12). As such, I included a portrait for each of the 14 participants.

Validity and Reliability

I have attempted to outline my methods for data collection in a clear manner to make it possible for another health researcher and educator to implement the methods in their own practice and increase reliability. Therefore, scholars have been clear that a narrative interview is a singular act influenced by the interviewer, the result of which is narrative rather than historical truth (Freeman, 2003). However, this does not make it any less valuable as a source of the true experience of the participant in that time and space.

Thus, understanding the creation of a story out of its situatedness also means that a narrative inquiry can never be repeated with the same participants; it would never receive the same stories. This variability does not mean that the data are not reliable; it is rather a sign of

them being narratives revealing how participants ascribe meaning to their lives from the perspective of the “here-and-now” (Wiklund-Gustin, 2010, p. 35.). Moreover, Josselson (2013) states that the result of the analysis of the interviews will represent *a* truth and not *the* truth, thereby reiterating that the interpretive responsibility is the researcher’s own.

Limitations and Delimitations

I did not purposefully recruit Black women and had been prepared for the inclusion of Latinas, as the population from which my sample was gathered largely comprises Latinas with T2D; however, the sample population identified as Black women. My intention was not to create a study regarding race or gender but to understand the experience of illness within the life of each woman. However, as the women were Black, race was often in the background of stories of their experiences but not explicitly examined by most participants. However, the fact that I was a white woman researcher of all Black women should have been explored more with the participants. The key aspects of my research method did fall short on demographic data. While it is in the nature of narrative research that the participants may not reveal such demographic data, it may have been helpful to add a questionnaire at the end of the research to understand the data in a greater context.

Riessman (2013) states that narrative inquiry “is a field characterized by extreme diversity and complexity. There is no single way to do narrative research, just as there is no single definition of narrative” (p.259). There is a multitude of issues and necessary caveats with narrative research, but as a hermeneutical phenomenological means of deeply understanding the lived experiences of others, it is the best methodology in my view. One such caveat is that as with much of postmodern methodology, narrative researchers must acknowledge that as a form of meaning-making, it is socially, culturally, and historically specific (Squire, 2013). While

narrative data are socially, culturally, and historically specific to the individual, analysis is likewise specific to the researcher. Moreover, narratives represent a moment in time for both the researcher and the story they research. The moment of time can at once contain multiple possible meanings. Further, visual narrative research adds a source of data specific to the individual participant, which helps the interview become more evocative. Thus, in using an image as a prompt to tell a story, the interviewee can more safely express complex and difficult experiences, thereby allowing a liminal space for the researcher and the participant to explore deeply.

Conclusion

The narrative portraits in the next chapter are a product of 21 hours of interview material; yet I, as the researcher, determined what to include or exclude. Another researcher would more than likely have made different choices. In addition, although I used only the interviews for data, the time we spent together in a group setting added understanding about each participant. Therefore, a longer duration allowed a closeness and familiarity among the participants as well as with me, thereby creating a good rapport. While the photographs and the interview transcripts came from the participants, the narrative portraits were written by me. Although they are based on the interview transcript and photographs from each participant, the narrative researcher must sympathetically craft the portrait. “The key issue is not who writes the narrative but which point of view it reflects. It is possible for the researcher to express a point of view that is very close to that of the research participant” (Krumer-Nevo & Sidi, 2012, p. 301).

Chapter 4: Participant Portraits

Sara Lawrence-Lightfoot (2005) describes research portraiture as a dialogue between art and science. “The portraitist is very interested in the single case because she or he believes that embedded in it, the reader will discover resonant universal themes” (Lawrence-Lightfoot, 2005, p. 13). Moreover, the role of the portraitist is to create a portrait of the interviewee that does not quite look like her but which capture her essence and seeks the familiar and exotic, thereby revealing a new perspective while being authentic to the voice of the participant. This attempt to capture the complexity of lives and people is a daunting methodology, which must be approached with care and compassion. Moreover, the role of the researcher as a portraitist is to focus on the experience of each individual in order to understand these 14 stories as a whole. As my research question was to understand how each of these women makes meaning of their T2D experience, my goal involved picking threads from each individual’s story to make the experience of women living with T2D clearer. In order to achieve this, each interview is carefully scrutinized for the threads allowing the whole story to be told. The portraitist must listen not just to a story but for a story (Lawrence-Lightfoot, 2005, p. 10).

Barbara: Color Picks Me Up Like a Drug

Barbara enters the room behind the “Cadillac,” a large pushcart that holds her necessities for the day. Barbara is 77 years old and was diagnosed with T2D 30 years ago when living in Barbados with her husband Paul. Her grandmother, mother, and aunt had T2D and lived until their nineties. Her grandmother refused to have her second leg removed even though she knew she would die. Barbara’s husband died three years before her interview. She speaks about him as a man with faults but whom she clearly adored: “He was a hell of a guy, everybody liked him: sometimes he could be a pain in the ass but can’t we all?”

Barbara's participation in the group is motivated by an altruistic desire to help others with T2D. She has had her issues; once even being hospitalized with blood sugar levels over 600, which she has since managed to maintain at around 110–150. She uses many devices that enable her to keep well, which she photographed for her narrative and commented that she hoped others would find it useful, including dosed medication cardboard pill cases she obtains from a pharmacy. She has both a talking blood sugar meter and an insulin pen with an audible click to indicate dosage. Her emergency home alert button once saved her life when she discovered she had an allergy to pistachios. Barbara has good insurance, Senior Whole Health: "I tell everyone they should get it. [My husband] had it when he died. Didn't pay a dime for that, and you know it was a smoking bill."

Barbara grew up in a predominantly white neighborhood from kindergarten through ninth grade. She has many happy memories, but things changed when she got to high school:

I'm proud; nobody had to tell me "I'm black and I'm proud" because my father already told me that. My father was one of the first black men to own his own cabs here in [the neighborhood] . . . I am used to white people not talking to me; I was brought up in that neighborhood and I was taught by my father if they don't speak back, to hell with them because you are somebody. And I tell that to my nieces and my nephews. I say: you are somebody.

Barbara chose a postcard photograph of Black and white kids playing. Recalling it in the interview, she said:

I had some good friends who were white from kindergarten to high school, but only two of them stayed friends with me once I got into high school. It was peer pressure that

made them: people saying if you talk to her I won't talk to you anymore . . . It's when the adults influence children.

Barbara's mother was physically abusive after her father died, resulting in the family having financial problems, and Barbara's mother took it out on her: "My mother beat my butt every day. Maybe it was because I look like my daddy . . . I don't dwell on it; never did. [Pause, laugh] I was a handful, though I didn't do anything to deserve that." While Barbara does not dwell on the T2D and gets on with her life, she does not like how it sometimes makes her feel:

It makes me feel lazy, and I don't like that. I like to be able to get up and go. I can make a plan and I can know what I want to do, but I wake up the next morning and, because I don't feel right, pfff [makes a disappearing gesture with her hands]. So, I don't do it or I do it and I feel miserable.

Barbara finds joy in many aspects of her life. Color is important to her: it "picks me up like a drug." She recounts that she painted her kitchen as well as her bathroom while balancing on a ladder propped up in her bathtub. For her, the color of T2D is:

Grey, it draws everything out of you. Black kills you, grey drains you. And T2D doesn't affect anybody the same. My sister can have blood sugars of 300 and 400 and she's great. And I can't believe it. My blood sugar gets up 198 and I'm ready to cave.

Kara: Cookie Crumbles

I had been told by the outreach coordinator at her healthcare practice that Kara had anger issues. After the first meeting where Kara was silent, she became involved, animated, and engaged. Kara has medically unconventional health beliefs grounded in the confidence that she knows her body better than anyone else:

T2D doesn't affect how I eat because I still eat cupcakes, but my metabolism is sometimes different from other people. I can eat a bag of cookies and I won't gain nothing. Sometimes, I would eat a hot dog and I would gain 5 pounds for that.

Kara also has a high pain tolerance since she was a child. When she was young, she was outside buying candy at the local store and was hit by a car. She described bouncing off the car bumper and hitting her head on the curb. She went inside to see if it left a dent in her face, but she was not hurt. Kara also reports a violent relationship with her mother:

She'd hit me in the head with the frying pan, but I didn't hold grudges. [Afterwards] she went into her room and locked the door. You have to picture it. When someone gets hit in the head, it is like the Three Stooges. It's no effect.

Kara speaks of T2D in a way that shows she is not concerned about it changing her way of life:

I know my body well enough to know "the cans and the cants . . . I deal with my T2D, I do what I have to do because I mean if you don't take care of yourself, ain't nobody going to take care of you. . . . T2D is just another challenge.

Kara was a professional wrestler for many years fighting as "Cookie Crumbles." From the age of 18 through her mid-30s, Kara traveled the world as a professional wrestler, and she is proud of her unusual career and her travels: "That's why T2D is something that I just live with; I've done things that most people haven't."

Kara tried different things in her youth and had many jobs after her career in wrestling ended, including as a security guard for Muhammad Ali and at Logan Airport where she met the Shoe Bomber. Most recently, she was injured at her job as a mental health assistant while restraining a patient. She wants to go back to work soon, as it is important to her: "It gives me

like an outside world. I'm a loner, I don't like to be around a lot of people. Working helps me mentally and physically."

Kara does substantial walking, which involves strolling from her home to visit a friend in another neighborhood. She likes nature and reflects that in her choice of photographs for her visual narrative. She's an observer, who sits in the park and listens to "wise" older people.

Her life now, as her childhood, involves violence. Once, in a group meeting of the study, another participant recounted how the story of her relative being gunned down at a party was all over the news. Kara says, "Yeah, it was next to my house." During the photo elicitation interview referring to a photograph, she said, "I didn't take a picture of the shooting, but that's the house."

Geneva: Make the Best of It

Geneva, 66, has two children with her husband. She says that she left him after he acted like a fool; she did not provide any details. She supported her children by working at an organization that helped mentally disabled young adults lead lives in the community. She started as a counselor but ended up running three homes with 28 people as staff. She is proud of her work and that she brought up her children on her own. Geneva received a full scholarship to a college in Baltimore but refused it and ended up going to community college to study psychology.

Geneva walks with a limp; one of her legs is notably shorter than the other. She lives in assisted living. Geneva's attitude to life and to T2D is rooted in her early experience with adversity in the polio outbreak of 1955. Her verbal enthusiasm was born in the five years when she was in an iron lung, where she could only move her head and her mouth:

I had very supportive parents. I never had a problem with that because my father told me I was as good as anybody else . . . I knew that I had my limitations but my parents stressed education so I always had jobs that accommodated my disability. . . again, that's all I could do from ages four, five, six, seven, eight was talk to the person next to me!

When Geneva was diagnosed with T2D, her attitude toward her new illness was equally accepting:

Because I'm positive about everything, getting T2D it didn't really change my life . . . being paralyzed, T2D is nothing! Plus, there's always someone worse off than you. . . You're alive! So, you got life, make the best of it. Don't be sullen and whining about what, this happened, that happened. You're here!

Geneva says she loves living in her housing complex because she lives on the ground floor, which looks out on The Plaza. Her visual narrative is filled with gardens and the neighborhood where she has lived for five years. She has a small garden next to her access ramp. On her iPhone, Geneva recorded the following about her photographs:

Planting my flowers outside and enjoying them; watching my grandchildren playing outside; exciting group shot of me and three of my grandchildren. I enjoy nature, family, and loved ones. This all helps me with my T2D.

Regarding the joy she feels living in her ground-floor apartment with a small garden, she says:

Listen, being paralyzed, I do enjoy the outside. Flowers. Gardening. People. That's why I took pictures of those particular things because that excites me! Because for them, here as I was in a little lockdown position, that iron lung did everything for me. The only thing that was open was my head.

She quit smoking three years ago but started again when her daughter was diagnosed with throat cancer and two brain aneurysms and moved back to the catchment area with her two kids to escape an abusive relationship. Geneva is trying to stop smoking again, “I am smoking less. So eventually I’m gonna quit again.”

Lela: So Many Gottas in My Life

Lela, 73, approached the project with concerns about her high blood sugar and difficulty managing her T2D, which she had had for 11 years, but emerged with a new understanding about the rheumatoid fever that left her partially paralyzed at the age of 12. At the first group meeting, she wore a white denim jacket over a brightly colored shirt and slim-leg jeans. Lela has a partially paralyzed left arm and leg: “I don’t use a walking aid, and I don’t want to. I think that it limits your independence.” Lela’s lilting Louisiana accent trails off to an inaudible whisper.

Herein lies the key to Lela’s narrative:

Yes, you have to be the author of your own story, but . . . you . . . I don’t have the confidence . . . I see myself but not well enough because if I did, I would have the understanding about myself and I would do what Lela needs to help *her* . . . it is a conflict in me, in my story.

Lela has never been married, has no children, and lost her mother as a child. She was raised by her aunt and lived in Louisiana, Maine, California, and now the catchment area. She went to college and works at the local Senior Commission. She has a boyfriend who, like past boyfriends, is a good cook:

But if I cooked really well, perhaps my T2D . . . I wouldn’t be so deep into this bad thing because then I would just be able to prepare whatever I felt was good and healthy for *me* and without questioning . . . but I never do so. I depend on the cooking of others.

Despite her dependence on others for cooking, autonomy is a strong theme in her narrative. She returns repeatedly to the drive to maintain her independence. After the rheumatic fever, Lela worked to regain her ability to walk. Now, it seems as if she regrets not working more on increasing the mobility in her arm. Her visual narrative is dominated by photographs of her walking. In addition, there are several photographs of her doing physical therapy exercises:

I just knew I had to walk. The hand, well, is just a hand . . . I used to cry because the exercises were so painful. And I guess my parents feel, probably, they gave over to me and they didn't push me . . . say, "come on work that hand; work those muscles" and I don't blame her . . . So, I guess, the decision's for *me* . . . came basically from *me*.

The relationship between autonomy and a consequent self-blame does not seem to help Lela.

She says:

I don't know if I have the confidence in myself to do it, but *I got to* do it, to keep working and building my strength. So, then I have to muster myself, somehow "You gotta eat better than you do. Stop skipping your meals. You gotta take your medication that you should and stop skipping them when you feel like doing that." So, there are so many *gottas* in my life!

With both rheumatoid fever and T2D, Lela blames herself over lack of progress and consistency and feelings of inadequacy. The roots for this tendency toward self-blame come from Lela's childhood: "They used to talk about it in my church where our minister used to say, 'If you know something is right, and you don't get on the path to doing that, you will . . . be whipped with many stripes.'"

Often in her narrative, Lela conflates what she must do in physical therapy to maintain her physical independence along with good, healthy behavior around her T2D. She berates

herself about not exercising her hand, and then berates herself over having an ice cream. Late in the interview, Lela has a realization:

Maybe that's what it is. I'm saying something to the world, but I'm not saying it simply enough inside of me and that's not too good. Well it's . . . I don't think it was the T2D that changed me and the way I feel. I think it was the rheumatic fever . . . Not just work with but work *effectively* . . . maybe I should eventually wind up seeing somebody, you know that? Sometimes it's in here that goes towards doing. I hear a conflict inside of myself . . . could be self-love, it could be . . .

Lela's illness identity is entangled with both illnesses. She says, "this thing, T2D, affects me psychologically, emotionally, socially, physically, the whole gamut, it really does. It does affect me in all those areas." In thinking about her T2D and looking at possibilities, Lela thinks about seeing a nutritionist at the local clinic. Her knowledge about good health behavior is high but she often does not take her medication, saying, "I know if I do the right things as I see them, I won't be always plagued with "Did you do this? Did you do that? Why didn't you?" So, my emotions sometimes are all over the place because I know the right thing to do and yet I don't do it, I know."

Lela is not always so hard on herself and tries to have fun in life, occasionally having a piña colada because she says, "You have to have a piña colada. You just can't let all of life go by you. And then what happens when you die and you didn't enjoy a piña colada. Honestly, you can't do that."

Cecilia: Three Days at a Time

Cecilia's struggles began early. Her mother was diagnosed with breast cancer at the age of 14 and succumbed when Cecilia was a toddler. She and her brother were raised by their

grandmother. Her family suffered many illnesses, and she was confronted by multiple losses. Her brother, to whom she was close, died contracting HIV from a female intravenous drug user in California. He was in California on a full basketball scholarship to UCLA. She has sickle cell anemia and was diagnosed seven years ago with T2D. She struggles daily with a desire for a Pepsi and McDonald's french fries.

Cecilia's identity as a mother is tied to her troubled relationships with abusive men. She had her first child at the age of 12 by a physically abusive older teen. The child later died. Cecilia was addicted to cocaine for 30 years and struggles with sobriety:

I wish I could take three days at a time, but I have to take one day at a time. I find a lot of battles and a lot of demons, and I am still fighting them. It seems, it goes good for a minute and then things go bad and the demons come back. Like now, I am looking for a new place to live.

It is painful when she now sees the child's father around her neighborhood because he was abusive:

It was my first experience having sex and it was my first experience of having an abusive relationship . . . I had my next child when I was 14 or 15 years old, and I had two children by the father and he was just totally abusive, and some of that is down to depression, just mistreating myself and also drugs . . . I've only had four relationships in my life and every one of them was abusive. I've had kids by them all.

Cecilia became homeless with her 14-year-old daughter just after the interview. She has a difficult relationship with her eldest daughter. After her brother died, she had one of her five or six relapses with drugs. When she was pregnant with her fourth child, her three eldest were in

child protective services because her eldest had been sexually abused by the father of her other children. Ever since, her relationship with her children has been fraught:

This is a picture of my three-year-old grandson. I took him to the playground. Here, I really know that I'm a grandma. A year ago, he ran away from me and got hit by a car . . . I felt really, really bad, and my daughter would say, 'can you watch him?' and I wouldn't even go to the corner with him anymore because he's too fast and he runs away from me.

Due to her family history, Cecilia has been checked for cancer every year since she was 14. Her second daughter had cervical cancer when she was 16. Blood disorders run in her family and her T2D is uncontrolled; during her diagnosis, her blood sugar level was over 600. She says that having T2D has affected her confidence: "I'm not very understanding about myself, including my self-image." Her grandmother passed away three years ago: "I was close to her; she raised me [sighs]. Since T2D, self-image and identity have been a real problem for me." She is still in a relationship with her youngest child's father, who is verbally abusive and financially controlling but not physically abusive. She responds to these stressors with poor health behavior, such as drinking alcohol and Pepsi and eating fast food:

Often when I get mad, it affects my T2D. I don't take my medicine and I don't take care of myself. I don't know why; I'm not hurting anyone but Cecilia. Some days I do want to die, but I still have this last kid and also, I want to see my grandkids grow up . . . they call me 'Ma'.

She liked a quote she had seen (and photographed) by Margaret Mead, that says, "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it is the only

thing that ever has.” It touched something that Cecilia was trying to understand about herself and her life so far:

I really like the quote. I don’t fully understand what it means, but I like what I understand of it. You know, it takes a village to raise children, and I’ve seen a small group change many people’s lives. . . . In her community, my grandmother was on the task force and tried to help people. This quote really grabbed me. I wanted to take the time to really read it and understand it.

Mia: Mauby and Soursop

Mia, 69, was 32 years old when she moved here with her parents, brothers, and sisters from Trinidad. Mia has been with her boyfriend Tony for nine years. He is younger than Mia by 11 years. They had met in church; they look after each other: “I have an excellent man. If it wasn’t for him, I don’t know what I would do. He really looks after me. If it wasn’t for him, when I was sick, they would have found me already dead in the apartment.”

Mia suffers with T2D and depression. She has two birth children, three adopted children, and many foster children: “That is something that I always wanted to do: help others. I like helping others. That’s what I do.” Mia has suffered from depression for many years, but it has been worse since her T2D diagnosis:

My depression comes on worse than how it was, because sometimes when I have to stick my fingers four times a day, now I take needles three times a day. My depression got worse with the T2D. When the depression is coming on I just know . . . When I’m depressed, don’t talk to me; don’t say nothing to me.

Mia does not take any medication for her depression. She feels she already takes too many pills and medications for her T2D. She relies on exercise and traditional medicines from Trinidad.

Mia makes tea from soursop bark and mauby to keep her sugar down, which are traditional remedies from the Caribbean. Although she does test her blood, she says she can tell when her sugar is high or low without testing.

Mia loves cooking. T2D did not change the way she eats because she always ate proportionally, but she eats much less now. She was shocked when she was diagnosed with T2D:

It was because every time I go to the doctor and they do my finger stick, my sugars were always normal . . . when they take my sugar, it was over 500 . . . I started crying. I say, “Why? Why me?” . . . I say, “But I don’t use sugar.” She says, “Anybody in your family is a diabetic?” I say, “Yes, my mother.” When I get home, I say, “why do you have to have T2D and I have to get it?” She says, “I haven’t done anything to you.” . . . I say, “well, okay. I have to live with it the rest of my life.”

After Mia’s mother died five years ago, she had had a troubled time and ended up in a homeless shelter. However, she was organized with her paperwork and found a new home within months along with a new purpose at her assisted living building. Mia is the task force manager and cook for her building. She likes to look after people. Three years ago, Mia had breast cancer.

Although now there is no sign of the cancer returning, Mia lives in a cycle of T2D and depression. She says that it has been difficult for her and Tony to look after each other:

Last year, Tony had an aneurysm . . . he refused to go to the hospital . . . Then I went and I said, “Tony, I love you. When I was sick, you took care of me. You let me take care of you.” I said, “If not, I will put you outside in the hallway, and I will lock my door. I love you but if you don’t want to go, I don’t want the dead in here.”

In the end, Tony had surgery and in November they celebrated their nine-year anniversary together.

Mercy: Hey, This is Where I Belong

Mercy has a problem with her dentures. She had her teeth removed when she could not afford to have them repaired. The dentures rub her gums and cause her great pain. On the day of the interview, Mercy is not wearing her dentures. She has not been able to wear them for weeks and has not been eating solid food.

Mercy spent her younger life in foster care homes. “It was sad. I’ve been beaten. I’ve been raped. It is very sad. I can’t believe that I am here.” Mercy went into foster care because her mother “was mentally retarded.” Mercy knew her mother and her mother’s siblings, but she never lived with her mother until she moved in with Mercy shortly before being hospitalized for the last time. “We found out very late in her life that she was diabetic. Then, I found out that I had T2D and it ran rampant in my family. I have nine aunts and five uncles, and they all had T2D.”

Mercy was diagnosed with bipolar disorder when she had her first child at the age of 17. She and her husband had three girls together:

He was an auto mechanic, a racing car driver, a bowler: he was all of those things . . . but he did not know how to treat me. When I got sick, he changed. I knew that it was time for us to break up, but he didn’t know how to. My doctors would say they wanted him to come in and be with me in the talks and everything.

Mercy found out she had T2D five years ago. Two years ago, she had a gastric sleeve procedure; she was 5’1” and 260 pounds. That was not the body Mercy felt she should have. When she was in her 30s, she began weightlifting to help her cope with her mental health disorder. In a few

years, she was teaching the weightlifting class at the local YMCA. She could benchpress 250 pounds:

I had to throw myself into something . . . This is because of the bipolar and everything . . . The thing about it is, when I first went to the Y, it was like this: the guy goes, “Hey, lady, you should be in an aerobics class.” I say, “I know what I’m doing.” The only reason why I knew what I was doing because I read books on bodybuilding and it was something that interested me.

Mercy happily took over when the teacher moved out of town: “I felt like, ‘Hey, this is where I belong,’ and I stayed there for five years. It was wonderful. I was happy. Life was good.”

Mercy felt comfortable in her skin for the first time.

But things changed after an accident when she fell from a ladder: “I thought I could go back to work out . . . come to find out, I have my wrist broken and I had herniated a disc in my back.”

Mercy was not able to lift-weights or teach. Her weight increased rapidly.

Mercy expresses concern and worry about her children and grandchildren. She feels concerned but also relies on the support of one of the daughters, who looks after her. Her youngest daughter, who inherited Mercy’s bipolar disorder, has five children in foster care. Another daughter, who helps Mercy is very heavy and plans to have bariatric surgery. Mercy feels that this is positive for her daughter.

The lack of a car is also a significant stressor for Mercy, who used to have a car, which gave her much more access and flexibility in her life. She was less tired as she did not have to take an often-unreliable public transport system. She had been paying off accumulated parking tickets, which can be common in large cities. Her daughter had borrowed Mercy’s car to travel

to work, and while driving home one day, she had fallen asleep at the wheel and hit a wall.

When she was in the hospital, Mercy opened the glove compartment and masses of tickets, that her daughter had received and never paid, fell out. Mercy lost her license and will have to wait until tax returns give her enough money to pay everything off.

Mercy copes with her stress by attending a neighborhood church and caring for her three cats that she inherited from her boyfriend of five years. She had looked after him when he was dying, and he had made her promise to take the cats so the landlord would not have them euthanized. The cats give Mercy much-needed comfort and support:

I have three cats. This one. . . . he's always all over me. It feels wonderful. It feels wonderful to have them because they're comfort. They sleep with me . . . When I open the door, they're right there, right at the door. They're waiting for me, waiting for me to come home. It's a good feeling.

Moreover, she copes by eating candy: "I have to have candy. I don't know why, but I have to eat my candy. I can't do without it. Now, I don't have any candy, and I'm dying. I'm really dying." Mercy had a gastric band procedure done because of her high blood-sugar. She does not eat enough; in fact, she requests half portions at meals that she cannot finish, but her blood-sugar levels continue to be high.

Gabrielle: Saved by T2D

Gabrielle is 60 years old, has one daughter, two grandchildren, and one great grandchild, belonging to a large and complex family. She was addicted to cocaine for 24 years. Four of her nine siblings are still addicted to drugs. Gabrielle came to the interview with a completed relational map and a written narrative in her notebook:

When I was first diagnosed with T2D about 12 years ago, I was already suffering with PTSD, depression, and anxiety. I was on drugs; crack cocaine. I was a mess. When they told me that I had T2D, my blood sugar was 500. I was afraid, and I felt so alone. I wished that my mother was still alive. I needed to be comforted, but I had no one to comfort me. I have my daughter, but she already had two children. She already had her hands full with two children and another one on the way.

I went into denial and refused to own the fact that I was a diabetic. I continued to eat what I wanted, drank sodas, and I got high. I didn't keep my hospital appointments and rarely took my medication. When I finally did keep a doctor's appointment, I was told that along with taking Metformin, I would be put on insulin. This scared me a lot.

I prayed to God to give me the strength to help myself. Later that night, I called my younger sister. I told her that I was tired of the life I was living and to please come and get me. She came right away. This was 12 o'clock at night. She had gotten up, out of her bed, to come and get me. She is the mother of four children and they was all small at this time. She was also working eight hours a day and going to school at night to become a medical secretary.

She came and got me because she knew that I was serious. Through my years of addiction, I never tried to quit. Never asked for help. I stayed the night at her house, and the next morning on her way to work, I had her to drop me off at [a medical center].

I checked into [a mental health center] for my depression. From there, I went to [a women's detox facility]. I stayed here for 48 days. [After that] God blessed me with an SRO, single room occupancy, where I lived for seven years and I joined my church.

I gladly take my medication. I am now living in an apartment where I enjoy having my family come and spend time with me. What is a good thing is that my family come and spend time with me. I love myself now. I want to live. I'm enjoying life. I just need to lose some weight. I keep my appointments; take my medications. I have chronic kidney failure, but as long as I do as my doctor says, it's something I can live with. I am truly grateful that my God is a God of second chances.

Gabrielle says she did not have a childhood. She began changing baby diapers when she was a three-year-old. When Gabrielle was eight years old, her mother came home from the hospital and handed her one of the new twins and said Gabrielle was responsible for raising her.

Gabrielle has always looked after her siblings, and many of her siblings still rely on her.

Gabrielle was sexually abused from ages seven to nine by her stepfather, who had raised her since she was six months old. She never told her mother: "She would probably have killed him and we'd all have all been separated. I never told her. She died not knowing that." It is still difficult for Gabrielle because she is close to her siblings and they want to be close to their father. She has confronted him in order to move on with her life:

When I got older, I asked him, "Why did you?" He said, "It's not like you're my child." She asked her pastor for counsel. He told her to forgive him. She replied, "I'm sorry, pastor, you're wrong. I was the child. He was an adult. He should come in asking for my forgiveness.

Gabrielle became pregnant at the age of 14. Her mother took her to get an abortion. At age 15, Gabrielle was in the waiting room for another abortion, when she had the sudden sensation of a voice telling her to leave. She stood up and told her mother, "No, Ma. I'm not getting rid of this baby. It may be the only child God blesses me with." She had her daughter but also a very

serious case of gonorrhea from the baby's father, who later molested their daughter when she was 15 and their granddaughter when she was five.

She commented on other complexities of daily life with T2D. In her relational map, a large circle is filled with the time consumption during medical appointments. Moreover, cooking is time-consuming: "It's very complicated, trying to make two different meals at one time," referring to making a meal that is T2D-compliant for herself and another for her boyfriend and her 17-year-old granddaughter who now lives at her home. Gabrielle is looking for a way to balance all her health needs. She has been told that her weight is her biggest issue and believes that gastric surgery may be the best option.

Another area of concern with her T2D is obtaining healthy and affordable food. Gabrielle commented that she might read the nutritional labels but first she reads the price label. She said, "You still got to buy what you can afford. That's the way you keep food in the house." Gabrielle buys what she can and uses food pantries. She feels that being hungry as a child made her realize the importance of everyone having enough to eat, because of which she began a food pantry at her church: "This is a great joy in my life. I enjoy doing this. It's giving back. I don't believe nobody should be hungry. I remember, as a kid, we were hungry a lot."

Recently, Gabrielle has had trouble with high blood sugar. She had to stop taking Metformin due to conflicts in her medicines. On the morning of the interview, her fasting sugar was 320: "I use a meter and check my sugars. They're just high. That's just getting to be depressing."

Gabrielle commented on a photograph she has included in her visual narrative, which shows her changing the understanding of her self-image: "This is the picture I took of myself,

when I first joined this group. Skeptical but I'm happy I joined. It's helping me out. The others helped me a lot." About another photograph, she said:

This is me looking in the mirror at myself, wondering if the sickness got me aged like this, or is this how I'm supposed to naturally age? It's showing in my face, that I'm sick. That's sad, that makes me feel sad; it really does.

Gabrielle says that T2D saved her life. She has been off cocaine for 11 years and is slowly weaning off the cigarettes. Her boyfriend is still working at age 68, and they are both clean. She has made peace with her past abuse and drug addiction: "I started on drugs. Life was hard, but it's better now. God won't give you no more than you could handle. I had to let him carry me through. I know I can get through this."

Sylvia: Fighting Something

Sylvia is Gabrielle's younger sister. Like Gabrielle, Sylvia came to the interview with her completed relational map. Sylvia also wrote a poem. She has been writing poetry since she was 13; she says she uses it to cope in the moment but does not spend much time going back to look at them. When Sylvia and her twin were 15, their mother left home. It was well over a year before Sylvia learned from her older sisters that her mother had cancer.

Sylvia's teenage years were difficult. She had a baby, and when the apartment she shared with her sister burned down, she became homeless at the age of 17 with her young baby. Sylvia moved from one sister's house to another. When her son was six years old, he complained of a headache and was diagnosed with leukemia.

Sylvia's life went from bad to worse. When her son was in the hospital, the biological father arrived, and Sylvia did not want to deny her son the opportunity to spend time with his father although it was quite stressful for her. Simultaneously, her twin sister was diagnosed with

cancer for a second time. Sylvia felt torn and did not know who she should spend time with; both her sister and son were in different hospitals with cancer.

In this troubled and vulnerable time, Sylvia succumbed to the temptation of taking cocaine:

When I started it, I didn't think it was addictive . . . as I did it, then I felt myself wanting it, not thinking about [my son and sister], but it was knowing that I was forgetting about them at the same time. Then, I forgot about my children too, and I forgot about myself, too. Then, I forgot about everybody. Then, I felt myself just being taken away by the drugs.

During this time, she had an abusive relationship with her boyfriend, whom she'd been with for years and had a three-year-old daughter with. Later in the interview, she revealed that she is currently with him.

Sylvia could only see her terminally ill son one hour a week. While juggling the beatings, the hospital, her son's and her twin sister's cancer, and her drug habit, Sylvia let her three-year-old slip through her fingers:

I had left her when I was using, with this guy that I trusted. I was ready to take her home. Then, she told me that he touched her. I brought her back to his house. I told him that he'd sexually abused my daughter. I looked at her. She was swollen.

The man had threatened Sylvia and told her that children would be taken away because she was high when her daughter was abused. As such, fearing for the health of her daughter, Sylvia took her to the hospital. She was still high and lay down in the waiting room and fell asleep: "I got woken up by the police, and they told me that they were taking her. They felt that I was high. That I didn't take responsibility. My daughter was only three years old."

In the end, Sylvia lost both of her children to foster care. The foster home where her son ended up was not reliable since the parents had stolen her son's morphine. Sylvia felt that she had to tell the authorities so that her son would get his medicine. Although he asked her not to, she did not want him to be in pain. The foster family were furious and made it even more difficult for Sylvia to see her son. Her son succumbed to his cancer. Three days after her son's funeral, the foster father overdosed on morphine. After her son died, and Sylvia lost her daughter, she survived. She got off drugs, but there were always complications with her daughter.

Sylvia did not discover that she had T2D until it was in an advanced stage. She had kidney and heart failure by the time of her diagnosis. It is not clear why the diagnosis was not made earlier—either she did not go to the doctor, or they did not test for it. She struggles with her health due to multiple comorbidities. Sylvia says that she was healthy before her T2D diagnosis. She has learned to accept it, but it is a daily struggle:

It's like my life is still terrible because I have the feeling of . . . I never had the feeling of fighting something. I felt like it was normal, and I just don't feel normal to have to be fighting something.

Due to all the difficulties and betrayals she experienced in her life, it is difficult for Sylvia to trust people now:

I don't have friends. I don't deal with people, basically. I find it hard. I want to be honest, but I hate that when I am honest, I think people will try to hurt me instead of help me. I don't like to get judged.

She says that taking the photographs gave her great confidence. She even went up to strangers, spoke to them, and took their pictures.

When dealing with and reflecting on her life and her illness, Sylvia often relies on religion:

I'm like, God takes, God gives, and God doesn't give you no more than you can handle. Apparently, God felt that I can handle losing my son. My son was here for a purpose. He served his purpose . . . I can't make a choice, but God does that for you because God knows which one you can handle more, and God is always right . . . God is always there, but God helps those who help themselves.

Ruth: A Pepsi Challenge

Ruth is a tall, 56-year-old woman who was diagnosed with T2D 10 years ago. Ruth has five grown children whom she raised as a single mother after leaving her abusive husband. She is cautious about her friendships; her best friend is Marianne. "We talk every day. We have for 23 years. We've been through a lot and I call her anytime I'm having a problem . . . we support one another." She goes on to express her caution by saying, "I live by myself. I have very few friends. Marianne is one of them. You don't know who you can trust, so you make your circle small. You have your children and the people from Bible study." Marianne also has T2D. They talk every day and help each other cope with T2D.

In our first group meeting, Ruth discussed how her mother's T2D was instructive to her in her own experience. As Ruth explored her experience about her T2D through photography, her feelings changed. The knowledge of her mother having T2D did not mirror how Ruth understood herself:

[I didn't feel] great about the diagnosis because the only time that I had to go to the hospital before the T2D was to deliver a baby and I was never that connected to hospitals.

When I became diabetic now, I have to stay connected to the medical world . . . I was healthy.

Ruth learned as much as she could about T2D at the time of diagnosis, including going to the library and taking out *The A to Z of T2D*. Now, Ruth feels more conflicted about her T2D:

Because T2D is a double-edge sword. What I mean by that is, if you don't eat enough, your sugar will be too low, and if you eat too much of the wrong thing, your sugar goes high. So, it has to be a balance and you have to take your medicine the doctor prescribes.

Further, she said, "The thing is, it was hard for me when I learned I was a diabetic because I didn't want to go to hospitals, and when you are diagnosed, now you are connected, and you feel no way out." She sees a counselor for anxiety and depression but mostly relies on her religion and church for support: "Sometimes, I get a bit depressed or a little bit sad . . . I tried depression medicines and they just didn't help . . . If you go against the grain it won't help you."

Religion has offered Ruth welcome guidance. In her visual narrative, she ensured placing the photo of her Bible first, describing it as the "main book" that she reads; she states that the Bible has brought her a long way. Bible study is the focus of her social life and the source of her support:

It is very positive place to be. It's about three minutes from where I live . . . Pastor J. is teaching us about meditation; it's very awesome. And it helps to calm your mind and everything. And I don't bring the cigarettes when I go to the Bible study. That's 2 1/2 hours or three but I'm not smoking.

Ruth credits her pastor and his wife as good health behavior role models: "I see the pastor and his wife, and they are walking together after dinner to stay healthy. They are older but they look good, healthy." She also included a photo of Pastor J. in her visual narrative, explaining, "He is

very important to me . . . every time I was in the hospital, he came to visit me, and he would bring a Bible for me to read if I needed one. He's a very nice guy."

Food and finances are a constant source of concern and worry in Ruth's life, including not just what to eat to stay healthy but also the difficulties of eating well on her benefits: "I'm on SSI, and I receive about \$800 a month, but by the time you pay the bills and rent, there's not a whole lot left to get you through the month." She spoke of the difficulties occurring due to Supplemental Nutrition Assistance Program (SNAP) not covering non-food but essential items such as cleaning supplies. Ruth tries to supplement her SNAP benefits with food pantries, but she says there are few good food pantries in her neighborhood.

In addition to her issues regarding the medical system due to her T2D, Ruth has a difficult relationship with the health community because of the trauma she suffered at the time of her lung removal surgery due to lung cancer:

I was really traumatized by the surgery . . . I was in ICU in critical condition, tubes everywhere . . . so they put me in a medicated coma and then they gave me a shot and paralyzed me . . . it was very traumatizing.

Ruth finds it difficult to quit smoking and giving up Pepsi, which concerns her as she is aware how dangerous sugared drinks are to her health. In fact, Ruth took a picture of Diet Pepsi for her visual narrative, both to emphasize the importance of it and to express her difficulty: "This is a picture of the Diet Pepsi that I'm starting to struggle with. I really tried to like it but it was hard because it's a bitter taste, and it takes the fun out of it. I bought it, but I won't buy it again."

Shanda: Trust and Believe

When Shanda, 62, came in for her interview, her sister Kim had died the day before from a heart attack. Kim had many health issues and continued to use drugs. She did not want to

change her lifestyle when the doctor told her that she had to or she would die. Shanda and her sister took different paths. She regrets that her sister did not choose hers:

Just watching my sister, it's a shame. I was with her the day the doctor told her, "You have to change your lifestyle if you want to continue to live." When we left that office, she said, "I'm not changing shit." That is what she did. She just had to have that joint. It's not going to be me. Mmmmm, I refuse. I did my share, trust and believe; not anymore. I am ready to live.

Shanda was very close to her sister and struggles with difficult feelings while contemplating her own past drug use:

I have a lot of emotions. I'm going through those now, emotions. Something I can say out of all of this is I'm getting better and stronger and stronger. Because if all this stuff had to happen to me, five, six years ago, I would be out there using drugs. The simple fact is, when you use drugs, for me is, it will cover all the pain that I was going through. I didn't want to feel that . . . once you go back, it's harder to get back, to come back in, once you're out there. I find out that the disease gets even worse. Every time you relapse, it gets worse.

Right now, Shanda's illness focus is smoking. She knows she needs to exercise but she gets out of breath; she views smoking as "the biggie" and says that one of the main reasons why she smokes is depression and being around people that smoke in her building. She wants to quit, but she needs the support of an aid to quit smoking. She can get a prescription for a patch, but it costs too much money:

Who will pay for the patch? That's the problem; if the patch was like a dollar, fine, but it's not a dollar; it's for five dollars . . . given my co-payments right now, I'm fighting with [my] pharmacy, now, about my co-payments.

Shanda, like other women in the group, has many illnesses to cope with alongside T2D. She deals with the complexities of many medications as well as the cost of the co-payments: "I'm on a lot of medicines . . . I take the medicine for the fluid around my heart. It's interrupting my life . . . I pee all the time . . . I can't sit there and hold it."

She asked her doctor for Chantex, a medication she saw on a TV commercial; she thought might help her quit smoking. But it is contraindicated with her depression medication. She was diagnosed with T2D four years ago, which is when her depression started:

Afterwards, yeah, I snapped out a little bit. I talk; talking to people now. Before, I would never talk. I would just hold the shit inside. That's what really made me go crazy. This time around, I opened up and I was talking.

After smoking, the second concerning issue is Shanda's diet. Her two daughters are very health conscious and often talk to her about her diet:

I know they do it because they love me. Sometimes, I follow their advice. Sometimes, I don't. I noticed I'm getting heavier and heavier. Can't take it no more. I always thought it was my back. But it's my weight for sure. I want to live longer.

Shanda is coming to terms with her T2D but began to understand the implications of the disease only recently: "Some people don't realize T2D is really, really serious. I'm now finding out how serious it is. I didn't before. There should be more education on it to."

In addition, another stressor for Shanda is her living situation. Years ago, she married a man with whom she had lived for a couple of years. They moved down to Georgia, where he

became abusive. She was desperate to leave. When they had moved, Shanda had given up the apartment where she had lived for 25 years and given away all her furniture. She returned to the catchment area anyway and ended up at a local women's shelter. She was determined to find a new apartment and took a place in the public housing authority "projects." It was quite dangerous, which is why her kids would not visit. It took a long time for Shanda to get out of there. She eventually moved into an assisted living home comprising mostly elderly people. However, it did not suit Shanda because she was not allowed to spend her own money, cook her own food, or even pay off her burial insurance. Now, Shanda lives in a halfway house, which is better but "not where I want to be. This is my steppingstone. I want to have my own apartment, kitchen, living room, bedroom, bathroom."

Shanda took a photograph of the poster of Malcolm X, Martin Luther King, and President Obama in her apartment, which says: "We've come a long way, yet so far to go."

Shanda says, "To me, that means I came a long ways and yet so far to go with my health. It's these three, being black, means something but not just for Blacks, whites, Spanish, everybody."

She also points out a postcard she photographed that says, "God grant me the serenity to accept the things I cannot change and the courage to change the things I can," commenting, "They help me to remember, don't mess up."

Willow: Keeping Moving

At age 79, Willow traveled the farthest to get to the participant meetings. She is in an electric wheelchair and is the oldest of the group. She has rheumatoid arthritis as well as T2D. Willow had one child, a son, when she was 16 years old. She thinks he is 61 now. Willow jokes that, "He's old; as old as me." She has three grandchildren and six great-grandchildren. Her son

moved out to Seattle, but all the “grands” live in her neighborhood. After she became dependent on her electric wheelchair, she had to move away from the neighborhood where she had lived for over 30 years to find housing. She still maintains many relationships, including with Shanda—whom she has known for 50 years—who told Willow about this research.

Willow has several coping mechanisms in her life: collecting, shopping, and playing bingo and the lottery. Her refrigerator is covered with magnets that people have sent her from all over. Her theme for her bathroom is of zebras. Willow goes to the mall on Sunday morning mostly for window shopping. In all types of weather, she speeds along the sidewalks in her wheelchair, looks around the mall and gets a slice of cheesecake. Her shopping is mostly saved for the home shopping channels:

I have a lot of bills, because I’m on the TV all the time to HSC and QVC . . . yeah, I’m always buying something . . . it’s a problem for me. You know how much I owed to HSN? \$5000 . . . It’s the buying of it. I see it, I like it . . . I’ll pay \$1000 for something for me. It’s for me. Why wouldn’t I treat myself? If I buy something, one thing, I might buy three or four of it.

In addition to shopping, Willow likes to gamble; she believes in luck: “I play the lottery, terrible. It’s my downfall. I play a certain number every day. It feels good to play the lottery. I think it has a greater meaning.” She also plays bingo with her girlfriends three times a week: Monday, Tuesday, and Wednesday. I know everybody in here. It’s nice and social. It’s in Central Square. I just ride down to Central Square [in the wheelchair] when the weather’s good, from my house.

Having chronic illness has not made Willow feel different about herself. She accepts her T2D as her rheumatoid arthritis. She keeps her spirits up by playing bingo, lottery, and moving

around in her neighborhood in her electric wheelchair. She sees her health issues as a combined problem and does not distinguish between her T2D and her other chronic health issues:

I feel all right. You just have to take one day at a time; you just keep moving on. If you sit down, like my other girlfriend, she doesn't come out. She stays in her house. I said, "Why don't you go out?" And she said, "Oh, all my friends, they don't like to go out." I said, "I don't care. It's as long as I can walk, talk, and see." Well, not walk, me in the wheelchair, and see and hear, I'm getting out!

Jessie: Searching for a Narrative

Jessie is very thin but strong, which reflects the dancer she was in her youth. She is 74 years old with a family history of T2D. Jessie is an alcoholic. Her speech reflects mercurial emotions. The narrative in her interview seems to get lost by the end of a sentence. She uses figures of speech and fill-in strings of words, such as, "Duh, duh, duh" and "such and such and such." In her visual narrative, she begins with her selfie practice photo, which she took when we were exploring how to use the camera. She has a huge smile in it and was laughing while capturing the image. Jessie's situated selfie was carefully planned clear and quite linear, in contrast to her normal speech:

The shoes meant I'm supposed to wear them for my health, for my T2D. They are orthopedic. Because T2D can make you have that's what the . . . not neuropathy, but they're going to be numb and your toes will curl up.

On top of a book given to her by the Seventh Day Adventists with a picture of a coffin on the front, she placed a butterscotch pudding and an orange. The orange represented what she should eat, while the pudding represented what she's not supposed to eat. But it also tells another story.

She recalls that she felt scolded for not eating the pudding and apparently threw the pudding at one of the aides at her assisted living building.

Jessie says that when she was married at age 17 and had a baby, she had postpartum psychosis. After “10” (unclear if she meant years, months, or weeks), she was diagnosed with bipolar syndrome. At the time of her mental illness diagnosis, it appeared she was self-medicating with alcohol: “I’d be staying awake for like . . . because I was like in the half-gallon department.” She emphatically believes that the doctor is wrong about her diagnosis of alcoholic neuropathy, dementia, and especially issues with anger management:

I don’t ever need any temper management, because sometimes they ask me stupid question like, “What does this such and such . . . ?” If I tell them, say it once it’s just like I’m bipolar. If it goes right through, and I guess the answer right, but, I call it, quote dry them eyes, because if I don’t do it, my mind and I don’t have any dementia.

At some point, Jessie “escaped” from her assisted living home and managed to travel to New Mexico:

When I got real sick, and I didn’t know, and the doctor told me, I said, “I never had any DTs.” He said, “You never want to. People die from alcohol withdrawal system.” I didn’t know the first time, and someone said such and such, and such period, the second time, they kept sending me to the cracker factory . . . don’t tell me. . . . I went to New Mexico, and I came back, I didn’t know where I was for six months.

She had seizures, which may or may not have been due to alcohol withdrawal. She calls alcohol her “nemesis.” She says,

That could kill me. . . . Tell the truth and scare the devil. I’ve been going to meetings. That put a lid on it . . . yeah, it’s hard, but it beats the tubes up your nose and dying, and

kidneys, and all like that, liver. I go to NA [Narcotics Anonymous] meetings because the AA [Alcohol Anonymous] is a little more . . . because any drug is a drug . . . it's something I can identify with, some of the stories, and it's good to sit down. Sometimes, I don't have a dollar.

Jessie has one daughter and two sons. She is interested in her genealogy and talks about Prof. Henry Louis Gates and his genealogy search program on public television and that it's too expensive to get all the birth certificates that she needs. She has some photographs and stories:

My grandmother would be speaking, and then she'd say . . . "They're always call me Old Black Sadie." Her name was Sarah . . . I asked why they called grandma Old Black Sadie. They said because her mother was white . . . my uncle, sometimes he'd have a few, and he'd spill the beans . . . my mother said, "Yeah, they used to put rice powder on my face." On their face, because they were kind of fair, but, so they put it, when they use to go visit the white relatives.

Jessie finds solace in religion:

Yeah, religion helps me . . . religion, I pray for everyone and myself. It isn't funny to me, but sometimes you're praying to the wrong . . . you're in the right pew with the wrong . . . right church wrong pew . . . my mother would always say, you can go to any church as long as you go to your own first. I like to go to the church that's right here, but it isn't the same church. It's New Hope Baptist Church . . . Then, I go to another church . . . Sister Rock, she played the piano. "I sit down on my knees, and the trouble rise. I speak to Jesus, up in the sky. You promised me; he'd hear my plea. If I tell him, down on my knees." [laughs]

Doris: Excruciating

Doris, 68, has a clear slow voice. Although thoughtful, she has lost the thread of her narrative due to memory loss. She remembers that she's an alcoholic. She took pictures for this project but does not remember doing so. She does recognize a few of the people in the photographs from her assisted-living building and recalls that she was in the U.S. Army with her husband and that they lived in Vincenzo, Italy, for a while. She does not remember what she did in the Army. Her husband was physically abusive to her through their 10 years of marriage. She left him when her daughter was very young:

I didn't want to get killed. I asked him if he wanted to go to a marriage counselor, but he didn't respond to it. I said, "I've got to get out of here. I can't take this anymore"

because I don't want to go to jail for killing him, because I probably would have.

When asked if she has children and grandchildren, she answered that knows she has a daughter who does not see her and, Doris thinks, lives in California. She has pictures of her grandchildren, which, when she looks at, she feels "love."

Doris lives in the present. Her past is dim; she only remembers glimpses of the major outlines. She talks about her siblings but cannot remember which of her brothers is dead. Her sister comes to visit once a month. When asked how she feels about not seeing the rest of her family, she says, "It doesn't make me sad. I know I'll see them one day. I'll see them again one day." Doris's visual narrative contains photographs of her friends playing cards. She does not remember that she took them, or who they are, but studying them closely, she recognizes a few bits of furniture from the assisted-living house:

That looks like it might be Mary. Mary is one of the ladies I play cards with, one of my friends; that looks like her. I play cards with the ladies on the weekends; this is Sue. We

do it in the dining room. I wouldn't say I have a lot of friends, but I have friends. This must be in the assisted living. Yeah, the dining room. I took that picture? Wow. I took all these pictures?

She says that she enjoyed her time as a participant in the research and that it gave her self-confidence. Doris came to the group sessions and the interview with her friend Jessie, who is in her assisted-living house. On discussing her life at the assisted-living facility, she speaks of Jessie's temper.

Anyone that is mad, I just ignore them. I don't say anything to them. I figure they need to get their feelings expressed. It's best not to say anything to them, because it just makes them madder. No matter how much I might want to comfort them, it just makes them worse. I just leave them alone and let them get their anger out.

Doris does go to the doctor for her T2D but struggles to remember the words to describe how she feels about having T2D. She tries several times during the interview but gives up, saying she feels frustrated. After she puts her photographs in order, I ask her how it feels not to be able to remember. She answers firmly, "excruciating."

Chapter 5: Findings

Chronic illness experience is, by nature, shaped by daily experience. Moreover, the experience of an individual is shaped by the biopsychosocial environment in which they live. My research question was: how do these women make meaning of their experiences with T2D? The interview data resulted in six primary findings. I will illustrate the findings with verbatim text from the interviews, some of which have been seen in the previous chapter, as well as data from the relational maps and visual narratives created by the participants. The findings reflect complex lived experiences of these women with T2D. I have chosen to explore this data to demonstrate the complex and rich experiences that the narratives reflect.

The first finding states that the T2D experience can exacerbate stress in the lives of participants; while the majority show diabetes-related stress, others find mastery over the management with positive results. According to the second finding, T2D experience influences the generalized feeling of control in life or the lack thereof. As a sub finding, three participants expressed self-blame as a means of establishing a feeling of control. The third finding is that T2D concern fluctuates in the hierarchy of importance in the lives of participants in response to other social stressors. In the fourth finding, all participants use a variety of stress relievers, some conflicting with T2D management; in addition, participants engage in many other activities such as having pets, engaging in humor, exercising, and performing social activities that also relieve stress. The fifth finding is that significant childhood trauma had a role in T2D experience. Based on the sixth finding, all participants speak of God in their narratives, but the role that God plays is varied for each participant

Finding One: T2D Exacerbates Stress for Some Participants; Others Can Accommodate T2D into Their Lives

Stress can influence how one can cope with a chronic illness. For people with other social factors or illnesses, stress is potentially more complex. Among the 14 study participants, eight reported mental illness as a significant factor in their lives, out of which six reported being diagnosed with depression, and two reported being diagnosed as bipolar. The remaining six people did not mention being diagnosed with any mental illness. Furthermore, every person with depression said that their depression had become more severe since being diagnosed with T2D. Indeed, Shanda expressed that she did not have depression before T2D. She feels that her experience with T2D is an emotional burden, saying, “I have a lot of emotions. I’m going through those now, emotions.”

Distress at diagnosis. Five participants—Mia, Sylvia, Ruth, Shanda, and Cecilia—reported that their blood sugar was over 500 when they were diagnosed. They were surprised and distressed by the diagnosis though all reported a positive family history of T2D.

When they took my sugar, it was over 500 . . . I started crying. I say, “Why? Why me?” . . . But I don’t use sugar.” When I get home, I say [to my mother], “Why do you have to have diabetes and I have to get it?” I say, “Well, okay. I have to live with it the rest of my life.” *Mia.*

[I didn’t feel] great about the diagnosis because the only time [I went] to the hospital . . . was to deliver a baby and I was never that connected to hospitals . . . now, I have to stay connected to the medical world . . . I was healthy . . . when you are diagnosed, now you are connected, and you feel no way out. *Ruth.*

Years since diagnosis not relevant. The number of years since diagnosis does not guarantee confidence in T2D management among the participants. Years of experience with T2D alone does not gain an ability to cope with this disease; it requires something beyond time. Geneva and Barbara are confident about their T2D management and not overwhelmed by their illness. This contrasts with Lela, who has had T2D for 11 years, same as Geneva.

Geneva considers as assets what others may see as restrictions:

I didn't even know I was doin' the food pyramid. It's just how I ate . . . See, I think that's why I'm controlling the diabetes so well now. 'Cause, that wasn't a big thing!

Love vegetables, love fruits . . . I must be doin' the right thing! So, I really didn't give up anything I like to eat. It's just that I kept with my balanced portion sizes. *Geneva.*

While Geneva and Lela both have had T2D for 11 years and partial paralysis since childhood, their experience of T2D is very different. At the time of her interview, Lela had great difficulty in managing her T2D. Lela feels T2D robbed her of the confidence that had propelled her through life despite her partial paralysis:

I don't know if I have the confidence in myself to do it, but I *got to* do it . . . You gotta eat better than you do. Stop skipping your meals. You gotta take your medication that you should and stop skipping them when you feel like doing that. So, there are so many *gottas* in my life! *Lela.*

Lela was very particular about the order of her photographs. She was clear that she was exploring both her T2D and her physical disability regarding the effects of the rheumatoid fever. Her story of T2D was entwined with her physical disability and the surrounding trauma. She struggles to keep her hard-fought autonomy by staying mobile as shown with many photographs of her walking and at physical therapy (see Figure 2). She says, "You either had to make the

adjustment [in your life] or you will yourself to a life of uselessness and I knew I didn't . . . I just didn't want that." She recognizes a conflict in her narrative that she appears to accept her disability and work hard to combat it, but her experience with T2D is fraught.

Barbara has had T2D for 30 years. She does not remember much about her diagnosis, except that it was in Barbados and they gave her an insulin dosage pen. In common with the other participants, Barbara's motivation for being involved in this research is partly financial—due to the \$100 given on the completion of the research—and involves the desire to share what she has learned through her T2D experience with those who may be struggling.

The emerging finding involves that the stories of struggle and adjustment with T2D include empowerment through the adaptation of the illness into their lives. Lela, Cecilia, Jessie, Mercy, Mia, Ruth, Shanda, and Sylvia experience different but significant stories of struggle with T2D, which contrasts with Barbara, Geneva, Kara, Willow, and Gabrielle. The latter



Figure 2. Lela at physical therapy

participants feel powerful and proud at overcoming and putting the illness in its place. They demonstrate the ability to find shortcuts to make their illness experiences meaningful and gain ownership over their illness. They feel proud and accomplished in each step of overcoming their

obstacles. These participants speak of triumph over their experiences with T2D in very different ways and means of controlling the illness.

Issues of self-management. The self-management of T2D requires constant introspection and self-monitoring; all participants who showed distress demonstrated this fact in their narratives. Moreover, there is no room for a thoughtless bite of food, skipping meals or taking medication off schedule. This is shown in the relational map that Sylvia made in her journal before the interview (see Figure 3). She has hospital visits, eating right, exercise, and taking medication as the primary location in her map placement. In addition, her siblings and grandchildren are present in her relational map. Furthermore, she has had a troubled relationship with her siblings and children who were taken into foster care. She reflects that these social factors have a significant effect on her experience with T2D.

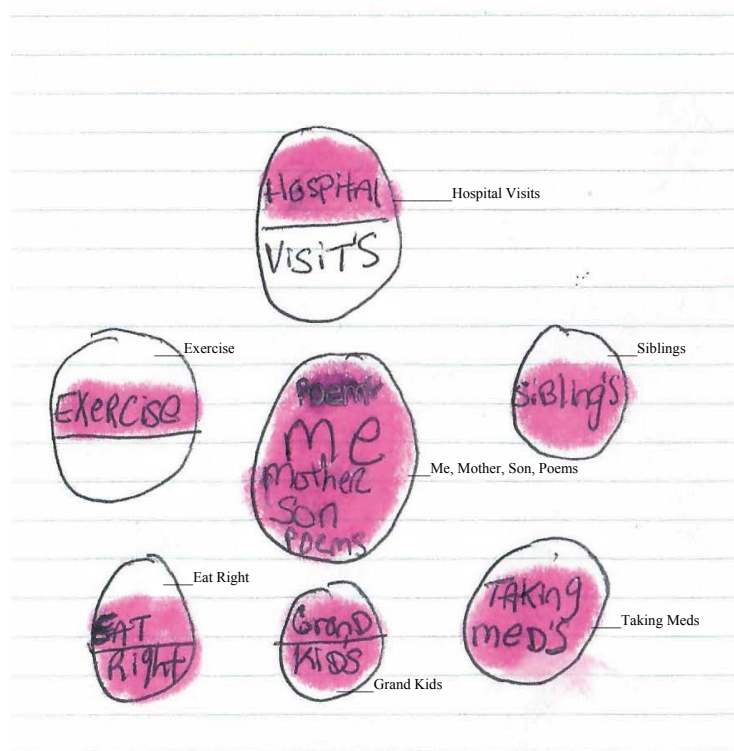


Figure 3. Sylvia’s relational map in her journal prior to the interview.

People with T2D test interview their blood two, three or more times a day. Mia explains that “Since I have [had] diabetes, my depression came on worse than how it was because sometimes I have to stick my finger four times a day. I now take in needles three times a day.” People with T2D test by lancing or piercing the skin of the fingertip and squeezing until it bleeds. The droplet of blood is put onto a small strip of testing paper and inserted into a monitor. The choice of blood sugar monitors is governed by one’s affluence and/or insurance.

For Mia, who has often relied on the traditional remedies of her native Trinidad, T2D has become an unbearable intrusion and disruption of who she is in her world:

The only thing I think of about myself is sticking myself every day . . . Diabetes have a lot to do with [my depression], because I am not the same . . . When I was in Trinidad, I was never sick. I was never . . . You imagine, diabetes changed my life a lot.

Sometimes, I just sit and cry. Alone, sometimes, I just sit and start to cry. *Mia.*

The sorrowful effect of T2D on her life is echoed in the coloring of the entire relational map in addition to the heavy coloring within the circles as shown in Figure 4. Religion and church played an important part of Mia’s life. She relates in her narrative that she no longer can attend church or participate in the choir, which is a great loss to Mia. In addition, she had to retire early from her work as a teaching assistant. As such, she exercises to help her depression, which has become much worse with her T2D. When Mia is depressed, she goes walking. She says that when her daughter realizes that she is out walking, she knows Mia is feeling depressed. While exercise may be a positive indicator for some, for Mia, it is a sign that things are going wrong.



Figure 4. Mia's relational map colored in to show the extent to which T2D affects her life.

Medication regime and doctor appointments. Ten participants reported that their medication regimes were burdensome and that they feel overwhelmed by the number of medical appointments. Ruth feels connected to the hospital through the many appointments she must keep. Gabrielle and Sylvia place the issue of appointments and medications large and weighted in their relational map that they made before their interviews (see Figure 3 as an example of Sylvia's relational map). Shanda says that her life is taken up by appointments: "I have a lot of doctors' appointments. I am very sick . . . I'm sick. Between a therapist, psychiatrist, the heart doctor, arthritis doctor, podiatry—got to keep the podiatry—and the PCP that's six."



Figure 5. Lela's medicine box.



Figure 6. Lela's pills on a table.

The use of medication is cited as an area of focus in some relational maps such as in Sylvia's, as shown in Figure 3 and in the photographs taken by participants. For example, the photograph in Figure 5 shows Lela's organization of her medications. Lela does try to keep them organized by having a special medicine box, but she mentions in her interview that remembering to take her medications is a central issue of her experience with T2D. She also included a photograph in Figure 6, which shows that her organization is not always effective with the pill bottles spilled on a table. Lela shows her difficulties with medications are shown with the desire to use both photographs in Figures 5 and 6.

I make sure that my medication is in order for selection by keeping it in a little [box], and that they're all in the same place. I used to use a pill case, but I don't anymore. I just make sure I have it in the mornings to come with me. Although that might be easier.

Lela.



Figure 7. Barbara's pre-dosed medications from her pharmacy.

Barbara's photograph shown in Figure 7 is different from that of Lela. She has managed to make the experience of taking her medications less burdensome by availing herself of the pharmacy that pre-packages her medication for no additional charge. Regarding the photograph of her medications, she says:

I wanted to show how compact things are and how easy it is to take my medication.

These are my morning pills. They come prefilled from the pharmacy. You know when you . . . open a bottle and the telephone rings, you can't remember if you took two or three or any . . . these are already prepackaged. The pills for the morning are yellow, in here at the back are the ones for the evening. They're all color-coded. *Barbara.*

Blood testing and insulin dosage. Only Barbara has a dosage pen and a talking meter. The remaining participants use a conventional meter with a visual readout and a traditional syringe. They must keep a supply of sterile syringes, put one inside a glass vial, withdraw an appropriate amount of clear liquid, and inject it into their tissue, often into their stomach fat. Participants such as Gabrielle expresses the fear involved:

When I finally did keep a doctor's appointment, I was told that along with taking Metformin, I would be put on insulin. This scared me a lot. I had a fear of needles. I knew, because my father and stepmother both were diabetics. *Gabrielle.*

Blood testing and taking insulin through needles was a concern for participants who used needles. The use of these medical devices feels intrusive and burdensome to the participants who do not have the same user-friendly devices. This is shown by the inclusion of the photograph taken by Lela (see Figure 8) where she demonstrates the finger prick to test for blood sugar.

Barbara expresses confidence in her T2D management. She has many tools to make her self-management easier. Moreover, she has good insurance and a much more positive



Figure 8. Lela demonstrates using a lancet to take blood sugar.

experience that she is eager to share in her visual narrative. This contrasts with Lela, Shanda, Sylvia, Ruth, Cecilia, Mercy, and Mia, who express many issues and struggles with their T2D

management. Barbara uses an insulin dosage pen, saying, “You dial it for the different doses; you can hear the clicks to tell you the dose.” In addition, Barbara has three daily sets of her medications in color-coded packages prepared by the pharmacy, for which her insurance pays in full. In Figure 9, Barbara groups her medicines, helpful books, insulin pens, and meter (see Figure 9). These aids have helped Barbara gain confidence; she expresses the desire to share this with others in an acknowledgment of the importance of her medications.



Figure 9. Barbara’s dosage pens and blood glucose meter.

Finding Two: T2D Experience Influences Generalized Feelings of Control in Life or the Lack Thereof

The study reveals that in their narratives, individuals who show the understanding of the ability to affect change also feel that they can limit the intrusion of T2D into their lives. Accordingly, eight of the participants express that they have little freedom to exert decision-making in their lives and illness. As Lela says, there are so many “gottas.”

Feelings of few choices. The majority of participants, eight of 14, expressed in their narratives that they feel they have few or limited choices in their lives, which is discussed in relation to their illness experiences. These participants express that there are few options in relation to food, diet, medications, and healthcare appointments. Two participants, Lela and Sylvia, illustrated feeling that their choices are limited.

Lela. Lela’s narrative illustrates a picture of a conflict about autonomy and ability to

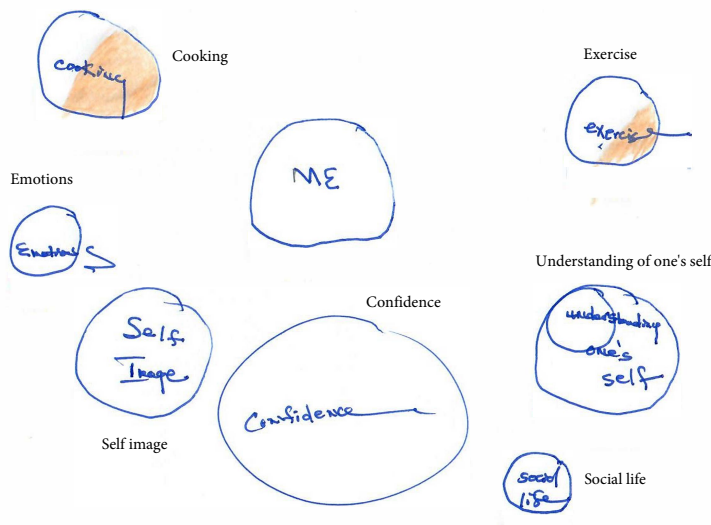


Figure 10. Lela explores her understanding of self in her relational map.

control events and outcomes in her life. She has had an active work life and continues to work as a volunteer at the age of 73. She speaks of the “gottas” in her life, by which she expresses a feeling of being frustrated that her life is not in her control since her T2D diagnosis:

It hurts because I don’t know if I have the confidence in myself to do it, but I *got to* get it . . . I have to muster myself somehow: [She speaks to herself] You gotta do better than you do. Stop skipping your meals. You gotta take your medication as you should. And not skipping them when you feel like doing that. So, there are so many gottas in my life.

Lela.

Lela feels that T2D has affected her life to the extent that she has lost confidence in making any choices in her life: “It affects me psychologically, emotionally, socially, physically, the whole gamut. It really does.” In Figure 10, Lela introduces the concepts of confidence, understanding of one’s self, self-image, and emotions in her relational map. In understanding of one’s self, Lela replaces a small circle with a larger circle to show the importance in her narrative of her T2D experience.

Lela expresses that she knows what she is “supposed” to do to look after herself, but she feels burdened by the *gottas* and feels frustrated and angry with herself:

If I do the right things, I won’t always be plagued with “Did you do this? Did you do that? Why didn’t you?” So, my emotions are all over the place because I know the right thing to do, and yet I don’t do it . . . I don’t have enough confidence in myself. *Lela.*

Sylvia. Sylvia’s life story depicts a sense of never feeling in control of events, with things being done to her: abandonment by her mother at the age of 15, denial of parental responsibility by the father of her child, homelessness with a baby at the age of 17, and the “24/7” beatings by the man with whom she still lives. Sylvia found out that she had T2D when she was admitted into the emergency room. She was so ill that she could not breathe. She was diagnosed with advanced T2D as well as heart and kidney failure. She did not understand the severity of her illness even when she was given her medication:

I asked them how long I had to take it for . . . that was the first time that I heard I had to take a medication for the rest of my life. I just knew again my life wasn’t going to be the same . . . I feel like, the sickness, it doesn’t get better . . . I wonder every day if I’m going to wake up though. That don’t get no better. *Sylvia.*

Sylvia’s belief that she cannot change her life is created by her life experience. She does not feel that she has many choices and that she is not in control of the events in her life, including her illness. In her relational map (see Figure 11), she circles the map and places a circle over the whole with God in control. She includes her missing father, her lost son, and late mother, saying that God controls and chooses for her:

I can’t make a choice, but God does that for you because God knows which one you could handle more, and God is always right . . . You get things that you have no choice but to accept . . . you don’t make many choices now once God takes over; you don’t have no choice now. You just have to accept it now. *Sylvia.*

The role of religion will be further explored in Finding Six.

Feelings of control. Four of the 14 participants expressed feelings of control. Barbara, Geneva, Willow, and Kara feel that they have control over their lives despite complications, loss,



Figure 11. Sylvia’s relational map showing God in control.

and other health issues. While their lives are far from easy, they feel authority over their lives, which gives them the confidence to cope with obstacles including T2D.

Geneva. Geneva's narrative is an example of someone confident in her belief that she can control the events in her life. She has known disability since contracting polio at the age of four. This ability to feel in control over events is demonstrated by her feeling that T2D is not a challenge:

I have diabetes on top of everything else, and because I'm positive about everything, so trust me, getting diabetes, it . . . it didn't really change my life. You're alive! So, you got life; make the best of it. Don't be sullen and whining about what—this happened and that happened. You're here! Be the best you can be and you can do. *Geneva.*

Geneva's early experience of polio is central to her life. Geneva explains this by placing her childhood experience of polio as the first photograph in her visual narrative (see Figure 12); she sent it to me saying that it was the most important photograph even though it was taken well before the research began. She says:

I was in an iron lung. I went in at age four and I got out when I was nine . . . because I'm positive about everything, so trust me, getting diabetes it didn't really change my life . . . being paralyzed, diabetes is nothing! Plus, there's always someone always worse off than you. *Geneva.*



Figure 12. Geneva in polio hospital.

Geneva speaks of her family support throughout her illness with polio. Her older sister came to teach her to read; her parents came daily and read to her from the newspaper. Even from her vulnerable position, she felt in control of her voice: “All I could do from the age of four, five, six, seven, was talk . . . I always had jobs that accommodated my disability.” This formative experience of illness shaped Geneva through confidence even when she was lying in an iron lung.

Barbara. Barbara demonstrates her feelings of control over her life by discussing her past experiences with feeling proud of her heritage and ability to manage T2D in a manner which makes her feel in control. Discussing possible future blindness, she uses a humorous approach to discuss a worrying subject. Although she speaks jokingly, she is concerned. “I’m just afraid if this one [operation] fails, I’m going to be totally blind. I don’t want to live with none of my sisters and I know they don’t want to live with me!” She speaks about her childhood in a white neighborhood; she tells stories of betrayal by white friends who were pressured in high school to distance themselves and stories of overt racism that she has combatted over her life. She says, “I’m proud; nobody had to tell me ‘I’m black and I’m proud’ because my father already told me

that.” Barbara’s decision to join the study is motivated by an altruistic desire to help others with T2D. She has had her issues; one time being hospitalized with blood sugar over 600. She now manages to keep it around 110–150. She uses many devices that enable her to keep well.

Willow. Willow has rheumatoid arthritis as well as T2D. She does not let either illness slow her down. She uses her electric wheelchair to travel and goes to many social events in her neighborhood. When she wants to go somewhere that her wheelchair cannot take her, she ably uses the services available to her, including taking rides for the disabled across the city. She also does not have time for people who feel sorry for themselves:

Just have to take one day at a time, just keep moving on . . . I don’t care as long as I can walk, talk, and see. Not walk, in the wheelchair. I’m not staying in the house, for what? To winnow away and die. You can’t let [illness] affect your life. You’ve got to just keep, like I say, moving. *Willow.*

Kara. Kara’s narrative shows an independent and strong person. Her attitude toward T2D is quite similar to Willow’s:

It doesn’t really get me down. Some people are like woe is me, but I still walk, I am not going to sit around and feel sorry for myself. It is more or less because I was a wrestler. You don’t baby your injuries, or you will never get well. *Kara.*

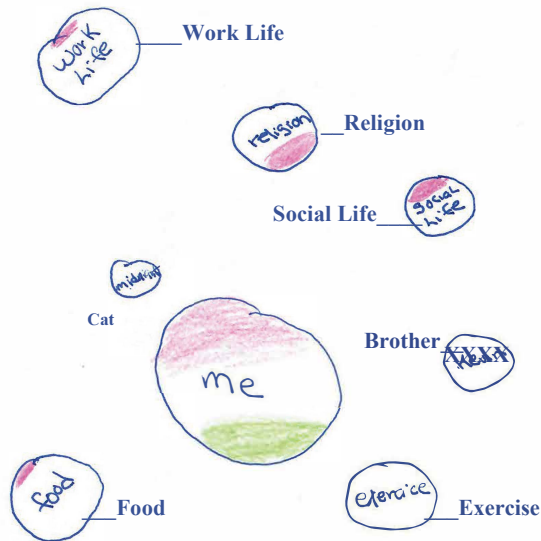


Figure 13. Kara's relational map with "me" emphasized and her cat close to self.

She wants to return to work because she feels that it helps her have an "outside world," otherwise she is a "homebody." She has strong opinions on many subjects, including the role God should play in people's lives: "God will take care of those who take care of themselves. When people get sick, they walk around saying, 'God help me,' when they are well, they are all high and mighty." Kara's relational map (see Figure 13) has several elements pictured as small and she chooses to make her circle of "me" the largest and the most colorful, suggesting that she is the center of her own life.

Finding Three: T2D Concern Fluctuates in the Hierarchy of Importance in the Lives of Participants in Response to Other Social Stressors

A social stressor can be defined as any specific source of psychosocial stress that "triggers stress response" (Schneiderman, Ironson, & Siegel, 2005, p. 607) and, which over time, can have deleterious effects on health. This could include a loss of job, trauma, violence, abuse, homelessness, or daily sources of stress such as racism, sexism, or stigma. Narratives of the participants often discuss feelings of stress, frustration, concerns about money, including current

unsafe situations or past experiences of abuse. These emotions are often expressed as intertwined with their illness experiences of T2D. When asked about their experiences of T2D, participants spoke of these feelings and experiences, including sexual and physical abuse and feelings of being unsafe. The diagnosis of a potentially fatal disease can be perceived as one of the many stressors to combat. This is reinforced by the statements of two participants of them not considering (in the past and present) T2D as serious. It is probable that the seriousness of T2D was expressed to them by their doctors and nutritionists at diagnosis and subsequent appointments, but T2D became one of many stressful situations or occurrences already present in their lives. I will illustrate this through the participants' discussion of common societal stressors:

Some people don't realize diabetes is really, really serious. I'm now finding out how serious it is. I didn't before. There should be more education on it too. There should be more signs going up, like they have signs on the buses, or a big billboard, so people could see how serious diabetes is. *Shanda.*

It made me look at diabetes as a serious issue, nothing to play with, so it was a real wake-up call . . . it helps for me to take it more seriously. I learned from other people who are managing well. *Ruth.*

Housing. Housing can be a stressor for the population from which the sample was drawn. Five participants have previously been in homeless shelters, or in the case of Cecilia, right after the interview, she became homeless. All the participants brought up their housing situations: either they had recently seen an improvement in their living situation and expressed great relief, or they were still stressed by their living situation. Lela and Willow moved from their old neighborhood to a new one because they needed disabled access. Doris and Jessie live in the same assisted living home. Jackie often fights with the staff and other residents of her

home. Mercy and Mia met at their elder/assisted living building and have made a home at their housing community by participating in running the kitchen. Geneva has finally found an apartment that gives her great joy. Barbara is in the same apartment that she shared with her husband of many years and has made it a colorful plant-filled space to share with her dog Dottie. Cecilia became homeless shortly after her interview. She has only one child who is under 18. She was forced out of her home of 15 years because her children “aged out,” thus no longer entitling her to a house accommodating a large family. She tells me at the interview that she hopes to be able to sleep on her aunt’s couch. She also hopes to be able to keep her cell phone, which is not a luxury when one is homeless with a child aged 14.

I lived in this place for 15 years, and now I have to move out . . . I have Section 8 and just the point of finding someplace that will take it is going to prove very difficult. The Housing Authority just let the landlord collect the money and these houses are not up to code . . . I love that house . . . I don’t want to move too far away from my doctors.

Cecilia.

Shanda has struggled with housing for most of her adult life. She looks forward to being 62 years old because she says that that many elder living homes allow entry at that age. Since fleeing from an abusive relationship, she has been in a homeless shelter, an apartment building in a violent neighborhood, an assisted living home for the elderly and disabled, and now a halfway house. The dangerous neighborhood where she lived for 15 years caused a rift in her family:

They wouldn’t dare come over there where I lived because my oldest daughter was there one day when somebody got shot and he went on her car. She said, “Never again. I’m not even bringing my kids down here.” I stayed there for around 15 years . . . They’re

still having problems over there. A little girl got killed; a young kid got shot the other day. *Shanda*.

Shanda lives in a house for people who have been homeless or are at risk. She feels disrespected by the monitoring she has in this living situation:

I didn't reach 61 years old to go to a place that you have to tell me when I can have company and when I can't have company, when I can spend the night out and when I can't spend the night out. I'm 61 years old. I told the director, "I've got one foot in the grave and one foot out the grave. I'm not doing this." That's what I told him. *Shanda*.

Confusion about and cost of food. The availability and cost of healthful food are a daily struggle for all the participants who do not live in a facility where food is provided. Even Jessie's case, the food is provided but is not always compliant with her diet, frustrates and angers her, as for instance, when she threw the cup of pudding at a staff member. Every visual narrative had photographs of food. Participants express both confusion about a healthy diet and frustration over what they can buy with their financial restraints. Participants all discussed the management

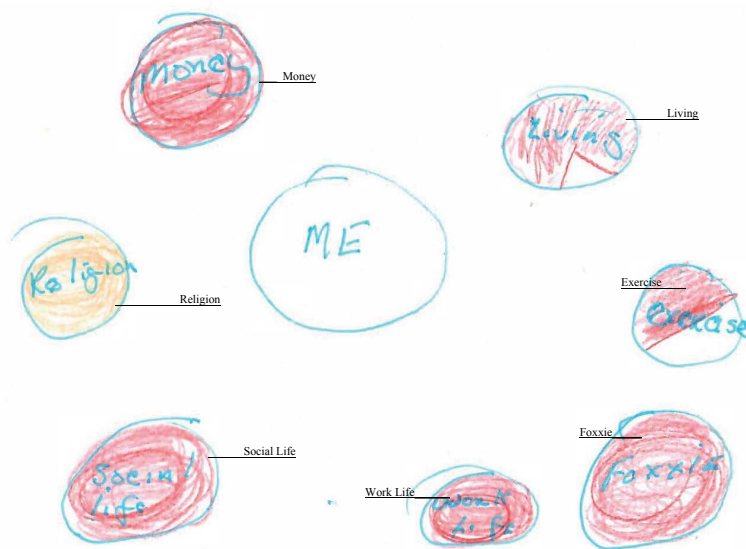


Figure 14. Barbara's relational map emphasizing issues with money and loss of work-life.

of their budgets during the interview; six gave money a prominent position in their relational maps.

Ruth, Leda, Gabrielle, and Barbara specifically spoke about the trouble they had managing within their budgets. Barbara uses a strong color and deep coloring of money and loss of work life in her relational map (see Figure 14) as well as in her narrative interview, but she is proud of her ability to find a bargain. Ruth discussed her difficulties of living on SNAP. All the participants commented on the difficulty of making decisions about how to spend their limited resources and the complexity of shopping wisely. Ruth comments on how she must travel to many stores and shop around to find the best deals:

I used to go to Market Basket; it used to be cheaper, but I went to Stop & Shop and it appears to me that Stop & Shop appears to me to be a little cheaper. . . . I'm on SSI [Supplemental Security Insurance], and I receive about \$800 a month, but by the time you pay the bills and rent, there's not a whole lot left to get you through the month. *Ruth.*

Of the 14 participants, ten prepare food themselves, of which eight stated that they used food pantries. Ruth has struggled to make ends meet financially and has tried several food banks in her area:

They don't check the cans to see if they are out of date. So, one time, I came home and opened a can and just think if I did not have my nose because it looked OK, but it smelled rotten. And I refuse to put poison in my body. I just refuse. *Ruth.*

Gabrielle tries to purchase and cook proper food for her T2D diet, but there are stressors and complications. When discussing the importance of reading the nutritional label to see if the food is compliant with T2D diet before purchasing an item, she says, "Yeah. You still gotta buy what you can afford. That's the way you keep food in the house. You got to buy what you can

afford to eat; it’s just terrible.” Gabrielle lives with people who do not have T2D, so she must consider cooking a meal for herself as well as the people who may be on a less restrictive diet: “It’s very complicated, trying to make two different meals at one time.” All of the participants in this study experienced a multitude of stressors; how they mediate this stress varies. Some mediation is a concern for the participants as it is not always considered a healthy choice. Gabrielle speaks of “trying to eat healthy” in her relational map that she made before the interview (see Figure 15). In the interview, she spoke of the importance of starting a pantry in her church.

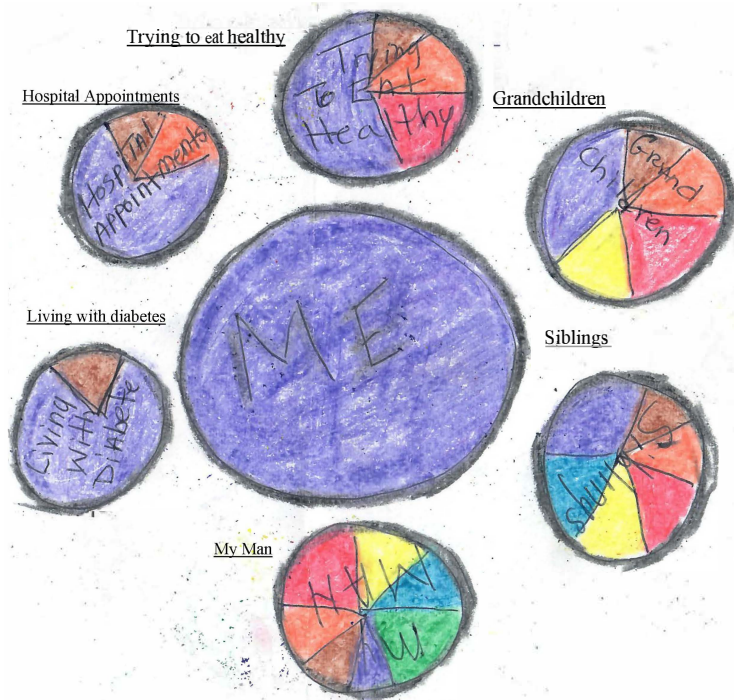


Figure 15. Gabrielle’s relational map made in the journal before the interview.

Finding Four: Participants Use a Variety of Stress Relievers

A common belief that bad habits can be broken with effort and willpower is rejected by all the participants, as they view the aforementioned as a necessary relief for their persistently

stressful lives. They use food that they feel are off-plan by the nutritionists and, in some cases, cigarettes, drugs, or alcohol as an adaptation to manage the stress they feel is all-pervasive in their lives. The prominent meaning of food and its often-problematic role in the lived experience of these participants is shown in the many photographs of food and the prominent location of food, cooking, eating well, smoking, and drinking in their relational maps. Stress relieving food is often out of bounds for many participants, from the diet that they have been prescribed by the nutritionists. When they speak of using these mediators, they often use language such as “need” or “have to” in relation to these stress relievers.

Food as stress relief. Cecilia spoke often about her feeling dependent on fast food and sugary soda. In addition, she also struggles with the temptation to use cocaine and alcohol. When she feels stressed, she eats fast food instead of reaching for drugs and alcohol from her past. She tries to eat well and healthfully, but she often reacts to the stresses around her by turning to the friendly yellow arches of McDonald’s:

I struggle with that every day, so that’s a big one . . . when I get mad, it affects my diabetes. I don’t take my medicine and I don’t take care of myself; I don’t know why; I’m not hurting anyone but [myself]. *Cecilia.*

Mercy was in foster homes for her entire childhood. She says, “It was sad. I’ve been beaten. I’ve been raped. It’s very sad. I can’t believe that I’m here.” When she started to exercise and lift weights to relieve the stress of her bipolar disorder, she says, “I felt like a human being. I felt life was worth living . . . It was wonderful. I was happy. Life was good.” After a serious fall from a ladder, Mercy’s injury, and her experience with T2D got out of control and her weight “ballooned.” She is 5’1” and weighed over 260 pounds. The one constant in Mercy’s life was candy. She always had candy nearby and popped one piece after another in her mouth. A gastric

band operation helped Mercy lose over 100 pounds. She cannot eat very much, but she does eat candy. She says she needs it, and although she does not know why, it comforts her: “I have to have candy. I don’t know why, but I have to eat my candy. I can’t do without it. Now I don’t have any candy, and I’m dying. I’m really dying.”

Shanda and Ruth both believe that they should make a change in their diets. The major issue for Ruth is her consumption of sugary cola. The desire for sugary sodas is a common refrain among the participants in the group activities, but this is especially true for Ruth who placed a bottle of diet Pepsi under a lamp in her home to take a photograph for her visual narrative (see Figure 16):

This is a picture of the Diet Pepsi that I’m starting to struggle with. I really tried to like it, but it was hard because it’s a bitter taste, and it takes the fun out of it. I bought it, but I won’t buy it again. I could try Diet Coke; my mother liked Diet Coke a lot. *Ruth.*



Figure 16. Ruth struggles with diet soda.

Although only four participants specifically refer to ice cream as a stress reliever in their interviews, it was often a topic of conversation in the participant groups. When Geneva suggests

they could have low-fat and sugar-free ice cream, Leda, Ruth, and Shanda say that they have tried it but it does not satisfy what they need. The rush of glucose and fat is a relief of stress for these participants even if they believe it is bad for their T2D:

Like I said, that can of soda, I really shouldn't have. I had it because I wanted something sweet . . . Yeah, especially ice cream. I haven't had none in a couple of weeks. That's a plus for me. *Shanda.*

For all of the participants, “forbidden” items are consumed in periods of exacerbated stress as a means to control what often feels out of control.

When I get mad and upset, it affects my diabetes. I don't take my medicine and I don't take care of myself like I should. I don't know why . . . Some days, I do want to die, but I still have this last kid to care for and I want to see my grandkids grow up. *Cecilia.*

Cecilia is being evicted from her home of 15 years, her child is in an unsafe environment, and any of the myriads of stressors that exist in her life—present and past—might lead her back to cocaine; instead, she eats french fries.

Smoking cigarettes as a stress mediator. Six participants are cigarette smokers who have expressed a desire and intent to quit smoking. Shanda put smoking in a prominent place in her relational maps. Two additional participants are former smokers, and I have no knowledge about the others in relation to cigarettes. The participants who smoke cigarettes all state that they smoke due to stress:

And then my children had different little issues and stress factors and I started smokin' again . . . [My daughter had] throat cancer, they discovered that she had brain—two aneurysms . . . now, after all of that, she got this abusive guy . . . who threw glass all in

her face and harassed her . . . he's in jail now . . . before he went to jail, before she died with her kids [before she is killed along with her kids]. *Geneva.*

As stated previously, Shanda lives in a halfway house where smoking is common. She puts smoking prominently in her relational map in Figure 17. Although she had planned on quitting smoking with her sister as a Thanksgiving pact, her sister died suddenly of a heart attack the day before the interview. Shanda hopes to continue to honor the pact, saying, "I'm going to keep the bet. Even though she's not here, I know she's listening to me. She's here. I'm dealing."

Further, she says that her reasons for continuing to smoke are both emotional and financial:

Stress and being around other people that smoke; boredom. Those are the three and plus what I just went through. That was the fourth, my sister [who died] . . . [The doctor will] probably try to put me on the patch, but I'm saying who will pay for the patch? That's the problem. Even my copayment . . . If the patch was like a dollar, fine. It isn't a dollar.

Shanda.

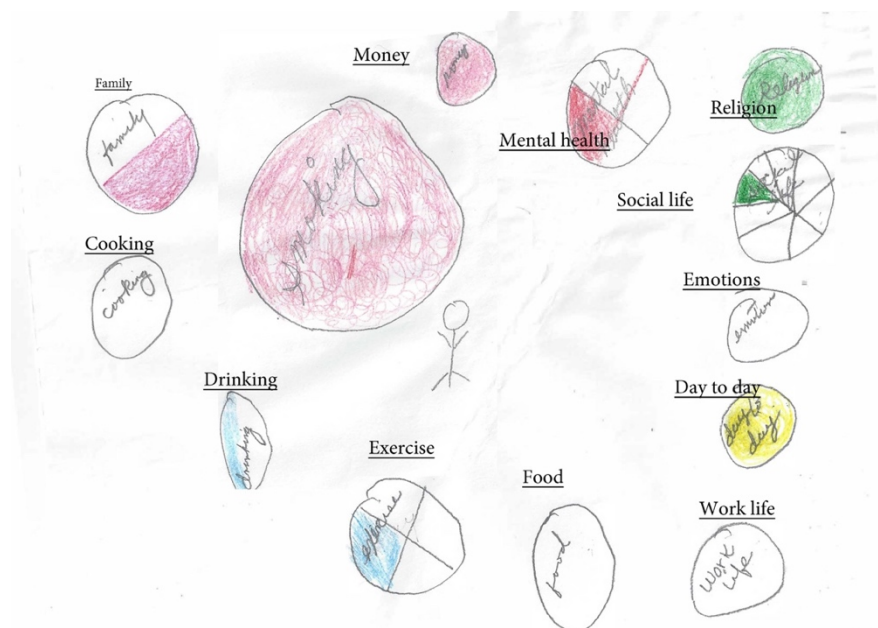


Figure 17. Shanda's relational map with smoking as the largest factor.

The difficulty in breaking the cigarette smoking habit is also expressed by Ruth, who uses a cup of tea and a cigarette to moderate her stress levels: “I know people who were on heroin went into recovery and they don’t use heroin, don’t drink, but they still can’t give up coffee and cigarettes.”

Alcohol and drugs as stress mediators. Six of the participants disclosed that they had a past addiction to alcohol and/or drug abuse. This is important for several reasons. While eight participants did not discuss past drug and alcohol abuse, the fact that this is disclosed by six participants in an interview about T2D shows that the pressure of drugs and alcohol have a large impact on their experiences with T2D. Secondly, these participants have the additional pressure of the struggle with past addiction or abuse on top of other issues while dealing with T2D. When these individuals have a stressful experience, they contend with the temptation to relieve stress with what is perceived as “forbidden” food but with the possibility that they will relieve the stress with a return to drugs and alcohol.

It is unclear from Sylvia’s narrative when exactly she started using cocaine. This narrative confusion may be because her son who died of leukemia is named Michel, as is the boyfriend who physically abused her “24/7.” She says her sister offered her cocaine to help her with her stress “over Michel.” In either case, Sylvia was offered cocaine as a stress mediator. She was told that it would make her forget all her problems for as long as she wanted:

“You’re going to have no more problems. All your problems will go away.” Then I felt myself just being taken away by the drugs. I still have a temptation to do so . . . right now, I’m working on quitting smoking cigarettes right now. *Sylvia.*

Cecilia, one of the four the participants who discussed a past addiction to crack, expressed the daily struggle in her narrative:

I am still fighting sobriety . . . sometimes, I think if I go back that way, I will feel better, but the problem will still be here even if I smoke crack. I wish I could take three days at a time, but I have to take one day at a time. *Cecilia.*

When she refers to the demons, it is often clear she is speaking of addiction, while other times, it seems as if she is speaking about the other stresses in her life: “I fought a lot of battles and a lot of demons and I’m still fighting them. It seems like it goes good for a minute and then things go bad and the demons come back.” Cecilia is one of three participants whose children went into foster care because the mothers were deemed responsible for putting the children at risk when the children were found as victims of sexual assault. Cecilia and her daughter have a fraught relationship that causes Cecilia great stress and guilt. She struggles with demons in the present such as homelessness; demons from the past such as the death of her first child, whom Cecilia had at the age of 12; demons from the past that persist into the future such as her current abusive relationships and her daughter’s anger.

Shanda never explicitly states that she was addicted to drugs. She does, however, obliquely allude to an issue with drugs in her past:

If all this stuff had to happened to me, five, six years ago, I would be out there using drugs. Simple fact is, when you use drugs, for me is it will cover all the pain that I was going through. I find out that the disease gets even worse. Every time you relapse, it gets worse. *Shanda.*

Anger as a stress mediator. Two of the participants use anger to release stress. In Jessie’s case, it is used as a steam valve; Kara uses it as a means to gain control in a stressful life. Throughout her narrative, Jessie discusses her issues with anger while denying that she has anger

issues. Her friend Doris lives on the same floor of the assisted living house. Doris talks about her relationship with Jessie:

Anyone's that mad, I just ignore them. I don't say anything to them. I figure they need to get their feelings expressed. It's best not to say anything to them, because it'll just make them madder. No matter how much I might want to comfort them, it just makes them worse. I just leave them alone and let them get their anger out. *Doris*

Jessie's energy is frenetic and her speech hard to follow. She has communication issues. She admits to her anger but justifies it with the frustrations of not being understood. Jessie placed a butterscotch pudding in the middle of her situated selfie. As she explained, the pudding was an example of what she should not eat. In telling the story, she expresses her stress about the lack of catering to her T2D-compliant diet at the assisted living facility. She tried to explain this to the catering staff, but the frustration was expressed through anger and she threw the pudding at the staff member. Jessie says in her narrative that she is an alcoholic; for her, her addiction to drinking and its effects are linked. She has had a stroke as a result of her drinking, which has caused issues with communication and which caused her anger. When she talks about throwing the pudding, she is not repentant but feels justified in her angry response. In her relational map (see Figure 18), she has written drinking but has not filled it in. She refers to drinking as her "nemesis . . . that could kill me. I'm not going to announce it, tell the truth and shame the devil." I ask her why she does not color it in all the way and she says,

Oh no. I have been going to meetings . . . that put a lid on it, yeah, it is hard, but it beats the tubes up your nose and dying, and kidneys, and the liver . . . I go to NA [Narcotics Anonymous] meetings . . . because a drug is a drug. *Jessie*

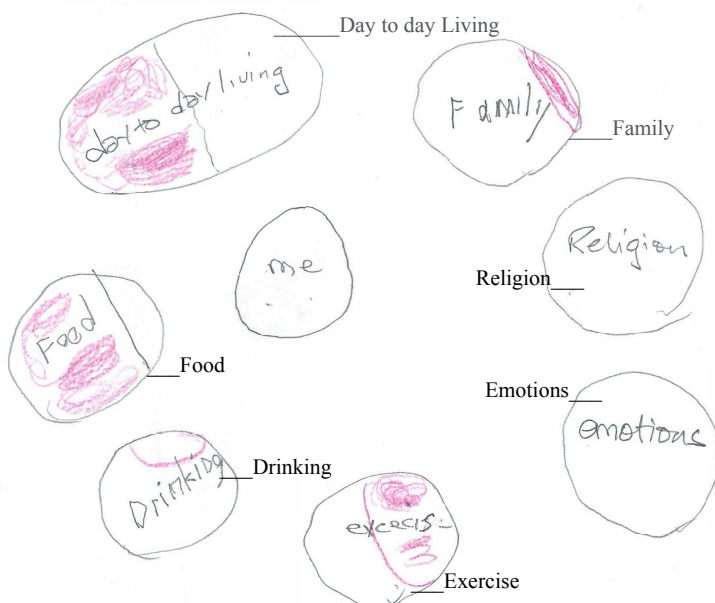


Figure 18. Jessie’s relational map.

Kara’s anger issues are expressed covertly rather than explicitly. As she says, she has “pet peeves.” When Kara talks about the auxiliary medical people in her life, she implies controlled anger with phrases such as, “Why should I waste my time?” or “It’s a no-no.” She is quite explicit about her anger towards her case manager:

She’s useless. She doesn’t realize she’s getting dismissed. She supposed to be doing things, like when I need a ride she should put in the paperwork if I have an appointment at 9 o’clock, I don’t need you to come at 9:05 because that’s not going to work. . . .

That’s your job, not mine. If I have to follow up on things, I don’t need you. *Kara*

Kara has strong opinions about many things. She expresses annoyance about things that occur every day, such as riding the bus:

I’m the type of person that’s you know, if I’m on the bus for handicapped/disabled/seniors, and for some reason, people bring a baby carriage and they

assume automatically that they can take a full seat in the front I'm like, I'm not getting up. I have a senior pass. I'm not getting up. *Kara*

Comparing the use of anger with her high pain tolerance levels, she implies that both are methods of controlling aspects of her life.

Other stress mediators that do not conflict with T2D: pets, humor, exercise, and social activities. Participants also use other mediators that do not conflict with the management of their T2D as defined by the medical community.

Pets. Pets, owned by five participants, provide a great deal of happiness, stress relief, and support. These participants inserted pictures of their pets in their visual narrative, demonstrating how important their pets were to their lives and health (see Figures 19, 20, and 21). Three participants have cats, a valuable stress mediator for them:

This is my [cat] Patience. And as you can see, she lays next to me. . . . And at night she sleeps right on the pillow next to me in the bed. I can feel---and if I move my back, she comes around and she looks like this in my face to make sure I'm breathing. *Geneva.*

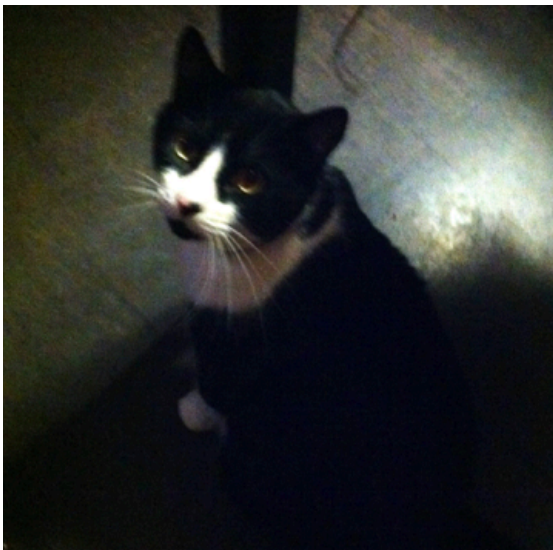


Figure 19. Mercy's cat.



Figure 20. Geneva's cat.

My cat is my life. I love it to death . . . He's always all over me . . . It feels wonderful to have them because they're comfort. They sleep with me. Like I said, they're all over me. When I open the door, they're right there, right at the door. They're waiting for me, waiting for me to come home. It's a good feeling. *Mercy*

Kara says about her cat: "she's human, she's like human when it gets dark, she's on curfew, she knows she's gotta go home. She's a very smart cat. That's why I do spoil her."



Figure 21. Kara's cat.

Kara says, “I’m a homebody. I don’t really like to be bothered with people. . . I have a lot of rituals and pet peeves. I never was a crowd person.” Her cat is central to her life and happiness. Her cat is placed as close as possible to herself in her relational map (see Figure 13).

Humor. Barbara and Geneva use a sense of humor to help them accept the ups and downs in their lives. Many people have social activities that seem to help them with stress, either orchestrated, such as Ruth’s Bible study and Barbara’s exercise class, or more casual, such as Kara walking in parks and chatting with friends; the role of religion in general will be discussed in Finding 6. Barbara uses all three of these mediators:

I’m just afraid if this [operation] fails I’m going to be totally blind. I don’t want to live with none of my sisters and I know they don’t want to live with me! I can talk to Him when I can’t talk to anybody else. They say He answers you, but I’ve been waiting.

Barbara

It’s been three years because it was just before Paul died. There is a group of people from the Tubman house, there’s a bunch of seniors that take [aqua aerobics classes] over there. [The senior center] pick them up and drop them off. *Barbara*

Dottie is very bright. She used to do her business on the newspaper and when I got the mat, she just went over and immediately did it. She’s very important to me. *Barbara*

Exercise. Exercise is another stress reliever for some like Barbara, who likes to do aqua aerobics in a group of other women her age. Others like Kara love to walk from one neighborhood to another or walk with their grandchildren, like Geneva. For still others, the goal and need to exercise can add stress as well. For example, both Shanda and Gabrielle state the goal but cannot walk for extended periods because they smoke and run out of breath. They know they should quit smoking and get moving but struggle to achieve this goal. Ruth likes to walk

because she has a rule that she does not smoke outside while she is walking, thus accomplishing two of her goals at once. For Mia, exercise is a sign to her friends and family that depression is coming. While many participants put exercise in their relational maps, it has a different meaning for each.

Social activities. All participants speak about their families. In the cases of those who have grandchildren, this familial relationship is part of what makes life worth living. Others engage in social activities, such as group exercise for the elderly, Bible study, or participating in events in their neighborhoods. All the participants who have grandchildren included many photos of them in visual narratives of their T2D. In most cases, they provide stress relief. In cases of familial separation, such as Cecilia and Sylvia, there is a great deal of longing and desire to be closer. Social activities are also important, be they organized and purposeful such as aqua aerobics or Bible study, or ad hoc, such as events in the local squares and parks. These social events create connections that are vital to control stress.

When the participants do choose to take what is perceived as “forbidden” foods or cigarettes, it is not arbitrary. The discussions around these choices are not spoken of lightly; they smoke a cigarette when they “have to,” or they “need to have something sweet.” Cecilia says she lives her days one at a time; the cravings for cocaine and alcohol are real demons for her. The choice to eat ice cream or french fries is necessary to cope with the stress each day and night bring to her. She chooses to eat those foods instead of drinking alcohol or smoking cocaine. All the participants use a variety of stress relievers to cope with stress-filled lives. While many spoke of “forbidden” foods, they did so in ways that show they are used necessarily to deal with stress or prevent themselves from doing something that has more serious consequences.

Finding Five: Significant Childhood Trauma Plays a Role in Coping with T2D

All the participants in the study spoke of some trauma in their lives, but seven spoke at length and in detail about personal trauma. For the purposes of analysis, I am categorizing childhood trauma as a sustained period of trauma as a child, significant because they spoke of it at length in their narrative. Seven participants easily fit into this category. The significant childhood trauma could be regular beatings by a mother, loss of a parent, a life-altering childhood illness, or sexual abuse. Of the seven women who reported significant childhood trauma, four had the most difficulty and distress dealing with their T2D, while three spoke of overcoming past trauma in their narratives.

Mercy. Mercy spent her entire life in the state childcare system; her life is marked by violence and assault. She cannot believe she is still alive after being beaten and sexually abused regularly from an early age. Her mother was institutionalized for an intellectual disability shortly after Mercy was born. When Mercy had her first child, she was diagnosed as bipolar; she says she was not sick beforehand. She had three daughters with her husband, but he was never supportive of her illness and refused to be involved in her mental health treatment. Even though Mercy had gastric bypass surgery and lost over 100 lb., she still had very high blood sugar. She eats candy all the time. As soon as she finishes a piece, she searches her bag for another. When she talks about it in the interview, she says that she has needed to constantly eat candy since she was a child. In her interview, she came close to linking the candy she eats constantly and coping with her past childhood trauma. When I saw her in the last meeting, she said she had cut way down on the candy after our interview.

Lela. Lela contracted rheumatoid fever at the age of 12. She had lost her mother when she was three, although she was never told exactly how she died. On reflection, she said she

thought her mother probably died of some complication of childbirth, because she lost a baby sibling at the same time. Lela was raised by her aunt and uncle, both of whom she describes as very busy with other things. For Lela, the loss of her mother and sibling, her paralysis, and the lack of family support, all combined and were perceived as a sustained trauma. By the end of the interview, Lela determined that her difficulty dealing with T2D was entwined with her early experience with rheumatoid fever and she decided she should see a therapist to talk about the issue.

Sylvia. Sylvia was abandoned by her mother at the age of 15. Her father had previously abandoned his family. She had a troubled relationship with her boyfriend Michel and she slept with another man. She became pregnant with his child, thus enraging Michel, who subsequently physically abused her “24/7.” It is with some trepidation that Sylvia admits this is the same man she is with today, adding “I ain’t gonna lie.”



Figure 22. Sylvia introduces herself.

By the time Sylvia was diagnosed with T2D, she was so ill that she had heart and kidney failure. Up to that point, she did not know that she was physically ill; any feelings of illness were attributed to her stressful daily life. When she expresses this out loud, she realizes what she has endured. She continues to write poetry about the physical abuse she has endured with

Michel. Sylvia mentions the word “trust” in her interview and her poetry seven times. She elaborates that it is hard for her to meet and trust people after all that has happened in her life. In her visual narrative, Sylvia meets two people, introduces herself, and asks to take photos. She later says that this was a unique experience for her. She says to one man, “Can I shake your hand?” She then says, “I grew a lot of confidence. I remember that day. It was really nice” (see Figure 22).

Cecilia. Cecilia asked me to write her relational map for her as she feels uncomfortable with spelling (see Figure 23). She emphasized issues with money, self-identity, and family.

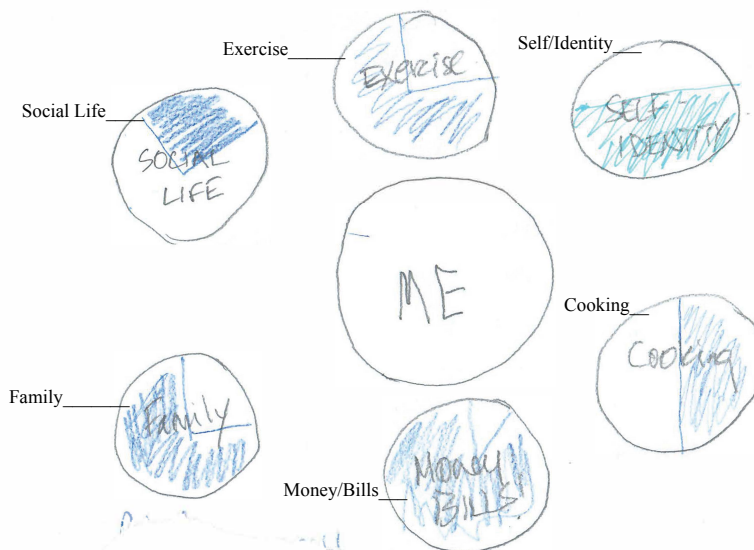


Figure 23. Cecilia’s relational map with emphasis on money, family, and self-identity.

These issues are combined in her troubled relationship with the father of her last child. He uses money to control her. He is the first of the men in her life who did not physically abuse her, but she had recently concluded that controlling her through money was also abuse.

Cecilia’s T2D diagnosis did not happen until she was 42 years old; she is now 50. She says she wishes she had found out when she was 35 years old; she could have handled it better

when she was younger. In her relational map, she places self-identity in a position of prominence. She says, “since diabetes, self-image, and identity have been a problem for me.” T2D was not discussed in her family, but she recognizes that several people probably had T2D. She lost her mother at the age of four and never met her father. Cecilia does not describe her sexual relationship with an older man at the age of 12 as child abuse; she describes it as her “first experience having sex.” Cecilia became pregnant and lost that child. She says, “I’ve only had four relationships in my life and every one of them was abusive. I’ve had kids by them all.” When talking about her diet after being diagnosed with T2D, she comments, “I don’t think I have . . . I’m not very understanding about myself. Including my self-image.” She talks about the grandmother who raised her, who appears in her visual narrative, “She passed three years ago; but I was close to her, she raised me. Since T2D, self-image, and identity have been a problem for me.” Cecilia says that she has trouble coping with her stress and self-image and identity since she was diagnosed with T2D. Her narrative recounts her past trauma as a significant part of her experience with T2D. She feels lost and has a poor self-image. For her, T2D and its self-management is the one thing that puts her stress beyond coping.

Gabrielle. Gabrielle and Sylvia are sisters, but they did not share the same experience growing up. Their mother gave birth to 15 children, of whom 10 survived into adulthood. There were several children between Gabrielle and Sylvia. Gabrielle implies that her mother had some degree of instability and says that, like Gabrielle, her mother was sexually abused as a child. When her mother was pregnant with Sylvia and her twin sister, she was often in the hospital and the mother and two girls nearly died. While her mother was in the hospital, Gabrielle was sexually molested by her stepfather, who had raised her from the age of six months. Gabrielle says now that not forgiving him was instrumental to her drug addiction. She recounts the story

of finally bringing her ex-husband to justice. He sexually abused both his own daughter and granddaughter. Gabrielle had hoped that she would find justice for her daughter and granddaughter through the criminal justice system after the injustice of her sexual abuse by her stepfather.

In addition to surviving sexual abuse from the age of seven to nine, Gabrielle and her family were hungry and cold:

I remember as a kid, we were hungry a lot. Had no clothes, hand-me-downs. I remember going to school with my stepfather's socks and my mother's bedroom slippers in the wintertime. *Gabrielle*

She says that she now always has plenty of food in the house because of that experience. She struggles with her weight and feels she cannot exercise because of her smoking. She has many co-morbidities that cause complications with her medication regime. She recently had to change medication for her T2D because it conflicted with her heart medication. As a result, her blood sugar is now less controlled.

Kara. Kara was often beaten by her mother but speaks of it without emotion. She describes one experience as of greater importance, being hit over the head with a frying pan and of the surprise on her mother's face when Kara was not dead. Kara says she does not feel pain like other people. She speaks of this as an advantage when she chose to go into wrestling as a career. Kara feels just as strong about her management of T2D. She says of T2D management:

That's why T2D is something that I just live with; I've done things that most people haven't. . . . I know my body well enough to know the cans and the can'ts . . . I deal with my T2D, I do what I have to do because I mean if you don't take care of yourself, ain't nobody going to take care of you. . . . T2D is just another challenge.

Her unconventional approach to her life and T2D is formulated by childhood trauma that she has re-storied as a strengthening experience.

Finding Six: Religious Belief is Spoken of by All Participants, but God Plays Varied Roles

All 14 participants talk about God. The link between speaking about God and involvement in social religious groups varies from participant to participant. Doris and Jessie's difficulties in narrative coherence do not preclude them from speaking about God. In fact, Jessie includes a photograph of a book given to her by the Seventh-day Adventists in her situated selfie. She does have several religious social outlets but does not mention attending any specific church.

Geneva often evokes God in such phrases such as, "God put me in the right spot," meaning her apartment opens onto a plaza where she can sit and smoke and chat to people as they go by. Geneva speaks about her supportive parents and the great deal of influence they had on her. She also says that they told her as a child that "When you with Jesus you don't gotta worry about nothin' else." She adds that she has kept up with this belief: "I still work like that. So that helped me with all these things," as she refers to the various challenges, including T2D. Geneva and Barbara are confident about their T2D management but do not say explicitly that their personal relationship with God or Jesus is significant in helping them with it. Their relationship to God or Jesus is part of a matrix of support in their lives.

Social religious groups. While involvement in a social religious group can offer support, it does not necessarily mean that they feel confident about their T2D management. Ruth speaks about God, reads the Bible at home, and attends a Bible study group led by Pastor John, who she says is "very supportive." She has few friends beyond her Bible study group and relies on it for support and new ideas, saying that she has recently learned about meditation. Despite

the support that she feels from Pastor John and the Bible study group, Ruth still struggles with her T2D management; she has returned to drinking sugary soda.

Shanda talks about attending a local church, initially going there to eat, “sausage, eggs and toast. That’s a treat for us.” She made a personal connection to a pastor there, as she was someone Shanda grew up with, saying, “That’s strong for me.” She also invokes God in her Alcoholics Anonymous treatment. She has the serenity prayer on her wall, saying that it reminds her, “don’t mess up.”

Mia used to attend a church but now expresses how she is too tired to go because of her illness:

When I don’t go to church, I feel different. I feel like I’m missing something if I don’t go to church. When I go to church, I come back and say, “I feel like a weight has been lifted off my shoulders.” [But] when Sunday morning come, you know what? I don’t feel like going to church this morning. I will lay down. I feel tired. *Mia*

Religion is important to Mia as she used to be a missionary. She used to sing in the choir, but now her frequent urination makes going to rehearsals difficult.

Mercy belongs to a neighborhood church and speaks about her relationship with God as a very demanding one:

Jesus has to be number one before anything, and everything else is second. He has to be first. He’s a jealous God. I have to put him first and I do. I have my Bible and because I have a bad memory, I have to write everything in the Bible, to put everything in the Bible so that’s what I do. *Mercy*

God chooses. Sylvia’s relational map (see Figure 11) is a clear indication of her understanding of God as omnipotent, as she places a circle around her relational map indicating

God's governance. Sylvia feels that God makes choices for her. She says, "There is one God, and that God is someone we're going to have to answer to." She feels that God is the one who makes the choices in her life: "you don't make those choices, once God takes over, well, you don't have no choice now. You just have to accept it." Her understanding of God is one in which God gives and takes away in equal measure. The loss of her son and the abuse of her daughter lead her to believe that there was a purpose to all the tragedy in her life:

God doesn't give you no more than you can handle. Apparently, God felt that I can handle losing my son. . . . I can't make a choice, but God does that for you because God knows which one you can handle more, and God is always right. *Sylvia*

You have to pay. Lela expresses conflict and self-blame in her narrative. She expresses difficulty in her T2D management as well as in coping with the paralysis that she has had for 60 years. In discussing her illness narrative, Lela talks about her church when she was growing up. She invokes a minister who said that "you will be whipped with many stripes": that God will discipline you if you knowingly do something that is wrong. She goes on to say, "I have to pay for what I don't do; I can only look back at myself and say, 'You knew. You. Just you.'"

God and religious belief have an important role in most of the narratives. It is how that belief is used to cope with illness and adversity that separates the experiences. The clearest contrast is between siblings Gabrielle and Sylvia; one uses her faith to help her cope with T2D and the other gives to God the agency she needs to cope with her illness.

Conclusion

The narratives show lives of great complexity and stress. The participants make their experiences with T2D meaningful as part of the psychosocial experience of their worlds. While the findings are more descriptive than demonstrative, I feel the complexity of their experience is

reflected in the findings, understanding the rich and complex lives of the participants and their experience with T2D. It is clear that there are participants who suffer significantly with the experience of T2D and nearly as many that are successful at integrating the illness into their often complex and challenging lives; some participants can become empowered through the process.

Chapter 6: Analysis and Synthesis

Each of the 14 illness narratives in this study is as unique as the individuals who created them, yet there are certain commonalities that may enlighten the experience of T2D as a whole. There are many similarities with other chronic illness experiences; however, in the necessary integration into lives for some participants, T2D can create a singularly difficult illness experience. The integration of this complex disease into already complicated lives yields stories of suffering, but, importantly, also yields stories of triumph. A significant minority of the participants had experiences with T2D that showed an ability to integrate the illness into their everyday lives. In doing so, they achieved feelings of accomplishment and a sense of altruism in their desire to share their mastery with others in their community. Due to the nature of narrative inquiry, data is bound by what the individuals chose to share, so it is not possible to isolate all the social determinants relevant for the participants other than age, race, and gender. My data does reveal that participants include their social context and experiences as vital framing for their narratives of T2D. Therefore, I suggest that the participants believed that these social contexts were important and influenced their illness experience.

I organize this analysis by findings, followed by a section on how these findings compare to the existing literature. I will discuss what I perceive as relationships between the findings. At this stage, it is useful to re-examine the original research question that I set out, grounded in the attempt to phenomenologically understand the lived experience of these women: *how do these women make meaning of their experience with T2D?* In the concluding section, I will explore takeaways, or gleanings, from my research and the recommendations that flow from it.

Finding One: T2D Exacerbates Stress for Some Participants, Others Can Accommodate T2D Into Lives

While the majority of the participant narratives (eight of 14) show diabetes-related stress, five do not (Doris's memory issues made her unable to communicate on this). My goal in this research was, in part, to reveal the experiences of people who struggle and never come to terms with their illness. While exploring this, however, I found that many stories illuminate a different experience where participants can successfully incorporate this complex disorder into their lives.

I have separated this analysis into three parts. The first part explores individual narratives that describe severe initial shock and distress at diagnosis that might continue many years past diagnosis, leading to struggles with self-management of T2D. The second part examines issues and struggles with self-management apparently particular to T2D. In the third part, I will explore those narratives that did not speak of diabetes-related stress and how these five narratives might be illustrative to the eight who are struggling with T2D.

Distress at diagnosis. For everyone, diagnosis of a life-long chronic illness means a shift from thinking of themselves as someone who is well to someone who is ill; it changes how one thinks about self and body and how one interacts with others and the world. I believe there are aspects of T2D that make its diagnosis and experience a singular challenge. The T2D diagnosis of eight of the women in this study caused them to become distressed and stay so even many years later. Why would this be? T2D is intrusive and requires constant monitoring—the enactment of the disease is often an intertwining of one's embodied experience and illness through the daily repetition of the coping experience. By embodied experience, I mean the enactment of life through multiple interactions, how one views oneself within one's social world. With a strong sense of who they are in their worlds, some participants can accommodate the

illness. I believe this invasive and daily aspect of T2D makes its diagnosis and experience more invasive and makes the illness itself a greater challenge to handle. By invasive, I mean the use of medical paraphernalia, language, and the possible sublimation of the individual's cultural knowledge by the foreign medical knowledge of T2D. Those who show less distress can accept or accommodate the invasive nature of T2D through distinctly individual ways dependent on their past life experiences, personality traits, and feelings of resilience. Listening to these experiences of living with T2D, the intertwined and pervasive nature of this chronic illness stands out; T2D is embedded in their daily lives and embodied by its bodily experience. It is a chronic illness in which routine choices have lifelong results. The imposition of daily rules devised by the medical world in their personal lives can add to participants' expressed feeling of distress, beginning from the moment of diagnosis through a blood test.

Blood testing. Most people with T2D understand themselves as being well until they are told otherwise by a doctor or nurse. This was the experience for 12 of the participants in this study, who said the diagnosis was a surprise to them. T2D existed within them but was unknown, unnamed, and unembodied. By embodied, I mean that which is held within and experienced by the individual body, an often-unspoken knowledge of oneself. As Shanda says, "They took my blood. . . they find everything in the damn blood. They took my blood and that's how they found out." With the pull of an institutional syringe, those that lived in the world as well individuals become patients under the medical gaze. The participants who showed distress are the same who felt shocked or surprised by being diagnosed. They felt entrapped by the medical system, which makes the accommodation of the illness more difficult for them. This is further exacerbated by the occult means of diagnosis through the blood test. Something seems suspicious, that they had T2D and they did not know or were not told. This combined with the

daily medicalized regime of blood-sugar testing and insulin needle use makes the goal of accommodation of management into lives more difficult for some.

Family history of T2D. Among the 11 participants who spoke of a family history of T2D, some were surprised by the diagnosis and often were the most distressed. It appears counterintuitive that most of the participants expressed shock and surprise at the diagnosis when most have a positive T2D family history. These same participants experienced difficulty incorporating T2D management into their lives. They felt that if they did not eat sugar it would prevent T2D. The derivation of this kind of thinking is the public and, to a large degree, the medical community that supports a theory of personal responsibility in health, combined with the underweighting of the genetic factor in T2D. This may create an unrealistic expectation that participants can prevent T2D by not eating sugar. A lack of confidence in all medical practitioners could underlie this experience relating to T2D diagnosis and affect how participants comply with the self-management routine they are given. These participants believed that they could escape a disease that is to a great extent inherited through a complex pattern of genetic inheritance and some lifestyle triggers. It is not a surprise that they felt angry and betrayed. Medical appointments and T2D management take over lives. I postulate that the effect of participants' daily lives being appropriated by medical apparatus, medical appointments, and new imposed dietary regimes, combined with the tiredness due to the illness itself, causes most participants to express distress. This is a continuation of the alienating nature of the diagnosis. The adoption of the ways of knowing and language of the biomedical other can make an individual feel alienated from her world. Her understanding of herself has been formed through intersubjective interaction with others in her community as a well person; now she is changed. In addition, the frequent discussion in the narratives of numbers of doctors, hospital

appointments, and oppressive routine of daily management indicate that they feel their lives are taken over by the illness, usurping their old life and their understanding of their place in it. For example, Shanda says her life is taken up by appointments “I have a lot of doctors’ appointments. I am very sick . . . I’m sick. Between a therapist, psychiatrist, the heart doctor, arthritis doctor, podiatry—got to keep the podiatry—and the PCP. That’s six.” They feel that the medication is life-altering; Sylvia says, “That was the first time that I heard I had to take a medication for the rest of my life. I just knew again my life wasn’t going to be the same . . . I feel like the sickness it doesn’t get better.” In the cases of those with the greatest distress, their whole lives feel affected by T2D; Lela says, “It affects me psychologically, emotionally, socially, physically, the whole gamut. It really does.” I suggest that this sense of being part of but alien from one’s life seriously affects the participants. Those with the most difficulty and distress were those who felt that their means of making meaning are not theirs but imposed on them by the medical world. Mia’s understanding of herself is tied to her culture. As previously discussed, Mia felt a great deal of depression and disconnection from her life and became depressed when her traditional remedies were challenged and disparaged by the medical community.

In conclusion, the participants’ daily embodied experience of managing their illness is through adoption of medical meaning-making and medical apparatus such as needles, syringes, blood-testing kits, and glucose monitors. This seems to cause some participants to feel alienated from themselves as well as stress and, in some cases, distress. They must graft medical language, knowledge, priorities, values, and medical devices into their lives. For many of the participants, this process may create a conflict that makes adjustment and self-management of their disease onerous.

Stories of successful T2D experience. While the majority showed diabetes-related stress (eight showed diabetes-related stress, five showed none, and one was unknown), I feel that the analysis would not reflect the complexity of experience if I did not explore the narratives that did not show diabetes-related distress. What is different about the narratives of those who do not speak of diabetes-related stress? What life approaches do they use to help them cope with such an intrusive disease? What is significant is the ability of these participants to make T2D their own, to show ownership over the experience. It shows agency to change and adapt to the limitations of illness and, moreover, to come to see that the overcoming of obstacles is powerful.

There is something in their identities and past experience that keeps them feeling they have control even when things are not going well. These participants know themselves and understand their places in their world. This strength of self-knowledge does not allow T2D to control their lives and take over their understanding of themselves. However, their approach to T2D is different depending on their personalities, personal history, and circumstances. For example, Barbara feels confident about her experience with T2D just as she feels confident about much in her life. Barbara's narrative demonstrates an identity that accommodates and adjusts to cope better with her experiences. She has several ways of keeping the biomedical intrusions in her life to a minimum. The less medical and more user-friendly insulin dosage pen obviates the medical daily syringe and needle that others endure and medication in color-coded cardboard sheets of bubble press-out doses eases the burden of managing the prescriptions. She sees herself as someone who has triumphed over her past troubles, including feeling alienated when growing up in a mostly white neighborhood. Barbara speaks narratively, often constructing stories with a punchline at the end.

Geneva relies on a strong identity developed when she survived a long-term life-changing illness event in her childhood. Her narrative is one of adaptability, positivity, and optimism, seeing each negative experience as a potentially positive one. She says that if she can cope with polio, T2D is nothing to fear. She gathers strength and support from her family and contacts from long years working in the community. She expresses ownership of her T2D in the same way she expresses adaptability and resiliency about her polio. Geneva is used to accepting her limitations, and sees them as positive, such as her ability to talk with confidence learned in the iron lung.

Willow has multiple illnesses, including rheumatoid arthritis, which keeps her in a wheelchair; however, her discussions about herself in contrast to others tells us that she will not be isolated or held down by illness. This shows a determination not to be conquered by her illnesses. Kara uses a profound self-understanding of her physical strength and ability to overcome adversity, such as her childhood beatings by her mother or the pains and dislocations of her wrestling career. She also uses anger to generate some of her feelings of control.

Gabrielle has a unique path to accommodating her illness in her life. She says several times that getting T2D saved her life. Her narrative is one of overcoming one obstacle of drug abuse by another obstacle, T2D. In addition, she uses the experience of T2D as a way back to the family she felt isolated from because of her stepfather's abuse. This re-scripting of herself from feeling like a victim to feeling powerful and able to cope with T2D is a profound change for her. Each individual finds a different way to incorporate T2D into their narrative. They can make T2D just part of their lives, not the whole. What seems clear is that there is self-confidence and a desire to feel empowered. All the participants who are confident about their T2D have a greater agency, which will be discussed in Finding 2.

Comparison to the existing literature. That most participants in my study have diabetes-related stress fits into the existing literature about diabetes-related distress. Wagner et al. (2015) define diabetes-related stress as demonstrating depression, frustration, poor motivation, fatigue, and increased blood glucose. The narratives of the majority of participants show all of the symptoms of diabetes-related stress. Diabetes-related stress “reflects compromised mastery, self-efficacy, problem-solving, adherence, self-control, and motivation” (Wagner, Tennen, Feinn, & Osborn, 2015 p. 7). Many studies in the literature focus on those who have not adapted well; however, I believe that we should also focus on those who have managed to accommodate T2D in their lives to fully understand how these women successfully cope with a complex disease.

Additional aspects in this finding relating to T2D and stress add to the existing literature. One, the effect of privileging Western medical knowledge over the individual’s cultural understandings can cause great harm. Mia’s experience of trying to incorporate her traditional cultural remedies is dismissed by her doctors and yet is closely tied to her self-understanding, which leads to distress. I conjecture that by devaluing cultural knowledge and embodied experiences there is a greater chance of distress and difficulty in adherence. Two, I feel that the particular nature of T2D makes it more of a challenge to cope with than other illnesses, due to the intrusive and constant actions that must be taken daily. By this, I mean that the lived experience of T2D necessitates that the participants entirely re-conceptualize life. The participants’ daily embodied experience of managing their illness is through the adoption of medical meaning-making and medical apparatus, such as needles, syringes, blood-testing kits, and glucose monitors, as well as a medically imposed diet, which can be confusing. The daily monitoring of food intake and blood sugar heightens bodily awareness, a process that can be

adaptive or maladaptive (Mehling et al., 2009). This is especially the case when participants feel that they are managing their T2D well, but this belief is not reflected in positive outcomes. In almost all cases, that T2D is a progressive disease is neither well understood nor easily accepted. There is no day off in T2D, no thoughtless eating, or holiday from taking medicine.

As discussed in Chapter 2, there are few studies about Black women that research their lives coping with T2D. Pierre-Louis et al. (2011) looked at the meaning of T2D in women's lives within the context of their cultural experience of slavery and the struggle for civil rights as well as their primary financial, emotional, and educational role in raising families. They often found isolation and frustration in the stories they heard.

Hotz (2015) interviewed Black women in a church-based clinic. She also found that "claiming" the disease was crucial in the successful management of T2D. By claiming she meant that they had to gain a sense of ownership over the illness and not let it control lives.

What is clear is that the existing literature predominantly does not seek or find many stories of successful coping and accommodation of T2D in the lives of Black women. The studies appear to look for stories of failure in coping with T2D, framing the questions through a lens of pathology and failure. I do not feel that these studies intend this, but they seek means of proscribing a fix rather than looking at the individual experiences. While Hotz (2015) and Pierre-Louis et al. (2011) looked at the cultural contexts and meaning-making of Black women, they found, as with most previous studies, participants who were struggling to cope with T2D, not those, as in my study, who were able to find different and successful means of incorporating T2D into their lives.

Finding Two: T2D Experience Influences Generalized Feelings of Control in Life or Lack Thereof

The same eight participant narratives that show diabetes-related stress (the majority in Finding 1) also express feelings of little choice in the course of their T2D experience (the majority in Finding 2). A key to understanding this finding is that these participants show low levels of agency and self-efficacy. Self-efficacy is understood as a feeling that one can change the outcome of the illness experience by one's own actions. Agency is understood as an internally located self-determination and the ability to act on it. I feel that the participants who show low levels of agency feel that they have little choice in their illness experience and that the location of the driving force of their experience is located outside of themselves. I believe that the nature of T2D exacerbates these feelings; those who have this illness experience of low agency will have more difficulty in making meaning and maintaining a strong sense of self. The quotidian nature of T2D diminishes a sense of ownership of life experience. Someone who feels that she has no ownership of her life will express less self-efficacy. This low self-efficacy diminishes feelings of agency and drains a sense of being able to control events and outcomes.

External location of control. As Lela explains clearly, "There are so many gottas in my life." What distinguishes the sense of ownership and agency over the illness is the turning of the "gottas" into "want tos." The ability to gain this sense of self-determination and ownership over the confines of the disease may lead to an internalization of the externally formulated restrictions of the illness. It is the lack of ownership and external location of the "gottas" that led most participants to feel little agency. Agency is a necessary component in T2D experience because self-management is critical to survival. Therefore, the daily stakes in T2D are higher in the moment and daily behaviors have long-term consequences.

In many cases, individuals with little agency feel that they are forced to rely on institutions they have little trust in. This can feel alienating and contributes to the feeling of little choice, which may be further exacerbated by having their lives taken over by hospital appointments and medical artifacts used daily, such as blood testing machines, insulin needles, and monitors. For those like Sylvia, the idea of being able to control life's events has been crushed through years of abuse by those with more power, telling her that she does not have any choices. Sylvia uses the word "hospital" 47 times in her narrative. I believe that the site of many of Sylvia's photographs in her narrative being a hospital was a means of gaining some agency over these difficult experiences. When speaking about doctors, she says, "They don't stop to hear the story . . . when you talk, you're just being judged." She felt that her story was not heard, that she had no place within the medical system, yet she was tied to the hospital and medical world. She did not take her medicine or watch her diet and passed away shortly after the interview.

On the contrary, those five of the 13 who express a feeling of agency rarely speak of hospitals and doctors in the narratives of their experience with T2D. I believe those with a higher agency feel a sense of ownership about the disease. Those with the greater ability to accommodate T2D feel confident enough about their illness experience that they are keen to pass on their understanding to other participants. The fewer times they mention "doctor" or "hospital" in their narrative indicates that the location of the knowledge of T2D is with them and not in the hands of the healthcare practitioner.

Demonstration of effect of low agency and high agency. In a clear demonstration of the difference in illness experience with a high and low level of agency, Geneva and Lela both have similar childhood illnesses with similar lifelong effects but dramatically different ways of

finding meaning in their experiences. Geneva's and Lela's experiences of illness may appear similar in that they both have partial paralysis from a childhood illness and have had T2D for 11 years. Looking at Geneva's and Lela's physical limitations—respectively partial paralysis since the age of four and partial paralysis from rheumatoid fever at age 12—Geneva tells stories that do not express any sense of hindrance from her limitations. However, Lela's narrative indicates low agency and a lack of ownership of both the paralysis and T2D. Geneva feels that her experience of overcoming her early illness lends her agency in her experience of T2D. Their health behaviors and beliefs concerning T2D are shaped by their feelings of self-efficacy. These two women could have had different responses to similar early childhood illnesses and consequent paralysis due to their individual psychological approaches or attributes or different levels of social and family support. Geneva's strong narrative identity can withstand and even flourish under the pressures of her illness. We can learn more about their stories by listening to the stories of other women who have strong agency in this study. Barbara speaks of her empowerment in her life through a sense of triumph over her early childhood adversity of fighting for identity in a largely white neighborhood and of losing her father and their money. Kara as well speaks of overcoming early adversity by finding her emotional strength through her physical strength. The women who can find strength from adversity, rather than just surviving adversity show a greater agency and self-efficacy in their illness experience with T2D. The resilience gained by the experience of becoming stronger from adversity is further utilized by the five participants who show greater agency in their illness experience with T2D.

Comparison to the existing literature. The role of agency and self-efficacy about illness experience is prominent in health research and literature. The finding that participants express feelings of little choice is largely supported in that literature; however, the particular

nature of T2D contributing to this experience is a new insight. The health locus of control is defined as an individual's belief in their ability to exert influence over their health outcomes (Walliston, Walliston, & Kaplan, 1976). An external locus of control is largely demonstrated by less self-efficacy in health and poorer health outcomes (Lau, 1982). I can say that those participants who felt they have little choice are people who have less self-efficacy and an external health locus of control. However, I feel that the specific intrusive nature of T2D contributes and exacerbates an external health locus of control and that it is more dangerous for participants so affected. This has not been given attention in the existing literature and is especially damaging to those who have low levels of agency and self-efficacy. Those individuals who have an external locus of control, like Sylvia, become overwhelmed by the intrusive nature of T2D. Barbara, Geneva, Kara, Willow, and Gabrielle's narratives show strong agency. There is no question who the author of their stories is. The literature does not feature these stories of strong Black women coping with complex lives and complicated health conditions. In this small study, I was able to find several agentic and confident women who not only located the management of their illness within themselves but were eager to teach other women to handle their illness.

Finding Three: T2D Concern Fluctuates in the Hierarchy of Importance in the Lives of Participants in Response to Other Social Stressors

The participants' T2D experiences are set within a web of social stressors that weigh on them. The relational maps created by the participants in the interviews showed that they see their T2D experience as part of a life replete with stressors. Some participants used stress mediators and were able to counter their stress, thereby creating positive outcomes, such as keeping pets and close contact with families. Gabrielle and Sylvia made their relational maps

before the interview, both filling a full page with stressors. Cecilia, Lela, and Shanda kept adding stressors to their relational map as the interviews progressed. These multiple stressors establish a hierarchy of immediate response. I believe that participants did not deny the critical nature of T2D and the effects on their lives but that, in the noise of stressors they face, T2D could get pushed to the background. That is, in the light of multiple stressors, the long-term consequences of T2D are often not of immediate prominence. This is often misdiagnosed by healthcare practitioners as non-compliance. By not bringing T2D into present urgent consciousness, the participants were responding to different levels of urgency. In some cases, participants had stressors such as financial constraint and stress related to unsafe living situations. Six participants discussed drug or alcohol use in their narratives in addition to the multiple stressors they must face. It was a better choice in their personal contexts to resort to food than relapse into drug or alcohol use. They responded to the urgent stressors with the mediators least likely to inflict damage in the short-term.

Diabetes is not understood as serious. Anyone who has spent time in a T2D education center will be familiar with the volume and variety of pamphlets paid for by pharmaceutical companies and community health non-profits. In light of this, it was of note that two participants expressed that they had not taken the health effects of T2D seriously before the study. It is likely that T2D educators, nutritionists, and physicians expressed the dangers of T2D to these participants on numerous occasions. One explanation for this sub-finding is that their lives are so replete with stress that they are not able to isolate T2D as an urgent matter that demands attention. For many participants, T2D was put into a basket of stressors, including financial pressures, violence, discrimination, abuse, and housing insecurity. While these participants'

treatment of the disease as less serious might be mistaken for ignorance or noncompliance, I believe it is a valid response to the cacophony of stress in their lives.

Fluctuating and temporal aspects of meaning of the illness. A temporary normalization of the seriousness of T2D postpones a crisis; in other words, the ability to temporarily push the seriousness of the illness out of the current mind frame is a coping measure, one which can fluctuate over time and depends on the disease's progression. Some of the women in this study can cope with their difficult and complex lives by temporarily shifting the importance and meaning of T2D. Shanda and Ruth can temporarily maintain an apparent conflict in their stories; thus, they are surprised at the seriousness of T2D even when they have a family history of T2D and were diagnosed 10 years ago in Ruth's case and four in Shanda's case. The variable threat of T2D over time and circumstance is reinforced by its multiple meanings depending on the interaction between people in their lives and the threats to their understanding of its meaning to them at that moment. This was illustrated in Ruth's and Shanda's narratives; many of their acquaintances have lived with T2D and so the seriousness of the disease lessened in their minds as they encountered more people living with it. One possibility is that when they see so much T2D in family and community, their perception of its seriousness is lessened. Could we say that this is an instance of denial? I would say that is too simplistic an explanation. The high prevalence of T2D in the participants' communities lessens the threat of it in their own lives; however, when confronted with a reminder of the seriousness of the consequences, such as meeting someone who has lost a limb or been diagnosed with a comorbidity, the meaning of T2D changes for the individual. Ruth speaks of the shock and sadness she feels when she meets a woman who has lost her leg. Within the same narrative, she talks about how she cannot

tolerate diet soda and has reverted to sugary soda. She is able to simultaneously hold two truths or meanings of her illness.

What becomes clear when reading these narratives is that these women lead complicated lives while trying to cope with a disorder that necessitates a great deal of daily management. Due to a multitude of factors, the women who have the most difficulty coping have lives that are stressful due to financial stress, housing issues, food insecurity, and fractured and complex family lives. The women who cope best are those who have housing stability and some feelings of security either through good insurance, a successful work history, or family stability, resulting in a strong narrative identity. The lower number of stressors helps them to create a space for ownership of their T2D and gives them a chance to accommodate the complex illness.

Finding Four: Participants Use a Variety of Stress Relievers

Coping strategies. The hierarchy of risk for participants makes understandable use of stress mediators that conflict with T2D management. I make the case that the number and severity of stressors in the participants' experience make even the diagnosis of a potentially fatal disease just one of many stressors to control. It is highly likely that these coping strategies may be adaptive to the circumstances. For these participants, consuming food that they and their healthcare practitioners considered bad for T2D management is a means of mediating daily stress. It is safer to eat ice cream than to mediate the stress with drugs or a cigarette. Six participants smoke and expressed a desire to quit. Six spoke of drug and alcohol abuse in their backgrounds. Drugs and alcohol are judged to be more of a risk by many of the participants—due to past issues with drug use—than the more long-term effects of eating a diet high in sugar. When the participants speak of so-called “forbidden” food or cigarettes, they often use the word “need.” This can be explained in many ways. They need to find an alternative to alcohol and

drugs. They need something to cope with stress, either current in their lives or as continued coping with past trauma and abuse.

It is worth exploring the concept of “forbidden” or “bad” food. While an exploration into the language and meaning of diets is beyond this study, the use of language concerning labeling food as something good or bad, or in the case of some participants, use of the word “forbidden” can create an environment of self-blame around food. T2D management is largely about food consumption and the use of such pejoratives around food can create a sense of self-loathing and self-punishment. To label any food as bad or good creates a cycle of self-blame around food that may have serious consequences for people whose food consumption is vital for their survival. Participants who choose to have ice cream or a cigarette in times of stress are making a choice that is necessary for them in the moment to prevent a worse outcome by turning to drugs or alcohol.

Overlaying all of the stressors is the issue of mental health disorders. Most of the participants (nine of 14) told me that they had mental health issues ranging from anxiety and depression to bipolar disorder. These participants volunteered their issues with mental health in their narratives of T2D; therefore, I surmise that they felt that the stressors of mental health had an important role in their experience of living with T2D. Without a doubt, existing mental health issues are worsened by the stress of T2D. Every participant who spoke of depression felt that it was made worse by their experience of T2D. Of the participants who had significant past trauma, a majority felt that their experience of T2D made them more reactive to stress. It is difficult to determine whether this is causal or a manifestation of untreated traumatic experience. The stressors of mental health issues in these complex lives feel overwhelming.

All the participants took photos of food, either to show that they were trying to change their diet or were tempted by what they perceived as “forbidden.” As anyone who has tried to adhere to a restrictive diet knows, there are many social situations where food temptations arise. Bringing and sharing food is a part of every culture and restrictive diets can be isolating. For many of the women in this study, food has a central place in their understanding of themselves and their place in their social structure. Helping them to maintain their cultural food choices with adaptations is a means of maintaining their cultural identity while accepting that they can be adapted for their dietary restrictions.

Comparison to the existing literature. The results in this study are supported by other existing research where there is a link between sexual assault and abuse survivors and “maladaptive coping strategies” such as drug and alcohol use (Bryant-Davis, Ullman, Tsong, Tillman, & Smith, 2010; Ullman, Relyea, Peter-Hagene, & Vasquez, 2013). However, my study differs in that I feel that food is a rational alternative to drug and alcohol abuse as a response to stress. I would go further to say that these are not “maladaptive coping strategies,” but that turning to food as an alternative to drugs is an effective adaptive strategy in times of stress. If it is recognized as such, it would lessen the sense of self-blame, which is counterproductive, and perhaps provide a sense of ownership that may lead to a reduction of stress through other means compliant with participants’ T2D. It is vital to reexamine the relative success of the individual within the context of her own life experience. Half of the participants volunteered the information that they were either physically or sexually abused. The fact that they brought up abuse in the context of their experience with T2D shows that although they may not have articulated a link, in their minds there is some effect. Mercy speaks of her addiction to hard candy and understands that she used candy to help her cope with her past life of daily rapes and

beatings. Many of the participants described eating for emotional reasons. This agrees with the existing literature that describes depression as a trigger for emotional eating (Mayer et al., 2015), but I believe that these are correct adaptive strategies in their individual circumstances.

Finding Five: Significant Childhood Trauma Plays a Role in Coping with T2D

To understand the effect of past trauma on the meaning-making of the participants, I return to an understanding of the individuals' social contexts. It is possible for someone who has undergone past trauma to be resilient, but these experiences are part of what makes up self-understanding. Unsurprisingly, those who experience past trauma have lifelong effects. What is noteworthy is that three participants did experience significant childhood trauma but could be resilient in the face of that trauma, indeed showing post-traumatic growth. Of the remaining four participants with past trauma who did not show post-traumatic growth, past trauma contributes to less agency and self-efficacy in the face of T2D.

Family support. One contributive factor is the support the individuals felt from their family. The supportive family framework may provide resilience in the face of adversity. The belief in oneself instilled by one's family allows for adaptation to challenging circumstances throughout life. Among those who spoke of the support of their family was Geneva. She spoke frequently of her supportive family in her narrative, even compared to the other children in the polio hospital, "If you have a background where they support and love you and- and make you feel good about yourself, then nothing can hold you back." Conversely, Lela lost her mother at an early age and felt that the aunt who raised her was busy and inattentive to the progress of her recovery from rheumatic fever, "I guess my parents didn't push me." Lela feels that she does not have the willpower to control her T2D and feels self-blame. Through the narrative interview,

she concludes that her issues with coping with T2D are based on her past traumas. I believe that the unresolved past trauma inhibited her ability to cope with T2D.

Role of post-traumatic growth. Of the seven narratives that explored past trauma as a part of their illness experience, three showed post-traumatic growth. In this study, I interpret post-traumatic growth by participants, who speak of past trauma yet find a means of making the experience positive, in terms of their attitude or behavior. The four narratives that did not show post-traumatic growth showed a tendency to bring their past trauma into their narratives as a tool of meaning-making. The trauma is embedded into their narratives. Mercy, Lela, Cecilia, and Sylvia tell often harrowing stories of their past trauma that they use to understand their current life experiences. Geneva, Gabrielle, and Kara use their past trauma survival to tell the story of how they can deal with and make meaning of their T2D experience. Geneva shows post-traumatic growth in her narrative because she takes the experience of her past trauma and uses it as a meaning-making tool that affords her the feeling that she can surmount T2D. Geneva has positive psychological change as a result of the struggle with past trauma. What can cause this difference in resiliency in the face of T2D? I believe that part of the answer is a family support structure that allowed Geneva to process her trauma and the lack of it that caused Lela to bring her traumatic meaning-making into her understanding of self in T2D. These two participant narratives illustrate post-traumatic growth contrasted with a post-traumatic stress response.

Gabrielle's narrative also demonstrates post-traumatic growth when she credits the diagnosis of T2D with saving her life, as she conquered her addiction to crack and re-established relationships with her family. Perhaps faced with the certainty of death due to her drug use, she saw T2D as a motivational factor to try to exert control in her life. In addition to post-traumatic growth in relation to her T2D, Gabrielle demonstrates post-traumatic growth when she credits

her establishing a food pantry in her church to her hunger as a child, “I love to help feed people because I remember plenty of times being hungry.” Her resilience in the face of her multiple stressors is an example of trauma becoming a source of growth. T2D was an opportunity for her to use her T2D as a meaning-making tool for her past trauma. She faced an existential crisis and decided to stop running from her childhood abuse. She says T2D saved her life because it forced her to come to terms with her stepfather’s abuse and her drug addiction. This is an unusual reaction to the diagnosis of T2D but worth examining as it shows a way to find growth in even the darkest experiences.

Kara’s narrative of post-traumatic growth is rooted in a strong narrative identity formed from the experience of physical abuse. She says that her physical strength gives her the power to overcome T2D, just as it formed her toughness to be a professional wrestler. Her resilience is founded on this unusual belief that she does not feel pain nor does she have the same physiology of her metabolism as other people. I would equate this narrative post-traumatic growth with Gabrielle’s. Both participants were able to retell their stories to find a positive meaning in their past trauma. Moreover, they could reconfigure their past traumatic narrative into one of strength. I would hesitate to say that this is a common experience but one that three participants of 14 showed in their narratives. It is worth exploring as a way to find meaning for those who have had significant trauma, as the majority in this finding who do are unable to find positive growth and have a significantly more difficult time coping with T2D.

Comparison to the existing literature. The incidence and variance of post-traumatic growth among individuals I found in my study are supported in the literature, where post-traumatic growth has been found in people with several highly challenging life events (Lindstrom, Cann, Calhoun, & Tedeschi, 2013). Ullman (2014) found several correlates in

women who survived sexual assault—women of color, age, and social support—and the lack of maladaptive coping measures such as avoidance or self-blame.

Finding Six: Religious Belief is Spoken of by All Participants, but God Plays Varied Roles

All the participants refer to God in their narratives, but religion has many roles in their lives; their relationships to God or Jesus are part of a fabric of support that they call on in their lives and that forms part of their narrative identity. The role of religion in illness is a complex topic, but my data indicate that there are both positive and negative aspects of the role of spirituality and religion on the experience of illness. For example, Gabrielle is able to formulate a relationship with her religion where it supports her mastery and agency, unlike Sylvia, who sees God as the master of her fate; this belief contributes to low self-efficacy. All participants spoke of having attended church in the past or were currently attending a church or Bible group. Religion was part of all of their narrative selves. The majority of participants spoke of God and religion as social support that helped them in their lives, even by providing a warm meal eaten in a social setting. For some participants, like Mia, Mercy, and Ruth, church has a central role in daily life and meaning making. Mia spoke of feeling more depressed and distressed about her illness because it stopped her attending church and singing in the choir. For her, religion and church were central to her narrative identity. T2D caused a crisis of self because it threatened her attendance of church, which was the key constituent of her narrative identity.

Health fatalism. Health fatalism is a possible explanation for conflicting or overlapping statements about participant meaning making of T2D concerning religion. Health fatalism is the belief that one's health outcome is predetermined by a higher power, whether fate, luck, or God, and not under one's control. Mercy, Sylvia, Ruth, Lela, and Mia express a form of health fatalism, saying that God is a jealous God and that you have to give control up to Him. This

health fatalism is seen in participants who have the most distress regarding their experience of illness and finding agency in their illness experience. Fatalist religious beliefs can lead to fatalistic health beliefs and behaviors. Saying that God is a jealous God will not in itself create fatalistic health behaviors; it leads to health fatalism when combined with other factors, such as low levels of agency of self-efficacy, in my study.

I believe that there is a fine line between fatalism and acceptance of adversity. The negative health effects of raging at an unfair system may be equally damaging as health fatalism. To be secure of one system of support, church, God, or spirituality is important to these women, who have stressful lives. It is a matter of degree of agency given to the role of God and the church. Those who view God as part of their matrix of support or as part of their narrative identity seem to have better outcomes in this study. The social support aspect of the role of religion, like other forms of social support detailed in the narratives, such as group exercise or lunch with people, appears to be the primary focus of spirituality for the remaining participants. It is part of their support system and, for most participants, it is a positive one.

Role of religion in agency. To understand the role that religion plays in the experience of illness of the women in my study, it is useful to contrast Sylvia's use of religion and God and her sister Gabrielle's. God and religion support Gabrielle's self-efficacy rather than weaken it. Gabrielle views God as a force to support her control and agency, not as a means to accept the loss of control. While God provides support in her journey, she is not on God's path but her own. The rest of the participants fall on a spectrum where Gabrielle and Sylvia are seen as endpoints. Of course, people call on faith when they are in a period of stress or have had a traumatic experience. This need for faith will likely vary over the course of their lives as it does for these participants. Sylvia's narrative is one of someone still in the throes of grief from the

loss of her son. Understandably, she would be seeking to find some meaning in her loss and gravitates to religion. However, this external location of her agency in God is detrimental to her ability to be in control of her illness. In her case, her response to grief further diminished her agency and sense of self. This had a serious deleterious effect on her illness experience and health.

This difference in the use of religion as the location of agency can be best highlighted by referring to the general exploration of agency found in Finding 2. The women who achieve strength from adversity, rather than just surviving adversity show a greater agency and self-efficacy in their illness experience with T2D. The resilience gained by the experience of becoming stronger from adversity is further utilized by the five participants who show greater agency in their illness experience with T2D. Similarly, religion is a tool of support for those women who are able to achieve strength from adversity. For those women who have survived their adversity without growth, religion can further take agency and self-efficacy from them.

Comparison to the existing literature. Health fatalism has been explored in the literature (Franklin et al., 2007; Hotz, 2015) and my study supports the role it can play. I find fatalism an understandable reaction for people with chronic illness, comorbidities, and those who have to cope with other events in their lives where they feel powerless, such as when Sylvia loses her son to leukemia. I agree with Hotz (2015), who speaks to this fatalism as an understandable reaction in light of the preponderance of illness in these individual's communities; there seems to be little option but to feel fatalistic. However, this sense of fatalism and giving up power to God may be an effective response when the individual has few feelings of agency and support. The relationship to a faith community is valuable, as is a need to feel purpose and belonging. It could be called fatalistic or an attempt to gain control.

Hayward, Krause, Ironson, and Pargament (2016) found that passive deferral to the divine was associated with negative health outcomes but a better sense of life satisfaction. My understanding of passive deferral is that agency is situated not with the individual but with God. My data supports the notion that a passive deferral strategy can create difficulties in illness experience. This passive deferral strategy is one where the individual gives her agency over to God. In the time since the completion of this research, Sylvia passed away. I postulate that the ceding of her life to God may have had negative health consequences, but equally, those beliefs may have kept her going each day and given her more satisfaction in her life. Those who can find a supportive and social role of religion have a better chance of finding a successful path through this complex disorder.

Health locus of control is how one understands the agency that one has in effecting a change in the outcome of an illness. Spiritual health locus of control is an attempt to understand how religious beliefs can influence agency concerning health. Cecilia, Lela, Mercy, Ruth, and Sylvia believe that God will intervene and help them with their health. This is a demonstration of an external spiritual health locus of control. My study finds that there is an association between low agency, health fatalism, and passive deferral to God or external spiritual locus of control. The participants who view the role of God as the location of their agency have a difficult experience with T2D. Particularly in the cases of Sylvia, Mia, and Mercy, these beliefs and behaviors are associated with low self-efficacy and a belief that they are unable to effectively alter the courses of their illness, consisting instead of a dependence on God to decide their fate. Debnam (2012) explores the role of spiritual health locus of control that can shed some light on how religion may impact health behaviors in my study. This passivity was associated with less post-traumatic growth in women recovering from breast cancer and is

supported in my study. Results of some research on the role of religion in health indicate that there are positive relationships between spiritual and religious beliefs and good health outcomes (Park et al., 2016). My study finds that there is a positive relationship between spiritual and religious beliefs and agency in health in the cases of Ruth, Gabrielle, and Geneva.

Patterns Across Findings

There are some relationships between the findings that might help to further understand the lives of these participants. For example, every instance of Finding 1, where most participants have diabetes-related distress, co-occurred with Finding 2, where the participants had feelings of little control or low self-efficacy/agency. This indicates a high degree of association between the two findings, which is important because it indicates that agency is important in the successful management of T2D. It also shows that those who have low agency are more likely to feel diabetes-related stress, demonstrating depression, frustration, poor motivation, fatigue, and increased blood glucose, which can result in compromised self-efficacy, self-control, and motivation. This interesting correlation indicates that a focus on improving feelings of control and choice over their illness might also have a positive effect on diabetes-related stress. The clear link between low agency and diabetes-related stress is an important finding from this study. Relatively easy and inexpensive changes can be made to help those experiencing diabetes-related stress feel more agency, which would then have a positive effect on reducing diabetes-related stress.

An analysis of those participants who are successful in their management of T2D in their complex lives crosses all findings, as shown in Figure 24. This figure details a multifaceted matrix of factors to accommodate T2D in these already complex lives. A few points of the analysis should be highlighted here. The number of years that an individual has T2D is not

significant to their ability to be successful. The mastery of T2D may increase feelings of competency in other areas of their lives. The greater self-efficacy shown may have been present before or a result of their mastery of T2D. The internalization of T2D management is a function of greater agency. Those that show this greater agency use God as part of a system of support and not as the sources of control. Finally, the role of past trauma and growth from the resolution of that trauma is an important factor in the ability of these participants to make meaning of that experience and apply it to their T2D experience: Because I survived that, I can survive this.

Examining the seven participants whose narratives included significant childhood trauma (Finding 5), I can split them into two groups: group one, those who also indicated Finding 3 (T2D concern fluctuates in the hierarchy of importance), and group two, those who had a consistent understanding about T2D regardless of the stress in their lives. The four participants that had fluctuations of concern relative to stress also had high blood glucose and struggled to manage their T2D successfully. They used meaning making from their past trauma to understand their illness experience with T2D. Perhaps due to their unresolved trauma, they were hyper-reactive to their daily stressors and unable to maintain a consistent meaning for T2D. If the participants have unresolved trauma as well as other stressors, such as housing or stressful home lives, they are hyper-reactive to stress and could easily become overwhelmed. The importance of management of their T2D becomes less important as they are overburdened by other stressors.

The other three participants—those who do not indicate fluctuating concern (Finding 3)—use their past traumatic experience to learn lessons that they apply to their T2D, thus showing post-traumatic growth. Geneva's apparent resilience and ability to manage her T2D suggests that she is able to draw strength from, rather than continue to suffer from, the effects of her past

trauma. Kara was able to view herself as tough and resilient—not as a victim but as a fighter. Indeed, her long and successful career as a professional wrestler is an embodiment of this. Gabrielle viewed her diagnosis with T2D as a means of exerting control over her addiction. Indeed, she says T2D saved her life. This shows that, having processed the past trauma, they no longer have a hyper-reactive stress response and are more resilient and less reactive to other stressors. This also indicates that those who have processed trauma have a better experience with T2D.

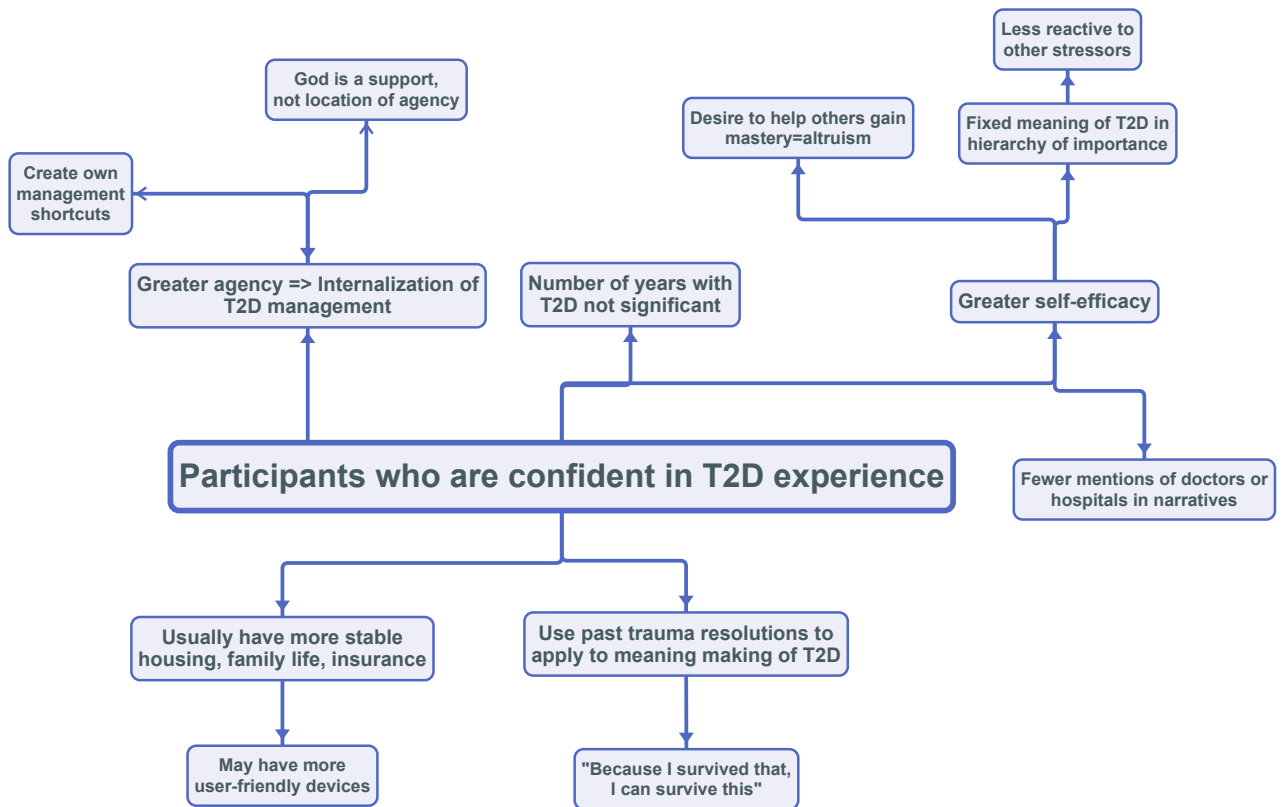


Figure 24. Participant factors in confidence in T2D management.

The role of self-efficacy in the successful management of T2D is explored in the juxtaposition of Finding 5, discussion of childhood trauma, and the aspect of Finding 6, comprising evidence that they believe that God is in control. Of the five participants who

believe that God is in control, four also told stories of significant childhood trauma. The role of God as the main agentic force may lead to the location of agency in God and not within themselves. In my study, those individuals who do not have an internal location of agency struggle with their illness experience. Of course, it is common that individuals who have trauma may turn to religion for support. Of the participants who used their past traumatic experience as an effective meaning-making strategy, none believed God was in control. They all showed agency and felt they had self-efficacy. There is no question that God is mentioned frequently in the data, but the role He plays in their meaning making is the significant factor. The role of God as support was helpful to those participants, but the role of God as location of control was detrimental to the participants who expressed this belief. Those who had significant childhood trauma and no post-traumatic growth all indicated that they had diabetes-related stress and low agency and self-efficacy.

However, the correlation in this study is that placing God as agentic is linked with low self-efficacy and agency and poor health outcomes. These individuals also do not indicate that they have resolved their past trauma and do not show that they have used what they experienced from their past trauma to help them in their experience with T2D unlike the other participants in this group. Those that do show post-traumatic growth are those who use spirituality as a part of their matrix of support and find agency within themselves.

Conclusion and Reflections

In this study, I have explored meaning-making for participants with T2D illness experience. I believe that the use of a narrative participant-generated photo-elicitation methodology was key to understanding the experiential lives of these participants. These are stories of survival and triumph in the face of enormous structural and personal adversity,

financial stress, and for many, trauma and abuse. The overwhelming burden of their difficult choices in the context of stress and limited resources must be considered. These women lead complex lives and enact them with this complicated disease. Some experience real distress trying to incorporate this illness into their lives. Others can accommodate T2D with great success.

Disempowerment and empowerment. I conclude that the illness experience of T2D can exacerbate an external location of agency and reinforce a tendency toward low self-efficacy. The daily hyper-vigilance needed for successful self-management of T2D exacerbates a feeling that one is not in control, that lives are taken over by illness. This has an effect of reinforcing low agency and self-efficacy by devaluing individual knowledge and locating that source of agency outside of themselves. For those individuals, it is difficult to feel a sense of agency or empowerment, both of which are needed for self-management, which is the medically suggested treatment for this serious disease. For participants who successfully incorporate T2D into their lives, there is an opportunity for empowerment. The ability to deal with the complexities of life with T2D provided the participants with feelings of accomplishment and empowerment. In addition, participants who successfully manage their T2D are keen to share their mastery with others.

“Forbidden” mediators should be seen in context. These participants all use food as stress relief at times, but this does not indicate disinterest or noncompliance with the self-management. I think it indicates that these women lead complex and stressful lives. They have numerous stressors and potentially serious complications with past drug and alcohol abuse. The choice to mediate extreme stress with food or off-program foods is not maladaptive behavior; it

is adaptive to a different hierarchy of risk. These are not bad habits or even bad choices; they are understandable responses to overwhelming stress.

Role of post-traumatic growth. The components that make one resilient are undoubtedly—at least from my data—familial support, a sense of humor, and a strong sense of agency. The effect of social factors such as poverty and trauma can severely impact all of these. Participants chose to include their stories of trauma in their narratives about T2D; therefore, I believe that they believe it had some role in their illness experience. Those who were able to use past trauma as a means of meaning-making were successful in their T2D and felt more empowered as a result. Those who continued patterns from unresolved trauma in their meaning-making of T2D, such as Mercy, Cecilia, Lela, and Sylvia, had more trouble coping with this complex illness experience. These participants were also more reactive to stressful events that threw off their plans for T2D management.

Narrative exploration benefits. Although I did not intend for participants to benefit psychologically from the study, I had hoped that the experience would be valuable to them. Mercy and Lela spoke directly to the benefits of the experience. Mercy discovered that her hard candy eating was keeping her blood glucose high in spite of losing 100lb. During the interview she learned through reflection that she ate hard candy for comfort and had done so during her traumatic past. Mercy confided that she did not feel the need to eat candy all the time, at least for now. Lela disclosed at the end of the interview that her troubles with T2D were rooted in her past trauma with rheumatoid arthritis and that she would seek therapy to resolve it. She had had T2D for eleven years; through her participation in this study and the use of narrative exploration, she was determined to find help. Through narrative exploration, participants such as Lela and Mercy could find reasons for behavior that hindered their successful management of T2D. Both

these participants were able to reflect on their behavior through narrative exploration and determined that they were repeating old patterns stemming from their past trauma that were not helpful anymore; however, the effects of that trauma would always be part of their narrative, just as a supportive family was part of Geneva's.

Reflecting on a life that has been traumatic and difficult unearths unwelcome pain; however, that pain unheeded can prevent coping with a disease such as T2D, which requires vigilance in every moment. The confluence of personal trauma and social suffering act to reduce the ability to cope with T2D. Social suffering can be defined as the consequences and destruction that social forces can cause to the individual (Kleinman, Das, & Lock, 1997). These social forces are economic, political, and institutional forms of oppression that act in general but have a specific injury for an individual. The illness experiences of women like these participants in my study may be a bellwether for the future of the U.S. healthcare system. It is by closely and deeply understanding the experience of the few that we can see the many. Individual voices of illness are not often heard directly, but if these stories are listened to, they may speak to a larger story of the effects of illness and the extra burdens the healthcare system puts upon some in our society. Reflecting on a life that has been traumatic and difficult unearths unwelcome pain; that pain unheeded can prevent coping with a disease such as T2D that requires vigilance in every moment. The confluence of personal trauma and social suffering act to reduce the ability to cope with T2D. Those individuals in this study who are able to find strength and resilience in overcoming their own personal and social suffering are able to successfully navigate this serious and complex disease. Those who have survived suffering without being able to gain empowerment through the survival cope less well with T2D.

Limitations

Portraiture. Portraiture methodology of the type used in this study is open to critique that the researcher takes too great a role in re-telling participant narratives. As a part of the data creation and collection, any qualitative researcher using portraiture methodology must be cognizant of introducing their own biases into the data. This is addressed by remaining close to the data of the participants while writing the portraits.

Participant recruitment. In the sampling and recruitment in this study some of the participants knew each other from the neighborhood, while others came through the “gatekeeper” health centers. There may have been some self-selection by participants via the encouragement of the gatekeeper. There were many motivational impetuses of the participants including the fee, further education about T2D, and for some who wanted to share their own means of establishing confidence regarding their illness. Most participants were recruited through a healthcare setting which may have had some bearing on their interest in attending the research.

Participant contact. Participants may have spoken to each other about this study prior to or during participation, but if so, it did not seem to have substantially affect the data.

Data collection. The pre-interview group sessions may have had a bias for participants to align responses. Additionally, the relational map protocol had some limitations. They were devised as an interview tool to re-orient the interviewee to the subject of the interview, her experience with T2D. Not every participant fully completed the relational map or felt comfortable with the writing aspect of creating it. The relational maps were a useful source of data later in the analysis phase of the study; however, if each participant did complete the maps it might have elicited more insights or further supported findings.

Recommendations

This study's findings contribute to the understanding of the lived experience of Black women living with T2D. The findings indicate that while their lives are complicated, some participants in this study were able to find ways of making meaning with T2D to successfully navigate this complex illness. There are several recommendations that result from the findings in this study. Most wide ranging is the application of photo elicitation and visual narrative creation as a tool towards reflective narrative exploration may help women better manage their T2D. This could be utilized in several environments such as community-based settings, healthcare sites, in T2D education, elderly care, and faith-based settings. This methodology is especially suited for those individuals who have had childhood trauma which may result in difficulties in coping with T2D. The impact of grief and post-traumatic stress on the experience of individuals with chronic illness is an urgent inquiry. In this study, the participants clearly felt that the trauma had an impact on their illness experience and it would be helpful if there were other studies to explore this important topic.

Many of the participants in this study had a positive family history of T2D and felt that they were doing the right things to prevent a diagnosis of T2D. In those cases, the individuals had more diabetes-related stress. A study to investigate this role of positive family history and prevention belief resulting in diabetes-related stress after the diagnosis would be useful to further explore why this population has diabetes-related stress.

The exploration of the stress mediators in this study is useful on several levels for further research. The use of alternate stress relievers that do not affect illness management, such as pets, humor, and social activities, is an important finding. Pet ownership was demonstrated to give empowerment and a sense of purpose to some of the participants and may be supported by the

community. A study exploring the potential positive benefits of pet ownership in relieving stress and providing positive attitudes in illness experience would be a useful next step.

In this study, the finding that the role of faith and religion provided some interesting possibilities for further research. For example, this suggests that a study to examine the different roles individuals give God, as a location of agency in contrast to a means of support, on illness outcomes could provide interesting data.

I postulated that my study showed that the lived experience of T2D has a greater burden in daily life and had the potential to be a great burden on the lives of the participants. I recommend that this can be further explored with a study comparing the lived experience of other chronic disease and T2D to evaluate the proposition that T2D has the potential for a greater burden. There are many further avenues for research among this under-researched population. My finding that there was a substantial minority of the participants who managed to successfully navigate this complex disease in the contexts of their stressful and complex lives is an obvious area for further research.

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Appendix A: Poster for Recruitment

Are You a Woman Diagnosed with Type II Diabetes?

Make a photography book with your story of living with diabetes to keep and share and get \$100.

Fun and innovative methods: take photos about your life with diabetes.

Learn to tell your own health/illness story.

People who create an illness narrative have better health outcomes and more empowerment and are better at health management.

What will it be like?

4 sessions, conducted in XX 2016, plus interview.

You will be provided with a smartphone with a camera and recording app to take pictures.

\$100 will be given when the phone is returned and you have completed the project.

Who will you be working with?

Sarah Gurley-Green, MA, is the lead researcher and will utilize this project for her doctoral thesis for Lesley University. She is a teacher, writer, and patient advocate.

Mary-Gayle Sweeney, BS, is a registered dietitian.

Call Sarah Gurley-Green: XXX-XXX-XXXX

Appendix B: Researcher Outline

Picturing Health; Picturing Life: Researcher Outline

Session One:

Aim:

- The goal of this project is to use photographs taken by you to tell the real story about what it is like to live with Type 2 Diabetes (T2DM).
- You will express through photography and telling the story of the photograph: why you took it, what it meant to you, and why it is important.
- This kind of photography is not like “holiday snaps.” We all tend to like photos that show “ideal happy snaps” and not life as it is.
- There are no wrong answers. We are interested in your own experience.

What to Expect?

- We will have four two-hour sessions as well as additional time for interviews (one each) about photographs.
- You will take photos and write or record some words about them. We will practice with the cameras and apps.
- You will receive a “visual narrative” with your own photos and words to share your story with whomever you like.
- You will receive advice from a dietitian.
- You will receive a \$100 check when you complete the program.

Review: Picturing Health; Picturing Life

- Thinking and discussing common problems, observations.
- “Brainstorming” together.
- Learning about photography; ethics of taking photos.
- Taking pictures.
- Interview about the pictures with Sarah.
- A visit from the dietitian.

Narratives: Why tell our stories?

- Through telling our stories, we create bonds with others.
- Helps order the importance of influences and key episodes in our own understanding of experiences.
- Stories can heal during the telling as well as listening.

What do I get out of the study?

- Telling your health/illness story helps you deal better with diabetes.
- People sometimes feel overwhelmed by diabetes. Taking photographs of experiences and sharing in the interview helps become more empowered.
- You learn from others in the group.
- You get some diabetes counselling.
- You get \$100 at the end!

Situated Selfie Photo

- Situated Selfie: A self-portrait photograph with a background that holds meaning for you.
- Please take a situated selfie outside of class after the first day.

Session Two

- Share “situated selfies.”
- Introduce the idea of a relational map.
- Brainstorm together about what we might take pictures about.

Situated Selfie Sharing

- What do you have in common?
- What do you see?
- Can you see yourself in others’ selfies?
- What is different?

Session Three

- Return the phones to download pictures.
- Reflect together on the experience of taking pictures.
- Give diabetes nutritional materials for the dietitian visit.
- Schedule individual interviews.

What Happens in the interview?

- I will print out all the pictures. We will videotape the sessions.
- We will make a relational map.
- You will select and discard the pictures for your story.
- You will put the photos in a story form that makes sense to you.
- I will ask you questions about the photographs. I may ask other questions as they arise.

Session Four

- Dietitian will visit.
- Give visual narrative books with your photos and words.
- Share them with others if you wish.
- Completion of the project!

Appendix C: Participant Outline

Picturing Health; Picturing Life: Participant Outline

Session One

Aim:

- The goal of this project is to use photographs taken by you to tell the real story about what it is like to live with Type 2 Diabetes (T2DM).
- You will express through photography and telling the story of the photograph: why you took it, what it meant to you, and why it is important.
- This kind of photography is not like “holiday snaps.” We all tend to like photos that show “ideal happy snaps” and not life as it is.
- There are no wrong answers. We are interested in your own experience.

What to Expect?

- We will have four two-hour sessions, as well as some additional time for interviews (one each) about photographs.
- You will take photos and write or record some about them. We will practice with the cameras and apps.
- You will receive a “visual narrative” with your own photos and words to share your story with whomever you like.
- You will receive advice from a dietitian.
- You will receive a \$100 check when you complete the program.

Review: Picturing Health; Picturing Life

- Thinking and discussing common problems and observations.
- “Brainstorming” together.

- Learning about photography; ethics of taking photos.
- Taking pictures.
- Interview about the pictures with Sarah.
- A visit from the dietitian.

What do I get out of the study?

- Telling your health/illness story helps you deal better with diabetes.
- People sometimes feel overwhelmed by diabetes. Taking photographs of experiences and sharing in the interview helps become more empowered.
- You learn from others in the group.
- You have some diabetes counselling.
- You get \$100 at the end!

Situated Selfie Photo

- Situated Selfie: A self-portrait photograph with a background that holds meaning to you.
- Please take a situated selfie outside of class after the first day.

Session Two

- Share “situated selfies.”
- Introduce the idea of a relational map.
- Brainstorm together about what we might take pictures about.

Situated Selfie Sharing

- What do you have in common?
- What do you see?
- Can you see yourself in others’ selfies?

- What is different?

Session Three

- Return the phones to download pictures.
- Reflect together on the experience of taking pictures.
- Give diabetes nutritional materials for the dietitian visit.
- Schedule individual interviews.

What Happens in the interview?

- I will print out all the pictures. We will videotape the sessions.
- We will make a relational map.
- You will select and discard the pictures for your story.
- You will put the photos in a story form that makes sense to you.
- I will ask you questions about the photographs. I may ask other questions as they arise.

Session Four

- The dietitian will visit.
- Give the visual narrative books with your photos and words.
- Share them with others if you wish.
- Completion of the project!

Appendix D: Consent Form

Lead Researcher: Sarah Gurley-Green, MA.

Faculty Senior Advisor: Robin Roth, Ph.D. Professor of Sociology and Social Policy, College of Liberal Arts and Social Sciences, Lesley University, Cambridge, MA 02138.

Description and Purpose of Research:

This is a doctoral research that uses the methodology of narrative inquiry using photography and individual interviews. Consequently, the participants are considered as co-researchers who make important decisions in the content of the research, such as what pictures to take to tell their own health/illness stories. The purpose of the research is to understand and describe the everyday experiences of women who have been diagnosed with Type 2 diabetes. This included the process of creating visual narratives using photography, written narratives co-created through interview and writing throughout the orientation, and photography projects. The research methods include visual narrative inquiry and audiotaped and transcribed participant-generated photo elicitation interviews.

What will be expected?

Attendance at four two-hour sessions.

Take photographs and write/record notes about them.

Allow photos and narratives to be used for research, dissertation, publication, and conferences.

There is an option for you to use a false name or your own associated with the photographs.

Participate in an audiotaped interview.

The project is expected to occur XX-XX 2016.

Session One: What is a health/illness narrative? Why is it important for chronic illnesses? Participant rights and duties are part of this process, including instructions on smartphones cameras and journaling, and discussion on the ethics of taking photographs and gaining consent. Take a situated selfie.

Session Two: Introduce photography. “Situated Selfie” sharing.

Session Three: Share experiences of the photographic narrative.

Individual interview

Session Four: A group meeting to share the visual narrative books and dietitian advice.

Risks/Benefits: There are no foreseeable risks to being involved in this activity, and the potential benefits include greater empowerment and self-management of diabetes. Once the audio files have been coded, they will be destroyed. This is a voluntary project and the subjects can terminate participation at any time.

There may be some triggering of past trauma in the process of narrative creation, but studies indicate this is beneficial. Severe triggering will be referred to a counsellor.

There is a Standing Committee for Human Subjects in Research at Lesley University to which complaints or problems concerning any research project may, and should, be reported if they arise. Contact the Committee Chairperson at irb@lesley.edu

I have read the information above and consent to participating in Picturing Health;
Picturing Life

_____ **Date** _____

Name of participant

Please provide your contact information:

Appendix E: Interview Plan

Orienting statement:

You are participating in this study because you are a woman with T2D.

I am interested in your experiences living with T2D in your own life. There are no wrong answers; you are the expert.

You will do several things today to help me understand your experiences.

Do you want to use your own name or a different name instead?

Relational map making:

How does diabetes affect your life? What things help?

Please look at this list and make a map with yourself in the middle along with other aspects of your life around you.

Show me how much things are affected or help by coloring in with a color of your choice.

You may look at this list to get ideas or make up your own.

Photo elicitation interview:

Sort through your photos.

Put them in an order that tell me the story of your experience with T2D.

You can discard some if you like.

I will ask you why you took each picture.

Visual Narrative Book

I will take the interview and put into a book with your photos for you to keep.

Appendix F: Demographics Table

Table 4
Demographics

Name	Age	Ethnicity	Mental health	Drug use	Smoker	Years with T2D	High self-efficacy	T2D family history	Pet
Barbara	77	Black	Unknown	No	No	30	High	Yes	Yes
Cecilia	49	Black	Depression	Crack/Alcohol	Yes	7	Low	Yes	No
Doris	68	Black	Unknown	Alcohol	Unknown	Unknown	Unknown	Unknown	No
Gabrielle	60	Black	Depression	Crack	Yes	12	High	Yes	No
Geneva	66	Black	Unknown	No	Yes	11	High	Yes	Yes
Jessie	74	Two or More	Bipolar	Alcohol	Unknown	Unknown	Unknown	Yes	No
Kara	54	Black	Unknown	No	No	3	High	Yes	Yes
Lela	73	Black	Unknown	No	No	11	Low	No	No
Mercy	60	Black	Bipolar	Unknown	No	5	Low	Yes	Yes
Mia	69	Caribbean	Depression	No	No	10	Low	Yes	No
Ruth	57	Two or More	Depression	No	Yes	10	Low	Yes	No
Shanda	62	Black	Depression	Alcohol/Crack	Yes	4	Low	Yes	No
Sylvia	52	Black	Depression	Crack	Yes	7	Low	Yes	No
Willow	79	Black	Unknown	Unknown	No	5	High	Unknown	No
Totals			8 of 14	6 of 14	6 of 14		5 of 14		4 of 14