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The Meaning of Type 2 Diabetes to a Sample of African American Adults and Their Adult Children

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**The meaning of type 2 diabetes to a sample
of African American adults and their adult children**

by

Margaret C. O'Connor

A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of
MASTER OF SCIENCE

Major: Human Development and Family Studies

Program of Study Committee:
Tera R. Jordan, Major Professor
Carolyn Cutrona-Russell
Daniel Russell
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Iowa State University

Ames, Iowa

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ABSTRACT

Research has explored how illness and its meaning can impact families (Scollan-Koliopoulos, 2004). However, there is limited literature on the interaction between parents who are ill and their adult children, and how family history influences communication about the illness. The purpose of this study therefore was to investigate the communication between African American parents diagnosed with Type 2 diabetes (T2D) and their African American adult children, especially because of the high rate of T2D in this population. More specifically, this study used the Family Systems Illness Model and Illness Narrative to investigate the meaning that T2D had in the lives of 20 African American families. The study sample was recruited from the Family and Community Health Study (FACHS), a longitudinal project on stress and health, producing interviews of 21 diabetic adults and their adult children. This study analyzed these data.

A phenomenological approach was used in this qualitative study, which had a unique perspective as both the parent diagnosed with T2D and their adult child were present for the interviews. The results showed that T2D's onset, course, outcome, and degree of incapacitation in relatives, as well as beliefs about T2D, impacted the meaning of the illness for both the diagnosed parents and their adult children in this sample. These findings underline the importance of family experiences with T2D as potentially contributing to better healthcare programs for individuals and families affected by this illness.

CHAPTER 1: INTRODUCTION

In the United States, 29.1 million people have been diagnosed with diabetes, with 1 in 3 adults being pre-diabetic (Centers for Disease Control and Prevention, 2014). Of those diagnosed every year, most are in middle to older adulthood (CDC, 2014). However, 1 in 3 people in the United States who have type 2 diabetes are undiagnosed (CDC, 2014). In 2012 alone, \$245 billion was spent on healthcare costs associated with diabetes. Specifically, Type 2 diabetes (T2D) can cause several health complications such as limb amputations, stroke, heart disease, and neuropathy (Xu, Qui, Wahlin, Winblad, & Fratiglioni, 2004).

T2D has three main stages. T2D starts with insulin resistance, which develops into mild postprandial hyperglycemia, which is high blood sugar following a meal, and then develops into diabetes which requires pharmacological treatment with daily doses of pills and/or insulin shots (Ramlo-Halsted & Edelman, 2000). Insulin resistance is when the pancreas needs to produce more insulin since the body is not producing insulin properly. Insulin resistance is due to cells failing to respond as they normally would to the hormone insulin. This would be the first stage of type 2 diabetes, which is typically called pre-diabetes. Eventually, the pancreas is not able to produce extra insulin to keep blood glucose levels normal. This leads to the need of lifestyle changes, oral medication, and insulin. There are groups who are at more risk for developing T2D, including African Americans. Certain risks associated with T2D are related to individual and family behaviors, increased age, cultural context, and genetics (CDC, 2014).

Background and Context

African Americans have an increased burden of illness when they have T2D. They are 1.4 to 2.3 times more likely to be diagnosed with it than their White counterparts (American Diabetes Association, 2001). African Americans also experience poorer T2D management, have higher comorbidities, as well as an increased rate of mortality related to the disease (CDC, 2014; Kirk et al., 2006).

Some studies have found that T2D can greatly impact health-related quality of life (HRQL) (Landman et al., 2010; Laiteerapong et al., 2011; Rejeski et al., 2006; Thommasen & Zhang, 2006). HRQL addresses a variety of quality of life components, including both physical and mental health. Those with T2D compared to those without it have lower HRQL scores and tend to be older, overweight, less likely to exercise, and more likely to have comorbidities such as hypertension, coronary artery disease, etc. (Weinberger, Kirkman, & Samsa, 1994).

Laiteerapong et al. (2011) found that HRQL was indeed lower for those diagnosed with T2D, across all components. Even more concerning were the results of a study of T2D patients by Landman et al. (2010), who after a 9.6-year follow-up, showed that 42% of patients had died, 49% of whom had cardiovascular disease. As can be seen, T2D has a number of comorbidities and the risk of other complications, such as limb loss or vision issues. Lower physical and mental HRQL have also been associated with a higher total mortality rate and cardiovascular mortality rate in patients with T2D (Landman et al., 2010). Moreover, the president of the American Diabetes Association during their annual meeting called for more research in regard to mental health and diabetes (Marrero, 2015).

The meaning of illness, for the purpose of this study, is defined as the association people make between the illness they or a loved one have been diagnosed with, which is influenced by personal, and family experiences with the illness. In T2D, the meaning of an illness may be related to, but is not limited to, management, lifestyle, quality of life, family history, the labels or language associated with it, perceptions, how one prevents T2D, and its causes, which may be viewed as genetic or inevitable. Understanding the meaning of illness from the perspectives of families who have T2D may be beneficial so that we better understand how these families interpret the illness and to see how family perceptions on T2D can influence family members' understandings of T2D.

Although there has been some research as to the meaning of an illness, or illness narratives, there has been none on the multigenerational legacy and meaning of T2D in African American families (Bhattacharya, 2012; Egede & Bonadonna, 2003; Liburd, Namageyo-Funa, Jack, & Gregg, 2004). This lack of research related to T2D and its meaning is of great concern since many studies have found that the meaning of an illness is greatly influenced by a person's family of origin, and how an illness develops and changes their life (Acury, Skelly, Gesler, & Dougherty, 2004; Alcozar, 2000; Bhattacharya, 2012; Broom & Whittaker, 2004; Castro-Riveras, Boutin-Foster, Milan, & Kanna, 2014; Egede & Bonadonna, 2003; Liburd et al., 2004; Manoogian, Harter, & Denham, 2010; Poss & Jezewski, 2002).

To address this lack of research on the meaning of T2D in relation to the African American family, I used the Family Systems Illness Model (FSIM) in this study. This model is an excellent tool to show the connections individuals have with their illness and how their family has influenced the meaning that they have associated with it. Although several

studies have discussed how family may influence the meaning of a person's illness, they were limited to only one family member, not multiple members, which could have allowed us to see a family's connection to the meaning of its member's T2D.

Problem Statement

Research has indicated that African Americans are significantly more at risk for developing T2D and co-morbidities related to it (CDC, 2014; Kirk et al., 2006). For this reason, the research for this thesis addressed what T2D has meant to a number of African Americans diagnosed with it, in relation to their family members' views, including their adult children. Understanding an illness such as T2D and what it means to an individual and their family may be key to addressing other health-related disparities in the African American community.

Statement of Purpose and Research Question

The purpose of this qualitative study was to explore with 20 African American families the meaning they associate with their illness of T2D. A better, well-rounded understanding of the meaning of T2D could better inform our understanding of what this disease means from the perspective of those who have it and their adult children who have observed their experience of it. To better understand this healthcare issue, the study addressed this primary research question: What does T2D mean to African American adults who have the disease and to their adult children?

Research Approach

With the approval of my university's institutional review board (IRB), I studied the experience and perceptions of 20 African American families regarding T2D from previously

collected interview data. These participants had a family history of T2D and were asked “What does diabetes mean to you?” I used a phenomenological approach for this investigation because this methodology allowed me to better explore the meaning of T2D for African Americans, from their viewpoints, using in-depth interview data of persons having the disease in their family. The results of this study include an analysis of the themes and patterns that emerged from the in-depth, individual interviews. The purpose of this method was to provide a detailed description of the participants’ experiences to better understand any nuances of meaning regarding their experience of T2D.

Assumptions

Based on my personal experience and background as a researcher and my experience of T2D in my family of origin, I made two primary assumptions regarding this study. First and foremost, family is essential to understanding a chronic illness, especially when that illness has occurred across generations, as T2D often has. This assumption is based on previous research that has explored the meaning of T2D, which was a common theme across the research (Acury et al., 2004; Alcozar, 2000; Bhattacharya, 2012; Broom & Whittaker, 2004; Castro-Riveras et al., 2014; Egede & Bonadonna, 2003; Liburd et al., 2004; Manoogian et al., 2010; Poss & Jezewski, 2002). Second, adult children’s understanding of what T2D is through their experience of having a parent who has been diagnosed with it presents a unique perspective. This assumption is based on the Family Systems Illness Model (FSIM) because it explores the history of illness, loss, and crisis across generations (Scollan-Koliopoulos, O’Connell, & Walker, 2005). This model helped address the multigenerational nature of T2D in the families that were interviewed, the results of which are reported in this thesis.

The Researcher

While I conducted this study, I was a research assistant in my third year of graduate school in Human Development and Family Studies. I had three and a half years of experience conducting and analyzing qualitative research, from which I had published two papers on T2D in Black men. Although I did not directly interview the subjects for the current research, I attended a number of their interviews, as well as listened to and read about many experiences other people have had with T2D. But also, I had first-hand experience with T2D in my family, specifically with my mother who has had the disease for about 12 years, and as a prediabetic myself during my early adolescent years (13-15).

Although my personal experience with T2D could have been a source of bias in the analysis of the study interviews, I believe it greatly benefited the analysis. It allowed me to reflect on my own experiences with a family member's T2D, and more importantly, it enabled me to connect with the study's data in a personal, meaningful way. To address concerns about subjectivity, my committee chair, Dr. Tera Jordan, reviewed my analysis of the data.

Rationale and Significance

The rationale for this study originated from my desire to uncover the meaning T2D has in African American families through the multigenerational experiences they have had with this chronic illness. It is important to give voice to these families and their experiences with T2D and to better understand the unique perspective they bring to this critical healthcare issue.

Increased understanding of the topic of an illness narrative, or the meaning of illness, is essential to better understand the perspectives of individuals who have been diagnosed with T2D. Specifically, understanding the multigenerational legacy of T2D, and the meanings associated with the disease that have been passed down through generations, is important for creating programs to help address the disparity in illness onset and its course in the African American community.

Chapter Summary

In summary, this research study sought to understand the meaning of T2D for a sample of African Americans, and the impact it has had on them and their families. This thesis includes an evaluation of the current literature in order to address the gaps in the research on the multigenerational effects of T2D. Following the literature review in the next chapter, I discuss my methodological approach to this thesis in Chapter 3. Following the methodical approaches used in this study, I discuss my analysis in Chapter 4. Finally, in Chapter 5, I discuss main themes from this thesis, limitations, and implications.

CHAPTER 2: LITERATURE REVIEW

Individuals are not just individuals; they come from different families, communities, cultures, and societies, as do those who have been diagnosed with T2D. So, it is important that we think about individuals in this context as it can help us better understand the perspective they may bring to discussing what an illness means to them. Understanding this perspective can help define an illness and determine the relationship between the illness and the family life they may have (Newby, 1996).

The purpose of this study was to explore the meaning of T2D for 20 African Americans diagnosed with T2D and their adult children. Specifically, I wanted to understand how their experiences could influence their definition and understanding of this disease. The guiding research question was: What does T2D mean to African American adults who have the disease and to their adult children?

Overview

To conduct this literature review, I used multiple sources, including books, dissertations, Internet resources, and professional journals, which I accessed through the ProQuest and PubMed databases. First, I discuss the Family Systems Illness Model (FSIM), which I used as a guiding theoretical framework for this thesis, including belief systems. Second, I describe the use of the Illness Narrative as it was also important to this study. Third, my literature review includes a critical assessment of the previous research on T2D, among African American families. Finally, in a synthesis of the literature review, I illustrate how the literature informed my understanding of T2D related to families, and how it guided the current study.

Family Systems Illness Model

In this study, I used the Family Systems Illness Model as the framework to understand and explain the healthcare issue under study. I chose the FSIM because it specifically addresses the history of illness, loss, and crisis across generations (Scollan-Koliopoulos et al., 2005). This model helped me interpret the multigenerational nature of T2D in the families that were interviewed for the study, I used phenomenology to discover what T2D means to the study participants based on their experiences.

The FSIM was created using a family systems framework, and was developed by Rolland in 1994. It has been used to address concerns about coping with different family members' illnesses, which at times can impact the whole family, especially children. This model has typically focused on children's illnesses and the impact they have had on parents (Rolland, 1994). When someone is diagnosed with a chronic illness, such as T2D, it affects the whole family. Such a diagnosis can lead to the destabilization of a family as they change in order to address the illness's effect on their family member (Galvin & Young, 2010). The FSIM provides a framework to understand this complexity of familial interactions with an illness, especially one that may have genetic factors such as T2D.

This model integrates the main influences of a disease on the family system and how they relate to chronic illnesses: illness type and beliefs about the illness (Fig. 1). The type of illness is represented by the center ring of this model. The second ring indicates the individual, family, and life illness cycles. The third or outer ring represents the family belief systems, which include culture and ethnicity.

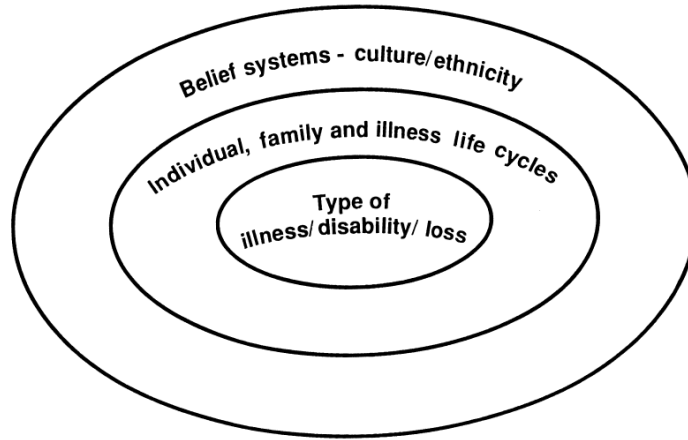


Figure 1. The Family Systems Illness Model (Rolland, 1994).

Type of Illness

Understanding the type of illness helps clarify the connection between the family and the family member's illness. It is therefore important to consider how the illness has presented itself in the family before. Rolland (1988) used four dimensions to describe the typologies of an illness: (a) onset (gradual vs. sudden), (b) course (progressive vs. constant vs. relapsing), (c) outcome (recovery vs. terminal), and (d) degree of incapacitation.

Onset.

All illnesses can be divided into two main categories, having either a sudden or a gradual onset. A sudden onset is an illness that appears rapidly and typically does not have prolonged symptoms before occurring. Gradual onset is one in which symptoms worsen over time. For an illness that occurs very rapidly, the family needs to respond quickly to solve the problem at hand, in what are often emotionally charged events (Rolland, 1994). For T2D, both gradual and sudden onset are possible. Some individuals may not notice the symptoms, or have none at all (ADA, 2015). These symptoms are sometimes attributed to other issues

such as stress or another illness. In one study, African American participants, who on average had been diagnosed with T2D for 11.6 years, had varying reactions to their diagnosis, from expecting it to disbelief at having contracted the disease. Although all of the participants experienced T2D symptoms, not all initially attributed them to T2D (Wenzel, Utz, Steeves, Hinton, & Jones, 2006). Even though individuals may not attribute their symptoms to T2D, it should still be considered an illness with gradual onset since most experience symptoms before their diagnosis.

Course.

There are three trajectories for the course of an illness: progressive, constant, and relapsing/episodic. A progressive illness is one that gets worse over time such as T2D. Although T2D is manageable, it is still considered a progressive course illness. T2D generally has a clear progression from pre-diabetes to medication dependency (Fonseca, 2009). With this type, a family lives with constant symptoms, their roles as individuals changing as the family member's illness worsens. A constant course illness is one that is typically followed by a stable and predictable change over time. A relapsing or episodic course illness has a distinguishable alternation between mild symptoms and flare-ups. This kind of illness requires a family to be flexible between times of normalcy and flare-ups.

Outcome.

Rolland (1994) explained that when a chronic illness leads to death and shortens someone's life span, it can have a devastating effect on the family's well-being. There is a continuum of illnesses that ranges from those that impact the life span, such as terminal cancer, to those that typically do not impact life expectancy but negatively impact quality of

life, such as arthritis. These illnesses, especially those that have a generational legacy, such as T2D, can impact how a family thinks about an illness. For example, if a person had limbs amputated as a complication of T2D, which eventually led to their death, family members may more likely associate this illness with one that shortens their life span.

Degree of incapacitation.

Illnesses can incapacitate an individual in a variety of ways, which range from impairment of cognition, sensation, movement, stamina, disfigurement, and those that cause individuals to experience social stigma (Rolland, 1994). How these incapacitations occur, or if multiple ones co-occur, can greatly affect a family's stress and what they associate with an illness. All of these effects are possible in T2D.

Belief Systems and Culture/Ethnicity

Understanding a family's cultural background and beliefs about an illness is important in addressing concerns they may have about it and the impact it may have on them. Family environment and family relationships are also important to consider as both have been seen to affect self-care behaviors and adherence to T2D treatment (Pereira, Berg-Cross, Almeida, & Machado, 2008).

According to Rolland (2012), two beliefs can impact how a family interprets an illness: (a) those relating to the origin of an illness and (b) those about the management of an illness. Furthermore, understanding the multigenerational legacy or history of a family illness is essential in that it helps establish what family members learn about the illness by witnessing what other family members have experienced with it (Scollan-Koliopoulos, 2004).

Beliefs relating to the origin of an illness are an important influence on the meaning a person associates with the illness. Since the beliefs about the origin of T2D can be intergenerational, the family myths, taboos, expectations, and belief systems related to the disease may be intermingled and influence the meaning patients attach to it (Walsh & McGoldrick, 1991). For example, if family members believe that T2D is genetic, they might also believe that having T2D is out of their control or inevitable. They might also worry that they could pass T2D onto their own children, which could cause them guilt. The severity of the illness and the experience family members have had with it could also influence the meaning and beliefs they have about illnesses (Rolland, 2012). Examples of more traumatic experiences patients may have had with T2D in their family could include death as a result of the illness, amputation, or comorbidities such as hypertension or coronary artery disease.

Family history plays an important role in the management of T2D. Family members who have been diagnosed with T2D may serve as a reference on how to manage the disease and can also greatly impact how they manage their own. From the perspective of T2D as a multigenerational illness, having parents who have been diagnosed with this illness could have a negative or positive influence on their attempts to prevent their own complications from the disease. Those who have observed their parent's management of their T2D may believe that they have a full understanding of the disease and thus not seek management education for themselves. On the other hand, patients from families who have had multiple members with T2D could possibly increase their own disease management as they might have more social support and understanding of the disease from others in their social network (Scollan-Koliopoulos, 2004).

It has been found that although culturally appropriate T2D self-management programs have better outcomes for patients with the disease, many physicians have not incorporated this element when recommending and coordinating T2D management programs (Smith, 2012). Yet, understanding a person's cultural beliefs about an illness, which is a part of their meaning making, could better help us understand the perspective of individuals diagnosed with T2D.

Cultural beliefs influence a person's conceptualization of their illness, which includes the origin, prevention, symptoms, and perceptions of treatment outcomes. Individuals within a culture often share a single cultural belief about the prevention, symptoms, complications, causation, and treatment of T2D as well (Smith, 2012). According to McGoldrick, Giordano, and Garcia-Preto (2005), culture is defined as the customary beliefs, social forms, and material traits that a group holds. The cultural beliefs about an illness, such as T2D, become a shared knowledge about the experiences of an illness in families and their community.

Cultural beliefs can also influence how a patient treats, manages, and gives meaning to T2D (Corin, 1995). In one qualitative study, African American participants (n = 31: 16 women, 15 men) had a general distrust of doctors' prescriptions for managing their T2D. Instead, these patients discussed their use of herbal medicines, homemade preparations, and "grandmother's recipes," which took care of them when they were young and helped manage their T2D, but only took medicine prescribed by a doctor when they were not feeling well (Bhattacharya, 2012).

Summary of FSIM

I chose the FSIM as my theoretical framework to guide my analysis of the data from the qualitative interviews I used (Scollan-Koliopoulos et al., 2005) because it addresses the history of illness, loss, and crisis across generations. This model also helped me address the multigenerational nature of T2D in the families interviewed, as well as in the context of their African American background. Using phenomenology in this study to discover what T2D means to those who have a family member who has been diagnosed with it, or have been diagnosed with it themselves, was expected to provide insight into some health behaviors and outcomes in this ethnic group.

Using the FSIM theoretical framework helped me identify a few key components to look for in the interview data on the study participants. I was looking for how T2D presented itself in their family, which could be reflected in how the participants described their family members' experiences of the onset, course, outcome, and degree of incapacitation from T2D. Second, I considered the individual, family, and illness life cycles of T2D and explored how the illness unfolded over time across each of these cycles. I also examined how the participants' belief systems and culture/ethnicity played a role in their understanding about the origin and management of T2D. All of these points were important to reflect upon in this study of multigenerational families in order to learn more about the meaning of T2D, especially related to their ethnicity.

Illness Narrative

As humans, we use the telling of stories to learn about ourselves, families, and cultures. This storytelling has commonly been referred to as narrative. These narratives tie

individuals together as well as help them make sense of the world through others' experiences. Chronic illness narrative has been used to explore the disruptive nature of illness, its meaning, and what is done to deal with it (Burry, 2001). Because T2D is a chronic illness, as well as one that occurs through generations of families, I explored how these familial experiences with T2D might impact an individual's understanding and meaning of their illness. Using this framework was beneficial to understanding part of a person's perspective on illness and the meaning they attach to it.

Illness narratives have been used in the medical setting to help facilitate better care for those diagnosed with T2D, including their physician (Kumagai, Murphy, & Ross, 2008). Because physicians and patients have different experiences with T2D, their narratives of how they understand this disease are inherently different from one another. Understanding the patient's interpretation of the illness is important for physicians as it can lead to better care (Broom & Whittaker, 2004; Hornsten, Sandstrom, & Lundman, 2003).

When it comes to understanding T2D and the risks it poses, some patients may have fatalistic expectations. Having expectations such as the possibility of amputations and needing to watch their blood sugar closely due to the fear of these amputations, have been seen to have poorer outcomes in terms of the patient's management of their T2D (Bhattacharya, 2012). From the perspective of the clinician, it may be helpful to understand the patient's underlying fears, worries, concerns, and familial history with the illness, which can influence how someone takes care of their T2D.

The interpretation of the illness after one has been diagnosed with it is influenced by a person's past experiences with it. Attempting to understand the illness narratives of African Americans and their beliefs about T2D may indeed provide clinicians and health

researchers a better understanding of T2D from the cultural perspectives of these individuals (Bock, 2012). Understanding their patient's familial history of the illness may be important for health practitioners in treating the patient.

The illness narrative takes into account how an individual experiences T2D through their family as well as their community. Liburd et al. (2004) used the illness narrative to understand the meaning that T2D has for African American men (n = 16, average age = 56.7, average duration of T2D = 8.5 years). In their qualitative study, the themes that emerged from the narratives they shared included: how someone develops T2D, the symptoms experienced before diagnosis, the significance T2D had in their life, as well as how T2D is a culturally marked disorder. The last theme was of particular interest as Liburd et al.'s (2004) participants felt that T2D was normative among African American populations, which made them feel more comfortable sharing that they had T2D with others. Their study underscores how the illness can reveal important information about how families view T2D.

Previous T2D Research

Based on my review of the literature on T2D and the meaning individuals associate with the illness, there were two main points of emphasis in the research. First, the methods used to determine these meanings were qualitative. Second, family is an important influence regarding an illness narrative and how it plays out in the meaning made of T2D. In my literature review, I found 11 studies regarding the meaning of T2D for individuals, all of which used qualitative methods to conduct their inquiry, which may show the importance of using an inductive approach to explore the meaning that individuals attach to this disease. Seven of the studies used open-ended or semi-structured, individual interviews (Acury et al., 2004; Alcozer, 2000; Bhattacharya, 2012; Broom & Whittaker, 2004; Brown, Avis, &

Hubbard, 2007; Liburd et al., 2004; Poss & Jezewski, 2002). The other four used focus groups (Carter-Edwards et al., 2004; Castro-Riveras et al., 2014; Egede & Bonadonna, 2003; Manoogian et al., 2010). Both open-ended/semi-structured interviews and focus groups can be used for a phenomenological study such as I conducted. A phenomenology is used to describe what participants have in common when they experience a phenomenon, in a sense, finding a universal essence (Creswell, 2013).

The samples in these 11 studies varied by ethnicity or country, although I found very few that focused on African Americans and the meaning they attached to T2D. The samples used in these studies included these ethnic groups: African Americans (Bhattacharya, 2012; Egede & Bonadonna, 2003; Liburd et al., 2004), African-Caribbeans residing in the United Kingdom (Brown et al., 2007), Appalachian Americans (Manoogian et al., 2010), Australians (Broom & Whittaker, 2004), Latino Americans (Castro-Riveras et al., 2014), Latino immigrants (Acury et al., 2004), and Mexican Americans (Alcozer, 2000; Poss & Jezewski, 2002).

Importance of Family in Illness

One common theme that persisted throughout a number of these studies, which helps show transferability, is that family is important and influences the perceptions, ideas, and meanings individuals attach to an illness. People experience illness in a context. They experience different things through their families as well as their community. These experiences inherently influence how individuals see the world around them and how they interpret things that happen throughout their lives. One of these experiences is illness, and for many, specific illnesses are a generational phenomenon. Illnesses such as T2D typically do not happen to just one individual in a family or in a community, as many experience it

themselves or through the lives of others. How individuals view T2D is influenced by how they see their family members handle their diagnosis and manage their illness.

Past experiences with an illness can affect an individual's understanding of it and what having it means to them. The FSIM shows that experiencing a more severe outcome of T2D, such as watching a relative lose a limb, can greatly impact how they may interpret and relate to the illness. In almost all of the studies in this literature review regarding the meaning of T2D, family history and past experiences played important roles in the participants' understanding of the disease (Acury et al., 2004; Alcozar, 2000; Bhattacharya, 2012; Broom & Whittaker, 2004; Castro-Riveras et al., 2014; Egede & Bonadonna, 2003; Liburd et al., 2004; Manoogian et al., 2010; Poss & Jezewski, 2002). These studies can be broken down even further into family experiences with T2D and its causes.

In several studies, when asked what causes T2D, many participants said that it is hereditary. In four of the studies that interviewed Latino populations, the heredity of T2D was a common theme as well as family members' experiences of the illness (Acury et al., 2004; Alcozar, 2000; Castro-Riveras et al., 2014; Poss & Jezewski, 2002). One of the Latino studies in particular revealed how the participants who did not have T2D, but had a family member who had been diagnosed with it, experienced and interpreted T2D. In the study by Castro-Riveras et al. (2014), the participants who had a parent diagnosed with T2D viewed the illness as something inevitable for themselves. They had a fatalistic interpretation of the illness, in which they believed they were destined to contract T2D because they are Latino and had a first-degree relative diagnosed with T2D. A first-degree relative is a blood relative such as a parent, sibling, or child (National Cancer Institute Dictionary of Cancer Terms, 2016). This fatalistic view was also observed in a study of African Americans as follows.

In Egede and Bonadonna's study of T2D self-management in 39 African Americans (2003), fatalism was the major theme. Most of the participants believed that T2D was inevitable for them. Their study revealed that the participants believed that T2D was a generational "curse" and that the only way to get rid of it was to not "claim it." Not claiming T2D meant that a person would, even if diagnosed with it, deny its existence, and not take medicine for it, as well as refuse laboratory testing and follow-up visits after the diagnosis. Some of the participants also believed that they could neutralize the family curse or have it skip their generation by not giving it power, that is, by choosing not to claim it. Most participants in Egede and Bonadonna's (2003) study had seen family members or friends who had T2D and either complications or some loss of normalcy because of their diagnosis. From these experiences, they interpreted a diagnosis of T2D as a death sentence. In another study, Mexican American women who observed T2D's negative impact on their family and friends interpreted it as something that shortens one's lifespan (Alcozar, 2000).

Manoogian et al. (2010) discussed how three communities in the Appalachians (n = 78) had a long family history of T2D. In their study, the participants talked about not wanting to pass along this disease to future generations as they saw its consequences in their own lives as well as in past family members who had suffered T2D. Similarly, Alcozer (2000) found that Mexican American women who had seen the illness course of T2D in family members, including both complications and death, greatly influenced the meaning they associated with having it. From this multigenerational experience of T2D, they viewed the disease as having future health complications and a shortened life expectancy. In another study where the participants were first-degree relatives of someone who had been diagnosed with T2D, they also viewed the illness as inevitable (Castro-Riveras et al., 2014). These

participants experienced first-hand what T2D had done to a family member with physical and emotional consequences that were both devastating and destructive. Castro-Riveras et al.'s (2014) explanations of this illness, both from the perspective of those who have T2D and those who have a first-degree relative who was diagnosed with it, show how family experiences influence the narrative and explanation of an illness.

EM as a Framework for T2D Research

In previous research, the Explanatory Model (EM) was used to identify the meaning of experiences with T2D (Alcozar, 2000; Acury et al., 2004; Poss & Jezewski, 2002). The EM can be used to illustrate why and how things work, or to explain a phenomenon and its intricacies. In medicine, the EM is used to elicit meaning about illness from the perspective of the patient so that the doctor can address concerns or issues the patient may have. As discussed in Lynch and Medin's research (2006), understanding the framework from which an individual is coming can be helpful to discover the meaning an illness has for them.

According to Alcozer (2000), the EM is used to develop the context in which one experiences T2D through both family and community. Using this framework, this author discussed how understanding an individual, which includes their family and community history of T2D, the genetic predisposition for T2D some individuals felt they had, and its perceived life threat, would be helpful to discuss the best course of intervention for that individual. Although most studies found in this literature review did not mention the EM, the questions the researchers asked individuals about T2D were similar to those in this model, which helped elicit the meaning of T2D for the individuals interviewed.

Synthesis of the Literature Review

What we know is that the interpretation of T2D is significantly influenced by individuals' family experiences of the disease, which shapes how they see the illness (e.g., as unavoidable, a death sentence, having complications, or as abnormal functioning). How researchers determined the meaning a person associates with T2D was found by using an inductive approach, that is, by using both individual interviews and focus groups. Both methods are excellent for use with a phenomenological approach in research (Creswell, 2014).

However, there are things we still do not know, as scholars have missed the mark when addressing the meaning of the experiences African Americans have had of T2D. The literature is lacking in this area. What this review also revealed is that although family greatly influences the T2D experience and the meaning of the illness, there has been little research on how a person's family has influenced the meaning of this illness for them. The research found regarding family and illness was limited to an interview of only one participant in the family (Acury et al., 2004; Alcozer, 2000; Bhattacharya, 2012; Broom & Whittaker, 2004; Brown, Avis, & Hubbard, 2007; Carter-Edwards et al., 2004; Castro-Riveras et al., 2014; Egede & Bonadonna, 2003; Liburd et al., 2004; Manoogian et al., 2010; Poss & Jezewski, 2002). Specifically, the intergenerational component of T2D is missing from the research (e.g., parent and adult child). Therefore, my thesis focused on this missing link. If we do not understand how T2D experienced in a family impacts the meaning individuals associate with it, we will fail to create family-based programs and interventions that will address the concerns someone has about T2D based on their familial association with the disease. Understanding the meaning of the illness is the first step in creating well-

rounded treatment and prevention programs for African Americans with T2D or potential T2D.

Chapter Summary

Although family beliefs have received plenty of consideration in terms of how they affect the meaning and definition of an illness, there has been significantly less research on the intergenerational transmission of these beliefs, even though it is a core tenet of this model. What is even more concerning is the lack of research on this transmission of illness beliefs specifically among African Americans in regard to T2D, especially given the fact that they are 1.4 to 2.3 times more likely to get the disease than other groups in the U.S. (American Diabetes Association, 2001). Family is the core source of education about T2D (Scollan-Koliopoulos et al., 2005). Therefore, understanding the family history of this disease will be essential to understanding the meaning individuals attach to it, as well as the influence this may have on their own children's interpretation of T2D.

Another limitation of the current literature is how cultural beliefs have influenced African Americans and the meaning they attach to T2D. Although there is a significant amount of literature on how culture can influence one's origin, prevention, symptoms, perceptions, and treatment outcomes of an illness, there is little research on how cultural beliefs can impact one's interpretation of an illness, especially for African Americans. This area is of great concern as there has been a call for more programs and research that are culturally tailored, because such programs have found better adherence rates and outcomes for individuals (Black, 2002).

Although previous research has used the EM to discuss and describe the illness narrative, the FSIM is used in this thesis as it also addresses the intergenerational component of the illness narrative. The FSIM is an important conceptual framework to help researchers, practitioners, and policymakers better address concerns about T2D. Understanding the individual and family meaning-making of what T2D is will be an important step in this process. There are several important reasons for understanding what this illness means to individuals. By understanding how they interpret an illness such as T2D, we can begin to have a clearer view of how their interpretation has been influenced by their family experience.

Illness has a multigenerational component. We can begin to see this in the interpretation of an illness such as T2D by asking individuals what T2D is and what it means to them, which will lead us to better address concerns individuals may have about the disease. For example, someone who sees negative outcomes from poor management of T2D may have a different interpretation and understanding of the illness than someone who has seen people positively manage their T2D. By understanding this notion, especially as practitioners, we can provide better and more individualized treatment plans for those diagnosed with T2D and possibly prevention programs to change behaviors and the lives of families who have experienced T2D in their own families as well as their communities.

To address the lack of a family component in the literature, I chose to analyze data collected from adults who had been diagnosed with T2D and their adult child. who was interviewed concurrently. During the interview, each parent and their adult child were asked the following question: What does having T2D mean (e.g., loss of freedom, loss of life)? Prior to analyzing the interview data, I hypothesized a few relationships. First, there will be

a family narrative about T2D between the parent diagnosed and the adult child. Second, the lived experience of having T2D as well as seeing a family member with it and their experience, will inherently influence the meaning of T2D for the participants. Third, there will be parent-child interactions that will influence the adult child's meaning of T2D.

CHAPTER 3: METHODS

The purpose of this study was to discover the meaning a sample of 20 African American adults associated with the diagnosis of their T2D, and their adult children's response to their disease and its implications. For lack of research exploring the perspective of what it means to be diagnosed with T2D as an African American, and their adult child's response, it is important to give this population voice.

Therefore, for my study, I focused on the sample's meaning-making of their T2D, which was central to addressing my research question: What does T2D mean to African-American adults who have the disease and to their adult children? To further understand the participants' perspectives, I used a phenomenological approach to derive the meaning of T2D from their experience, using data from previously conducted personal interviews. Studies have shown the importance of this kind of research, particularly in the social and health sciences (Edwards & Titchen, 2003; Nieswiadomy, 1993). A phenomenological approach was essential to give voice to this underserved group, which had not been studied in depth in regard to their T2D diagnosis. To obtain a fuller understanding of what T2D means to African American adults and their adult children, I used a qualitative approach to review previously acquired interview data that were relevant to this study.

A phenomenology is intended to describe what participants have in common when they experience a specific phenomenon, in a sense, to identify a universal essence through their personal experience (Creswell, 2013). According to Creswell (2014), there are characteristics that make a sample particularly appropriate for this approach. The participants for this study were heterogeneous. They had all experienced T2D, through a family member and their own diagnosis. Also, their lived experiences of T2D had been both

subjective and objective. In addition, the data collection procedure involved interviewing 41 individuals (parents and adult children, 1 family of both parents and 1 adult child) who had experienced this phenomenon. Lastly, the analysis of this interview data focused on what the participants had experienced and how they had experienced it.

Research Sample

Purposeful sampling was employed to derive participants for the study, who were recruited from the Family and Community Health Study (FACHS), a longitudinal project about resilience and vulnerability in African American families, which has been conducted since 1997 and included a cohort of 733 families, half residing in Georgia and half living in Iowa. The FACHS recruitment procedures have been described in greater detail elsewhere (Cutrona et al., 2003). The Iowa sample was used in the present study and was recruited between May and July 2014. We recruited one member from the parents' generation and their young adult child whose average age was 27 years (n=41) for qualitative interviews. Thus, for this study, each family was comprised of two members of different generations. The selection criteria also included a current diagnosis of T2D in the parent or adult child and at least one other biological relative (e.g., parent, brother, grandparent), living or deceased, who had been diagnosed with T2D. Both the parent and adult child had to consent to participate in the study.

In total, 18.4% of FACHS primary caregivers and romantic partners were diagnosed with T2D in Wave 6. The mean age was 49.86 (range 25 to 93). The average household income was \$35,000 (range less than \$10,000 to \$200,000 or more). The average individual income was \$25,000 (range \$0 to \$200,000). Parent mean education was some college (range fifth grade – advanced education (i.e., PhD, JD, DDS, MD). The mean target age was 23.59

(range 21 to 26). The mean target individual income per week was \$400 (range \$0 to \$1750). Mean target education was some college (range third grade to graduate training).

Families from the FACHS cohort were mailed information describing the proposed qualitative study in Iowa, after which FACHS personnel called the potential participants to request that they take part in the study with their adult child. A total of 57 families met the eligibility criteria for the study. Of these, 20 families agreed to participate, 8 declined, and 14 were ineligible; 1 did not show for the interview, and 13 could not be reached for scheduling (35% response rate). The sample size of the eligible participants was 41 (males = 14; females = 27). In total, 21 parents who were diabetic (males = 6; females = 15) and 20 adult children (males = 9; females = 11) took part in the study. All participants were African American.

Altogether, 20 parent-adult child interviews were conducted, each dyad being interviewed at the same time. In one family, the parent and her partner had both been diagnosed with T2D, so both participated in the interview with their adult child. Of the adult children who participated, 19 were nondiabetic while 1 was diagnosed with T2D. All participants identified as African American. The mean age of the adult parents diagnosed with T2D was 56 (range 46 to 78). The mean age of the adult children was 27 (range 20 to 28). The mean annual income of the adult parent diagnosed with diabetes parents was \$30,000-\$39,999 (range \$4,999 or less to \$70,000 or more). The mean annual income of the adult children with a diabetic parent was \$30,000-\$39,999 (range \$4,999 or less to \$70,000 or more), with one participant abstaining. The mean educational level of the adult parents diagnosed with T2D included some college or technical school (range: from less than high

school to a college degree). The mean educational level of the adult children was some college or technical school (range: from less than high school to a college degree).

Ethical Considerations

The data for my proposed study had already been collected from the research sample just described. I had been involved in that study as a research assistant in the Department of Human Development and Family Studies at Iowa State University. A detailed outline of that proposed study was submitted to the university's Institutional Review Board (IRB) State University for research with human subjects, and approved prior to the data collection (see Appendix). I participated in part of that data collection, which is described as follows.

Data Collection Methods

I derived the data for my study from the semi-structured interviews of 41 participants selected through FACHS by the primary investigator for whom I was a research assistant. I helped in conducting some interviews but the principal investigator interviewed all participants. Prior to the interviews, signed informed consents were collected from the participants, which detailed both the benefits and risks of participating in the study, issues of confidentiality, and the overall purpose of the research. All the interview questions, protocols, and informed consent forms had been approved by the Iowa State IRB prior to the data collection. Table 1 presents the interview guide used for the main research question: What does T2D mean to African American adults who have the disease and to their adult children?

Table 1***Interview Guide***

Areas to Explore	Key Questions	Probes
Meaning of being diabetic	<ul style="list-style-type: none"> • What does it mean to be diabetic? • What causes someone to become diabetic? You? • What places someone at risk for diabetes? • What can people do to prevent diabetes? • Given your family history of diabetes, what (if anything) can you do to help prevent or reduce diabetes in your family? 	<ul style="list-style-type: none"> • For Blacks? For men? For parents and children? For families? • Myths? Misperceptions?

The interviews of the consenting participants had been conducted during the summer of 2014 by Dr. Tera Jordan, an African American faculty member with advanced training in qualitative methods. The participants were interviewed at community recreational centers, with the exception of one adult with T2D who was homebound. The interviews were conducted in private meeting rooms at local community centers in both Des Moines and Waterloo, Iowa, and lasted 45 to 90 minutes each. These centers were chosen because they were centrally located in both communities. The meeting rooms were easily accessible to the participants and provided privacy. As a research assistant to Dr. Jordan, I observed the interviews to gain an understanding of how the qualitative interviews and research were conducted for the data I would use for my study.

Except for one family (involving both a parent and a romantic partner), there were two participants (parent and adult child) in each interview, the parent with T2D and their

adult child. They were all asked open-ended questions pertaining to their T2D and experiences with this chronic illness. This method allowed both the parent and the adult child to reflect on their T2D and its impact on their family. The interviews were recorded on two audio devices to make sure the contents were captured completely, then transcribed by professional transcriptionist Malinda Mabry-Scott. Dr. Jordan had a previous working relationship of 10 years with this transcriptionist, who transcribed the digital interviews electronically. Mabry-Scott's transcripts were then checked by members of a research team, comprised of both undergraduate and graduate students, to ensure that the audio recorded interviews were as accurate as possible. The interviewees were assured anonymity, all identifying information was removed from the interview transcripts, with each participant's transcript being given a code in place of their name. These transcripts were kept on a secure server at the university to further protect their confidentiality.

Overview of Information Sought

My goal in the current study was to describe the participants' perceptions of the meaning of their experiences of T2D through my analysis of the data from Dr. Jordan's interview transcripts. To address my study's research question, I analyzed demographic and perceptual response information from the transcripts, which I had permission to use as indicated in the IRB approval of Dr. Jordan's study. The participants' demographic information (e.g., age, gender, ethnicity, income, education, family history of T2D) were important for exploring what might underlie the meanings these adults' and their adult children's associations with the parents' T2D.

In addition, I analyzed the phenomenological data about how the interviewed adults viewed the meaning of their T2D. To address my research question, it was important to learn

these African Americans' perceptions of what it means to be diagnosed with T2D. Specifically, I intended to uncover their recollections of their lived experiences related to how they attribute meaning to their T2D.

Overview of the Research Design

Guided by the Family Systems Illness Model, I conducted my phenomenological qualitative research inquiry using the data from Dr. Jordan's interview transcripts, to examine the meaning of having T2D from the perspective of African Americans who have had a family history of the disease. A qualitative research study would provide a unique perspective that had not previously been used in other research of this kind. This study would also help provide a more accurate, rich description of the meaning of T2D for these African American families, and the perceptions they have about what T2D is.

Data Analysis and Synthesis

To analyze the data from the previous interviews, I coded the questions and responses as they related to the meaning of being diagnosed with T2D as an African American. I used open coding to find the emergent themes in each interview, which has been found to be a useful technique for analyzing qualitative data (Creswell, 2014). For this process, I specifically examined questions in the interviews that related to the meaning of having T2D. At other times, I looked at what the participants mentioned regarding how they felt or what they identified as a diabetic. I read each transcript carefully to find all the pertinent information related to the research question. During this process, I noted instances in the transcripts of when the participants discussed the meaning of T2D, coding them as I went through them. After I had gone through the interviews once and coded them, I looked for

emerging themes and how the interview responses related to one another. I used content analysis to identify these themes. To help establish my coding schemes and check for credibility, my coding was checked by my thesis advisor who is an expert on African American families and qualitative research methodology. I had also received thorough training by my advisor for the past three years in qualitative studies, specifically phenomenology.

To capture the dyadic nature of this study, I analyzed the data from each interview of both the parent and adult child, individually, and noted instances of communication about the meaning of T2D between the parent and adult child. There were times when the parents and adult children agreed, disagreed, or called each other out when the other family member was not forthcoming or honest with information they were presenting, as these family members talked about their disease and the impact it has had on their individual lives, as well as on their family and community.

Issues of Trustworthiness

For this qualitative study, I considered three issues regarding the trustworthiness of the research: (a) confirmability, (b) dependability, and (c) transferability (Bloomberg & Volpe, 2012). These issues are important to consider when performing a qualitative study, as well as my role as a researcher to give a clearer picture of how I systematically reviewed the data. Addressing my personal health history and role as a researcher were also vital to understanding any influences my background might have on my data analysis and findings.

Credibility

Credibility is important when considering if the findings of a qualitative research study are accurate from the viewpoints of the researcher, the participant, and the reader. This is a vital component of a qualitative research design to help test the validity of conclusions reached (Creswell, 2014). To address the issue of the trustworthiness of the research and increase the rigor and validity of this study, I analyzed the data using several different methods. This data set is incredibly rich in information, as these types of interviews often are. I listened to the audio recordings as well as read the transcripts of the interviews, which gave me a fuller and richer understanding of the phenomenon of what meaning is attached to T2D is from different perspectives. I carefully read each case again to find more instances in which individuals shared their experiences about being diabetic and what it means to them as well as to their adult children. To help clarify my thought process for coding the data, I maintained an audit trail as well as, using an Excel document containing the participants' examples of the meaning of their T2D. I was the only person to code the data for this project; therefore, there was no inter-rater agreement to be computed. To help ensure that their responses were interpreted in a way that best reflected them as individuals, I revised and discussed my emerging findings with my master's thesis chair, Dr. Jordan.

Dependability

In quantitative methodologies, dependability is usually referred to as reliability. With qualitative research, reliability is found in how consistent and dependable the data collected are. When inconsistencies in coding are found, i.e., cases that do not fit the schemas already seen in other cases, it is important to note them instead of eliminating them. Inconsistent cases could possibly lead to a new coding schema or a new code altogether. To help create

dependability in this study, I listed my process of coding in great detail after I had completed the analysis and indicated how I came to my conclusions from the coding I used. This process would also give these data more confirmability, along with using an audit trail.

Transferability

Transferability is about whether or not this particular phenomenon in this particular context could apply to another particular context. I have provided a thick, rich description of the participants' responses as well as the context of their experience of T2D. Descriptions of participant responses as well as methodologies used is important so that this research can be replicated in the future and could potentially be transferable to other groups and families residing in other geographic locations. The families interviewed were residing in an urban area and thus, had a shorter distance to access health care, if desired. As was shown in the literature review, families experience chronic illnesses together, and illnesses such as T2D affect the entire family.

My Background as a Researcher

T2D manifests as a disease as a result of both lifestyle factors and strong heredity links (Ali, 2013). I have a strong family history of T2D. On my maternal grandmother's side of our family, nearly all her siblings have T2D except for herself. On my maternal grandfather's side, which has a Latino heritage, the majority also have T2D. My mother has had T2D for 12 years. I have seen her struggle greatly with managing this disease since her diagnosis. I, myself, was pre-diabetic for quite a few years as a teenager.

My personal tie to T2D has been a significant influence on and role in my interest in researching the social aspects of this disease. My mother's illness has been an important

facilitator of how I understand T2D from the perspective of someone who has it. This experience has been beneficial in how I related to both the adult parent with T2D as well as their adult child in my research. I found I had much to relate to in understanding the disease from the perspective of a child of someone who has T2D.

Limitations and Delimitations

This study had a few limiting conditions, some of which are related to common critiques of qualitative research. Careful thought and consideration were given to some of these limitations to minimize their potential impact. One critique that qualitative research often receives is that the analysis depends on the thinking and choices of the researcher, which can create subjectivity, which can affect the interpretation of the data. I addressed this concern in a few ways. As the researcher, I acknowledge my own family history with T2D. Although this history may have been a concern for biasing the interpretation of the data, I argue that it was, indeed, a strength to be able to relate to the study participants' diabetic experiences in a meaningful way. Having a parent with T2D myself, as well as having been diagnosed with prediabetes myself in the past, had given me knowledge and understanding of how T2D impacts the family.

Understanding the perspective I brought to this study was important as it also guided how I analyzed the data, just as theory guided my analysis. After attending a workshop with Johnny Saldana (2015) regarding coding in qualitative research, I began to understand how my perspective on T2D influenced my research interest and has given me a passion for research about families who have a family history of T2D. The view of a researcher in qualitative research is based on the researcher's own values, attitudes, and beliefs about a topic (Saldana, 2011).

Like the theoretical framework, my perspective gave this thesis a framework as well. I have personally seen how T2D impacts the family, especially how the illness is communicated to offspring and relatives. The view that I brought to this study helped me frame the experiences of these families in trying to understand what T2D means to those who have a long family history of the illness. As the adult children discussed their fears and concerns about their T2D in the interviews, I was reminded of my own fears and worries about it since I am at a high risk for developing T2D since my mother has T2D, as well as several of her aunts and uncles. I could personally relate to these adult children as perhaps another researcher who had not had experiences like mine could not have, or not understood as I did. Therefore, my personal insight was truly a strength for analyzing and establishing the themes, and keys to the communication that the families in the study have had about T2D.

Chapter Summary

In summary, this chapter has provided a detailed description of the research methodologies that were employed in this qualitative study. A qualitative interview methodology helped illustrate the phenomenon of the meaning that people attach to T2D, both from the perspective of African American adults diagnosed with it and their African American adult children. The sample for this study included 20 carefully selected families, and their interview data were reviewed until themes emerged. A review of the literature had been conducted to help create the conceptual framework for the analysis of the interview data that were used in the study. Through careful analysis of the data set, I have identified key themes and coded each case accordingly.

CHAPTER 4: RESEARCH FINDINGS

The purpose of this qualitative inquiry was to explore the meaning T2D had for a number of adults diagnosed with type 2 diabetes and the responses of their adult children to their parent's disease. The following research question informed this study: What does T2D mean to African American adults who have the disease and to their adult children? A better understanding of the context in which this illness occurs, from the perspective of families who have a deep familial history of T2D and how they have communicated this illness, helped me understand the experiences and perspectives of the sample relative to this condition.

This chapter presents the key findings from my analysis of the data from 20 face-to-face, previously conducted, individual interviews where both the parent with T2D and their adult child (n=41) were present together. I conducted a phenomenological analysis of the interview transcript data, from which the following two major themes emerged:

1. Illness type (onset, course, outcome, degree of incapacitation)
2. Beliefs about the illness (family environment, family relationships, family communication)

Theme 1: Illness Type

Past experiences with diabetes influence individuals' meaning, which was part of the storied nature of the legacy of diabetes in these families. To be included in this study, the participants were required to have had other family members who had been diagnosed with T2D. All the participants then had past experiences with the illness, aside from their own personal ones from the time of their diagnosis. These helped define the illness type that T2D

was in regard to onset, course, outcome, and degree of incapacitation, as they emerged from the data.

Onset

The onset of an illness can impact the meaning individuals attribute to T2D. Did T2D come on suddenly or was it more gradual in the family? How individuals experienced onset may have influenced their perceptions about T2D. In all the cases, all the family members in the study had experienced the onset of T2D through the experience of a parent being diagnosed with T2D. This onset varied for the adult children as they were all at different ages when their parent was diagnosed. The parents diagnosed with T2D also had different experiences related to diagnosis, from being diagnosed during a routine doctor's visit to experiencing complications because their T2D had gone undiagnosed. There were three emergent ways that the participants' diabetes had been diagnosed: (a) no symptoms, (b) mild symptoms, and (c) severe symptoms.

No symptoms.

Six families discussed how they had not experienced symptoms prior to their diagnosis. In these families, T2D was discovered through a routine checkup with their healthcare provider or when they were seeking medical attention for an unrelated reason. Susanne, the 47-year-old mother of 27-year old Morgan, had been seeking a knee replacement when she found out from her doctor that she had diabetes: "I kept going to the doctor for, cause I had a knee replacement, so I kept going to the doctor for my knee so then he did some tests and then he did more tests and then he caught me with it and said I was a diabetic. Well, actually I was at my, actually I was at my mom's when I got the call and, uh,

he called me personally, so I knew something was up, and then he said “diabetes” and I’m like “ok.” And my mom was like “Well, I knew it.”

Other families were at a routine annual checkup when they were diagnosed as Annie, 54-year-old mother of 28-year old Ryan, explained, “I went to the doctor and you know how they just give you a, a general, uh um, check over and then they’d ask me, ‘You know anybody have diabetes?’ and I told them that my mom did and they said, ‘Well can we check you for that?’ and they did, and then that’s how I found out.”

Moderate symptoms.

Eight families in the sample experienced moderate symptoms of T2D, which led to their diagnosis. The moderate symptoms these individuals had were related to either vision problems, such as it going blurry, or extreme thirst. Teri, the 53-year-old mother of son 26-year old Taylor, who had been experiencing vision changes, Teri said,

....\ I had to go to the eye doctor cause my eyesight kept changing; it was just doing weird things so I went and got the prescription for the glasses and then like two weeks later it, the prescription was not working, so I had to go back to the eye doctor and he’s the one who told me to check and see if I was diabetic and that’s how I found out that I was diabetic. I went to my primary care physician and, um my, when I was there that it was so high that it didn’t even read and, but she didn’t do anything for me! No. I mean she kinda just sent me home and so there was another doctor in that office who, um, got me in, got me started on the insulin. Yeah, she just, yeah. She just sent me home; didn’t give me anything, no medicine, no nothing, no nothing and it was. And then even when they sent me to the like the classes, the nutrition classes

and they you know was checking our, um, our sugar and mine was still on something, it was off the chart; you couldn't, it wouldn't even register so they advised me to go to the emergency room.

Severe symptoms.

Eight families experienced severe symptoms of T2D, which required medical attention and often delayed seeking care. These symptoms lead to their diagnosis and were primarily related to hospitalizations due to these symptoms. Since these individuals were unaware of their diagnosis, they were at times, participating in harmful behaviors, such as drinking sugary drinks.

Sally, 50-year-old mother of 29-year old Kevin, had been experiencing severe eyesight problems. She did not want her family to worry about her, so she did not tell anyone what was going on with her. She instead elected to let her daughter borrow her car rather than drive her to work as she had been doing in the past as she continued to have vision problems and was not able to drive anymore. After experiencing vision loss, where she ran over the curb while driving, she began to experience extreme thirst, which lead her to drink Kool-Aid, a sugary drink:

Um, what happened...I thought I had the flu or something. I remember going to the casino on Halloween and there was so many people in there. It was real smoky and I have a lung condition also. So I had to leave out of there cause there was so much smoke, and when I got home I just kept coughing, coughing, coughing, so I went to the doctor. They said I had bronchitis so they gave me something, uh, a nebulizer machine, and I went home, and it started getting worse so I went back to the doctor.

They said I had pneumonia, so they gave me some different medicine so I started taking that. Well, I started feeling better but then something was still getting worse and worse and worse, and I started getting so thirsty. I just stayed thirsty and I couldn't understand it, and I was going to make Kool-Aid, wrong thing. I didn't know. And I was going to make Kool-Aid and I would get me some and go sit down and drink it, and finally that wasn't enough. I started just making the whole pitcher of Kool-Aid and taking it, the whole pitcher to the couch with me, and I would just drink it, and I was drinking like two or three pitchers of Kool-Aid a day, water cause I was just so thirsty. And I didn't know and then, um, one night I got up to go to bed but when I woke up, it was the next morning and I was still in my den, and I lived by myself, my head was the only thing on the couch. My body was on the floor so I'm like, ok, I must have stood up and then passed out or something.... And I never called anybody asked for them to come take me to the doctor. I don't voluntarily go if I don't have to so I, but I called my brother and, no, I called him and I asked him to come take me to the emergency room. He was on his way to work. He told me to call my brother. He said but if he can't come call me and I'll call into work. So I called my brother and he already, when I said come take me to the emergency room, he just said I'm on my way. I don't remember how he got in my house or nothing but he came and he took me to the hospital. What I hadn't told him was I had been losing my vision, and I didn't know what was wrong. I was scared to tell them like how close we're sitting I couldn't see your face. And so, she [nurse] um, put me in the room and they drew blood. They came back a few minutes later and was like, and "How long have you been diabetic?" I said I'm not diabetic. They was like "Yes,

you are.” I said, “No, I’m not.” She said they looked back at my blood work history and it had already been recorded but nobody ever said anything to me. And that day my blood sugar registered so high it was over a thousand. They said they knew it was over a thousand because that’s high as it goes on their meter. Now, what it really actually was they don’t know. To bring my sugar down. Well, I went to sleep, well I didn’t go to sleep. I just was closing my eyes. I was just laying there and I could hear the nurses outside. They thought I was asleep and I heard the nurse say I don’t know why he’s wasting the time to take her up to ICU. My kidneys and stuff had started shutting down. And he said she might, he might as well just leave her down here until everything was over with. I’m like over with? And she was, like yes, she was like that’s just a waste of time and room and everything. I was like, oh God, they think I’m asleep so when my brother came back in, he’s a minister. I was like “X” they think I’m going to die. He was like what? So he pulled the curtain and he started praying and they came in and they gave me insulin and, um, in like 20 minutes my blood had come down to like three something so they still admitted me into the hospital. But that’s how I found out I was diabetic.

During the interview of Sally, her son Kevin also reflected on his mother’s experience, saying,

I mean it was just like she said, it was pretty eventful, you know, and then like, I mean, I didn’t know like I guess how bad it was till after it was all over ‘cause like maybe a few weeks after her episode my same uncle had the same episode where he went blind. He, I mean pretty much the same thing that happened to her happened to her brother. you know, the same episode of the. uh, the diabetes or whatever. so I

mean it was, it happened so fast you know. Now that I look back at I'm, you know, thankful or whatever but at first it was just like, you know, just kind of a loss for words 'cause I mean, you know, we just had our mom growing up so.

Course

Participants revealed two themes about management during the course of their illness. Family members who did not properly manage their T2D had more complications, which shows that T2D is very progressive. Individuals saw family members deal with the ins and outs of managing their T2D, such as watching what they ate, testing their blood sugar, and sometimes taking insulin to help properly manage their blood sugar. The two courses of management that emerged from the data analysis were: (a) diabetes as an everyday part of life, and (b) diabetes and vigilance.

Diabetes as an everyday part of life.

Eight families discussed how diabetes impacts their everyday life, from checking their blood sugar to watching their diet. When someone is diagnosed, diabetes care, compliance, and proper management are vital for preventing complications. Management becomes an everyday part of life. As Marcus, 62-year old father to 28-year old Christy, reflected, "Well, to me it's not the end of the world. You know diabetes is a disease you got it and you just got to live with it." Teri, 53-year old mother to 26-year old son Taylor, who was experiencing vision changes prior to her diagnosis, reflected on how she remembered her mother managing her diabetes, saying,

Um, basically, just making sure that she kept a, a log on, you know, whether her sugar was low or high. Um, she, hers was controlled through medication and not the

insulin. Mine is both, so that's when I really started paying attention to it, and then I had a girlfriend that, um, had, was diagnosed with diabetes and she was gosh, probably in her 20s, and she was really, um, like tripping about having to give herself shots, and so she would carry this orange around and, um, you know poke the orange like she was giving it a shot to try to get herself you know ready for it.

Diabetes and vigilance.

At times diabetes requires extra care when taking care of oneself. Although there were similar experiences of diabetes being daily part of life, participants also discussed how important it was to be extra careful when managing it. What was common through these four families' narratives was seeing other family members suffer from complications of the illness. Individuals took extra care to manage their diabetes because as the participant Paul, 55-year-old father of daughter 28-year old Beth, reflected, he "doesn't want to go down that route" as his own mother had who had many complications from diabetes including vision loss and amputation. While Teresa, 78-year-old grandmother of 27-year old Eric, discussed how important it is to be careful, saying, "Oh, to be a diabetic, it means that you've got to be very careful about things that you eat. You don't eat a lot of fried foods; you try to stay from that. It just means you are just careful of what you do and the portion size of what you eat."

Lacey, 27-year-old daughter of John, had watched both her father and stepmother, Martha, manage their T2D. When reflecting on their illnesses she explained why she did not want to get diabetes someday:

Um, it makes me think I don't want to get diabetes just because you have to stick yourself with a monitor. Um, you know what you're eating and sometimes you have

to be on a specific diet too – how to maintain that, I feel like I have my dad who is diabetic, but I don't think he is the same as my mom gets, if he goes too low then he starts to having shakes, and I remember my stepmom would have to carry candy around a lot because he would just have the shakes. So I kinda can see both extremes and same thing – didn't Uncle Ronnie pass away from his blood pressure – I'm sorry, his blood sugars being too high? So I see a lot of negatives around that and, um.

Outcome

There were two main outcomes of diabetes that were related to not being able to perform the same tasks as prior to diagnosis, or having a shortened lifespan/death. The outcome for these individuals was either from seeing family members die from complications of diabetes, or in a couple of cases, men discussing how some men could not perform sexually after the diagnosis of T2D.

Death/shortened life span.

Five families discussed how diabetes had led to a premature death of a loved one. In one, the death of their aunt who was diagnosed with T2D determined the food choices in the house after her passing. As Nancy, 51-year-old mother to daughter 28-year old Alice, explained, “Um, the Aunt that raised her [mother] as an infant, uh, she had diabetes. And, uh, she went blind and she later died from complications of diabetes, so no sugar was allowed across the threshold. Dad was diagnosed when I was six months of age with heart disease, so no salt was allowed across the household threshold and no meat brought in the house.”

Ron, 56-year old father of 28-year old Kim, reflected on his mother's death, saying, “And uh, she suffered and she probably let it go for years before she really, uh, had doctors

check her out and put her on the meds and stuff. And, uh, she got to the point where she lost an eye and lost a leg, and right before she died, they were talking about, uh, taking her other leg. And that was into the 80's. She ended up passing in 2001.”

Not being able to perform physically.

Two participants openly discussed how either they or a relative were unable to function the same sexually as they had before being diagnosed. Don, the 54-year-old father of 29-year old Tim, talked about his uncle, saying, “I mean my uncle used to talk about it. He said he can't be a man to his woman because he got diabetes. So you know when they said that I really wasn't saying nothing. Well, my uncle, well his “X” wife left him because he couldn't be a man no more. And then when he got blind, she said, “I don't want no blind man.” She left him, got her a younger guy, and I was a teenage when that happened so when I heard that I was, like, whoa, I really don't want to get that one.”

Degree of Incapacitation

The degree of incapacitation can impact how individuals see both themselves and family members who have been diagnosed with T2D. Fourteen families experienced some degree of incapacitation. There were two emergent themes: (a) complications of T2D, such as limb loss or blindness, and (b) loss of stamina. Both had affected the quality of life for those diagnosed, which was sometimes observed by the adult children.

Complications from T2D.

Ten families discussed the complications they saw from T2D and how it impacted their family. Adult children at times had seen their own parent experience complications such as blindness. Many families discussed the fear of amputations as they had seen other

family members having toes or legs removed due to their T2D. For these families, diabetes meant that there was a real risk of possibly having an amputation if diabetes was not managed correctly. Anita, the 46-year-old mother of 28-year old Stephanie, remembered watching the movie *Soul Food*. When the beloved character Mama Jo had an amputation due to not managing her diabetes, Anita remembered, “For me it just took me back to like my grandfather, I mean some of his siblings cause he had that amputation.”

Laurie, the 27-year-old daughter of Maria, did not understand what diabetes was exactly, as she was very young when she first heard the word, saying, “Yeah, I first heard about it when I was young, and I didn’t know what it was, but you see the effects of it, and so I didn’t know what it was, but I’m like, well, you can lose your legs so you know, you lose body parts and stuff, so I knew it wasn’t a good thing, but didn’t really know what caused it or what it was.”

Other families watched as family members experienced blindness or other vision problems related to T2D. John, 61-year-old father to 27-year old Lacey, said,

My grandmother had cataracts, my mother’s grandmother, and sometime the onset of early diabetes make your cataracts, ‘cause I would have gotten cataracts at a later age, but because of my diabetes I have, I had cataracts, and I got, uh, toric lenses, and they said if you hadn’t had diabetes, cataracts wouldn’t have come on so quickly, So I had to get my lenses cornea – I mean my lens replaced, but nobody in my family ever had limbs or kidneys failing that I know of.

Loss of stamina.

Four family members discussed how T2D had reduced their energy level. Not having energy for some meant that they could not travel or exercise as they had before their diagnosis. Others noted having little to no energy or feeling drained as being a constant struggle in their everyday lives. Sally, a 50-year-old mother, explained how T2D has affected her ability to use the degree she had worked so hard to get:

Just takes all your energy. I don't have any energy. You know I graduated from Hawkeye in '03 with my marketing degree that I had been wanting, but I've been sick ever since. I haven't ever been able to put it to work. So when your mind is good, but your body doesn't follow what your mind wants to do, it gets frustrating sometimes. I would travel a lot more if I could.

Kevin, Sally's 29-year old, agreed that his mother would be traveling more, saying, "She wouldn't be here right now to be honest. She'd probably be taking care of her sister but she just [can't], I mean." Sally, who has a sister who has cancer, then commented, "So, um, it was the sick taking care of the sick basically. She had her couch and I had my chaise lounge, and you need anything, "No I'm ok. Ok I'm going to lay down and take a nap."

Theme 2: Beliefs About Illness

Certain beliefs about their illness were expressed several times in the sample. These included causes, myths, and the origin of T2D. Communication between parents and their adult children about the illness, as well as their own personal experiences from watching their parent or other family members manage it, directly influenced their adult children's

beliefs about T2D. The findings regarding their beliefs about T2D produced these categories: (a) behavioral, (b) hereditary, and (c) kept in the dark.

Behavioral

Thirteen families believed that T2D was caused by one's behavior such as eating too much and not getting enough exercise. Beth, the 28-year old daughter of 55-year old Paul, explained that diabetes is caused from "Heavy drinking of soda." Earlier in this interview, when Beth was asked when she first heard the word diabetes, she said, "When my dad told me about it." When asked what he had told her about it, she responded, "That he had it when he was younger and we always watch what we eat."

Others believed that diabetes was due to not taking care of yourself correctly as Kevin's mother Sally did,

Umm, basically to me it seems that it, I mean this is what I get from it as far as our family is concerned, that it came from not taking proper care of yourself. And my grandmother which was my mother's mother, she took care of everybody else on her own end and my mother was the same way. She made sure everybody was ok first and then her and that's the way I am too so.

Other times, families believed that T2D could be managed and controlled through eating right and exercising. Maria, the 53-year-old mother of 27-year old Laurie, stated, "And it's up to the individual whether they want to take, uh, actions to correct the situation." Other individuals felt that diabetes was caused by gaining weight. As Teri, Taylor's 53-year old mother, explained,

I think back when I was more of a healthy eater than I am now, um, but I've gone through quite a few health [problems] like the thyroid and that was the one that made me gain weight 'cause I am heavier than I have ever been in my entire life and I'm not feeling good about that so, um, but I think the health issues that I have, all of them have been, like a domino effect and it, it all goes back to you need to eat healthy and you need to exercise so.

Hereditary

Seven families shared similar beliefs about the cause of diabetes in their family, namely that it is hereditary. Some believe that diabetes is unavoidable and cannot be prevented because it is in the "gene line." In these families, several other members had also been diagnosed with T2D. Nancy, the 51-year-old mother of 28-year old Alice, said,

Well, I, I know what can happen if you don't respect it. My uncle refused to accept the fact that he had diabetes because he was thin. Well, most the people in our family are thin; that's got nothing to do with weight where we're concerned. It's hereditary, and I couldn't convince him for the whole time. I said, "Please, please, take your metformin; please take your medicine." [His reply:] "No, I have heart disease; I don't have diabetes, no, no." He wouldn't have diabetes; they, they love sugar – they ate too much sugar, and I said, "No Uncle Allen, I don't eat too much sugar and I still had two strokes and a heart attack from it. Please take your medicine." And he refused to do it, and a year later he had kidney failure, then in '92, he didn't qualify for anything so he passed on into the other way. So, uh, even though I told the doctors that I felt it was my blood sugar they wouldn't believe me and they thought because of some demographic that I'm not a member of, that my strokes and the heart attack

at age 33 and 34 were caused by me taking street drugs. And I said I was raised in the church, practically born in a pew. I don't smoke, I don't drink alcohol, I don't you know not that – “Why don't you do it?” I choose not to and I exercise every night an hour before I went to bed, religiously, you know. I kept telling him [doctor] that something's wrong, I don't feel right you know and they waited til I stroked out and then blamed it on me.

Alice's 28-year-old daughter Nancy also reflected on how T2D was hereditary saying, “Um, well, um, you know, like she said, you know, a lot of it's heredity. There's not too much you can do, but I try to do my part and I try to watch what I eat and exercise, um, you know, so you know, I try to minimize the sugar as much as I can. You know um sometimes I just go on no – a no sugar fast for 30 days like around like holidays, I purposely go on sugar fasts in October and December [laughter]. There's just too much around, too much temptation.”

Kept in the Dark

Two families in the study had misconceptions and fears about T2D because their parent had not disclosed their illness or talked about T2D with their adult child. Parents who did not reveal their T2D diagnosis with their adult children had strong caregiver or protective tendencies. The parents in these families did not want their child to worry about them. Teresa, a 78-year old adoptive mother to 27-year old Eric and mother to Heather (age not given), who was currently taking care of Teresa, explained why she did not test her blood sugar in front of her children: “Well, really, I didn't want them to be afraid and to think it was a dying situation and it's not.” When the adult child, Eric, was asked what he knew about diabetes, he stated, “Nothing, really, 'cause she pretty much kept me in the dark.”

What was most concerning in this case was that Eric, her adopted son, who was not told what T2D was or its risks and complications, believed that amputation from diabetic complications was a myth, i.e., that “if you don’t take care of it, you will lose limbs.”

In one case, only the parent diagnosed was interviewed, because the son had not shown up since he did not have transportation, although he consented to a brief phone interview later on. During that interview, Lisa, 54-year-old mother of Tyler, 28, explained how her son did not know about her T2D diagnosis, saying,

He know I’m sick, yeah, he knows that, but I never want to burden my children. So I don’t even want to have the, I don’t even bring it up, uh, comment on it. It’s a thing that, hey, we just hope mama be living. You know and I get through whatever it is, but I have to let my children know if I die today don’t think it’s their fault. They don’t know the diabetes. They know I got some sickness, but they ain’t never asked me what it was.”

During the interview, later, Tyler said he first heard of diabetes during a high school class, but said he did not know anyone with it.

Chapter Summary

This chapter has presented two themes, Illness Type and Beliefs About Illness (two parts of FSIM), and subsequent subthemes as derived from the participants’ narratives. My analysis of the data from interviews of 20 family dyads revealed how these parents and their adult offspring think about diabetes in these categories and what T2D might mean for these families. The words and experiences these families shared from their viewpoints, as part of

this phenomenological study, portray the reality of T2D in their lives and those of their extended family members.

The primary finding of this study is that families communicate the meaning of illness through sharing, or at times—not sharing, their interactions to it with their own children, or others family members, to warn or encourage others to avoid a disease such as T2D. Both were seen in the subthemes of Illness Type and Beliefs about Illness. The FSIM was used as a framework to discover the past experiences families have had with T2D, which ultimately influenced their communication about it, which in turn influenced their Beliefs About Illness. All 20 families in the study had experienced T2D, either through a family member or first-hand through their own diagnosis.

Using the Illness Type of the FSIM, four characteristics of T2D were identified in varying degrees, which included the onset, course, outcome, and degree of incapacitation. In onset, we saw how the parents of the family dyad interviewed were diagnosed with T2D. Family members' diagnosis came from reporting no symptoms of diabetes, but having it diagnosed during a routine doctor visit, from moderate symptoms such as vision changes, and in some cases, severe symptoms such as stroke that led to hospitalization. When looking at the disease course, we can see how the interviewees managed their T2D and how it has impacted family members' perceptions of the place it has in their lives, such as a daily part of living, disease management, or as need for vigilance and prevention. Outcomes of T2D were seen in terms of how diabetes and its complications could shorten one's life, or prevent a person from no longer being able to do activities they had prior to their diagnosis. In regard to the degree of incapacitation T2D can have, family members saw how it could cause limb

amputations, vision loss, exhaustion, and eventual death in some cases. All four parts of the Illness Type applied to the analysis of these family interviews.

The experience with T2D ultimately influenced the Beliefs about Illness these family members had. They included the causes of T2D, such as behavioral and hereditary, as well as some adult children being unaware of T2D in the family, or it not being discussed with them. Behavioral causes of T2D were attributed to both poor diet and lack of exercise, as well as weight gain. Hereditary causes of T2D were often related to something someone was determined to get due to genetic factors in their family. Being left in the dark meant that one son was unaware of his mother's T2D diagnosis, because she hid it, and in another case, an adopted son was not told the risks of T2D.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

The purpose of this phenomenological study was to explore, with a sample of 20 African American families, the meaning of T2D in their lives. The conclusions from this study were assessed using the FSIM as a guiding theoretical framework to answer the question of what T2D means in the family context to those diagnosed with it and to their adult children, along with the Illness Narrative. This chapter discusses the major findings from this study, followed by limitations and future directions, and a final reflection.

Findings

The major findings or themes of this research study emerged as illness type, illness beliefs, and illness narrative, which are summarized in the following sections.

Illness Type

The first major theme of this study was illness type, which is the core component of the FSIM. An important part of this study, the FSIM was chosen as a theoretical framework for how it views the history of illness in the family context and how loss can impact the generational meaning of T2D (Scollan-Koliopoulos et al., 2005). Using the illness type, we can begin to understand how T2D has presented itself in the family by looking at how it occurred, how it progressed, what its results were, and the effect it had on the member or members' physical health. These four aspects are the context in which these 20 families personally experienced T2D in their everyday lives. T2D is not an illness that only individuals experience, but may be associated with a story in the family, for example, a relative who had a toe amputated because of poor diabetes management.

With the onset of T2D, we can follow how individuals were diagnosed with the illness and how it impacted their family life. Looking at how diagnosis may have caused a destabilization of the family due to the family addressing the illness is important as the family copes with it (Galvin & Young, 2010). Understanding how it was diagnosed in the parent can help us recognize how it affected the family's life. For example, if the diagnosis was sudden due to a serious complication such as blindness, which may have led to an ER visit, it might change how a family talks about T2D. We need to understand why someone may have not have talked to their adult child about symptoms, or why symptoms may have been ignored. In this study, we saw how some family members may not have experienced T2D symptoms prior to their diagnosis, as also reported by Wenzel et al. (2006). The results of my study add to theirs by including both moderate and severe symptoms of diabetes that led to hospitalization.

There are a few implications of my findings about the onset of T2D in families. In families who have had no symptoms, family members were diagnosed at a routine doctor's visit or while being checked for other illness unrelated to T2D. For these families, there was clear communication about regularly seeing the doctor which may be because of their relationships with their health care providers. In families that had more moderate or severe symptoms that led to their diagnoses, they did not always have positive relationships with doctors. Although all families had another biological relative diagnosed with T2D per the study eligibility guidelines, not all of the participants were aware of the symptoms that are related to T2D. This may indicate that although T2D was present in the family health history, there may not be good communication among family members about this illness. The reason why this is an important finding is that family communication about illness needs to be considered when developing programs for both intervention and prevention of T2D. It may also be important for doctors to regularly ask their patients if they have a family history of T2D so that preventive measures can be taken such as checking fasting blood glucose once a year. Another reason for not seeking care could be insufficient insurance coverage or avoidance coping attributable to heredity, bad experiences, and skepticism or mistrust of the health system.

Understanding the course of T2D allows us to see how the illness has progressed and what individuals diagnosed are required to do to manage it. When those diagnosed with T2D had both seen and heard of other family members' complications because of poor disease management, they were more likely to understand how important it is to be vigilant in their own management. To them, diabetes means that they too have to be careful to check their blood glucose throughout the entire day for fear that it might be too high or too low. Having

diabetes means that it is an everyday part of life because it requires testing blood glucose, taking oral medication, and at times needing insulin. Diabetes is an illness that needs to be carefully monitored or it could shorten one's lifespan, impact their quality of life, or lead to complications such as limb amputation or heart disease. In this sense, diabetes means constant vigilance to avoid such issues.

How might understanding the course of T2D impact family communication? In families who have regularly seen the management of T2D, there may be a better understanding of how T2D is treated. Although many families had watched other family members manage their diabetes, there was little discussion of how to avoid being diagnosed with T2D so that they would not have to "use needles," which was a common fear. For health practitioners, it may be important to include other family members when talking about treatment plans after the diagnosis of T2D, such as diet changes, exercise, promoting quality of life, and medication. Including family members may increase support received for those diagnosed with T2D, which would help the entire family understand the implications of a T2D and could increase better communication.

The outcomes of T2D had a profound impact on how the individuals in this study viewed their illness as well as themselves and their ability to lead a normal life. In some cases, those who saw T2D leading to the death of a loved one suggested that having T2D themselves meant that they too would have a shortened life span. Alcozer (2000) reported this view among Mexican American women who had seen both complications and eventual death of family members diagnosed with T2D. Some individuals in the Alcozer (2000) study also saw its potential to impact their ability to perform as they had before their diagnosis, for example, work as they had, or function sexually as a man.

Outcome of T2D may also impact family communication about an illness. For the families who had experienced watched a loved one die due to T2D complications, they reported fear of dying early and also expressed that they did not want their health to proceed down that same path. Understanding the outcome of T2D, which includes having a shortened lifespan and an ability to lead a normal life, may be important for health practitioners. If families have seen poor outcomes caused by T2D, discussing this with their health care team may lead to better care as the health care team could use this information to create a better treatment plan.

The degree of incapacitation was one of the strongest subthemes to illness type in this study. Both parents and adult children reflected on the complications that can occur with T2D as well as issues with stamina. Many individuals knew the serious risks that T2D could pose if not properly managed, such as limb loss and blindness. Complications of T2D were seen in other family members diagnosed with diabetes for the most part, but few adults diagnosed with it had experienced these complications first-hand from having undiagnosed T2D. The way in which T2D incapacitates an individual determines its meaning for a family. Those who saw complications were more likely to believe that T2D could lead to blindness or limb loss compared to those who had not.

Degree of incapacitation is another area that health practitioners should consider when addressing the legacy of T2D in families. As was seen in this study, those who had watched other family members experience limb amputations, blindness, or fatigue had a better understanding that T2D could have some serious complications. It is clear that some who are diagnosed with T2D do not always understand how serious T2D can be when not properly managed. This is a clear area of communication that needs to be established during

diagnosis of T2D since the outcomes of not communicating this could have serious consequences. Further, given the severity of the possible consequences associated with T2D (e.g., amputation, blindness, cardiovascular challenges, hospitalization), these data highlight the urgency of addressing the meaning of T2D to prevent such deleterious consequences

A conclusion that can be drawn about illness type is that families have personal experiences of T2D, either by being diagnosed with it personally, having seen other family members with it, or heard about family members' experiences with it.

Illness Beliefs

The causes, myths, and origin of T2D come from individuals' past experiences with the illness. Illness beliefs also allow us to see how T2D is being communicated in families. How individuals talk about the illness with their children directly influences the child's meaning making about T2D in their adulthood. Witnessing firsthand how an illness, such as T2D, impacts someone's life, as well as behaviors related to T2D management and care, establishes what family members learn about T2D (Scollan-Koliopoulos, 2004).

Many families in this study who talked about T2D and how it occurred in their family were more likely to believe that it was hereditary, which meant a few things for individuals. For some, T2D meant something that was unavoidable, that regardless of their weight or how they ate, T2D was in their future. This fatalistic approach to T2D could influence their health behaviors. In the study by Castro-Riveras et al. (2014), with Mexican Americans, this fatalistic view of T2D as being unavoidable was also observed. Again, this was reflected by Egede and Bonadonna (2003), where African American participants believed that T2D was inevitable. For others, T2D, although hereditary, meant that it was something that they

needed to watch out for, but indicated that when talking about T2D with other family members, the rest of the family was unsurprised when they were diagnosed.

Other families and their members believed that T2D was caused by behaviors such as not being active or eating too much. Some may believe that T2D is just behaviorally caused because someone was not taking care of themselves, and that it is up to the individual to start doing so.

In families who did not talk about the diagnosis or even hid their management of the disease, the adult child may have some confusion about what T2D is and how it affects someone's health. For those who did not talk about their diagnosis, their adult child might be more likely to believe that complications, such as limb loss, are just a myth. The origin and cause of T2D may be unclear for these individuals as well. For these adult children, diabetes may mean nothing until they personally see complications or finally hear their parent talk about the illness.

Illness Narrative

Medical professionals have used the Illness Narrative to understand how the family history has influenced a patient's beliefs about an illness (Burry, 2001; Kumagai, Murphy, & Ross, 2008; Broom & Whittaker, 2004; Hornsten et al., 2003). In this study, the Illness Narrative ties together the experiences family members have had with T2D through both the FSIM and Beliefs About the Illness. Several illness narratives came through detailed analysis of these data, but, more importantly, we can see how intergenerational communication about an illness deeply affects its meaning and understanding for individuals and their families.

Communication about T2D, between the parent diagnosed with it and his or her adult child, as well as seeing other family members or friends who have had diabetes, have contributed to the adult child's illness narrative. As seen from their beliefs about the illness, adult children who were not told about their family member's T2D were often uncertain of its causes and outcomes. In these cases, the adult children were unaware of the risks that T2D can pose. When other families were very open about T2D in their family, the adult children had a clearer understanding of the causes, risks, and management required. Families in the study who used clear communication and saw management of T2D through its course, outcome, and degree of incapacitation, better understood how it develops, what its symptoms are, and how it has impacted family members, as corroborated by a study by Liburd et al. (2004).

Understanding the illness narrative in families can help us understand how both the family system and beliefs about an illness can determine the meaning T2D has for families. The illness narrative brings together past experiences and the communication that is occurring in families about T2D. In families where T2D is openly discussed, an everyday occurrence or an incident that is not life threatening, such as getting a cut, would be taken in stride. But lack of communication about the disease could affect how an adult child interprets information about T2D, such as believing that its complications are a myth.

Limitations and Future Directions

In this study, a few aspects may have been limiting. The current study was qualitative in nature at a particular time in a particular setting. As such, the findings in this study may not be reflected in the larger population. The interviews used for this study were unique in that the participants included both African American adults diagnosed with T2D

and their adult children. Since there have been no studies designed to include both family members, it may be difficult to also assess the replicability of this study (Bhattacharya, 2012; Egede & Bonadonna, 2003; Liburd et al., 2004). I therefore suggest that future research on families who have a generational legacy of diabetes include multiple family members. Doing so would allow researchers to observe the family's communication about the illness through an intergenerational dialogue. Understanding this dynamic may be key to addressing T2D in the family context versus the individual or societal context. Another consideration is that participants may have responded differently in individual interviews as opposed to the dyadic interview approach that was employed in this study. The gender of the parents and adult children could also impact communication and while gender effects did not emerge as an important factor in this study, future studies should attend to this.

Another possibility for future research would be to include families of other races and/or ethnicities. How does communication about T2D differ based on the population? With the \$245 billion cost of T2D every year, more than one third of Americans are diagnosed with it (CDC, 2012). Thus, T2D must be addressed as a major public health problem, especially among populations where this chronic condition disproportionately affects people, such as racial/ethnic minorities, the socioeconomically disadvantaged, and older adults. Understanding how families communicate about illness is essential for preventing T2D from occurring in future generations. What might this mean for the future health of adult children, especially from families who do not talk about this illness? If they do not know the warning signs and go undiagnosed, they might have adverse T2D experiences, such as blindness or limb amputations.

The lack of health insurance meant that nearly one-third of undiagnosed individuals in this study were not seeing a doctor regularly. One woman in the study who went temporarily blind and eventually passed out because her blood sugar was so high did not have access to health care. Also, her care was compromised when she was diagnosed because she did not receive the education needed about proper management of her T2D. One factor that should be explored in more depth is how has the T2D diagnosis has changed since the Affordable Care Act (ACA) went into effect, although the current study occurred before this health care reform became law in the United States. What does diagnosis and treatment of T2D look like now compared to when individuals were diagnosed with it before affordable health care insurance? Several study participants previously had negative experiences following their diagnosis, having lacked health insurance at the time. T2D can cost individuals considerable money without health insurance between the medication required to treat T2D and doctor's or specialist's visits. However, under the ACA, individuals cannot be denied coverage for pre-existing conditions such as T2D, and there are several preventative services for it that are now cost free with this healthcare plan.

Previous research has explored the FSM, Beliefs About an Illness, and the Illness Narrative and how they are related to illness in the family (Bhattacharya, 2012; Broom & Whittaker, 2004; Galvin & Young, 2010; Hornsten et al., 2003; McGoldrick et al., 2005; Roland, 1988, 2012; Scollan-Koliopoulos, 2004; Walsh & McGoldrick, 1991). However, limited research has investigated the intergenerational legacy of T2D in African American families (Scollan-Koliopoulos et al., 2005). But to understand the meaning of an illness, we need to first look at the type, which is related to a person's immediate and intergenerational experience of the illness and the family system it is occurring in. Understanding individuals'

experiences of other illnesses helps us understand how their beliefs about T2D are developed. These experiences are what the Illness Narrative are made up of. It is through listening to these narratives that we can begin to understand the meaning that T2D has for those who have been diagnosed with it, as well as for their family members. By understanding what it means to have diabetes, we can then develop better healthcare programs including prevention to help address the growing T2D epidemic.

Although the FSIM and Beliefs About Illness, as well as the Illness Narrative, do well to explain some of the interactions within the family system, discussion of outside factors that affect T2D, such as health insurance, and other comorbidities, has been lacking. Past research has shown that T2D has several comorbidities such as coronary artery disease, hypertension, and neuropathy (Weinberger et al., 1994). Other diabetes health-related factors are of great concern as one study showed that after nearly a 10-year follow up, 42% of patients had died, 49% of those from cardiovascular disease (Landman et al., 2010). A future direction for research then could be to examine how individuals can manage their diabetes while experiencing other health problems, such as the colorectal cancer one study participant had to focus on, while ignoring or neglecting her T2D. It could be extremely difficult to manage T2D while trying to manage another major disease.

It is my hope that T2D research continues and that better programs and implementation of these programs can occur. For better programs to be established, it is important that we understand how the family makes meaning of a person's illness. Programs also need to change according to the population they are serving as well as what is happening in the community at the time. Programs should change to reflect the community in which they are occurring to better address the needs and concerns of its residents (Philis-Tsimikas

& Gallo, 2014). Policy and programs addressing the growing health epidemic of T2D require regular evaluation of their own effectiveness. We can no longer continue to pay for programs that are not working to address T2D management and prevention. One way in which we can ensure that better programs as well as better health care practices occur is to begin to delve into how the experiences of T2D in the family setting influences a family's knowledge about T2D its causes, how it is diagnosed, treated, managed, and the consequences that can occur from T2D when not properly treated. Knowing this, it is important that we create programs that foster better communication between family members as well as their doctors so that proper prevention and management can occur.

Studies that are currently investigating how the Diabetes Prevention Program (DPP) is affecting T2D care are underway, and have been reviewed by Ackermann et al. (2015). All five of the experiments that were mentioned by Ackermann et al. (2015) were missing a qualitative portion to analyze how these programs are working. As the synthesis of my literature review showed, we can clearly see that an excellent way to look at how families interpret an illness is through qualitative methodologies and to really ask them the kind of impact T2D has had on their lives (Acury et al., 2004; Alcozer, 2000; Bhattacharya, 2012; Broom & Whittaker, 2004; Brown et al., 2007; Carter-Edwards et al., 2004; Castro-Riveras et al., 2014; Egede & Bonadonna, 2003; Liburd et al., 2004; Manoogian et al., 2010; Poss & Jezewski, 2002). By understanding the family's perspective on illness, we can better develop programs to address their concerns in an appropriate way that will fit their family and community needs. These perspectives are important when creating effective programming (Hurt, Seawell, & O'Connor, 2015).

Final Reflection

I am thankful that the study participants shared their experiences of T2D in an open manner, which allowed me to begin to tell their story in the context of their family and African American community. T2D does not occur in a bubble, but in the family and the environment in which individuals live.

While analyzing the interview data, I found that my personal experiences with T2D was similar to those of the adult children in the study. While researching this topic, I found myself talking with my mother about her T2D, from her diagnosis 12 years ago to living with T2D every day and how it affects her life. I also learned while doing this study that my mom did in fact have gestational diabetes while she was pregnant with me, which caused some complications with her pregnancy. Her gestational diabetes had created a greater risk to develop T2D, and increased my own risk for developing the disease.

As I read the experiences of the participants in this study, and learned how scary a diagnosis can be and what may happen if someone does not manage their diabetes well, I found myself worrying about my own future health. I also found myself often worrying about my mom's diabetes more than I had before I knew the increased risk of developing complications and comorbidities if it is not managed well. It may annoy her now, but I often ask her what her blood sugar is. This study has allowed me to further my own family communication about T2D, as I saw firsthand how vital such communication between family members is.

I also have learned more about T2D than I would have ever sought to know prior to doing this research. Having become more aware of the risk of developing T2D from

hereditary factors, such as my mother's long family history of the illness, has made me realize that I need to start participating in health-seeking behaviors before it is too late. I agree with Lacey, an adult child in the study who commented, I do not want to have to "stick [myself] with a monitor." I am hoping that with this journey to health—which I feel I have struggled with most of my life—I can make significant changes to reduce my risk of T2D. Without having heard the narratives of these study participants, I am not sure if I would have understood how dangerous this illness can be. So I am incredibly grateful that they shared their personal experiences with Dr. Jordan, and through her, with me.

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APPENDIX: INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL

IRB ID: 14-097

**INSTITUTIONAL REVIEW BOARD (IRB)
Application for Approval of Research Involving Humans**

Title of Project: An Exploration of Multigenerational Legacies of Type-2 Diabetes Within African American Families		
Principal Investigator (PI): Tera R. Jordan		Degrees: Ph.D., M.S., B.S.
University ID: 68531262816	Phone: 515-294-9804	Email Address: trh@iastate.edu
Correspondence Address: 4380 Palmer HDFS Building, Suite 1364		
Department: Human Development and Family Studies		College/Center/Institute: College of Human Sciences
PI Level: <input checked="" type="checkbox"/> Tenured, Tenure-Eligible, & NTER Faculty <input type="checkbox"/> Adjunct/Affiliate Faculty <input type="checkbox"/> Collaborator Faculty <input type="checkbox"/> Emeritus Faculty <input type="checkbox"/> Visiting Faculty/Scientist <input type="checkbox"/> Senior Lecturer/Clinician <input type="checkbox"/> Lecturer/Clinician, w/Ph.D. or DVM <input type="checkbox"/> P&S Employee, P37 & above <input type="checkbox"/> Extension to Families/Youth Specialist <input type="checkbox"/> Field Specialist III <input type="checkbox"/> Postdoctoral Associate <input type="checkbox"/> Graduate/Undergrad Student <input checked="" type="checkbox"/> Other (Specify:)		
FOR STUDENT PROJECTS (Required when the principal investigator is a student)		FEB 26 2014
Name of Major Professor/Supervising Faculty:		
University ID:	Phone:	Email Address: @iastate.edu By IRB
Campus Address:		Department:
Type of Project (check all that apply): <input type="checkbox"/> Thesis/Dissertation <input type="checkbox"/> Class Project <input type="checkbox"/> Other (specify:)		
Alternate Contact Person:		Email Address:
Correspondence Address:		Phone:

ASSURANCE

- I certify that the information provided in this application is complete and accurate and consistent with any proposal(s) submitted to external funding agencies. Misrepresentation of the research described in this or any other IRB application may constitute non-compliance with federal regulations and/or academic misconduct.
- I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subjects are protected. I will report any problems to the IRB. See Reporting Adverse Events and Unanticipated Problems for details.
- I agree that modifications to the approved project will not take place without prior review and approval by the IRB.
- I agree that the research will not take place without the receipt of permission from any cooperating institutions when applicable.
- I agree to obtain approval from other appropriate committees as needed for this project, such as the IACUC (if the research includes animals), the IBC (if the research involves biohazards), the Radiation Safety Committee (if the research involves x-rays or other radiation producing devices or procedures), etc., and to obtain background checks for staff when necessary.
- I understand that IRB approval of this project does not grant access to any facilities, materials, or data on which this research may depend. Such access must be granted by the unit with the relevant custodial authority.
- I agree that all activities will be performed in accordance with all applicable federal, state, local, and Iowa State University policies.

Signature of Principal Investigator Date

Signature of Major Professor/Supervising Faculty Date
(Required when the principal investigator is a student)

- I have reviewed this application and determined that departmental requirements are met, the investigator(s) has/have adequate resources to conduct the research, and the research design is scientifically sound and has scientific merit.

Printed Name of Department Chair/Head/Director

Signature of Department Chair/Head/Director Date

For IRB Use Only	Full Committee Review: <input type="checkbox"/>	Review Date: March 19, 2014
Approval Not Required: <input type="checkbox"/>	EXPEDITED per 45 CFR 46.110(b): 1 Category 6, 7 Letter	Approval/Determination Date: March 18, 2014
Not Research: <input type="checkbox"/>	EXEMPT per 45 CFR 46.101(b):	Approval Expiration Date: March 18, 2015
No Human Subjects: <input type="checkbox"/>	Not Approved: <input type="checkbox"/>	Risk: Minimal <input checked="" type="checkbox"/> More than Minimal <input type="checkbox"/>
IRB Reviewer's Signature: _____		