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# INTERGENERATIONAL COMMUNICATION ABOUT AFRICAN AMERICAN WOMEN'S HEALTH: THE SHARING OF HEALTH MESSAGES BETWEEN DIABETIC MOTHERS AND THEIR NON-DIABETIC ADULT DAUGHTERS

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# ABSTRACT OF DISSERTATION

Angela F. Cooke-Jackson

The Graduate School

University of Kentucky

### INTERGENERATIONAL COMMUNICATION ABOUT AFRICAN AMERICAN WOMEN'S HEALTH: THE SHARING OF HEALTH MESSAGES BETWEEN DIABETIC MOTHERS AND THEIR NON-DIABETIC ADULT DAUGHTERS

### ABSTRACT OF DISSERTATION

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Communications and Information Studies at the University of Kentucky

By

Angela F. Cooke-Jackson

Lexington, Kentucky

Co-Directors: Dr. Philip Palmgreen, Professor of Communications and Dr. Nancy E. Schoenberg, Associate Professor of Behavior Science

Lexington, Kentucky

2006

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### ABSTRACT OF DISSERTATION

### INTERGENERATIONAL COMMUNICATION ABOUT AFRICAN-AMERICAN WOMEN'S HEALTH: THE SHARING OF HEALTH MESSAGES BETWEEN DIABETIC MOTHERS AND NON-DIABETIC ADULT DAUGHTERS

The prevalence of type II diabetes is high among African-American women but research that emphasizes black mothers and their adult daughters is rarely studied in social sciences or communication research. Though existing research addresses various domains of the mother-daughter relationship scant information addresses the significance of talk or the transmission of health information between African-American diabetic mothers and their non-diabetic adult daughters. For that reason, this dissertation investigates information sharing among a sample of African-American mothers with type II diabetes and their non-diabetic adult daughters.

This study's two primary research objectives were to: 1. describe whether and how African-American type II diabetic mothers and their non-diabetic adult daughters engage in information sharing about type II diabetes; and to 2. describe whether and how the sharing of health-related communication messages shapes African-American mothers' diabetic health behavior and/or shapes adult non-diabetic daughters' diabeticrelated health behavior.

This study used a modified grounded theory approach, in which I concurrently collected, coded and analyzed data. While an intention behind grounded theory is to develop theory "from the ground up," I also used the Health Belief Model (HBM) and Social Cognitive Theory (SCT) to inform research questions. I conducted 10 interviews

with members of mother-daughter dyads; two with each mother and two with each daughter. I concluded my interviews with both mother and daughter present, yielding a total of 50 interviews. Dyads were comprised of African-American type II diabetic mothers (age 45 and older) and their non-diabetic adult daughters (age 20 and older) living in New Mexico, Ohio and Kentucky.

Information gathered from interviews yielded five patterns of communication used by mothers and daughters to talk about type II diabetes. The patterns encompassed the ongoing ways in which mothers' and daughters' negotiated the illness. This study described this negotiation as a unique "culture" that entailed 1) an historical knowledge of diabetes, 2) a present and personal experiences of living with diabetes and 3) an understanding of the future implication of diabetes for mothers, their adult daughters, and their entire family.

This study represents the first step toward understanding the diabetic interaction between mothers and adult daughters living with a chronic illness. Results suggest that mothers and daughters are motivated to talk about diabetes, even though talk does not always address prevention in their health behaviors. This study is useful to inform practitioners of the significance of oral tradition as one mode of transmitting health care information within African-American culture and the value of integrated medical visits, particularly for diabetic mothers and their adult daughters. As well, health communication scholars can use this information to develop, test and implement innovative health education media and message strategies for families and motherdaughter dyads that address diabetic health information.

KEYWORDS: African-American, type II diabetic mother and non-diabetic adult daughter, mother-daughter dyads, health behavior, health messages

Angela F. Cooke-Jackson July 24, 2006

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> July 24, 2006 Date

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# DISSERTATION

Angela F. Cooke-Jackson

The Graduate School University of Kentucky

## INTERGENERATIONAL COMMUNICATION ABOUT AFRICAN AMERICAN WOMEN'S HEALTH: THE SHARING OF HEALTH MESSAGES BETWEEN DIABETIC MOTHERS AND THEIR NON-DIABETIC ADULT DAUGHTERS

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2006

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Dedicated to my Mother, Elfreda June Hocker and my Aunt, Rose Marie Sims

#### ACKNOWLEDGEMENTS

A few months prior to beginning my doctoral course work I trained for and completed the Flying Pig's Marathon in Cincinnati, Ohio. I thought... "If I can go through the intense training and mental fortitude necessary to complete a marathon than I can complete my Ph.D.".

Just like the marathon, the journey toward the completion of my doctorate has been intensive, cumbersome and bewildering at times. The process of completing my coursework, taking my qualifying examinations, submitting a proposal, collecting and analyzing my data, and writing and re-writing my dissertation at times seemed insurmountable. I often felt like I spent a major amount of time tripping over my feet and falling to the ground...only to wipe myself off, stand up and take a few more steps forward. While there were times I wondered what the heck I had gotten myself into, there was never a time when I thought I would walk away. I believe this was because I had an amazing "training team" who saw in me great potential and the ability to complete something beneficial for my future.

Thank you Dr. Derek Lane and Dr. Sonja Feist-Price for your constant encouragement and helpful suggestions throughout this process. Thanks also to Dr. Phil Palmgreen and Dr. Nancy Schoenberg for serving as the Co-chairs of my committee. My heart is filled with gratitude and appreciation toward both of you. Thank you for your persistence, insights, patience and encouragement. You both read and re-read my chapters so many times that I am sure on many occasions you had to wonder if I was getting it. Even still, your expectations and persistence helped me immensely. You have both been exceptional motivators throughout this journey, but what I have most appreciated is how you both lead by example, modeling for me what an exceptional teacher, researcher and mentor looks like.

Dr. Debbie Bush Haffey, you started me on this journey years ago and you have truly been the wind beneath my wings. Thank you for your honesty, your critical discernment, and thank you for reading and editing. You have been an amazing friend, mentor, and confidante and shaped my life in an amazing way. I only hope that I can give to you the treasure of love and commitment that you have bestowed on me.

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I am indebted to my sister, Lynne Jones, for her ability to part the waters for me after the loss of our mother. Lynne, thank you so much; with you around nothing seemed impossible. You always were and have been ready to help me with the most basic needs that I had. When I was hungry, you fed me. When I needed something to wear, you clothed me. When I felt discouraged and defeated, you gave me a shoulder to cry on and the encouragement to continue my journey. You deserve so much; I'd give you the world if I could!

Carltaro, you are the love of my life. Throughout this process you called me your hero. You told me how amazing I was. You told me you were honored to know me...but it is *you* who I am honored and blessed to have in my life. You were my constant cheerleader; you never doubted for a moment that I would not complete my work. You looked to my future, assuring me that my potential was beyond what I could realize. I thank you and deeply appreciate you, my soul mate.

There are numerous others that have encouraged me, some for the duration of my life and others for short periods of time. Deep appreciation to my family...my siblings, I love you Cassandra, Benson and Freida. Thanks for your investment in my life from my toddler years into my adulthood; you have all been steadfast. Thank you to my Papa. Thank you to my wonderful nieces and nephews, I love all of you as if you were my own. Thanks to all my dear friends that were constant in your encouragement and prayers. I am moving onto other life events and want to thank you all for being a part of my journey. Thanks for helping me to cross the finish line and make my doctoral marathon a worthwhile endeavor.

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### Chapter One

### Introduction

I am black but comely, O ye daughters of Jerusalem, As the tent of Kedar, as the curtains of Solomon Look not upon me because I am black, Because the sun hath looked upon me; My mother's children were angry with me, They made me the keeper of the vineyards, But mine own vineyards have I not kept. ~ Song of Solomon ~

The author of the Song of Solomon uses the word *vineyard* metaphorically to describe the maiden's body that has not received the appropriate care. Though far removed from biblical times, these truth-telling words describe with amazing accuracy the health status of black<sup>1</sup> women living with chronic illness. Countless black women living in the 21st century have worked diligently, attending to the vineyards of their families, close kin relations, and communities, yet have neglected their own vineyards (Banks-Wallace & Parks, 2001; Jackson, 1991; Jones, 1985; Smith, 2002). The challenges of caring for others often results in Black women's own health neglect which may increase the likelihood of suffering from serious chronic diseases like type II diabetes. By understanding the implications of this neglect and its relationship to black women's adult children, namely their daughters, there is hope that researchers can effectively assist mother-daughter dyads and their families with preventing and caring for diseases like diabetes.

### Rationale for the Study

The prevalence of type II diabetes is high among African-American women (Gillum, Mussolino, Madans, 2000). As well, Black women value their interpersonal relationships. Unfortunately, communication among African-American women about health is rarely studied in social sciences or communication research, particularly among black mothers and daughters. Recent studies report that individuals whose parents have had type II diabetes potentially face similar complications (http://diabetes.about.com/cs/africanamericans, 2004). To address this lack of important

<sup>&</sup>lt;sup>1</sup> Throughout this dissertation the terms "African American" and "Black" have been used interchangeably, which is a common cultural practice among the population.

information, this dissertation investigates information sharing among a sample of African-American mothers with type II diabetes and their non-diabetic adult daughters. Specifically, this dissertation will investigate whether health messages about type II diabetes are communicated between mothers and daughters. As well, thought will be given to how these messages are communicated and the implications of these messages for the diabetic self-care of mothers and preventative health behaviors of their adult daughters.

This study has two primary research objectives:

- To describe whether and how African-American type II diabetic mothers<sup>2</sup> and their non-diabetic adult daughters engage in information sharing about type II diabetes, and
- 2) To describe and understand whether and how the sharing of health-related communication messages shapes African-American mothers' diabetic selfcare and/or shapes adult non-diabetic daughters' diabetic-related health behavior.

### Prevalence of Type II Diabetes

Type II diabetes, hereafter referred to as "diabetes", presents significant health problems, accounting for significant morbidity and premature mortality in the United States (Gillum, Mussolino, & Madans, 2000; McNabb, Quinn, & Tobian, 1997; Rajaram & Vinson, 1998). Harrison, Hindorff, Kim et al., (2003) report that Type II diabetes cost society \$98 billion annually and also estimate that the numerous untreated and undiagnosed individuals may forego treatment, resulting in diabetic complications prior to clinical diagnoses (Harrison et al., 2003).

Non-insulin dependent diabetes mellitus (NIDDM), frequently referred to as "adult-onset" or "type II diabetes" and, often among older African Americans, as "sugar diabetes" or "sugar" (Schorling & Saunders, 2000);

http://www.blackwomenshealth.com/diabetes.htm, 2004), has reached epidemic proportions among African-American women, with one in four black women age 55 and older having diabetes (<u>http://diabetes.niddk.nih.gov/dm/pubs/statistics/index.htm</u>, 2004;

<sup>&</sup>lt;sup>2</sup> Increasingly, health care professionals are using the phrase "persons with diabetes" to decrease the reductionism of the term "diabetic". However, to maintain fluidity and to enhance readability in this dissertation the term "diabetic person" is used.

Jefferson, Melkus & Spollett, 2000). For this reason, type II diabetes among African-American women remains a significant health concern.

# An Overview of African-American Women as Health Care Alliances

African-American women have always been cognizant of the mental and physical health issues within their communities and families (Billingsley, 1968, 1974; Smith, 2002; Jackson, 1991). Their roles have been defined in literature as that of nurturers (Bell-Scott, Guy-Sheftall, Royster, et al., 1991), matriarchs (Brook-Rochester, 2000; Collins, 1987), caregivers (Bank-Wallace, 2002; Tirrito & Nathanson, 1994), healers (Jones, 1985; Randall-David, 1985), and "othermothers" (Collins, 1991). Some researchers find these roles useful for understanding how the historical, cultural, and economic status black women faced positioned them at the bottom of the ladder in terms of their health needs (Fisher Collins, 1996; Jean & Feagin, 1998; Jones, 1985; McBarnette, 1996). Though black women displayed an awareness of mental and physical health issues in their communities, they were not a part of the discussion to advance changes. The health care system did function as a vehicle of health information for Black women, specifically regarding illnesses like diabetes (Fisher Collins, 1996; Smith, 1995). This marginalization of African-American women by the health care system served as justification for black women's roles as health "layworkers" in their communities (Smith, 1995).

One of the first historical documents to account for the treatment of black women in the health care system was "Era of Denial – 1900-1930" (Beardsley, 1987); (see Fisher Collins 1996, chapter 5, p. 76 for a detailed overview of this work). Beardsley documents the injustices that black women experienced in the early 1900's noting "that African-American women were denied access to health professionals and hospital services accounting for childbirth deaths of both mothers and infants, as well as rampant tuberculosis and syphilis" (p. 128). His work details the "scourge of African-American women that resulted in high morbidity - death from other causes – diabetes mellitus … Pre-1940 data are scanty, but current knowledge suggests that diabetes was a serious illness then, especially for women over 50" (p. 128). His second work, the "Era of Inclusion 1930 –1960," notes that when African-American women did receive access to health services (i.e., hospitals), this entailed a sub-standard ward that was understaffed, poorly equipped and attended by racist white physicians. So while black women were able to use hospital services, there was no guarantee they would receive high quality care. Another inconsistency black woman faced was their inability to afford health care. Though opportunities for care at hospitals were legally available, poor black women did not possess the means to obtain services. As well, those who could afford treatment had prior knowledge of the injustices, thus creating a sense of fear and tension that prevented their use of medical care (Fisher Collins 1996; Jones 1985; McBarnette, 1996).

In short, the history of health care for black women heightened the mistrust blacks had toward the white healthcare system and thereby reinforced racial separation (Fisher Collins, 1996; Jones 1985; Litt, 2000; Townes, 1997). This racial division contributed to a strong alliance of African-American women with their families and communities in rural and urban areas across the country.

When we look at the historical conditions of black women in the realm of health care, it becomes easy to understand the attitudes of contemporary black women toward the health system. Because of mistrust toward the medical system, injustices toward black women and poverty, it was normal<sup>3</sup> for black women to serve as resources for health information for other black community members as well as for the traditional medical establishment (See Smith 1995 for information on the role of black midwifery) (Fisher Collins, 1996; Giddings, 1984; Litt, 2000; Smith, 1995). Often given the role of community "layworkers," these women have been described as "the backbone of the black health movement and were central to the founding and maintenance of black public health projects" (Smith, 1995, p. 1). Frequently black female "layworkers" would come together in informal groups to take care of specific health needs in rural and urban communities (Smith, 1995). For instance, in the 1940s, black rural midwives, also referred to as "granny" midwives, provided health services such as health education to the community, immunization programs, and prenatal and postnatal medical examinations (Smith, 1995). Besides black preachers and teachers, "granny" midwives were some of the most influential women in the rural community. For this reason, black

<sup>&</sup>lt;sup>3</sup> Fisher Collins (1996) notes, "to buffer themselves against racism induced by the social and health care system, African-American women turned to their social support network to mediate their health outcomes and the stressful life events they experienced" (p. 83).

"layworkers" were described by their peers as the translators or the center of the traditional healing network in the black community (Smith, 1995).

Historically, in urban areas, African-American women rallied together. They would typically seek out family support for health care needs before pursuing help from formal relief agencies (Clement, 1993). Black women also went to their community churches for assistance. They created "beneficient societies" to financially assist members that became ill. Whatever one paid into the society, one could receive for themselves or their family member when they became ill.

### Significance of the Oral Tradition

These historical descriptions show the informal network that African-American women used to address pressing *health disparities*<sup>4</sup> within their communities. Because African-American women lacked access to and were not embraced by the dominant culture, they took on crucial health roles in their communities when no one else would (Clement, 1993; Jones, 1985; Litt, 2000; Smith, 1995).

One unique feature about this informal system of disseminating health information and taking care of health needs was the means by which it was spread. Prior to the early 1960s, many black women were illiterate (i.e., southern black women's illiteracy rates were five times higher than those of women living in northern urban areas) and thus, an oral tradition was created to convey necessary information (Jones, 1995; Smith, 1995). While historical records document the significance of African-American oral traditions (i.e., storytelling) and this tradition's role in affirming and nurturing African-American people, little research exists that documents this oral tradition as a tangible means of transferring health messages (Banks-Wallace, 2002).

Extensive literature addresses African-American oral histories (Banks-Wallace, 2002) and storytelling (Goss & Barnes, 1989). Both speak to the unique subculture African-American women inhabited and the manner in which African-American cultures

<sup>&</sup>lt;sup>4</sup> The National Institutes of Health developed the term *health disparities*. Their objective was to address the differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States. The primary focus has been on the reduction of disproportionately poor health outcomes among racial and ethnic minority populations: African Americans, Asians, Pacific Islanders, Hispanics and Latinos, Native Americans, and Native Alaskans.

have used communication to pass on information (Jones, 1985; Smith, 1995). For instance, Jean and Feagin (1998) note that,

Knowledge gained (in the form of storytelling) from mothers strengthens the bridge between family of origin and one's own family, between past and present. It is common for events, traditions and secrets to be transmitted matrilineally, from mothers to daughters and daughter-in-laws for the benefit of posterity. These traditions are seldom shared with persons outside the extended family network. For this reason, discussion of oral traditions and their role is critical to best understand the present day relationships that occur among mother-daughter dyads in African-American family units (p. 185).

Oral traditions can "provide unique opportunities to contribute to the development and testing of theories or interventions while promoting the health of study participants" (Banks-Wallace, 2002, p. 424). For that reason, the communicative health-emphasis on conversation exchanges (interactions) between African-American diabetic mothers and their non-diabetic adult daughters is a particularly relevant topic for public health and/or improvements to health. Understanding the communication interaction between diabetic African-American mothers and adult non-diabetic daughters may suggest communication interventions that are foundational for behavior change and health promotion among mothers and daughters and other family members.

A substantial body of public health literature acknowledges the value of family members possessing a thorough understanding of their families' health history to prevent common chronic diseases, such as diabetes, coronary heart disease, and cancer (Harrison, et al., 2003; Yoon, Scheuner & Khoury, 2003). Unfortunately, most literature does not recognize the value of familial communication as an avenue to disseminate knowledge of such chronic diseases. Many chronic illnesses are hereditary, yet research does not give specific attention to the communication process that transpires where people talk to their family members about symptoms, treatments, and prevention of various diseases. Because there is growing evidence that communication can greatly enhance health promotion efforts and positively affect health outcomes, improving our knowledge of the transmission of health information is necessary (Kreps, 2001).

### Methodological Framework

The aim of this qualitative research is to better understand African-American mother and adult daughter dyad's communication regarding type II diabetes. Miles and Huberman (1984) note that qualitative research has the potential to provide a "source of well-grounded, rich descriptions and explanations of processes occurring in local contexts" (p.15). Therefore, this dissertation positions the African-American motherdaughter dyad at the center of data gathering to gain a rich understanding of their lived experiences with type II diabetes. A modified grounded theory approach was used as the method of analysis. Typically, grounded theory acts as an independent methodology; however, I used the Health Belief Model (HBM) and Social Cognitive Theory (SCT) to inform research questions (See "Research Design" below). I concurrently collected, coded and analyzed data in order to develop a substantive or formal theory about the phenomenon (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This constant comparative method required that I routinely compare one incident with another incident to observe and name similar phenomena; it emphasizes the development of categories and eventually themes (Strauss & Corbin, 1990). Sterns (1980) notes two appropriate uses of a grounded approach: a) in new situations, where no theory regarding a situation exists or where salient variables have not been identified because of the complexity of the phenomenon to be studied, and b) in gaining a new point of view in a familiar situation. Thus, this dissertation used a modified grounded theory approach to gain insights about the contributions of oral traditions and communication patterns/styles to the transmission of health information among African-American mothers with diabetes and their adult daughters.

### Research Design

I conducted 10 interviews with members of mother-daughter dyads; two with each mother and two with each daughter. I concluded my interviews with both mother and daughter present, yielding a total of 50 interviews. Open-ended questions regarding health issues were asked in the first interview (see Appendix) while the second interview used components of the Health Belief Model (HBM) and Social Cognitive Theory (SCT) (Strecher & Rosenstock, 1997; Bandura, 1977, 1986) (see Appendix B). These theories were used as general, yet flexible, guidelines during the second interview to help clarify

the understanding of the mother-daughter dyad's description of health behaviors. The objective for using this modified grounded theory approach was to facilitate discussion among mothers and daughters that addressed their perceptions of: a) the seriousness of diabetes, b) their susceptibility to diabetes, c) actions taken to prevent diabetes or diabetic complications, and d) modeling of health behaviors in the dyad.

Existing research does address various domains of the mother-daughter relationship; yet, scant information addresses the transmission of health information between African-American diabetic mothers and their non-diabetic adult daughter or the significance of talk about health behaviors. In the following chapters, an extensive review of literature is presented, and several research questions are formulated from the review of literature. The method of research is discussed, followed by an analysis and report of the data. Lastly, discussion of the implications of the results, the limitations of the study and directions for future research are presented.

#### Chapter Two

Review of the Literature In search of my mother's garden, I found my own. ~ Alice Walker ~

Chronic illnesses, including type II diabetes, have gravely affected African-American individuals and therefore African-American families. As well, literature confirms the widespread consequences of type II diabetes among African Americans, in particular, black women. To best understand the lived experiences of African-American women and type II diabetes, a brief definition and overview of diabetes, with an emphasis on type II diabetes among African Americans, is presented.

Next, literature on the African-American family will be examined with an emphasis on the role of the black family. To best understand how African Americans manage diseases like type II diabetes, an overview of the socio-cultural networks used by Blacks will be discussed emphasizing how these networks influence diabetic information distribution. Part of the socio-cultural network used by Blacks is a reflection of their oral tradition. Throughout history, African Americans have used oral tradition within the family and community to pass shared beliefs, traditions, values, and customs from generation to generation. Given that this form of communication is a primary means of transmitting information among Blacks, a brief section describing the significance of the oral tradition shall be discussed.

Self-care, briefly described as activities individuals take on in an attempt to prevent and limit disease and restore and maintain health, (Sackett & Haynes, 1976) is a fundamental part of living with type II diabetes. Typically, diabetic family members attempt to negotiate their illness using lay consultation from close and extended family networks, in particular adult daughters (Sayles-Cross, 1995). For this reason, it is important to analyze self-care while observing how lay networks (i. e., families, adult daughters) shape self-care. Next, literature on caregiving and social support are examined with attention to the role of the black woman within the family system. To conclude, an overview of the mother-daughter relationship will be provided giving attention to the unique aspects of the African-American mother-daughter relationship (Collins, 1991,

1994; Banks-Wallace & Parks, 2001). Finally, the implications of this study as well as the study objectives are outlined.

### Definition and Overview of Diabetes

Diabetes, a metabolic disease where insulin is not produced or properly used in the body, is classified according to three major categories: type I diabetes, gestational diabetes, and type II diabetes, (Centers for Disease Control and Prevention, 2003). Type I diabetes is caused by the complete failure of the pancreas to produce the hormone insulin, which is responsible for the absorption of glucose in the body's cells. It most frequently begins in childhood or adolescence, and without treatment in the form of regular injections of insulin, the type I diabetic can fall into a coma and die (King, Carroll, et al., 2002). Gestational diabetes develops during pregnancy and affects approximately 4% of all pregnant females in the United States. As the pregnant woman's hormone levels increase (around 24 weeks into her pregnancy), it becomes more difficult for her body to use insulin, which leads to insulin resistance (KBRFSS, 1997-1999). A third form of diabetes, type II, is the most common of the three, accounting for about 95% of all cases of diabetes in the United States. It occurs when a person's pancreas produces some, but often times not enough, insulin or the body's cells are resistant to the action of insulin (KBRFSS, 1997-1999; CDC, 2003). It is associated with older age, obesity, family history of diabetes, prior history of gestational diabetes, impaired glucose tolerance, physical inactivity, and race/ethnicity (CDC, 2003). People with type II diabetes frequently can control blood sugar levels with a proper diet and exercise program, losing excess weight, taking oral medication and/or insulin, and carefully monitoring their drug regimen (CDC, 2003).

### Diabetes and African Americans

The National Health Survey during the past 35 years shows that among the 16 million Americans living with diabetes (<u>http://diabetes.niddk.nih.gov</u>, 2004, <u>http://joslin.harvard.edu</u>, 2004), the percentage of the African-American population that has been diagnosed with the disease has increased dramatically (<u>http://diabetes.niddk.nih.gov</u>, 2004; CDC, 2003). African Americans bear a disproportionate share of the disease's impact (Carter, Pugh, et al., 1995). In 1976-1980 the total prevalence of diabetes in African Americans age 40-74 was 8.9 percent. From

1988-1994 the total prevalence had increased to 18.2 percent, doubling the rate in just 12 years (Harris, 1990, 1991; Wetterhall et al., 1992). The same CDC survey (1988-1994) reported that among those age 40-74 years, the rate was 11.2 percent for whites.

African Americans have numerous risk factors and suffer high rates of diabetic complications (Office of Minority Health, 1999). A disturbing but relevant aspect for this study is the familial risk factors among individuals whose parents have had Type II diabetes. A National Health Interview Survey (1976) found that 29% of people with a medical history of diabetes reported having diabetic parents, compared to 4% of non-diabetic persons. As well, the 1976-1980 NHANES II survey (1985) found that 35% of people aged 35 to 74 with a medical history of diabetes reported that the mother, father, or both were diabetic, suggesting the relevance of targeting African-American family members.

The burden of diabetes is particularly high among African-American women, ranked as the fourth leading cause of death. The prevalence of diabetes increases with age in both blacks and whites; however, for black women, the rate is strikingly higher after 45 years of age (McNabb, Quinn, & Tobian, 1997). Specifically, diabetes is eight times more prevalent in the 65 to 74 age group than the 20 to 44 year age group with black women age 65 to 74 having a higher prevalence than white women (Rajaram & Vinson, 1998). Furthermore, as black women age, they are faced with a higher rate of complications from diabetes, namely cardiovascular disease, kidney disease, nerve damage, and amputation (http://www.blackhealthcare.com/BHC/Diabetes, 2000).

### The African-American Family

To best understand the many nuances of Black women, specifically regarding their health behaviors and the implications of diabetes in their family unit, a brief overview of the African-American family is fundamental. The black family historically has received much attention and controversy. Black families initially were described as being assimilation-oriented, structurally disorganized, unstable, fatherless, femaledominated, and overpopulated (Bernard, 1966; Frazier, 1939; Moynihan, 1965). However, as time progressed, other scholars who sought to understand this unique group

endeavored to promote a more accurate interpretation of the black family. The emergence of black scholarship in the 1960s was the impetus for well-informed observations regarding the black family (Billingsley, 1968, 1974; Littlejohn-Blake & Darling, 1993; Staples, 1994). Billingsley (1968, 1974), one of the early researchers in this area, observed that early investigations portrayed the black family as *deviant* or a social problem. His work pointed out that, "the African-American culture has been shaped in large measure by our history and experience in America" (1974, p. 12). What many researchers alluded to as social problems among black families were, from Billingsley's perspective, "a resilience in the face of constant judgment and mistreatment" (1974, p. 12). His work declared that the black family represented one of the most important aspects of black's struggles for survival, affirming that the black family, more than any other institution, had helped African-American people survive and find meaning in life to reach remarkable levels of achievement. Billingsley's work suggested that black families were "functional entities" (Dobson, 1997). His work was advanced by a number of scholars, namely, Virginia Young, Robert Hill, and Wades Nobles. Nobles (1974; Nobles et al., 1976), examined the African-American community's ability to maintain its resilience through the use of extended families. Hayes and Mendel (1973), Hill (1971), and Stack (1974), confirmed Nobles' findings in their work on the unique characteristics of the black family network. Stack's (1974) seminal work, for instance, has been used extensively in the social science literature to confirm the intricate networks blacks developed to assist in the financial and social support among poor black inner-city communities.

Despite the varied views on black families, most researchers agree that black families historically have developed unique cultural patterns such as supportive and flexible extensive social networks, flexible family relationships, strong religious beliefs, fictive kin, and a strong self-identification (McAdoo, 1997) to deal with the oppression and racism they have faced. Social inclusion was not a part of the African-American family structure, so once again, black families, especially black women, relied heavily on a "mutual aid network" whereby relatives, church members, or neighbors would provide each other with needed service.

### Social Contexts and Diabetic Information:

### Socio-cultural Networks among African Americans

Given that African Americans are at elevated risk of having type II diabetes and face numerous complications from the disease, understanding the key socio-cultural contexts in which diabetes is lived is important. An understanding is necessary of the way black families, particularly black women a) talk about the disease, b) convey information about the disease and c) approach disease prevention.

### Kinship Networks

Bailey (1991) observed that "there is an extensive sociocultural network pattern which influences how African Americans seek health care" (p. 34), one that she emphasizes is kinship network based. Bailey used participant observation and semistructured interviews to distinguish how African Americans use kinship networks to negotiate their health care seeking patterns. Her study was completed on a population of blacks seeking medical care in a hospital in Detroit Michigan. She observed that 1) typically, if a elderly parent was ill, the female relative cared for them, and 2) consultation regarding the illness was sought first from extended family members, friends, and/or extended relatives and then from health care professionals. Bailey verifies in her work, which extends earlier research (i.e., Sokolovsky, 1985 as cited in Bailey 1991), that blacks more than whites "talk about" their illness with extended family members and friends and that black women, in particular, provide a great range and depth of emotional and cooperative familial support. She concludes that African Americans use their informal lay socio-cultural network extensively for health care problems because the reciprocal give-and-take relationships act as a buffer between the individual, their kinship networks, and the stressful situations. She further notes that these kinship sources alleviate stress by helping the person instrumentally and/or psychologically better cope with the situation thereby providing everyone with the opportunity to be involved in the healing process.

Agee (2000) offers another example of how black women use socio-cultural networks to convey important health information. Agee (2000) found that African-American women who grew up in the segregated South suggested that their mothers provided them with the knowledge and power to negotiate difficulties during the

menopausal process, while many middle-class Euro-American women said that their mothers did not. The transmission of this knowledge for African-American women took place in public spaces (i.e., seeing older women fanning themselves in church), as well as in kinship relationships (e.g., grandmothers, aunts, "othermothers"<sup>5</sup>, or female neighbors). Agee observed that this group of Southern working-class and middle-class African-American women relied on their own knowledge and that of their mothers and "othermothers" over that of health professionals and were self-reliant when addressing health issues of menopause.

Litt (2000) provides an explanation for this unique "kin network" and its attributes noting:

Medical treatment was virtually unavailable to the rural southern African Americans: There was a severe shortage of hospital bed space for African Americans; most of the black hospitals were located in cities, which few blacks had access to; and there were very few black physicians. Furthermore, many white physicians continued to believe in the biological inferiority of African Americans – and took little interest in treating them. (p. 72) By the time the public health establishment identified the poor health status of the

southern African-American population during the early part of the 20th century, black women had established a strong "kin caretaking" network. Blacks migrating to the northern region of the country experienced similar disenfranchisements that helped carry on their strong "kin caretaking" networks (Sudarkasa, 2001). For instance, Beardsley, (1990) noted that "expectant black mothers were particularly victimized by Chicago racism: their own black hospitals often had no space for them, yet many maternity beds lay empty in white hospitals" (p. 137) (See also Fisher Collins, 1996).

Thus, Litt (2000) notes, "the women's everyday 'caretaker' created a boundary around her community; one that created a zone of safety for her at the same time as it kept strangers, in this case the white doctor, out" (p. 76). Hence, poverty, isolation, inadequate health care, and racism created an "arena for enacting allegiance to

<sup>&</sup>lt;sup>5</sup> Shenk (2000) states, 'Othermothers' are women who assist bloodmothers by sharing mothering responsibilities (Collins, 1991). This cultural value placed on cooperative childcare found institutional support in the adverse conditions under which many black women mothered. The majority of African-American women had to work outside the home and could not afford the luxury of motherhood as a noneconomically productive, female "occupation" (p. 112).

community and kinship ties" in which black women saw themselves as protectors of each other (p. 76).

While menopause and type II diabetes are different health challenges, both Agee (2000) and Litt (2000) recognize the great trust African-American women display toward each other rather than toward the formal medical system.

### Provision of Diabetic Information

While scholars have observed that socio-cultural networks can impact whether and how African Americans seek health care, one area not thoroughly explored is how researchers can provide findings to health practitioners to insure useful and appropriate provision of health information to prevent and reduce chronic disease complications and mortality. While some scholars believe diabetic education programs (e.g., church base programs, inner-city weight loss programs) can encourage the dissemination of information about diabetes, its prevention and its control (Kanders, Ullman-Joy et al., 1994; Kumanyika & Charleston, 1992; McNabb, Quinn & Rosing, 1993), others believe that physicians and health care practitioners must be more involved in culturally oriented education (Jacobs, Kohrman, Lemon, & Vickers, 2003). While most scholars have advocated for strategic channels (e.g., the church network) to address the dissemination of diabetic information, a strong link between the socio-cultural networks and the provision of health information has not been made. For this reason, a valuable starting point is to understand the unique attributes of the African-American family and specifically to understand the way in which black mothers and adult daughters talk about health, particularly as it relates to diabetes. As we shall see a) African Americans view their oral tradition as an important channel in which to pass information from generation to generation (Resnicow & Braithwaite, 2001), b) historically black families, especially the women, place a high priority on the family, extended family, and community members (i.e., they receive from and invest in these family units; Stack, 1974) and c) African-American mothers and daughters assume key roles in the family (e.g., caregivers, social support providers) (Sayles-Cross, 1995).

### The Significance of Oral Tradition

For a number of years scholars from diverse disciplines (e. g., social historians, anthropologists, and folklorists) have examined the oral traditions of black Americans (Heath, 1989). They have discovered that for the African-American culture the oral tradition has served as a fundamental vehicle for survival, reflecting the collective spirit of blacks and functioning to preserve their heritage (Smitherman, 1986). Numerous scholars believe that oral tradition provides the lessons and precepts about life and survival that are passed from generation to generation through the medium of song, story, and folk sayings, and rich verbal interplay among everyday people (Folb, 1980; Goss & Barnes, 1989; Hannerz, 1969; Resnicow & Braithwaite, 2001; Shenk, 2000; Smitherman, 1986; Stewart, 1997 as quoted in Banks-Wallace & Parks, 2001). Oral traditions continue to be used to prepare future generations for their place in mainstream culture. Even the contemporary black teenage culture verifies the value of oral tradition to inform their musical styles (e. g., rap, hip-hop, rhythm and blues; Folb, 1980).

Most research that examines oral tradition approaches it from the perspective of its ability to provide historical lessons about survival of culture (Shenk, 2000). For instance, Banks-Wallace and Parks' (2001) study of oral tradition and mental health encourages mental health providers to understand the impact of race and racism on the mental health, well-being and health behaviors of African-American women attempting to negotiate their lives. This research has shown that protecting daughters within a racist environment was viewed as a primary maternal task. Mothers shared stories with their daughters about their experiences growing up in racist settings, how they dealt with racism and what they did to combat racist situations. (Banks-Wallace & Parks, 2001; Banks-Wallace, 2002). By giving daughters insight into the history of oppression among African-American women via storytelling, Banks-Wallace verifies that mothers helped daughters locate racism and understand it in their present day environments (i. e., the academic setting, and the workplace).

Oral tradition has served as an important communication source among the African-American culture, particularly as it relates to storytelling; thus, it is imperative to mention oral tradition as an avenue to transmit information from generation to generation

in black communities<sup>6</sup> and how it might presently serve as an avenue to disseminate health information.

### The Significance of Health Communication

Literature addressing the dissemination of health messages among African Americans is sparse. Given that health communication, generally defined as "the way we seek, process and share health information" (Kreps & Thornton, 1992, p. 2) has been shown to serve an important role in health education, it is crucial that health scholars understand the personal and cultural context in which people live and then provide informative health information to these populations. DuPre (2000) believes effective health communicators must be concerned enough to pay close attention to people's behavior and knowledgeable enough to recognize cultural and personal preferences that make people different. If health communication scholars begin to understand the context of interpersonal health messages among the African-American mother-daughter dyad, it may become more likely that African-American individuals and families at high risk for diabetes will be given and/or receive accurate information about the implications of this widespread disease (Pryor & Mengel, 1987). This would allow the individuals the opportunity to blend pertinent health information into their own cultural ideas and experiences (DuPre, 2000).

Within the health communication field, communication is conceptualized as the central social process in the provision of health care delivery and the promotion of public health (Atkins, 1994; Kreps 2001). Communication is pervasive in creating, gathering, and sharing health information. As noted earlier, health information and the provision of that information is the most important resource in health care and health promotion because it is essential in guiding strategic health behaviors, treatments, and decisions (Kreps, 1988, 2001; Rogers 1994; Atkins, 1994).

Communication research has been effective in educating the public about health promotion and disease prevention by using mass media, face-to face interactions, and other communication channels (Lapinski & Witte, 1998). These promotions have

<sup>&</sup>lt;sup>6</sup> There is an extensive body of literature on slave narrative that can provide an understanding of how important the spoken word was for blacks, particularly while they were enslaved. It was the vehicle of communication used to relay stories of their African tradition, their escape via the underground railroad, etc.

successfully persuaded individuals to take positive steps to protect their health. Typically called "health communication campaigns" or "health prevention programs," these health interventions have been applied to the problems of women's alcohol consumption (DeCarlo & Parrott, 1991), AIDS (Witte, 1992), skin cancer (Parrott, Glassman, & Burgoon, 1989), and mammography promotions among African-American women (Sung, 1992).

Despite the numerous health communication campaigns focusing on women, most that address African-American women's health concerns have lacked important elements (Silver 2001; Frisby, 2002). After a comprehensive literature search on communication campaigns targeting black women, it became evident that most had been inadequately conducted (i. e., used small populations, poor evaluation instruments or lacked a theoretical base). For instance, Frisby (2002) sought to use a health communication intervention project in four black beauty salons in Los Angeles to reach high-risk older African-American women. The intervention project delivered breast cancer education information to four local beauty salons. Pamphlets were given to all African-American female customers who entered the salon and a video entitled "A Life Saving Choice" was played continuously during the hours of the salon's operation. Finally, prior to any woman's departure she was given a voucher for a free mammogram at a local clinic and encouraged to have yearly screenings. To address financial concerns about mammography's women received a list of available low or no-cost screening services. Any women who did not have health insurance or who did not meet financial qualifications to receive a mammogram on a regular basis were informed that a second alternative (i. e., a mobile mammography van) would also be available for free screenings. While a campaign of this nature has important relevance for addressing cultural diversity and a primary health concern such as breast cancer among black women, Frisby (2002) did not address the effectiveness of the study for the research population. As well, the research was not theoretically grounded. In order to move closer to helping black women change negative health behaviors, researchers' findings must be used among health practitioners to develop gender specific programs that have direct communication messages which are culturally relevant to that group. Silver (2001) makes a constructive argument, stating,

One of the greatest unused resources for a community's health care development is the community itself. Communication provides a means through which to tap this invaluable, commonly overlooked resource. But communication is not simply a matter of transmitting information and assuming it will be understood and acted upon. Effective health communication involves the transformation of health knowledge into messages that can be readily understood, accepted, and put into action by the intended audience (p. 53)

Health communication campaigns that address the importance of prevention have worked effectively with other health issues such as breast cancer and HIV/AIDS (Witte, 1992; Sung, 1992). Type II diabetes is similar to other chronic disease in that behavior changes or modifications can lead to a better quality of life. For this reason, health communication research must seek to understand the unique communication channels used among black women and create interventions that tap into their behavioral and educational knowledge to assure that black women are receiving sufficient health information regarding diabetes.

A substantial area of health communication research emphasizes creating messages that utilize effective means to target the desired audience thus encouraging individuals to change negative behaviors (Atkin, 1994). As noted earlier, health education is limited in its effectiveness, thus educating people in how to prevent or manage their health problems is the most practical and cost-effective means of improving a nation's health (Silver, 2001). This dissertation's findings can be instrumental in understanding the degree to which African-American women talk with one another about successful self-care health behaviors. Eventually, the research findings here may facilitate the creation of an effective intervention that addresses type II diabetes among African-American women. Effective interventions that highlight the severity of diabetes, and address the barriers and benefits of self-care (including communication barriers) can foster positive self-care behavior among African-American women with diabetes.

### Diabetic Self Care

An important aspect of type II diabetes is the self-care behaviors in which individuals with the illness engage. A large body of social science and biomedical literature has been written that addresses *diabetic adherence* and *self-care* (Hampson, Glasgow, & Toobert, 1990; Hunt, Pugh, & Valenzuela, 1998). As well, there are fairly clear guidelines for diabetic adherence and self-care and existing instruments to measure it (Toobert, Hampson & Glasgow, 2000). Given that a portion of this dissertation seeks to understand if/how communication with non-diabetic adult daughters shapes African-American mothers self-care behaviors, a clear definition of both and a logical rationale for using the term *self-care* which is "lay-initiated" (Stoller, 1998, p. 24) is important.

Adherence refers to "the extent to which a person's behavior coincides with medical or health advice" (Sackett & Haynes' 1976 definition as cited in German, 1988) while *self-care* refers to "activities undertaken by individuals to promote health, prevent disease, limit illness, and restore health." The distinguishing element of these definitions is "self-care practices are lay-initiated and reflect a self-determined decision-making process" (Stoller, 1998, p. 24) while adherence reflects a biomedical "physiciancentered" approach to treatment decisions (Schoenberg, Amey, & Coward, 1998). Diabetic self-care, which involves the majority of health activities that individuals with diabetes engage in day-to-day without the direct support or supervision of the health care provider, includes a wide-range of activities, including but not limited to blood glucose monitoring, diet, exercise, medication, and routine foot care and eye examination (Polly, 1992; Samuel-Hodge, Headen, Skelly, et al., 2000; Schoenberg & Drungle, 2001; Toobert, Hampson, & Glasgow, 2000; Tu & Barchard, 1993). One of the primary barriers to adequate self-care behaviors is the need for individuals to make numerous and simultaneous behavior modifications. Additionally, self-care is not static but is pursued throughout the lifespan of the chronically ill person. Self-care is a life-long process because diabetes is not curable, but rather a manageable condition which individuals must endure for the remainder of their lives (Day, 1995). So while clinicians recommend adherence to diabetic protocols for optimal disease management, many individuals with diabetes find their self-care process problematic. Typically, the greater the number of self-care procedures required (e.g., maintaining diet and glucose monitoring in conjunction with exercise) the higher the probability that poor self-care will result (Dunbar-Jacob, Burke, & Puczynski, 1995; Sullivan & Joseph, 1998), not to mention the cost associated with optimal self-care for an often low-income population (Fisher Collins, 1996). Another major issue that complicates self-care for those living with diabetes is the major constraints on lifestyles that can lead to feelings of depression, frustration, guilt and a reduced quality of life (Lustman, Griffith, Gavard, & Clouse, 1992). Because

lifestyle changes can be extremely demanding, people with diabetes may suffer psychological disturbance, particularly depression (Peyrot & Rubin, 1997; King, Carroll, Newton & Dornan, 2002). For instance, Sullivan and Joseph (1998) reported that participants described the task of maintaining such changes as "a continuing battle" (p. 77) leaving them depressed and frustrated.

For the most part, individuals living with diabetes typically "attempt to prevent, contain or manage their illness" by themselves (in situations where extended family is absent) or with advice obtained from family members, or other personal relations in conjunction with health care professionals (Stoller, 1993; Kart & Engler, 1994; Schoenberg & Drungle, 2001). Research suggests that most disease management, including diabetes, occurs within the home setting. Research further suggests that how family relationships are organized around the disease affects how the disease is managed over time (Fisher, Chesla, Skaff, et al., 2000; Fisher, Nakell, Terry, & Ransom, 1992; Peyrot, McMurry, & Kruger, 1999). For instance, Brody (1985) found that families, as opposed to the formal health care system, provide 80% to 90% of medically related and personal care (i.e., household tasks, transportation, purchasing and administering medication) for older adults, with the older daughters generally serving as the principal caregivers. This informal health care or absence thereof is said to be a fundamental element in how individuals negotiate their illnesses (Cole & Reiss, 1993). Given that family members are a major source of help where illnesses like diabetes occurs and given that chronically ill older adults rely on family members (i. e., daughters) for principal support it seems logical that understanding how African-American mothers and daughters discuss disease is imperative. This is particularly true in situations where the adult daughter plays a crucial role in different dimensions of caregiving for their diabetic mothers.

In recent years literature focusing on the role of care administered by the family and extended family network has received more attention (Stoller, 1993, 1998, Stoller & Wisniewski, 2003). A seminal piece of research by Stoller & Wisniewski (2003) describes the multiple functions of the lay consultation networks, including influencing adherence to regimens and providing a context in which people can tell and retell their stories. Stoller and Wisniewski (2003) also report that women maintain more diverse

networks than men, which, they state, is consistent with "the role of women as lay producers of health within the family" (p. 502).

Research points to adult daughters as primary caregivers and as participants as lay providers of health (Sayles-Cross, 1995; Stoller & Wisniewski, 2003). Thus, one can argue that adult daughters are a primary part of the lay network in the African-American family, especially for their diabetic mothers. While the importance of family influences on diabetic self-care has been recognized in certain disciplines, attention to this area of research remains sparse, especially in health communication literature (Fisher, Chesla, Bartz, et al., 1998).

#### Caregiving and Social Support

The caregiving/social support literature has described many of the distinctive characteristics attributed to the African-American family (e. g., the strong sense of filial responsibility, close kinship bond, high value placed on caregiving roles, and positive parental influence regarding socialization). The caregiver literature addresses the role of African-American adult daughters as primary caregivers to their aging mothers (Sayles-Cross, 1995). For instance, Feagin, Hayes, and McAdoo (1978), whose primary objective was not central to informal social support, found that African-American families and their relatives were involved in extensive exchanges of mutual support.

The social support literature emphasizes the adult daughter and other extended family members as a primary source of social support that play a positive role in their parents' adherence to diabetes regimens (Boehm, Schlenk, Funnell, et al., 1997; Ruggiero, Spirito, Bond, et al., 1990). Small-scale studies that focused on informal social support within black families describe the role of the adult daughter. (Barker, Morrow & Mitteness; 1998; Taylor, 1986). One study examined the implications of social support and caregiving among 45 urban community dwelling African Americans over the age of 65 (Barker et al., 1998). Each respondent participated in in-depth interviews along with a six month long observations and follow-up interviews. The researchers focused on understanding participant's views of their informal social support networks. Barker et al., (1998) found that a) a small population of the respondents interviewed lived in predominately female multi-generational households, b) women's social support networks, suggesting that

gender was a key influence on the size of informal social support networks of elderly, urban African Americans, and c) the primary caregivers played more important roles in older women's than in older men's informal networks. As noted in prior literature, Barker et al., observed that caregiving daughters held a strong physical presence in the homes of their mothers (more so than their fathers), and that daughters had a stronger presence of extended generations involved in the caregiving roles (i. e., their children and extended family kinship networks)

While the caregiving and social support literature does not directly address the function of health communication messages, it does suggest that health outcomes are influenced by the presence of social relationships and positive caregiver roles involving daughters, family members, friends or other extended family members (Drummond, 2000; Lau, Quadrel, & Hartman, 1990; Winett, 1995; see also Young, et al., 2001).

# **Overview of Mother-Daughter Relationships**

While existing literature addresses a broad array of health issues surrounding African-American women, rarely does it address how these health issues can be understood in the context of health messages communicated between African-American women, specifically mothers and daughters (Brook-Rochester, 2000; Leigh, 1995). For example, it is typical for research to concentrate on comparisons between black women and white women with type II diabetes, to examine white mother-adolescent daughter dyads with diabetes or to address non-adherent behavior of diabetic African-American women (Bobrow, AvRuskin, & Siller, 1985; Samuel-Hodge, Ammerman, Skelly, et al, 1997; Weatherspoon, Kumanyika, Ludlow, et al., 1994). While comparisons of white and black women offer useful insights, little is known about how African-American women care for themselves through talking with one another about type II diabetes. Instead of making comparisons, this study will seek to improve our understanding about the role of communication in the African-American type II diabetic mother and non-diabetic adult daughter dyad.

The small body of literature that addresses the exchange of health-related information in the family unit, with mention of African-American mothers and daughters, focuses on parent-adolescent communication about the negative consequences of teen pregnancy, contraction of sexually transmitted diseases, and HIV (Dilorio &

Hockenberry-Eaton, 1996; Lau, Quadrel, & Hartman, 1990; O'Sullivan, Meyer-Bahlburg, & Watkins, 2001; O'Sullivan, Jaramillo, Moreau, & Meyer-Bahlburg, 1999). For example, Fox and Inazu's (1980) research on parent-adolescent communication found that mother-daughter communication about sexual matters could socialize teen daughters about responsible sex norms' and less risky sexual behavior. Their study used a sample derived from the 1978 Mother-Daughter Communication study conducted in Detroit, Michigan. Their sample of 898 black and white urban mothers and their teenage daughters were questioned about their patterns of communication on six specific sexual topics: menstruation, dating and boyfriends, sexual morality, sexual intercourse, and birth control. Fox and Inazu (1980) noted that while various sexual topics were difficult for white mothers to talk about, namely sexual intercourse and birth control, for the most part black mothers talked freely with their daughters about the six sexual topics. Fox and Inazu (1980) believe that research that addresses mother-daughter communication is valuable for understanding how cultural, educational, and social status can influence discussion of sex and how this knowledge can facilitate effective educational programs.

In another study that examined the African-American mother-daughter dyad, researchers found that dialogues between African-American mothers and their adolescents served as a conduit for providing sexual education, particularly for adolescent daughters (Dilorio & Hockenberry-Eaton, 1996). Twenty-nine African-American mothers participated in one to three focus group sessions at the Boys and Girls Club in a large metropolitan area. The analysis of focus group transcripts yielded insights into three major communication approaches mothers used to talk with their adolescents about sexual and reproductive issues. Two significant findings perceived by the researchers were a) the need for mothers to have the "big talk" with their adolescents and b) the need for mothers to inform their adolescents of the negative consequences of sexual intercourse (e. g., sexually transmitted diseases and unwanted pregnancy). Researchers found mothers more likely to discuss sex and reproductive issues with their daughters than with their sons.

A recent study (Crosby, Wingood, DiClemente, & Rose, 2002) exploring associations between family-related measures and sexually transmitted disease (STD) history confirmed that the immediate family environment has an influence on adolescent

behavior. Researchers collected data from 170 pregnant African-American adolescent females, 14 to 20 years of age attending a prenatal care clinic in a large urban area of the South. Crosby et al., (2002) found that young women became pregnant during their teens but had family support, parental monitoring, and relationships with their parents (especially discussions with their mothers) were more likely to take protective steps to prevent STDs. Researchers made a number of suggestions from their findings. A primary suggestion was that further research should investigate how mother-daughter discussions translate into reduced risk of STD infection. This finding extends previous family communication research by suggesting that frequent mother-daughter communication about preventing infection with the AIDS virus may be an important primary prevention strategy against STDs among African-American adolescents. The findings from the above studies focus on sexual education, not chronic illness, but they all can be useful because they address the importance of positive and preventative health information among mother-daughter dyads.

### African-American Women: Views on Motherhood and Mother-Daughter Relationships

Over the past two decades African-American scholars have more rigorously addressed varying perspectives of mothering and motherhood among African-American women (Collins, 1991; Bell-Scott, Guy-Sheftall, Royster et al., 1991, Joseph, 1991; Banks-Wallace & Parks, 2001). A perspective most prevalent in the white male dominant culture views motherhood as two oppositional spheres wherein the "male" is the economic provider and the "woman" is the affective nurturer. Black scholars purport that a sector of white society continues to validate this white stereotype and prejudice power structure of black motherhood, even in the 21<sup>st</sup> century.

A more acceptable view among black scholars (Guy-Shetfall, 1990, 1995; Collins, 1991; Joseph, 1991) argues that motherhood is central in all aspects of life. This they believe is a given for black women who are raising black children in a racist society. As Collins (1991) states, black women never functioned in two different places but were expected to be all things at all times. Some black scholars believe that it is absolutely crucial to speak of mother-daughter roles and functions from the perspective of the African-American community and the community's relation to the dominant white society (Collins, 1991). They also concur that the mother-daughter interaction must be

observed in the context of the Black family network (Joseph, 1991). Finally, many believe that the role of the mother should be synonymous with our African ancestors, positioning the role of the mother as one which provided emotional care and physical survival that were interwoven as interdependent, complementary dimensions of motherhood (Collins 1991). As such, Collin's concurs with other black scholars arguing that since much of our African heritage has been retained, black families must reconceptualize the role of women in the black family networks. Collin's notes this view as one that is contradictory to the dominant cultural views of motherhood (Collins, 1991)<sup>7</sup>.

Numerous black scholars have supported examples of the contrasting perspectives that African-American women share regarding their position in the dominant culture (Banks Wallace-Parks, 2001; Joseph, 1991). One example that has relevance for health communication research is Banks-Wallace and Parks' (2001) work on mental health among African-American women. Their work examines the implications of racism and the importance of protective nurturing within African-American mother-daughter dyads. Their primary aim was to examine the maternal tasks related to the protection of daughters, and to understand the impact these tasks had on women's personal well being. Maternal tasks included a) maintaining housing in safe neighborhoods with good schools, b) providing aesthetically pleasing physical and social environments for their daughters, c) teaching daughters to resist opposition, d) protecting their daughters' spiritual wellbeing against internalized racism and, e) ensuring shared responsibility by community "sister-mothers" and kin relations. Banks-Wallace and Parks recognize that "the protection of daughters is a central mothering task for African American women" (p. 82) supporting the notion that black mothers' and daughters' life experiences are interwoven. These points are also useful for understanding health issues as they relate to chronic illnesses. Banks-Wallace and Parks' (2001) concluding discussion exhorts health care providers to take a multi-faceted approach to the mental health, well-being, and health behavior of the African-American mother-daughter relationship. They explain that often mothers feel their maternal tasks go unappreciated and are invisible in the dominant

<sup>&</sup>lt;sup>7</sup> Collins believes that dominant ideology continues to foster socially constructed images of black womanhood. She maintains that even though these negative images reflect the dominant groups' interest in maintaining black women's subordination, black women must transcend these defined images and look to our African heritage (Collins, 1992, p. 176).

society (p. 94). Thus, Bank-Wallace et al., confirm that African-American mothers should be provided with safe spaces, in the form of self-help groups that promote openness, honesty, and that celebrates them as black women. They further contend that mental health providers, most of whom are white, must work to educate themselves about the impact of racism on the mental health of Blacks. They state, "African American mother-daughter relationships are one of many human experiences significantly influenced by race and racism" (p. 94).

Banks-Wallace and Parks (2001) validate Collins' (1991) Afrocentric ideology by confirming that African-American mothers frequently take on a protective role to insure that their daughters face minimal racial harm from the dominant<sup>8</sup> culture's worldviews. They observed that African American mothers blended emotional support with hard-core protective education to increase the likelihood of emotionally strong daughters. Both researchers assert that most African-American mothers take specific steps to ensure their daughters receive a culturally balanced education, protective communal family relations with kin and "othermothers," and nurturing. Though these black feminist authors approach the topic of motherhood and the mother-daughter relationship differently, they both feel that health practitioners must stay clear of conceptual frameworks developed using predominately white, male, middle-class standards and instead seek to understand the contexts in which African-American women negotiate their lives (Banks-Wallace, 1999; Banks-Wallace & Parks, 2001; Collins, 1991).

Public health and mental health research that take a black feminist approach is useful for a number of reasons; first, it recognizes the significance of health issues via intergenerational communication among family units, specifically among African-American mothers and their daughters. Second, it recognizes and factors in the unique relationship that transpires within the mother-daughter dyad; and finally, it acknowledges the protective and proactive role black mothers have in shaping their daughters lives.

# Varied Contexts of Mother-Daughter relationships

Though not inclusive of African-American mother-adult daughter, research on the mother-daughter relationship does exist for other cultures. Most studies either focus on

<sup>&</sup>lt;sup>8</sup> African American feminist literature often uses the term "dominant culture" to refer to a white male perspective specifically, and the white middle and upper class perspective generally.

college-age and younger daughters or examine the life transitions of mother-daughter relationships, noting the closeness of mother-daughter relationships in several cultures (Boyd, 1985, 1989; Blieszner, Usita, & Mancini, 1996; Mancini & Blieszner, 1992; Patsdaughter & Killien, 1990; Rastogi & Wampler, 1999; van Mens-Verhulst, 1995). For example, Boyd's (1989) review of the literature provides a constructive assessment of the mother-daughter relationship noting the mutuality and interdependence between the dyad as the daughter ages.

Some literature on the mother-adult daughter dyad comes from gerontology and some uses a feminist framework to investigate the relationship. For instance, Blieszner, Usita, and Mancini (1996) used gerontology along with a feminist perspective to investigate the late-life relationship between mothers and their daughters. They found that elements of companionship, cohesion, and conflict underscore perceptions of relationship quality between mothers and adult daughters.

Fingerman's (1997a, 1997b, 1998, 2001) extensive body of research on the mother-adult daughter relationship has increased knowledge of adult daughter-aging mother interpersonal tensions, perceptions of continuities and change in mother-daughter relationships, and other distinct aspects of interpersonal conflict between healthy elder mother and adult daughter dyads. Fingerman asserts that the increased longevity of women has ramifications for the negotiation of parent-adult daughter relationships. She observes that mothers report deeper positive and negative emotions in their relationships with adult daughters than do fathers and adult sons (2001, p. xii), particularly for those mothers and daughters who live in close proximity.

Another study that extends the mothers' relationship with adult daughters investigated the *communicative* dynamics within the mother-adult daughter relationship. Based on prior research that examined communication satisfaction among adult sons and fathers, Ontko (1976), examined adult daughters' perceptions of mothers' communication styles and their effect on daughters' perceived relationship satisfaction. The author found that adult daughters were more satisfied with their mothers' communication messages than adult sons were with their fathers' communication messages. As well, Ontko found the communication styles in three areas (mothers' responsiveness, judgmental and hypocritical) between mothers and daughters to be more fluid and comfortable than of fathers and adult sons. Ontko (1976) noted that a large percentage of daughters rated their mothers with a perfect satisfaction score, which was associated with their communication style. This study contributes to research findings that support the unique bond and communication dynamic in the mother-adult daughter relationships.

Randall-David's work suggests that the oral transference of health messages can influence the health behavior of female family members. Her dissertation (1985) provides one of the strongest arguments for the value of understanding the transmission of intergenerational health care beliefs. She examined the influence of black women as healers and health care resources in a small southern rural community. Randall-David concluded that the "sources of health information and the continuities and discontinuities that exist as health beliefs, values and practices vis 'a vis hypertension are transmitted from one generation to another" (p. 3). Her research focused on three generations of African-American women: grandmothers, daughters, and granddaughters. Randall-David found that female relatives and other significant female members of the community orally passed health care attitudes, beliefs, and behaviors from one generation to another. Randall-David found that while influence of health care systems and public health information sources includes community resources along with information resources such as television, radio, school, and contact with the medical system, older women in the community also were perceived as important sources of general health care information. She found that younger respondents can gain knowledge from both biomedical belief and familial information.

In sum, the literature says that a) African-American women place significant value on shared accounts of oral history (Banks-Wallace, 1999; Banks-Wallace & Parks, 2001); b) African-American women place a high value on the family, and caregiving and motherhood are important familial responsibilities (Collins, 1991; Sayles-Cross, 1995); and c) African-American women take great care in protecting and nurturing their daughters to knowledgeably negotiate the dominant cultures' worldview (Bank-Wallace & Parks, 2001).

Information from this qualitative dissertation on the communicative aspects of diabetic-related health behaviors can improve discourse about type II diabetes, serving as a reference for researchers and practitioners to understand shared information about type

II diabetes, diabetic self-care, and non-diabetic health behavior among the motherdaughter dyads and members of the African-American family unit (Schoenberg, Amey & Coward, 1998; Schorling & Saunders, 2000).

#### Objectives of the Study

Because of the impact that health information can have on the African-American mother-daughter relationship, it is important to understand the context in which health messages are shared and how these messages can inform health behavior for type II diabetes. This dissertation will focus on both the mother's self-care and their non-diabetic daughters' health behavior in union with health information and knowledge. This study addressed the context, setting, and nature of health information exchanged among African-American mothers and daughters to observe if and how this information is extended. For that reason, the following research questions were asked:

RQ1: Do African American mothers with type II diabetes communicate (i.e., talk) with their non-diabetic adult daughters about type II diabetes, if so how?

RQ2: Do non-diabetic African American adult daughter communicate (i. e., talk) with their type II diabetic mothers about type II diabetes, if so how?

RQ3: If type II diabetic mothers and their non-diabetic adult daughters do communicate (i.e., talk), what situations prompt communication from a) the type II diabetic mother to her non-diabetic adult daughter and from b) the non-diabetic adult daughter to her type II diabetic mother?

Finally, it is important to understand how the potential sharing of health messages between mothers and daughters may shape mothers' self-care behaviors and daughters' diabetes-related health behavior. Hence, the final question:

RQ4: If diabetic mothers and non-diabetic adult daughters do share information, does sharing these health communication messages shape African-American mothers' diabetic self-care and/or shape adult non-diabetic daughters' diabetes-related health behavior?

Information from this qualitative dissertation can improve dialogue about type II diabetes by promoting information sharing among dyads and eventually African-American families (Schoenberg, Amey & Coward, 1998; Schorling & Saunders, 2000). As well, this health-related communication focus can add a new dimension to the caregiving and social support literature by addressing how health-related communication occurs in families living with chronic illness.

### Chapter Three

### Research Methodology and Design

The fact that the adult American Negro female emerges a formidable character is often met with amazement, distaste and even belligerence. It is seldom accepted as an inevitable outcome of the struggle won by survivors, and deserves respect if not enthusiastic acceptance. ~ Maya Angelou~

# **Preliminary Observations**

The impetus for this study arose from my personal experience as the daughter of a mother living with Type II diabetes and my research experience with a veteran researcher who studies health experiences of women with diabetes and coronary heart disease. During my research experience I interviewed African-American women about health concerns, primarily heart disease. I observed that African-American adult daughters were involved in the care for their ailing mothers. In some cases, adult daughters maintained their mother's home, took care of nutritional and medical needs (i.e., preparing meals, purchasing food and medication), or drove their mothers to doctor's appointments. Equal to the care given by the adult daughters was the information sharing and nurturing role provided to adult daughter by ailing mothers. Through my research and personal experience I began to document the nature of this mutual give and take relationship between the mothers and adult daughters, particularly as it pertained to the communicative aspects of chronic illness. Shortly after this research experience, I began to search the literature to gain insight on the way in which mothers and daughters talked about their health and the implications of their health information.

As a course requirement, I conducted an in-depth semi-structured interview with a Type II diabetic mother and her two adult daughters during the Spring of 2001. Given the paucity of research in this area, a qualitative method was selected to obtain insight into the mothers' and daughters' lived experience of type II diabetes. This inquiry examined how the triad felt, thought, functioned, and communicated in their natural settings (Frey, Botan & Kreps, 2000). Continuing this line of research, my dissertation most closely follows an inductive grounded approach with focus on the communicative context of the

mother-daughter dyad's perspective of the phenomenon. This entailed the use of a constant comparative analysis, and data abstraction followed by developing of codes and establishing of themes (Strauss & Corbin, 1990).

### Methodological Choice

My primary research objective was to find out whether and how type II diabetic mothers and their non-diabetic adult daughters talked about their health behaviors. My secondary research objective was to observe how the transmission of health information shaped self-care and health behaviors among the dyads. To best understand this problem and answer the research questions posed, I used a modified grounded theory (GT). However, I structured questions in the second interview with the Health Belief Model (HBM) and Social Cognitive Theory (SCT) to provide new insight on mother-daughter health behaviors. Research on the communicative context of mother-daughter dyads living with chronic illness (i.e., diabetes) has not been investigated nor does existing theory explore this phenomenon (Maxwell, 1998). Thus, GT provided useful strategies for studying the communicative experiences between mother-daughter dyads dealing with type II diabetes (Frey et al., 2000). As Sterns (1980) notes, "the strongest case for the use of grounded theory is in investigations of relatively uncharted waters, or to gain a fresh perspective in a familiar situation" (p. 116). This form of qualitative research is used to generate an understanding of the concepts and theories held by the people you are studying – what Maxwell (1992) calls "interpretations". These interpretations provide the researcher with an understanding of the *meaning* that the phenomena and events have for the actors who are involved in them, and the perspectives that inform their actions (Maxwell, 1998). Not only does this type of qualitative approach generate an understanding of the concepts held by participants, it also has the potential to produce conceptual models and theories that are most representative of the actual lived experiences of those participants. As well, the outcomes provide a form of internal validity that is a strength of the qualitative approach to research (Hoshmand, 1989; Patton, 1990).

In GT, data collection, analysis, and theory construction take place concurrently and therefore in "reciprocal relation" (Strauss & Corbin, 1990, p. 23) to one another as

theoretical constructions repeatedly are verified by the data. This investigation of recurrent themes and issues, which is referred to as "theoretical sampling"<sup>9</sup> is fundamental to the use of a grounded approach (Strauss & Corbin, 1990). The grounded theorist endeavors to build theory with the data collected from the lived experiences of the respondents, focusing primarily on how the respondents construct meaning (Strauss et al., 1990). The "continuous comparative analysis" (i.e., comparing every piece of data with every other piece of data) yields theoretical constructs of the phenomenon (Sterns, 1980). The wonder of this process is that initially it prohibits the grounded theorist from assigning meaning to the phenomenon and defers that role to the research meaning the respondents attribute to the phenomenon. An example of this can be seen in Charmaz's (1990) examination of the effects of long-term chronic illness on ill people's selfconcepts. Her intention as the researcher was to understand how "ill people" experience their constructions (i. e., of their illnesses) and the diverse situations in which they experience them as *their* reality. The lived experiences of her participants shaped her approach to data collection and analysis. One female respondent in her study (1990) maintained her employment even during serious illness episodes. The respondent did so because of her desire to avoid having illness inundate her life and her identity, not because she disavowed its presence. In an effort to maintain the integrity of her respondent's lived experiences, Charmaz affirmed, checked, and refined her developing ideas working to limit any "preconceived hypotheses or possibilities of following the prescribed canons of traditional random sampling required for statistical verification" (p. 68).

# Methods

### **Participants**

In this study, a purposive sample of type II diabetic African-American mother and adult non-diabetic daughter dyads (N = 10 dyads) was recruited in Albuquerque, New Mexico; Lexington, Kentucky; and Cincinnati, Dayton and Yellow Springs, Ohio.

<sup>&</sup>lt;sup>9</sup> Charmaz (2000) notes, theoretical sampling is used to develop emerging categories and to make them more definitive and useful. This means researchers cannot produce solid grounded theory through one-shot interviewing in a single data collection phase. Researchers must complete the work of comparing data with data and have developed a provisional set of relevant categories for explaining the data (p. 519).

Sampling allowed me to glean important information about respondents, their settings, and events that were important for answering the research questions (Maxwell, 1990).

Individuals interviewed for this study were selected according to the following criteria: self-identified, African-American mother-adult daughter pairs, not estranged from each other, both living within a one hour distance of each other and willing to engage in 3 interviews each (each person had two individual interviews and one dyadic interview) lasting one and one-half to two and one-half hours in length. Given the a) high rates of diabetes among African-American women, b) the familial patterning of this disease and c) the unique relational bond among black mothers and their daughters (noted in Chapter 2), this dissertation sought to give primary attention to the communicative relationship of mother-adult daughter pairs. Three interviews were conducted to provide respondents with ample opportunity to reflect on research questions and to insure that any recurrent themes or issues in the interviews could be followed up on as needed (Glaser et al., 1967).

Research validates the influential role that African-American mothers have with their daughters and on their daughters' development (Gilligan, 1996; Kerpelman, Shoffner and Ross-Griffin, 2000), particularly between adult daughters serving as caregivers for their aging mothers (Joseph, 1991; Sayles-Cross, 1995). For that reason, understanding the communicative influence diabetic mothers have on non-diabetic daughters as well as the communicative influence non-diabetic daughters have on their mothers is important. Those categorized as mothers were type II diabetics and at least 45 years of age or older. To guarantee that the mothers understood the on-going challenges of type II diabetes, the mothers in the study must have been diagnosed with type II diabetes for at least 3 years. Typically, women diagnosed for 3 years or more encounter a wide-range of obstacles when living with type II diabetes (Sullivan & Joseph, 1998; Tu & Banchard, 1993). To gain their perspective on the nature of communication about diabetes, adult daughters (age 20 +) in the study were non-diabetic, which included never having been diagnosed with gestational diabetes. Prior to the actual interviews, mothers and adult daughters received a screening interview to insure each met the criteria of study (Appendix C). This screener included questions like; a) How often do you see mother/daughter, b) Are you close or not speaking with your mother/daughter, c) How

would you describe your relationship and, d) Do you two talk about health issues with each other? In cases where family units had more than one daughter over the age of 20 willing to participate in the study, mothers were asked to decide which daughter should participate based on the daughters' location and availability. For instance, in one such dyad the mother had two daughters willing to participate but the elder daughter had a number of work constraints. For this reason, the mother felt strongly that the younger daughter would be better for the interviews.

Characteristics of and demographic information about type II diabetic mothers and their non-diabetic adult daughters (i.e., state location, age, distance between dyads, years of schooling, years of diagnosis with type II diabetes) are presented in Table 3.1 and 3.2. Lexington Kentucky, Cincinnati, Ohio and the surrounding areas (i. e., Dayton, Yellow Springs, Ohio) were chosen as the research site because they have sizable concentrations of African-American communities (unlike Albuquerque, New Mexico where I initially started and completed 2 dyadic interviews). My prior residency in this region (Cincinnati, Ohio and Lexington, Kentucky) also made them accessible and familiar places to locate respondents. Most women interviewed lived in one of the two states for the majority of their lives or moved there at very young ages. Diabetic mothers ranged in age from 45 to 75 and their adult non-diabetic daughters ranged in age from 20 to 56. Two of the ten dyads lived in the same households. The remaining eight motherdaughter dyads lived at least 15 minutes and no more than 45 minutes in driving distance from each other. Mother's range of education varied from 10<sup>th</sup> grade to a Master's Degree plus 2 years. One mother stopped her schooling after 10<sup>th</sup> grade while three mothers received their high school diplomas, four mothers were working toward completion or had received their bachelor or associate degrees, and two mothers were working toward completion or had acquired their master's degrees along with extended college course work. Thus, mothers could be characterized as a fairly well-educated sample. The length of diagnosis for mothers living with type II diabetes ranged from three to 17 years. Two mothers believed they were pre-diabetic,<sup>10</sup> yet received inaccurate information prior to their official diagnosis. Thus, they believed they had been diabetic longer than their

<sup>&</sup>lt;sup>10</sup>In some people, blood glucose levels are higher than normal but not high enough for them to be diagnosed with diabetes. These individuals are described as having pre-diabetes. People with pre-diabetes are at higher risk of developing type 2 diabetes than people with normal glucose tolerance (NIH, 2002).

diagnosed three-year period. The range of income among the mothers ranged from \$20,000 a year to over \$50,000 a year. Mothers who had lower incomes (below \$20,000 a year) were married and accounted for their income independent of their spouse or lived with other family members (typically daughters). Mothers above \$20,000 were employed and/or referenced income from retirement, spouse or other sources. For instance, one woman rented half of her duplex to college students.

Just as the range of education varied among mothers the same held true for daughters (see Table 3.2). Of the ten adult daughters interviewed two had received their high school diplomas, the other eight had attained bachelor degrees, and three of these eight were in the process or had completed their master's degrees. Daughter's income ranges were typically higher than their mothers. Only one daughter's income started at \$5,001 to \$10,000 yearly. Of the remaining nine daughters, income ranges were above \$20,000 to the mid \$40,000s.

Dyad Number	Marital status	Number of children	Highest Grade	Age	Employ- ment	Distance from daughter	Income level	Years w/ diabetes
Dyad #1	Never married	3	12 <sup>th</sup> + Vocational classes	48	F-T supervisor	Live in same home	С	17 years
Dyad #2	Never married	1	3 <sup>rd</sup> year college	45	Not employed- disabled	45 minutes	В	4 years
Dyad #3	Divorced	2	12 <sup>th</sup> + course for Vocational classes	63	Retired	15 minutes	С	6 years
Dyad #4	Divorced	4	12 <sup>th</sup> grade	75	P-T receptionist	5 minutes	В	8 years
Dyad #5	Married	5	12 <sup>th</sup> + 2 yr. Assoc.	62	F-T parent liaison	20 minutes	С	10 years
Dyad #6	Widowed	3	BA	54	homemaker	Live in same home	D	10 years
Dyad #7	Widowed	5	10 <sup>th</sup> grade	61	Factory worker	30 minutes	В	11 years
Dyad #8	Separated	2	High school	55	Elem. school computer asst.	10 minutes	D	11 years
Dyad #9	Married	4	MA + 2 years	71	P-T sub teacher	20 minutes	С	3 years
Dyad #10	Married	2	BA + 2 years	55	P-T High school monitor	20 minutes	В	5 years

Table 3.1: Mothers' Demographic Table

Income Chart (dollars)

A = 5,001 - 10,000	B = 10,001 - 20,000	C = 20,001 - 30,000
D = 30,001 - 40,000	E = 40,001 - 50,000	

Dyad Number	Marital status	Number of children	Highest Grade	Age	Employ- ment	Distance from mother	Income level
Dyad #1	Never married	0	Masters Spring 03	26	F-T AOL consultant	Live in same home	D
Dyad #2	Never Married	0	BA + 2 assoc. degrees	23	F-T UNM Adm. Asst.	45 minutes	С
Dyad #3	Divorced	0	12 <sup>th</sup>	42	F-T KY phone co.	15 minutes	D
Dyad #4	Divorced	2	Masters	56	F-T peer counselor	5 minutes	Е
Dyad #5	Married	1	Masters	37	F-T operator	20 minutes	В
Dyad #6	Never Married	0	BA	23	P-T PR intern	Live in same home	D
Dyad #7	Married (2 <sup>nd</sup> )	2	12 <sup>th</sup>	39	Senior Policy Ser. Asst.	30 minutes	D
Dyad #8	Married (2 <sup>nd</sup> )	2	12 <sup>th</sup> +JR college	33	F-T Clerk- typist	10 minutes	Е
Dyad #9	Divorced	1	BA +1year MA	44	F-T elem. Teacher	30 minutes	Е
Dyad #10	Never Married	1	Started college in Fall 03	20	F-T restaurant manager	20 minutes	А

Table 3.2: Daughters' Demographic Table

Income Chart (dollars)

A = 5,001 - 10,000	B = 10,001 - 20,000	C = 20,001 - 30,000
D = 30,001 - 40,000	E = 40,001 - 50,000	

### **Recruitment Procedures**

Several approaches were used to identify respondents. Initially recruitment began in my home state (Albuquerque, New Mexico) with the intent of using purposive sampling; however, because of the paucity of African-American respondents, research was eventually conducted in four Midwest cities (Lexington, Kentucky; Cincinnati, Ohio; Dayton, Ohio and Yellow Springs, Ohio). These cities provided access to concentrated African-American populations and could be easily accessed from my temporary place of residence. Information packets enclosed with a formal letter, information fliers and contact information (see Appendix A) were sent to several acquaintances prior to my arrival in the Midwest. Acquaintances (i.e., medical doctor, educators, and business professionals) gave information fliers to family members, churches, and health organizations that were frequented by Blacks. The objective of sending information ahead was to assure that upon my arrival contacts would be established. Approximately one week after my arrival in Ohio contacts were made with my acquaintances. These acquaintances helped in the recruitment of other respondents, which then created a network sample through the use of a snowball sampling technique (Frey, et al., 2000). As these acquaintances located mother-daughter dyads, the respondents in turn suggested other potential participants in their social networks (Warren, 2002). I was able to have an instant rapport with each dyad because I was referred to respondents by acquaintances. Though snowball sampling does not offer generalizability across a population, it is valuable for locating more specific and/or particular populations (i. e., African-American mother-adult daughter dyads) for which it is difficult to construct a sampling frame (Frey, et al., 2000).

Most contacts made came from my acquaintances' family members, church communities, co-workers, family friends, neighbors and social organizations. As I received phone numbers, calls were made to either the mother or daughter. Typically individuals were responsive to my first call because they were told about my research, told to expect a call from me, and given my name and number. This initial phone call was used to establish rapport with each respondent and schedule appointments. Because each individual had prior knowledge of my research objectives, most were helpful and more

than willing to be involved in the interview process. Upon agreement to participate, each individual was asked to provide a day, time and location that would work with her schedule.

# Institutional Review Board Protocol

The research protocol was reviewed and approved by the University of Kentucky Institutional Review Board, with institutional review board protocols being administered for the protection of human subjects. This protocol included a complete explanation and written description about the purpose, the method, the potential risks and benefits of participation in the study, and the protection of confidentiality. Each respondent was given an opportunity to ask questions and decline or agree to participate in the study. Upon meeting with mothers and daughters I provided an overview of the dissertation objectives, gave each respondent a copy of the informed consent form (see Appendix A), and proceeded to read the consent form to each individual encouraging them to ask any question before the interview began. Each respondent signed two consent forms prior to their interview -- one form was given to those who agreed to participate and I kept one, which was placed in a secured file box. All respondents received a pseudonym to assure their privacy. Upon completion of each interview, tapes, interview data, and consent forms were stored in a secure file cabinet. Respondents received a thank you note and a \$25 incentive for their participation after the completion of all three interviews.

# Data Collection Methods

My data collection methods included in-depth semi-structured interviews, memo writing, fieldnotes, and general observations. All data collection and data analysis were conducted simultaneously until theoretical saturation was achieved. This process can be a time consuming and arduous task. However, without accurate and complete fieldnotes, memos and well-defined observations, the findings themselves suffer from a lack of density (or depth) (Glaser & Strauss, 1967; Rodger & Cowles, 1993, Strauss & Corbin, 1990) and interpretability or transferability (Lincoln & Guba, 1985) which are essential components of any rigorous qualitative study (Rodger & Cowles, 1993). Theoretical saturation is a process whereby a) no new or relevant data seem to emerge, b) the categories developed have depth and c) the relationships between categories are well established and validated (Glaser, 1967). The first part of this process starts with the interview questions and is enhanced through the use of memo writing, fieldnotes, and general observations. The interview format and questions are flexible and reflect insights obtained during previous interviews. This process is typical when using a grounded approach. The questions normally moved from general to specific (unless the participant directed the conversation in a different direction) and probed into specific areas of ambiguity or incomplete information (Maxwell, 1998).

# **Pilot Interviews**

Prior to actual interviews, I conducted 4 pilot interviews from January 2003 to March 2003. These interviews included; 1) two interviews with dyads of diabetic mothers and their *diabetic* adult daughters, 2) one interview with a bi-racial daughter of a diabetic mother (attempts were made to interview the mother who is Native American, but they were not successful), and 3) one interview with a diabetic mother. All interviews included questions that were used in the dissertation research.

The pilot interviews provided me with the opportunity to revise and improve the interviewing protocol, the process of taping and transcribing data, and the process of data analysis. As Maxwell (1992) states, pilot interviews are useful to generate an understanding of the concepts held by the people you are studying. Thus, I was able to think more clearly about potential themes that might occur and reflect on concerns with my interview protocol. A veteran researcher with extensive experience in qualitative data analysis evaluated the pilot study and gave useful feedback (Schoenberg & Rowles, 2001). Recommendations from the pilot interview were incorporated into the actual interview protocol. Hence, the interview guide/questionnaire was carefully designed and tested to assure that it was an appropriate tool for data collection (Kerlinger, 1986).

# Actual Interviews

After identifying and calling respondents, I initiated actual interviews. Most interviews were conducted in a convenient and comfortable place for the respondent, usually in their homes or at their work. Some interviews were conducted during the weeknight in a location specified by respondents, typically their homes. For those respondents who had full work weeks and evening responsibilities, I conducted their

interviews on Saturday mornings and/or Sunday afternoons. Finally, one mother needed to conduct her interview at her place of employment because of schedule constraints; for this reason, she and her daughter completed their interviews in a grade school teacher's lounge.

The first two sets of interviews with mother and daughter were conducted separately, however, because I sought to understand the dyadic relationship, a final interview was conducted with both mother and daughter present (Sohier, 1995). This process was useful because the time spent with both mother and daughter provided clarification and jogged some memories of issues not addressed in prior interviews while the time spent apart allowed mothers and daughters to speak more freely about their private thoughts and feelings (Frey, Botan & Kreps, 2000). Charmaz (1990) notes that the nature of chronic illness requires several interviews. Multiple interviews provide the respondent with an opportunity to share detailed information on illness while assuring that the researcher has ample opportunities to address important information. A total of ten dyads were interviewed over a period of 6 months (March 2003 to August 2003). This yielded a total of 50 completed interviews (40 interviews with mother and daughter individually; 10 joint mother-daughter interviews). Aside from the 50 interviews, a number of other dyadic interviews were started but were terminated because of unanticipated circumstances. Hence, of the 55 interviews that I conducted, 5 were not completed.

### Interview Procedures and Memo Writing

The first interviews lasted approximately 1½ to 2½ hours and began with the reading and signing of the informed consent document. After an initial conversation, participants were asked to talk a little about themselves. For instance, I asked respondents to "Tell me a little bit about yourself and your present health." This typically was followed by asking respondents 1) to describe what being healthy means, and 2) to provide a detailed overview of the health of their family and extended family members. For most respondents it was natural for them to provide an in-depth overview of their family's health history, particularly as it related to diabetes. This type of generational detail was typical for each interview and provided me with a rich perspective of the

chronicity of diabetes within the dyads' families. To best grasp respondents' knowledge of diabetes they were asked a two-part question: If you had to describe diabetes to a complete stranger 1) what would you tell them it was and 2) what would you say it does to a person who has it? The purpose of this two-part question was to gauge each respondent's knowledge of the disease. The question also served as a jumping off point for them to discuss their concerns, insights and frustrations regarding having type II diabetes or becoming type II diabetic.

The next segment of the interview addressed diabetes-related questions such as mothers' duration of diabetes, mothers' diabetic complications, daughters' knowledge of diabetes, and mothers' diabetic education experiences or daughters' diabetic-information seeking experiences. Demographic data are then collected and included questions on participant's age, marital status, educational background, occupation, and income-level. Throughout the interview I used layperson terminology to refer to diabetic-related information or medical terms in an attempt to avoid confusion during the interview (See Appendix C for questions asked in this interview).

To maintain the integrity and assure consistency of all mothers and daughters responses in interviews, I tried not to let the time between interviews go more than 5 days in length, therefore, the second interview typically transpired the next day or shortly thereafter. In the second interview I used general concepts from the Health Belief Model (HBM) and Social Cognitive Theory (SCT), which have been found to be very useful in previous health communication studies in explaining health behaviors. The HBM and SCT served as guidelines to address additional information about health behavior or selfcare (See Appendix C for questions asked in this interview). Components of the HBM included a) how serious mothers and daughters perceived diabetes to be, b) how susceptible to diabetes or future complications from diabetes they believed themselves to be, c) their perceptions of barriers and benefits of diabetic and non-diabetic preventative behaviors, and d) what non-diabetic adult daughters believed would serve as cues to action or "triggers" most likely to cause a change in their health behavior (Strecher & Rosenstock, 1997). For example, one cue to action daughters mentioned was the amount and administration of medication (i. e., shots) mothers had to be subjected to on a daily

basis. One daughter noted that taking pills would not bother her, however, administering painful injections everyday would be enough to make her change her negative health behaviors (i.e., stop drinking cola, eating fried foods). A concept of SCT that was useful for my study was observational learning which entails a person's ability to learn from other people not only by receiving reinforcements from them but also through observing them. Also defined as *vicarious reward* or *vicarious experience*, Bandura (1977, 1986) described observational learning as a process that occurs when a person watches the actions of another person and the reinforcements that person receives. Baranowski, Perry and Parcel (1997) note that various types of behaviors can be learned through observational learning, accounting for why and how family members might display common behavioral patterns.

In my second interview each question elicited a clear descriptor of how mothers and daughters viewed different nuances of their experiences of living with diabetes. For instance, mothers were asked a number of questions like, "What do you think about diabetes? Do you think diabetes is serious? Do you talk with your daughter about the benefits of not becoming diabetic? Is there anything that makes it difficult to talk with your daughter about diabetes, If so what?" In contrast, daughters were asked question like, "Is diabetes serious? How serious would it be to become diabetic? What types of things does your mother talk about that would lead you to believe diabetes is serious? Would you say there are actions you could or have taken to prevent being diagnosed with diabetic? Do you see yourself as capable of practicing healthy behaviors?" The second interview was useful for a number of reasons. First, it allowed me to clarify information provided in the first interview. Next, it provided a theoretical perspective from which to look at and examine responses to interview questions. As well, the second interview provided an opportunity to establish trust, increase researcher credibility and build a stronger rapport with respondents and myself. (Cantania, Gibson, Chitwood, & Coates, 1990).

The third and final interview, conducted with the mother-daughter dyad, lasted approximately one to two hours and used broader open-ended questions to encourage dyads to converse openly about their collective perceptions of diabetes (See Appendix

C). In accordance with a grounded approach, questions were based on prior interviews. For instance, both mother and daughter were asked to help me understand concepts from previous interviews. As such they were asked, "In other interviews mothers have stated that it was important to inform their daughters about health information. Talk to me about how you both feel about this". They were also asked if they found talking about health issues such as diabetes to be valuable. One dyad in which the mother had talked about her inability to share diabetic information with her daughter offered a very candid observation during this question. These open conversations were useful because they gave mothers and daughters the opportunity, in an interview setting, to hear the others' perceptions regarding diabetes.

# Memo Writing

During the interviewing process, memo writing, which can be described as freewriting (i.e., writing anything without constraints of evaluation, or of audiences), was ongoing (Charmaz, 1995, 1995c). The objective of memo writing is to generate thinking that encourages the researcher to reflect on her data and codes in fresh ways; it is extremely useful for reducing mental blocks in thinking (Charmaz, 1995, 1995c). Memo writing leads to the exploration of new codes and eventually helps provide substance and structure for sorting data. Charmaz (2000) notes memo writing is "the intermediate step between coding and the first draft of the completed analysis" (p.517). I used memo writing at different stages of my research, especially when I began to see the situations that led mothers and daughters to talk with each other about diabetes. For example, early in my data collection, mothers spoke about their frustrations with being a diabetic. Initially, I had uncertainty about how this information was important to my research. However, as more interviews occurred, it became clear that referring to frustration was common among all mothers. Jotting notes about how mothers expressed frustrations helped me recognize a process common among mothers in which they used their fears/frustrations to discuss concerns they had for their daughters' health and well-being. These personal concerns were typically the impetus for mothers' talks about diabetes with their adult daughters. For instance, one mother stated, "I am so afraid of losing a limb to this disease, my father lost his leg...I'm always telling my daughter to take care

of her feet, make sure you dry them properly after you shower, check for sores and don't cut your toe nails too short...". Memoing (i. e., taking notes) about these re-occurring incidents helped me code them under an initial category which I referenced as *diabetic fear talk* and *diabetic frustration talk*.

# Data Analysis

As previously noted, I analyzed the data using a grounded theory method, which culminates in the construction of a theory that is closely based on, or grounded in, the actual lived experiences of the respondents. Consistent with GT, a theory is generated by a series of steps that proceed, both sequentially and concurrently from the data collection to a) generation of concepts from the data and the categorization of all the available data, b) synthesis of these many categories into a few salient constructs, and finally, c) articulation of a theory in which the emergent constructs and their interrelationships are described (Glaser & Strauss, 1967).

Finding theories and constructs that best describe the lived experience of the respondents can be a daunting endeavor. Hence, to ensure some level of dependability, I used a process Lincoln and Guba (1985) refer to as "peer debriefing". Qualitative research encourages the use of more than one analyzer to reduce research bias as constructs emerge from data analysis (Marshall & Rossman, 1989). These multiple perspectives can assist in the ongoing articulation and management of the subjective components of GT data analysis. Throughout my data collection and analysis two communication colleagues and a graduate student familiar with grounded theory methodology reviewed sections of my transcripts checking for accuracy and providing feedback on emergent categories, constructs and themes most representative of the phenomenon.

All 50 interviews that I conducted were tape-recorded and transcribed verbatim as soon as possible after each interview in accordance with grounded theory (Strauss & Corbin, 1990). After interviews, all tapes were recorded onto CD-R (re-readable) disks to assure security, provide a secondary hard copy, and offer me the opportunity to listen to each interview a second time before actual transcription. I next listened to tapes,

transcribing all interviews myself. I then engaged in a "proofing process" which allowed me to check the transcripts against the audiotaped interviews from which they were prepared (Sandelowski, 1995, 199b). This thorough procedure let me gain familiarity with each respondent's experience and the events, issues, and meanings of each experience (Lindlof, 1995).

An analysis process, described by Strauss and Corbin (1998) as theoretical sampling, let me a) generate as many categories/incidents as possible related to health messages among mother-daughter dyads, b) further my understanding of what individuals do or do not do (actions) regarding talking about diabetes, and c) see the range of conditions of actions/interactions and their variations (Strauss & Corbin, 1990). Throughout this process, data were reduced to a manageable size and sorted by "selecting, focusing, simplifying, abstracting, and transforming 'raw' data" (Miles & Huberman, 1984, p. 21; Lindlof, 1995; Wolcott, 1994). After my first analysis, a master list of 76 different communicative concepts of mother-daughter talk was generated. The concepts were derived from a) mothers' self-care behaviors, b) adult daughters' health behaviors, c) mother and daughters' health beliefs, and finally d) modeling behaviors particularly among adult daughters. Self-care terms were words and/or concepts that represented various aspects of the mothers' self-care management of her diabetes. Health behavior terms were words and/or concepts that represented various aspects of the daughters' health behavior. For instance, if I heard reoccurring statements from daughters like, "I try to eat right" or "I get on my mother about her eating" I coded this concept as eating right talk (Table 3.3). If codes were repetitive (i. e., as can be seen with the code familial history talk) those codes were only counted once although the significance of the repetition was noted as important to the overall findings. Examples of preliminary code names representative of mother and/or daughter talk included "dietary restriction talk," "monitoring talk," "food awareness talk," "fear of further complications talk," "frustration talk," and "scolding talk".

# Coding

Through numerous readings, and feedback from my peers, I began to analyze transcripts looking for specific incidents or similar patterns of occurrence regarding

mother-daughter talk. These recurring incidents were then translated into concepts, a process referred to as initial or <u>open coding</u>. Open coding is a process of breaking down, examining, comparing, conceptualizing, and categorizing data line by line. This line-by-line process keeps the researcher grounded as the collected data is examined, "rather than lapsing entirely into theoretical flights of fancy which have little connection to the data" (Charmaz, 1994, p. 81). The open coding forced me to start making decisions about the mothers' and daughters' views of their realities instead of imposing my own views on the data. I developed codes from the actual language used by the mothers and daughters and from my own description of what the dyads were expressing (Glaser & Strauss, 1967). A master list of concepts was generated from all the participant's transcripts that consisted of 22 distinct, distinguishable concepts (e. g., dietary talk, encouragement talk, information sharing talk, information seeking talk) relevant to how mothers and their adult daughters communicated (Table 3.4).

These concepts, next, were compared to one another for similarities and then were abstracted and grouped into categories. Any basic concepts that had theoretical relevance (i.e., continually present or absent when comparing incident after incident) received the status of "categories." As Maxwell (1998) notes, this coding strategy is used to find relationships, "within a particular context to be placed in a coherent whole" (p. 90). Again, I sought the advice of my peer researchers to assure that I was not projecting my own personal bias on categories<sup>11</sup>. This process resulted in separate categories being extracted from the data. I then used <u>axial coding</u> to determine relationships among categories generated in open coding and to group them into higher order key categories (1990). This coding process involves putting data back together in new ways after open coding by making connections between the categories (1990). If a number of codes existed for the same data (Glaser, 1978), the codes were placed in all related categories to maintain the conceptual richness of the phenomenon under investigation (Frey et al., 2000).

<sup>&</sup>lt;sup>11</sup> To remain bias free, I asked peer researchers to read transcripts and provide observations on relevant concepts.

The next step, selective coding was used to determine whether key categories were deemed saturated. More specifically, this required asking if continued reading of the data failed to provide new information and if the categories were well represented among respondents (Strauss & Corbin, 1990). Selective coding is a process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development. The process does not deviate much from the axial process but requires the researcher to sort the data with a goal of producing theory about the research phenomenon. Thus, it is more directed and typically more conceptual than line-by-line coding (Glaser, 1978). Steps in selective coding include a) explicating the story line, b) relating subsidiary categories around the core category, c) relating categories at the dimensional level, d) validating those relations against data, and e) filling in categories (Strauss & Corbin, 1990, p. 117). The ultimate aim of selective coding is the selection of a core category and the relating of all major categories both to it and to each other (1990, p. 142). Thus, after a final discussion with peer researchers, saturation was achieved. The key categories were accepted as critical to the emerging themes. The process also revealed where re-organization of key categories was necessary for existing data to make sense, and resulted in a reduction of the number of categories from eight to five higher order constructs that became the salient organizing elements of the emergent themes (Table 3.6).

Table 3.3: Example of Preliminary Codes
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Dyad Mother I	Dyad Daughter I
Meal requirement talk	God can heal you context talk
Isolation talk	Eating right talk
Frustration talk	Frustration with the mother talk
Fear of further complications talk	Proactive exercise program talk
Guilt talk	Encouragementyou can do this talk
Worry talk	Familial concerns about illness
Exercising and dietary talk	
Daughter concerned talk	
Proactive talk	
Make sure you are getting a check up talk	
Familial connection to the illness talk	
Dyad Mother II	Dyad Daughter II
Refusal to accept diabetes talk - avoidance	Is that allowed talk
Denial of the illness talk	Gaining medical information talk
Agitation with illness talk	
Protesting the required changes talk	
Dyad Mother III	Dyad Daughter III
Sharing dietary information talk	Scolding talk
Inquiring about doctor's recommendation talk	Backdoor approach talk
Recognition of loss of freedom talk	Making mother aware of inadequate eating talk
Restrictive food frustration talk	Church family with illness talk
Uncertainty about doctor's diagnosis talk	
Fear of more complication talk	
Concern for daughter health talk	
Familial connection to the illness talk	
Dyad Mother IV	Dyad Daughter IV
Doesn't like to talk about diabetes	You can be healed talk
Second generation talk (i. e., talk to the	Scolding talk
grandchildren about diabetes cause daughter doesn't	Avoidance talk
want to talk about it)	
Fear talk	
Denial of illness talk (i. e., I don't think my doctor	
really know what's going on)	
Food restrictions change talk	
Familial connection to the illness talk	
Dyad Mother V	Dyad Daughter V
Fussing about food choices talk	Humor talk
It's (i. e., diabetes) not taken seriously talk	Food monitoring talk
Eating out (i. e., fast food restaurants) talk	Backdoor approach talk
Humor talk	Scolding talk
Medical visits talk	What did your doctor tell you talk
Future concerns talk	Take care of yourself talk
Make sure you are getting annual check ups talk	Family history of illness talk
Familial connection to the illness talk	
Dyad Mother VI	Dyad Daughter VI
Grocery store list talk	Cautionary talk
Resignation talk	Policing talk
Frustration of having diabetes talk	Self-monitoring talk
Fear of being diabetic talk	You need to exercise talk
Future concerns talk	You can't eat that talk
Familial connection to illness talk	

Dyad Mother VII	Dyad Daughter VII	
Sheepish talk	Correction of behavior talk	
Resignation to illness talk	Monitoring talk	
Fatalistic talk	Encouraging talk	
Dyad Mother VIII	Dyad Daughter VIII	
Third party talk	Backdoor approach talk	
Humor talk	Inquiring talk	
Fear of future complications talk	Humor talk	
Reflective talk "I wonder what Blacks have done to	Question asking talk	
get this disease cause so many of us have it"	Confrontational talk	
Familial connection to illness talk	Type I diabetic child talk	
Dyad Mother IX	Dyad Daughter IX	
Inquiry about what to do talk	Confrontational talk	
Fear of future talk	Educational talk	
Frustration talk	Sharing health information talk	
Stress alleviation talk	Fussing talk	
Medical concerns talk	Motivational talk	
Familial connection to the illness talk	Affirmation talk	
	Family history awareness talk	
Dyad Mother X	Dyad Daughter X	
Naïve knowledge about the illness talk	Role modeling talk - Daughter does a lot more	
Need for daughter to exercise talk	listening, observation and modeling of mother.	
Need for daughter to eat better talk	Question asking talk	
Concern talk		
Scolding talk		
Familial connection to illness talk		

Table 3.4: Example of Open Codes

- 1. Dietary talk M/D
- 2. 3rd party talk M
- 3. Denial talk M
- 4. Frustration talk M
- 5. Guilt talk M
- 6. Family History talk M/D
- 7. Food resignation and monitoring talk M
- 8. Medical Information sharing talk M
- 9. Concern about daughter talk M
- 10. Monitoring talk D
- 11. Religious Healing talk -D
- 12. Fear talk M
- 13. Teasing talk D
- 14. Prevention talk D
- 15. Intervention talk D
- 16. Encouragement talk D
- 17. Information seeking talk D
- 18. Awareness talk D
- 19. Information sharing talk M
- 20. Role Modeling talk D
- 21. Weight Watching talk M/D
- 22. Observation talk M/D

Table 3.5: Axial Codes		
Mother Codes	Daughter Codes	
<ol> <li>Dietary talk</li> <li>3<sup>rd</sup> party talk</li> <li>Denial talk</li> <li>Frustration talk</li> <li>Guilt talk</li> <li>Familial connection</li> <li>Food resignation and monitoring talk</li> <li>Medical talk</li> </ol>	<ol> <li>Monitoring talk – scolding, policing, humor</li> <li>Encouraging talk</li> <li>Familial inquiry talk</li> <li>Importance of exercise and dietary talk</li> <li>Medical inquiry talk</li> <li>Concern about mother talk</li> </ol>	
7. Concern about daughter talk		

Table 3.6: Axial Codes to Selective Categories	

Mother Codes	Daughter Codes
Past knowledge diabetic talk	<ul> <li>Concern for mothers' well being talk</li> </ul>
<ul> <li>Diabetic talk from present/personal experiences</li> </ul>	
	Recognition of familial health
Diabetic talk about future implications and concerns	dynamics regarding diabetes talk

A number of approaches were taken to increase the reliability and the validity of my data. For instance, Kerlinger (1986) suggests that pilot testing and revising interview protocol increases reliability. This step was taken in my data process. Internal consistency was achieved by using more than one analyzer of the data analysis process. Ongoing use of multiple analyzers at different junctures of the coding, categorizing, and development of themes continually challenged assumptions and provided alternate explanations of the data (Marshall & Rossman, 1989).

My research process has face validity because the data generated the results directly and therefore created results credible to both the respondents and the investigator of the research (Patton, 1990). External validity, however, is more questionable. When asking if the study can be generalized to the larger population, qualitative researchers argue that the more accurate question would be to consider the study's "transferability" (Maxwell, 1998). A study is known to have "transferability" when the original research provides such a "thick description" that enough descriptive data can be transferred to other settings (Lincoln & Guba, 1985). I have attempted to include "thick description" throughout my research with the objective of transferring it to future research on Native American and Hispanic American type II diabetic mother-non-diabetic adult daughter dyads in New Mexico. The "trustworthiness" of this study can be considered reasonably high since the themes generated are grounded in and emanate directly from the data (Lincoln & Guba, 1985).

#### Chapter Four

#### Results

The mother-daughter relationship has been characterized as "the greatest love affair" and one of the most difficult. We all know that it is a relationship that has much importance on our lives. I don't believe that there is a relationship that can teach as much or bring you as much strength. N. Brook-Rochester ~ About Healing – In Souls of my Sister ~

Prior to my mother's death in the fall of 1998 from diabetic complications, she lived with the illness for twenty years. Like many other individuals living with this chronic disease, she had to make numerous life style adjustments. These adjustments required adherence to her physician's recommendations to change her diet, exercise and to lose weight. I remember being very mindful of these drastic changes because they affected our family lifestyle. My mother incorporated a routine exercise program and completely removed some foods as recommended by her dietitian. She was diligent about care for her eyes, feet, and teeth. Her commitment to managing this disease included educating her spouse, children and even grandchildren. These experiences are still vivid in my memory. Her lived experience with type II diabetes in many ways became our family's lived experiences as well. As siblings, we talked with each other about her illness and we also shared our thoughts, feelings, frustrations, and apprehensions with our mother. For example, the whole family, including nieces and nephews, knew how to administer her insulin shots. We were knowledgeable about her medications and were comfortable with its administration. We even knew foods she could and could not eat and were diligent to check her dietary intake, meals, etc., when it appeared that she was digressing. The experience of living in a household with my mother was life transforming and valuable for my dissertation research because it afforded me an insider's perspective. I believe this research offers empirical evidence from an insider's perspective on the communicative dynamics that transpire between type II diabetic mothers and their nondiabetic adult daughters.

This dissertation's objective has been to understand whether and how health messages are communicated among mothers and daughters. My specific goal was to understand, a) if diabetic mothers communicated (i.e., talked) with their adult daughters,

b) if adult daughters communicated (i.e., talked) with their diabetic mothers, c) what prompted diabetic mothers to talk and what prompted adult daughters to talk, and d) how sharing of health information between dyads shaped mother's self care behavior and/or shaped daughters' health behavior. To fully understand these patterns of communication all interviewees were asked to provide a history of their overall health. Mothers were asked to share their overall health history along with their health histories since their diagnosis of type II diabetes. Daughters were asked to share their health history over their life span including any outstanding health issues or problems. Mothers and daughters were also asked to answer questions about their knowledge of diabetes, when they learned they were diabetic or heard of their mother's diabetes. In line with the Health Belief Model, mothers and daughters were asked to talk about the seriousness of and their susceptibility to diabetes. Mothers and daughters were asked to discuss barriers to diabetic care and health behavior as well as what they perceived as the benefits to positive self-care and positive health behavior. Finally, daughters were asked to discuss if and how their mothers demonstrated positive and/or negative health behaviors, and the implications that modeling had on their [daughters] health behavior.

The information gathered from these interviews has been used to understand the patterns of communication that mothers and daughters used to talk with each other about type II diabetes. In the following section, I describe, in detail, patterns that emerged from interview transcripts with mother-adult daughters. The patterns encompass the ongoing ways in which mothers' and daughters' talked with each other.

Mothers' diabetic talk encompassed their past knowledge, present experiences and future anticipations and concerns. Basically, their "talk" emerged from: a) their prior understanding of the illness (each named specific family members who had lived with and died from diabetic complications), b) their lived experience with the illness, and c) their concerns about the future implication of the illness on their adult daughters and themselves. Consistent with the literature, mothers located themselves in different spaces than their adult daughters, functioning as the bridge builders of valuable health information (Jean & Feagin, 1998). Their health information (i.e., research gathered from their personal investigations of the Internet, reading pamphlets and other resources), shaped their personal and medical knowledge. These factors along with on-going

observation of grandparents, siblings, aunt and uncles, who had suffered from diabetes, influenced the urgency with which they shared information.

Daughters' diabetic talk encompassed their present-day, more pragmatic knowledge of the illness, their concern for their mothers' health and their personal concern about becoming diabetic. Daughters' "talk" emerged from: a) an understanding of diabetes derived from their mothers' shared information, b) their own personal knowledge of diabetes (i.e., research gathered from their personal investigations of the Internet, reading fliers, pamphlets and other resources), c) their medical understanding of its implications, and d) their personal concerns about the implications of diabetes in their lives. Daughters located themselves as caregivers, monitoring and policing their mothers as they helped them negotiate the illness (Sayles-Cross, 1995). Most presumed an allegiance to their mothers' self-care; others addressed concerns but were not always sure of how to support mothers in their journey. On varying levels, each daughter expressed concern for her own present health behaviors and potential future complications. For instance, one daughter commented, "I read about diabetes so I am aware of what it is, but I do ask my mom a lot of questions cause I know it's [diabetes] in the family and I want to know what to do to prevent it [diabetes]".

The remainder of this chapter details the results of this analysis as they pertain to each of the research questions.

Ways Mothers' Communicate with their Non-Diabetic Adult Daughters' about Type II Diabetes

The objective of RQ1 was to understand whether and how type II diabetic mothers communicated about type II diabetes with their non-diabetic adult daughters. During early coding, words emerged that eventually developed into the following patterns of communication: a) diabetic talk from past knowledge, (i.e., what mothers knew of family members and relatives experiences of living with diabetes), b) diabetic talk from personal experiences, and c) diabetic talk of future implications. For instance, each mother shared stories with daughters about family members who were diabetic or had died from diabetes. These conversations embodied the long history of diabetes and mothers' recognition of the number of family members who lived with and/or died from diabetes. This language was labeled with a preliminary code called, "familial connection

to the disease" and developed into one category/pattern of diabetic talk that extended from mothers to daughters in which mothers talk to daughters from their past knowledge of the disease.

#### Pattern One - Diabetic talk from past knowledge

Woven into the tapestry of each mother's diabetic experience was the prevalence of type II diabetes within her extended family. This often made the topic of diabetes an important issue and a "normal" aspect of conversations. Most mothers had strong familial ties (all of the 10 mothers interviewed had their lives touched by a family member who was diabetic or had died from complications of diabetes). These strong familial ties increased the likelihood of mothers talking candidly with their non-diabetic adult daughters about the implications of diabetes in their families. They also shared stories with adult daughters of conversations they had within their informal socio-cultural networks regarding diabetes (Bailey, 1991; Agee, 2000). It was evident that this knowledge of family history, conversations with friends, church members and relatives all served as a buffer to help mothers negotiate their diabetes as well as a venue to pass important health information to their daughters. For instance, most mothers shared stories of conversation they had with friends and/or family members that helped them work through different aspects of their illness. They seemed to find relief in these discussions (Agee, 2000). Talk for mothers was both self-centered and other-centered; it reduced personal stress and anxiety, helped them gain a comprehensive point of view of their disease, it positioned them as protector of their daughters and occasionally "talk" was used as a scare tactic to motivate adult daughters.

For instance, Sadie, a seventy-five year old divorced woman notes,

My mother and my brother were diabetic...I'm not sure about my other brother that died. I think he ended up as a diabetic too. So, I talk to my granddaughter about her weight and I talk to my daughter about keepin' an eye on my granddaughter's weight. I tell her [granddaughter] that young people are having diabetes because of their diet and I try to get my daughter [her mother] to help her out and not let her eat bread but sometimes she's [the adult daughter] no help to her. I don't know what's the matter with these parents...[they] don't recognize how serious it is...it's [the lack of exercise and excessive eating] not good for her,

[granddaughter] especially cause it's so much in our family. While Sadie used her granddaughter as one conduit to talk with her older daughter about the history of diabetes, most mothers found it natural to talk to their daughter about their familial connections with the illness.

*Yolanda*, a mother of three adult children is a fifty-five year old widow who grew up in St Louis but later moved to Ohio. A musician [singer] by trade, Yolanda went blind at the age of twenty with a disease called optical neuritis, lost her husband to cancer in her 30s and was diagnosed with diabetes when she was fifty-two. She reflected,

I knew my aunt was diabetic cause I would get her insulin and watch her give herself shots, but I never thought about it relating to me, nor was I ever told to be careful, and my mom's a nurse...I was never told anything about my health...I never heard about the genetic ramifications of it [diabetes]...Now knowing what I know, I would like to talk about it at a family reunion...at least pass literature, because hypertension, hearing loss, diabetes, you know, stroke, heart attack...it's in the family but it's never discussed.

Yolanda has translated her early experiences into an urgency to talk with her daughter *Kai*. She affirmed that talking about her illness is very important, stating, "The main reason for me is for them [her daughters] to be aware that it's in the family and not to think that it can't happen to you".

Another mother reflected,

I have a cousin who didn't have a lot of family [no immediate family member around to participate in her care] ...she wasn't a real strong person...you have to be a strong person and want to follow orders and want to help yourself...she was not a person like that because they wanted her to take therapy and she refused. She started having trouble with her legs, they had to amputate it...she just lay on her bed and she wasn't taking therapy or anything, now she lost both her legs and then later they started giving her shots for sugar [diabetes].

Though un-intentioned this mother shared information (i.e., past information about the families diabetic complications) with her daughter almost as a scare tactic to make sure her daughter understood how crucial it was to care for her personal health. Most

mothers shared routinely with their daughters accounts of friend, family members and kinship networks that lived with and died from diabetes. This dialogue was a normal part of conversations just as one would share their happenings of the day. For instance, a mother might comment to her daughter, "I heard that Ms. Jones, from church, is having her leg amputated 'cause she hasn't been taking care of herself [i.e., her diabetes]".

As noted from the above narratives, it was not abnormal for mothers to use past knowledge of family members and friends complications with diabetes as a venue to talk with their daughters about type II diabetes; on the contrary, talk transpired because most mothers and daughters alike recognized the insidiousness of the illness in their families' history, among friends and among kinship networks.

## Pattern Two – Diabetic talk from present/personal experiences

A second pattern of communication emerged from mothers' present/personal experiences of living with diabetes and framed how they talked with their adult daughters. Words like fear, worry, guilt, agitation, resignation were used to describe mothers' viewpoints when asked how they talked with daughters about their illness (see Table 3.3). For example, one mother said, "I tell her I am afraid of this disease" while another mother stated, "I don't know what I did to deserve this". These communications included mothers' frustrations of having diabetes, their personal fears of diabetic complications and/or fear of daughters becoming diabetic, and their guilt, depression, confusion and/or uncertainty of living with diabetes, and on one occasion their denial, associated with becoming diabetic.

For instance, mothers conversed about how "worried and concerned" they were about diabetic complications, stating that reflecting on their illness [diabetes] made them anxious and sometimes depressed. Often these feelings intersected with each other making it difficult to discern which feeling was most dynamic. Yet, it was evident that these feelings influenced how mothers' communicated with their daughters and the frequency in which they communicated. Most importantly these feelings served as the impetus for mothers' talk with their daughters.

## • Frustration talk

On numerous occasions, as mothers' expressed their present/personal experiences of living with diabetes, an attitude that I, in time, documented as "diabetic frustration" emerged. They carried the burden of being out of energy and out of hope with their illness. Sometimes mothers' talk transpired because of their frustration that they "had diabetes". Sometimes mothers' talk transpired because of their frustration with their lack of knowledge about diabetes and its affect on their bodies. Occasionally their talk stemmed from their frustration with medical providers or their lack of trust in the medical system to give them accurate and current information regarding diabetes. An example of this could be seen with *Juanita*, who occasionally asked her adult daughter [a nurse] about her prescribed medication. She noted in frustration, "I just wondered if he [the doctor] knows what he is giving me; he tells me one thing and then sometimes he tells me something completely different [about the purpose of her different meds]". Typically these different forms of frustration were the impetus for communication with their adult daughters as noted in *Sherrie's* example. A forty-eight years old, and the mother of three daughters, a set of twins and an older daughter, she stated,

I think with my health I don't feel necessarily healthy because I'm sick and I have a lot of other sicknesses that probably caused the diabetes. I've always been obese...so people fault you for that...I'm not a very happy person... [She begins to cry]...just because I have diabetes, and other problems...I'm not happy...and today is probably one of my more depressing days.

I learned in my interviews with Juanita's daughter that her mother's expressions of frustration left her feeling overwhelmed and powerless; not knowing what to do for her mother or what to say to her mother. Throughout interviews I observed a range of emotions that shaped the way mothers communicated with adult daughters. Their wide array of emotions embodied their lived experiences with diabetes along with the stressors they felt from their family members regarding their own self-care.

The case below describes the frustration one mother felt about being teased by her daughters.

*Betty*, a highly energetic woman who described herself as a "bad patient" commented in our first interview that "she wouldn't wish diabetes on anybody but never

took it seriously" even with the prevalence of diabetes in her immediate family. She reflects,

It wasn't until I was diabetic for a number of years, experiencing a number of complications [i.e., taking five different types of medication, having to administer insulin shots twice a day, fatigue and bouts of sickness, etc...] that I really understood how horrible diabetes was.

Betty describes her relationship with her four daughters as being close, thereby making the topic of diabetes a normal occurrence. Betty stated that *Angela*, the daughter interviewed, routinely comments on Betty's self-care routine. In noting her frustration with diabetes she comments that her daughter's communication about her diabetes only creates additional frustration. "She acts like she's my mother and I have to remind her that I'm the mother. I tell her, I know what my doctor told me to do…I don't need your help".

Betty admits that one of the frustrations she experiences is her daughters' teasing her about her adherence [besides the one daughter interviewed, Betty has three other daughters], particularly her forgetfulness in taking her medication and her unwillingness to stick to a healthy diet. This teasing intensifies Betty's frustrations about being diabetic and her frustration about maintaining a diabetic regiment and serves to validate her daughters' misunderstanding about diabetes and her life as a diabetic. She stated, "sometimes they talk about me...they say, 'If you don't behave we are gonna put you in a nursing home'." While the teasing Betty receives from her daughters is a part of her experience of living with diabetes and is a style of communication that the daughters use with their mother to let her know they care, it also served as a constant reminder that reinforced the magnitude of her illness.

• Fear talk

Another sub-area that emerged under mothers' present/personal experiences of living with diabetes was mothers' diabetic fears talk. During transcriptions, this category emerged as I noted the incidents in which mothers' spoke about their conversations with daughters regarding their diabetic fears. Some mothers talked candidly with daughters about fears that they [i.e., daughters] might become diabetic, others shared their personal fears of the diabetic complications, including death, with daughters. These fears were a

primary reason most mothers found it necessary, even imperative, to talk with their daughters. One mother simply wanted to ensure that her adult daughters understood what type of end of life care should be given if an untimely death occurred. She noted that she would probably die one day from her diabetic complications and that she, "just wants them [her two daughters] to know what to expect." Mothers' fears caused them to pursue a number of different avenues to make daughters aware of the illness. For instance, one mother stated, "I try to make them get checked whenever they say they [her daughters] are going for a doctor's visit." Another mother commented, "I keep tellin' them that they need to make sure they get checked cause it's in the family".

Mothers' projected their fears of diabetes onto their daughters' health, however, most experienced an equal amount of personal fears of the illness. For example, one energetic mother named *Meg*, reflected on when she first talked to her daughter *Sherri* about her diabetes. She noted,

After a medical visit I called Sherri within a few days to let her know about the diagnosis. It was two or three days later...I called her (Sherri) and told her I was a diabetic and that I was scared...I don't know what I told Sherri, but Sherri is like close to her mom and we talk about a lot...our health problems...and I don't remember all the things I said to her but as soon as I was diagnosed I told her. As with other mothers, Sherri's newly diagnosed illness created an influx of emotions, namely fear, that would become an ongoing challenge of living with their disease.

Other mothers expressed their *fears* with comments like, "When I was first diagnosed I told my daughter I couldn't believe it...I was like Lord, what's happenin' to ya? [as if addressing the Lord]...You didn't hear my prayers". She commented that she was really afraid of becoming diabetic; she had seen its ramifications on family members and friends. Thus, when she was first diagnosed she could only cry out to the Lord to ask why He had not heard her pray. Another mother noted, "We have seen so many of my friends suffering from diabetes, it's scary...we [she and her daughter] talk about it". As noted from these quotes, fear served as a communication motivator, bringing relatives and friends together to talk about the "scary" ramifications of diabetes.

# • Guilt talk

Feelings of guilt associated with diabetes emerged as a yet another sub-area of present/personal experiences of living with diabetes. *Sherrie* talked candidly about the guilt she experienced when one of her twin daughters was diagnosed with type II diabetes. Feeling as though she had "given" this daughter the disease intensified her desire to talk with Lynette [her non-diabetic adult daughter] about the woes of diabetes. She noted,

I felt so bad when my other daughter got diabetes...[she shakes her head in disbelief]. I talk to Lynette and I tell her... diabetes is a silent killer cause you don't know you got it...I feel like I was cursed...I feel like, why me I have so much other stuff in my life.

*Sherrie's* guilt, even frustration, that she and her older daughter became diabetic served as the impetus to give her non-diabetic daughter, *Lynette* verbal warnings about becoming a type II diabetic. Though these warnings transpired regularly in conversations with her daughter, one that comes to mind is her exhortation to her daughter, who enjoys fried foods, to "watch what you eats...it's no fun [i. e., living with diabetes]". For *Sherrie* talking to *Lynette*, even though it emerged from her personal guilt, served as a means to educate her daughter about diabetes.

• Denial talk

Though not as overt as frustration, fear and guilt talk, I observed dyadic incidents whereby denial emerged as a notable sub-area from mothers' diabetic talk regarding present/personal experiences of living with diabetes. For one mother, her denial sent a loud message to her adult daughter expressing how much she despised and even refused to accept her diagnosis of diabetes.

For instance, early in one interview, *Sheila*, a forty-two year old shared that she was not particularly fond of talking about her health status with anyone. As I probed her for details, I learned that she didn't like going for medical visits, didn't like her family asking her about her health, and would rather as she stated, "forget that she was a diabetic". This "defiant" attitude often created complications in Sheila's self-care. When asked about her day-to-day management of her illness she vacillated but then stated,

On days when I want to forget I have it I won't take my medication and I won't prick my finger to check my sugar levels...I hate doing that. I just want to forget it's there, thinkin' maybe it will go away.

Because of some major birth defects, Sheila had undergone 16 major operations from the time she was 6 months old until she was seventeen. This, she noted, was part of her rationale for not wanting to go to medical visits or discuss her medical problems. In her words, "I've had enough health complications to last me a life time and diabetes isn't something I want to accept". As she reflected on how she has adjusted to being diabetic for the past 3 years she stated,

I've been through 16 major surgeries since the time I was 6 months old and I was thinkin', why Lord do I have to deal with this [diabetes]...but...oh well, we'll see what happens.

I asked her, "Do you talk with your family about your diabetes?". With a roll of her eyes and a chuckle she remarked,

Not really, my mother gets on me 'take care of yourself' and she'll ask me how things are going. My uncle is the one that has type II...he'll question me every now and then and just call me and ask me how's it going, but I don't voluntarily share anything, they have to ask. If something is going wrong then I will tell them...otherwise I don't like to talk about it.

I then asked, "What about your daughter...do you talk with her about your diabetes?". She reflected and stated, "Not really...I don't want to worry her." She shares that she has been through so many other health complications and did not want to worry her with the diabetes. When asked why she didn't share information about her diabetes with her daughter or family she candidly stated, "I don't like to talk about it. I just prefer that it would go away... [She chuckles]. I just don't like to talk about it, I guess." I later learned in interviews with her daughter that this lack of communication has the opposite effects on *Sheila's* daughter, causing her to worry more about her mother and the implications of diabetes for her. Thus, for *Sheila's* daughter, *Cassandra*, her mother's denial of her illness and the resistant style of communication created anxiety. Cassandra noted in our second interview, "I think mom believes she is protecting me by not talking about her illness, but it's really frustrating 'cause I never know what's going on with her". She continued, "her resistance to share only leaves me worried and anxious".

Another mother stated that she had worked through her denial early in her diabetic diagnosis but still struggled with her illness. She stated, "It was really hard...I had to learn to adjust to it [her diabetes]...I had to adjust, but now I've accepted it."

As can be observed, the pattern in which mothers' diabetic talk emerged from their present/personal experiences of frustrations, fears, guilt and denial seemed to reflect the emotional rollercoaster each women rode daily. These emotions reflected the intra and interpersonal dynamic mothers' dealt with on regular bases, revealing the emotional specificity of each mothers' talk as well as the general anguish common in all mothers' talk.

#### Pattern Three - Diabetic talk about future implications and concerns

A final pattern that emerged from mothers' talk involved their communication with their daughters about the future implications of the disease for their adult daughter. Typically, it entailed mothers' sharing the implications of their illness with their daughters and what this could mean for daughters' health in the future. Dialogues included giving daughters a plethora of information about diabetes, its complications and what to do to prevent it. Most mothers gave lengthy speeches to their daughters describing how important it was to maintain healthy lifestyles. Even mothers who were not adhering to their own diabetic management regimens were quick to note that they wanted their daughter to, "stay healthy and not get this disease." Often the dialogue about diabetes occurred in conversations mothers had with daughters about their overall health. For instance, they encouraged their daughters to walk or encouraged them to have annual medical examination, which entailed sharing information with medical providers regarding the family history of diabetes. In some shape, form, or fashion mothers attempted to educate their daughters regarding the complications of type II diabetes. At times their concern for their daughters' health motivated mothers to talk with their daughters, on other occasions mothers' knowledge and experiences of living with the illness motivated talk.

*Joanne*, for instance, used information sharing with her daughter because of her concern for her daughter's health. In our initial interview *Joanne* chuckled when she talked about her daughter *Juanita*.

She is very outspoken, so getting her to listen is not always easy. When I talk to her about diabetes she'll say to me... 'I hear you momma and I don't hear you,' cause she doesn't want to hear what I have to tell her.

She reflected for a second and then stated,

Like I tell her, right now she needs to lose weight, and I think she is too young to be a diabetic...I'll talk to her but, like right now and for the past two years she's been in a stressful job...very stressful. So the Lord will work something out for her, but it is hard...this affects her health...a lot of nervous energy...that makes her eat.

I probe further, asking Joanne to share more about how she talks with Juanita about diabetes. She immediately responded,

Oh, we discuss it all the time, she's real aware because I am always telling her to be careful, but I'm not gonna say that she lives like me cause she eats fast foods. She's right across the street from McDonald's [her place of employment]...she goes there all the time, on her lunch hours. So far she hasn't had anything [diabetic symptoms], not saying it will not develop later but I sure hope it doesn't.

Another mother notes the urgency to talk to her daughter about her health and believes it equally important to share her personal concern that her daughter could become diabetic in the future. *Nora*, for instance, indicated that while she felt her daughter did not understand what diabetes was and really didn't seem that interested in understanding, as her mother she felt it necessary to take steps to encourage *Donita*, her twenty year old daughter. Nora made sure Donita came home [to Nora's house] to eat her meals instead of eating at the fast food restaurant that she managed. In addition, Nora stated, "I try to motivate her...I tell her come over when you get off work so you can walk with me". Despite Nora's commitment, she notes, "Donita doesn't spend enough time thinking about becoming diabetic, that she could get it.". She further commented, "I don't even think she know anything about my diabetes, I don't think she even thinks about it."

When I asked Nora about conversations she and Donita shared regarding diabetes, she reflects on a conversation they shared after Donita had her baby girl.

I think the time that I talked to my daughter was probably after she had her baby...maybe six or seven months after. That time I told her she should lose weight cause she was too young and she know that diabetes runs in our family and sometimes it shows up when you have a baby or gain weight. I was more worried about her cause I watched her go fifty, fifty-five pounds overweight and you know that is the main thing...and I told her, 'you know you need to lose weight cause you know diabetes runs in our family' but I just don't think she gets it [Joanne shakes her head]!

Like Joanne and Nora, most mothers engaged in some form of diabetic information sharing to concurrently ensure that their daughters understood how critical, life threatening and life transforming diabetes can be. They badly wanted their daughters to invest in their own personal health and well-being for prevention. One mother stated firmly, "I tell her once you become a diabetic you can't come back." The patterns that emerged spoke well to the first research question. While it seemed like most mothers were concerned about diabetes and how the disease might affect their daughters, the ways that they conveyed this concern took a variety of expressions. As we shall see in the next section, the mother's ways of communicating served as a precursor to the way daughter's communicated with their mothers regarding their illness.

Ways Non-Diabetic Adult Daughters' Communicate with their Type II Diabetic Mothers' about Type II Diabetes

The objective of RQ2 was to understand whether and how non-diabetic adult daughters communicated about type II diabetes with their diabetic mothers. Initially when I began my interviews with adult non-diabetic daughters I assumed that they would be less likely to communicate with their mothers about type II diabetes. However, as I conducted interviews and read through the transcripts, engaging in what Strauss and Corbin (1990) called *in vivo coding*, I discovered that though communication among daughters was more indirect, they did communicate with their mothers about type II diabetes in a number of unique ways; ways that could only be understood through the daughters' voices (Charmaz 2000). During early coding, words emerged that eventually

developed into the following two patterns of communication in which daughters talked to their mothers. Words that emerged were policing talk, monitoring talk, dietary talk and spiritual talk to name a few. The two patterns/themes they most represented were a) daughters' concern for their mothers' well-being and, b) daughters' recognition of familial health complications. Basically, daughters used policing and/or monitoring talk, whereby they utilized talk to regulate their mothers' health behaviors, or in some cases used talk to supervise or oversee their mothers' actions. They watched carefully what mothers ate throughout the day and as needed reminded mothers that they should not be eating certain foods. Daughters engaged in dietary talk, exhorting their mothers' to follow dietary recommendation given by their medical practitioners. It was not abnormal for daughters to make routine commentary, be they direct or roundabout, about their mothers eating behaviors, fussing with their mothers about diet and exercise (i.e., are you allowed to have that cake, or what does your doctor say about eating a particular type of food, have you been exercising). Daughters engaged in spiritual talk, confirming mothers with comments like, "God can heal you" or "God is in control". For one daughter spiritual talk was punitive. For instance, her beliefs in God's power to heal all sickness left her unsympathetic about her mother's diabetes. She regularly exhorted her mother to pray and ask God for a healing. Or made comments like, "let God heal you of your disease". Some daughters used teasing talk in union with humor to make commentary that would playfully coax their mothers' to think about their health and self-care behaviors. As shall be observed, most daughters used more than one of these ways to talk with their mothers about diabetes. As well, the patterns of daughters' concerns for their mothers' well-being were varied and depicted a range of daughters' perceptions and views about type II diabetes.

#### Pattern One - Concern for mothers' well being

All daughters interviewed expressed concern for their mother's health. The level of concern was often dependent on the severity of their mother's diabetes. Even when mothers seemed to be in control of their diabetic management regimens, daughters still maintained a watchful eye if mothers' didn't eat meals on time or forgot to take medication. At least 8 of the 10 daughters stated that they spoke with (i.e., checked in with) their mothers on a regular basis. One daughter noted that she called her mother at

least 3-5 times a day to see how she was feeling. This was just one of the many ways that daughters expressed concern for their mothers and inquired about their well being and health. These expressions of concerns and inquiry were all instrumental in shaping how daughter's talked with their mother's about diabetes. Daughters' talk encompassed monitoring their mothers' self-care behavior and matching their talk to the current situation. For instance, if a mother forgot to take her medication her daughter addressed this issue with questions like, "Mom, did you take your meds today?".

Policing and monitoring talk seemed to be the most prominent type of talk that daughters engaged in with their mothers. Policing and monitoring transpired when daughters engaged in regulation and/or overseeing of their mothers' various health practices.

## • Policing and Monitoring Talk

*Juanita*, the lively 42 year old daughter of *Joanne* states that she is, "The baby of two...my mom only has two kids, two girls". She was not hesitant to dive right into a conversation about her knowledge of type II diabetes and her perception of her mother's experience of living with diabetes.

As we talked in-depth she recalled one of many occasions when she needed to monitor her mother's diabetic management. She stated, "When we go out shopping I am like...you know mom, you can't just hang out with us [her and her older sister] all day long and not eat something". Juanita recognized that her mother's diabetes meant that going without meals was not acceptable health behavior. She notes, "I don't like for her to run around and not eat a little something...she could get sick". For Juanita, this overt dialogue with her mother served to let her mom know it was time to stop whatever activity they were doing and get something to eat. Juanita saw her monitoring as a natural activity that ensured her mother adherence to important self-care behaviors [dietary regimen given by her medical practitioner].

*Kai*, the daughter of *Yolanda*, has an open yet confrontational relationship with her mother. For this reason monitoring her mother health behaviors is a normal part of Kai's lifestyle.

Kai is the youngest daughter of three and presently lives at her mother's house which Kai believe makes it easy for her to keep an eye on her mother. Her mother

describes Kai as a "harsh realist". During the interviews, it was apparent that Kai's quest for maintaining a healthy lifestyle was not only for the preservation of her mother's health, but with hopes of not adding diabetes to her already existing health problems.

She notes that her life journey has not been an easy one, having to deal with such health issues as bi-polar disorder, vision problems, ectoderma dysplasias (a genetic disorder) and severe eczema. She believed that each of these experiences had been instrumental in shaping her life course and creating a spirit of resilience, honesty and directness. When I asked Kai if she communicated with her mother about her diabetes she reflected,

We have a lot of conversations around planning meals...planning a healthy diet for her. Um, I'm trying to get her to exercise more...encouraging her to go out and walk with Calder [her seeing eye dog].

Kai further notes that she loved to bake but since she moved back in with her mother she has stopped baking. She notes,

I use to bake...I love baking every now and again, but there have been a few too many times when I caught mom eating some of my cookies, or cake. We can't have that...it will only make her diabetes worse...so I stopped doing it [baking]. Kai admits she has to be straightforward and open in her relationship with her mother,

I've had to tell her, mom are you trying to kill yourself? She knows better...she can't eat that. I've even had to confiscate a Snickers bar from her. I don't get it. We [Kai and her mother] know what this disease does to people.

Kai believes she is so direct with her mother because she does not want to become overwhelmed and discouraged about her own health. She also notes that keeping a watchful eye on her mother from her perspective helps her and her mother be more aware of the implications of diabetes. She notes, "I know from friends and other family members that living with this disease can be really difficult...we gotta make sure we keep an eye on how we live".

Another daughter, who herself struggles with lupus, notes that policing/monitoring her mother [what she termed as "keeping an eye on her mother"] can be challenging and on occasion a daunting task. *Leah, Laurie's* overly protective daughter states, "Not only do my mother and I talk a lot, but generally I will accompany her to doctor visits because

of her other health complications". Leah's mother also suffers with multiple sclerosis and needs a lot of assistance from her adult daughters and son (e.g., transportation to and from medical visit, occasional help preparing meals, etc). Leah reflects on how she reprimanded her mother during their Thanksgiving celebrations last year. Leah's monitoring and policing talk is clear when she states,

She was trying to sneak a piece of cake after Thanksgiving dinner...I just happened to checked her bag, saw this piece of cake, took it out... I said, 'mom you know you aren't suppose to be eating this stuff'. My brother is really hard on mom when he sees stuff like that. He was there at the house and he gave mom an ear full. Mom are you trying to kill yourself...he said.

Leah then states, "she knows better" she becomes silent and shakes her head in disbelief. After a short pause she stated, "I just don't know".

For Juanita, Kai, and Leah policing and monitoring their mother's health behaviors were ways of expressing their concern for their mother's well-being. It was also evident that policing and monitoring was an exhausting and perplexing process for daughters. Because most daughters lacked an understanding of what it feels like to be diabetic, it can be argued that their frustration stemmed from believing their mothers' disregarded aspects of their self-care directives. For most, policing/monitoring patterns transpired in different contexts but surfaced as a clear avenue of communication used to talk about their concern for their mothers.

• Dietary Talk

Another sub-heading that emerged under daughters' concern for mothers well being was dietary talk. Dietary talk was just as significant as policing and monitoring talk. Most mothers had dietary regimens that were mandated to them from their diabetic nutritionist or medical practitioner. Dietary talk entailed just that; talking to mothers about their diets. Like policing and monitoring talk, dietary talk seemed to be on-going in each mother-daughter relationship. It seemed to have a unique dynamic because most mothers were very aware of how they should eat but struggled regularly to maintain their eating plan. For this reason, having their daughters input was not always coveted information. Some mothers struggled with eating well balanced meals, while other mothers struggled with remembering to eat their 3 to 6 meals a day to keep blood sugar levels regular.

admitted getting caught in poor eating behavior like snacking randomly throughout their day which typically affected how they felt (tired, fatigued, moody). Each daughter was watchful of her mother's eating patterns which, on occasion, annoyed mothers. For daughters, dietary talk took on the form of question asking, like "Mom, have you eaten yet?" Dietary talk transpired in the form of commentary not necessarily spoke to the mother but spoke at the mother, as if daughters were thinking out loud, "I know you're not getting ready to put that in your mouth". Dietary talk was occasionally aligned with monitoring and policing talk like, "mom you are not allowed to have that".

For instance one daughter, *Laurel*, notes that even though her mother's dietary habits are pretty sound, she has to be careful when she addressed her mother's dietary behavior, especially if she addresses the dietary concerns at a period of the day when her mother has not eaten and is experiencing a drop in her blood sugar. She notes,

When her blood sugar is low...[she laughs]...when her blood sugar is low, don't ask her anything...don't say anything...and you can always look at her and tell when her blood sugar is low and she is hungry she always has a attitude. All you say is do you want something to eat and where do you want to go...that's all you ask her. That's it.

Laurel notes that asking her mother any more then that can create tension. She continues, "Or mom will say, I'm hungry, take me to get something to eat". You can always look at her and tell when she really needs some food.

Laurel emphasizes the importance of talking with her mother about her dietary needs when they both were in a neutral environment and before her mothers blood sugar dropped and she became hungry. She notes, "if I try to talk to her when her blood sugar is low she will bite my head off".

Laurel further notes her mother's strong commitment to her diabetic diet when she states. As far as food intake, she makes sure that she is eating the right amount of carbs, she makes sure that she is not eating something that she's not suppose to, she reads labels...a lot...she reads a lot of labels...a lot of label reading. Um, no sweets, nothing...every now and then she might say, "let me taste that" but she will just take a little pinch of it and she'll eat it and she's fine. But if her blood sugar is low she'll say okay, I need something, give me a piece of candy but she will

not...anything that she is not suppose to have she will not eat it. It was not problematic for this daughter to function as her mother's inner voice of awareness regarding her diet. However, Laurel had to be acutely aware of when and how she needed to address her mother's dietary plans. While acting as her mother's inner voice was not always coveted by Laurel's mother, Laurel felt it clearly communicated her concern.

Another daughter, *Sherri*, who keeps an eye on her mother's random eating behaviors, stated, "I usually scold her when she is trying to eat some cake...I have a cake business on the side and whenever I make them she is trying to do a bit of tasting on the side, saying, 'I can have a little of it'. I tell her don't taste that, you can't eat that...so I fuss at her about that or ask her, 'are you exercising properly, have you been to the Y' ...that kind of stuff". *Sherrie* further notes, "I got her a cell phone because our lives are so busy but I make sure to touch base with her once or twice a week".

Like Laurel, Sherrie believes her mother works hard to maintain healthy dietary habits. She states, "for the most part my mom is good about what she eats, however when she slips I try to let her know and help her get back on track".

• Spiritual Talk

Spiritual talk associated with diabetes emerged as another sub-area daughters used to express their concern for their mothers' well-being. One interview that presented the greatest challenge with daughter's spiritual talk transpired with *Sadie* the eldest daughter of *April*. Not only did April police and scold her mother about her diabetic management, she also gave her mother a number of dietary recommendations interwoven with spiritual advice. For a number of reasons, primarily her strong religious beliefs, April felt that talking about illnesses was in direct conflict with her beliefs that God could heal all diseases and ailments. It was this strong religious belief that shaped how April talked with her mother about diabetes. First, April believed that her body was a temple of the Holy Spirit that needed to be cared for with exercise, appropriate diet and rest and that to speak about illnesses or ailments was to give "victory to Satan" and claim God powerless. For that reason, when I asked April whether she talked with her mother about her diabeter sher immediate response, which was coded as "spiritual healing talk" was,

No we don't talk about it... I'm always tellin' momma not to speak those words of defeat out of her mouth. She has to believe that she can be healed of this disease and if she would just believe and not speak those words... 'I am a diabetic' then she could be healed from it.

After more probing (in the second interview) I asked April again if she could think of any situations in which she and her mother had discussed type II diabetes. She thought for a while and stated,

Well, we've talked about some of the things that she's been eating and whenever we're having family dinners, etc...you know the traditional breads, rolls, macaroni and cheese, I won't have that stuff, I will have something totally different. She will say 'Well aren't you gonna have rolls; and I will say, No momma it's not necessary...all these starches and gravy.

April's continues,

Eatin' a lot of macaroni and cheese, rolls and sweet tea. It's just a set up! All those wonderful desserts that she makes. Man at Christmas time she goes for broke...that stuff is not good for you and I don't think that diabetes would have manifested if she had not been partaking of these things, mashed potatoes and the gravy...She has to remember that her body is the temple of the Lord's. If she would just do what she needs to do and stop trying to eat all that stuff she wouldn't be dealing with this diabetes.

It was difficult to separate April's policing talk from her spiritual condemnation of her mother's diabetic health behaviors. It was apparent that while April was concerned about her mother diabetes she struggled to express her concern without punitive condemnation.

Other daughter's used spiritual talk to dialogue with their mothers about diabetes, however, unlike April their talk served to encourage mothers, motivate mothers and/or make mothers aware of the connection they had with their higher power to "bear their burdens".

For instance, Sherrie illustrates how she used spiritual talk to encourage her mother. She simply reminds her mother, "Mom, God is in control". Another optimistic 22 yearold daughter states, "I tell her we gotta live...go life...God is going to help you through this and you have to believe that".

# • Teasing Talk

Finally, daughters engaged in what I eventually coded as teasing talk. Teasing talk was described as humorous commentaries that daughters used to chide mothers to think about their self-care behavior from a comical perspective.

A poignant example of this transpired when Ann would call her mother by her first name and state, "Betty if you don't strengthen up we [Ann and her sisters] are going to admit you to the hospital".

Another daughter commented, "I tease her sometimes, especially when she doesn't do what she knows she needs to be doing". She notes she has been known to make comments like, "Well there goes a toe if you keep eatin' that stuff".

While most daughters viewed teasing talk as something that was done in a lighthearted manner, some mothers resented this kind of communication. Mothers made statements like, "She needs to remember that I am the mother...she can't tell me what to do". One daughter stated, "At times I feel as though I become the 'mom' even though I am the daughter. My mother basically told me, 'remember I'm the mom and you are the daughter!' Another daughter noted, "sometimes she says I talk too much...like I'll ask did you walk today and what did you eat. You know it is the role reversal happening...you know".

Regardless of daughters' perspectives of role reversal or taking on a motherly role, many believed these types of talk were their ways of expressing concern. As I talked with daughters about their concerns for their mothers I learned that most found it necessary to talk to their mothers about their illness; most were candid with their mothers and were eager to ask questions and encouraging good health behaviors. Each daughter used various types of talk to communicate the importance of mothers taking care of themselves and to show their concerns for their mothers' diabetes.

# Pattern Two - Recognition of familial health

One consistent theme throughout interviews with each mother and daughter was the general information dyads shared regarding their family and the family's history of diabetes. Daughters in particular possessed a personal interest in understanding and knowing more about this complicated illness. As outside observers, most daughters watched and tried to understand the numerous diabetic complications occurring with their mothers. Most could recall a period in their lives when their mothers' were healthy and free of the illness. As well, each one could attest to the change in their mother's health; the various life style adjustments. During my interviews one daughter described the emotional roller coaster her mother experienced when she was diagnosed. She notes, "my mother made comments like, 'I can't believe I have this...what did I do to deserve this disease.". Not only did mothers' illnesses influence daughters' lives, each daughter had their lives touched by other family members or friends who had suffered with diabetic complications. Therefore, daughters talked with their mother about the familial health dynamics of diabetes. Conversations addressed the dynamics of the family, the mother and future implications for the daughters.

*Ann*, for instance, is the youngest daughter of *Betty*. She is married and has one child. Among other health complications she suffers from Crohn's disease. Though she does not understand the lived experiences of a diabetic, her illness makes her extremely aware of the frustrations someone living with type II diabetes might face. She and her husband lived in Florida for a number of years but returned to the northern region to be close to her family, particularly her mother. Early in our conversation Ann spoke of the prevalence of diabetes in her family.

Both her grandparents on her mother's side of the family were diabetic as well as a number of aunts and uncles. She recalls administering insulin shots to her grandfather and later that day watching him eat a whole piece of cake and saying, 'I'm alright baby', knowing that he was not following his recommended diet. Ann noted that diabetic talk was routine in conversations with her mother because of its prevalence in her family. Regarding her mother, Ann stated,

Mom doesn't take care of herself the way she should even though she knows what

'sugar' will do to you....goodness she saw her grandparent's die from the disease. Ann remembers when she was first made aware of her mother's diabetes.

She just told me...maybe when she was in the hospital<sup>12</sup> one time and they did test on her...she said, I need to start taking medication. Her saying that didn't

<sup>&</sup>lt;sup>12</sup> Ann's mother had been hospitalized a number of times for fainting spells and what she described as anxiety attacks. It was during one of these hospitalizations that she was diagnosed with type II diabetes.

shock me. I probably didn't even blink cause I knew...if she didn't have it (diabetes)...I knew it was forthcoming.

She further notes,

My mom is very back door when it comes to talking about her health...won't talk until it is completely necessary. I remember I was over her house one day and her insulin needle dropped out of the refrigerator, at that time I didn't even know she was taking shots...I knew she was on medication but not shots. She didn't even acknowledge that it dropped so I said, 'mom your needle fell on the floor you might want to pick it up'.

Some of this resistance to talk is because since Ann can remember, her mother has been the caregiver for the family. Ann's mother cared for her parents, grandparents and now her own family. Ann reflects,

My mom is the absolute caregiver of this family, she's not gonna admit she has anything until she is laying in the hospital on her back and the doctor is standing over her saying she has this or that. You would think she would be on top of things with all the diabetes she saw growing up. She reminds me of my

grandfather...acting like nothing is wrong when really everything is wrong. Throughout our interview Ann expressed bewilderment that diabetes is so prevalent in her family but does not get the attention it should regarding diet, exercise and other preventative measures.

The information Ann seeks regarding the history of diabetes in her family is at times difficult to obtain; however, *Laurel*, the daughter of *Bonita* was very knowledgeable about the family history and found this information to be natural in her interaction with her mother. Laurel is the mother of two children, a daughter and son. For her, information sharing regarding the family history of diabetes was always very candid. She attributes this to the fact that her older son, Ricky, was a Type I diabetic. As well, her mother's father suffered from diabetes and diabetic complications during his last years of life. When asked about her families' health history she notes,

My mom...she is diabetic, her brother is a diabetic and my grandfather was a diabetic (type II). I have an older brother and he is fine...no health issues.

My mother takes the position that education is the key to prevention, particularly regarding type II diabetes.

While Laurel's family history of the illness is extensive, she notes that she has worked diligently to keep her weight off and watch how she eats. She further comments, "This family history and watching my mother struggle makes me want to understand this illness. That means I gotta ask questions. My mom is pretty educated [about diabetes] so she's good at answering questions".

Some daughters were able to describe clearly their recollection of the illness in their families. For instance, when *Lynette* described her first recollection of conversations with her mother about her type II diabetes she recalls,

I think I was already...prior to my mom having it...I was already exposed to it. One of my aunts who was very close to us; we knew she took shots and you know African Americans referred to it as 'sugar' and that's what they'd (her aunt) talked about and a lot of different members of the family had it, so I was already exposed to it. So I kinda expected some things (her mother to become diabetic) but I don't think I asked her (her mother) any questions because I was so exposed.

I believe one daughter's statement best describes the general attitudes that many of the adult daughters had regarding their family history of type II diabetes,

I think we should talk about it [diabetes] because it's hereditary. So I mean I'll ask my questions...sometimes I can drill people [her mother and others] with my questions cause I want to know, cause I think about one day if I want to have children...I need to know about daddy's health, my mom's health and my own health.

On some level each daughter described her families, the influence of diabetes in families and how and why it was importance for her to talk about diabetes with their mothers. Some might say that diabetic information was not always readily accessible but that this lack of access to information was not a deterrent to daughters' asking questions and seeking answers from their mothers. It was clear that daughters not only wanted, but needed familial diabetic information to help them understand the implications of the illness on their lives and the lives of their family units. As earlier noted, daughters talked with their mothers about their concerns for mothers' self-care behaviors and concerns for

their personal health behaviors. It was apparent that talk of this nature encompassed their fear of becoming diabetic in union with their fears of their mothers' future complications.

Diabetic mothers and adult daughters talked about type II diabetes. Mothers initiated talk based on their past knowledge of the illness, their present/personal experiences of living with the illness and their recognition of the future implications of diabetes. Daughters initiated talk and advocated for preventive behavior based on concern for their mothers' well-being and their recognition of the familial dynamics of diabetes. *Prompts that Promote Communication (i. e., talk) about Type II Diabetes between Mothers Living with Diabetes and their Non-Diabetic Adult Daughters* 

Understanding that mothers and adult daughters talked about diabetes was important, however, of equal importance was understanding what prompted or motivated the mother-adult daughter dyad to communicate with each other about diabetes. The Health Belief Model (HBM) clarified the rationale for what prompted dyads to talk. The HBM conceptualizes health behavior as a function of both the desire for health and/or avoidance of disease and its consequences along with beliefs that particular actions are valuable in fulfilling that desire (Rosenstock, 1974; Strecher & Rosenstock, 1997). Mothers lived with ongoing concerns for their daughters' health and well-being [desire for health and avoidance of disease]. As well, adult daughters lived with daily concerns for their mother's self-care behaviors and future health complication. For both parties, concern stemmed from a) their knowledge of the severity of type II diabetes, b) mothers concern for daughters susceptibility to diabetes as well as their concern for their susceptibility to ongoing complications of the illness and, c) daughters concerns for their susceptibility to the illness as well as their mothers' susceptibility to potential complications. Each mother and adult daughter talked to each other not just about the severity of and susceptibility to diabetes; they also conversed about the benefits of practicing good health behaviors and the barriers they faced. Interspersed within their conversations was an inherent desire to help each other deal with the nuances of diabetic complications or diabetic diagnosis.

Each mother clearly talked about the <u>seriousness</u> of diabetes. For most the seriousness was communicated in their dialogue about the family history of the illness. Each mother shared an account of a family member who had struggled with diabetic

complications. Their stories were vivid, even painful for some to discuss. These vivid reminders often served as the impetus to prompt talk with adult daughters about becoming diabetic and the ongoing problems that diabetic individuals experience.

Each mother had an intense reaction to diabetes that fueled conversations. Generally, mothers made statements like, "I hated this disease", "I feel like I've been cursed", "I don't know what I did to deserve becoming diabetic" and "I wouldn't wish this disease on anyone". This perspective served to create opportunities to talk with their daughters about the numerous woes of diabetes.

*Joanne* understands the seriousness of diabetes and while her overemphasis of the topic frustrates her daughters she still talks. She states,

Well, they know everything about me and they tell me I talk too much...like I will share this letter [one she received from her physician] this afternoon with them. They know when my medicine changes...any thing like that...you know. They sometimes say, 'okay momma, we know ...we know, momma'. I think I talk about it because the kidney part concerns me and I tell them, you know I'm not gonna be here always...so it's good to talk these things out so that everybody has an understanding.

Mothers' concern about their <u>susceptibility</u> to future complication and their daughters' <u>susceptibility</u> to diabetes prompted conversation about the illness as well. Most worried on some level and talked regularly with daughters about eating habits, medical visits and weight gain. Interestingly, one mother was not forthcoming with diabetic information because she feared her daughter becoming diabetic. Though she knew her adult daughter could be susceptible, talk about the susceptibility was uncomfortable, as if sharing the information would doom her daughter. She notes, "I make occasional comments...I remind her to watch what she eats or tell her to make sure she stays active...Even though I worry about her becoming diabetic, I don't like being diabetic, don't like thinkin' about it and I don't think I talk to her about it enough."

Generally, most mothers' believed that the numerous <u>benefits</u> to managing their diabetes far outweighed the <u>barriers</u>. A few mothers could provide a list of benefits to managing their diabetes. They could also name the benefits for their daughters to not "get diabetes". However, some did not always practice what they preached. Some made

statements in interviews like, "I don't play around...I've seen too many people die from this...I do what my doctor tells me to do" only to have daughters paint a different picture of how they perceived their mothers' health behaviors. Without prompting, daughters would note, "Mom lets too much stuff get in the way of taking care of herself," or "She has so many resources, my brother is a doctor, her mother had diabetes...sometimes she seem distracted, sometimes she doesn't do what she should". It was evident from daughters' comments that they recognized mothers' barriers. This behavior prompted numerous and varied talks between mothers and daughters.

Betty for instance was quick to tell her daughter to stay healthy but described herself as a "bad patient". *Ann*, Betty's daughter is often prompted to talk with her mother based on her observance of her mother's lack of self care but obsession with family care giving [Betty is the caregiver for her diabetic husband and mentally challenged adolescent son]. She notes, while her mother is good about being a caregiver, "she has been a caregiver as long as she has been walkin' this earth, she [her mother] is remiss in exercising the same diligence to care for herself". Ann states, "…as far as my dad [who also has type II diabetes] is concerned she takes care of his [diabetes] much better than she does for herself".

Each daughter was keenly aware of the <u>seriousness</u> of diabetes. Thus, most daughters used talk to address the seriousness. One daughter frankly comments, "this illness is no joke!" Daughters' experiences with their mothers' as well as close relatives, typically grandparents, served as an ever present reality check on the seriousness as well as their susceptibility to diabetes. No daughter was excluded from sharing stories about a grandparent who was amputed, a friend or family member on dialysis, and/or a cousin who was living with an additional chronic disease because of their resistance to properly care for their diabetes. Daughters who understood the seriousness of diabetes were quick to scold their mother and monitor their exercise and eating habits. While it was natural to assume that a dialogue with mothers about the seriousness of diabetes would yield daughters who practiced healthy lifestyle behaviors, the contrary was sometimes evident.

Daughters talked candidly with their mothers (using policing, monitoring, teasing and other forms of talk) to address mothers' <u>susceptibility</u> to potential diabetic complications. As well, daughters spoke candidly with their mothers about the possibility

of becoming diabetic. However, some daughters' concerns did not translate into their lifestyle choices. For example, Ann verbalized her increased susceptibility to the illness (both grandparent and parent were diabetic) but resisted the idea of removing certain behaviors. She states, "If you ask me to give up my soda then I don't know if I could do it (she pauses)...now if I had to get insulin shot maybe I would reconsider, but I do love my Coke". Further into the interview she notes, I'm really lazy...love to nap and watch my programs [referring to soap operas she routinely viewed] I can't see myself out there exercising but I know I should be". Another daughter bluntly comments, "You gotta enjoy each day...if I become diabetic I will cross that bridge when I come to it." She continues, "I want to live my life on my terms...I enjoy my candy, especially my Twizzlers and I just can't see giving that up right now because I think I might become diabetic." She quickly notes, "I'm not saying I want to get it, cause I know a lot of people who have it and their lives are not that great, but I'm just not ready to give some things up...you know." Even though she understood her susceptibility and was comfortable with her views, her laid-back attitude stressed her mother who stated "I worry that even though she's not diabetic now she could become one". For Kai her fear of becoming diabetic created anxiety and worries which prompted her to talk with her mother. She states, "I ask my mother a lot of questions about her diabetes...how she feels. I watch what she has to do...taking shots and stuff...I don't want it but I sure want to know about it and what I need to do to not get it". For some daughters like Kai, there was a sense of being in harm's way. It appeared that their closeness to their mothers both physically and emotionally served to heighten their concerns about becoming diabetic. Still, this heightened concern did not rouse most daughters to monitor their health behaviors.

Daughters were asked if they believed "there were <u>benefits</u> to not becoming diabetic. All answered with a resounding yes. Some noted they would not have to take medication or insulin shots, other commented they would not have to watch their diets so vigilantly. Most daughters quickly recalled that on numerous occasions their mothers had detailed the benefits of not having diabetes. Just as quickly as they shared the benefits they were fast to share what they perceived as the <u>barriers</u> to using positive health behaviors. Oddly, what most daughters were quick to scold their mothers about were clear barriers for them. For instance, some daughters ate a regular portion of fast foods,

some lacked the desire or interest to participate in regular exercise, some named time constraints; being overly committed as a barrier to practicing positive health behaviors. One adult daughter simply stated, "It's just hard...I see what my mom goes through but it's hard". Another daughter comments, "I respect my mother's hard work...I have no excuses 'cause I don't even have the disease. I have an advantage but I don't take advantage...you would think I would practice good health behaviors...I have no excuses". Some daughters made excuses but seemed more willing to take responsibility for their shortcomings. They were more positive about their future health outcomes. For instance Kai stated, "I don't always do what I know is best for me but I do try and I think about it a lot".

As noted, the Health Belief Model was useful, providing insight into what prompted and motivated mothers and daughters to talk with each other about type II diabetes. Although the HBM was useful for this research it was not clear about the extent to which Social Cognitive Theory (SCT), which was used to understand mother's modeled behaviors toward daughters, influenced daughters' health behaviors.

The literature maintains that observational learning entails a person's ability to learn from other people not only by receiving reinforcements from them but also through observing them (Strecher & Rosenstock, 1997). Gauging the degree to which modeling, a concept from SCT prompted daughters to talk with their mother and thus practice healthy behaviors was not as noticeable. Baranowski, Perry, and Parcel (1997) found that various types of behaviors can be learned through observational learning. This, they note can account for how family members might display common behaviors. In my research, some daughters noted that they did observe their mothers behaviors but they did not believe this observation was useful for their own health care behaviors<sup>13</sup>. In an attempt to understand modeling behavior, I asked daughters if, "they believed their mothers' modeled health behaviors [positive or negative] that helped them to live a healthy lifestyle?" Most stated that while they had been watchful observers not only of their mothers' health behavior but of family and friends living with diabetes, their observations had not created a significant change in their health behaviors. While self-reports are not

<sup>&</sup>lt;sup>13</sup> Interviews lasted on average 1-2 hours thus it was difficult to observe the extent to which modeling behaviors transpired among daughters; I could only rely on daughters' self-reports.

always accurate, daughters who had lost family members to complications from diabetes did not believe that observational learning had changed their own lifestyles that much. Most literature that uses the concept of observational learning to understand health behavior does so over an extended period of time. Active ongoing participant-observation in the lives of the daughters was not the objective of this dissertation. Hence, I was not able to observe the true implications of observational learning on the lives of the adult daughter over their lifespan. To better understand the significance of observational learning for adult daughters it would be necessary to conduct a secondary qualitative research project or conduct several follow-up studies focusing exclusively on daughters and using participant-observation techniques. While it was clear that daughters observed their mothers' positive and negative health behaviors, whether the observation served to change daughter's health behavior was not as apparent.

# Shared Health Communication Messages and Ways They Shape Self-Care and Health Behavior

Finally, this research sought to understand how the sharing of health information served to shape African-American mothers' diabetic self-care and/or shape adult nondiabetic daughters' health behavior. Early in my data collection it was evident that health information was being transmitted within each dyad, from type II diabetic mothers to non-diabetic adult daughters and from non-diabetic adult daughters to their type II diabetic mothers. It was also evident that there were a number of circumstances that prompted mothers and daughters to share information. Unfortunately, it was not clear that the transmission of health information had been instrumental in shaping mothers' and/or daughters' health behavior.

For instance, all dyads talked from their shared knowledge of diabetes in their immediate and extended family. However, they were less likely to talk about how this knowledge impacted the need to change their health behaviors. As such, some mothers were aware of the complications they could face if they were negligent of their self-care but had attitudes like *Betty* who said, "Well I guess I'm just a bad patient" or like *Sadie* who admitted, "it's just so hard to let go of all my good foods." As well, some daughters were aware of the prevalence of diabetes in their family system but stated that until something critical happened in their lives they probably would not change their health

behavior. Lynette, a daughter who understood the numerous ramifications of preventative care commented, "I don't want anyone tellin' me what I can and cannot eat" and *Juanita* who also understood preventative care stated, "I'll cross that bridge when I come to it."

Though the collection of this research did not provide adequate time to observe how extensively the transmission of health information had shaped mothers and daughters lives, there were instances when it was apparent that mothers and/or daughters had set a specific course of action in place to promote a healthier lifestyle.

For instance, *Sherri*, *Meg's* daughter took an active role in seeking information to share with her mother to decrease her stress around managing her diagnosis of diabetes. In addition, Sherri used some of the information she gathered for her mother to create a meal plan to help herself lose weight. At the time I conducted the interview Sherri was using her new meal plan with the objective of losing 10 pounds. She noted, "I need to keep my weight down…my mom is always on me about that and I know it will only be good for me in the long run".

As well, *Donita* worked to promote a healthier lifestyle by walking with her mother and eating meals from a diabetic menu at her mother's home. She felt this would ensure that she maintained healthy eating and exercise habits.

The conversations that took place between *Yolanda* and *Kai* about the prevalence of diabetes in their family through the generations motivated them to eat a healthier diet. Kai stated, "For me to prevent myself from becoming diabetic my diet and exercise are what I do."

Just as there were instances when it was apparent that mothers and/or daughters had set a specific course of action in place to promote a healthier lifestyle there were instances where talk among some dyads did not help shape mothers and/or daughters health behaviors. Basically, mothers and daughters that shared their perceived barriers to self-care or healthier lifestyle or those that believed adopting a treatment regimen was not relevant to prevention were less likely believe that talk helped shape their health behavior.

For instance, *Ann*, the daughter of *Betty* confessed that she would not change her behavior until she became diabetic and had to take insulin shots. She admits that her

mother gets on her when she sees her drinking Pepsi saying, "you know you need to cut that down...cut that down now and you won't become one [a diabetic]". Ann later reveals that if "the doctor told me he was gonna put me on that needle, or...I had to take more medication then I already take, then I would do a whole lot better...it's all about the needle...you know I'm afraid of them and I just couldn't do it [give herself shots] everyday and two and three times a day". She later reflects that she has seen family members like her grandfather administering insulin shots since her childhood. Still, her mother's constant reminders and her knowledge of the disease did not shape Ann's perspective about becoming diabetic or the peril of the illness.

*Sheila* notes that even though her family members [i. e., uncle, mother and daughter *Cassandra*] ask her about her management of diabetes she, "would rather not talk about it, wishes it would go away and even likes to forget she has it some days". This Sheila does on days when she "doesn't want to take her medication or prick her finger". Ultimately, what seemed to be important to both mothers and daughters was the communication relationship they shared regarding diabetes. Throughout my interviews at least 8 of the 10 dyads were relatively comfortable sharing health information about diabetes. The mothers and daughters who did not share as freely generally expressed feeling of stress with the lack of information or found other avenues through which to share the information, like Sadie who used her granddaughter as a means to talk about the illness. Even though mothers and daughters did share information and had a number of different prompts that encouraged them to do so, the ways in which the information shaped their health behaviors was less apparent through their self-reports.

The findings from this study are consistent with Litt (2000) and Agee's (2000) reports that African-American women use their socio-cultural network to convey important health information. In my study, diabetic mothers and their non-diabetic adult daughters transmitted diabetic information not only among the dyad but among other family members, friends and kinship relationships. Most mothers and daughters were comfortable talking with each other about the mothers' diabetic lifestyle and/or the daughters' health behaviors. Mothers' talk encompassed talk from their past knowledge of diabetes, their present experiences of living with the illness and their future anticipations and concerns of diabetic complications. Daughters' talk encompassed their

present knowledge of the illness and their concern for their mothers' health and on some levels their concern for their own health. While talk transpired in a number of different contexts and different types of talk were used to convey concerns, this study found that mothers and daughters did talk about type II diabetes.

Mothers and adult daughters who recognized the seriousness of diabetes, their susceptibility to becoming diabetic or struggling with diabetic complications were more likely to talk candidly with each other about the illness. Often, the depth of the conversations was dependent on the range of experiences that mothers or daughters had with diabetic friends or family members. For some mothers the vivid memories of parents who suffered with diabetic complications served as an ever-present prompt to talk with their daughters. For most daughters, watching their mothers struggle with the illness or watching grandparents or family members dealing with the disease served as prompts to talk about and understand diabetes. While some daughters understood the seriousness of diabetes and their susceptibility to the disease, talk was not always valued or did not yield lifestyle behavior changes.

In sum, type II diabetic mothers did talk frequently with their adult nondiabetic daughters about diabetes and non-diabetic adult daughter did talk frequently with their type II diabetic mothers. The dyads used a number of different talk patterns to discuss diabetes. Most talk represented the high value the dyads placed on family, caregiving and mothering (Collins, 1991; Sayles-Cross, 1995). Past knowledge, present experiences and future concerns of the disease prompted mother-daughter talk about the perils of diabetes. Though not all mothers and daughters freely admitted that talked prompted them to alter their health behaviors, there is evidence in this study which suggests that in some cases behaviors were altered.

#### Chapter Five

## Discussion and Conclusion

# "If Black women don't say who they are, other people will and say it badly for them" ~Barbara Christian~

I grew up as the youngest daughter of a type II diabetic mother. The impact of diabetes in my mother's life left a deep impression on me, my older brother, and three older sisters. Even though my mother passed away in September of 1998, my siblings and I continue to talk with each other about mom's diabetes and how her illness continues to affect our lives. My mother exerted extra energy encouraging me and my sisters to watch our diets, exercise, have routine medical check ups, etc. I never had the opportunity to ask her whether her motivation to chide her daughters stemmed from her recognition that we would be more susceptible to neglect our "vineyards" than my brother. It is my opinion that not only did my mother have lifestyle concerns about my sisters and me (my sisters and I battled with our weight and were less diligent about our eating habits) but she also may have recognized that genetically we were more susceptible than my brother to becoming diabetic (my mother had a few female relatives as well as an older sister who were diabetic). Her awareness of the history of diabetes among the women of the family, as well as her personal experiences of living with the illness, made it critical for her to talk with my sisters and me about diabetes. As I reflect on the core premise of this dissertation and compare my findings to my personal experiences, I see the parallels between my findings and my personal experiences. My objective has been to recognize the unique relationship that exists between African-American mothers and daughters, while gaining insight on 1) how and why African-American mother-daughter dyads talk about type II diabetes and 2) the implications of talk among dyads. The usefulness of understanding this communication dynamic will be to develop specific health interventions that capitalize on this unique bond while understanding how a chronic illness such as diabetes is addressed through the transmission of health information.

The objective of this dissertation was to answer four research questions. First, do African-American mothers with type II diabetes communicate (i.e., talk) with their nondiabetic adult daughters about type II diabetes and how? Second, do non-diabetic African-American adult daughters communicate (i.e., talk) with their type II diabetic mothers about type II diabetes and how? Third, if type II diabetic mothers and their nondiabetic adult daughters do communicate (i.e., talk), what situations prompt communication from a) the type II diabetic mother to her non-diabetic adult daughter and from b) the non-diabetic adult daughter to her type II diabetic mother? Finally, if diabetic mothers and non-diabetic adult daughters do share information, does sharing these health communication messages shape African-American mothers' diabetic self-care and/or shape adult non-diabetic daughters' diabetes-related health behavior? The following discussion addresses the theory that emerged and the implications of the data, limitations of the study, and possible directions for future research in this area.

# The Culture of Diabetic Talk

As a novice grounded theorist, my objective has been to take my findings and "construct a picture that draws from, reassembles, and renders subjects' lives" (Charmaz, 1995). As such, my investigation of data culminated in a *substantive theory*<sup>14</sup>, substantiated by supporting data from this investigation, which is closely based on, and grounded in, the actual lived experiences of the research participants (Richie et al, 1997). Thus, the negotiation of diabetes and the dialogues that transpired between mothers and adult daughters about the illness (i.e., how mothers and daughters sought to make sense of the disease and understand its various nuances) embodies a *substantive theory*.

The term "culture" was used because it best described the particular set of attitudes that characterized mothers and their daughters. The word "culture" is generally defined as the shared values, beliefs and practices associated within groups (Geertz, 1973; Hall, 1966). For this dissertation, the term was useful for describing the unique dialogues and interactions that manifested in the form of dyads' values, beliefs and practices. In this study the values, beliefs and practices entailed the shared health messages regarding diabetes. Hence, the "culture" of diabetic talk embodies the meaning mothers and daughters ascribed to the illness, and also serves as the interpretation of their actions and situations that lead to talk.

<sup>&</sup>lt;sup>14</sup> Mullen and Reynolds (1995) note that grounded theory uses comparison as an analytical tool to generate concepts and hypotheses and to interrelate them through core variables which are both parsimonious and broad in scope. The final goal of GT is <u>middle-range substantive theory</u> in a specific content area such as

As my research emerged, I observed a unique "culture" of shared values, beliefs and practices that were associated with how mothers and daughters directly and indirectly associated, related to and addressed health-related behaviors which influences the acceptance, adoption and/or rejection of various health messages regarding diabetes. For instance, mothers and daughters <u>valued</u> the family, their relationship and their interactions. Next, it was evident from mothers' and daughters' <u>beliefs</u> that diabetes was complicating and potentially life threatening. This belief was shared among all the dyads interviewed. Finally, mothers and daughters engaged in diverse <u>practices</u> that were specific to their understanding of diabetes (i.e., discussing medications, health practices most conducive to self-care, meal planning and preparation, etc.). Hence, for this study the word "culture" was used to describe the learned and transmitted blueprint for living that guides each dyad's thoughts and actions (Jones, 1972). It affects many aspects of the dyad's daily lives and influenced the appropriate approaches on how to prevent and treat illnesses (Airhihenbuwa, DiClemente, Wingood & Lowe, 1992).

The "culture" of diabetic talk can be seen within five dominant themes; a) mothers' past knowledge of the disease, b) mothers' present/personal experiences of living with diabetes, c) mothers' concerns about future implications of diabetes, d) daughters' personal concerns for mothers and e) daughters' familial understanding and concerns about the illness. The implications of the themes are as followed.

# Implications of Data

## *Theme I – Mothers' past knowledge of the disease*

As noted previously, among most African Americans, the oral tradition of sharing information is important. My findings in the study concur with past research.

Mothers' patterns of communication originated from their prior knowledge of the disease, particularly their knowledge of the disease as it relates to extended family members (i.e., parents, grandparents, family members). Mothers' prior knowledge of diabetes in their families served as the catalyst for talking to daughters about diabetes. The implications of this knowledge are as follows.

dying, pain management, recovery after a heart attack, or <u>formal theory</u>, that is theory generalized over a number of specific areas such as status passage, life-style redesign, or awareness context (p. 129).

First, as noted earlier, mothers have learned about diabetes from family members and passed this information onto their adult daughters. This knowledge shaped the culture of diabetic talk by functioning as a springboard for passing down health knowledge through the oral tradition. Within the "culture" of diabetic talk, oral tradition is one of the major means for mother-daughter dyads to learn about and pass on information about the disease and how it affects their family members and friends.

Thus, it is necessary to emphasize the importance of health messages via diabetic talk as an extension of the African-American oral tradition, noting that it is one of the main modes of transmission of health care information within African-American cultures, particularly between diabetic mothers to their adult daughters. Knowledge of the strong oral tradition can help mothers and daughters be more aware when talking; recognizing that their stories and their health histories are valuable. Not only can this awareness enlighten mother and daughter's conversations, but it can also provide awareness to mothers and/or daughters' practitioners. This insight helps practitioners signify the value of oral tradition and serve as a mechanism to help mothers and daughters address health concerns during medical visits. Basically, practitioners who have been educated about the oral tradition and incorporate that dialogue into their medical exchanges with African-American mothers and adult daughters validate the significance of the oral tradition among black woman, black culture and black communities. As well, practitioners' willingness to acknowledge oral tradition as a mechanism to deal with diabetes help dyads embrace both the cultural and medical angles of this chronic illness. This action creates a union of cultural histories and medicine, which can promotes a continual influx of new information, while assuring that the historical dynamics of the "culture" of diabetic talk are valued.

Health communication scholars can authenticate the "culture" of diabetic talk by providing culturally appropriate health information and health campaigns that support the importance of oral traditions, and accurate diabetic information. Health communication scholars can work in union with practitioners as educators by empowering black mothers and daughters with relevant information that they can understand, subsume and take back to their cultures. Campaigns, like Susan Komen's breast cancer awareness, have served to motivate women to talk more openly about breast cancer, early detection and screening,

specifically among women in family systems. In the same manner, campaigns that focus on the implications of type II diabetes among African-American mothers and daughters and their families can be beneficial. Health communication scholars can provide educational literature to diabetic mother, adult daughters, as well as, their families and communities that disseminate the significance of oral tradition and culture. The distribution of a mother – daughter handbook which focus on diabetic dialogue can provide guidance about how mothers can use oral tradition to share the implications of diabetes from a historical perspective and how daughters can be co-constructor of diabetic health information in their families and in their kinship relationships. By using this material both parties will not only have accurate educational information that is culturally appropriate, but they will also have the opportunity to gain a better understanding of how to have culturally relevant dialogues that embrace African-American oral traditions.

### Theme II – Mothers' present and personal experiences of living with the disease

A second pattern of communication that influenced the "culture" of diabetic talk emerged from mothers' present and personal experiences of living with diabetes. Not only did mothers extend support to their adult daughters, which is consistent with the social support literature, but in many instances during their dialogues mothers used personal experience to teach their daughters how to cope with illness specifically and the world generally (Collins, 1991; Bell-Scott, Guy-Sheftall et al., 1991). Like Carother's (1990) work, my results indicate that black mothers did not want to hide the world from their daughters. Hence, "information about what it takes to deal with their (the mother's) reality is readily available to black daughters, which makes daughters quite knowledgeable about their mothers' own struggles" (p. 242-243). In the same context, diabetic information about living with type II diabetes was readily available to their daughters with the hope and expectations that it would be used in a beneficial manner.

An implication of present and personal experiences for both mothers and daughters is to 1) help mothers understand their influence on their daughters and the significance of their present and personal experiences, and 2) teach daughters how to acknowledge and validate their mother's experiences. Throughout this study mothers talked openly about their diabetic experiences and given their close relationship with their mother's, daughters were often on the receiving end of this information. Unfortunately, mothers did not always recognize the connection of their present and personal experiences to their diabetic fears, frustration, anxieties and guilt, nor did daughters comprehend how to help mothers work through their diabetic experiences. Hence, on numerous occasions this conversational dissonance left both parties frustrated, leaving mothers in angst and daughters succumbing to levity, condescending or teasing of their mothers.

Mothers and daughters must understand that mothers' ability to talk with their daughters from their present and personal experiences diffuses mothers' psychological/emotional issues. For this reason, helping daughters address their mothers' feelings and beliefs is critical and would be beneficial for them to understand. Namely, daughters need to understand the implications of condescending and/or teasing, and ways that such actions might heighten anxiety and/or frustration among mothers and exacerbate their frustrations, fears, and guilt of living with diabetes. For instance, one mother expressed that while she understood her daughter's teasing as a sign of love, it increased the mother's sense of frustration with her poor self-care habits. So, while mothers were quick to let daughters know this was a disease their daughters should avoid, they wished their daughters could walk in their shoes, even for a short while, to understand how overwhelming the illness could be. Helping daughters understand how to "walk in their mother's shoes" is imperative to help them understand more fully how mothers can feel defeated, because in spite of doing their best, the disease progresses.

A second step will be to encourage practitioners and/or health communication researchers to work in harmony supporting mother-daughter dyads in the development of community-based settings that promote sharing (among other mother-daughter dyads) of personal life experiences/stories in union with personal illness accounts. Promoting prevention, self-efficacy, accurate information about diet, medication and health management amongst each other and within their families and extended kinship relationships has the potential to improve health outcomes.

Creating a tangible site where mother-daughter dyads can work both collectively and individually with a culturally sensitive health professional to develop and use a manual for type II diabetic mothers and their adult daughters would be beneficial. For

instance, a manual titled, "Your Self, Your Daughter: Toward understanding and talking about diabetes among African-American Diabetic Mothers and their Adult Daughters," could provide empowering information. A manual of this type could give the mother specific diabetic self-care instructions and help her understand how to frame her talk when she shares with her daughter. It could heighten her awareness about the complications of diabetes, how to care for herself adequately, how to ask for help and support when she struggles with her self-care, etc. It could also help her see how to use motivational prompts with her daughter when she thinks the daughter needs to be more proactive about her own health issues. Health professionals could teach mothers how to make statements like, "I noticed you've been losing a lot of weight and you haven't been trying. It's not normal. What would you think about seeing your doctor to make sure everything's alright?" instead of "I feel like you need to go to the doctor." Such statements might assist daughters to think more seriously about their own health and to actively participate in achieving and maintaining optimal health. Knowing how to frame statements, questions and concerns for their daughters might encourage daughters to become more proactive in preventing or delaying the diagnosis of diabetes. Many mothers expressed concern about what would eventually happen to their daughters (i. e., will my daughter eventually become diabetic given that I am?) It was natural for this concern to agitate their fears about what might one day happen with their daughters if they were diagnosed with the illness. Some daughters were prone to make cavalier statements when hearing their mothers concerns (e.g., "Momma, stop bothering me about that stuff...I'm fine"). Such statements only serve to heighten the mothers' anxiety. For that reason, it is important to provide daughters with a resource such as the manual that reminds them how cavalier comments are counterproductive if they are attempting to understand and respond to their mother's concerns about their health.

A manual like "Your Self, Your Daughter: Toward understanding and talking about diabetes among African-American Diabetic Mothers and their Adult Daughters", used in a comfortable setting with culturally competent health professionals can serve to increase daughter's perceptions, knowledge and sensitivity about diabetes, thus allowing them to offer empathetic listening rather than teasing, which can offer their mothers a sense of hope rather than hopelessness. My research confirms the importance of mothers and daughters *hearing* about and *listening* to the emotional implications of the illness. Thus, it's important to create an environment which promotes daughters paying attention to their mother's physical status and mental state of mind and mother's use of clear descriptive dialogue while extending support that encourages productive health care.

## Theme III – Mothers' concerns about future implications of diabetes

As mothers' faced the present and personal challenges of living with diabetes, a natural consequence for each was dealing with the future ramifications of the disease. Thus, concerns about future implications served as a third catalyst for mothers' dialogue with their adult daughters. Each mother wanted her daughter to understand not just the past but also the future outcomes of the illness for them and their daughters.

For this reason, mothers and daughters must talk openly about the repercussions of the disease, as well as understand what the future holds. Having open dialogues regarding self-care behaviors, health concerns, and potential future complications of diabetes helps mothers and daughters see the whole picture instead of just individual nuances. As well, if done with accurate education information, open dialogues can lessen and potentially eliminate any myths or misdirected knowledge that both parties might have gained from other inaccurate information channels (i.e., family members or friends). Addressing the future implications and concerns of the disease 'out loud' can also serve to dissipate fears that mothers and daughters might have internalized. Dialogues about future implications of diabetes help to eliminate myths and dissipate fears as well as serves to piece together what mothers view as fragmented and/or compartmentalized medical information. This act recognizes that diabetes (its history, present and personal experiences with it, and its future implications) does not transpire in a vacuum but involves numerous illness dimensions that address the disease and the impact of the disease in both parties' daily lives.

Furthermore, practitioners who share the complexity of diabetic care in culturally sensitive messages can help mothers, daughters and family units work on treatment plans that incorporate both short and long-term goals. Typically, though mothers talk with their daughters about diabetes and that talk leads to an initial impact for shaping self-care behavior, the challenge of total lifestyle change, which is a major and typically an

unsuccessful endeavor, can lead most mothers away from the behaviors they worked diligently to change. Thus, a treatment plan which allows dyads to have a more collaborative relationship with their practitioner and experience greater long-term success in the management of their disease would be beneficial. A plan of this nature can also help mothers feel that they have the support of someone whose professional perspective and opinion they value, instead of feeling punished for not being perfect in how they managed their diabetes.

#### Theme IV – Daughters' personal concerns for mothers

A fourth pattern of communication that influenced the "culture" of diabetic talk emerged from daughters' personal concerns for their mothers. A number of daughters expressed the importance of their mothers taking care of themselves. However, their roles as daughters sometimes precluded their complete involvement. Such was the case with daughters *Ann* and *Bonita*, whose mothers became adversarial when their daughters attempted to give self-care directives. Both mothers noted that while advice from their daughters was useful, they had to remind their daughters that they were the mothers. Still, most daughters felt that their concerns for their mothers meant at times they had to become the "mother figure".

Educating daughters on the different aspects of diabetes will help them talk with heightened sensitivity and intelligence to their mothers about their symptoms when they are placed in situations to act as the "mother figure". Social support literature can help daughters understand their role as a key component of their mother's informal social support network. As such, daughters can see the importance of social support in their relationships and potentially give mothers the directive and language to assure that while they cannot personally identify with their mother's illness they can effectively sympathize and provide support in a proactive and productive manner. Equally, practitioners can encourage daughters to participate in mother's medical visits. As well, they can offer support to adult daughters during visits by encouraging them to participate in talk with their mothers about diabetic self-care. Finally, it is important for practitioners to provide daughters with resources (i.e., diabetic pamphlets, videos, small group programs) that encourage them to engage in empowering talk as opposed to critical or teasing talk. Daughters' concerns for their mothers' well being can then be used to foster

goal-directed talk about diabetes with their mother as well as physicians and practitioners, thereby, making the daughter an important part of the healthcare team.

Finally, a few mothers in this study stated that much of their daughters' support in their self-care management helped them be more proactive early in their diagnosis of diabetes. For instance, during one mother's (Margaret) first few examinations she became dissatisfied with the lack of information she received from her primary care physician regarding treatment of her diabetes. This dissatisfaction was communicated to her daughter whenever they talked on the phone or visited with each other. This mother reflects on one conversation in which her daughter suggested she investigate other practitioners who might serve her needs more adequately. She trusted in her daughter, who expressed her desire for her mother to have the best care she could. She also wanted her mother to seek the opinions of other family and friends who had knowledge of diabetes. This mother-daughter dialogue caused this mother to seek the services of a new practitioner. As the daughter shared her story with me she closed by noting that her mother's primary care physician, "let her know he was not happy with her change in practitioners". She reflected that her mother's comments were simply, "I didn't care, cause I gotta deal with this illness, not him". Practitioners must understand more than ever that information from daughters, families and friends influences how mothers make decisions and seek care from healthcare practitioners. Most diabetic mothers are becoming savvy about seeking and selecting a physician or practitioner with whom they can work to manage this life-long chronic disease. For this reason, practitioners must make sure they address not just the concerns of the mothers but the concerns of families as well. Recognizing the collective dimensions of the black family assures that not just mothers but family systems will be satisfied with and continue to seek care. *Theme V – Daughters' familial understanding and concerns about the illness.* 

A fifth pattern of communication that influenced the "culture" of diabetic talk emerged from daughter's familial understanding and concerns about the illness. Most daughters were aware of the prevalence of the disease in their relatives, but were perplexed about how to interpret what it meant for them. Some noted that while they themselves were not diabetic, it was something of which they were constantly mindful. Unfortunately, some daughters were mindful of the potential risk of diabetes given its

prevalence in their families, but were not ready to maintain regimented exercise, diet or lifestyle practices. Basically, they did not understand the seriousness of the illness or the degree to which they were at risk for inheriting this chronic disease. Given that most of the daughters interviewed were willing to "talk about diabetes" but lacked the insight or internal motivation to become proactive or committed to not being diagnosed with diabetes, it would be beneficial for health practitioners to encourage daughters to participate in medical sessions with their mothers. With a mother's permission, physicians can grant daughters and/or other family members permission to participate in medical visits. Mothers need only execute a special document called an "Authorization for Disclosure of Protected Health Information" applicable to specified family members and others that the mother wants informed about her medical condition (http://www.femcentre.com/dr\_ridley\_hippa.html, 2005). As well, this opportunity can provide daughters with medically relevant literature about diabetes that might promote better compliance for their mothers, and possibly prevention of the disease for the daughters. Allowing them the opportunity to be a part of the discussion during the medical visit (i.e., hear the physician's discussion of medication, see the nurse draw blood, hear the mother and physician discuss dietary and lifestyle limitations) could also help daughters experience first-hand the challenges associated with attempts to control diabetes. Routinely experiencing their mother's health care behaviors through the lens of the medical visit might encourage more vigilant care for themselves.

In union with daughters participating in medical visits, health communications scholars can create and disseminate literature that specifically addresses daughter's misunderstandings and ambivalence regarding diabetes. This literature could help daughters not only understand the role they play with their mothers but also the importance of long-term health practices for themselves.

## Implications for physicians and health care practitioners

Practitioners must recognize that African-American women's concerns surpass just thinking about themselves, and encompass other health issues besides diabetes (Abraham, 1994). Historically, black women have served as the caregivers for their families and communities (Collins, 1991; Sayles -Cross, 1995). If practitioners keep this in mind when seeing the African-American mother, it will go a long way toward establishing trust, building rapport, and empowering the mother to assist her family and community. Providing accurate and useful information that can be passed along can surpass just offering advice and education for the mother. For instance, practitioners can probe on a deeper level to engage mothers in conversations about their frustrations and concerns regarding their diabetes and their present treatment plan. Discussion of the management plan should be thorough and include culturally appropriate alternatives to self-care management for mothers.

Much like the family's adoption of healthy lifestyle behaviors, practitioners must also work to develop a flexible model of care to maximize positive outcomes. Partnering with a mother's loved ones can empower the diabetic mother to adhere to the prescribed treatment plan. As the literature notes, "enlisting family members as allies in the fight against illness is one of the most potent interventions physicians can employ" (Jacobs, 2000).

It would be prudent for physicians and practitioners to recognize that when mothers arrive at medical visits with daughters, including daughters in the consultations can be advantageous for both type II diabetic mothers and her adult daughters. The literature confirms that many "disease management practices are influenced by culturally based family role behaviors that are part of the family life" (Fisher et al., 1998, p. 604). So, family decisions regarding health care and health related behaviors are not always the responsibility of the person with the disease but are made by or in conjunction with other family members (Fisher, et al., 1998). Furthermore, medical visits are typically short, involving a plethora of information and medical jargon. Typically, physicians give their patients extensive mandates regarding diabetic care (i. e., "take this medication at this time, with or without food...make sure you don't take it with other meds."). The old cliché that "two heads are better than one" is a perfect rationale for practitioners to let daughters participate in the medical visit. Daughters can help mothers decipher complicated medical jargon, keep facts organized, and address pertinent questions for which they might need answers regarding the mothers' care. This simple step can be instrumental in the medical visit, helping both mothers and daughters glean a better understanding of diabetes and incorporating their joint knowledge into the mother's selfcare and daughter's health behavior management. This information can strengthen the

mother-daughter relationship, empowering both individuals and families with diabetes knowledge, as well as build trust between practitioners and families.

Physicians can further develop their relationship with families by using a family health chart to document information from family health histories and focus on how to decrease the prevalence of these diseases in individuals and families (Harrison et al., 2003). The usefulness of such tools could set the stage for providing intentional education for the patient and their family members.

Finally, specialist that are involved in diabetic health care (i.e., diabetic specialist, pharmacist, social service agencies, etc...) must understand that social support is dynamic and situational, and can be perceived as both positive and negative. Hence, they can help improve communication among family members by learning mothers' needs as well as educating family members in order to make support more meaningful for type II diabetic mothers, promote better diabetes management, and help prevent type II diabetes in other family members at risk.

### Implication for health communication researchers

Health communication researchers can use information from this research to legitimize the social value of communication research and education for African-American people generally, and African-American mother-daughter dyads, specifically. Furthermore, health communication scholars can work to develop, test, and implement innovative health education media and message strategies for families and motherdaughter dyads that address diabetic health knowledge. As well, scholars can evaluate the effectiveness of different diabetic health information, help tailor message strategies to meet the information needs of mother-daughter dyads, along with developing new communication programs and technologies to promote health education.

### Implications for the type II diabetic family units

Another promising insight from this dissertation is the importance of understanding other family members' perceptions of type II diabetes and engaging them in dialogue as a family unit. Inclusion of the whole family in diabetes education and screening programs has been found to enhance adherence to the dietary regimens (Fisher, Chesla, Bartz et al., 1998). An understanding of each family member's perceptions of the illness offers the whole family an opportunity to talk about and seek to learn more about the disease, thus improving the health of generations to come.

Not only is it important to understand familial perceptions of diabetes, it is also important for the family to support the affected family member's endeavors to perform required tasks to manage their disease. Too often the member of the family who is diabetic changes his/her behaviors while other family members observe but do not engage in similar behavior changes. *Meg*, [a diabetic mother] spoke of how frustrating it was that her husband did not understand that she had to eat at certain times during the day, had to make frequent trips to the bathroom, and had to test her blood sugar throughout the day. By encouraging the whole family to adopt healthy behavior changes, the mother's self-care management becomes not just a family activity but also a part of the normal day-to-day routine.

## Limitations of this Study

While the data from this study suggest a number of steps to improve self-care management among type II diabetic mothers and their non-diabetic adult daughter dyads, there are several limitations that must be acknowledged. First, the sample may have obscured the problematic relationships that exist in some mother-daughter dyads. To participate in this study, it was necessary for type II diabetic mothers and their nondiabetic adult daughters to have on-going relatively positive relationships. Therefore, the study likely overrepresented well-functioning dyads and did not provide ample opportunities to investigate the various relational nuances that exist between mothers and their adult daughters.

Next, I relied on *self-reports* to evaluate ways mothers and daughters talked with each other about type II diabetes. Self-reports shared by respondents do not always depict what happened, specifically as it relates to how mothers and/or daughters talked about their diabetic self-care or health behaviors (Lindlof, 1995). While the use of dyads helped to diminish some of the inconsistency in self-reports and increase validation, mothers' and daughters' perceptions of their self-care and health behaviors might not have been completely accurate.

Another limitation of this study was the short period of time in which the interviews transpired. Even though each mother-daughter dyad participated in five

interviews, the short time line made it difficult to evaluate how health messages shaped health behaviors over time. Therefore, it will be important to design further studies that take a more in-depth and long-term look at how talk shapes mother and daughter's health behaviors.

A unique aspect of my research that might be considered a limitation is that my ethnic background [I am an African-American woman and had a mother who was a type II diabetic] afforded me an insider's perspective, but also a potential lack of objectivity. Throughout the interviews I worked to keep multiple checks and balances in place and attempted to withhold personal information about my knowledge and experiences with type II diabetes; however, maintaining objectivity was at times difficult. Still, Lindlof (1995) affirms that similar cultural attributes can provide the researcher with a common experiential grounding. For instance, he notes if women study women and African Americans study African Americans it helps to "smooth the way initially, promote empathy, and leads to better field relations and quality of data" (p. 140).

This study used a modified grounded theory. Though this approach offered a number of advantages for the examination of type II diabetic mothers and their nondiabetic daughters, some limitations existed. Overall, GT has a natural applicability to analyzing the transference of health messages within mother-daughter dyads. The method's open-endedness and flexibility allows the researcher to examine an issue thoroughly rather than rely on previously collected data (Glaser et al., 1967). Most agree that the use of GT requires a major investment of the researcher's time and that the origination and organization of emergent themes can be a daunting task. For this reason, as themes emerged through data collection, coding and analysis, I made an effort not to generate unrelated hypotheses that require investigation which were beyond the scope of the study. I also set clear research parameters by using the HBM and SCT as clear, but flexible theoretical frameworks within my second interview questionnaire and keeping overall research questions straightforward and specific. These steps helped to minimize the investigation of tangential issues. Furthermore, I conducted pilot interviews and utilized the expertise of researchers experienced in grounded approaches to critique questions, offer feedback on emergent codes, categories and themes in an effort to minimize ambiguity and uncertainty about data. These steps helped me to create the types

of talk, which explained the data in terms of how the mothers and daughters communicated. To further strengthen the validity of the study, a procedure that solicits peer checks on the data analysis was used. Communication colleagues trained in grounded theory methodology reviewed my transcripts to check for accuracy in the coding process. Given that grounded theory necessitates careful verification of the transcripts, the process of peer checks transpired until I completed the interviews and analysis of all my data.

Given the intrinsic value of grounded theory, GT's validity is a concern because GT is dependent on the competence of the researcher, the adequacy of data collection, and the researcher's interpretation of the data collected (Strauss & Corbin, 1990). I had to consider, among other issues, the verification of findings provided by the study's research respondents for accurate data analysis. This is a limitation because if/when such care is not taken the validity of the study can be compromised.

As a grounded theorist, my effort to accurately describe reality was dependent on the richness of the information gathered and was not concerned with large, representative samples. This can be considered a limitation of the study. Because this study involved purposive sampling, had a small number of respondents, and included Type II diabetic African-American mothers and their non-diabetic adult daughters, these findings may not be generalizable to other populations.

Another issue that can be considered a limitation of grounded theory is the potential for the individual differences among type II diabetic mothers and non-diabetic daughters to dissolve once analytic procedures are set in motion. When using GT, distinct thoughts reflecting each respondent's exclusive experiences have to be reduced to general, abstract categories. These categories are typically limited to the important story line of all respondents. For this reason, what is characteristic of most of the mothers and daughters is what is articulated in the themes, while variant responses receive somewhat scant attention in the reporting of results. This problem is ironic given that GT researchers deliberately choose this approach for its promise to give voice to previously unheard, diverse experiences. I attempted to minimize this problem by narrating in detail the communication that took place in each mother-daughter dyad to assure that their

unique stories were not lost in the emergent themes; however, it was impossible to capture in totality their rich narratives (Richie et al., 2001).

Finally, this study conducted an in-depth examination into the lived experiences of type II diabetic mother, their non-diabetic adult daughters, and their unique culture of diabetic talk. There are other dynamics inside the social environment that either positively or negatively affect the health of mother-daughter dyads, their families and communities that this study was unable to explored. Understanding how different social determinants (e.g., socioeconomic status, housing, transportation, accessibility to health care resources, race, gender) influence mother-daughter communication and health behaviors would have been valuable.

## Future Directions

This study offer insights into the understudied area of health dialogues, specifically the transfer of health messages between type II diabetic mothers and nondiabetic adult daughter dyads. This study offers a variety of possibilities and serves as the impetus for expanding research in several directions.

Based on the extensive review of the literature, this study is the first of its kind to investigate the transmission of health messages between African-American type II diabetic mother and their non-diabetic adult daughters. For that reason, several different directions for future research would be beneficial. First, because mothers and daughters share a unique relationship that entails a "culture" of diabetic talk, it would be beneficial to administer a follow-up set of interviews with mothers and daughters to observe whether and how their levels of communication may have changed over time (e.g., the past year). A longitudinal study would allow the researcher to observe the ramifications of diabetic talk, prompts and/or motivation to talk and whether and how talk has been instrumental in shaping health behaviors. Second, it was evident, in some instances that talk shaped health behavior; however, it was difficult to account for behavior change or determine the process of behavior change. To best assess the extent to which this transpired, more in-depth observation should take place over a period long enough to determine whether specific factors related to talk do, in fact, shape health behaviors.

While the HBM and the SCT were helpful for understanding dyads' views on the seriousness of diabetes, their susceptibility, perceived barriers and benefits of

preventative behaviors, etc. neither theory adequately addresses how access to care, socioeconomic status, and other factors influence self care and/or health behaviors. For instance, research shows that socioeconomic positions of individuals and groups are defining characteristics of ones health and disease status (Lynch & Kaplan, 2000). However, the HBM and SCT do not account for these factors. Making connections between socioeconomic and cultural factors (e.g., racial and economic segregation) and diseases such as diabetes means that practitioners, health care providers, and health communication scholars must engage in dialogues and discussions that are not only respectful of diverse perspectives and priorities but also account for racial and health inequalities. For instance, if mothers or daughters struggle to gain access to needed services to manage diabetes or other chronic illnesses because of race or poverty, they may focus their energies on obtaining these services, but feel angered by the lack of engagement of practitioners or health care specialists. Or, if mothers have experienced racial tensions with their practitioners during a medical visit, what practitioners might perceive as an unwillingness to comply with dietary and physical activity recommendations might actually be due to a mother's feelings of powerlessness and/or mistrust of her practitioner. Such feelings can move mothers away from optimal self-care behaviors, leaving them feeling anxious, ignored and frustrated (Schultz, et al., 2005).

Social determinants of health like poor medical treatment due to racism and discrimination are important on an inter-individual level, but they are only part of a larger issue. Other factors like inadequate access to health insurance, or income inequality in work environments are also linked to broader health outcomes, particularly among minority populations, and for this reason must be considered in future research that seeks to understand health behavior. While the interview questionnaire for this study addressed HBM and SCT, it did not ask dyads to relate sociocultural and economic determinants, like lack of health insurance or availability of decent paying employment, to health behaviors. So while asking mothers questions like, "do you believe diabetes is serious, how serious do you think it is, or do you think there are benefits to not becoming diabetic" or, asking daughters, "given that your mother has diabetes, do you ever consider that you could become diabetic or do you believe there are actions you could take to prevent becoming diabetic," are important questions, such questions do not address larger

social inequalities. Therefore, a more thorough examination of these issues in future research will not only advance the development of a more robust communication theory but will also offer a clearer understanding of self-care management and health behaviors among type II diabetic mothers and their non-diabetic adult daughters.

In addition to exploring social determinants of health, it will be important for future research to examine the relationship between mothers' conversations about their anxieties, fears, frustrations and guilt about living with their illness with depression. While most mothers did not directly address issues of depression, most talked about various emotional concerns they believed stemmed from being diabetic. Research that investigates depression among diabetic patients has been insufficient; however, there is evidence that depression is a common mental health issue among people with diabetes and other chronic diseases (deGroot, Auslander et al., 2003; Lustman, Griffith, Gavard & Clouse, 1992). Thus it would be beneficial to do more comparison studies among diabetic mothers who are treated for depression and those who are not to understand how they talk with their adult daughters about their illness and how they manage their self-care.

Because daughters functioned as caregivers to their mothers, remaining vigilant to check on mothers, talk with them on the phone and engage in numerous conversations, it would be beneficial to see how adult daughters whose mothers are living with advanced complications (i. e., dialysis, amputations, and renal failure) associated with type II diabetes talk with their mothers about the illness. It would also be interesting to investigate the differences in the quantity/quality of the communication depending on the severity of diabetic complications. Advanced complications of this nature might motivate daughters to take a more active role in caregiving for their mothers. For instance, mothers might delegate tasks to their daughters such as picking up medications, making phone calls to practitioners on their behalf, or participating in clinic visits. Providing extensive care might heighten daughters' frustration, even intensifying their concerns as caregivers.

Also, some daughters in this study were not ready to change their own health behavior. One daughter informed me that she would, "cross that bridge when she came to it". Therefore, investigations need to examine daughters' resistance to change their health behavior despite diabetes prevalence in the family and its genetic propensity to become a disease they must manage some day.

Both mothers and daughters in this study talked about the importance of sharing and knowing their family health history. Thus, research is needed to explore the impact of type II diabetes experience for African-American women and their family members regarding the family history of the illness. Exploring health histories can encourage families to create a visual tool such as a generational health charts and talk more candidly about the implications of diabetes. Epidemiologic studies examining the association between type II diabetes and family history consistently find that a positive family history among first-degree relatives confers an increased risk of type II diabetes and that the risk is greater when both parents are affected (Harrison et al., 2003). Currently, data on the effect of family history information on prevention, screening, and treatment behavior are limited, and more research on the utility of family health history is needed. Because dyadic studies do not account for the influence of a chronic illness on other family members (Mancini & Blieszner, 1992) a more in-depth behavioral study of the larger family group should provide a more representative picture of the health behaviors, the nature of health and illness, and its impact within the family unit.

One of the biggest criticisms leveled at researchers engaging primarily in health communication work is that the majority of studies have been conducted in a formal health care or medical setting where investigations are restricted to the relationship between physician and patient. However, most Americans spend the majority of their time talking about health-related issues and learning health-related information in nonmedical settings. Therefore researchers should systematically examine health-related interactions between family members in a naturalistic, home environment (Drummond, 2005). For instance, Blacks are more likely to acquire knowledge on different health topics when it is presented in settings in which they dialogue comfortably (Airhihubuwa, 1992). Researchers must understand that there are other environments besides formal health care settings in which talk transpires and encourage talk in these environments.

Not only are culturally-driven interventions targeting diabetic screening, diabetic prevention, and diabetic education tailored to the social and cultural context of African-American women essential (Rajaram et al., 1998), interventions replicated among other ethnic groups such as Native and Hispanic-American mother-daughter dyads are necessary. Like many African Americans these groups share a high prevalence of type II

diabetes and similar family values

(<u>http://diabetes.niddk.nih.gov/dm/pubs/statistics/index.htm</u>, 2004). Research can be used to help different ethnic populations, particularly mothers and adult daughters, talk about other chronic diseases.

Lastly, additional research findings can be used to educate certified diabetes educators, health professionals, and health communication specialists concerning how to use a collaborative approach that is culturally and linguistically appropriate to promote healthy outcomes for mothers living with diabetes and their families. A partnership of this kind could yield new and creative teaching material that addresses all the nuances of the illness (i. e., menus, lifestyle recommendations) and therefore empowers the patient to act proactively toward managing this chronic disease. Also, health care professionals can develop modules that look at different types of talk and incorporate the beliefs and values of the African-American culture to enhance the process of changing unhealthy lifestyle behaviors by developing program tracks which meet the diversity of African-American women's needs (Fox et al., 1980).

## Appendix A Consent to Participate in a Research Study

"Health Messages among type II diabetic African American mothers and their nondiabetic adult daughters."

## WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to take part in a research study about type II diabetes among African American mothers and their non-diabetic adult daughters in African American families. You are being invited to participate in this study because you are an African American mother or daughter. If you take part in this study you will be one of 20 women. WHO IS DOING THE STUDY?

The person in charge of this study is Angela F. Cooke-Jackson of the Department of Communication at the University of Kentucky. She is being guided in her research by Dr. Philip Palmgreen and Dr. Nancy Schoenberg. There will be other people on her research assisting her with the transcription and coding of data at various times during this process.

## WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to understand if/how African American mothers talk with their adult non-diabetic daughters about their health behavior regarding type II diabetes, and if/how African American non-diabetic daughters talk with their diabetic mothers about their self-care management of type II diabetes.

## WHERE IS THIS STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The research procedures will be conducted in your home or any mutually agreeable location where you feel it would be most convenient and comfortable. Your participation in this study will include 2 individual interviews and one interview with your mother or daughter present. This means a total of 3 interviews. Each interview will be 1-2 hours in length depending on the dialogue that transpires between you and the researcher.

## WHAT WILL I BE ASKED TO DO?

If you wish to participate in this study you will be asked to sign and date this consent form. You will be asked to answer questions about how you talk with your daughter or mother about type II diabetes self-care and health behavior. These questions will be tailored for both the mother and daughter to understand the differences in communication about these issues. All of the interviews will be tape recorded so the researcher can transcribe, code and analyze each one. This information will be confidential.

## ARE THERE REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY?

The only reason you should not take part in this study are if you are a non-diabetic mother or a type II diabetic daughter or are under the age of 55 for mothers and under the age of 20 for daughters.

## WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no foreseeable risks or discomforts associated with this research.

## WILL I BENEFIT FROM TAKING PART IN THIS STUDY?

Yes there are two benefits of participating in this study. First, I will be offered a participant incentive of \$25 to be provided upon completion of my participation in the study. Also, I will receive an informational packet about type II diabetes.

## IF I DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in this study you can inform the researcher of that at anytime during the study. You will still receive the informational packet about type II diabetes for your time.

## WHAT WILL IT COST ME TO PARTICIPANT?

There are no costs associated with taking part in this study, however this study does not replace regular medical care or take the place of a medical visit with my physician.

# WILL I RECEIVE ANY PAYMENT OR REWARD FOR TAKING PART IN THE STUDY?

You will receive a \$25 incentive to be provided upon completion of all three interviews. You will also receive a informational packet about type II diabetes.

## WHO WILL SEE THE INFORMATION I GIVE?

Your information will be stored in a locked cabinet. Every effort will be made to prevent anyone who is not involved in the research from knowing that you gave this information, or what the information is.

Your response will not be shared with your physician or anyone who works in the medical environment.

There are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as the University of Kentucky.

## CAN MY TAKING PART IN THIS STUDY END EARLY?

If you decide to take part in the study you still have the right to later decide at any time that you no longer want to continue. No one will think badly of you or treat you differently if you decide not to take part in this study.

The individual conducting the study may need to take you off of the study. They may do this if you are not able to follow the directions they give you, if they find that you being in the study is more risk then benefit to you, or if the agency sponsoring the researcher decides to stop the study early for a variety of scientific reasons.

## WHAT IF I HAVE QUESTIONS?

If you have any questions about the study, you can contact Angela F. Cooke-Jackson, at: 216 Grehan Building College of Communication and Information Studies University of Kentucky Lexington, KY 40506-0042 Email: Angela.Cooke-Jackson@eku.edu Phone: (505) 453-4158 Or you may also contact Mrs. Cooke-Jackson's research advisor, Dr. Philip Palmgreen or Dr. Nancy Schoenberg, at: Dr. Philip Palmgreen 246 Grehan Building College of Communication and Information Studies Lexington, KY 40506-0042 Email: pcpalm1@pop.uky.edu Phone: 859-257-7801 Dr. Nancy E. Schoenberg Department of Behavioral Science 125 College of Medicine Office Building Lexington, KY 40506-0086 Email: <u>nesch@pop.uky.edu</u> Phone: 859-323-8175

If you have any questions about your rights as a research subject you can call the Office of Research Integrity at 859-257-3138. You are to keep a copy of this consent form for your records.

## WHAT ELSE DO I NEED TO KNOW?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

Signature of person agreeing to take part in the study

Printed name of person agreeing to take part in the study

<u>Angela F. Cooke-Jackson</u> Signature of person obtaining informed consent

Date

Date

## Appendix B

## **INTERESTED IN BEING INTERVIEWED**

I am a doctoral student in the College of Communication at the University of Kentucky. I am completing research for my graduate school degree. I would appreciate your willingness to participant in some interviews.

I am interested in understanding how African American families, particularly African American mothers and their adult daughters talk about health.

If you are a part of an African American family in which the mother has <u>type II diabetes</u> and the adult daughter is <u>non-diabetic</u> you would be a perfect participant. Each participant will be paid \$25.00 upon completion of all interviews and receive an information packet about Type II diabetes.

## **PARTICIPANT REQUIREMENTS:**

- Mother must be age 55 or older and have been diagnosed with Type II diabetes for at least 3 years.
- Daughter must be age 20 or older and Non-diabetic. This includes never having had gestational diabetes.
- Live in the same city and visit each other regularly.
- Each participant must be willing to complete 2 individual interviews and one interview with your mother/daughter.

All information would be confidential. Interviews will last 1 to 2 hours and could be conducted in your home or any place of convenience at a time suitable for you.

# Call: Angela F. Cooke-Jackson, University of Kentucky 245-8485

Mrs. Angela F. Cooke-Jackson 9180 Coors Blvd. NW #3003 Albuquerque, NM 87120 505-453-5148

Greetings:

Thank you for taking the time to read this information. My husband and I recently relocated to Albuquerque, New Mexico and are gradually become comfortable in this beautiful Land of Enchantment.

I am completing my Ph. D. in the field of Health Communication from the University of Kentucky. My research objective is to understand if and how type II diabetic African-American mothers talk with their non-diabetic older daughters about type II diabetes. A major aspect of my research entails making contact with and interviewing 10 African-American mother-daughter pairs to understand how they communication about the implications of type II diabetes. By conducting individual interviews as well as one with the mother-daughter pair, I hope to hear their stories and reveal how health messages are passed from one generation to another among mothers and their older daughters. This information will undoubtedly increase knowledge about how we as African Americans talk about our health with each other and how type II diabetes influences black women. Ultimately, this research will be used to develop interventions that encourage communication among African-American families and between mothers and daughters about this pandemic disease.

The duration of the interviews will be anywhere from 2 to 3 hours in length and ask a variety of questions about the mother's diabetic self-care and the daughter's health behavior. Each individual will receive \$25 for their participation and an information packet when all interviews have been completed.

If you or your organization can help me in this process by posting the enclosed fliers or passing this information onto someone who might fit the criteria it would be greatly appreciated. If you know of anyone who might fit the criteria please contact me at 505-453-5148 or pass my phone number on to them.

Thank you in advance for your help.

Angela F. Cooke-Jackson SREB Doctoral Scholar Lyman T. Johnson Scholar

## Appendix C

## PRELIMINARY SCREENER FOR BOTH MOTHERS AND DAUGHTERS

- 1. How often do you see mother/daughter?
- 2. How would you describe your relationship?
- 3. Do you two talk about health issues with each other?

## PRELIMINARY SCREENER FOR MOTHERS

- 1. Do you have any daughters?
- 2. How many?
- 3. What are their ages?
- 4. How often do you talk with your daughters about your diabetic related issues?
- 5. How often do you see your daughter X, your daughter Y or your daughter Z?
- 6. Where does daughter X live, what about daughter Y or Z?

Would you say that you and daughter X talks about health issues? If so, how frequently? (Or) Of the daughters you mentioned who over the age of 20 talks with you the most about diabetic-health issues?

## **MOTHER-** Interview I

## Overall Rationale:

Establishment of rapport and compilation of background information.

## Components:

(1) Completion of informed consent and background information.

- a. Please tell me a little bit about yourself.
- b. Please tell me a little bit about your family.

Thank you for sharing that information. Is there anything else you would like to add? Now I would like to understand more about your health. As you answer the following questions please feel comfortable to share any details that you believe helpful.

- c. Please tell me how you define health, for example what does it mean to you to be healthy... how do you think about being healthy with you own health care behavior?
- d. Please tell me a little bit about your health (how has your health been over your lifespan)?
- e. What about your present health status, how would you describe it?
- f. Do you presently have any other health conditions or illnesses? What are they and how long have you had these illnesses?
- g. Where would you say you get your information about health?

I'd like to ask you some questions about your experience of living with diabetes. Again, please feel comfortable to share any details that you believe helpful.

- 1. When were you first diagnosed with type II diabetes?
- 2. How did you feel when you were told you were diabetic?
- 3. What do you think caused your diabetes?
- 4. What kind of information did you receive when you were told you were diabetic?
- 5. If this information was in the form of education sessions
  - a.) When was your last education session?
  - b.) What specific information from that session or other trainings helped you manage your diabetes? If none then please state why.

- 6. Do you feel that your other health conditions affect your diabetes? (For those who have other health complications)
- 7. Do you think there are things you could have done to prevent having type II diabetes? What could you have done?
- 8. What do you do to manage or control your diabetes?

I'd like to talk a little about your family and your daughter and their knowledge and understanding of diabetes.

- 9. Do other members of your family have type II diabetes? If so who in your family presently has type II diabetes?
- 10. Do you share information with your family to help them deal with your diabetes?
- 11. Do you ever talk with (insert name of daughter) about diabetes?
  - a.) What do you talk about?
  - b.) What does she say to you?
  - c.) Does what she says make a difference with you? (If so how If not why not?)
  - d.) Do you think there are things that (insert name of daughter) could do to prevent having type II diabetes? What can she do?
  - e.) What do you see your daughter doing that might lead you to believe that she is concerned about her health?
  - f.) What do you see your daughter doing that would lead you to believe that she is not concerned about her health?
  - g.) From your observation, is she concerned about your diabetes?

h.) Does she try to get you to follow your doctor's orders (recommendations)?There are just a few more questions I would like to ask you before we end this session.These questions regard different demographic information.

Demographic questions:

1. Are you currently married, separated, divorced, widowed, or have you never been married?

a. Married \_\_\_\_\_ b. separated \_\_\_\_\_ c. divorced \_\_\_\_\_

d.	widowed	e. never married	f. ref
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- 2. How many children have you ever had or adopted? Please count all (including any you had from a previous marriage).
- 3. What is the highest grade that you finished in school?

## College level 00 01 02 03 04 05 06 07 08 09 10 11 12 13 14 15 16 17+

- 4. How old were you on your last birthday?
- 5. Are you currently employed? Yes/No
- 6. If yes are you employed \_\_\_\_\_full-time or \_\_\_\_\_part-time
- 7. If so, what is your occupation?
- 8. How far does your daughter live from you? (*about how long would it take for her to come visit you on any given day*)
- 9. Where would you put your household's income per year (show card)?

Under \$5,000	\$20,001-30,000	\$50,001 and over
	\$5,001-10,000	\$30,001-40,000
	\$10,001-20,000	\$40,001-50,000

Thank you for your time, Are there any questions or comment that you would like to make before we close? Next time we meet I would like to talk a bit about your health, how you feel about your

## **DAUGHTER-Interview I**

## Overall Rationale:

Establishment of rapport and compilation of background information.

## Components:

Completion of informed consent and background information

- a. Please tell me a little bit about yourself.
- b. Please tell me a little bit about your family.

Thank you for sharing that information. Is there anything else you would like to add? Now I would like to understand more about your health. As you answer the following questions please feel comfortable to share any details that you believe helpful.

- a. Please tell me how you define health, for example what does it mean to you to be healthy... how do you think about being healthy with you own health care behavior?
- b. Please tell me a little bit about your health (how has your health been over your lifespan)?
- c. What about your present health status, how would you describe it?
- d. Do you presently have any health conditions or illnesses?
- e. What are they and how long have you had these illnesses?
- f. Where would you say you get your information about health?

*Next, I'd like to ask you some questions about your experiences with a mother with diabetes. Please feel comfortable to share any details that you believe helpful.* 

- 1. When did you first learn that your mother had type II diabetes? How did you feel when you found out about her diagnosis?
- 2. At that time (prior to your mother's diagnosis) did you know what diabetes was?
- 3. Do you remember asking your mother any questions about her diabetes? If so, what do your remember asking?
- 4. Is there anything that you presently do with or say to your mother to help her manage (live with) her diabetes?

- 5. Are there things you see your mother doing from day to day to manage her diabetes?
- 6. Are there things you see your mother doing from day to day that hinder the management of her diabetes?
- 7. How do you think your mother would describe her experiences of living with diabetes?
- 8. Do you believe that you could become diabetes yourself?
- 9. Do you try to prevent getting diabetes?
- 10. Do you ever talk with your mother about diabetes?
  - a. If so, how would you describe the discussions?
  - b. What do you say to her?
  - c. Do these discussions, from your impression, make a difference with your mother? If so, how? If not, why not?
- 11. What things do you observe your mother doing that might lead you to believe that she is concerned about her diabetes control?
- 12. What things do you observe your mother doing that would lead you to believe that she is not concerned about controlling her diabetes?

There are just a few more questions I would like to ask you before we end this session. These questions regard different demographic information. First...

## **Demographic questions:**

13. Are you currently married, separated, divorced widowed, or have you never been

a. Married	b. separated	c. divorced
d. widowed	e. never married	f. ref

- 14. How many children have you ever had or adopted? Please count all (including any you had from a previous marriage).
- 15. What is the highest grade that you finished in school?

### College level

00 01 02 03 04 05 06 07 08 09 10 11 12 13 14 15 16 17+

16. How old were you on your last birthday?

17. Are you currently employed? \_\_\_\_Yes or \_\_\_\_No

18. If so are you \_\_\_\_Full-time or \_\_\_\_\_ Part-time

19. If so what is your occupation?

20. Do you live with your mother or in a different location?

21. Where would you put household's income per year (show card)?

Under \$5,000	\$20,001-30,000	\$50,001 and over
	\$5,001-10,000	\$30,001-40,000
	\$10,001-20,000	\$40,001-50,000

Thank you for your time, do you have any questions or comment that you would like to make before I close? Next time we meet I would like to talk a bit about your health and how you manage your health. Do you have any questions or final information you would like to share?

## Interview II

Questions for Mother - Interview II	Questions for Daughter - Interview II
Do you believe you could suffer from any complications now that you have diabetes? If so what? How do you feel about that	What do you think about diabetes? Do you think it is serious? How serious do you think diabetes is?
possibility?	How serious would it be to become diabetic? What makes you say that?
What do you think about diabetes? Do you think it is serious? How serious do you think diabetes is?	What types of things does your mother talk about that would lead you to believe that diabetes could be serious?
Do you talk with your daughter about what she thinks of diabetes? What kind of things do you share with her?	Given that your mother has diabetes, do you ever consider that you could become diabetic?
Do you think there are any benefits to not becoming diabetic? If so what?	Do you talk with your mother about problems she could face with her diabetes? How do you talk with her about this?
Do you talk with your daughter about the benefits of not becoming diabetic? If so what do you say to her?	Do you talk with your mother about other problems she could encounter since she has diabetes? If so, what do you say to her?
Are there things that make it difficult to talk with your daughter about her health?	Would you say there are actions that you could or have taken to prevent becoming diabetic?
Are there things that make it difficult for you to do that which makes it necessary for you to control your diabetes?	Are there things that encourage you to stay healthy (non-diabetic)?
Who, if anyone, would you say plays a part in how you deal with your diabetes?	Do you ever talk with your mother about the many things that would help her to maintain good habits?
Are there things that you see or hear that play a part in how you live with your diabetes?	Do you talk with your mother about her diabetes? If so, does anything make it difficult to talk with you mother about her diabetes?
How would you describe your diabetic routinewhat does it involve?	What things make it difficult for you to do the kind of things that might prevent diabetes?
Do you believe you are able to follow your diabetic routine?	Does anyone talk to you about taking care of yourself (health) to prevent becoming diabetic? If so, who? Does that help you?
What things prevent you from following your diabetic routine?	What things do you see or hear that play a part in how you prevent being diagnosed with diabetes?
Are there things that encourage you to follow your doctor's recommendations? Is there anything else?	Does you mother tell you that she believes you can prevent becoming diabetic? Does that help you?
Does your daughter tell you that she believes your can manage you diabetes regimen?	Do you see yourself as capable of practicing healthy behaviors? What things encourage you to practice healthy behaviors? What things prevent you from following healthy behaviors so you can prevent becoming diabetic?
Do you believe your health behavior has affected how your daughter deals with her attitudes about type II diabetes?	What things does your mother do or say to you that model positive behaviors that encourage you to practice healthy lifestyle behaviors?

## **Interview III**

## Mother and Daughter dyad interview

Well it is great to have you both together in this final interview. Within the next hour or two I would like to ask you both a few questions and get your insight on how you talk with each other about health behaviors. Please feel comfortable to share anything that you believe will be helpful and talk freely as well. If there is anything that you believe would add to the interview don't hesitant to share that information.

- 1. Talk a little bit about how you interact with each other, especially about health issues.
- 2. Do you two talk about diabetic-related health issues?
- 3. What do you talk about when you talk about diabetic related health issues? (Or, directed at daughters) what do you talk about when you talk about behaviors to prevent becoming diabetic?
- 4. Share with me times, events or situations that take place in which you talk about diabetes related issues.
  - Is it helpful for you (insert name of mother)?
  - What about you (insert name of daughter) is it helpful for you?
- 5. In my talks with other mothers and daughters they've told me that (e.g., they never talk about diabetes with each other/they talk about the diabetes with each other). Is that true of you two? How does talking with each other or not talking with each other make you both feel about this diabetes?

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