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Relational-Cultural Perspectives of African American Women with

Diabetes and Maintaining Multiple Roles

A Dissertation Presented

by

Ayesha Ali

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
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RELATIONAL-CULTURAL PERSPECTIVES OF AFRICAN AMERICAN WOMEN

WITH DIABETES AND MAINTAINING MULTIPLE ROLES

A Dissertation Presented

By

AYESHA ALI

Approved as to style and content by:

_____
Cynthia S. Jacelon, Chair

_____
Genevieve E. Chandler, Member

_____
Alexandrina Deschamps, Member

_____
Stephen Cavanagh, Dean
College of Nursing

DEDICATION

This is dedicated to my mother and my always supportive husband.

ABSTRACT

RELATIONAL-CULTURAL PERSPECTIVES OF AFRICAN AMERICAN WOMEN

WITH DIABETES AND MAINTAINING MULTIPLE ROLES

SEPTEMBER 2017

AYESHA ALI, B.S. UNIVERSITY OF MASSACHUSETTS AMHERST

M.S. UNIVERSITY OF MASSACHUSETTS AMHERST

Ph.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Cynthia S. Jacelon

The growth of diabetes in the United States is viewed by some as epidemic with a particular concern as related to African American women. African American women experience diabetes disproportionately to other groups with higher risks of complications and premature death. Historically, they have led all women in labor force participation and maintained roles within and outside the home. The purpose of this study was to gain understanding and meaning of the lived experience of African American women with diabetes and maintaining multiple roles using sensitizing concepts of Relational-Cultural theory. Relational-Cultural theory was described as related to use with women and the incorporation of the influence of culture. The literature review used proxy terms for the concepts of connection, disconnection, mutuality and power over related to limited use of theory concepts in the literature. The review yielded few research studies. Interpretive phenomenology following Ricoeur in philosophy and methodology was used. Three composites of the day-to-day experiences of African American women with diabetes and maintaining multiple roles were provided. The concept of connections diverged into two types of connections with multiple themes. Mutuality themes were not a matter of age but

what each brings to the other and closeness developed over time. Themes that emerged related to concepts of disconnections and power over were the will to keep negativity out, disappointment in others, shackles on, shackles off, financial stress makes life difficult. Themes of informational support in the neighborhoods, trust is necessary and need for African American nurses related to the role of nurses with enhancing connections and mutuality. Further nursing research is needed related to use of Relational-Cultural theory and African American women with diabetes and maintaining multiple roles to increase a contextual understanding of their lived experience. Incorporation of Relational-Cultural theory into practice and nursing education was also suggested based on two decades of neuroscience evidence about the importance of relationships.

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CHAPTER 1

INTRODUCTION

African American women experience diabetes disproportionately to other groups, excluding Native Americans. Diabetes affects nearly 12% of all black women ages 20 years and older. African American women are more likely to be diagnosed with diabetes and are more likely to experience complications of the disease than non-Hispanic white women when adjusted for age. It is estimated that nearly 50% of African American females born in the year 2000 and beyond will likely develop Type 2 diabetes in their lifetime (Gregg, E.W., Zhuo, X. & Cheng, Y. J., Albright, A.L., Narayan, K.M.V. & Thompson, T.J. (2014). Yet despite the staggering diabetic statistics, African American women remain involved in formal and informal roles over the course of their lifespan (U.S. Department of Labor Statistics, 2012; Jones-DeWeever & Lewis, 2014).

African American women have historically maintained roles within and outside the home. Jones-DeWeever & Lewis (2014) suggests that African American women have led all women in labor force participation since their beginning experience in the United States, including when they have been mothers of small children. Labor force statistics of African American women related to family structure are important contextual characteristics of this ethnic group. Forty-five percent of Black families in 2011 were maintained without a spouse by women, compared to 25% of Hispanic families, 16% of White families and 12% of Asian families (U.S. Department of Labor, 2012).

Additionally, the Department of Labor Statistics' definition of children within a household is "children are 'own' children and include sons, daughters, stepchildren and adopted children. Not included are nieces, nephews, grandchildren, and other related and

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unrelated children" (U.S. Department of Labor, 2012, p.40). The narrow definition of 'own' children, and in the larger sense of family, may exclude the cultural and historical ties of the African American experience and meaning of children and family. The historical backdrop within the experiences and varying roles of African American women includes community and church "family", extended and fictive kin (Pierre-Louis, Akoh, White & Pharris, 2011; Carlton-LaNey, Hamilton, Ruiz & Alexander, 2001; Goldstein &Reiboldt, 2004). Statistics and research such as indicated above and the complexity of the diabetes illness experience suggest the need for exploration of multiple influencing factors with this population. Physiological aspects of diabetes along with a growing acknowledgement of psychosocial perspectives of diabetes are equally important to understanding the diabetic illness experience as they relate to diabetes prevention, treatment and successful management (American Diabetes Association, 2014; Gonder-Frederick, Cox & Ritterband, 2002).

The Institute of Medicine (2001) describes the importance of understanding health and health behavior in the context of social, cultural and other ties. The report suggests that attention to these ties is more likely to result in improved health and quality of life for individuals. Current literature has described social support and varied roles of African American women with diabetes. However, relational-cultural perspectives of these women with diabetes who maintain multiple roles have not been described. Two broad concepts from relational-cultural theory are useful to include. The first concept relates that women view, experience and develop differently from men and that sense of self in women is through connections with others. Reid-Cunningham, Synder-Grant, Stein, Tyson& Halen (1999) suggest that relational-cultural Theory "provides a framework for

understanding the ways in which women respond to and continue to develop with the experience of chronic illness" (p.2). The second concept is that relational experiences are shaped and influenced by an individual's ethnic, social and historical context. A greater understanding of context of the lived experience of African American women may provide insight to inform practice and further research toward improving the health and well-being of these women.

Purpose

The purpose of this study was to gain understanding and meaning of the lived experience of African American women with diabetes and maintaining multiple roles through a relational- cultural perspective. A phenomenological focus was meant to bring light to the experiences of these women whose voices have historically been limited in research.

Rationale for Research Approach

Qualitative methods, in general, may uniquely contribute to new ways of understanding the psychosocial illness experiences of African American women with diabetes and maintaining multiple roles. The essence of illness experiences is based on personal meaning of events surrounding the illness and suggests that personal meaning most often is influenced by the day-to-day convergence of beliefs, norms and interests (Allen & Jensen, 1990; Kleinman, 1981). Additionally, illness experiences are context-dependent, diverse and may not initially be understandable; therefore, they are well-suited for Hermeneutic phenomenology research, where "meanings may not be immediately understandable and require interpretive efforts" (Allen & Jensen, 1990, p. 241). An interpretive phenomenological research design was used in this study.

This type of qualitative phenomenological method supported the purpose of exploring the lived experience of African American women with diabetes and maintaining multiple roles through a relational-cultural lens. This approach was meant to find meaning and significance of the phenomena through the interpreted narratives of the participants. The researcher, in this type of phenomenology, uses frameworks, such as relational-cultural theory, to explore the relationships and meanings that knowledge and context may share (Penner & McClement, 2008; Lopez & Willis, 2004).

Interview was the mode of inquiry, one-on-one, face to face interactions between each individual participant and the researcher. Interviews took place at primarily at the homes of the participants; other places chosen by participants were churches, small rooms at local colleges and a library.

Research Questions

Specific inquiry questions incorporating theory concepts included:

1.   What are the day to day experiences of African American women with diabetes?

2.   How does maintaining multiple roles impact the day to day experiences of African American women with diabetes?

3.   How do relationships experienced as mutually connected, empathetic and empowering with feelings of zest, worth, productivity, clarity and a desire for more influence African American women with diabetes and multiple roles?

4.   How do relationships experienced as mutually disconnected, lacking empathy and empowerment influence African American women with diabetes and multiple roles?

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5. How do relationships experienced as mutually respectful with the capacity to impact and open to change by the other influence African American women with diabetes and multiple roles?

6. How do relationships, experienced as hierarchical, fostering a sense of powerlessness, influence African American women with diabetes and multiple roles?

7. What role might nurses play in enhancing connections and mutuality experiences of African American women with diabetes and maintaining multiple roles?

Definitions Relevant to the Study

The following terms were used in the study. Some concepts were direct definitions from the original founders of Relational-Cultural theory while one concept, power over, was adapted for the purpose of this study.

- Connection was defined as "an interaction between two or more people that is mutually empathetic and mutually empowering. It involves emotional accessibility and leads to the 'five good things' (zest, worth, productivity, clarity and desire for more connection)" (Jordan, 2010, p.102)

- Disconnection was defined as an interaction in a relationship "where mutual empathy and mutual empowerment do not occur; usually involves disappointment, a sense of being misunderstood … and a sense of impasse" (Jordan, 2010, p. 103)

- Mutuality was defined as mutual growth "toward an increased capacity for respect, having an impact on the other and being open to being changed by the other" (Jordan, 2010, p.105). It is a shared activity where all involved are participating as fully as possible, noting that, mutuality does not mean sameness, equality or reciprocity

(Miller & Stiver, 1997). Engagement in creating mutual, interactional growth, learning and empowerment is occurring in the relationship (Coll, Cook-Nobles & Surrey, 1995).

- Power Over was defined as a hierarchical relationship where a dominant individual, group or situation engenders power over others and does not foster mutually empowering relationships (Jordan, 2010). "If someone has power over another or is perceived in that way, true mutuality becomes threatened. This concept is frequently used in a societal context; however, it is adapted for use in the context of family (including extended family and fictive kin), community and religious relationships for the purposes of this study.

- Relational images are internal pictures of self in relationships developed overtime. This historical reference creates a set of beliefs about one's understanding of relationships, in general. Relational images can be positive or negative and can influence expectations of all relationships with which one is involved and one's sense of worth (Jordan, 2010).

- Formal roles were defined as responsibilities external to home or family.

- Informal roles were defined as responsibilities within the home and/or with family, noting that meaning of family, from an African American cultural perspective, may be broadly inclusive of extended, church and fictive kin.

  The term social support served as proxy to the theoretical concepts in the proposed study related to limited use of the proposed study concepts in research literature.

- Social support was defined as the functional content of relationships that are categorized into four types of supportive behaviors (Heany & Israel, 2008):
1. Emotional support – providing empathy, love, trust and caring

2. Instrumental support - providing direct tangible aid and services to assist someone

3. Informational support – providing advice, suggestions and information

4. Appraisal support – providing constructive feedback and affirmation

In summary, when contrasting the two sets of theoretical concepts, the following differences were evident: Relational-Cultural constructs are relational qualities and are bi-directional (Frey, 2013). Social support concepts are functional qualities and, based on the definition, can be one-directional. Despite the differences, social support served as proxy for the relational-cultural concepts used in the study; however, as described, the two sets of concepts are uniquely different from each other, noting that relational-cultural concepts are mutual with care moving in both directions. Roles were used from 2 perspectives: formal and informal; with informal roles incorporating a broader view for African American women.

Conceptual Framework

Relational-Cultural Theory is a psychological developmental theory which suggests that relationships are the lynchpin of human experience across the lifespan. This theory contrasts with the dominant psychological developmental thought and practice which depicts an evolving process of separation from relationships and promotes the development of a separate self, with the assumption that this leads to the healthy development of individuals (Jordan, 1999). The values of separation from early relationships developing an independent self, competitive individualism and self-sufficiency are hallmarks of traditional models of psychological development. Jordan (2010) describes these notions as "the myth of the separate self" and suggests that this myth of self and independence obscures the inevitable dependence and

interconnectedness of human beings" (p.2-3).

Alternatively, Relational-Cultural Theory proposes that interacting in mutually empathic and mutually empowering relationships is growth-fostering for all human beings throughout the lifespan (Jordan, 1999; Jordan 2010). People develop more fully through meaningful connections with others, thereby suggesting that relationships are the cornerstone of growth rather than autonomy (Miller, 1986b). Aspects of self-development, such as creativity, autonomy and assertion, emerge in the context of relationship and relational competence (Jordan, Kaplan, Miller, Stiver & Surrey, 1991). Over time, people become relationally more complex rather than increasingly individuated and autonomous; this phenomenon is described as differentiation. Duffey & Somody (2011) conclude that a contextual and relational lens to understanding human development is promoted by Relational-Cultural Theory.

Additionally, relationships are embedded in culture. Understanding culture and cultural perspectives is necessary to understanding individuals within a culture (Jordan, 2010). Placing culture beside relational theory recognizes that culture informs connections/relational experiences (Jordan & Walker, 2004). The cultural component of the theory addresses varying experiences and meanings of relationships across cultures.

Although Relational-Cultural Theory has primarily been used in social science disciplines related to patient-provider relationships, Reid-Cunningham, Synder-Grant, Stein, Tyson & Halen (1999) suggest that the theory offers a framework for "understanding the ways in which women respond to, and continue to develop with, the experience of chronic illness"(p. 2). They also suggest that at the center of one's ability to live successfully with a chronic illness is the quality of relationships. Concepts from the

theory were used in the study as defined in the previous section. Key concepts used in describing the promotion or deterrence of human flourishing were connections, disconnections, mutuality and power over.

Methodology Overview

The methodology of this study was congruent with the philosophical underpinning of interpretive phenomenology in the Ricoeur tradition. The interpretive method recognizes that individuals are inextricably situated in their world and the knowledge of both participants and researcher are inextricable the research experience. Relational-Cultural theory emphasizes the importance of human connection to the development of health and well-being or one's ability to live successfully with chronic illness (Morton & Konrad, 2009; Reid-Cunningham et al., 1999). Therefore, bracketing is not required in interpretive phenomenological research and in deciphering meaning and understanding of the phenomenon of interest.

The Ricoeur tradition added essential components to the understanding of the methodology. Discourse takes on another meaning once it appears as text and distances "itself" from the original speech; this describes textual plurality "(that preunderstandings lead interpreters to interpret the same text faithfully yet differently) and multiplicity (that texts have many meanings)" (Geanellos, 2000, p.113). Distanciation has four forms: 1) speech is set once it is written and the meaning becomes more important than the speech; 2) the text becomes autonomous and is open to many readings and interpretations; 3) the text is freed and can "open up" to context such as socio-political, historical and cultural influences; and, 4) written word overcomes limitations of discourse (Geanellos, 2000).

To facilitate understanding and meaning, the researcher initially read the text as a whole, referred to as naïve reading. The researcher then interpreted at a "deeper level" through structural analysis or breaking the text into smaller units. And, finally, the researcher interpreted with the whole again. However, the hermeneutic circle results in movement back and forth, explored the parts in relation to the whole and the whole in relation to the parts. This method of textual analysis was a "good fit" for perspectives of African American women with diabetes and maintaining roles.

Summary and Significance of Inquiry of Phenomenon to Nursing

Nursing practice is the diagnosis and treatment of human responses, in part, to the illness experience of individuals and the responses that are based on personal meanings. It is expected that this study will provide insight about the complex lives of African American women with diabetes and maintaining multiple roles as related to their perspectives of connections or lack of connections and sense of mutuality or power over with others in their lives. Eisenberger and Lieberman (2004) conclude that life-long social connections are as basic as physical needs to survive. The convergence of evidence from the social- and neurosciences regarding the importance of relationships/connections related to human flourishing is increasing (Jordan, 2010; Cozolino, 2006). It is hoped that the use of relational concepts in this study, currently underutilized in nursing research, education and practice, reflected the growing body of evidence-based research in other helping profession fields (psychology, psychiatry, social work) in the 21st century.

The lived experience of African American women incorporating context and meaning provided a greater depth of understanding of African American women's needs related to the current health outcomes in this high risk population. Nurses may be the

most consistent healthcare providers during the lifelong chronic illness experience of diabetes with African American women, through monitoring illnesses in homes, clinic visits or during public health activities. A gender- and culturally informed knowledge base about this population may assist nurses with improved anticipatory and ongoing care of these women with diabetes maintaining multiple roles.

CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of this review was to explore existing research of relational-cultural perspectives of African American women as related to the roles in which they are engaged and their experiences with type 2 diabetes. The literature review was organized based on Relational-Cultural Theory concepts of connection, described as positive relational images, disconnection, described as negative relational images, mutuality, described as positive relational images and power over, described as negative relational images (Jordan, 2010). Each of the concepts was reviewed in the context of African American women with diabetes and African American women maintaining multiple roles (See Appendix_ A_). The review began with connection and disconnection; these concepts required use of the proxy term social support and related terms, based on sparse use of the theory terms in the literature. Mutuality and power over concepts followed. The theory concept of power over was not found in the general research literature; therefore the construct of powerlessness substituted as a search word.

The databases CINAHL, Social Science Abstracts and PsychInfo were searched using the keywords of African American women, type 2 diabetes, multiple roles, connections/social support, mutuality, powerlessness and related terms. Inclusion criteria were primary research articles related to multiple roles of African American women and African American women with type 2 diabetes published in English between 2000 and 2014. Exclusion criteria included African American women with type 1diabetes and African American women maintaining less than 2 roles. Sample size was 13. Articles

were stratified into Relational-Cultural conceptual categories and placed into a matrix

format for synthesis.

Table 2-1 Link between Theory Concepts to Research Keywords to Interview Cues

Theory Concepts	Language Searcher	Interview Cues
Connections	Social Support/ Social Connections	Interactions/relationships with emotional accessibility, connections
Disconnections	Lack of social connections	Lack of interactions/relationships with emotional accessibility; lack of connections
Mutuality	Mutuality	Relationships open to change by one another; able to impact one another
Power Over	Powerlessness	Relationships with lack of control; controlled by others; powerless

<u>Connections of African American Women with Diabetes</u>

Connection is a relational interaction or experience between two or more people

that is mutually empathetic and mutually empowering. No research studies related to

connections and African American women with diabetes were found in literature search.

One research study was found using social support, the proxy term used for connections

for this review of the literature, of African American women with diabetes.

Tang, Brown, Funnell & Anderson (2008) examined the relationship of diabetes-

specific quality of life and self-care behaviors to social support. The study included 29

African American men and 60 African American women with type 2 diabetes who were

40 years of age or older. A cross-sectional, observational design was used. Diabetes-

specific measures of quality of life, self-care behaviors (healthy eating, physical activity,

self-monitoring of blood glucose, foot care, medication use, demographic background

and diabetes-related social support) were completed by the participants. Social support

measures that were diabetes-related included amount of social support received, social support satisfaction, positive and negative support behaviors and primary source of social support.

From a measure outcome variables two tools were used. The Diabetes Distress Scale, with a Cronbach's alpha of .93, measured diabetes-specific quality of life and items from the Revised Summary of Diabetes Self-Care measured self-care behavior. The Diabetes Family Behavior Checklist-II was used to assess the independent variables of positive and negative support behavior.

From a gender demographic perspective, the researcher found that men, currently married, received a greater amount of social support, had great satisfaction with social support and had more positive support behavior than unmarried participants. Multivariate analysis revealed the following: 1) participants more satisfied with received social support reported experiencing a better quality of life, 2) participants who received a larger amount of positive social support behavior followed a healthy eating plan, evenly spaced carbohydrates throughout a day and performed 30 minutes of physical activity over the past week more frequently and, 3) blood glucose monitoring was performed more frequently over a week by participants who were more satisfied with received social support. The researchers concluded from the findings of this study that the general concept of social support has an important role in diabetes-specific quality of life and better self-management performance. The findings also revealed that negative support behavior was associated with poor medication adherence. Roles of the participants were not addressed in this study.

The researchers reported 4 limitations of the study. First, the study was a cross-sectional design and could not infer a causal relationship between social support and self-care behaviors. Second, there was no relationship found between social support and the self-care behavior of foot care. Third, the four types of social support were not assessed in the study. Four, the findings cannot be inferred on any other ethnic group.

Connections of African American Women Maintaining Multiple Roles

delBene (2010) sought to understand African American grandmothers raising of grandchildren within a marginalized community and their perception of the lived experience. The following questions of interest were identified by the researcher: "what is the lived experience of raising grandchildren; how has caring for your grandchild affected caring for yourself; what is your relationship with the parent(s) of the grandchildren and what are your greatest concerns about caring for your grandchildren"? (p.35-36).The researcher used hermeneutic interpretive phenomenology with 15 African American grandmothers. Purposeful sampling supported rich data and sampling until saturation was achieved.

The four themes that emerged from the study were: the role of confidante, power of the group, finding a voice to match medical needs, the relationship with the biological parents and legal issues (delBene, 2010). The role of confidante was expressed as a benefit of meeting with a monthly group of similar women. The interaction between the women led to expressions of no longer feeling alone, a sense of group cohesiveness, a time to share along with experiencing a source of comfort, feelings of positive regard and acceptance. The other themes related to health concerns of the grandmothers and grandchildren, the generally poor relationships to the parents of the grandchildren and

lack of legal support in many of their situations. These themes were summed as impacts of societal marginalization of the grandmothers.

This research was one of a very few studies whose outcomes reflected the concept of connection of African American women maintaining multiple roles; this may have been facilitated by the hermeneutic methodology and rigor of the data analysis with the use of bracketing and peer checks. Implicit within the role of grandparent, maintaining a head of household/ parent role, are the multiple roles necessary within that role, such as cook, housekeeper, chauffeur; however, those roles are not documented in the study. The interactions between the African American women who participated in monthly group meetings led to mutually empathetic and mutually empowering feelings, congruent with the definition of connection in my research.

Disconnections of African American Women with Diabetes

Lui (2011) analyzed data of 9106 Caucasian and African Americans from the national second Longitudinal Study of Aging (LSOA II) to examine social connections and diabetes. LSOA II was an eight-year longitudinal follow-up study to improve understanding of determinants and functional outcomes of older adults based on interrelationships and disability pathways (Lui, 2011). The purpose of this smaller study was to determine if lack of social connections (LSC) and diabetes mellitus (DM) independently and jointly affected the risk of mortality amongst older white and African American adults (Lui, 2011). The researcher used two broad domains, social communication and social activity, as measures of social connections. Social communication was measured with two questions related to whether participants had spoken to friends, neighbors or relatives within the last two weeks (Lui, 2011). Social

activity was measured with five questions that inquired about activities such as: getting together with friends, neighbors or family, attending church/temple, movies or sports or going to a restaurant within the last two weeks (Lui, 2011).

Liu (2011) reported African American women had the largest percent of diabetes and lack of social connections was found in greater proportions for African American participants, with the exception of the measure for going to church or temple. Significant combined effects of LSC and DM on the risk of mortality had similar findings; even with adjusting for multiple covariates, African American women continued to be at significantly higher risk for mortality across gender and race comparisons.

Strengths of the study were the large sample size, participants from a national cohort and longitudinal time frame. Lui (2011) lists sets of data "built on standardized study design and procedures" and "the validity of outcome evaluations" as strengths (p.32). Lui (2011) listed the limitations of the study as related to poor data collection of: 1) biomarkers to test for possible mediators of associations, 2) self-care behaviors for possible association with social connections, and 3) incidence and diabetic severity for potential increased risk related to social connections. Lack of social connections, as defined by Lui (2011), served as proxy for the relational-cultural concept of disconnections, which suggested a dearth in the literature of the research concepts of this study.

Carter-Edwards, Skelly, Cagle & Appel (2004) examined the relationship between perceived social support and diabetes self-management of African American women with type 2 diabetes. A focus group format was used with a convenience sample of 12 female participants. Key themes generated from the participants of the study were:

1) a lack of understanding of the diabetic experience by family members and others in their larger network system, and 2) a lack of emotional understanding, which was the preferred type of family support over help. Sense of identity, maintenance of independence and control over their lives were essential to participants (Carter-Edwards et al., 2004). The one exception described by participants was a sense of increased emotional connection with church. The participants described motivation to engage in healthy behaviors would be through emotional understanding from people important in their lives (Carter-Edwards et al., 2004). The researchers suggested that adding diabetes management to the participants' already complex lives of providing for others and self was challenging. Complex lives included a listing of multiple roles such as: wife, mother, second mother, cook, household manager, worker outside home, chauffeur, church member, caregiver and confidante (Carter-Edwards, et al., 2004).

Strengths of this study were consideration of the contextual experience of African American women with diabetes related to their multiple roles, responsibilities and support of diabetes self-management themes from other studies (Carter-Edwards, et al., 2004). Additionally, triangulation of data sources occurred through audio tapes, transcriptions and session notes review by team members. Trustworthiness was maintained through member checks, paraphrasing and summarizing participant statements and probing. Peer debriefing with 75-80% consensus was met related to the data's primary themes. Transferability of results was limited to African American women.

Jones, Utz, Williams, Hinton, Alexander, Moore, Blankenship, et al. (2008) examined the impact of family and friends on management of rural African Americans

with diabetes and their willingness to be involved in a program that was culturally

tailored. The researchers described using "facilitated invited discussion sessions" where

21 participants could explain their diabetes management experiences and impact of

family and friends on their disease (p. 320). Seventy-five percent of the participants were

women. Six family and friends participated in one intervention session. An iterative

approach was used to identify recurrent themes of participants' responses and consensus

was reached of the final emerged themes. The use of audiotaped sessions and field note

observations strengthened the analyzed data. The iterative approach with consensus

added to the trustworthiness of the research findings; however, member checks would

have further enhanced the rigor of the findings.

Jones et al. (2008) described three emerging themes from the research findings:

family and peer involvement with diabetes management, diabetes is hard to control and a

positive attitude along with the use of prayer. Participants described interactions related

to family and friends that was "very supportive at times"; however, in their role of caring

for others caring for the diabetic self was not optimal related to diabetes management

(Jones et al, 2008, p.321). Unhealthy foods in the home environment and family and

friends lack of awareness of difficulty involved in diabetes management were verbalized

perceptions by participants. The difficult to control theme was described by the

participants in terms of personal challenges and personal failures. Positive attitude and

prayer, generally viewed as individual coping strategies, were a means to positively

manage diabetes and support and teach family and friends about the disease (Jones et al.,

2008).

Bi-directional social support was not consistently demonstrated; however, general positive attitudes of the research participants led to support of family and friends regarding their need to learn more about diabetes (Jones et al., 2008). Lack of social support served as proxy to the concept of disconnections in this literature review. The one-time intervention session of participants with family and friends suggested informational social support as the primary focus of need from family and friends related to the management of diabetes by the participants. Emotional support or lack of emotional support was more closely aligned with the construct, connection/disconnection of African Americans with diabetes of this author's study.

Disconnections of African American Women Maintaining Multiple Roles

Simpson & Lawrence-Webb (2009) examined perceptions of African American grandmother caregivers related to availability, access and responsiveness of family and community resources with regard to the care of their grandchildren. A purposive sampling of 7 participants was selected from a program in in urban Baltimore, Maryland. The researchers used the ecological and womanist theoretical frameworks to guide three face-to-face interviews that were held over an 18-month period with each participant. Audio-taped, semi-structured interviews included topics such as: the grandmothers' perceptions of family and community resources, experiences with social service agencies and concerns about environmental challenges. Grounded theory methodology was used for data analysis.

Simpson & Lawrence-Webb (2009) described three themes that emerged through their analysis: "traditional helping resources", "inappropriate or unresponsiveness of human service agencies" and "limited options and alternatives for grandmothers" (p.835).

Within the theme of traditional helping resources, the women described a diminished

reciprocal environment in the community. The women's previous sources of financial

and emotional support were no longer available or weakened within the family structure

related to deaths, community violence, drugs and poor economic and social

environmental conditions; as a result, grandmothers sought formal agencies for

assistance. The grandmothers described human resources agencies as having poor

decision-making and recommendations related to the care of their grandchildren. Fear of

losing their grandchildren led the grandmothers to avoid state-sponsored programs. The

grandmothers also attributed lack of clear information and guidance as other reasons for

not being a part of the foster care system.

Credibility of the study was enhanced by the rigor of data collection and analysis

process. Three sessions with each participant allowed for member checks. Peer de-

briefing was another tool used by the researchers. Simpson & Lawrence-Webber (2009)

suggest the limitations of the study as non-random sampling selection and women

providing care external to formal care services. Lack of social support resources were

described in the context of instrumental, informational and emotional support from

internal and external sources. Lack of social support serves as proxy for the construct of

disconnection in the proposed study.

Kelch-Oliver (2011) examined the experiences of African American

grandmothers raising grandchildren; the research question was: "what are the experiences

(and challenges) of grandmothers in GHF (Grandparent-Headed Families, my insert)

from their perspective?" (p.74). Eight open-ended, semi-structured interview questions

were used to encourage the grandmothers to tell their story. A convenience sample of six

grandparents from an urban setting participated in individual audio-taped face-to-face.

The five major themes emerged from the interviews were grandmothers'

roles/caregiving responsibilities, loss of independence/changes in quality of life, ways of

coping with caregiving situation, future goals for grandchild and advice to other

grandparents who are raising their grandchildren. The most prevalent throughout the

interviews was the grandmothers' strained or lack of relationship with the parents of the

grandchildren. The next most prevalent theme was loss of independence and changes in

quality of life related to social changes, such as: less contact with family and friends.

Loss of employment, benefits and lack of financial support were also within this theme.

The three less prevalent themes connoted more positive perspectives of GHF such as:

caregiving coping strategies, desires for grandchildren in the future and advice to other

grandparents raising their grandchildren.

Kelch & Oliver (2011) question transferability of findings to other GHF with

different demographic characteristics than participants such as race, socioeconomic status

and environment. Additionally, recruitment of participants from social support programs

may have impacted the grandmothers' experiences. More in-depth exploration of the

emotional meanings of the GHF multiple role experiences may have better informed or

related to the disconnection construct of my study.

Cagle, C.S, Appel, S., Skelly, A.H. & Carter-Edwards, L. (2002) explored

perceptions of the influences of multi-caregiver role, life stress/social support and work

on diabetes self-management and coping abilities with type 2 diabetes of African

American women. The researchers used focus group methodology with a total of 12

participants. The roles maintained by the participants, outside the home, included worker, community and church member and, within the home, parent, partner, cook and chauffeur. Four broad themes emerged from the research: family as core, work as survival, impaired role function and inner strengthening (Cagle, et al., 2002).

Cagle, et al., (2002) found that family as core was the most important theme across all 3 groups. The participants described family as top priority with the roles of matriarch and leader subsumed as their main functions; complications of poor diabetes self-management and fatigue perceived as secondary to role maintenance (Cagle, et al., 2002). The researchers found that despite lack of physical and psychological support from family the participants continued to prioritize family as first. The women described a need for an increased willingness of family members to share the head of the house role.

Cagle et al (2002) reported common participant responses related to work as survival were stress as the primary providers of the family with limited income, workplace discrimination and limited personal power connected to their gender, race and chronic illness. Another theme elicited through focus group analysis was impaired role function. This theme represented the restrictive nature of diabetes experienced by the participants and their ongoing concern about the impact of diabetes complications on their role functions for family and community (Cagle et al., 2002). Conversely, the participants described how the multiple roles of mother, partner, worker, family chauffer, cook and community/church member diminished the necessary time needed to manage their disease (Cagle et al., 2002). The fourth theme elicited through focus group analysis was inner-strengthening with connection to God, church and female church members.

The participants described perceptions of managing unmanageable lives by reading the bible and trusting and talking to God (Cagle et al., 2002). Notions of sharing selectively also transitioned to healthcare visits. Participants described a sense of a triple threat of discrimination when seeking healthcare, that of being of being African American, a female and having diabetes (Cagle et al., 2002). The researchers reported participants' descriptions of healthcare providers as primarily focusing on glucose numbers and not the context of their lives that could improve management of diabetes. And, lastly, in general the participants wanted to be distinguished by their strengths, such as their faith and being able to fulfill their head of family roles and responsibilities, not by their weaknesses, such as diabetes or lack of faith (Cagle et al., 2002).

Focus group methodology and use of an experienced ethnic group-congruent moderator fostered the rich data from the participants (Cagle et al., 2002). Focus group guided questions based in literature and piloted with similar women along with member checks following each session of collected responses added to the strength of the study. A small convenience sample of 12 participants was a limitation of the study. The researchers suggest that women from the same regional area may represent values and behaviors that are regional-specific and therefore findings cannot be generalized to the larger African American female population.

Mutuality of African American Women with Diabetes

Cooke-Jackson (2011) sought to understand dialogues that occur between mothers with type II diabetes and their adult daughters. Twenty women participated in 3 interviews each with each daughter participating in the final interview. A socio-ecological framework was used to guide all phases of the research. The researcher posed

two questions for the study, "is health information regarding diabetes shared from mother to daughter and (b) how mothers use their conversations with their adult daughters to negotiate their conflicted experiences with being a diabetic?" (p.238). All interviews were audio-taped and conducted with an open-ended, semi-structured format. Transcription occurred after each interview by the researcher followed by peer debriefing to check for accuracy and to provide feedback related to coding, themes and patterns. Cooke-Jackson (2011) describes the mother-daughter dyads as having close relationships and representing "the value and importance placed on kinship networks among African American women" (p.252). Additionally, close relationships are an important source of social support because a mutual cooperative exchange is offered (Wing, Marcus, Epstein & Jawad, 1991).

Cooke-Jackson (2011) described three major themes emerging through the diabetic talk: "(a) talk about diabetes among families; (b) talk about personal experiences of living with diabetes and (c) talk about prevention" (p.250). Strong family histories of family members with diabetes and friends, family and members of their larger kinship networks that died from diabetes increased the importance of sharing frank stories with their non-diabetic daughters. In the 2nd theme mothers shared their worry, concern and frustrations with diabetes. Fear, guilt talk and denial emerged with this theme also. The third theme revolved around the importance of prevention; the mothers discussed the importance of healthy lifestyles, encouraged annual medical examinations and sharing of relevant health information with health care providers.

Cooke-Jackson (2011) suggests several strengths to the study. The oral tradition of sharing stories continues to be an important means of teaching past and present

knowledge about a disease experience to present generations and "emphasizes the value of narrative" within African American mother-daughter relationships (p.250). The use of 3 interviews brings depth to the complex diabetes experience of these women and opportunities to address important information and gain clarity of information. The researcher lists the following limitations of the study; modest sample size, self-reports and closeness of these dyads suggesting that all mother-daughter dyads are not close.

This study represents the only research article found related to mutuality of African American women with diabetes. Jordan (2010) suggests that with mutuality, individuals grow towards one another with an "increased capacity for respect", the ability to impact one another and "being open to being changed by the other" (p.104).

Mutuality of African American Women Maintaining Multiple Roles

Goldstein & Reiboldt (2004) in a 2-year longitudinal study followed three families in a low income urban setting. The focus of the study was to describe resources used by families to be successful in a low socioeconomic community. The researchers found, over the 2-year period, the major topics discussed by the participants revolved around coping mechanisms used such as family, the roles of women and community participation. The multiple roles portrayed by the mothers in this ethnographic study were mothers, teachers, role models, community leaders, volunteers and caretakers (Goldstein & Reiboldt, 2004). The African American mother of one family was engaged in many roles as single-parent of three children, summarized as custodial single parent, sole provider of financial support (full-time employee) and household maintenance. She served as community activist, councilor to children in the neighborhood along with active roles in church. Multiple role engagement in community was associated with a sense of

reciprocity among other community care givers, neighbors and community members (Cagle et. al, 2002).

Despite the small number of participants, limiting external validity in this ethnographic study, the 2-year time frame of the study provided rich data and allowed for strengths of the families to emerge. Researchers gathered data from many sources and gained multiple perspectives as a result of informal interviews, attending community school meetings, neighborhood collaboratives and city-wide community events as participant observers. This research suggested that minority women, in general, provided primary and multiple roles within their own families and community. Low socioeconomic means influenced the roles maintained by the study participants. Parenting roles required strategies to meet the challenges of living in poor neighborhoods. Helping relationships led to support, advice, assistant and community activist roles to other families and individuals and were viewed as reciprocal relationships by all ethnic groups represented by the women in the study (Goldstein & Rieboldt, 2004). These authors suggested that multiplicity and reciprocity of roles are apparent from the interviews in their study. Reciprocity was a related search term; it connotes an equal exchange or equally shared activity as opposed to mutuality, which connotes a shared activity which does not mean sameness or equality in its' meaning (Jordan, 2010).

Power Over of African American Women with Diabetes

Penckofer, Ferrans, Velsor-Friedrich & Savoy (2007) used a descriptive, exploratory design with four focus groups (2 Caucasian American, 2 African American) to explore depression, anxiety and anger feelings experienced by women with type 2 diabetes and the impact of the feelings to their quality of life. Five major themes

emerged from the groups. Three themes were closely related to aspects of their physical health: struggling with changing health situation, worrying about diabetes-related health of present and future and taking a diabetic "break or holiday" from the rigors of the diabetic regimen (Penckofer, et al, 2007). Two themes were more closely related to relationships and multiple responsibilities.

Penckofer et al. (2007) described the theme of "encountering challenges in relationships" related to feelings of anger, anxiety and sadness or depression. These emotions revolved around relationships with self for not taking care of their own health and family, health care providers and others related to "the manner in which they were directed to manage their health" (Penckofer et al., 2007, p.365). Power over, a relational concept is defined in part as, "… not fostering a mutually empowering relationship" (Jordan, 2010). The other theme, "bearing responsibility for self and others" related to the multiple roles required of the participants in caring for others with little time to care for their own health care needs. Participants' perception of need to do for others over need to do for self suggests that "true mutuality becomes threatened" (Jordan, 2010, p.103) suggestive of the Relational-Cultural concept of power over and a sense of powerlessness. The researchers found that all emergent themes negatively impacted the participants' quality of life. The need for assessment of psychosocial health including relational health as part of the assessment of diabetics is supported by findings in this study.

Power Over African American Women Maintaining Multiple Roles

Davis-Sowers (2012) described the role of African American aunts caring for nieces/grandnieces and nephews/grandnephews using a modified grounded theory

methodology. The researcher listed the following research questions to guide the study: "How do Black aunts understand their decisions to parent nieces and nephews?" and "What factors affect the decisions of Black aunts who parent their nieces and nephews?" The researcher used snowball sampling and recruited 35 Black aunts.

Davis-Sowers (2012) discovered a "root theme" as foundational to all other emerging concepts. The researcher reported a perceived lack of agency in the decision to parent nieces and nephews; when confronted with family problems, the women were unable to see other choices or question possible options. The six sub-themes of the study were: perception of a crisis, fulfillment of family obligations, gendered expectations, faith in God, personal identities and the role of the Black aunt. Davis-Sowers (2012) suggested that these themes should be understood within the context of the overarching root theme.

Davis-Sowers (2012) suggested that the first sub-theme, perception of a crisis, was based on aunt views of children in peril and with a lack of stability in their lives; the only option for the aunts was acceptance of parental responsibility. The second sub-theme, fulfillment of family obligations, where the needs of children, emotionally, financially and psychologically, were to be met by members within the family system was the only option for the participants (Davis-Sowers, 2012). The third sub-theme of gendered expectations was attributed to the history of black women's responsibility to care for both kin and fictive kin without remuneration; the participants described this action as "a sisterhood of other-mothering and co-mothering" (p. 241). Faith in God sub-theme emerged as the fourth theme where caring for the children was an action entwined with trusting in God, using the bible and prayer and listening to spiritual teachers; these beliefs restricted the respondents' abilities to envision other options (Davis-Sowers,

2012). The fifth emerging theme was personal identities where the aunts viewed themselves as the caregivers and "kin keepers" in their families; refusing care was not an option (Davis-Sowers, 2012, p.243). The final sub-theme was the role of the Black aunt which was perceived as different from White aunts. White aunts were primarily gift-givers as opposed to black aunts, who equated their roles to be the same as mothers and parent extensions. The perceived gap in care of the children led to their defined caregiving role, passed down from previous generations, of "Black aunting affected their decision-making" (Davis-Sowers, 2012, p.244). The concepts of connections or social support were not included in this study.

Strengths of this research relate to the rigor of the analysis phase of the study, such as: the audio-taped face-to-face interviews transcribed by the researcher, use of field notes to add further validation of data and ongoing member checks. Careful monitoring of language used with participants to minimize hierarchical positioning of researcher strength of the study (Davis-Sowers, 2012).The findings of this study suggest a strong cultural foundation to the notion of kinship and kinship obligations of African American women and support of relational-cultural aspects of the proposed research study. The themes connote the cultural influence of generationally collective traditions, culturally-gendered expectations and the role of religion and personal identification of familial roles in the lives of African American women (Davis-Sowers, 2012).

Samuel-Hodge, Skelly, Headren & Carter-Edwards (2005) developed and tested a new multiple caregiving measure with a sample of 299 African American women with type 2 diabetes. The following themes emerged from 10 focus groups: helping and being available to help family and friends, interference of caring for self, related to caring for

family and friends, placing needs of others before self, a sense of obligation to help others and the inability to say 'No'. Two items were added to identify which women in the focus groups engaged in multiple caregiving roles and to gather data about the number of people to which the caregivers provide various types of support (Samuel-Hodge et al., 2005).

A multiple caregiving scale (MC-roles) and a multiple caregiving barriers scale (MC-barriers) resulted from a factor analysis used to identify underlying structures of the items. Cronbach coefficient *a* measuring internal reliability of the scales was acceptable with 0.72 for the MC-role scale and 0.76 for the MC-barriers scale (Samuel-Hodge et al., 2005). The results of the MC measure were confirmed. The researchers found no significant correlation between the MC-barriers and MC-role scales; however, both scales were significantly associated with two items, putting family's needs first and difficulty saying no (Samuel-Hodge et al., 2005).The women in the study who identified with the two behaviors were women who maintained and perceived more barriers with multiple roles (Samuel-Hodge et al., 2005). The number of children and adults helped/supported in the same household as the participant fostered more perceived barriers than those not living in the same household. There was a negative impact on feelings of well-being, perceived levels of control and competence in diabetes management. The researchers found that younger women in the study and those who had difficulty saying no were at greater risk of experiencing MC-related barriers. The concepts of connections or social support were not included in this study.

Strengths of the study were the large number of participants and the use of the focus group format. Limitations of the study are related to generalizability. The

participants were older, lower socioeconomic status and from the southern region of the United States; therefore, the findings may not represent other African American women with other demographic factors (Samuel-Hodge et al., 2005). Additionally, the researchers suggest that the usefulness of the developed instrument needs to be confirmed with other populations. This study occurred in an urban city in the northeastern region of the United States where inclusion criteria will be 18 years or older, type II diabetes and maintenance of multiple roles.

Chapter Summary

The literature review provided existing studies related to Relational-Cultural Theory concepts of the research study. Four relational concepts from the theory were used to explore perspectives of African American women experiencing diabetes and maintaining multiple roles; however, use of proxy terms were required with 3 of 4 relational concepts related to limited use of theory terms in the literature. Social support was substituted for the term connections; lack of social support was used instead of disconnections; powerlessness replaced the term power over. Mutuality was the only term from the study that both proxy and the relational term for literature review. Related terms were included in the literature search of all terms.

The chapter summary is presented in the same manner of the review; the sections are:

1) connections of African American women related to diabetes, 2) connections of African American women maintaining multiple roles, 3) disconnections of African American women with diabetes, 4) disconnections of African American women maintaining multiple roles, 5) mutuality of African American women with diabetes, 6) mutuality of

African American women maintaining multiple roles, 7) power over of African American women with diabetes and 8) power over of African American women maintaining multiple roles. This chapter ends with key points warranting this study based on the existing research literature.

Discussion of Chapter Sections

Connections of African American women with diabetes was the first section of the literature review and a relational-cultural concept used in this author's study. The review of the literature resulted in no studies using the sensitized concept of connections. One article related to the proxy term social support of African American women with diabetes was in the literature. This quantitative study found a positive relationship between amount of healthy support behaviors and social support satisfaction. Findings suggested that social support has a role in diabetes –specific quality of life and self-management behaviors or positive diabetes outcomes of African American men and women. Predictors of diabetes-specific quality of life and self-care behaviors from social support variables were key areas of interest for the researchers (Tang et. al, 2008). The social support variables used in the study did not include emotional support, the type of support most aligned to the concept of connectedness; however, generally, all social support concepts are one-directional as compared to the relational component of connections concept which is explored in this author's study.

In the second section of the literature review social support was used as a proxy term for connections of African American women maintaining multiple roles. One research study was found within this topic. Social support, described as a function and generally one-directional concept, was used as proxy instead of connections. The

researchers in this study used Hermeneutic Interpretive phenomenology to gain perspectives of the lived experience of 15 African American grandmothers raising grandchildren in a marginalized community (del Bene, 2010). This was the only research found in the literature that used interpretive phenomenology as in the present study which enabled context of the grandmother's caregiving experience. African American women's lived experience in the new role of chief caregiver was a strength related to the breadth and context of participants in the reviewed study and supports the use of this methodology in the present study. Details about the specific activities required within the new role of chief caregiver were not explicitly described or listed in the reviewed study and supports further exploration of roles as context of African American women in this author's research. It is one of three studies in the literature review where African American grandmothers were the research participants; African American women, 18 years and older, not only grandmothers, were the sample population sought for this author's study to gain insight from African American women across the life span.

Disconnections of African American women with diabetes was the third section of the literature review. The proxy term, lack of social support of African American women with diabetes was reviewed in the literature. Three studies, one quantitative and two qualitative, were found in the literature related to this topic. A longitudinal quantitative study by Lui (2011) was the only study in the review that used the term lack of social connections; however, the term was defined and used as one-directional and function concept. The findings indicated that African American women, approximately 13% of the 9106 women in the study, had the greatest proportion of lack of social connections and highest mortality rates.

The two other studies within this section were qualitative studies. Both studies explored aspects of social support related to self-management of diabetes; self-management is not an area of focus for the present study. Lack of understanding and lack of emotional support from family and friends were similar themes in the two studies. The findings of the Carter-Edwards, et al. (2004) related more closely to the concept of disconnection than other study in the review. The women's notions of being misunderstood and desiring more emotional closeness adequately represented some of the key characteristics of the concept of disconnection within this researcher's study. Spirituality (use of prayer and positive attitude) and religion (positive emotional closeness to church experience) were another common theme between the two studies. A third common connection between two studies was participants' perceptions of multiple roles as complicating the diabetes experience; however, specific roles of the participants were not included.

For the purposes of the literature review, the proxy terms of lack of social connections or lack of social support were used in place of disconnection, the concept that used for this author's study. However, disconnection is a relational construct and more distinctly represents lack of mutual empathy/empowerment (Jordan, 2010).

Disconnections of African American women maintaining multiple roles was the fourth section of the literature review. Lack of social support was used as proxy for the disconnections concept of this study. Three qualitative studies were found related to the topic of this section. The participants of two studies were grandmothers raising their grandchildren and maintaining multiple and complex roles. Lack of social support was similarly identified as parents of grandchildren and/or a general decline in traditional

supports, and one study identified formal support systems. Once again, disconnection is a bi-directional concept that cannot be easily equated with lack of social support, which is a functional and one-directional concept.

Grandmothers as caregivers were the focus participants of the two studies reviewed. The inclusion criteria for this author's study was 18 years of age or older with no restriction to role type; the goal was to reach a wide range of African American women with diabetes and maintaining multiple roles to gain some insight into the lived experiences across the life span. It is generally known that Type 2 diabetes is affecting younger populations than in the past and African American women are one of the highest risk populations related to this phenomenon.

The participants of the third study were middle aged African American women, ¾ of whom were still working. The purpose of the study was to gain perspectives of the participants about work and multi-caregiver role and identify influence of those roles on diabetic self-management and personal coping. Four themes emerged with Family as core as the prime theme. Family role was prioritized over care of diabetes, despite, perception of lack of emotional and physical support and need to share head of household responsibilities. These two types of social support in this study vary in meaning and are not relationally bi-directional. Context of the participants' life experiences was considered related to home of multi-caregiver role, life stress and social support and work. Discrimination in the workplace and with health care providers was another type of stress experienced by the participants of the study. Family role maintenance was a higher priority than diabetes care with African American women in this study.

Mutuality of African American women with diabetes was the fifth section with a literature review. One qualitative study was reviewed by Cooke-Jackson (2011). The purpose of the qualitative study was to understand conversations between type 2 diabetic mothers and their adult daughters. Diabetic mothers and adult daughters were described by the researcher as having close relationships. The researcher (2011) suggests that historically, black women have relied on relational, communicative aspects of community and that mutual cooperative interchange is possible with close relationships. Although, mutuality was not specifically addressed in this study; it was implied in the findings. Mutuality in the current researcher's study incorporates the definition as "increased capacity for respect, having an impact on the other and being open to being changed by the other" (Jordan, 2010, p. 105).

Mutuality of African American women maintaining multiple roles was the sixth section with a review of the literature. Limited use of the term mutuality, as defined, led to the use of reciprocity as a related term in the search. One qualitative study was reviewed in that context. Reciprocity between multi-role caregivers of the community and community members was apparent over a 2-year study (Goldstein & Reibolt, 2004). The women participants provided immeasurable support to their families, neighbors and community and, in turn, neighbors and community members supported the women. The researcher describes this as reciprocity which is defined as a mechanism through which stable social relationships can occur and establish balance in social exchange (Fyrand, 2010; Gardner, 1960). Mutuality, the concept in the current research, does not mean sameness, equality or reciprocity; it is a shared activity where those involved are participating as fully as possible (Miller & Stiver, 1997).

Power over of African American women with diabetes was a review of the literature in section seven. One article found related to the concept of power over through two themes in its findings: encountering challenges in relationships and bearing responsibility for self and others. Both themes connoted a sense of power over; however, the concept was not specifically included in the reviewed study. No other studies related to power over or powerlessness were found in the literature with African American women with diabetes.

Power over of African American women with multiple roles was the eighth section of the chapter. Two studies were found in the literature related to the concept of power over of African American women maintaining multiple roles. Lack of agency was a root theme in one study of black aunts related to extended family relationship obligations in becoming caregivers of nieces and nephews. Lack of agency or powerlessness was embedded in all other findings of the study. Two findings in the second study, putting family first and difficulty saying no connoted a sense of powerlessness, a proxy term for this researcher's study. These two articles supported the importance of incorporation of roles, culture and context within this population.

Key Points Warranting This Study

African American women are one of the highest risk populations for type 2 diabetes and historically have been involved in many formal and informal roles. The importance of understanding all facets of this chronic illness experience has been documented including the psychosocial aspects (IOM, 2001). Relational-Cultural Theory provided an opportunity for this author to explore this aspect through use of the theory's relational concepts. Based on the literature review, the following points warrant this

author's research: 1) lack of use of theory concepts in the literature; 2) difference in meaning of proxy terms compared to sensitized theory terms; 3) limited number of studies related to this topic with African American women as the research participants; 4) specific role descriptions was limited to two studies in the reviewed literature; and, 5) minimal use of interpretive phenomenology as a research methodology to obtain context of perspectives of connections of African American women living with diabetes and maintaining multiple roles.

CHAPTER 3

METHODOLOGY

<u>Phenomenology Research</u>

Two schools of phenomenology are most frequently described in the literature, descriptive and interpretive (hermeneutics). Each school has a unique philosophy and approach related to it. Lopez & Willis (2004) suggest that the philosophical underpinning of any research should provide a direct link and guide to the research. Ultimately, generated findings depend on the philosophical approach used. This study used interpretive phenomenology inspired by Ricoeur in philosophy and method.

<u>Philosophical Foundation of the Methodology</u>

A key element of Ricoeur's interpretive phenomenological philosophy is his distinction between discourse and text (Allen & Jensen, 1990). This difference is referred to as distanciation and is composed of four main forms. The first form is transcription of the dialogue into writing; it is what the dialogue said. Once the discourse is written, the meaning of the text "must stand on its own … becoming broader and more complex"; the interpreter cannot return to the participant for clarification (Allen & Jensen, 1990, p.242). The third form denotes a freeing of the text from the original speaker, freeing from a specific reference and opening up to unlimited readings and interpretations. In the fourth form, the written text opens up and "is now addressed to all readers" (Allen & Jensen, 1990, p.243).

The aim of this phenomenological approach is to uncover hidden meanings, "embedded in common life practices" (Lopez & Willis, 2004, p. 728). The focus of the researcher was on what participants' narratives implied about their everyday experiences

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instead of pure content or description of the subjective experience. As a result, interpretive frameworks are used to explore relationships and meanings between knowledge and context (Penner & McClement, 2008).

This type of phenomenology acknowledges how the researcher's prior knowledge, personal experiences and frameworks influence the understanding of the phenomenon (Dowling, 2004; Penner &McClement, 2008). This approach recognizes the human experience of researcher and participant as inextricable from their individual life experiences. As a result, a theoretical orientation or conceptual framework may be used to focus the research and bracketing of researchers' own preconceptions or theories is not required. Within the context of my research, I expected to gain access to textual meanings related to my evolving appreciation and understanding of the importance of connections (or lack thereof) within the lives of human beings and the incorporation of Relational-Cultural theory concepts within my nursing practice. Data was analyzed based on the philosophical assumptions of interpretive inquiry. Participants' narratives were examined to facilitate understanding of the contextual aspects of their experience and life worlds (Lopez & Willis, 2004).

Use of interpretive phenomenology was a good fit for the study of Relational-Cultural perceptions of African American women with diabetes and maintaining multiple roles. The following characteristics made it a good fit: it allowed for 1) inclusion of context of the lived experience of the participants, 2) inclusion of a conceptual framework to explore their contexts and, as a result, 3) an interactive and intersubjective knowledge development throughout the research. A major tenet of this approach is that humans are embedded in their world to such an extent that their subjective experiences

are inextricable from their social, cultural and political contexts (Heidegger, 1962).

Therefore, the underpinning of this approach was congruent with a call for the study of

African American women that reflected their social and cultural realities (Thomas, 2004).

The method allowed the researcher to seek meanings and relationships that knowledge

and context have together. The very nature of the hermeneutic circle facilitated

"understanding the parts of the text, in relation to the whole, and the whole text in

relation to its' parts" to adequately represent the many levels and complexities of context

within the lives of these women with diabetes who also maintained multiple roles in their

lives (Geanellos, 2000, p.118).

Participant Selection and Sample

African American women with Type II diabetes and maintaining multiple roles

were the target population of this study. Women with diabetes for at least 2 years were

sought for the purpose of the study. Goodman, Posner, Huang, Parekh & Koh (2013)

suggest that 12 months or more is a common duration timeframe for the definition of a

chronic illness (such as diabetes, my insert) in the literature. The two year minimum was

used to increase the likelihood of access to women with a depth and breadth of the lived

experience with diabetes beyond the initial diagnosis and acute phases (Streubert &

Carpenter, 2011).

To capture the phenomenological experience, multiple roles were defined as three

or more roles concurrently maintained by the women. The definition of multiple roles

included roles maintained within and outside of the home and relates to the generally

known historical, spiritual and cultural context of the lives African American women

(Cagle, Appel, Skelly & Carter-Edwards, 2002; Mitchell & Knowlton, 2012; Black women in the United States, 2014). Additionally, three or more roles adequately met the criteria for multiple as having or involving many individuals, elements or relations in the lives of these women (Cagle et al., 2002; Penckofer et al., 2007; Random House Webster's College Dictionary, 1991).

A purposive sampling strategy was used in this study. This was meant to select individuals based on their knowledge of the phenomenon and willingness to share that knowledge (Streubert & Carpenter, 2011). Inadequate numbers of participants and saturation through purposeful sampling led to the use of snowballing. Snowballing may be an additional technique used to recruit more participants if saturation is not met with the original participants. Wilson & Washington (2007) suggest that there is an assumption that people with like interests and similar experiences will know each other with this technique. Data collection continued until data saturation, where no new themes emerge from participants and a repetition of existing themes was achieved (Streubert & Carpenter, 2011).

Gaining Access and Entering the Setting

Two essential factors were embedded in the process of connecting with the appropriate population for this study. First was identifying an effective way of gaining access to African American women who met the criteria of the study and second was an understanding of the historical underpinnings of mistrust of researchers and the research process within the African American community. To address the first factor, a request to provide a presentation to members of a chapter of the National Black Nurses Association. The second essential factor is the historical context of research and researchers in the

black community. Research, such as The Tuskegee Study, may have, into present times, negatively impacted African American participation rates in research. Lack of trust in researchers and how research findings are used is an ongoing concern with this population. Hatchett, Holmes, Duran & Davis (2000) provide the following recruitment recommendations to address these concerns: (1) provide meaningful monetary incentive to create interest, (2) target places (for eg. churches, senior centers) as sites where information can be disseminated, (3) seek places where women congregate, and, (4) engage respected and recognized leaders, within the African American community. These activities were used as described above. George, Duran & Norris (2014) suggested that race congruence may ameliorate some mistrust held by potential participants; therefore, a small picture of me was placed on the flyer.

The first was addressed, as described above, by a granted request of the chapter. A presentation of the proposed study was presented to chapter members at a monthly meeting of the group. Many of the members actively serve as nurses and health advisors in their churches. Additionally, many of the nurses were involved in other organizations in the community where the study took place. Historically, African American nurses are respected and trusted members within their communities; these characteristics were helpful in gaining access to potential participants for the study. Sharing the possible benefits of the study to the health and care of African American women was highlighted in the presentation. Informational flyers were provided to the nurses to be placed in Sunday service church bulletins and displayed within the church buildings.

Informational flyers were placed in other places also, such as, black businesses (for eg. beauty salons), senior centers that service the African American community to

increase access to potential participants and to participants once the actual research

began. The flyer was developed based on the University of Massachusetts Amherst

guidelines (See Appendix _B_). Information about a monetary incentive as appreciation

for participation in the study was included in the flyer. Other information on the flyer

included 3 ways interested women could contact the researcher, e-mail, land and cell

phone numbers, approximate timeframe of the interview and maintenance of

confidentiality.

As the number of potential participants slowed using purposeful sampling,

participants were asked to recommend others they knew with similar characteristics and

respected leaders of the community were visited for assistance. These efforts led to

additional participants with data saturation ending in a total timeframe of 16 months;

longer than originally anticipated.

Protection of Participants and Ethical Considerations

Internal Review Board (IRB) approval was sought at the University of

Massachusetts (UMASS) Amherst. All participants were asked to sign a consent form of

agreement to participate in the research (See Appendix _C_) at the time of first interview.

An interview schedule will be used as prompts by the researcher along with pursuing

aspects of the description, not as a way of asking and answering a series of questions

 (See Appendix _D_). All participants were African American women over 18 years or

older and were appraised of their right to stop the interview at any time they felt they do

not want to continue.

All participants were given a pseudonym after the initial interview. The

pseudonym and audio-tape recording of that participant were co-coded, for eg.

Pseudonym1 = Participant 1= Audio tape1, Pseudonym2 = Participant2 = Audiotape2, etc. A master list of pseudonyms along with real names and numbered audio tapes were known by only myself and kept in a locked cabinet in my home. All raw data was secured and accessed by the researcher only. All information was kept confidential and secured with that systematic procedure.

Data Generation and Treatment

Subjective meaning of African American women with diabetes and maintaining multiple roles occurred with questions generated in the context of the sensitized concepts based on Relational-Cultural theory. Normal qualitative interviewing techniques were used to generate data with the process of data collection ending when new information was no longer emerging (Allen & Jensen, 1990).

The process of textual interpretation did not begin until each interview was complete; based on the Ricoeur method, each interview was taken as a whole and thought to be the text (Allen & Jensen, 1990). A three step approach was used which moved from a naïve reading to a structural analysis to interpretation of the whole. Naïve reading entailed analysis of the whole text of each interview. Geanellos (2000) suggests that the interpreter has a shallow grasp of the whole text. In this step, each interview was read through in its' entirety to gain familiarity with the text, reflect upon it and begin to develop ideas about its meaning for further examination during the structural analysis phase (Svedlund, Danielson & Norberg, 2001; Streubert & Carpenter, 2011). Coding and organization of data began here.

The second step, structural analysis, involved identifying meaningful units, condensing the meaningful units to a shorter form, to subthemes and finally through

further abstractions to new themes. This step, also called interpretive reading, was where patterns of meaningful connections were made and each interview was compared with other interviews (Svedlund et al., 2001; Streubert & Carpenter, 2011). Categories were compared, modified and further refined as this step progressed.

The third step, comprehensive understanding, was where interpretation of the whole occurred. It was meant to further reflect and gain a critical understanding of the whole text again. It involved a comprehensive inclusion of prior knowledge and conceptual frameworks of the researcher, noting that naïve reading and structural analysis are reconsidered and reflected upon (Svedlund et al., 2001). In this step, the researcher developed a deeper understanding of parts in relation to the whole and the whole in relation to the parts, referred to as the hermeneutic circle (Geanellos, 2000). Movement back and forth, from the text as a whole and returning to the structural units and structural units to the whole is described as the hermeneutic circle and is described as "coming to the understand the phenomenon" (Allen & Jensen, 1990, p. 247). Reflections and notations about the data were written as notes and used to aide thinking leading to explanation and understanding of relationship meanings of these women with diabetes and maintaining multiple roles.

Additionally, field notes were written following each interview. Observations not captured through voice recordings such as participant expressions, positional changes and other behaviors added breadth and depth to data analysis and facilitated "appropriate emphasis on emerging themes" (Streubert & Carpenter,2011,p.43).

Data Analysis and Management

Each interview was transcribed verbatim from the tape recording of each participant through a transcription service at a major university along with field notes. The first two transcriptions were reviewed by the researcher for congruency with the tapes. Further discussion of data analysis has been described in a previous section; however, the systematic management of data has not. Once all collected data, verbatim interviews and field notes was transcribed, it was placed into word files as rich text format (RTF) and entered into Atlas.ti computer software program. This software program handles large amounts of data to manage, extract, compare, explore and reassemble meaningful segments (Atlas.ti7, 2014). Atlas.ti coded for relational-cultural sensitizing concepts was used as a beginning framework for understanding and meaning of those concepts. However, the researcher switched to manual coding very early in the process related to the need to view and theme data in a more comfortable and personal way based on past manual coding experience. Themes were color coded which increased my ability to view and cross check with greater ease.

All participants' data was labeled consistently as they entered the study. Pseudonym1 = Participant1=Audiotape1 were labeled immediately as an example of the labeling that occurred consistently through the last participant. Pseudonyms were stored within 2 places: a Microsoft word files as RTF and tapes were saved as wavesound (WAV) within my password protected computer and labeled as described earlier, backed up on a flash drive kept in a locked cabinet; a master list of participants' real names was kept in a separate locked cabinet.

Each transcript of an interview was entered before analysis began as described in a previous section of this chapter. Overtime, themes emerged based on the hermeneutical circle of inquiry, which moves back and forth between explanation and understanding; ultimately affirming, that "through rigorous interaction and understanding, the phenomenon is uncovered" (Allen & Jensen, 1990, p.245).

Data Collector's Credentials and Training

I am a baccalaureate prepared Registered Nurse with a Master of Science degree from the University of Massachusetts Amherst (received May 1992). I have had a particular interest in the health and well-being of African American women for most of my nursing career. My master's thesis was a qualitative study entitled, The Social Support Perspectives of Elderly Black Women with Chronic Illness. Qualitative interviewing, text coding and analysis skills were used and led to successful completion of requirements for graduation. During more recent doctoral course work in qualitative methods, I used qualitative analysis in a small study. Interviewing, verbatim transcription and finding themes through data coding skills were further honed during that experience. Additionally, the course exposed me to other qualitative methods through readings, literature reviews, critical analyses and presentations by research experts of these methods.

Trustworthiness

Use of Ricoeur's philosophical and methodological frameworks poses contraindications as related to some criteria recommended for establishing trustworthiness. Plurality and multiplicity of textual interpretation is a fundamental tenet of the Ricoeur approach in hermeneutic phenomenology and is viewed as bringing

richness to the text with the multiple and intersubjective meanings (Geanellos, 2000). In spite of these concerns, the least dissonant techniques within the four criteria, credibility, was incorporated into the study to establish trustworthiness.

Credibility

Lincoln & Guba (1985) recommend four broad measures to establish trustworthiness of a research study, credibility, transferability, dependability and confirmability. Peer debriefing and member checks were the two activities used to establish credibility. Peer debriefing provided another point of view by exploring various parts of the research including substantive, methodological, legal or any other relevant research matter by (Lincoln & Guba, 1985). They also suggest that it is "the process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for exploring aspects of the inquiry that might otherwise remain implicit within the inquirer's mind" (p.308). A peer researcher with experience in interpretive phenomenology research participated in this capacity.

Member checks were used in this study to provide opportunities for participants to review researcher interpretations for accuracy and were another way of establishing credibility. Guba & Lincoln (1985) suggest that member checks provide the most credibility to a study. Clarification of participant responses was one way of member checking before each research visit ended. This was an essential step in this study. Additionally, permission for a 2nd visit or phone call follow-up was a part of the initial participant research discussion and informed consent process in the study. However, once all interviews were transcribed, the second form of distanciation began and "the text must stand on its own" (Allen & Jensen, 1990, p.242).

Transferability

Transferability or extrapolating findings from one study, group of participants or setting to another study, group of participants or setting is, in a sense, incongruent with qualitative research. The general philosophical stance of qualitative research is that reality is a construction in the minds of individuals and therefore there are an infinite number of multiple realities. Based on this perspective, Guba & Lincoln (1985) suggest that qualitative researchers can provide rich description which will allow the researcher is audience to contemplate whether transferability is possible. This study followed the philosophical and methodological approach of interpretive phenomenology of Ricouer, who proposed distanciation, a movement from form one of transcription in writing of the dialogue to text, ultimately to form four, the reading audience beyond the researcher. Considering this, rich description was provided by this researcher; ultimately, however, Guba & Lincoln (1985) summarize, "that if there is to be transferability, the burden of proof lies less with the original investigator than with the person seeking to make an application elsewhere" (p.298).

Confirmability and Dependability

Confirmability and dependability include other techniques that establish trustworthiness. Guba & Lincoln (1985) suggest that confirmability and dependability are intricately connected because a demonstration of one is sufficient to establish the latter. The audit trail and reflexive journaling was used for this purpose.

An audit trail provides a record of researcher thinking, methods, data collection processes and analyses. Several audit trail categories were used to establish trustworthiness in this study. Maintaining raw data such as: audiotape recordings and

written field notes about observations of the interviews. Items such as these provide descriptions of phenomena, events, feelings of and by the participants as audit trail evidence. Comprehensive written field notes were used to record observations that occurred during each interview. Physical expressions, gestures, intonations, not audible during the recorded interview, and any other thoughts about the interview were included in the field notes and incorporated into the transcribed narrative texts later; naturally occurring observations during interviews, such as these, should be analyzed concurrently with the interviews (Crist & Tanner, 2003).

This journal was used to provide a record of daily research schedule and logistics of the study, a methodological log where decision-making and "accompanying rationales" were recorded (Guba & Lincoln, 1985, p. 327). A personal journal for the purposes of bracketing was not used in this study based on the tenets of Ricoeur's hermeneutic philosophy and methodology that this researcher followed.

Guba & Lincoln (1985) reminds readers not to compare trustworthiness within conventional research to naturalistic research. They describe conventional research as a "closed system" where one is compelled to accept trustworthiness. The naturalistic inquirer's research occurs within an open system and can "at best persuade" the trustworthiness of the research though its activities (p.329).

Summary

The philosophical foundation of the research design and the methods consistent with interpretive phenomenology based on the influence of Ricoeur were described in this chapter. Rationalization for the chosen research design was explained, noting that use of Relational-Cultural Theory sensitizing concepts are a key interest of understanding and

meaning in the context of African American women with diabetes and maintaining multiple roles.

Methodology began with a discussion of inclusion criteria for the participants and a description of the use of purposeful sampling. Steps for gaining access to African American women for the research and review of key concepts related to gaining trust in this community for research participation was described. Protection of the participants through activities such as use of a consent form and how anonymity would be maintained was described.

The process of data generation was through interview and field notes. The use of Ricoeur's three steps of analyzing the data were followed and moved from naïve reading of entire text of each interview, to structural analysis of meaning units described as interpretive reading, to comprehensive understanding, interpretation of each whole text again. A deeper understanding was meant to occur in this step. Field notes during and after each interview were used and aided in data analysis. Qualifications for leading this research study were provided next.

Data management followed with details about use of the current Atlas.ti computer software for coding of transcripts. The researcher's move to manual handling of data with color coding themes was described. The hermeneutic circle of inquiry, unique to interpretive phenomenology, was also explained. Criteria that were used to establish trustworthiness followed. Peer debriefing and member checks were used for credibility. In interpretive phenomenology, the activity of transferability lies with the person seeking application of a study elsewhere. Confirmability and dependability are the last two criteria to establish trustworthiness. Audit trail of raw data, such as the audiotapes, field

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notes and reflexive journaling were used as part of establishing trustworthiness of the

study.

CHAPTER 4

FINDINGS

The focus of this study was to gain understanding and meaning of the lived experience of African American women with diabetes and maintaining multiple roles through a relational-cultural perspective. African American women have been identified as one of the highest risk populations with diabetes and diabetic complications. And yet, African American women are engaged in multiple formal and informal roles over the course of their lives and participate in the labor force longer than other ethnic or racial female population in the US.

To further understand context of the lived experience of African American women with diabetes and maintaining multiple roles interpretive phenomenology research in the Ricoeur tradition was incorporated along with sensitized concepts from Relational-Cultural theory for this study. Concepts used from the theory were connections, disconnections, mutuality and power over. These concepts were used as a basis for the research study questions and interview cues with the twenty African American women who participated in this study.

The inclusion criteria to participate in the study were African American women with at least 2 years of Type II diabetes and currently maintaining 3 or more roles. Informal roles were defined as responsibilities within the home and/or with family, noting that meaning of family, from an African American cultural perspective, may be broadly inclusive of extended and church family and fictive kin. Formal roles were defined as responsibilities external to home or family. (See Table 4-1)

Table 4-1 Demographic Characteristics of Participants

Age	Retired=R Not Retired=NR	Number of Roles	Education
50-59	A=NR	8+	College+
	B=NR	5+	HS diploma
	C=R	4	Completed 9th grade
60-69	A=R	5+	HS+
	B=R	5+	Unknown
	C=R	8+	College +
	D=R	8+	HS diploma
	E=R	8+	College +
	F=NR	8+	HS+
70-79	A=R	4	HS diploma
	B=R	8+	College degree
	C=R	5+	HS+
	D=R	8+	HS+
	E=R	4	HS diploma
	F=R	8+	College degree
	G=NR	8+	College+
	H=R	8+	College degree
80-89	A=R	4	Unknown
	B=R	8+	HS+
	C=R	5+	9th grade

Although the original intention of the study was to seek African American women across the life span into the study, all 20 participants were primarily older adults (see Table 4-1 above). Eleven of the 20 participants were 70 years of age or older, three of those participants were in their 80's. Only one of the 20 participants was an active caregiver; although many of the women were grandmothers, they were not regular caregivers of their grandchildren. One participant was the caregiver for her mother for 14 years; however, her mother passed away in 2014. At the time of the research, only one participant was involved in child care on a consistent basis. Most of the women were retired and the multiple roles maintained were primarily outside of their homes. Roles of

the research participants were as few as 4 and as many as 8 or more. As defined by this study, these informal roles included many church and community activities.

A return to the research questions of the study was used as a framework to present the findings in this chapter. Each section of this chapter provides themes that emerged from the analyzed data of participant interviews as related to those questions. Definitions of the concepts used in this study are reviewed in the appropriate section along with a section summary.

Section 1 includes the first and second research questions: what are the day to day experiences of African American women with diabetes and how does maintaining multiple roles impact the day to day experiences of African American women with diabetes? Participants' descriptions evolved into three composites; composite first person narratives interpretive method was used for this process.

Wertz, Nosek, McNiesh & Marlow (2011) described this method as an integration of the voices of participants and researcher thereby emphasizing the connectedness between participants, researcher and listeners. These authors suggested that first person narrative is a're-presentation' that draws a composite picture of the phenomenon emerging from the informants as interpreted by the researcher and is based on knowledge of the literature regarding the phenomenon, listening and hearing the stories of the participants and through the researcher's reflexivity during the process. This method provided a means to illustrate depth and breadth of the day to day lived experience of the participants.

Section 2 provides emergent themes as connected to influence of relationships experienced as connections of African American women with diabetes and multiple roles.

The research question was how do relationships experienced as mutually connected, empathetic and empowering with feelings of zest, worth, productivity, clarity and a desire for more influence African American women with diabetes and multiple roles?

Section 3 includes emergent themes related to the influence of relationships with disconnections of African American women with diabetes and multiple roles. The research question was, how do relationships experienced as mutually disconnected, lacking empathy and empowerment influence African American women with diabetes and multiple roles?

Section 4 describes emergent themes related to influence of relationships experienced as mutuality of African American women with diabetes and multiple roles. The research question was how do relationships experienced as mutually respectful with the capacity to impact and open to change by the other influence African American women with diabetes and multiple roles?

Section 5 includes emergent themes related to the influence of relationships experienced as power over (powerlessness) by African American women with diabetes and multiple roles. The research question was, how do relationships experienced as hierarchical, fostering a sense of powerlessness influence African American women with diabetes and multiple roles?

Section 6 provides themes related to the role of nurses in enhancing experiences of connections and mutuality experiences of African American women with diabetes and maintaining multiple roles. The research question was what role might nurses play in enhancing connections and mutuality experiences of African American with diabetes and maintaining multiple roles?

Table 4-2 provides a capsulated version of the six sections of this chapter: Three composite types of participants related to research questions one and two and emergent themes followed by affiliated Relational-Cultural concepts of the study. A detailed description of emergent themes is provided in the remainder of the chapter.

Table 4-2 Composites and Themes

Section 1				
Three composite narratives of participants related to day-to-day lived experiences of African American women with diabetes and maintaining multiple roles.				
Section 2 (below)				
First Type of Connection: Fulfilling Connections Theme 1 (Related to First Type of Connection) Relationships Foster Sense of Well-being	**First Type of Connection:** Fulfilling Connections Theme 2 (Related to First Type of Connection) Partnering with God in Faith and Health		**Second Type of Connection:** Mindfully-rejected Connections Theme 1 (Related to Second Type of Connection) No Time to Nurture	**Second Type of Connection:** Mind-fully-rejected Connections Theme 2 (Related to Second Type of Connection) Values of Past Inform the Present
Connections Concept				
Section 3 (below)				
Theme 1: The Will to Keep Negativity Out			Theme: 2 Disappointment in Others	
Disconnections Concept				
Section 4 (below)				
Theme 1: Not a Matter of Age but What Each Brings to the Other			Theme 2: Closeness Developed Over Time	
Mutuality Concept				
Section 5 (below)				
Theme 1: Shackles On, Shackles Off			Theme 2: Financial Stress Makes Life Difficult	
Power Over Concept				
Section 6 (below)				
Theme 1: Informational		Theme 2: Trust is		Theme 3: Need for More

Support in the Neighborhoods		Necessary		African American Nurses

Section1:The Day to Day Lived Experience of African American Women with Diabetes and Maintaining Multiple Roles

Research question one was: What are the day to day experiences of African American women with diabetes and research question two was: How does maintaining multiple roles impact the day to day experiences of African American women with diabetes? Three narratives, re-presenting the three broad types of daily experiences described, are provided to offer more of a "contextual" understanding of the participants' day to day lived experiences (Wertz, Nosek, McNiesh & Marlow, 2011). The three re-presentation narratives were formatted in italics to differentiate them from exact quotes of participants.

Type One Composite

I'm an early riser; I think it's because I worked just about all my life and I wouldn't feel right just lying around in the bed. I was raised in the south and that's how it was, so I was it, so I get up despite some aches and pains. I like to say my morning devotionals once I'm up while my head is still clear 'cause once I get moving, I have a lot things on my mind and I'm really busy. I might do a few things around the house; but I always take my blood sugar and I eat a decent breakfast before I get going. It's the Lord's work and it's important to me but I've got to be healthy. I'm at the church frequently throughout the week. Some days it's my job to open the church in the morning and lock it up at night; so, I'm out early to do that. I run a program for seniors once a week and we have discussions about the Bible as part of my missionary responsibility. Some days, I help prepare a lunch at the church for people and other days I go to the shelter and help to serve lunches there. Since I'm usually out at lunchtime, it's likely I eat what is being prepared and served that day, at one place or another. They have to follow food guidelines so it works out okay with my diabetes. I am careful of what I eat when not at home because I've seen what can happen to people when they don't think about their diabetes. It seems like since I retired, I have a taste for everything, I have a taste for all kinds of junk food, but I know I can't have it so I don't buy it. I leave it right where it is in the store. My body is God's temple and I to try to honor it. I'm the church transportation coordinator but most of the time I wind up being the driver because a lot the older folks at church don't have their driver's license anymore, since I still have mine. I'm retired and I enjoy doing work in the name of the Lord; it as a blessing. I'm thankful, I can do it, praise the Lord. So many of the church members have problems with

their diabetes that stops them from moving around so easily; some can't even get to church on a regular basis. So as part of the missionary work, I go out with one to two other missionaries and visit the sick and shut-in from a church list. I pray I'm getting blessings now 'cause I'll probably be on that list one day. I love being involved at church and in the community but I know that to keep being involved I have to also love taking care of my diabetes. You can't have one without the other and I understand that.

The composite above re-presents elements of several participants in the study who led busy lives with roles primarily outside of their homes; they were mindful of needed management of their diabetes. This composite was a reflection of some of the most active participants in the study. Participants re-presented in this narrative expressed an understanding that their desire to maintain active and engaged lives through their multiple roles would only continue through the care of their diabetes health. Additionally, their perception of the importance of maintaining diabetic health in order to be active in day to day activities was circumscribed by religion and spirituality. Caring for their bodies as a vessel of God was described by some of the women as enabling them to carry out their day to day role commitments, which were so important to them.

Many of these women had strong ties with members of their churches and communities. The day-to-day lived experiences of these participants involved working with and for others in these settings. Some of these women were involved in multiple roles with their closest relationships and the roles they maintained further exemplified their connections and mutuality.

Type Two Composite

Every day is a busy day for me. I'm so involved at church, in the community, school and my family, sometimes I lose track of where I am. And, everywhere I go there are celebrations for this and celebrations for that. Foods in my face all the time, sometimes you just have to give in. So, sometimes, I bring my own food for these situations, but it's so hard. The thing is … the more I deny myself, when I do start eating I go overboard. Or, I have to be somewhere early and I don't eat breakfast. Sometimes, I don't eat until 1 or 2 0'clock in the afternoon and I know

by that time I should've had at least two proper meals. I know what to do, but for some reason I don't. If someone calls me on a night when I've been running all day I don't even hear the phone. It's not a case of can't do but sometimes I get carried away with other things. In our community, we don't have the luxury of stepping out of our roles like others. The bottom line is I'm a helper, that's what defines me. I do get tired; and sometimes I'm just tired of being tired but I have to keep moving. And, because I'm not a Type 1, where you learn to live with it from early on, I have to unlearn to cook and eat how I've been cooking and eating all my life. So when I come home from a very busy day, do you actually want me to unlearn and relearn how to do these things a different way? I just fall back to my old habits 'cause I'm tired and I don't feel like thinking too hard on it. I actually thrive on the busy-ness. Sometimes I say, is it the women's group or Bible study tonight? Am I tutoring or working with parents? And, it goes on and on. I do get stressed out and I feel like I'm losing my sense of self but I don't even take the time to stop and regain myself. It's those times when I know it spills over into my diabetes. I'll pick up something from one of those fast food places and I know better but when I come home tired I'm not about to cook a meal even though I know I should. I come home tired and you know I don't feel like cooking or eating right; I just don't. I need to find balance in my life and I need to take better care of my diabetes.

The second composite re-presented elements of women in the study who were

engaged in multiple roles, particularly informal roles outside of the home. Commitment

to church, community and family, from the expanded definition of family, was evident.

The women in this composite verbalized frustration and indicated a need to change

without knowledge of how to change for the sake of their diabetes. Diabetes was

subordinate to roles in the lives of the women re-presented in this composite. A clear

connection to the influences of roles on their daily lived experience was consistently

expressed as having a negative impact on their diabetes, particularly from nutritional and

emotional perspectives.

The women whose words contributed to this theme generally maintained no close

ties with others. The day-to-day lived experiences of these women as described was "all-

consuming" and was associated with little time for connections or healthy management of

diabetes.

Type Three Composite

I don't have a lot of interests right now and I'm not involved in a whole lot of things. My children call; they don't live too far away; but, they have their busy lives and I don't want to get in the way. It's been like this for a while, really since I retired and my husband passed away. I've had diabetes for quite a long time, too. I don't really test my sugar anymore and I'm still here so it can't be doing that badly. I generally eat what I want and I don't feel any different. I even stopped taking my medicines for a time and my doctor didn't even notice. I was told that my diabetes numbers were up a bit from my previous visit and just watch what I eat a little more. So, it didn't really matter that much. I have days when I'm not feeling so good and days when I'm feeling okay but if you asked me what my sugar has been on those days , I couldn't tell you. I haven't always been like this because when I was working, I was also keeping my house up and I was involved in a few things. During those days I watched my sugar more and tried to improve my eating. Then I retired and stopped being involved and going places. So really, over time, I just stopped testing my sugar and I eat what I want.

This last composite re-presented elements of a few study participants whose small number of roles was a reflection of limited responsibilities within or outside of the home. These participants had limited involvement with family as traditionally defined or as described for the purpose of this population and study. The emerged elements of small number of roles combined with limited connections suggested an undercurrent of hopelessness and lack of purpose in this re-presenting of these participants. Their day to day lived experience revealed a diminished concern for diabetes health.

In summary, the day to day lived experience of African American women was re-presented related to diabetes and maintaining multiple roles of the research participants. Three types of women were re-presented through first person narrative composites. First person narrative format was used to enhance a contextual understanding of the day to day lived experience of the participants. Each narrative was a reflection of several research participants. Type 1 composite of participants shared perspectives about the importance of caring for their diabetes. They were involved in many activities, particularly revolving around church. Consequences of poor diabetes care were viewed as detrimental to their

ability to be actively engaged in their multiple roles and commitments. Care of diabetes was considered a religious obligation for some. Mindfulness that roles went "hand and hand" with diabetic health was evident. Maintenance of multiple roles to church/ community "family" and care of diabetes were inextricable. Church and community roles were frequently joint activities maintained with close friends/relationships; there was a triangular association between roles-relationships- and positive diabetes health behaviors.

Type 2 composite re-presented participants that communicated poor diabetes management, particularly revolving around nutrition and blood sugar monitoring. Their daily lives revolved around activities related to church, community and family. They expressed a sense of being overwhelmed at times with their many roles. The connection between poor diabetes management and potential consequences was acknowledged by the women with role commitments having greater influence on their day to day life activities. Daily roles and multiple commitments resulted in a ripple effect with constant confrontation with perceived poor nutritional options outside of home and physical exhaustion and fatigue leading to poor nutritional choices and behaviors when at home. Roles and commitments to church and community "families" overshadowed diabetes health commitments with these participants and lack of connections with others.

Type 3 composite re-presentations of the day-to-day experience of diabetes revealed the least number of roles maintained by these participants. A lack of roles was associated with limited to no regard of their day to day living with diabetes. These women worked and cared for partners and others throughout most of their lives; however, the continuance of these activities varied amongst these participants. Feelings of isolation, loneliness and boredom were communicated by these participants; these

women had few to no connections to others. Their narratives revealed intermittent

medication adherence and lack of interest in nutritional aspects of healthy diabetic eating,

along with limited self-monitoring yet unremarkable medical outcomes.

SECTION 2:Relationships Experienced as Mutually Connected, Empathetic and Empowering

This section describes themes derived from participants related to the research

question, how do relationships experienced as mutually connected, empathetic and

empowering with feelings of zest, worth, productivity, clarity and a desire for more

influence African American women with diabetes and multiple roles? Use of the concept

of connections was defined as "an interaction between two or more people that is

mutually empathetic and mutually empowering. It involves emotional accessibility and

leads to the 'five good things' (zest, worth, productivity, clarity and desire for more

connection)" (Jordan, 2010, p. 102).

The theoretical definition of connection, usually explained as one concept,

diverged into 2 types of connections: Fulfilling connections and mindfully- rejected of

connections. Within each type, the experience of diabetes and roles emerged with varying

levels of significance. The following themes emerged in the context of fulfilling

connections: relationships foster sense of well-being and partnering with God in faith and

health.

Fulfilling Connections

This first of two types of connections is most closely aligned with the definition

of the concept of connection. Discussion of two emergent themes within this typology,

relationships foster sense of well-being and partnering with God in faith and health follow.

Relationships Foster Sense of Well-being

Several participants described connections as bringing joy and meaning into their lives. Within this group, some participants lived with people with whom they had fulfilling connections; the connections of others were maintained through primarily daily phone calls and others experienced satisfying connections through the various roles they maintained. One participant shared about her relationship with her mother who had recently passed away. They were very close with a similar sense of humor. Her mother was bedridden for 14 years and the participant shared, "I took care of her all those years". She described her mother as funny, happy, honest and frank despite her illnesses and the participant was the same with her mother. The participant stated,

The last 14 years with her were full of joy and love. My mother had many health issues but we both had diabetes. There wasn't anything we couldn't talk about including our happy times and disappointments with the men in our lives, our faith in God and our health challenges. I had small jobs here and there and when I would get home we'd tell each other about our day. She really was my best friend. I'm very close with my mother's sister, who is just like her and since my mother's death even more so. I talk with her 2-3 times a day; she lives in the south and just like me and my mother, we share everything.

Even when the participant's mother was alive, the three would talk on the phone several times a day. "We both miss my mother but we keep one another's' spirits up; we have a mutual admiration and love for one another".

This participant's relationship with her mother and present relationship with her aunt illustrates an example of the bi-directional benefit of connections and association with positive health behaviors. The participant describes how she translates her sense of well-being into her experience with diabetes. She is a jogger and runs 6 miles daily; she showed the researcher the paths she runs using her phone applications and, barring very inclement weather, she jogs throughout the year. She encourages her aunt, who also has diabetes to be as active as possible. The participant shared that despite her aunt's age and some health issues, "she walks a few times a week and does the best she can. I'm very proud of her".

She attributes who she is today to her relationships with her mother and aunt. She shared that her caregiver role was an important part of her life. "My roles as daughter and niece to my mother and aunt have helped me to have the balanced life I have today". Even when she is experiencing some stress, her aunt encourages her to "run because it will help you to feel better". Running helps to clear my mind and decreases any stress I might be feeling". She adds that her diabetes has been stable without problems for many years. The participant describes how growing up with these two women helped her maintain her sense of a positive self; "they told me to surround myself with positive people and so I did with both of them. I'm very busy now, but no matter what, I talk to my aunt several times a day, either she calls me or I call her."

Some participants shared about close relationships to other women with diabetes. Each described how they connect on many levels because the other women know what it is like to have diabetes. Physical, psychological and emotional feelings are all part of what these women share with one another. These participants and their friends have been

diabetics for many years and the relationships have grown proportionately since that time. One participant described a connection with her friend through the following example:

> I share everything with her and she does with me, the good, the bad and the ugly. Whatever comes into her mind she'll tell me and I can't get upset 'cause she's telling me the truth. I can do the same with her; I can tell her anything about what I feel or think of what's she's doing. We trust each other; that's for sure; we are comfortable around each other and when we're around each other we can be for real. But, I am a private person with most everyone else.

They are each other's first line of advice, before calling their doctors, one participant explains, "… because I trust what she tells me. We help each other with our diabetes all the time".

Some participants with other disabling chronic health concerns do not maintain roles outside their homes. One participant within this group states, "We are on the phone several times every day and know each other's diabetes so well, it's like I have hers and she has mine". Another participant stated,

> My girlfriend had diabetes first and she had it so bad, she would have to stop at my house to go to the bathroom because she knew she wouldn't make it home. She was the first one to realize when I got diabetes. We are always on top of our health, she encourages me and I do the same to her; we plan on being here for each other for a long time, that's what our friendship means to us.

The participant added,

> We get together for each other's birthday celebrations and we have so much fun but one slice of cake is all they let me have. And, of course, they're right. We laugh all the time and rely on one another for more than just help. We are each other's best friends and even with all of our health problems, we encourage one another to try to be healthy.

This participant has severe arthritis in her hands. She described upkeep of her apartment and involvement with multiple church responsibilities. "I don't drive anymore because of my hands; so one of them picks me for different things I do at church. One time we

almost missed our missionary meeting because we were having too much fun". I'll fix

dinner for whoever is driving. This participant has severe arthritis in her hands, my

diabetes has been okay; the arthritis is what slows me down".

Another participant described a friendship that imbued trust and caring for one another.

"People call her 'mini-me' cause I'm a little taller but we look a lot alike". The

participant showed me a photograph of her and the friend and said,

> We go to the each other's family reunions. If somebody calls me mom, they call
> her grandma because people always see us together. She was with me every step
> of the way throughout my cancer ordeal and I was with her through her medical
> illnesses. She fusses at me if she sees me eating something I'm not supposed to
> and I listen to her. My girlfriend will ask my opinion about something on a
> personal level because she trusts me and wants my feedback to make sure she's
> on the right track. We do and share everything with each other; since we both
> retired but we are still busy at church and a few things outside of church. She
> helps me stay on top of my diabetes and I help her on top of her health concerns. I
> thank God every day for her.

In summary, relationships described were associated with healthy diabetes and

other illness experiences by fostering exercise, appropriate eating and nutritional choices;

the women within these relationships served as sentinels of one another's diabetes and

other illness experiences. Examples of listening and providing trusted advice to one

another were shared by most of the participants. Connections were associated with care

of diabetes, other chronic illnesses and general sense of well-being. Roles were also

associated with the number of health concerns and disabilities.

Partnering with God in Faith and Health

Some participants stated that they talked with God and viewed God as their

partner and most important connection. One participant said pointing to the bible on her

table,

> I have one good friend that I talk with and we are very close. But, most of the
> time I talk with God. I tell him, yeah, I've had enough. But my relationship with

God goes beyond those times. I feel he listens to me and I get advice from him through the good book.

Another participant does local missionary work and states that she talks with God every day and describes her close relationship with God as "*blessed*". Both participants describe their diabetes as stable or improving and their many roles are primarily religious-based "with God at my side and the one I turn to for all things. He is my partner in all things". They describe their daily lives as being "guided by him" in their health and daily commitments. One participant shares, "my A1C has been between 6 and 7; I pray on it". Their daily roles involve missionary work in the prison system, assistant pastors in their churches and graduate work for degrees in counseling to facilitate work with parishioners and members in community.

The other participant is a retired nurse and states, "I know what to do and he helps me every step of the way".

In summary, despite the dyadic meaning embedded in the concept of connections, these participants continued to describe God as their most important connection. The women shared that God brings joy to their lives every day and guides them towards health.

Mindfully-rejected Connections

Participants within this typology clearly verbalized and were aware of why connections were not wanted or desired in their lives at this time. Two themes emerged within this typology of connection: No time to nurture relationships and values of past inform the present. A common thread amongst the participants representing both themes was the importance of maintaining multiple informal roles within their church and community. There was less consistency amongst these participants related to

maintenance of formal roles. Formal roles were defined as responsibilities external to home or family. The two emerging themes are presented below.

No Time to Nurture Relationships

Time was a key component of this theme within the mindfully-rejected type of connections with some participants. These women described inability to put the amount of time they perceived as necessary to invest and nurture a relationship. These participants denied missing connections or being motivated to gain connections at this moment in their lives. One participant stated,

> I don't have any close relationships and that works for me because friends require time   and a lot of work and I don't have the time to cultivate a relationship; … friendships   revolve around the people who I am involved with at the time for that time. I don't take the time to take the time to do the appropriate things for a real friendship.

This participant shared that she is involved in so many activities now that "there are times when I don't take the time or don't have the time to have breakfast". She describes other meals of the day in the same manner. "There are times when I don't stop to take my medicine before I eat. A lot of times, I'm eating and traveling in the car; … sometimes I feel overwhelmed with the pressure and it absolutely spills over into the diabetes".

Another participant used the same term, nurture, when describing inadequate time for relationships and shared,

> Right now my life is so full, I don't have time. You have to nurture a relationship and I   just don't have time. A lot of times when I'm out with somebody, I won't get home 'til   late. You know when I think about it, I'm not even willing to work on a relationship right now. I'm just involved in so many things. I have many roles at the church … and I'm a very dedicated mother of one and she blessed me with those triplets. I try to give the triplets experiences that the parents don't have time to do. No time for relationship nurturing and I'm okay with that.

When asked for more details about her relationship with her daughter, she stated, "I'm very close with my daughter but I try to hide stuff from her because when she finds out something (about my health, my insert) she gets on my last nerves".

Another common thread with these participants was the positions they held within their religious and political communities. The perception of sharing to the point of connection, as defined in this study, resulted in a degree of heightened sensibility of potential problems that could occur. Trust in confidentiality was described as not plausible. One participant stated, "I have to be careful who I befriend. I have to be careful what I say. I can't let too much out … and so friendships are at a limit and the level of friendships are even more limited."

The emerging theme of these participants, no time to nurture relationships, was related to multiple roles in church and community settings. No time as a deterrent to connections was also related to participants' perception of lack of motivation or desire to have connections at this point in the lives. Status and positions held by these participants within their religious and political communities resulted in a perceived inability to confide in and trust others.

These participants verbalized how important these various roles were church and community commitments were to them. They perceived their lack of time and multiple roles had a greater influence on poor diabetes outcomes than their conscientious decisions to not have close relationships at this time in their lives. "I do take the time to check my sugar on my monitor but sometimes I just don't want to know." These participants all listed 8 or more roles at the time of their interviews.

Ultimately, fulfillment of roles taking precedence over attention to diabetes health was related to lack of time and position and status of these participants and resulted in a mindful rejection of close relationships at this time in their lives. Lack of knowledge of how to improve their diabetes health within the context of their present busy lives was verbalized as a concern by these participants.

Values of the Past Inform the Present

Some participants described influences from the past that shaped their present beliefs about connections. A few participants were born in the south and raised within large African American extended families. Participants' histories were embedded in cultural and familial experiences that influenced their present thinking about not being involved in connections. Jordan (2010) describes this as relational images which are internal pictures of self in relationships developed over time that create a set of beliefs about one's understanding of relationships. She continues that these images can be positive or negative and can influence expectations of all relationships. One participant spoke about people, in general …

> I talk to people and I listen to them and they're having so many complaints, and you know some of them are married and so I listen but I don't want to get involved in that kind of thing. And, if I get into it with a person, they could turn on me, just like that. If I say a thing it runs tail up and what she said. And that's why I keep my mouth shut. My mother always said, don't get into other people's business; you bring a load they carry one so don't give 'em no load to carry. That was my mother's way of telling me to keep to my own business and not get involved with other people other than polite social graces.

The participant describes her father as the major influence of why she stays busy and involved into the present day. Her father would see her sitting and he'd say, 'you sit down too much. You sitting down like that, you know sitting will make you lazy and lazy will kill you'. "So I thought that too. They had me brainwashed". She chuckled after

saying that. "If I'm sitting down I might die. Get up and do something". Family values

and cultural beliefs appear to have had significant influence on the participant's attitudes

about working and being industrious. Being "lazy" was viewed as a negative

characteristic and was to be avoided by staying active; being busy would be a benefit

towards a healthy life. Keeping busy and staying out of "other people's business" were

words she heard throughout her youth. Since retirement she reports I keep "busy at

church and I try to walk around the track near my house a few times every week, if the

weather allows". Family values and cultural beliefs appear to have had significant

influence on this participant's attitudes about relationships and connections. Her father's

influence of "keeping busy" and not being idle translated to an active lifestyle regime

through frequent exercise.

Other women described the cultural and family expectations of keeping

commitments, such as staying in marriages in spite of extreme challenges. The spousal

role was alluded to as a "duty until death" expectation and considered normal amongst

these participants. One participant stated, "I was married for many years to a man with a

drinking problem". She described the situation as "his problem" and shared about how

she cared for him at home and advocated for him in the hospital.

> They wanted to put him in a nursing home and I wouldn't let 'em. He stayed in the hospital until almost the very end of his life. He's in a better place now". Family values and cultural norms of the generation of some of these women circumscribed expected spousal and other familial role behaviors. The participant summarized the notion of connection through her role responsibilities as, "it so tainted me to getting too close to people. Now I can do things and go places and drive. …and here I am still busy and still happy.

This participant has been a widow for more than 10 years. "I'm a diabetic, so I go

to the gym 3x a week a week now, I goes to a track and walk sometimes and I have 3

pieces of equipment in my house that I use. I also go to bible study and Sunday school

every week in addition to all the other things I told you I do." Another participate stated, "I love my daughter; she is a very kind and good person. Sometimes we come to that line of closeness but we don't cross it. We're mother and daughter; we're friends … not best friends".

Some participants described how in their families and communities everyone had "assigned" relational roles and stayed within them. Strong family and cultural influences shaped these participants' views about connections, health and indirectly diabetes. These participants perceived connections and health as separate from each other.

In summary, the concept of connections diverged into 2 typologies: fulfilling connections and mindfully-rejected connections. Fulfilling connections revealed 2 themes: relationship foster sense of well-being and partnering with God in faith and health. Within the first theme, the participants experienced connections of mutual trust and caring for one another and emotional openness. The experience of diabetes was positive and generally healthy. The second emerging theme was Partnering with God in faith and health. The participants viewed God as their partner and this connection as influential in every aspect of their lives. The dyadic nature of the connection concept was redefined and diminished by these participants who verbalized strong statements and feelings about their one and true connection. The participants within this theme considered their diabetes as stable and identified God as the reason for that stability.

The second type of connection was mindfully-rejected connections. Women conscientiously chose not be involved in relationships related to the nature of their roles, such as their position and/or status within the church or community or the past familial, cultural and religious influences in their lives. Two themes emerged from this type of

connection: No time to nurture relationships and values from past inform the present. Commitment to and importance of roles was placed above commitment to their diabetes within the no time to nurture theme. One shared, "I know what to do about my diabetes; I just have to do it". Roles defined who they were to self and others; diabetes did not.

Within the theme values from past inform the present, participants' responses to relationships reflected family-embedded values from earlier in their lives. Culture framed their present attitudes about relationships. Thoughts about the potential hazards of relationships were a major deterrent and were emphasized during their conversations with this author. A second factor, from a cultural perspective, was described within the role of marital commitment and its' negative influence on relationships. One widow stated, "I did my duty until his death and now I'm busy but no more relationships". These participants are mindful of their diabetes and making attempts to maintain healthy behaviors, such as exercising as described earlier.

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Section 3: Disconnection Experiences of Diabetes and Maintenance of Roles

This section describes themes derived from data analysis of participants related to the research question, how do relationships experienced as mutually disconnected, lacking empathy and empowerment influence African American women with diabetes

and multiple roles? This study used the concept of disconnection; disconnection is defined as an interaction in a relationship, "where mutual empathy and mutual empowerment do not occur; usually involves disappointment, a sense of being misunderstood … and a sense of impasse" (Jordan, 2010, p. 103).

Two themes emerged from participants related to the research question of disconnection: the will to keep negativity out and disappointment in others. The will to keep negativity out emerged from adamant denials of disconnection within present relationships by most of the research participants. Several factors were revealed in support of this theme, such as: religion/God, culture, age and financial wherewithal to prevent disconnections and negativity. Some of these participants described earlier life experiences that related to relationships of disconnection. Only a few participants described a sense of mutual "separation" in their relationships with others; however, their stories provided clear examples of that sense. An underlying theme of disappointment in others emerged. Both themes will be described.

The Will to Keep Negativity Out

The most populous emergent theme of the study was based on adamant denials of disconnections by the majority of the participants. Many of the participants declared that they would not allow "it" in their lives describing a general intolerance of negative relationships. One participant stated, "I stay away from them (referring to relationships of disappointment and being misunderstood, my insert). I'm not going to worry my nerves". Another participant shared how she prevented disconnections, saying, "I'm gonna tell you, I won't tolerate stressful relationships. I'll tell you the truth and good communication is the key".

Some participants provided a spiritual or religious emphasis on why disconnections were not a part of their lives. One of the women stated, "I look for 'positiveness' in all relationships. I turn it around. I don't even 'see' disconnections because my religion moves me into the positive". With others, prayer served as a barrier to disconnections. One participant stated, "I pray on things and I can feel an evil spirit and if I feel it, I'm gonna try to stay away. When evil spirit speaks, I try not to hear it". Her thoughts suggested a combination of religion and culture as influencing her control over disconnections. Some participants related an association between past disconnections and poor diabetes outcomes.

Other participants shared stories about negative relationships in their younger lives impacting them on many levels and ultimately their diabetes. One participant described several people (husband, brother's son and a roommate) in the past and how trust and understanding were not really there. "I trusted them and thought our relationships were something they were not; they had to go. I monitor my blood sugar and I see a clear way to whom or what was in my life. I just won't allow it". Another participant shared,

> I have to say to my youngest son, you can't call me before a couple of days because you know I have to distance myself from that stuff. So that's my rule. If you're not dead, in the hospital or buried, don't call me. And they know that's the rule, if it's negative; it has to stay away because my sugar can't take it.

This participant has 7 children and explained, "I've gone through a lot with these children and by the time I got to him (referring to her last born child, my insert) I decided some things had to change".

The perceptions of participants about disappointment and being misunderstood in the past within this theme led to setting boundaries or providing clear messages to others

regarding negative relationships and cognitive reframing of what would no longer be acceptable to themselves. Failed marriages, unstable lives in the past and chronic illnesses in the present have led to various strategies to prevent disconnections in some participants' present lives.

One participant described using her financial stability to gain control of her life and reduce past unsettling experiences of disconnections. She humbly stated, "I bought a small house around the corner from me. My daughter-in-law and my grandson live there and pay a small rent. It stabilized their lives and decreased the negativity of the past that I experienced". This participant's financial capability provided a means to reduce disconnections and her sense of powerlessness. She shared about not being very healthy during those unsettling times. "Diabetes was in my family but I didn't think about it until I got it". The participant confided that she was not "eating right or exercising at all". This participant, now retired, lists engagement with community, church, occasional caregiver role with grandchildren and maintenance of her health as her top priorities. She shared, "I go to the gym four to five times a week but not the weekends; those are my days off". This participant attends aerobic and yoga classes at a local gym near her home.

Aging and a growing intolerance of disconnections was another example of the will or intentional removal of disconnections in another participant's life. She shared,

> I've come to a point in my life at my age that I can't let people stress me. I'm older and I'm not gonna take the stress; I'm not taking it on. You're an adult, you do what you gotta do and I'm not gonna come there and pretend and depend upon you. That's how I have to look at life now and I won't deal with it. God helped me through a lot of that and helps me with my diabetes now. My A1C was 6.5 at my last visit; I was surprised it was that low … and it's been staying like that for the last 2 or 3 years.

This participant's active engagement in removing disconnections from her life, suggested she viewed an association between keeping negative connections out and her present

healthy diabetic outcomes. This association was similar to other participant perspectives within this theme.

In summary, the majority of the participants denied relationships of disconnections in their lives presently resulting in an emerged theme of the will to keep negativity out. One group provided several explanations supporting this theme, such as: a general intolerance of negative relationships, spiritual and religious beliefs such as prayer and being positive, cultural beliefs such as refusal to "hear" evil spirits and prevention strategies such as good communication. Some participants associated negative relationships with poor diabetes outcomes in the past. Another group of participants within this theme identified other factors that contribute to their will to keep negativity/disconnections out of their lives. They described having negative relationships in past that have strengthened them against repeating those experiences in the present. Other participants described their growing intolerance of negative relationships as they have aged. Two strategies described by a few participants were use of present financial wherewithal and, as with the other group, clear communication. The participants' refusal to condone negative relationships/ disconnections in their present lives was associated with positive diabetes health behaviors, particularly regular exercise as important and maintaining appropriate ranges of their A1C levels.

Disappointment in Others

A second theme that emerged from relational disconnections was disappointment in others. A fewer number of participants described disconnections with individuals who were not within their family and others described disconnections with family members.

One participant describes a relationship with a group of women over several years. She

shared,

> We had a group that I felt was good for me. There were six of us. At first we
> talked about general things, not personal but as we became closer it did become
> personal. We shared and I opened myself up as a part of this group and it
> became very vicious. I took a royal beating for this. I felt stupid and disappointed.

These experiences occurred over an extended period of time. The participant remained

silent for periods of time during the conversation and then would continue.

> I know that during the height of this my blood pressure was up and even though I
> don't know for sure what my blood sugar has been; I'm sure it's up. I monitor
> my diabetes through my diet. But I can say since those events I am now waking
> up go to the bathroom and I can't get back to sleep and I'm eating all the time.

The participant was asked if she had had a doctor's visit since these experiences and she

stated, "Oh, I did go to the doctor and my A1C was high. She (the doctor) asked me if I

wanted to talk about anything; she knew something was wrong but I didn't want to talk

about it". The participant described herself as a private person who finally "risked" being

involved with individuals perceived to be similar to her and the consequences of the risk.

She verbalized her disappointment by sharing,

> I'd rather be alone in my house than alone here but my house was sold. She (the
> doctor) put me back up to 500 mg of the Metformin. It's been 4 months since this
> all happened and I'm pretty sure these changes in my diabetes complex of
> hundreds of people and I feel so lonely. We're still together but not really; it's like
> dead air.

The participant described herself as generally shy and historically and never stepping

outside of her usual comfort level. "I regret doing that now because look what happened".

The disconnection described by this participant was experienced with individuals who

were not related to her.

Other participants described disconnections they experienced with close relatives.

One participant shares a disappointing relationship with a son who just recently passed away.

> We use to be close; in fact, out of all 3 sons I felt we shared a lot. I trusted him and I thought he trusted me; he lived here for a while with his daughter. It was great! Then she left to live with her mother and something happened. He started doing things I didn't like. He became disrespectful to me. I lost all faith in him and we weren't getting anywhere with the way things were going so I asked him to leave and now he's dead.

This participant pointed to a table in the corner of her dining room. She called it her "death table" and points to members of her family that have died including her mother, sisters, brothers and "that's my son that recently passed". The participant attends church. "And when I go to church, church is church. It's not a connection with people that I don't know in church".

The participant described a sense of "betrayal and disappointment" with her son. She discussed being discouraged about "a relationship that maybe really never was". This participant is one of many participants who are on Metformin. She says, "I would take my medicine most of the time. I really was not eating right. I really didn't care about much of anything". She feels strongly that her lack of interest in her diabetes and much of anything else was affected by her disconnection with her son" However, just recently the participant started attending church and is pleased about being "more involved in things again". This recent change suggests an association between relational connections and psychosocial aspects of health through the participant's decreased isolation.

Another participant described a relationship "gone bad". She was referring to her mother and alluded to a period of time when "things happened to me and I know she knew about it". The participant asked that the tape recorder be turned off because of what she wanted to talk about. After she shared off tape, the participant allowed the researcher

to turn the recorder back on and shared, "That was many years ago and we are close in some ways now; but, deep down inside my disappointment in what could have been feels very real". She changed the topic and signaled she was ready to move on with the conversation. Speaking of diabetes she reported,

> I eat too much, and I have had diabetes since the age of 40; so I know better. I am an emotional eater; I finally figured that out. So I try to stay in the present and not wander back to past sadness. My blood sugars are so up and down the doctor is considering placing me on insulin. I don't want to go there. My mother has diabetes, too; so we do try to help each other in that way now. I keep busy these days and it's always challenging to me to eat right when I'm busy.

These participants were placed within the theme of disappointment in others. They comprised a small number of the twenty participants. One participant described disconnections with friends while others with family members. All of these women described disconnections as being associated with poor diabetic outcomes. Although one participant described herself as "very busy", the majority of these participants described limited engagement with internal or external roles.

In summary, two themes emerged from data analysis related to the concept of disconnections and influences on the diabetes experiences and maintaining roles of the women in the study: The will to keep negativity out and disappointment in others. The will to keep negativity out emerged as a theme with the majority of the participants in the study. They described reasons why disconnections were not currently in their lives or conscientious ways that disconnections were prevented from being currently in their lives. Age and a sense of learning from disconnections in the past influenced some participants' strong intentions to prevent similar relationships in their present lives. Intentional actions and strategies were used by some to prevent disconnections from their

past into their present lives. Religious, cultural and familial beliefs were viewed by many participants as having significant influence on preventing disconnections currently.

A very small number of participants were included within the theme of disappointment in others. Most described relationships of disappointment and misunderstanding with family members while one participant described a relationship with friends where the "risk" of disconnected friendships resulted in regret and feelings of vulnerability. Participants struggled with responses when cued about mutual disappointment. Two participants responded similarly by saying, "I don't know, you'd have to ask them;" the other participant said, "How would I know?" Interestingly, the majority of these participants maintained the fewest number of roles of all the women in the study. Disconnections were associated with limited monitoring of glucose and general disinterest in diabetic healthy behaviors.

Section 4: Mutuality

Mutuality is the third concept used in this study from Relational Cultural Theory. Mutuality was defined as mutual growth "toward an increased capacity for respect, having an impact on the other and being open to being changed by the other" (Jordan, 2010, p. 105)". Some participants shared about relationships that were mutually impactful on many levels. Two themes emerged: Not a matter of age but what each brings to the other and closeness developed over time. These themes are presented below.

Not a Matter of Age but What Each Brings to the Other

Participants described personal stories about relationships where similarity in age was not a common factor. Other characteristics such as: deep caring, respect and a track

record of trust for one another were most frequently spoken about or inferred by the women.

One participant who is 70 years old described the characteristics of the relationship with her friend of 7 years.

> She's only 52 but we hit it off right away". You would think that our age difference would be important but it's not; we're so much alike. We share everything and have helped one another in so many ways. She's a catholic and doesn't go to church and I'm a Christian but she has always listened to my thoughts and seems to understand my love for my faith. And, in turn, I listen to her views; we have interesting conversations. She doesn't realize it but over time she's grown spiritually. I'm a fretter and it has aged me. She has helped me to be more accepting of things that I cannot change.

The participant shares, "she's not a diabetic but her mother is, so we're always talking about how to keep healthy". The friend compares the participant to her mother and tells her, 'I wish my mother was at least trying like you are'; "I appreciate her comments because she speaks the truth. She wouldn't say it if she didn't mean it". The participant reports that the friend praises her about her improving diabetes healthy behaviors.

This participant is one of the most active in the study, such as: being involved in multiple activities at her church and pursuing a graduate degree to further her abilities within her faith and church. The participant summarizes, "my other interests are to stay busy. It keeps me going. I'm not going to be sitting at home doing nothing".

Another participant described a "favorite granddaughter" who is 26 and currently lives out of state. "She and I have been like this (she designates finger crossing meaning they have been close) for all her life". They had a brief period of difficulty with each other but "now we are back calling each other. I look forward to our phone conversations a couple times a week. I get off the phone and I feel so good and I know I have helped her immensely just through talking". Her granddaughter provides a sense of comfort to

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her just hearing her voice. "I tell her about my exercising; she tells me about the good things she's doing, so we help each other". The participant describes how her granddaughter has been encouraging her to get involved with activities outside the house "so I joined a church and I'm a greeter now. I want to make people feel comfortable, when they come to our church, to feel welcome". The grandmother values the concerns and advice about her health from the granddaughter and has benefitted from the advice by attending an exercise class for seniors. In turn, the granddaughter was in a relationship that ended and described feeling depressed to her grandmother. Through conversations on the phone, the granddaughter shared with her that she thought a lot about what I said to her and *"she's back on track"*.

Closeness Developed Over Time

Participants described lifelong or lengthy timeframes that grew to be relationships of mutuality. Some participants describe relatives such as siblings within this theme. One participant has a sister that she is now very close with. They attend the same church and share many activities together. The sisters have experienced family member losses and other tragedies that as the participant shared, "we've gone through so much together over time and as we've gotten older we just have developed a closer bond". Now both have diabetes and that has become another part of their shared experiences. Honest and open communication has always been a part of their life experience.

> We got that from our mother. We advise and listen to each other and have acted on the advice. She's thinking about joining the exercise class I'm in and I've adjusted what kind of food I buy now. She's up on nutritional stuff. We don't always agree but we laugh about and keep moving.

This participant and her sister have impacted one another on many levels as they have aged; common experiences such as family tragedies, losses and diabetes with a sense of

the importance of listening, sharing, humor and respect. They have impacted one another related to diabetes and other life situations.

Shared experiences of tragedies and joys were a common thread amongst other participants and supported the emerging theme. Other participants have had friends over decades, knew each other when working and well before retirement. A few participants grew up or met in church or in other settings many years ago and have been friends over these lengthy periods of time.

One participant described a platonic relationship with a male friend. She shared how the relationship has spanned over 30 years "where we both continue to learn from each other; I would say we almost have everything in common". Their similar interests include architecture, jazz, cooking and health. Both have chronic health concerns; however, he does not have diabetes. "We fuss at each other about taking better care of ourselves, me with the diabetes and him, with his blood pressure problems. That's our way of showing love for one another".

This participant describes a friendship of teaching and learning from one another that continues to this day, summarized by the participant as "life lessons". Neither of them are "exercisers, per se" but describes how active and involved in community and church. She listed her roles as the following: choir, missionary, feeding the homeless every Saturday and teaching Sunday school every week. "He tells me to stay active for my diabetes and I tell him to stay active for his high blood pressure". He owns his own business and still works. She states,

> I'll call him up and check on him 'cause he's a workaholic. When you're that age and you are a workaholic, it can be dangerous. I'll call him up and tell him to close shop and go home and he'll do it. He knows I have his best interest at heart.

This relationship was one of thirty years with both being married to different people over many of those years. A sense of mutual respect and ability to impact one another over this extended period of time was described.

Another platonic relationship was shared with the researcher that has existed for about 15 years. They met at her place of employment. He is married with one child and she is a single parent mother. She described a book club they started and although many people have entered and left the book club these two and one other individual have been a part of this book club since its' inception. She alludes to gaining so much more from the book club than expected, such as increased understanding of self and others on professional career levels and personal family levels. She values this relationship which has mutually facilitated these areas of her life.

In summary, the concept mutuality from Relational Cultural Theory was defined. Key characteristics of the concept are having the capacity for respect, open to impact and change one another. It is not a matter of age but what each brings to the other and closeness developed over time were the two themes that emerged in the study.

Age differences with some participants were dismissed as not important. Grandmothers and granddaughters and friends were examples of relationships that were mutually respectful and impactful. They helped each other by providing comfort through difficult times and listening and learning. Being open to change was exemplified by these relationships. The participants' relationships with younger individuals reflected diabetes as one of many aspects of these relationships from which a mutual benefits has been experienced.

The second emerged theme closeness developed over time. Siblings, friends and platonic relationships were provided as examples of participants whose sense of mutuality with others grew over time. Love, respect, common tragedies and losses moved siblings towards greater respect and capacity to learn from each other over time. Diabetes and other chronic illness have further deepened these relationships through the years and moved one another toward improved diabetic outcomes. Platonic relationships spanning over years has brought some participants to a sense of mutuality with others. Mutual respect and trust have led to improved health and growth in many other areas of their lives.

Section 5: Relationships Experienced as Power Over

This section of the chapter will provide an emergent theme related to the concept of power over from Relational Cultural Theory. Used in this study as a concept, power over was defined as a hierarchical relationship where a dominant individual, group or situation engenders power over others and does not foster mutually empowering relationships (Jordan, 2010). Some participants described a sense of powerlessness, a proxy for the power over theory concept related to informal roles within their family. The two themes that emerged through data analysis were shackles on, shackles off and financial stress makes life difficult.

Shackles On, Shackles Off

One participant shares her story of her sense of powerlessness from childhood. This participant began to softly cry. This author stopped the tape recorder for a few minutes and began again with her permission.

> My life from a very early age was one of caregiving. I was the oldest of all the
> children and my mother died at a very young age. When I was 15 or so, I got up

made breakfast for all my sisters, brothers, nieces, nephews. You didn't question your responsibility in those days; you simply did what you were told to do. I got them all off to school and then I went. When school was over, I came home and made dinner for everyone and then I went to work. I did not share my feelings with anyone; you knew to keep those things to yourself. I attended college for 3 years but left before entering my last year and got married. That was a mistake.

This history led to not easily sharing feelings with people to this this day. "I missed most of my childhood. Now when I'm playing dolls with my granddaughters and they want to play with mine … I won't let them". She chuckles after saying that.

I even raised 4 children that were non-relatives. And, I'm still caregiving. I take care of my great grandson every day; he's 18 months old and I love him to pieces. But you know, I'm retired and I'm tired. Sometimes I feel like I got on a bus when I was 15, I didn't know where it was going and I never got off.

This was alluding to others in her family that had power over her life.

This participant has several other medical diagnoses besides diabetes and takes a number of medications. With further interview cueing about her sense of powerlessness, she said, "That's why I told you my life story. When I got diabetes, it was just one more thing out of my control; I took it in stride". The self-realization of a possible connection between the sense of feeling out of control with her family all of her life and her diabetes seemed to unfold as the participant spoke about the love she had for her family and her caregiving role she had throughout her life. She concluded the interview by saying, "I don't test my blood sugar. I don't really want to know. It is what it is. I'm in misery".

Another participant works and maintains multiple roles on local and regional levels in her faith. She describes her family as very close and credits her parents for emphasizing the importance of family their developing years. She explains, that her mother was "very religious and the one who instilled strong religious values on the entire family". The importance of caring and protecting one another were other values this participant heard throughout her life. She describes loving her family very much;

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however, *"… some negativity is there. I remember when I was younger and trying to figure out what I was going to do with my life, I came home one day and my sister had enrolled me in nursing school and told me when I was to start"*.

The participant used a phrase*, "shackles on, shackles off "* as a way of saying she does not perceive a sense of powerlessness all the time; however, there is a constant undercurrent of power imbalance within the family's relationship with her that situationally emerges and causes feelings of unease and discontent within her. She shared, "I tell my sister everything but I know she doesn't share all with me. I don't think she does the same to me". The participant confides, "I think my sister wants to be my only friend. I try to manage it but I don't get rid of it*"*. Finally, she does not perceive her family experiences as impacting her blood sugars, *A1C* or diet.

In summary, these participants shared stories that provided rich data reflective of the theme shackles on, shackles off. These participants were highly engaged with their families over many years. However, their acceptance of feeling powerless and its' impact on diabetes differed. One participant appeared to have settled into feelings of powerlessness and does not engage in thoughts or expectations of changing the situation. Tolerance of a sense of powerlessness with family relationships and caregiver roles over her lifetime continues. Another participant verbalizes attempts to "manage" her sense of powerless by situationally ignoring it or acting on it in some way. Other participants in the study denied powerlessness with relationships.

Financial Stress Makes Life Difficult

A few retired participants described not experiencing powerlessness in relationships with others; but instead, shared stories of lack of economic freedom and

experiencing financial challenges as leading to a sense of powerlessness. The emergent

theme was financial stress makes life difficult. Some participants described the

challenges of keeping up with mortgage payments. Others spoke of concerns about the

city government "stepping in" because their house was in disrepair. One participant

shared,

> I was up on the ladder doing my porch ceiling; I try to keep the place up best I can. I'm trying to keep up with my bills but it's hard. That's what I was thinking about feeling powerless. It's not a people situation; it's my money situation. I think if I lost this house that would put me in the grave.

Another participant described, "My son moved in and I thought he was gonna help out

financially but he's not here half the time. And, then he lost his job". She could no longer

afford to maintain her car payments and gave her car up which has led to feelings of

isolation. "I usually don't feel any different but I don't check my sugar the way I use to

and I haven't been involved with much of anything for quite a while". Another

participant shared, "I had to give up my car". This participant could not maintain car

payments and insurance; lack of transportation left her feeling no longer in control of

where she could go and what she could do.

Perceptions of impact on diabetes were generally not verbalized about in the context of

financial stress with few exceptions.

In summary, this section described perspectives of relationships that foster a sense

of powerlessness of participants with diabetes and maintaining multiple roles. Two

themes emerged through data analysis: shackles on, shackles off and financial situations

make life difficult. Participants within the theme of shackles on, shackles off experienced

a sense of powerlessness in relationships with family members over their lifetimes.

Responses to these relationships differed between the participants. One participant

attempted to manage with some degree of success and does not perceive any influence on her diabetes. With another participant her feelings of powerlessness in relationships suggested some spill over into her diabetes.

The second theme of financial stress makes life difficult emerged through data analysis of other participants. These participants did not identify a sense of powerlessness from relationships; instead a sense of powerlessness was described related to a life situation of lack of financial adequacy. These participants are retired and expressed fears and anxieties related to keeping and maintaining their homes. The participants described consequences of inadequate financial means, such as decrease in roles and loss of means of transportation resulting in feelings of isolation.

Section 6: Role of the Nurse in Enhancing Connections and Mutuality Experiences

Data analysis as related to the final research question is described in this section. The final research question was: What role might nurses play in enhancing connections and mutuality experiences of African American women with diabetes and maintaining multiple roles? Three themes emerged from participant discussions about the question. The primary theme was nurses as informational support; this theme emerged as a major perspective with many of the participants. The second theme was trust is necessary and the third theme was need for more African American nurses.

Nurses as Informational Support

Many of the participants viewed nurses as primarily providing informational support. Some of the women described what it was like when nurses "use to be out in the neighborhoods". It was the perception of many participants that that was when "great nursing was done". A few participants suggested a newer version of nurse activities in the

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communities, such as block or neighborhood teach-ins. This vision of the role of the nurse in teaching diabetes, particularly, the importance of exercise and nutrition was described based on their memories of what nurses did when they were younger. One participant recalled, "Some women from the University use to come to people's houses and teach the mother's how to cook for their children with the surplus foods". She could not remember if the women were nurses. Others, also remembering what nurses did in the past, suggested that nurses should come into the homes to teach families about diabetes and cooking nutritiously, replicating what they recalled about the work nurses did in the past. A few participants suggested putting out surveys and based on that information provide local neighborhood seminars.

The majority of the participants thought of nurses as providing physical care and teaching about diabetes and other health topics. Participants did not envision nurses in a psychosocial role as related to facilitating meaningful connections between themselves and others. They described limited experiences of this nature with nurses in physicians' offices or when in acute care settings.

Trust is Necessary

A few participants described the importance of trust between nurses and clients. They described that trust was a priority before anything else could occur. One participant shared, "If there was trust between us (meaning participant and nurse, my insert), I think I would see clear to having a nurse work with me on that personal level. I'd be willing if I felt as if the nurse was striving to help … with relationships". She described that, thus far her experience with nurses has been in the doctor's office and in the hospital. This

participant concluded "there was never a time or an opportunity to develop that trust to go any further".

One participant described how close she was with her doctor. "My doctor asks me about how things are going. I feel so comfortable with her and trust her without any doubt. She actually sits down with me and has held my hand when I have discussed personal not physical concerns". She paused and then said, "If I had a connection like that with a nurse where there was that kind of trust between us then I would see the possibility of that nurse working with my family". Another participant shared, "I've seen some people in the building that have home care nurses and I hear about how they trust them and are very close with them. Some of the nurses come in the evening when family is here".

Some participants shared experiences of healthcare providers, including nurses, being judgmental about the outcomes of their diabetes numbers and their general diabetic health. They suggested that coming into people's homes would mean, "… leaving judgment at the door because judgement and trust don't can't go together". Another participant shared that, "judging on both sides would need to be let go". Two participants brought up the Tuskegee experiments on black men and one stated, "I guess I would have to let go some of my suspicions, if I would expect them to leave their judgements at the door."

Other participants described how important it would be to have nurses help individuals feel more "at ease" with their diabetes. They shared that health care providers, in general, made assumptions about them and made them feel guilty. These participants described how nurses could provide diabetes education without a "blame the

victim" mentality. One participant stated, "Nurses should not use language that puts a person down. Doing more asking and listening would be a great start".

In summary, trust is necessary emerged as a key theme of participants' descriptions of nurse involvement with relationships as connected to their experience with diabetes and maintaining roles. Historical references of health care providers' treatment of African Americans was a context for some participants' difficulty viewing nurses as assisting with their relationships with others. More recent personal experiences of negative judgement during nurse interactions with some participants diminished the plausibility of nurses' assisting with relationships as connected to their experiences with diabetes and maintaining roles. Strategies to increase trust and the likelihood of nurses being able to assist with relationships included asking more questions and listening more, increasing comfort level of patients about their diabetes and preventing judgement from being part of any interaction with patients.

Need for More African American Nurses

The need for more African American nurses was a theme that emerged with some participants. One participant described the need for more nurses that look like the people in the communities, "… helping our people with diabetes and having enough of them to help us over the hump. I don't know … six months or so and then give us our wings". She further describes that the language of an African American nurse,

> …would resonate with me in a different way. An African American woman can say 'listen' … and the minute you start a sentence with that word, somehow, it would come across like I ain't playing with you, and, that would be helpful to hear from someone that looks like me.

This participant suggested that direct language and communication from someone of her own race would be listened to; however, those same words from a nurse of another race

would be considered offensive. She ended by saying, "this is reality, based on our history, perhaps".

When revisiting the interview cue about a nurse's role with relationships of African American women with diabetes and maintaining multiple roles, the participant continued to include the importance of African American nurses working with African American families.

One participant shared, " … because she looks like me, I could see her working with my family to help everybody to be on the same page as far as nutrition and eating right. The nurse could help them to understand the importance of working together about the diabetes".

Participants primarily referred to diet and nutrition when discussing the role of nurses. However, a few participants similarly shared that nurses who come from the same background might be better able to help in relationships and encourage honest and open feelings about diabetes. One of these participants said that, "the first thing for all nurses is to be good listeners." Another participant said,

> An African American nurse would have to build a trusting relationship herself first and then, I think, just start asking the needed questions about improving family relationships to improve diabetes would work. Those types of questions could be more easily heard from a Black nurse than from a nurse of another race.

Participants struggled with the concept of any nurses, including African American nurses, working from a psychosocial perspective, such as relationships, despite sharing their experiences of relationships with others during the time spent with the author of this research. Some of the participants continued to return to African American nurses' need to work with families about diabetic nutrition and being healthy. A few participants concluded that African American nurses would need to first build a foundation of good

listening skills and trust; consequently, African American nurses would be able to ask relationship questions, more comfortably than nurses of other races. Some participants made historical references in the context of trust and connected this with the reasons of why African American nurses could be involved with relationships while other nurses could not.

In summary, three themes emerged related to the participants' perspectives about roles nurses might play in enhancing connections and mutuality experiences of African American women with diabetes and maintaining multiple roles. Informational support in the neighborhoods was the major perspective voiced by the participants. Some reminisced about nurses in neighborhoods when they were young. The women verbalized the need for diabetic knowledge beyond themselves but for African Americans, in general. This was the response of the majority of the participants. The second theme of trust is necessary was described as very important in order for nurses to be involved with family relationships. Some participants described experiences of health care providers, including nurses as being judgmental about the participants' diabetes numbers; others discussed the Tuskegee experiments. Some concluded that suspicions on their part would require some work, also.

Need for more African American nurses, the third theme, was described by some participants as a more comfortable experience if relationships were to be discussed. Others described the same background would increase the likelihood of honest and frank discussions. Race congruency was the focus of this theme; however, trust was still an essential part of the possibility of relationship work with people in the African American community.

Summary

The lived experiences of African American women with diabetes and African American women maintaining multiple roles were the first two research questions. Data analysis indicated three types of participants emerged. Each type was described through three composite first-person narratives. Type 1 and 2 composites re-presented participants who were engaged in multiple roles; however, what separated the two composites were the associations with diabetic health. Women within the type 1 composite viewed diabetes health as enabling them to carry out their day-to-day roles that was so important to them. Women within the type 2 composite perceived limited time to care for diabetes health and roles maintained a higher obligation to diabetes care. This led to poor nutritional choices in home, away from home and a perception of a deleterious impact on their diabetes. Women within the type 3 composite re-presented participants who verbalized limited concern for diabetes health, such as: poor medication adherence, lack of interest in appropriate diabetic diet and limited self-monitoring of blood glucose levels. In general, these participants had few roles within or outside the home. Lack of roles was associated with disengagement from others and feelings of boredom and isolation.

Concepts from Relational-Cultural Theory were used to explore how connections influenced African American women with diabetes and maintaining multiple roles. Analysis of data revealed participants' perspectives of varying kinds of connections. Two distinctly different typologies emerged from the data analysis as opposed to the classic definition of connections; they were: fulfilling connections and mindfully-rejected connections. Fulfilling connections revealed two themes, relationships foster sense of

well-being and partnering with God in faith and health. Mutual connections of the first theme were with mothers, aunts and friends with and without diabetes. Perceptions of joy, trust and love were described by these participants. Mutual encouragement to be healthy for self and others was described.

Partnering with God in faith and health emerged as a second theme with some participants despite the dyadic relationship integral to the meaning of connections. These participants were pastors and missionaries and connection with God was a daily experience which guides them in health. These participants communicated and experienced connections through prayer with God. They described their health as stable because communication guidance with God through prayer.

Two themes emerged from mindfully-rejected connections. These themes connoted intentional lack of relationships at this time in their lives. One theme, no time to nurture relationships was coupled with no time to care for diabetes. Diabetes care was second in priority to roles. The second theme, values of past inform the present emerged from descriptions of perspectives of relationships influenced by family values and culture beliefs. These participants despite lack of connections attempted to maintain diabetic health, particularly through regular exercise.

Two themes emerged from discussions with participants related to relationships experienced as disconnections of African American women with diabetes and maintaining multiple roles. The notion of disconnections was rejected by the majority of research participants and led to the emerged theme of the will to keep negativity out. Intolerance of disconnections related to age, cultural, spiritual/ religious beliefs, past history of relationships of disconnections and strategies of intentional efforts towards

good communication to prevent disconnections in the present. These participants

communicated exercise as the most consistent activity for health along with ongoing

attempts to improve nutritional status. The ability to associate changes in blood sugar to

negative mutual relationships was important and should be recognized as an insightful

strength of some participants. Disappointment in others was the second theme that

emerged from analyzed data. A few participants described disconnections with family or

friends and general disinterest in healthy diabetic behaviors. Some of these participants

had the fewest roles of research group.

Two themes emerged related to the research question about relationships

experienced as mutually respectful with capacity to impact and be open to change by the

other influence on African American women with diabetes and maintaining multiple

roles. It is not a matter of age but of what each brings to the other is the first theme. The

concept of mutuality was the focus of this theme. A large age spread of friends or

grandmothers and granddaughters did not influence ability to learn and grow from one

another. It was the quality of the relationships that influenced their ability to change and

grow that was the greater more important association from the sensitized concept of

mutuality. The second theme that emerged from the question was closeness developed

over time. Varying kinds of relationships of mutuality developed over a few years to

some that developed over decades. Improved diabetic and healthy diabetic behaviors

were associated with these relationships.

Data analysis related to the research question about how relationships with a sense

of power over influence African American women with diabetes and maintaining

multiple roles suggested two themes. The first theme was shackles on, shackles off. The

impact of power over was perceived differently with one participant describing no associated impact with diabetic outcomes or diabetic healthy behaviors and negative associated diabetic outcomes with one participant stating at the end, "I'm in misery". This outcome was associated with a lifetime of experiences of power over as described by the participant.

The second emerged theme was financial stress makes life difficult. Some participant's described financial difficulties more than connections as an overwhelming concern. Fear of losing homes and transportation resulted in a sense of loss of independence and feelings of isolation. These participants had decreased interest in diabetes care and monitoring.

The last research question related to what role might nurses' play in enhancing connections and mutuality experiences of African American women with diabetes and maintaining multiple roles. The three themes that emerged from data analysis were nurses as informational support; trust is necessary and need for African American nurses. The majority of the participants described the importance of nurses providing information to neighborhoods. They described a significant need for diabetes knowledge amongst communities of color.

The second theme of trust is necessary related to participants' perception of plausibility of nurses helping with connections and mutuality of relationships. Participants shared perceptions of judging about their blood glucose numbers and general diabetic health. They summarized that judgement and trust can't go together. Nurses who were able to increase the comfort level of people with diabetes and use other strategies

that would encourage nurses to do more asking and listening would have the possibility of helping with relationships.

The third theme emerged through data analysis was a need for more African American nurses. Some participants expressed the need for more African American nurses. Participants surmised that information coming from someone that looks like them would resonate better along with use of direct language. Race congruency was considered by the participants to be important; they concluded that trust would be important for any nurse to demonstrate that wanted to help with relationships.

There were unique aspects to the African American women who ultimately became participants in this study. Several characteristics of the individuals that participated in the research contribute to the uniqueness of this study. Age and other demographic characteristics of the women, such as the limited role of caregiving and roles primarily outside of their homes were discussed earlier in this chapter.

CHAPTER 5

DISCUSSION

Psychosocial aspects of diabetes have been cited as another component of the illness experience required to gain understanding of complex and multiple factors of diabetes for all populations (Institute of Medicine, 2001). Concepts from Relational-Cultural theory were used in this study to explore perspectives of African American women related to their influence on the experience of diabetes and maintaining multiple roles. Connections, disconnections, mutuality and power over from the theory were used to explore the influence of relational aspects and perspectives of diabetes and multiple role experiences of these women.

This chapter will provide areas of discussion related to the unique perspective of the study related to the theory concepts along with resulting challenges and a perspective on importance of understanding context within the lived experience of the African American women of the study. The next areas of discussion will include: Findings of this study that support previous research which include three themes from this author's study; new findings from this study will follow which include 10 themes; followed by a summary; implications for nursing research, education and practice, strengths and limitations of the study and a conclusion.

<u>**Unique Use of Theory Concepts and Resulting Challenges**</u>

As described throughout the previous chapters, Relational-Cultural theory and its concepts continue to be limited in the literature. Proxy terms had to be used for reviewing of the literature; however, the substitute terms had different meanings. The terms social support or lack of social support were used in this author's study as substitutes for the

concepts of connection or disconnection. Heany &Israel (2008) defined social support as functional qualities with four major types of supportive behaviors. Emotional support which provides empathy, trust, love and caring. Instrumental support provides direct tangible aid and services to someone. And, appraisal support which provides constructive feedback and affirmation. Informational support provides advices, suggestions and information. Most importantly, these varying kinds of support can be one-directional; for example, a caregiver might provide one or all four kinds of support and not experience one or all four kinds of support from the person to whom their support was provided.

Additionally, social supports are examples of varying types of relationships. Relationships is a broad term which includes relationships of social support, such as informational, instrumental, appraisal and emotional. Other types of relationships are relationships of connections, disconnections, mutuality and power over as defined by Relational- Cultural Theory.

The concepts from Relational-Cultural theory are interactions between two or more people and by definition are mutually experienced. Jordan (2010) describes connections as interactions that are mutually empathetic and empowering. She continues, disconnections are interactions where mutual empathy and empowerment do not occur. Mutuality entails mutual growth and capacity to impact and change each other (Jordan, 2010). Finally, power over are hierarchical relationships where one or more individuals are dominant over another (Jordan, 2010). The concepts defined above from Relational-Cultural theory are all bi-directional and are mutual interactions between two or more individuals.

Lui (2011) addresses similar challenges in a summation of his study of social connections related to a "multiplicity of terminology and measurement approaches that make it difficult to compare findings with other studies in the literature" (p.32). The challenges were similar to Lui's remarks related to the ongoing challenge of using terms that were essentially different in definition and yet the closest in context as needed for the purposes of the literature review for this author's study.

Context within the Lived Experience of Study Participants

The voices of the participants in this study clearly illustrated the influence and context relevance of their lived experience. In their stories, the women shared how God and religion, spiritual, historical, cultural and familial characteristics were an integral part of their day-to-day lives with diabetes and role maintenance. Some participants described their bodies as God's temple and connected this to the importance of regular exercise and healthy eating. Others described how prayer helped to maintain diabetic stability, such as their A1C numbers. Maintenance of roles was described as the Lord's work by some participants. Morning devotionals prepared some participants to fulfill the roles before them each day.

Alternatively, combined religious and community roles were associated with deleterious effects on the diabetes health of some participants. The context of their day-to-day lived experiences related to cultural, familial and religious commitments and influences resulted in poor diabetic health behaviors, particularly, nutrition and exercise. Religious, community and political role obligations resulted in diabetes health having a lower priority in the lives of some participants.

From a relational perspective, context was an integral component of many of the stories shared by the participants. Cultural values led to a larger perspective of the meaning of family and resulted in engagement in mutual caring with and for one another through examples of extended family (great grandchildren, aunts) and fictive kin (friends and church members). On the other hand, familial and cultural values influenced relational images and steered some participants away from relationships of connections. Religious, cultural and familial values strengthened some participants to reject disconnections resulting in setting up barriers and communicating clear messages to those who would bring negativity into their lives. Historical events of discrimination in the past along with personal discrimination experiences and judgmental interactions with health care providers in their own lives influenced perceptions of mistrust of health care providers, including nurses. As participants were asked about possible roles nurses might play in enhancing connections and mutuality experiences of African American women with diabetes and maintaining multiple roles historical context surfaced as a concern of some participants.

Context must be viewed as an intrinsic part of who these women are. Kaakinen, Coehlo, Steele, Tabacco & Hanson (2015) describe context as embodied because it not only shapes "external circumstances and opportunities but … physiology at a cellular level" (p.169). They continue by suggesting that people are influenced by and live within their contexts.

Findings of the Study that Support Previous Research

Three emerging themes supported previous research found in previously reviewed literature. Relationships foster sense of well-being, disappointment in others and trust is necessary will be described below.

Theme: Relationships Foster Sense of Well-being

Relationships foster sense of well-being theme supported findings in two studies in the literature reviewed in chapter 2, Tang, et al. (2008) and delBene (2010). Tang, et al. (2008) reported positive support behavior predicted healthy eating plans, spacing out carbohydrates evenly throughout the day and performing physical activity at least thirty minutes per day. The researchers also found that support satisfaction predicted improved diabetes quality of life and blood glucose monitoring. This author's study found that fulfilling connections described by the participants were associated with healthy diabetes. These relationships fostered exercise, appropriate eating and nutritional choices. The women within these connections served as sentinels of one another's diabetes experiences. A general sense of mutual caring, trust and mutual importance to one another was associated with care of diabetes, other chronic illnesses and a general sense of mutual well-being. Mutually empowering one another also could be deduced from data analysis.

delBene (2010) was a second study from the reviewed literature that is supported by this author's research. Role of confidante: power of the group describes women who expressed feeling a sense of comfort from one another related to sharing problems, feelings and thoughts. The participants were supportive of each other through group cohesiveness and "curative factors". This was defined by delBene (2010) as acceptance

of challenges experienced by the group members and the ability to process them. The researcher found that the participants had a general sense of survival because of the group. This study explored the lived experience of African American grandmothers and the importance of connections of these women maintaining multiple roles.

The participants in this author's study experienced similar benefits from the connections of mothers, aunts and close friends. Emotional accessibility was described by this author's study in terms of trust, comfortable around one another, helping each other and celebrating with one another. One participant in this author's study said, "I thank God for her everyday" somewhat connects with delBene's participants who described a sense of surviving because of the group.

Theme: Disappointment in Others

The theme disappointment in others emerged in this author's study. One participant described her relationship with her son who has since passed away. She described their relationship as very close for many years with a sense of mutual trust. The son's behavior and attitude changed with a sense of no longer understanding one another occurred; and ultimately, he was asked to leave her home. Mutual benefits of the relationship were no longer experienced. Disappointment in others supported findings of Cagle, et al. (2002) and Carter-Edwards, et al. (2004), two studies in the reviewed literature.

The theme of family as core emerged in the study of mid-life African American women with Type 2 diabetes (Cagle, et al, 2000). The participants perceived a lack of physical and emotional support from their children and husbands. Women within the focus groups concluded that African American women needed to raise more sensitive

children and husbands who would be willing to share head of household responsibilities (Cagle, et al., 2002). The women concluded that mutual benefits would occur: if participants were freed up to better manage their diabetes and the family gained more information about diabetes. Disappointment was not a concept within the study; however, disappointment can be inferred from the findings.

Disappointment in others was also inferred from findings in research by Carter-Edwards, et al. (2004). The participants declared a difference between help and support. Help meant physical assistance and support was emotional understanding. Family and friends lacked emotional understanding of the participants' illness experience. These participants perceived trivializing of their illness and a sense of power and control from family and friends. Once again, disappointment was not a construct within the study but could be inferred related to the responses of the participants. Lack of social support is a concept defined from a functional perspective and may be one-directional as contrasted with this author's concept of disconnection, which describes a mutual interaction with a sense of disappointment and misunderstanding.

Theme:Trust is Necessary

One study from the reviewed literature is supported by the theme of trust is necessary. Cagle et al. (2002) participants described a sense of a triple threat of discrimination when seeking healthcare, that of being of being African American, a female and having diabetes. The researchers reported participants' descriptions of healthcare providers as primarily focusing on glucose numbers and not the context of their lives that could improve management of diabetes. In general, the participants wanted to be distinguished by their strengths, such as their faith and being able to fulfill

their head of family roles and responsibilities, not by their perceived weaknesses, such as diabetes (Cagle et al., 2002). Participants in this author's study described historical references of health care providers' treatment of African Americans. More recent personal experiences of negative judgement during nurse interactions with some participants diminished the plausibility of nurses' assisting with relationships. Strategies to increase trust were provided by some participants included listening more, and preventing judgement from being a part of any interaction with patients.

In summary, three themes supported previous studies found in the reviewed literature provided earlier in this paper, relationships foster sense of well-being, disappointment in others and trust is needed. The theme of this author's study, relationships foster sense of well-being supported two studies in the reviewed literature. A common thread amongst the studies was positive social support behaviors or relationships were associated with healthy eating and exercising behaviors. Additionally, a sense of surviving because of positive social support or relationships was a mutual finding.

The theme of disappointment in others in this author's study was inferred in the findings of two studies in the literature review. Family and friends lacked adequate emotional understanding and participants sensed a trivializing of their diabetes experience. Mutual benefits were not experienced as a result of disappointment in these relationships. The theme, trust is needed from this author's study was similar in theme to research by Cagle, et al. (2002). A history of general discrimination and more current experiences of negative judgement in interactions with nurses suggest a common thread between the studies. Common strategies to increase trust were improvement of listening

skills to understand context of the lives of African American women and prevention of judgement during interactions with them.

New Findings of the Study

The concepts from Relational-Cultural theory were briefly discussed earlier in the chapter and may be referred to again in this part of the discussion. The research question will be presented as reference from where the themes are positioned in the study. This will be followed by themes related to new findings from this study in the following sequence: Within the two types of Connections, Fulfilling Connections and Mindfully-Rejected Connections, there are three themes that are part of new findings of this author's study: 1) Partnering with God in faith and health, 2) No time to nurture relationships and 3) Values of the past inform the present. Other new findings of this author's study that will follow are: 4) The will to keep negativity out, 5) Not a matter of age but what each brings to the other, 6) Closeness developed over time, 7) Shackles on, shackles off, 8) Financial stress makes life difficult, 9) Informational support in the neighborhood and 10) Need for African American nurses.

Fulfilling Connections

Fulfilling connections is one of two types of connections themed from the research question, how do relationships experienced as mutually connected, empathetic and empowering with feelings of zest, worth, productivity, clarity and desire for more influence African American women with diabetes and maintaining multiple roles? Two themes emerged: relationships foster sense of well-being and God is my partner in faith and health. The first theme was addressed earlier in this chapter. The second theme is addressed below.

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Theme: God is My Partner in Faith and Health

This theme emerged within the fulfilling connections area. These women were engaged in many roles, most roles revolved around the church. One was attending college for a master's in counseling to aid her ministry work; both were missionaries and very "devoted Christians". One participant noted that she was improving with her diabetes; she shared her A1C which was well within range. Another participant declared no problems with her diabetes; she was a retired nurse. Description and definition of the terms relationship and connection were provided through interview cueing; however, these participants were very clear about God as their partner and their closest relationship.

It is generally known through research studies that religiosity is a high priority amongst the African Americans. Lew, Arbuah, Banach & Melkus (2015) found in their study that the collective religious view of African American church leaders and members was based in a "personal relationship with God" which informed their approach to health and well-being on a daily basis. The participants in this study were predominately African American women with or at-risk for diabetes. God as partner, in similar context, was not found in the earlier reviewed studies.

Further research related to connections of African American women and other populations is required. Connection is defined as, "an interaction between two or more people that is mutually empathetic and mutually empowering" involving the "five good things" and emotional accessibility (Jordan, 2010, p.102).

Mindfully-rejected Connections

Research question three was: How do relationships experienced as mutually connected, empathetic and empowering with feelings of zest, worth, productivity, clarity and desire for more influence African American women with diabetes and maintaining multiple roles? Two themes emerged from this type of connection: No time to nurture and values of past inform the present. Both themes will be addressed below.

Theme: No Time to Nurture Relationships

This theme falls within the mindfully-rejected type of connections. The participants were engaged in multiple roles in their church and community. These women had some of the highest number of roles of the 20 participants; perspectives of status and position in their communities contributed in part to the reasons for not having relationships. Time and commitment were other key factors identified by these women. The participants suggested that lack of time and multiple roles as a greater influence on their diabetic outcomes than their choice to not have relationships at this time in their lives. One participant sees food as an ongoing challenge; church and community activities present nutritional challenges that are hard to avoid when faced with challenge in a variety of locations that these busy participants travel to.

Theme: Values of the Past Inform the Present

This was another theme within mindfully-rejected connections and reinforces the importance of understanding and inquiring about family values and culture beliefs related to relationships and connections. These participants expressed clear reasons why close relationships were not a part of their lives. One participant was raised to avoid close relationships; she exercises on a regular basis and has multiple roles through her church

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commitments. Another participant was negatively influenced by the unhappy relationship in her marriage. Cultural, spiritual and family influences were essential to understand about these participants. Understanding context of the lives of African American women continues to be extremely important.

Mutual Disconnections

Research question four was: How do relationships experienced as mutually disconnected, lacking empathy and empowerment influence African American women with diabetes and maintaining multiple roles? Two themes emerged from this question: The will to keep negativity out and disappointment in others. The theme of disappointment in others was addressed earlier in this chapter. The theme will to keep negativity out is a new finding and is addressed below.

Theme: The Will to Keep Negativity Out

This theme emerged related to the research question, how do relationships experienced as mutually disconnected, lacking empathy and empowerment influence African American women with diabetes and maintaining multiple roles? This was the most salient theme of the study. When asked about relationships that were mutually disconnected, the women replied with adamant denials that disconnections are in their lives. Many factors contributed to the denials of mutual disconnections in their present lives, such as: refusal to tolerate it (at my age), use of prayer to keep evil spirits away and stay positive, negative relationships when young informed and strengthened some participants in the present. Others put strategies together such as the use of financial capability to stabilize, block or prevent present disconnections.

Relationships Experienced as Mutually Respectful

Two themes emerged related to research question, how do relationships experienced as mutually respectful with the capacity to impact and be open to change by the other influence African American women with diabetes and maintaining multiple roles? The two themes are not a matter of age but what each brings to the other and closeness developed over time are discussed below.

Theme: Not a Matter of Age but What Each Brings to the Other

Some participants described relationships with wide differences in age, such as: friends and grandmothers and granddaughters. Each of them provided examples of how they have been open to one another and changed by one another. They described how the other makes each feel and how important they are to each other. Age was not a factor; the granddaughter encouraged the grandmother to take care of herself, to get out more and the grandmother advised about a detrimental relationship. They have both learned to become better listeners. The grandmother has improved her diabetic regime and shares with her granddaughter when they talk, as does the granddaughter with her grandmother. The listening before speaking is an example of respect towards one another. This grandmother-granddaughter connection has grown since the granddaughter has become and adult and lives out of state.

Theme: Closeness Developed Over Time

Family losses and tragedies over the years have brought two sisters closer together. The participant describes open and honest discussion; we're not the same but I have learned from her and she has from me. The participant goes to exercise class daily and the sister is a nutritional both; they have listened and changed one another. Other

participants described platonic relationships that have developed over many years, decades for some and shorter times for others. They describe learning from each other. Helping to learn about themselves through their relationships has improved their outlook overtime related to their diabetes.

Hierarchical Relationships

Two themes emerged from the interview cues related to, how do relationships, experienced as hierarchical, fostering a sense of power over influence African American women with diabetes and maintaining multiple roles? The themes of highly engaged with family and financial stress makes life difficult are discussed below.

Theme: Shackles On, Shackles Off

A few participants experienced a sense of powerlessness for years with their families. Different responses to this sense of powerlessness were described by participants. One managed by coping with it with some success; one participant did not perceive any influence on her diabetes. Others felt a sense of powerlessness in relationships had some influence on their diabetes. Chronic sense of powerlessness over time requires further research. Is powerlessness related to stress? There is significant evidence related to the physiological consequences of chronic stress over time.

Theme: Financial Stress Makes Life Difficult

Some participants described no concerns about relationships but grave concerns about their financial status. They described a sense of powerlessness about the constraints of inadequate income. Fears related to the upkeep of their homes, more importantly, the fear of losing their homes and debts owed; these were a major concern for a few participants and a constant struggle. These are women who have worked all of their lives

and have little to show for it. One participant stated, "I'm not gonna be worried about relationships if I don't have a roof over my head". Context of life experiences continues to be essential component to understand with this population.

Role of Nurses

The final research question of this study was: What role might nurses play in enhancing connections and mutuality experiences of African American women with diabetes and maintaining multiple roles? The three themes that emerged from the question were: Informational support in the neighborhoods, trust is necessary and need for African American nurses. Trust is necessary was addressed earlier in this chapter. The two remaining themes will be addressed below. Many of the participants had difficulty envisioning nurses in a psychosocial role and facilitating families and others with relationships. They could think of no role models from that perspective and therefore could not envision what they had not seen.

Theme: Informational Support in the Neighborhood

Many participants recalled when nurses came into neighborhoods and addressed health concerns. One participant recalled someone coming into her home and teaching her mother about nutrition; she is not sure. Some suggestions were block teach-ins, cook with families in their homes about diabetes and nutrition and provide neighborhood seminars. A majority of the participants thought of nurses as providing physical care and teaching about diabetes and other health topics. The prediction of more nurses in communities in the next couple of decades and fewer nurses in hospitals may fulfill the desires of this group of women. Providing primary and secondary prevention interventions is a natural "progression of back to neighborhoods" as recalled by these

participants has the potential to prevent health problems of individuals, families and communities.

Theme: Need for More African American Nurses

The need for more African American nurses emerged as a theme with some participants. Some women stated, "We need more nurses that look like the people in the communities; helping our people with diabetes until we get over the hump; I don't know… six months or so and then give us our wings". One participant alluded to language as the connector, proposing that an African American nurse speaking "would resonate with me in a different way" and direct language and communication from someone of her own race would be listened to but from another race would be considered offensive. The importance of increasing the numbers of health care providers from communities of colors has been documented for well over a decade.

Summary

Ten themes emerged from this study related to new findings. Each of these findings was reviewed in the context of the interviews with participants of the study. The importance of roles as context to the day-to-day lived experience of African American women with diabetes maintaining multiple roles surfaced as a major influence in the lives of this population. The impact of role deficit in some of the women had a greater association with decreased healthy diabetes-related behaviors and feelings of loneliness and isolation. The impact of multiple roles re-emerged related to relationships. In this situation, relationships were second to roles presenting diabetic challenges in terms of eating nutritionally.

The Relational-Cultural theory concept of connections was redefined by some participants. God as partner suggested a non-dyadic relationship as opposed to the definition within the theory as a mutually empathetic and empowering with emotional accessibility. Additionally, some participants' perspectives of cultural, religious, spiritual and family values and beliefs affected their perspectives of relationships or connections. The strengths of the women in this study surfaced related to denying negative disconnections into their current lives based on their religious, spiritual, cultural and historical experiences.

Some of the women were able to "see" beyond age related to the concept of mutuality in their relationships and others participants could "see" beyond time related to connections developing over time. Some participants experienced aspects of powerlessness, the proxy term for power over, throughout their lives with their family; the impact of this was not consistently viewed in terms of diabetic outcomes. Other participants placed the importance of relationships as less of a concern than the financial stress they were experiencing post retirement.

It was difficult for the participants in this study to view nurses from any roles other than a physical provider of care and teacher. As a result, the women listed many activities that nurses could do in neighborhoods related to diabetes. Viewing nurses involved in a psychosocial activity such as relationship work with people was a cognitive shift not considered by many of the participants.

Finally, several of the participants expressed the need for more African American nurses; particularly in communities to help people with diabetes. Some reasons provided

by the women were relatability, comfort level with race congruency and direct language and communication abilities based on culture.

Context of the lived experience of these women emerged throughout the new findings. The forthright and authentic sharing of their lives enhanced the understanding of their lived experience context.

Implications for Nursing Research

The importance of staying current with research and knowledge of the times is necessary for the profession of nursing. Use of Relational-Cultural Theory to guide the assessment of psychological development of individuals and families (however defined) is supported by current and evidenced-based knowledge. The study and use of Relational-Cultural Theory has occurred across disciplines, such as mental health counseling, psychiatry, psychology and minimally, in nursing (Duffy & Samody, 2011; Frey, 2013; Fox & Chesla, 2008; Zalaquett, Fuerth, Stein, Ivey & Ivey, 2008; Comstock, Hammer, Strentzchsch, Cannon, Parsons & Salazar, 2008). The more than two-decade neuroscience research about human relationships and connections offers a better understanding and use of this theory from a nursing perspective.

Although, nursing research, practice or education may lead the way as a nurse-identified problem is exposed; researchers in nursing may need to proceed in a more a linear fashion based on lack of use or modeling in nursing education or practice of this theory. Bomar (2004) concludes that nursing research needs to build a body of knowledge about assessing and intervening at levels of relationships to promote health and provide evidence based outcomes of differences in individual, family and community lives.

Additionally, as the evolution of the theory used in this study moved from Relational Theory to Relational-Cultural Theory in the 1990's the pioneers of the theory recognized the importance of cultural context to human development and the importance of impact of culture in daily life. Assessment of connections requires further research and analysis within African American women of this cultural group.

With a better understanding of the importance of incorporating culture and context in nursing research, this author's study may provide an impetus to continue research from a relational-cultural perspective of African American women with diabetes and maintaining multiple roles. This study suggests that the many contexts of this population require further investigation.

Implications for Nursing Education

This author's study, in particular, demonstrates the importance of learning about context of the lived experience of African American women. This is one of the key components of care with this population. In a sense, there is a need to "un-simplify" students understanding of the illness experience in this population of African American women with diabetes and maintaining multiple roles. Context of the daily lived experience and relationships of connections amongst African American women with diabetes and maintaining multiple roles may be complex; however, context may facilitate understanding of all aspects of the health and illness and thereby facilitate ways to improve the health status of those living with diabetes, as suggested by the Institute of Medicine (2001).

The importance of providing appropriate building blocks when preparing students for nursing practice is essential. The need to strengthen foundational nursing knowledge

about the importance of relationships of connections across all disciplines of nursing should be part of those building blocks and therefore begin in nursing school. It is also important to incorporate the notion of context of the lived experience of all humans in nursing education. And because, context is embodied, as described earlier in this chapter, nurse educators must incorporate pedagogies that facilitate students' conscientious consideration of "the interface of these differing contexts and how they shape … health and illness experiences" (Kaakinen, et al., 2015, p.169).

Pedagogies that support safe learning environments where students reflect on self and others' context of health and illness experiences may promote understanding of context as embodied. Two methodologies used in nursing are communicative dialogue and inviting local citizens into classrooms to dialogue with students and faculty. Mikol (2005) suggests that with sufficient time, sharing and hearing multiple perspectives about the social context of illness was found to promote student communicative dialogue through narratives.

The second method, suggested by Ironside, Scheckel, Wessels, Bailey, Powers & Seeley (2003) is having students and teachers dialogue with local citizens in classroom settings; this may offer insights about context not necessarily found in textbooks. These researchers found that local citizens, students and teachers created a new understanding of experience of chronic illness. Three collaborative themes emerged as ways to increase understanding of the chronic illness experience from this recommended experience: 1) the need to understand chronic illness from a person's perspective of concerns and commitments not just changes in functional status, 2) the need to have increased focus on the meaning of the chronic illness and less focus centered on symptoms and 3) the need

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to de-objectify the language of health care (Ironside, et al., 2003). Using these methods to explore the context of the diabetes experience and relationships of connections as related to African American women and other vulnerable populations is plausible.

These two educational methodologies used in foundational nursing education have the potential to move nursing students towards desirable attitudes and behaviors in their practice. A primary purpose of critical pedagogy is knowledge that transforms into action; students with this foundation have the potential to provide nursing care that fosters increased well-being of vulnerable populations, such as African American women with diabetes and maintaining multiple roles.

Implications for Nursing Practice

Nurses have assessed for social support adequacy of individuals and families and intervened by enhancing already existing social support or added formal supports as needed with individuals and families for many years. The important role of social support assessment in nursing and across many other disciplines has been clearly documented throughout research literature. As nurses we need to stay abreast of the growing evidence from neuroscience and other disciplines about the positive benefits of connections (relationships) across the lifespan.

The profession of nursing is a holistic practice. Learning about individuals from physical, social, psychological and emotional perspectives facilitates the ability to provide holistic care. Additionally, it is generally understood that individuals are part of a family and that nurses should provide family-centered care. Bomar (2004) describes the term 'family' as a misnomer and suggests that the term relationship is what is really

meant. She relates that nurses' "understanding of the bidirectional influence between relationships and health and illness is growing" (p. vii).

The concepts of connections and mutuality are perceived as strengths. The role of the nurse in family-centered nursing is to assess for those characteristics within families (however defined, my insert) and facilitate families to support and maximize responses to health and illness in everyday living (Gottlieb, 2013). As more nursing careers gravitate toward community, the ability of nurses to explore the meaning of connections related to diabetes and roles from a contextual perspective with African American women may be increased. Consideration of context may result in more successful interventions.

When working with clients and families in the community, there are things that cannot be controlled, for example, the genetic proclivity towards getting diabetes; however, there are things one can control, for example, keeping relationships of power over and disconnections at bay. Some participants in the study had been living with a sense of powerlessness (power over) for many years with their families. Although, the participants were not monitoring their glucose level in that context the potential negative diabetic outcomes must be considered. Assessing strategies used by clients to prevent disconnections and power over in their relationships may be another way to incorporate relationship building within individuals, families and communities.

Since nursing is a holistic practice, it is important to assess and teach the influence of connections and lack of or negative connections which may impact diabetes management. At the urge of these participants, "doing more asking and listening" may ultimately benefit this vulnerable population and others and continue to increase the effectiveness of nursing practice.

Strengths and Limitations of the Study

Several limitations of the study must be mentioned. The following limitations will be described: generalizability, one-sided perspective of dyad relationships, and generation factors. The findings of the study may not be generalizable with the modest number of 20 participants. All African American women with diabetes and maintaining multiple roles may not have the same experiences and perspectives as participants in this study; extrapolating these results disregards the diversity of African American women. However, a strength of the study lies with the breadth of understanding provided through the perspectives of African American women related to the influence of their relationships on the experience of diabetes and maintaining multiple roles. The findings in this study offer myriad opportunities for further research through qualitative and quantitative methods.

This research was conducted with the face-to-face interview method. Use of this method was chosen related to the perceived sensitive nature of questions associated with relationships of connections and mutuality but also relationships of disconnection and powerlessness. In addition, ultimately, the gaining of participants moved from purposeful sampling to snowballing technique when adequate numbers had not been achieved related to saturation. Wilson & Washington (2007) suggest that there is an assumption that people with like interests and similar experiences will know each other with the snowballing technique. With this change in technique, some participants knew others in the study and had the potential of having varying types of relationships amongst each other, as described above. Although use of focus group technique has been a

recommended format with this population, the author of this study chose face-to-face as more appropriate as explained (Guest, Namey, Taylor, Eley, & McKenna, 2017).

Another limitation may have included not having dyadic interviews. Relational-Cultural Theory is a relational theory. Incorporation of two or more individuals engaged in a relationship may have offered other perspectives and insights of the topic from of all involved and added to the understanding of the phenomenon. Alternatively, the participants had opportunities to share feelings of a personal nature to the interviewer that may have increased their willingness to be frank and forthright about feelings from their perspective. Future research might incorporate all individuals within relationships to benefit from multiple perspectives.

Generational factors may be a strength and limitation of the study. The convenience sample resulted in primarily older retired African American women. Their perspectives of connections were influenced by the context of the social, economic, historical and cultural life experiences which may be unique and different from those of younger generations of African American women. The study had hoped to gain perspectives of African American women across the lifespan. It is plausible to think that African American women with diabetes and maintaining multiple roles from a wider age range would offer perspectives not captured in this study. This invites an opportunity for future research that includes African American women across the lifespan to increase nursing's knowledge from that perspective.

Alternatively, some insights about this subset of the population were gained. For example, role perspectives were from women who were retired, primarily participating in roles outside of their home settings and were not caregivers to others. From a strength

perspective, no other study has been found related to this particularly unique segment of older African American women; further research about this particular group is encouraged.

Conclusion

The almost two decades of research evidence relating the importance of relationships across the lifespan led to this study in an attempt to better understand the phenomenon from the perspectives of African American women with diabetes and maintaining multiple roles. Insights gained about the benefits of connections and mutuality as related to healthy diabetic behaviors was revealed. The importance of understanding the cultural, religious, spiritual, familial and historical contexts was found to be integral aspects of understanding the lived experience of these African American women with diabetes and maintaining multiple roles.

The importance of listening to the stories of African American women through a Relational-Cultural lens as an integral part of partnering with them towards improving their diabetes health has filled in some gaps of the previous available research. Suggestions for nursing education, practice and further research have been made to bring the findings of this study closer to providing excellent care to this high risk diabetic population while maintaining roles in small and large ways.

APPENDIX A

LITERATURE REVIEW MATRIX

Relational-Cultural Perspectives of African American Women with Diabetes and Maintaining Multiple Roles

Author(s) (Year) Title	Purpose of Study	Method	Sample	Findings	Themes	Relation to Proposed Study
CONNECTIONS (social support used as proxy) OF AFRICAN AMERICAN WOMEN WITH DIABETES						
Tang, Brown, Funnell & Anderson (2008)	To examine the relationship of diabetes-specific quality of life and self-care behaviors to social support	Quantitative Cross-sectional, observational design	60 African American women 29 African American men	1. Positive social support predicted behaviors of healthy eating plan, even spacing of carbohydrates daily and 30 minutes of exercise daily 2. Social support satisfaction predicted		Social support is used as a proxy concept related to limited use of the concept connections in research literature. Social support was associated with diabetes healthy behaviors

				improved diabetes-specific quality of life and glucose monitoring		
CONNECTIONS (social support used as proxy) OF AFRICAN AMERICAN WOMEN MAINTAINING MULTIPLE ROLES						
delBene (2010) African American grandmothers raising grandchildren	A phenomenological perspective of marginalized womenTo understand the lived experience of African American grandmothers raising of grandchildren in a marginalized community	Hermeneutic interpretive phenomenology	15 African American grandmothers		1. Role of confidante/ power of the group 2. Finding a voice to match medical needs 3. Relationship with the biological parents 4. Legal issues Social support of grand-mothers toward each other led to positive feelings, sympathy, rewarded from and toward each other	The importance of connections with other women experiencing multi-role grandparent caregiving
DISCONNECTIONS (lack of social support/connection used as proxy) OF AFRICAN AMERICAN WOMEN WITH DIABETES						
Lui (2011) Social	To determine if lack of social	Quantitative	9106 of which 672	African American		Lack of social connections and having

connection, diabetes, mortality and older adults	connections (LSC) and diabetes (DM) independently and jointly affected the risk of mortality amongst white and black Americans		were African American women	women had the largest percent of diabetes and greatest proportions of LSC.		diabetes was highly associated with greater detrimental health effects in African American women, more than any other group in study
Carter-Edwards, Skelley, Cagle & Appel (2004) "They care but they don't understand": Family support of African American women with type 2 diabetes	To examine the relationship between perceived social support with type 2 diabetes and diabetes self-management among African American women	Qualitative	12 African American women		1) Lack of understanding of diabetes experience by family members and others in the larger network system 2) Lack of emotional support 3) Sense of identity 4. Maintenance of independence and control over one's life	Lack of understanding of diabetes by social support network. Findings suggested emotional support emerged as key element with this population. Emotional support is most closely aligned to connections/disconnection concepts of the study.
Jones, Utz, Williams, Hinton, Alexander, Moore,	To examine the impact of family and friends on the management of persons with	Qualitative	21 African Americans		1) Family and peer involvement with diabetes management 2)Diabetes hard to	Positive and negative mutual interactions occurred between women with diabetes and support network

Blankenship, Steeves, Oliver (2008) Family interactions among African Americans diagnosed with type 2 diabetes	diabetes and willingness to be involved in a culturally tailored program				control 3) Positive attitude along with use of prayer	
DISCONNECTIONS (lack of social support/connections) OF AFRICAN AMERICAN WOMEN MAINTAINING MULTIPLE ROLES						
Simpson & Webb (2009) Responsibility without community resources: Informal kinship care among low income African Americans grandmother caregivers	To examine perceptions of availability, access and responsiveness of community resources by urban African American caregivers	Qualitative	7 African American grandmothers		1) Traditional helping resources 2)Unresponsive-ness of human service agencies 3) Limited options and alternatives for grandmothers	African American women have multiple and complex roles along with declining traditional resources/ lack of formal and informal support
Kelch-Oliver (2011) The experiences of African	To explore experiences of African American	Qualitative	6 African American grandmothers		1) Grandmothers' roles/caregiving responsibilities 2) Loss of	Caregiving by grandmothers leads to multiple roles with positive relationships

American grandmothers in grandparent-headed families	grandmothers who are raising their grandchildren				independence/changes in quality of life 3) Ways of coping with caregiving situation 4) Future goals for grandchild 5. Advice to other grandparents raising grandchildren	with grandchildren contrasted with poor relationships with parents of grandchildren
Cagle, Appel, Skelley & Carter-Edwards (2002) Mid-life African American women with type 2 diabetes: Influence on work and the multi-caregiver role	To explore the influence of work and other multi-caregiver factors on the self-management and personal coping with diabetes	Qualitative focus groups	12 African American women		1) Family as core 2) Work as survival 3) Impaired role function 4) Inner strengthening	Lack of social support from family network impacted poor diabetes health. Context r/t financial imperative to work. Diabetes health
MUTUALITY OF AFRICAN AMERICAN WOMEN WITH DIABETES						
Cooke-Jackson (2011) A world of	To understand conversations between type 2 diabetic mothers	Qualitative	20 African American women		1) Talk about diabetes among families 2) Talk about	Mothers (with diabetes)/ daughters with close relationships were associated with some

difference: Unraveling the conversations African American women have with their with their adult daughters to negotiate diabetes	and their adult daughters				personal experiences of living with diabetes 3) Talk about prevention	evidence of impacting, respecting and changing each other
MUTUALITY OF AFRICAN AMERICAN WOMEN MAINTAINING MULTIPLE ROLES						
Goldstein & Rieboldt (2004) The multiple roles of low income, minority women in the family and community: A qualitative investigation	To obtain a better understanding of family and community coping mechanisms and resources affecting families within poor, ethnically diverse, urban neighborhoods	Qualitative Ethnography	3 families (1 family =African American)		Participants provided primary and multiple other roles within and external to the family	Diverse, intricate helping relationships and reciprocity (related search term for mutuality) experienced by women with multiple roles within family and community
POWER OVER (powerlessness served as proxy) OF AFRICAN AMERICAN WOMEN WITH DIABETES						

Penkofer, Ferrans, Velsor-Friedrich & Savoy (2007) The psychological impact of living with diabetes	To understand feelings and impact of depression, anxiety and anger on overall quality of life of women living with diabetes	Qualitative	4 focus groups= 2 were African American		"Diabetes Over-whelmus" as described by participants in this study 1) Encountering challenges 2) Bearing multiple responsibilities for self and others 3) Struggling with challenging health situation 4) Worrying about diabetes-related health of present and future 5) Taking a diabetic "break or holiday" from the from the rigors of diabetic regimen	Diabetes experiences and feelings are associated with sense of powerlessness related to family and multiple responsibilities
POWER OVER (powerlessness served as proxy) OF AFRICAN AMERICAN WOMEN MAINTAINING MULTIPLE ROLES						

Davis-Sowers (2012) "It just kind of like falls in your hands": Factors that influence black aunts' decisions to parent their nieces and nephews	To explore factors that influence the decision-making processes of black aunts parenting nieces and nephews	Qualitative/ Modified Grounded Theory	35 black aunts			Root theme: Perceived lack of agency in decision to parent and inability to see choices or question possible options	Sense of powerlessness with caregiver role is influenced by cultural role African American aunt caregivers
Samuel-Hodge, Skelley, Headren & Carter-Edwards (2005) Familial roles of older African American women with type 2 diabetes: Testing a new multiple caregiving	To examine how familial caregiving relates to family composition and psychosocial factors in older African American women with type 2 diabetes	Quantitative (Correlational, analysis of variance and multivariate analysis)	299 African American women	1) Two scales were developed (Multiple Caregiving Scale and Multiple Caregiving Barrier). Combined tool measured both with 12 items. Scales were significantly			Sociocultural context of African American female diabetics are important to assess. Multiple role responsibilities from a cultural perspective associated with results of 2 items, suggesting sense of powerlessness (proxy construct)

measure				associated with 2 items **(a)** putting family needs 1st and **(b)** difficulty saying "no" (c) Helping and being available to help family/ friends (d) Interference in caring for self (e) Related to caring for family and friends (f) Sense of obligation to help others		

CONSENT FORM

For Participation in a Research Study

University of Massachusetts Amherst

Researcher: Ayesha Ali, MS, RN
               Cynthia Jacelon, PhD, RN

Study Title: Relational-Cultural Perspectives of African American Women with
                      Diabetes and Maintaining Multiple Roles

1. WHAT IS THIS FORM?

This form is called a Consent Form. It will give you information about the study so you can make an informed decision about participation in this research.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and ask questions now and any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

2. WHO IS ELIGIBLE TO PARTICIPATE?

 You are able to participate if you are an African American woman, 18 years or older, with type

  2 diabetes and maintain multiple roles.

3. WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this research study is to explore relational-cultural perceptions of African American woman with type 2 diabetes and maintaining multiple roles.

4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?

The study will take place at your home or a place we mutually agreed upon.

5. WHAT WILL I BE ASKED TO DO?

You will be asked to talk about the relationships in your life and their connections with your experiences with diabetes and maintaining multiple roles. The interview is expected to last approximately 1½ hours and will be audiotaped. The researcher will request information, such as: Please share with me any feelings or insights about your relationships in your life that influence your day to day experiences with diabetes while maintaining multiple roles. You may skip any question you feel uncomfortable answering.

6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?

You may not directly benefit from this research; however, we hope that your participation in the study may help nurses provide better care to others with similar experiences.

7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the study.

8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?

The following procedures will be used to protect the confidentiality of your study records. Your name will be on two forms, this informed consent form and a master key, that will link names with code numbers. These two forms will be kept in a secure location separate from all other research study records. All other paper work and audio tapes will have code numbers only and will be kept in a separate secure location. The master key and audio tapes will be destroyed 6 years after the close of the study. All electronic files used will have coded numbers only and will be password protected to prevent access by unauthorized users. Only members of the research staff will have access to the passwords. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THIS STUDY?

You will receive a $25.00 gift certificate at the end of the interview as compensation for completing the interview. Partial compensation will be provided to you for time

10. WHAT IF I HAVE QUESTIONS?

Take as long as you like before you make your decision. We will be happy to answer any question you have about the study. If you have any further questions about this project or if you have a research-related problem, you may contact Ayesha Ali @ 413-210-1340 or 413-205-3517. If you have any questions concerning your rights as a research participant, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428.

11. CAN I STOP BEING IN THE STUDY?

You do not have to be in the study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

12. WHAT IF I AM INJURED?

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subject participant research, but the study personnel will assist you in getting treatment.

13. SUBJECT STATEMENT OF VOLUNTARY CONSENT

When signing this form I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

_____   _____   _____

Participant Signature: Print Name: Date:

By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

_____   _____   _____

Signature of Person   Print name: Date:
Obtaining Consent

Interview Cues: First Interview

Note: This guide is meant to provide cues for the PI to use during conversation with the participant. It is expected that all topics below will have been discussed by the conclusion of the interview. The interview will take approximately one hour.

1. Name, Age
2. Site where interview is occurring.
3. Telephone number
4. Education, interests
5. Please describe any roles you are presently involved in.
6. List and explain your medical diagnoses. What is your current health status?
7. Please tell me about how and when you found out you had diabetes.
8. Please describe how your roles and your diabetes have influenced one another.
9. Please tell me about the relationships currently in your life.
10. Please describe relationships with emotional openness to one another; with a sense of zest, worth, productivity, clarity and desire for more connection
11. Please tell me about how the above relationships influence your diabetes and maintained roles, if applicable.
12. Please describe relationships with a sense of being misunderstood and disappointed in one another.
13. Please tell me about how the above relationships influence your diabetes and maintained roles, if applicable.
14. Please describe relationships with the capability for mutual respect and open to impact and change one another.
15. Please tell me about how the above relationships influence your diabetes and maintained roles, if applicable.
16. Please describe relationships with a sense of powerlessness.
17. Please tell me about how the above relationships influence your diabetes and maintained roles.
18. Please describe any ways a nurse might assist with relationships as connected with your experience with diabetes and maintaining role.
19. Is there anything else you can tell me that would help me understand about your relationships as related to your diabetes and maintaining roles?

   The intention of the interview is meant to be a conversation that is free flowing with the participant sharing her lived experience. The interview schedule will be used as prompts by the researcher along with pursuing aspects of the description, not as a way of asking and answering a series of questions.

Interview Cues: Second Visit or Telephone Call

*Note: Similar to the first interview guide, this guide is meant to provide cues for the researcher to use during the conversation with the participant. It will not employ a list of specific questions. This second visit or telephone must be done **before** the transcription and analysis phase begins based on interpretive phenomenology in the Ricouer tradition (Allen & Jensen, 1990).*

The following topics will comprise a conversation between the participant and the researcher:

1.   Questions that emanate after listening to the first interview.
2.   Participant checking is meant to provide an opportunity for participant to clarify aspects of earlier conversation with the researcher.
3.   Anything else that the participant may want to add to help the researcher understand relationship impacts on the diabetes experience while maintaining multiple roles.

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