# Type 2 diabetes, spousal/romantic partner support and medication adherence among Black adults: A qualitative study

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#### Abstract

Medication adherence plays an integral role in type 2 diabetes mellitus (T2DM) self-management and optimal control of this health condition. Black adults are disproportionately impacted by T2DM compared to their White counterparts. Researchers suggest perceived social support from spouses and romantic partners can be beneficial in helping individuals to cope with T2DM and maintain adherence to the medication regimen. However, there is a paucity of research focused on Black adults married or in a romantic partnership living with T2DM and their perception of support from their partner and it's influence on one's medication adherence. This study focused on unveiling perceptions of Black adults related to this phenomenon.

In this study, a qualitative descriptive approach was utilized to explore perceptions of ten participants. Through semi structured interviews, participants vividly shared their attitudes and beliefs related to perceived social support. Several themes emerged through the analysis of the data, such as: having my back, encouragement to persevere, being a team, moral support, help with logistics of medication regimen, tangible checks and balances, and constant reminders from partners. In addition, data were further explored by dividing the participants into groups based on biological sex. From this exploration two additional themes emerged: coping with the consequences of diabetes and support translating to feelings of love.

Findings from this qualitative descriptive study can be used to provide important concepts related to spousal/romantic partner support and its importance to individuals managing T2DM. Self-management educational programs that include the partner can help

diabetes educators and practitioners empower Black adults to remain adherent to their medication regimen and cope with their illness.

#### **Chapter 1: Introduction**

#### **Problem Statement**

Diabetes mellitus is a major public health concern and chronic condition impacting the health of over 37 million individuals in the United States, with projections of 54.9 million by the year 2030 (McLaurin et al., 2024). Black Americans are disproportionately impacted by T2DM, with prevalence rates of 12.1% compared to White Americans with rates of 7.4% (McLaurin et al., 2024). Compared to other racial and ethnic groups, Black Americans suffer more complications, including renal disease, vision impairment and lower limb amputations as a result of this illness. The majority of individuals living with T2DM are managed with oral and/or injectable medication. Debilitating complications can arise from non-adherence to the recommended medication regimen.

Systemic racism within the healthcare system contributes to higher incidence rates (Anim et al., 2024). Providers' racial biases can negatively impact clinical decision making. According to one study, physicians rated Black patients as less educated, less adherent and more likely to use drugs and alcohol (Peek et al., 2010). Poor quality physician interactions and discrimination adversely affect health. Differences in level of care is evident in Black adults living with T2DM being screened for hemoglobin A1c at lower rates (Anim et al., 2024). Black Americans receive less health information and patient focused care than Whites (Peek et al., 2010). A long-standing history of racism and unequal treatment is one factor impacting higher incidence levels.

Medication non-adherence is a significant health concern for Black Americans living with T2DM. Medication adherence includes behaviors associated with taking medications as

prescribed. Decreased medication adherence is related to suboptimal therapeutic outcomes, increased emergency department use, decreased quality of life and increased mortality. Rates of medication adherence for T2DM patients is less than 40% (Shiyanbola, Brown, et al., 2018). Diabetes control is decreased by medication nonadherence and Black Americans have higher nonadherence rates compared to non-Hispanic Whites (Shiyanbola, Ward, et al., 2018). Evidence related to personal and cultural beliefs surrounding medication adherence and its impact on health maintenance of Black Americans with diabetes is lacking. In order to reduce disparities among Black Americans living with diabetes, it is integral for practitioners of nursing to have a better understanding of factors affecting medication adherence (Blackmon et al., 2016). Research suggests, social support is instrumental in managing medication adherence among T2DM patients. Social support enhances more favorable health outcomes and increases patient resilience (Abbott et al., 2021). This study explored perceptions of spousal/romantic partner support and the impact on medication adherence from the perspective of the patient living with T2DM.

## **Background and Significance**

Diabetes is ranked as the fifth leading cause of death among Black Americans (King et al., 2018). Nearly 85% of individuals living with diabetes are treated with oral medication, insulin or a combination of medications (Bockwoldt et al., 2017). Medication adherence supports achievement of optimal glycemic control. Lower medication adherence rates and increased incidence of complications among Black Americans necessitates further exploration on ways to best support adherence. Medication adherence is one of the components of diabetes self- management. Medication adherence is a multifaceted construct and is a

modifiable factor (Mayberry, Bergner, et al., 2016). Medication adherence entails a commitment to following the medication regimen. Moreover, it is an agreement between patient and provider to follow medication practices as prescribed. Within this agreement medication adherence also constitutes discussing side effects with the provider and getting information about the medication from the provider. One potential target for diabetes self-management interventions includes those that incorporate social support particularly spousal/romantic partner support (Albanese et al., 2019). Exploring how this support is perceived by those living with T2DM can help inform educational interventions intended to improve medication adherence.

Diabetes management, which includes medication adherence, is impacted by interpersonal relationships including marriage and romantic partnerships (August et al., 2013; Cohen et al., 2005; Iida et al., 2010; Rook et al., 2011, 2016; Wiebe et al., 2016). Individuals who have close relationships with others have been found to have improved physical health and live longer than those who do not (Rook et al., 2011). Supportive marital or romantic relationships can help individuals cope with psychological and physical stressors associated with T2DM (Iida et al., 2010). Clinical guidelines have not incorporated established assessment measures of family support of diabetes management in routine care, thus opportunities to assess this support are often missed (Cohen et al., 2005). Furthermore, evidence is mixed regarding whether support declines or increases over extended periods, typical of chronic conditions (Iida et al., 2010; Strom & Egede, 2012). Research suggests, partners find a sense of fulfillment and satisfaction with providing support to their partners with diabetes (Iida et al., 2010).

There are different types of social support, including instrumental, informational and emotional support. Instrumental support incudes tangible concrete forms of support (i.e., filling pill boxes, picking up medication from the pharmacy and financial assistance purchasing medication). Informational support helps with problem solving (i.e., recommendations or advice related to coping with the medication regimen). Emotional support provides feelings of love, esteem and empathy related to stress and coping (i.e. encouragement and listening) (Langford et al., 1997).

# Romantic partnerships and social support

Spousal/romantic partner provision of emotional, instrumental and informational support can promote daily adherence to diabetes medication regimens (Henry et al., 2013). In one study, racial/ethnic minorities reported that they found social support beneficial and felt more frequent support would help facilitate medication adherence (Peyrot, Egede, Funnell, Hsu, Ruggiero, & Stuckey, 2018). A number of studies exploring buffering effects of emotional, instrumental and informational support and external motivating aspects of social control on health outcomes exist in the literature (Strom & Egede, 2012). However, the exact mechanism is not well understood (lida et al., 2010; Strom & Egede, 2012; Wiebe et al., 2016). Research indicates that there is a complex interaction between social support experienced in dyadic romantic relationships influencing health (Ryan et al., 2014). Among couples in spousal/romantic partnerships evidence has shown that males have a stronger dependence on their romantic partner for social support compared to females who elicit support from a broader social network (Albanese et al., 2019; Stronge et al., 2019). Romantic partner dyads are indicated as supporting well-being through the provision of perceived social support. Romantic

partnerships are one of the most influential sources of social support among couples (Stronge et al., 2019). Exploration of social support aided in the conceptualization of this phenomenon.

# Benefits of spousal/romantic partner support

Engaging in a romantic partnership can serve as a buffer when coping with physical and psychological stressors. Emotional support from spouses has been associated with better health outcomes (lida et al., 2010). Spousal support can directly influence adherence behaviors and indirectly support psychological health (Mayberry, Harper, et al., 2016). Conversely, participants who report receiving support that is perceived as controlling and intrusive have been found to engage in less adherence behaviors and had decreased confidence in their ability enact behavior change (Mayberry, Harper, et al., 2016; Rintala et al., 2013; Wiebe et al., 2016). Studies investigating the impact of intrusive family behaviors on diabetes outcomes and how to mitigate these behaviors is sparse (Mayberry, Harper, et al., 2016). Spousal support related to adherence behaviors for those suffering from chronic conditions and associated stressors plays a paramount role in successful coping. Dynamic spousal/romantic partnerships impact the provision and receptivity of support in diabetes care, however, a small number of studies related to this phenomenon among Black adults have been conducted.

# Gender differences and support

Gender differences exist surrounding the provision of support. Research indicates, in heterosexual marriages support is not always equally distributed, with wives frequently providing more support. Researchers suggest, wives may be more attune to recognizing the need for additional support when their partner is undergoing stress, challenges or distress (lida et al., 2010). Spousal/romantic partner support can be perceived differently in relation to

gender, racial/ethnic background and cultural beliefs (Strom & Egede, 2012). In one systematic review, researchers found that Black adults with T2DM had better clinical outcomes and a greater need for social support resources from familial support providers (Strom & Egede, 2012). Among racial and ethnic groups lower perceived social support by partners was associated with lower medication adherence (Strom & Egede, 2012). In another study, males stated that their female spouse was a major source of support (Strom & Egede, 2012).

Perceptions of support were influenced by source, availability and level of support, with higher levels having a significant positive impact on health outcomes. Members of underserved groups had a greater satisfaction with social support from family compared to White counterparts who relied more heavily on support from health care providers (Strom & Egede, 2012).

To address the aforementioned gaps in the literature this study explored the role of spousal/romantic partner support/involvement on medication adherence among Black Americans living with T2DM. Using a qualitative descriptive approach, this study provides knowledge and increases our understanding of the influence of spousal/romantic partner support on medication adherence. A convenience sample, in which the person with T2DM self-identifies as Black, is currently married or involved in a romantic partnership, and currently takes oral or injectable diabetes medication were recruited. Participants self-identified their gender based on a demographic survey. The long-term goals of this research include informing innovative diabetes self-management educational interventions focused on spousal/romantic partner support designed to increase adherence and future studies can build on this knowledge to eventually improve patient empowerment in managing their diabetes.

# **Conceptual Framework**

The Developmental-Contextual Coping Model (DCCM) proposed by Berg and Upchurch (2007) provides a framework to aide in conceptualization of how romantic partners adjust and cope with diabetes medication adherence throughout the adult lifespan. Building on previous evidence and models of dyadic coping, the model purports among couples coping with chronic illness, management is a shared interdependent experience. The model suggests, sociocultural contextual factors, quality of romantic relationships, dimensions of illness (e.g., stability of illness course versus relapsing quality, ability to control through treatment engagement) influence dyadic coping (Berg & Upchurch, 2007). For example, perceived control related to constant and stable T2DM illness progression may facilitate behavior enactment supportive of medication adherence. Several assumptions are apparent in the model: congruency between shared appraisals of illness stressors by both partners will result in improved coping; crucial points in illness progression (e.g., initial diagnosis, coping with treatment regimens, daily chronic illness management) influence adjustment; and recognition of interdependence, connectedness and orientation towards shared perspectives of the illness process (Berg & Upchurch, 2007). This framework underpins the study and aides in conceptualization during study design, data collection and analysis.

Inherent within the DCCM are various dimensions of dyadic coping including: uninvolved, supportive (e.g., emotional, instrumental, informational support), collaborative, and control. The construct of supportive dyadic coping, can be measured through exploration of social support (Berg & Upchurch, 2007). Building on the aforementioned diabetes social support literature, increasing saliency of dimensions of supportive dyadic coping was integral in

addressing my research question. Berg & Upchurch (2007) suggests, illness such as T2DM requiring daily management may necessitate increased occurrence of dyadic coping interactions. Conceptualization of developmental factors in addition to chronicity, play an integral role in the study design and exploration of phenomena. As a developmental model, DCCM proposes variability in dyadic coping during young, middle and older adulthood, impacted by sociocultural norms and illness progression. This orientation of the model informed the research and was aligned with the inclusion of individuals across the adult lifespan and various stages of illness progression (including newly diagnosed and those engaged in treatment for decades). The DCCM provides a framework to understand sociocultural context, interpersonal relationship interactions, romantic partner support in relation to medication adherence, and undergirds my research.

The specific aims of this project are:

Aim 1: Explore the relationship between perceived spousal/romantic partner support including emotional support (e.g., listening, encouragement, reassurance), instrumental support (e.g., physical assistance with medication administration, paying for medication, filling pill boxes) informational support (e.g., advice and reminders about medication administration) and medication adherence among Black participants living with T2DM.

Aim 2: Explore whether the perception of the provision of spousal/romantic partner support differs between male and female individuals living with T2DM.

Medication adherence may be influenced by spousal/romantic partner support among Black adults living with T2DM. This project will build on knowledge from previous studies and improve understanding of the role of spousal/romantic partner support/involvement on

medication adherence among a population that is understudied and immensely impacted by negative health outcomes related to T2DM (Blackmon et al., 2016; Bockwoldt et al., 2017; Sherman & Fawole, 2018; Sherman & Williams, 2018; Shiyanbola, Brown, et al., 2018; Shiyanbola, Ward, et al., 2018). Findings from this study will elucidate and contribute to understanding the research question:

How do Black Americans living with T2DM describe their perceptions of the role of spousal/romantic partner support on medication adherence?

#### **Chapter 2: Literature Review**

#### Statistics and T2DM

Nearly 5.4 million Black Americans live with diabetes (CDC, 2024). Black Americans are twice as likely to be diagnosed with T2DM, compared to White Americans, and are two to four times as likely to develop renal disease, suffer lower limb amputations develop diabetic retinopathy, and numerous other life altering complications (Tarfa et al., 2024). Costs associated with diabetes is projected to reach over \$600 billion by 2030 (Tarfa et al., 2023). Nearly 125,000 deaths are reported annually related to nonadherence to diabetes medication and Black Americans have a lower rate of adherence compared to White Americans (Wen et al., 2025). Prevalence estimates project by 2060 over 60 million individuals will have diabetes with Black Americans expected to experience the highest prevalence rates, underscoring the importance of inquiry in this area (Lin et al., 2018).

#### **Defining Medication Adherence**

The origin of the word 'adherence' can be traced to the French adhérence, meaning action of adhering, or attachment (Oxford English Dictionary, n.d.). Oxford English Dictionary defines adherence as: steadfast commitment to a belief, practice, etc.; fidelity, devotion; strict or faithful observance of (a rule, promise, etc.) (Oxford English Dictionary, n.d.). In one concept analysis, adherence is defined as "a complex multidimensional concept impacted by essential elements such as autonomy, self-determination, self-efficacy and communication" (Gardner, 2015, p. 100). The World Health Organization (2003) defines adherence as the "extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (Sabaté & World

Health Organization, 2003, p. 3). For the purpose of this study, medication adherence was defined as the commitment to following a medication regimen as recommended by a health care provider.

#### Facilitators of medication adherence

Several studies have identified facilitators (e.g., positive attitudes, social pressure, positive beliefs about health care system, knowledge) of medication adherence among Black Americans (Bockwoldt et al., 2017; Fai et al., 2017; Sherman & Williams, 2018; Shiyanbola, Brown, et al., 2018). In one study, positive attitudes regarding taking diabetes medication facilitated medication adherence (Fai et al., 2017). If the experience taking medication was viewed as beneficial, adherence was increased. Social pressure had a positive influence on medication adherence (Fai et al., 2017). Employment duties and social role functions promoted medication adherence. Participants were motivated to adhere to medication regimens to avoid disease complications and death, enabling participants to spend time with their families, which was highly valued (Shiyanbola, Brown, et al., 2018). Participants also related positive beliefs in the health care system as a facilitator to medication adherence (Sherman & Williams, 2018; Shiyanbola, Brown, et al., 2018). Knowledge about the disease process increased confidence to take medication for some participants (Sherman & Williams, 2018). Participants who accepted their illness felt confident to manage their care (Sherman & Williams, 2018). Goal setting was important for some participants and helped them to look forward to the possibility of being able to discontinue medication (Bockwoldt et al., 2017).

#### Barriers to medication adherence

Administration of medication can act as a direct barrier to medication adherence. In two studies, fear of needles was cited by participants as a contributor to medication nonadherence (Bockwoldt et al., 2017; Sherman & Williams, 2018). For some participants fear of insulin was associated with experiences of friends or family who had amputations or hypoglycemic crisis (Bockwoldt et al., 2017). Some linked insulin injections with being similar to an intravenous drug user (Bockwoldt et al., 2017). Participants in one study conducted by Shiyanbola et al. (2018), expressed a general fear of taking medication and felt discontent about taking medications for a prolonged period.

Fear is not the only barrier to medication administration. Adherence was significantly decreased in participants taking several diabetes medications (Sleath et al., 2016). Participants in two studies were concerned about taking medication because of side effects, at a rate as high as 70.6% in one study (Blackmon et al., 2016; Sleath et al., 2016). In three studies, researchers reported that participants cited that they did not take their medication as prescribed because they forgot, at a rate of over 50% for two of the studies (Osborn & Gonzalez, 2016; Shiyanbola, Brown, et al., 2018; Sleath et al., 2016). In one study 23.6% of participants were intentionally nonadherent because they did not want to experience side effects of insulin administration (Osborn & Gonzalez, 2016).

Participants that had a health literacy level of eighth grade or below were significantly more likely to experience diabetes medication problems, compared to those who had health literacy of ninth grade or above (Sleath et al., 2016). Similarly, in another study low health literacy was positively correlated with medication nonadherence (Fan et al., 2016).

Limited financial resources and high costs of medications were also cited as a barrier to medication adherence. One participant stated when they lost their Medicaid benefits, they did not take their medication for six months. In the same study a participant stated, they prioritized paying for their electric and water bills over paying for medication (Blackmon et al., 2016).

Sleath et al. (2016) found that 54.9% of participants had difficulty paying for their oral diabetes medication. In one study, participants with a gross annual income less than \$20,000 had an increased incidence of being nonadherent to their medication regimens (Fan et al., 2016).

Research suggests, lower levels of diabetes medication adherence among Black

Americans compared to White Americans (Rao et al., 2020; Shiyanbola, Brown, et al., 2018).

Researchers investigating facilitators of medication adherence indicate preference for
prioritizing social support in culturally tailored patient-centered diabetes treatment and
educational interventions (Bockwoldt et al., 2017; Mayberry, Harper, et al., 2016; Rao et al.,
2020; Shiyanbola, Brown, et al., 2018). Prioritizing social support in interventions can help
support providers help patients with diabetes cope with a commitment to the medication
regimen. Social support can provide encouragement and support problem solving in patients
living with T2DM and encourage medication adherence. Medication adherence can improve
glycemic control, decrease incidence of complications, decrease morbidity and mortality,
decrease health care costs and improve quality of life (Alexopoulos et al., 2019).

# **Defining social support**

Social support can be defined as "exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (Shumaker & Brownell, 1984, p.11). Social support can be viewed as a mutual

nurturing and caring process and exchange. Social support can be perceived differently based on gender, ethnicity and cultural background (Strom & Egede, 2012). Social support can be provided by formal support providers such as doctors or other medical professionals. Similarly, informal support providers such as spouses, family, friends and peers can provide support to support recipients. Social support involves the perception that one is cared for, accepted and the provision of assistance from formal or informal support persons. Social support is characterized by enhancement of the recipient's well-being. Social support is the level of enhancement of one's social needs characterized by beneficial interactions (Strom & Egede, 2012).

#### **Instrumental support**

Instrumental support is a type of social support which includes addressing tangible needs of support recipients (Schultz et al., 2022). Instrumental support involves a support person or social network intervening and helping with unmet needs (Schultz et al., 2022). As viewed in health care, instrumental support includes specific actions such as assistance with personal and medical care, including picking up medications and filling pill boxes. Spouses and other support persons may assist individuals living with T2DM through the means of instrumental support. Chronic conditions such as T2DM requires daily behaviors to support wellness and manage good health and stability of the course of the illness. Instrumental support is one form of social support that can be useful in managing medication adherence.

#### **Emotional support**

Emotional support is distributed through communication and imparts knowledge and information that the support recipient is loved and esteemed (Langford et al., 1997). For

example, spouses or romantic partners can express their love and caring for patients living with T2DM to facilitate medication administration by supporting psychological will being. This support can be empowering and facilitate self-efficacy. Researchers suggest, emotional support is one of the most frequently rendered types of social support (Langford et al., 1997).

# **Informational support**

Informational support can be defined as the information, advice and guidance provided to a support recipient during times of stress. For example, when support providers are informed about medication administration they can provide guidance to the patient living with T2DM. Living with a chronic condition can be associated with stressful events, where informational support can be provided to support coping. Researchers suggest that informational support can help with problem solving (Langford et al., 1997).

#### Social support and T2DM

Evidence linking social support with diabetes management has been well established in the literature and the results of several literature reviews have indicated, the instrumental role of spousal support in adopting and maintaining behaviors that promote diabetes management (Helgeson et al., 2016; Peyrot, Egede, Funnell, Hsu, Ruggiero, & Stuckey, 2018; Rintala et al., 2013; Wiebe et al., 2016). Family support has been associated with better glycemic control, enhanced treatment adherence and positive health outcomes related to diabetes management (Oj et al., 2021). Social support has also been associated with diagnosis acceptance, emotional adjustment and decreasing stress associated with diabetes management (Strom & Egede, 2012). Conversely, spousal/romantic partner involvement that is overly controlling, critical and undermining can have detrimental effects (August et al., 2013; Henry et al., 2013; Rook et al.,

2011; Wiebe et al., 2016). Furthermore, lack of social support has been associated with increased rate of mortality and incidence of diabetes complications (Strom & Egede, 2012). Among studies investigating the role of spousal/romantic partner support on diabetes self-management, the majority have focused on prescribed dietary or physical activity adherence, but predominately include White older adults in long-term heterosexual marriages as a sample (August et al., 2013; Henry et al., 2013; lida et al., 2010; Johnson et al., 2014; Rook et al., 2011, 2016; Wiebe et al., 2016). These studies report the complexity inherent in spousal/romantic relationships related to diabetes care and the need for further investigation inclusive of racial/ethnic minorities. Less studied are perspectives of Black Americans with T2DM throughout adulthood, married or involved in romantic partnerships. In order to address these gaps, this study explored the role of spousal/romantic partner support on medication adherence as perceived by Black Americans with T2DM from middle adulthood and beyond.

#### Emotional, informational and instrumental support and T2DM

Emotional support has been associated with improved self-care among couples in which the recipient is living with T2DM. In one study, among newly diagnosed individuals with T2DM, those that felt cared for and understood, had greater motivation to engage in daily diabetes self-care behaviors (Helgeson et al., 2016). Extant literature exists exploring the outcome of emotional support on self-management behaviors, specifically physical activity and diet among patients with diabetes (Helgeson et al., 2016). This study focused on medication adherence as a self-management behavior to explore whether emotional support influences behavior in a similar fashion. Moreover, Helgeson et al. (2016) found individuals living with diabetes, exercised more on days and had higher dietary compliance when they perceived greater

emotional support from their partner. They concluded that individuals took better care of themselves when their partner understood them and made them feel good about themselves, proving optimal emotional and informational support. In contrast, partners who elicited socially controlling behaviors resulted in poor mood for both the recipient and partner and less compliance with self-management behaviors. Furthermore, conclusions from the aforementioned study indicated that intervention studies should focus on couples to support individuals newly diagnosed with T2DM.

Informational support may be employed most successfully when there are transitional stages of an illness when a threat to one's health becomes a realization. The most effective types of social support are dependent on the support needs of the individual. Since there are controllable and uncontrollable aspects of living with T2DM research suggests that emotional, informational and instrumental support can be beneficial depending on the stressor.

Instrumental support provision was found to impact diabetes self-management.

Helgeson et al. (2022) found that when partners and patients living with T2DM collaborated, there was a positive association with instrumental support. Furthermore, researchers found that spouses or romantic partners who supported and collaborated with the participant with T2DM, engaged in a higher level of diabetes self-management behavior (Helgeson et al., 2022). Thus, researchers concluded it is integral to involve partners in diabetes management interventions for coping and support (Helgeson et al., 2022).

#### Perspectives on Spousal/Romantic Partnerships

Throughout adulthood romantic partnerships can serve an instrumental role of profound importance impacting diabetes care (Rintala et al., 2013). Spouses or romantic

partners play a prominent role in an adult's social network. Romantic partners are highly influenced by their partners diabetes and play an integral role in daily diabetes self-care behaviors (Helgeson et al., 2016). Research suggests being in supportive relationships acts as a buffer to aid in coping with psychological and physical effects of coping with stressors including chronic illness, such as diabetes (lida et al., 2010). Diabetes illness progression and dynamics of romantic partnerships influence the social context surrounding medication adherence and pathways of support. Furthermore, researchers found more frequent provision, and higher perceived value of familial support among participants living with T2DM from racial/ethnic minority groups compared to White counterparts (Peyrot, Egede, Funnell, Hsu, Ruggiero, Siminerio, et al., 2018). Several recent studies investigating the role of spousal support have focused on prescribed diabetic dietary or physical activity adherence, with less attention to medication adherence (lida et al., 2010; Johnson et al., 2014; Rook et al., 2016). These studies have illuminated beneficial aspects of spousal support, intrinsic qualities of a multitude of characteristics of romantic relationships influencing diabetes treatment adherence, and the need for further investigation inclusive of racial/ethnic minorities. Furthermore, researchers suggest diabetes management interventions include partners and embrace diabetes management as a shared interpersonal experience (Helgeson et al., 2022). This study addresses the aforementioned gaps in the literature, unveiling perspectives of Black adults related to diabetes medication adherence, and the impact of unique defining attributes and facets of spousal/romantic partner support.

# **Gender and social support**

Social support is utilized differently among males and females (Kneavel, 2021). Research suggests there are gender differences in the provision of social support. Studies indicate among males, a lower incidence of providing or seeking social support compared to females (Kneavel, 2021). Furthermore, emotional support was less likely to be engaged in by males. One study found that females sought social support more frequently from their network of social support (Kneavel, 2021). Engaging in a romantic partnership was found to be a more influential factor in self assessed perceived social support, well-being and quality life among males compared to females (Stronge et al., 2019). Furthermore, research suggests that wives give more support to their partner when compared to husbands (lida et al., 2010). Research suggests wives may be more attune to sensing when social support is needed to support a partner during stressful situations such as living with daily stressors associated with chronic illness (lida et al., 2010). Less studied are perspectives of male support recipients. A number of studies focused on women as the support recipient and further elucidation of gender differences would provide greater insight into how to better support female support recipients (lida et al., 2010; Rintala et al., 2013). Studies examining social support among romantic partners with one individual coping with chronic illness typically involved females as the support recipient so less is known related to gender differences and the provision of support (lida et al., 2010). Thus, this study explored male and female experiences of social support from romantic partners.

## Chapter 3: Research Design

# **Positionality and Reflexivity**

Beliefs related to how knowledge is constructed inherently shape one's epistemological stance and further facilitate choices in methodology and methods used to conduct research (Carter & Little, 2007). I believe that knowledge is socially constructed; influenced by cultural beliefs and social contextual factors. This is a fundamental assumption of the social constructivist paradigm (Kivunja & Kuyini, 2017). "Shared constructions, especially among larger groups of individuals, become reified over time to become part of the sociocultural milieu" (Lincoln & Guba, 2013, p.54). Considering knowledge and the related context is an element that supports assumptions of social constructivism (Lincoln & Guba, 2013). Furthermore, illness perception is in many ways governed by our socially constructed reality. I believe that social reality is fluid and knowledge is multidimensional. Individuals do not passively receive knowledge (Ritchie et al., 2014). Highlighting my worldview through a social constructivist lens is how I arrived at the chief ontological question for my study and how this paradigm can be used to help bridge the gap.

Reflexivity helps to embolden the biases and assumptions that I carried with me into the research process (Sandelowski, 2000). Through co-construction of knowledge, I anticipated that my interactions with participants lead to reflections on my interpretations and biases related to medication adherence, as well as, allowed me to gain insight into the meaning expressed by my participants (Guba & Lincoln, 2005; Weaver & Olson, 2006). The subjective nature of this interaction contributed to my description of participant perceptions. Furthermore, remaining reflexive and keeping a reflexive journal increased trustworthiness and rigor (Korstjens &

Moser, 2018). *Intersubjectivity* between myself and the participants was pursued throughout the research endeavor (Weaver & Olson, 2006).

# **Design Overview**

This study employed a qualitative descriptive approach using in-depth, semi-structured interviews completed via Zoom among participants with T2DM to elucidate perceived spousal/romantic partner support and the influence on medication adherence.

# **Sampling Methods/Participants**

Study participants who were 18 years of age or older, diagnosed with T2DM who have a spouse/romantic partner 18 years or older were recruited. Romantic partners were defined as those individuals who the participant with T2DM had an intimate relationship with of at least six months, and identified as a primary support person. Inclusion criteria include: 1) individuals who self-identify as Black, defined as having African ancestry and not of Hispanic ethnicity, 2) adult 18 years or older, 3) diagnosed with T2DM for one year or greater, 4) prescribed at least one oral or injectable diabetic medication, 5) had a spouse or romantic partner of any race or ethnicity of the opposite sex or same sex, 6) had the capacity to give informed consent, and 7) had the ability to participate in an interview delivered in English. Adult participants across the adult life span were included to capture rich and in-depth responses related to age.

Recruitment occurred through the Northeast region of individuals in Sigma Gamma Rho Sorority Inc., a historically Black sorority with over 2,000 female members in this region. A flyer announcement was posted via an email list serve and emailed the various chapters to recruit participants. Announcements were made during monthly Sigma Gamma Rho Sorority Inc. chapter meetings and the annual Northeast region conference meeting. Recruitment also

occurred through the African American Genealogical & Historical Society, Greater New York chapter with approximately 135 members. A flyer announcement was distributed at monthly meetings. Convenience sampling was employed, appropriate for qualitative descriptive research, and provided for selection of information rich cases involving participants who were knowledgeable about the phenomena of interest (Palinkas et al., 2015; Sandelowski, 2000). Snowball sampling was also utilized during recruitment whereby additional participants were referred by participants already enrolled in the study. These additional participants were contacted, given an eligibility survey, and found suitable for participation in the study.

This qualitative descriptive study aimed to improve understanding of social contextual factors related to the provision of support from the perspective of the recipient in addition to unveiling differences related to gender. Qualitative methodology was well suited to explore perceptions, and personal meaning attributed to medication adherence within the context of intimate social partnerships (Denzin & Lincoln, 2013; Guba & Lincoln, 2005). Qualitative methodology was essential to understand the subjective experience of medication adherence. Specifically, a qualitative descriptive approach was appropriate in addressing the research question, enabling rich description of nuanced perceptions, conveyed in language that embodied participant representation of phenomena (Neergaard et al., 2009; Sandelowski, 2000, 2010).

Qualitative descriptive methodology was appropriate to address the research question:

How do Black Americans living with T2DM describe their perceptions of the role of
spousal/romantic partner support on medication adherence? Through this research,
perceptions of social support were explored and described to better understand its influence

on medication adherence. The goal was to elicit rich description of experiences and views related to the phenomenon. Through the use of semi-structured interviews and inclusion of prompts, participants were supported in openly sharing their perspective. Semi-structured interviews with participants uncovered "the who, what and where of events" or experiences (Sandelowski, 2000, p. 339). Qualitative descriptive methodology was used to elicit description of the subjective experience of medication adherence (defined as taking all prescribed diabetes medication the week prior to the interview) (Atal et al., 2021). Qualitative descriptive methodology was appropriate since researchers wished to elicit rich data to describe participant perspectives related to a phenomenon (Neergaard et al., 2009; Sandelowski, 2010). Variables and constructs of spousal/romantic partner support and medication adherence are not easily measured. There are empirical tools used to measure medication adherence however, perceptions of medication adherence are not fully captured using survey methods. Furthermore, voices of Black Americans are underrepresented in the literature and the utilization of qualitative methods helped to give voice to these participants.

The qualitative descriptive approach can be employed when the research question supports the development of a straightforward description of characteristics of a phenomenon of interest (Turale, 2020). Using a qualitative descriptive approach, the goal was to describe participant responses in everyday language with a low level of inference (Sandelowski, 2000). However, interpretation of data was evident in data collection and analysis. Using this methodological approach, the researcher stayed close to the data. Qualitative descriptive research was distinguished as a form of naturalistic inquiry and supported this research (Turale, 2020). As a researcher, I used qualitative methods to explore the natural state of events, and I

did not interfere with the natural unfolding of events through the interview process. As one of the lesser theoretical methodological approaches a conceptual framework underpinned this research to help frame and improve understanding of the findings (Sandelowski, 2010; Turale, 2020). The conceptual framework served as a guide, however the framework may be altered during the process of data collection and analysis (Sandelowski, 2010).

Qualitative descriptive methodology provides a vehicle of thoughtful exploration, related to a complex multifaceted topic such as medication adherence (Colorafi & Evans, 2016). In depth semi-structured interviews provided opportunities to gather rich information. Furthermore, follow-up questions and probes were implemented to gather further details related to the question posed. I had the freedom to explore questions in the interview guide with great depth and breath.

Health science scholars suggest that qualitive inquiry is appropriate when the intent is to "share individual stories, write in a literary flexible style, understand the context or setting of issues, explain mechanisms or linkages in causal theories...[and] when traditional quantitative analyses do not fit the problem hand" (Colorafi & Evans, 2016, p.16). The aforementioned elements were present in this research and exploration of medication adherence.

Engagement in diabetes medication adherence was influenced by illness stage, culture, gender, perceptions of support and required a level of depth and breadth in exploration facilitated by qualitative methodology. Support levels and intensity existed across a spectrum, requiring expansion of dimensions and facets of support. In-depth semi-structured interviews provided an opportunity to expound on beliefs and attitudes facilitating opportunities for less constrained, open expression and flexibility in discourse. Data were analyzed using thematic

analysis guided by the aforementioned dimensions of dyadic coping, open-ended questions on other relevant topics, inductive and deductive coding. Fundamentally, immersion and coconstruction of knowledge, through iterative processes of data collection and analysis contributed to intuitive understanding and interpretation (Sandelowski, 2010). Qualitative inquiry enabled interpretation of beliefs, attitudes and perceptions of medication adherence enabling rich description of phenomena, appropriate for this research.

#### **Ethical considerations**

This study involved human subjects and appropriate measures were taken to protect the privacy and well-being of involved individuals. The aim of this research was to uncover new knowledge and expand and build upon the nursing body of knowledge. Ethical considerations are crucial to studies involving human subjects. In order to ensure the ethical conduct of research, the University of Virginia's Social and Behavioral Sciences Institutional Review Board approval was obtained prior to starting the research endeavor to ensure that the project met standards and regulations for research involving human subjects. Informed consent was administered without coercion or inducement (Holloway & Wheeler, 1995). All of my participants received informed consent outlining the processes involved in the conduct of this research. Written and verbal information were furnished to the participants, and my contact information was provided for the purpose of clarification of any study details. Education and details related to what participation entailed, and answers to all questions related to research procedures, were discussed prior to obtaining consent. Electronic consent forms for all individuals conducting the interviews remotely were obtained. Informed consent was considered an ongoing process related to participation throughout the interview process.

Participants were made aware during the informed consent process, their participation is voluntary and at any point if they did not feel comfortable the interview could be terminated, and their participation withdrawn.

#### **Instrument-Semi-structured Interview Guide**

The principal investigator conducted individual in-depth semi-structured interviews approximately 30-60 minutes in length, using an interview guide to better understand participant perceptions. This data collection method supported acquisition of rich data preferred for qualitative descriptive inquiry (Sandelowski, 2000). Use of an open ended interview guide encouraged illustrative descriptive responses (Bradshaw et al., 2017). Examples of interview questions include the following: Tell me about the support/involvement you receive from your spouse/romantic partner related to managing your diabetes medications? How does your spouse/romantic partner support you emotionally related to taking your diabetes medication? For example, listening to concerns about your medication?

#### **Data Collection Procedures**

Potential participants were given an eligibility survey via Qualtrics. Participants who met the inclusion criteria to participate in the study received a consent form virtually before any study related data was collected. Electronic consent via Qualtrics survey was provided to review and sign prior to scheduled interviews. Once signed informed consent was obtained interviews were scheduled. Participants completed a demographic survey to collect background information (e.g., age, gender, duration of T2DM). Interviews were conducted via Zoom and audio recorded. Field notes capturing information related to contextual responses were maintained and recorded following the interviews. In addition, a reflexive journal throughout

data collection and analysis was maintained. To ensure confidentiality each participant was assigned a code. Individual names were not used during the interviews. Use of de-identifiers aided in protection of participant confidentiality (Kaiser, 2009). Transcribed data and field notes were maintained on a password protected computer.

# **Data Analysis**

Data was analyzed using thematic analysis, guided by the constructs outlined in the conceptual framework. Thematic analysis was used during coding of semi-structured interviews. The Zoom audio recordings were uploaded without the video and the transcripts were generated. All interviews were transcribed verbatim and compared with the audio recordings to confirm accuracy. Transcripts were independently coded using Dedoose software. Codes were derived from the data, data collection and analysis occurred concurrently, and as new intuitive understanding of the data was gained, codes were revised (Sandelowski, 2000). Several levels of analysis were performed, building on one another. The individual interviews of participants with T2DM were coded, clustering statements and developing themes, through an open-coding approach. Codes were created to categorize data within female and male interviews and then clustered into themes attributed to male or female gender. Comparison across and within female and male participant interview data were explored. Similar themes present across genders were coded. This analysis assisted with exploration of "open reality" (individual descriptions) and "hidden reality" (meaning and interpretations of support) (Eisikovits & Koren, 2010). Codes and categories were organized, analyzed and collapsed into themes. Data analysis was an iterative process and multiple revisions occurred when creating themes (Bradshaw et al., 2017). Inductive and deductive content analysis, including returning to the data to clarify and compare to other interviews was essential when interpreting data (Elo et al., 2014).

#### **Maintaining Rigor**

Trustworthiness was supported based on established criteria used to maintain rigor in qualitative research including: authenticity, credibility, confirmability and dependability (Lincoln & Guba, 2013; Neergaard et al., 2009). Authenticity was supported through representation of the emic perspective (Neergaard et al., 2009). Participants were allowed to openly express their views, promoted through the use of open-ended questions contained in the semi-structured interviews. Credibility of research findings was provided through the accurate portrayal and interpretation of participant responses (Korstjens & Moser, 2018). Confirmability was established through maintaining an audit trail throughout the research process including design, code creation and data analysis (Korstjens & Moser, 2018). Dependability was assessed through evaluation of congruity with established standards for methods used in qualitative descriptive inquiry (Korstjens & Moser, 2018). Member checking, through clarification of statements and inferences, immediately after the interviews aided in credibility and dependability (Lincoln & Guba, 2013; Neergaard et al., 2009). Maintaining clear and detailed notes throughout the research process was essential and supported trustworthiness of the study. Reflexive journaling allowed the examination of personal biases, assumptions and preconceived notions that influenced choices made during the research process and supported the aforementioned methods employed to maintain rigor (Korstjens & Moser, 2018).

# **Chapter 4: Results**

A total of ten Black adults living with diabetes participated in the semi-structured interviews of the study. Of the ten, nine participants were married and one participant was involved in a romantic partnership. Seven of the participants were female and three were male. Nine of the ten participants were adherent with all their diabetes medication the week prior to completing the interviews. Demographic data are provided in Table 1. Qualitative data were categorized by type of social support (emotional, instrumental, and informational) perceived by participant from their spouse or romantic partner. The following themes (or patterns) were found related to these types of social support: having my back, encouragement to persevere, being a team, moral support, help with logistics of medication regimen, tangible checks and balances, and constant reminders from partners. In addition to the themes related to social support, themes emerged related to gender differences and the impact on support perceived by the participants: coping with the consequences of diabetes, support translating to feelings of love. All of these themes are described and illustrated using participant quotes in the coming paragraphs.

Table 1: Participant demographics

Pseudonym	Gender	Age	Race/ethnicity	Duration	Duration of	Days non-
	identity			of	marriage or	adherent in
				diabetes	romantic	past week
				(years)	partnership	
					(years)	

Elizabeth	female	75	African	36	39	0
			American			
Jane	Female	57	African	20	25	0
			American			
John	male	62	African	26	39	0
			American			
Joseph	male	81	African	50	58	0
			American			
Josephine	female	64	West Indian	10	30 (romantic	0
					partnership)	
Lily	female	68	African	11	15	0
			American			
Michael	male	83	African	9	21	0
			American			
Rachel	female	57	African	13	1	0
			American			
Sarah	female	58	African	10	30	0
			American			
Susan	female	46	West Indian	3	23	1

## **Emotional support**

# Having my back

Six of the female participants and three of the male participants cited instances where they perceived emotional support from their spouse or romantic partner related to managing their medications and medication adherence. Susan age 46, married 23 years and living with diabetes for three years described the support she received as her spouse "having their back" related to managing her medication. For example, "So when I was having a challenge with other stuff, it was like, okay, let's go to doctor and see if this is because the meds, so it's more of a like. I got your back kinda thing." This participant struggled with medication side effects related to her diabetic medication regimen. She felt supported by her spouse and confident in seeking help with her spouse from her endocrinologist. She acknowledges in the interview that she knew she could depend on her spouse's emotional support to cope with issues that she had related to her medication regimen, citing that she could depend on her spouse for support. The following quote by Susan further illuminates how she felt about the emotional support she perceived, "It makes me feel good. It feels good to know somebody has your back. And even through the weight gain or the nausea you know, they're still there." This quote highlighted the participant perceived that she can depend on her spouse as a resource to help her cope with the medication regimen.

The theme "having my back" was a consistent theme throughout the interviews. Rachel 57 years old married 1 year and living with diabetes for 13 years states, "I do think he's supportive. He really has my back. I know he's very supportive, but he is allowing me to do what I need to do, and he can physically see the the results of what the medication is supposed to

do." Rachel was coping with a new medication regimen and was appreciative of the support she received from her spouse. He was active in helping her to cope and she could rest assured knowing he had her back. Participants stated that they were grateful they had a spouse/romantic partner they could depend on to be there for them to offer support when they needed it. This support was unique because it was ongoing and for many had lasted for decades in their relationship together as they continue to live with diabetes. Sarah age 58, married 30 years and living with diabetes for approximately 10 years, states "So I know he's paying attention. He has my back. You can see well he will tattle tail to the doctor. So I know he's paying attention." Sarah acknowledges her spouse is attentive and he has her back and she is grateful for the support. Although 90% of the couples lived together and were married, the majority of participants felt secure in their relationships knowing someone had their back. This type of emotional support was instrumental in remaining adherent to their diabetes medication regimen.

# **Encouragement to persevere**

Encouragement to persevere is a theme that emerged from the interviews. Participants reflected on the emotional support they received from their spouse or partner in the form of constant encouragement and care to continue with their medication regimen despite challenges. Josephine age 64, with her romantic partner for 30 years and living with diabetes for 10 years, proclaimed that she felt good about the support she received from her romantic partner, and the perceived support, enabled her to be adherent with her diabetes medication regimen. For example, "It's good. It's good. I probably would slack off if, if I didn't have that extra additional support. Yeah, it makes it easier to slack off when you don't have that support.

Even though you know that's what you should do." Without the encouragement to persevere she could possibly not adhere to the medication regimen and become laxed with managing her diabetes. This participant goes on to say that the support she perceives from her romantic partner is not harsh or overly critical and she finds the support encouraging, "He doesn't criticize me for taking it. And he'll ask me if I took my medication when he and he doesn't criticize me for taking my medication. But he does encourage." These positive and encouraging views related to adhering to the medication regimen are perceived favorably and help the participant to remain adherent. Susan describes her husband's encouragement:

he'll encourage me to take my meds now. He's like, oh, did you take them? And we kinda have like an understanding he's not gonna harass me, but he like we are gonna work together... Like I said, we try, he doesn't make it frustrating, but he does encourage so he's more of a supporter.

Joseph age 81 married 58 years and living with diabetes for 50 years states that his wife is deeply involved in his care and he feels encouraged by her support. For example, "well, she's involved with it with everything I do, you know, physically and mentally, you know, she's a great support system, you might say...well, it's good to know that you had a support, you know, so. You know, I feel I don't feel bad about it I feel encouraged." Joseph, like many of the participants shared they feel encouraged by their spouse/romantic partner. This encouragement was something that they felt on a daily basis. Although, participants experienced some challenges with managing their diabetes, the encouragement helped them to overcome the difficulties that are associated with managing diabetes, especially remaining adherent to the medication regimen.

John age 62, married 39 years and living with diabetes for 26 years, expressed similar sentiments related to describing the perceived emotional support as encouraging. For example,

"Well, she's very positive, you know, always encouraging me to okay, follow the rules of being a diabetic...She looks after me." This participant describes his wife as being very positive and a person he can depend on to support him in following "the rules," including diabetic medication adherence. Her positivity and encouragement were extremely meaningful. Having a spouse to help to motivate the participant, exemplified the unity in their marriage to one another.

# Being a team

Participants described being a team when it comes to managing their diabetes. John states "So, you know, we're a team." This participant goes on to share in their relationship, they depend on each other for support, and he feels immensely supported by his wife. "Actually, I get a lot of great support from her...Yeah, yeah, but no, you know, it's one of those things it's always been from day one, you know, she takes care of me, I take care of her." Another point raised by this participant is teamwork in the marriage is integral to managing his diabetes and staying adherent to the medication regimen. John states:

Oh, well, like I said, basically, you have to be a team. You know what I mean? so, in the event that she was sick, she would need my support. You know, if I'm sick she gives me her support. You know, it has to be a team because it can't be an individual thing...You know, so, and I thank God that I have who I have. Like I said, we're Batman and Robin.

This participant was adamant about the importance of emotional support in managing diabetes as being a team effort between patient and spouse. It's part of the team dynamics of being married or in a romantic partnership. Both partners were supportive of one another when coping with the challenges of living with diabetes. John stresses an important point about coping with diabetes as not being an individual endeavor. Teamwork between spouses/romantic partners was unique to this intimate type of relationship. As stated earlier

this bond remains strong throughout adversity and helps the person living with diabetes to cope and remain focused on the goals of care and longevity.

# Moral support

Michael age 83, married 21 years living with diabetes for 9 years described the emotional support he received from his wife as moral support. She was proud of him taking the medication as prescribed and adhering to the medication regimen. This sentiment resonates in the following quote:

Actually, you know, the, the only, as far as the medications, the support that I get from my wife is just you know just that, just kind of moral support, you know, she, she's very proud of me you know, of me taking the medicine and, and, you know, taking the necessary steps to, to keep myself healthy. But she's she's always there for for that that that moral fortitude.

# Michael goes on to say:

There's so many people who are my age and younger who refused to take their medicine, you know, and, and to their own detriment you know, so I don't have that problem. I understand. the importance and, I wanna, I wanna keep breathing for a few more years. And she's there to support me, you know...Just by letting me know you know, that she loves me and she loves the fact that I take the medication as I should.

There is an emotional connection and stated love regarding adhering to the medication regimen and thus serving as an emotional support for the participant. He also states that he felt cared for in addition to the love that his spouse felt for him.

#### **Instrumental support**

# Help with logistics of medication regimen

Instrumental support includes the tangible, physical things a support person gives. Four of the females and two of the male participants shared the perceived instrumental support they received from their spouse or romantic partner related to picking up medication from the

pharmacy or bringing them their medication to ensure they take their medication as prescribed and adhered to the medication regimen. The quotes below represent some of the statements that participants made regarding this instrumental support. For example, Sarah states the following, "so, if medication has to be picked up and he's there, he picks it up." Jane age 57, married 25 years and living with diabetes for 20 years states, "If I'm home and my spouse is home, he'll make sure he makes me breakfast and he'll bring my medications along with it...and so yes he knows what I'm supposed to take. So he'll bring it in the morning and at night." This couple were in synch regarding the participant's medication regimen. The participant could depend on her spouse to bring her medication on a daily basis at specific times during the day that coordinated with meals. She had that meaningful instrumental support to help her remain adherent to the medication regimen.

Joseph suffers from memory loss and reflects that his wife is instrumental in the ordering and organization of his diabetic medication. He states,

Some of the memory I have a little bit of memory loss, so my wife has been helping with the medications, ordering the medications. We have 2 of the weekly medication. What do you call it? Weekly medication cases. So, we sit down together at the table, we'll go through the medications and we'll fill out, my wife will help me fill up my weekly medications and we do it for a 2 week period.

This type of instrumental support from the spouse was integral to the participant to ensure that he continues to adhere to the medication regimen.

# Tangible checks and balances

Participants shared that there were checks and balances in their relationship where their spouse/romantic partner would help monitor they were taking their medication as prescribed. Lily age 68, married 15 years and living with diabetes for 11 years notes that her

spouse checks with her and wants to see proof that she takes her injectable diabetic medication. She did not find the support intrusive or worrisome. This was a tangible checks and balances support to ensure that she follows her diabetic medication regimen. She states,

so yeah, my husband does ask me if I took the medication. And he wants to see proof of it. He wants to see that I empty the PIN, you know, that it doesn't have that cap on it anymore because you pulled it off to inject the little cap that's at the bottom of the syringe, so he looks to make sure that I really took it that day.

Having these tangible checks and balances in effect helped to ensure that participants were adherent to the medication regimen. Having someone there on a daily basis helped to support the participants in their daily diabetes management. Furthermore, participants were grateful they had this assistance.

# **Informational support**

#### **Constant reminders from partners**

Informational support includes advice, guidance and knowledge that a support recipient receives from their spouse or romantic partner. This support also includes reminders to take medication as prescribed. Six participants reflected on instances where they received informational support from their spouse or romantic partner. For example, Susan reflects "when it comes to taking the meds he'll remind me when I forget so I stay on track." Other participants welcomed reminders from their spouse because they sometimes didn't want to take their medication. John reflects, "you know, so there there are times when I'm in the house and I'm on a computer doing something, you know, and then she'll remind me, you know, it's time to take your medication." Joseph reflects on how the support and reminders makes him feel. "How it makes me feel? Well, well, it's good. You know, that you have someone that's with you, that's gonna support you and remind you what you should be doing and when so that's

good you know." The support he received from his wife helped him to remain adherent to the medication regimen. Another participant shares similar sentiments. Sarah states,

and some days I just don't wanna take it. Because I don't like taking medication. And, that's just the extra added one that the doctor added for me to take. My husband knows I take it. And he said it. He was telling me it has a lot of great benefits to it, so you know, don't stop taking it if the doctor ordered it.

Sarah was adverse to taking medication and her spouse was sharing information with her about the pros of taking the medication. Sharing information helped her to make an informed decision related to remaining adherent to the regimen. Thus, this informational support helped to reinforce the information that she received from the doctor and served as external motivation to continue with the medication regimen.

Susan states, "When it comes to taking the meds and he'll remind me when I forget. So I stay on track." Susan was grateful for the support she received from her spouse to give her reminders so that she remained adherent to her medication regimen. Sarah age 58, who has been married 30 years and living with diabetes for 10 years shared similar sentiments related to having a spouse on whom she could depend on for informational support. This spouse was present in the relationship and she knew she could depend on her husband for support. "Ummm I'm glad to have someone that's there with me that's knowledgeable about what I'm living with. And, so if something did go wrong. He would know what to do or who to call." Furthermore, this participant could rest assured, her spouse could be depended on for support should an emergency arise or if she was experiencing serious side effects from her diabetic medication. Sarah states, "One medication that the doctor added for me to take my husband knows I take it. And he said it. He was telling me it has a lot of great benefits to it, so you know,

don't stop taking it if the doctor ordered it." This informational support translates to being knowledgeable about the participants medication regimen in order to support them. For example, John shared the following about his wife's support,

Well, she usually accompanies me to doctor's appointments. You know, so. She knows more about what's going on because you gotta remember as just as a spouse that doesn't have diabetes they need to have information too. You know, to help you out.

John acknowledges that the spouse of an individual living with T2DM has to be informed about the regimen and what daily management entails to act as a support.

The themes above shed light on how the participants perceived emotional, instrumental and informational support from their spouse/romantic partner. All of the participants were grateful for the support they received and shared specific instances, where the support impacted the choices they made to remain adherent to the medication regimen and maintain this daily/weekly behavior.

#### **Gender differences**

# Coping with the consequences of diabetes

The majority of female participants cited that they benefitted from the support of their spouse/romantic partner when coping with side effects of diabetes medication. For example, Susan states,

when I was going through like, I don't like this medication, it's giving me UTIs, it's doing this, it's doing that. That was more of like a more emotional support. So it was like, oh he was just there for me like hugging. It's gonna be okay. When I was throwing up, or having diarrhea he was there.

Susan received support from her husband regarding coping with the side effects of the medication and was grateful for the reassurance and support. Similarly, Rachel 57 years old

living with diabetes for 13 years and married for 1 year, shared reflections on coping with side effects of diabetes medication. She states,

Oh, he's been very supportive. First of all, he was very concerned at the drastic change. There's been periods of time, especially with the introduction of the new medication, where I could not keep anything down, and he was like, you need to stop taking this, have you talked with your doctor? You know what's going on? Do I need to get you to the hospital.

Rachel had been experiencing numerous challenges coping with diabetes and medication side effects. Her husband had an active presence in her care and was there to help her cope with the challenges. Conversely, male participants did not share the same sentiments. Male participants did not express needing emotional support to cope with medication side effects.

### Support translating to feelings of love

All of the male participants reflected that support from their wives made them feel loved explicitly. Furthermore, one male participant said he felt like royalty. Michael states,

I guess in a word like a king. I feel like. I feel loved. I feel that, you know. Unlike a lot of people my age and younger I, unlike that, I feel that you know, that someone really cares about me...How do I feel about it? I feel like I'm, someone who, God is smiling on I feel, truly blessed.

Michael felt the emotional support that he received from his wife made him feel loved and truly blessed. Furthermore, he felt the support he received from his wife helped him to cope with living with diabetes and remaining adherent to the medication regimen. Their marital relationship was strong and the support he received translated to feelings of love. John shared similar sentiments. John states, "I am truly grateful for the love and support I receive from my wife...I take my medication as prescribed and she is proud of me for doing so, and for this recognition I feel truly loved."

Although female participants stated that they felt cared for and loved, these feelings were more pronounced from the male participants. The emotional support males felt from their wives was extremely evident throughout the interviews. In contrast, female participants felt a vast array of support that was emotional, instrumental and informative in nature.

#### **Chapter 5: Discussion & Conclusion**

This study explored perceptions of Black adults living with T2DM of spousal/romantic partner support and medication adherence. Analysis showed Black adults vividly describe their perceptions of emotional, instrumental and informational support received from their spouse or romantic partner. Participants provided thoughtful reflections related to how support impacts medication adherence.

Little is known regarding spousal/romantic partner support and medication adherence among Black adults living with T2DM. However, the participants involved in this research showed that they perceived emotional, instrumental and informational support from their partner which helped them to cope with medication adherence. These findings are on par with research among their White counterparts (Peyrot, Egede, Funnell, Hsu, Ruggiero, Siminerio, et al., 2018). Furthermore, among the participants, emotional support was discussed repeatedly. This also aligns with research involving predominantly White participants, which suggests emotional and instrumental support being the most frequent type of social support perceived from individuals living with T2DM (Helgeson et al., 2022).

Several main themes that emerged from data analysis will be discussed in the coming paragraphs. Research from systematic reviews has shown that perceived family support is valuable to patients living with T2DM, however the best way to deliver this support is unclear (Suhamdani et al., 2024). Research suggests strong family support perceived by individuals living with T2DM had better blood glucose control and medication adherence (Olagbemide et al., 2021).

The theme having my back was a very saliant finding among the participant data. Having my back was described as a feeling of perceived emotional support for participants that helped them to feel secure and content. Participants expressed they felt confident knowing their partner was there to provide emotional support and help them cope with diabetes management. Moreover, they were confident in knowing their partner would be there to support them amidst any potential challenges should they arise. In contrast, research suggests loss of or absence of support from family, including spouses can hinder the implementation of diabetes self-management including medication adherence (Suhamdani et al., 2024). In order to better understand the importance of the aforementioned theme, research related to loss of support including divorce or loss of support provider needs to be conducted.

Research indicates incorporation of a spouse/romantic partner in self-management programs helps to mitigate poor health outcomes (Adu et al., 2024). Research shows individuals living with T2DM who perceived social support from family have better medication adherence. Furthermore, social support helps to sustain self-management behaviors and overcome challenges with T2DM (Adu et al., 2024). The theme *encouragement to preserve* describes the importance of spousal/romantic partner emotional support of encouragement. Several participants described their perception of encouragement as helping them to be motivated to self-manage their diabetes care. This encouragement helped them to not waiver from the goal of managing their illness. This encouragement supported the idea that they were determined to succeed in overcoming the challenges of their illness. Perseverance meant they would remain devoted to achieving success despite any difficulty should that arise. Participants discussed their challenges and potential remedies in the form of emotional support that support partners

gave and that they perceived from that support. Similar to perseverance, literature on the impact of social support and resilience is associated with better diabetes self-management. The aforementioned theme aligns with current research indicating that social support has a moderating effect on resilience (Parviniannasab et al., 2024). Research is needed with larger scale studies to more fully understand this theme involving patients who are experiencing challenges with their diabetes medication regimen.

The theme *support translating to feelings of love* was described as receiving consistent support from a partner turning into feelings of love. Participants shared they were grateful for the feelings of love from their partner. This form of affection and emotional support helped them to remain dedicated to managing their diabetes care and remaining adherent to the medication regimen. This theme aligns with research findings that indicate, among Black adults, knowing that support was provided as a show of love made that support acceptable to the support recipient (Naqvi et al., 2023). Furthermore, research findings in the literature indicated that unsolicited emotional support specifically, may be more desirable than instrumental and informational support. Future research is needed to explore types of social support separately to better assess desirability (Naqvi et al., 2023).

## **Limitations/Potential Difficulties**

Challenges to the study existed related to recruitment, sampling and transferability.

Convenience sampling can introduce researcher bias and use of interviews can introduce social desirability bias from participants. However, recruitment continued until the point of saturation of emergent themes (Palinkas et al., 2015). Small sample size was another limitation.

Interviewer bias can be introduced when using semi-structured interviews. Incorporating

prompts in the interview guide, helped to prevent leading and early closure (Elo et al., 2014). In order to mitigate subjectivity, it was integral that the larger research team be involved in the stages of data analysis. Furthermore, recruitment from sorority members, presents limitations related to homogeneity of the sample, limited to similar demographics including age, gender and educational status. The study included Black participants and transferability to other ethnic underserved groups cannot be assumed. Younger adults were not represented in the study and that impacts transferability to this age group. Furthermore, 90% of participants were adherent to their diabetes medication regimen, and findings may have differed among individuals who are not adherent.

# **Implications for Nursing Practice**

This study has valuable implications for nursing practice. The participants expressed a strong emphasis on the importance of spousal/romantic partner support in their daily lives to help cope with medication adherence. The insights from the study showed diabetes self-management educational programs that include the spouse/romantic partner could be beneficial to support coping with T2DM. These are important factors that nurses, diabetes educators and physicians need to be aware of to improve patient outcomes.

Nurses are frequently the first point of contact for patients living with T2DM in healthcare encounters. Accordingly, nurses are able to build trust and establish a rapport with patients seeking care for their diabetes. Furthermore, there are opportunities for nurses to educate patients and their spouse/romantic partners about diabetes self-management including medication adherence. Nurses can support open dialogue with patients and help them to feel comfortable discussing issues patients have regarding medication administration

and support to adhere to the medication regimen. Acknowledging the extreme importance of nursing supportive care can undoubtably improve patient care outcomes.

#### **Recommendations for Future Research**

Findings from this study are similar to the limited studies of spousal support and diabetes care among Black adults. Another insight includes potential differences in perceptions of support across gender. In this study only three males participated in the study. Future qualitative studies involving only males would be beneficial in investigating the phenomenon of spousal/romantic partner support and medication adherence. New insights from this study will support further investigation in larger scale studies. The majority of participants were in long term marriages. Future research involving individuals that were married for shorter intervals of time are needed to determine if similar themes emerge. It would be beneficial to perform qualitative studies exploring intrusive support from spouses/romantic partners, to determine whether diabetes management outcomes differ. Future qualitative research is needed among younger adults, since this population was not included the study. Moreover, research among individuals who are not adherent to their diabetes regimen are needed. Other potential gaps include exploration of how support is perceived when both partners have diabetes and whether this serves as a facilitator or barrier to support. Another gap in the literature includes exploring issues related to including spouses in diabetes self-management care. Furthermore, larger scale studies across a larger geographic region with a more heterogenous sample would be beneficial for future studies.

#### Conclusions

This study used a qualitative descriptive approach to explore perceptions of spousal/romantic partner support and medication adherence among Black adults living with diabetes. Ten participants were interviewed and their feelings about living with diabetes and medication adherence were explored. Participants openly shared their perceptions and vividly shared and described their experiences. The participants openly expressed their feelings about spousal/romantic support and medication adherence. Furthermore, they spoke about how important perceived support is in their daily lives as they live with T2DM.

Findings in this study suggest, emotional, instrumental and informational support are of paramount importance in coping with the challenges of living with T2DM. Furthermore, nursing professionals, physicians and educators should include the spouse/romantic partner in diabetes self-management education whenever possible to improve health outcomes. Utilizing the information related to emergent themes from this study will help health care professionals build trust among diabetic patients and help to empower them to remain adherent to the medication regimen. The descriptions from these men and women will help prompt future investigation and improve understanding of diabetic medication adherence.

## Appendix A

# **Electronic Informed Consent Agreement**

**Study Title:** Black Americans type 2 diabetes spousal/romantic partner support and medication

adherence

Protocol #: IRB-SBS #5990

Please read this consent agreement carefully before you decide to participate in the study. Purpose of the research study: The purpose of this study is to explore individual perspectives of Black adults living with type 2 diabetes on spousal/romantic partner support and medication adherence. Patients living with type 2 diabetes continuously manage their condition on a daily basis and informal support such as spousal/romantic partner support may be relied upon to help cope with medication adherence. This study will help to increase understanding of this phenomena and help to inform self-management educational programs. This knowledge will provide an avenue to inform educational programs geared toward diminishing complications and mortality from type 2 diabetes.

What you will do in the study: If you choose to participate in this study:

- You will be interviewed by a PhD candidate nurse researcher and asked questions about your experiences.
- You will be interviewed in person, over the phone or online at a mutually agreed upon time and place. You can skip any question in the interview that you are not comfortable responding to or end the interview at any time.
- Your interview will be audio recorded by a digital recording device or online on the Zoom platform with audio recording.

**Time required:** The study will require about 1 hour of your time.

**Risks:** We will minimize potential risks to participants. Potential risks of fatigue from the length of the interview are possible. If this occurs the interview can be paused or completed in more than one session.

**Benefits:** There are no direct benefits to the participants in this study. However, participants may benefit from exploring how they manage their medication and type 2 diabetes. Knowledge gained from this study can be useful to the design of diabetes self-management educational programs. This benefit can extend to individuals and society in the future.

**Confidentiality:** The information that you give in the study will be handled confidentially. Your information will be assigned a code number. The list connecting your name to this code will be kept in a locked file. When the study is completed and the data have been analyzed, this list will be destroyed. Your name will not be used in any report. All audio recordings of the participant's interviews will be destroyed after transcription at the end of the study.

**Voluntary participation:** Your participation in the study is completely voluntary. Your participation in this study will not impact the medical care that you are receiving to treat and manage your type 2 diabetes.

**Right to withdraw from the study:** You have the right to withdraw from the study at any time without penalty. If you choose to withdraw from the study your audio/video recording will be destroyed and not used in data analysis.

**How to withdraw from the study:** If you want to withdraw from the study, tell the interviewer to stop the interview. Should you withdraw from the study all audio/video recordings (physical/digital) will be destroyed. There is no penalty for withdrawing from the study. **Payment:** You will receive \$25 in the form of an Amazon gift card for your participation in this study.

**Using data beyond this study:** The data you provide in this study will be retained in a secure manner by the researcher for 5 years and then destroyed.

## Appendix B

#### Adults with T2D Interview Guide:

Thank you for agreeing to be interviewed for my dissertation project. The questions focus on the experience of living with diabetes. I am interested in your own experiences and thoughts. Answering the questions is completely voluntary and if you prefer not to answer a question that is fine. I would ask your permission to audio record this interview so I can be sure I capture your responses accurately. Do I have your permission to record the interview? Do you have any questions before we get started? [Turn on recording/live transcript in zoom and verify it is recording]

- 1. Tell me about your experience living with type 2 diabetes?
  - a. Prompt: Tell me about a day in your life living with T2DM.
- How is your spouse/romantic partner involved with your T2DM care?
   (If not involved: How is your friend, family member or peer involved with your T2DM care?)
- Tell me about the support/involvement you receive from your spouse/romantic partner related to managing your diabetes medications?
   (If no: Tell me about the support you receive from a friend, family member or peer related to managing your diabetes medication)
- 4. Tell me about any <u>physical assistance</u> your spouse/romantic partner provides related to taking your diabetes medication. For example, picking up prescriptions from the pharmacy, paying for medication or filling pill boxes.
  (If no: Tell me about the physical assistance you receive from a friend, family member or peer related to taking your diabetes medication)
- Does your spouse/romantic partner <u>remind you</u> to take your diabetes medication or insulin injections? If so, how do they remind you?
   (If no: Does a friend, family member or peer remind you to take your diabetes medication or insulin injections?)
- 6. Does your spouse/romantic partner <u>help you</u> take your diabetes medication or insulin injections? For example, do they help you administer your injections? (If no: Does a friend, family member or peer help you take your diabetes medication or insulin injections?)
- 7. How does your spouse/romantic partner <u>support you emotionally</u> related to taking your diabetes medication. For example, listening to concerns about your medication (If no: How does a friend, family member or peer support you emotionally related to taking your diabetes medication?)
- 8. How does your spouse/romantic partner <u>support you with information or advice related</u> to taking your diabetes medication? (If no: How does your friend, family member or peer support you with information or advice related to taking your diabetes medication?) Prompt: Give me an example of information or advice related to taking your diabetes medication that your spouse/romantic partner gave you.

- 9. Do you have any fears related to injecting medication or worries about medication side effects that your partner helps you cope with? How does your partner help you cope with these fears?
  - (If no: Tell me about how your friend, family member or peer supports you with any fears or worries about taking your diabetes medication.)
- 10. How does your spouse/romantic partner encourage you to take your medication? (If no: How does your friend, family member or peer encourage you to take your medication?)

So far we've talked a lot about the types of support you receive to help manage your T2DM

- 11. How does your spouse's or romantic partner's support (or non-support) make YOU feel?
- 12. How do you feel about the encouragement from your spouse/romantic partner?
- 13. What kind of support would you like to receive from your spouse or romantic partner related to your diabetes medication?
  - (If no: What kind of support would you like to receive from your friend, family member or peer related to your diabetes medication?)
- 14. Why would you like to receive this type of support from your spouse/romantic partner?
- 15. Tell me about your hopes for the future related to your diabetes management and health. Would you like to add any other comments about your experience living with T2DM?

That concludes our interview. Thank you for your participation and sharing your experiences with me.

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