Formal Care, Quality of Life and Patterns: Decision-Making Involvement of African American Dementia Dyads

By

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CHAPTER I

Background and Significance

Dementia is a multifaceted disease characterized by a decline in cognitive functioning that can impair social functioning and eventually impair a person's ability to care for oneself; the fifth leading cause of death for adults 65 years and older (S. Murphy, Kochanek, Xu, & Heron, 2015). An estimated 5.7 million people in the United States had a diagnosis of dementia in 2018; with total payments for health care, long-term care and hospice estimated at $277 billion (Alzheimer's Association, 2018). The impaired psychological and behavioral functioning characteristic of dementia negatively influences quality of life (QOL) of persons with dementia (PWD) (G. Logsdon, Gibbons, McCurry, & Teri, 1999; Hurt et al., 2010) and their caregivers (Sorensen & Conwell, 2011). Better QOL, on average, for PWDs and their caregivers has been associated with using formal care (e.g., outpatient services) (Ward & Ashaye, 2008) and perceived involvement of the PWD in everyday decision-making (Menne, Tucke, Whitlatch, & Feinberg, 2008). Though more non-Hispanic White older adults are living with dementia, African American older adults are disproportionately more likely to develop dementia compared with them and Hispanic older adults (Alzheimer's Association, 2018). Despite the estimated incidence in African American older adults—9.4% of African American older adults compared to 6.9% of non-Hispanic White older adults (Alzheimer's Association, 2018)—dementia is understudied in this population.

Of the 12 known studies that have included African American PWDs, most samples consisted of a small portion (range from 11% to 40%) of African American PWDs, limiting the knowledge gained and the ability to generalize to the African American population (G. Logsdon et al., 1999; Hinrichsen & Ramirez, 1992; Husaini et al., 2003; Kosloski, Schaefer, Allwardt, Montgomery, & Karner, 2002; Menne, Judge, & Whitlatch, 2009; Menne et al., 2008; Menne & Whitlatch, 2007; B. Miller & Mukherjee, 1999; Moon, Townsend, Dilworth-Anderson, & Whitlatch, 2016; Moon, Townsend, Whitlatch, & Dilworth-Anderson, 2017; Scharlach et al., 2006). There are, however, advances in dementia research that can provide new insights. Dementia research in the last two decades has moved towards a dyadic approach (including both the PWD and the caregiver) (Lyons, Zarit, Sayer, & Whitlatch, 2002; Nagpal, Heid, Zarit, & Whitlatch, 2015; Reamy, Kim, Zarit, & Whitlatch, 2011, 2013; Sebern & Whitlatch, 2007; Whitlatch, Feinberg, & Tucke, 2005; Whitlatch, Piiparinen, & Friss Feinberg, 2009). A dyadic approach is aligned with African American culture reflecting one of the strengths of the African American family—strong kinship bonds (Billingsley, 1968; Hill, 2003; Kane, 2000; Katz, 1973).

Consistent with strong kinship bonds of the African American family are the cultural beliefs that African American older adults are respected and reverenced within the family (Billingsley, 1992). In a recent qualitative study, African American caregivers reported holding African American PWDs in high regard and preserving their values of personhood (Lindauer, Harvath, Berry, & Wros, 2016). Given the primacy of family and the respect bestowed African American older adults, the role of the African American PWD merits further study. In order to study the African American dementia dyad (i.e., African American PWD and their African American caregiver), there should be consideration for the variability that exists within African Americans regarding cultural beliefs and traditions (Billingsley, 1968, 1992; Sayegh & Knight, 2013; S. E. Williams, 1992) , which can influence the caregiving process of African American dementia dyads. Thus, the studies in this Dissertation will examine, from a cultural context, the variability that exists within the caregiving process for African American dementia dyads concerning: 1) formal care use by the dyad, 2) the associations of various factors within the family with QOL of both members of the dyad and 3) the associations between decision-making of the PWD, formal care use and QOL of African American PWDs and their caregivers.

Literature Review

Dementia Diagnosis in African Americans

Dementia is a predominant concern for older adults, impacting African Americans at greater incidence rates than other racial/ethnic groups (Alzheimer's Association, 2018). The prevalence of African Americans 65 years and older in the United States is estimated to rise from 8.8% in 2012 to 12.3% in 2050, with a projected total of 10.3 million African American older adults (Ortman, Velkoff, & Hogan, 2014). African American older adults are almost twice as likely to develop Alzheimer’s disease and other dementias when compared with non-Hispanic White older adults (Alzheimer's Association, 2018). Given there is no cure for dementia, early recognition of dementia symptoms, diagnosis and treatment are the “gold standard” to slowing impaired cognitive functioning.

Formal diagnosis of dementia occurs in a health care setting (e.g., outpatient or inpatient visit); yet, the diagnosis of dementia is more commonly missed in African American older adults (Alzheimer's Association, 2018; P. C. Clark et al., 2005). In P. C. Clark et al. (2005), a missed diagnosis was associated with the characteristics of the caregiver and the provider. Greater than 50% of African American caregivers regardless of whether they live in urban or suburban areas indicated the following reasons for not seeking physician consultation: changes were perceived as normal aging (57%), uncertainty of the severity of the problem (55.7%) and it was difficult for the caregiver to discuss the memory changes with the African American older adult (53.2%) (P. C. Clark et al., 2005). Additionally, African American older adults were no more likely to be diagnosed with Alzheimer's disease during the first physician visit, whether the visit occurred with a specialist or a family physician (P. C. Clark et al., 2005). A missed diagnosis by the caregiver and/or the provider has created delays in care resulting in limited treatment options, greater morbidity and increased health care costs (Chin, Negash, & Hamilton, 2011; Mukadam, Cooper, & Livingston, 2013; Zuckerman et al., 2008). In addition, the Alzheimer's Association (2018) found the diagnosis of dementia in African American older adults may be severely underreported, possibly due to the lack of formal care used by African American older adults (Chin et al., 2011; Dilworth-Anderson, Williams, & Gibson, 2002; Mukadam et al., 2013).

Formal Care

In this Dissertation, formal care is based on the National Institute of Health's description of formal care— the administration of services provided while the PWD is in the home from various agencies (National Institute of Health, 2017). Thus, formal care includes formal services (National Institute of Health, 2017). Formal care is defined specifically as outpatient health care visits, inpatient health care visits, adult day service, respite care and paid assistance with activities of daily living (ADL) or instrumental activities of daily living (IADL). Formal care can be described based on access, use and need.

Formal care access. Formal care access in this Dissertation recognizes whether health care services and other social services are available to the members of the community (e.g., the location of the nearest hospital or respite facility). Minority older adults had poorer access to health care and prescription drug insurance coverage (Institute of Medicine, 2003). For example, a sample of African American caregivers reported not applying for Medicaid perceiving the African American PWD would not qualify, fearing loss of their home to receive services or frustration with the application process (Kingsberry & Mindler, 2012). Less access to medical services has translated into fewer provider visits, greater time before diagnosis and fewer prescription medications for African American older adults (Institute of Medicine, 2003). Thus, the lack of access to formal care for African American PWDs and their African American caregivers could negatively impact the use of formal care by the African American dementia dyad, placing both members of the dyad at risk for poorer outcomes.

Formal care use. Formal care use is defined in this Dissertation as obtaining the medical and/or social services available (e.g., scheduling and attending health care visits, PWDs spending time at the adult day service). African American caregivers reported a strong desire to have family input in decision-making regarding the initiation of formal care (Levkoff, Levy, & Weitzman, 1999). Edwards and Morris (2007) identified African American PWDs who lived alone without the support of caregivers were more likely to use formal care (e.g., paid assistance, respite care and adult day service). Thus, the presence of family caregivers may negatively influence the use of formal care.

Despite evidence of African American PWDs less frequently using formal care, there is one service that is used statistically more often when compared to non-Hispanic White PWDs—emergency room and inpatient stays (Alzheimer's Association, 2018; Cooper, Tandy, Balamurali, & Livingston, 2010). In one study that examined the racial differences of Medicare beneficiaries of health care costs, African American PWDs (compared to non-Hispanic White PWDs) were hospitalized for significantly more days (on average 4.5 more days) with significantly greater health care costs, on average; more than $17,000 per person (Husaini et al., 2003). Similarly, Hinton, Franz, and Friend (2004) identified the most common pathway to a dementia diagnosis for African American older adults was having a severe behavioral event leading to hospitalization. There are no clear indicators of why African American dementia dyads are not using some formal care as consistently (e.g., outpatient visits, respite care, or adult day service) when compared to non-Hispanic White dementia dyads. Yet, they are overrepresented in the emergency room and inpatient setting. More understanding about decision-making of African American PWDs and formal care use in this understudied population is clearly needed.

Evidence has found the reasons regarding the use of formal care by African American dementia dyads to be multifaceted. Previous research suggested the following reasons for less frequent formal care use: feelings of shame by the caregiver (Mukadam et al., 2013; Sayegh & Knight, 2013), obligations that prohibit the use of formal care outside of the family (Desin, Caban-Holt, Abner, Van Eldik, & Schmitt, 2016; Dilworth-Anderson et al., 2002) and/or formal care is not considered culturally sensitive by African American caregivers (Chin et al., 2011; Dilworth-Anderson et al., 2002). There are fewer suggestions regarding the increased use of emergency rooms and inpatient hospitalizations. Hinton et al. (2004) suggested a diagnosis that occurs during hospitalization or shortly after may be more common in vascular dementia or related to significant delays in treatment which tend to be more common in African American older adults (Alzheimer's Association, 2018). The complexities of formal care use may be better understood by identifying the formal care needs of the African American dementia dyad, something that has not been done yet.

Formal care need. Formal care need is defined in this Dissertation as the belief that a medical and/or social service is a necessary support (e.g., paid assistance with ADLs/IADLs, outpatient health care visits) by the African American caregiver and/or African American PWD. Formal care needs have been identified by African American caregivers in previous research and include: more daytime respite care (Desin et al., 2016) and specific needs for medical care and nursing homes in their geographic location (Gerdner & Simpson, 2009). Hinrichsen and Ramirez (1992) found that African American caregivers significantly endorsed the need for formal care when compared to non-Hispanic White caregivers (Hinrichsen & Ramirez, 1992).

Despite the formal care needs that were reported in the literature, Desin et al. (2016) conjectured on the African American caregivers' endorsements for more family involvement of social support than the need for respite care use. In the two other studies, historical oppression was cited as a possible reason for greater need for formal care by the African American caregiver (Gerdner & Simpson, 2009; Hinrichsen & Ramirez, 1992).

History Affecting Formal Care

African Americans have a unique historical foundation in the United States. During slavery and beyond, African Americans were used in medical procedures and research without consent or explicit explanation of the treatment (Washington, 2006). Due to the years of mistreatment and shared knowledge of these experiences through the generations, Dr. Harriet Washington—an African American researcher with expertise in bioethics— coined the term iatrophobia to describe the aversion African Americans have towards medicine, specifically medical professionals and medical institutions (Washington, 2006). After slavery, health care systems were racially segregated— with minority institutions being poorly funded by the government— resulting in inferior care provided to African Americans (Institute of Medicine, 2003). The historical experiences during slavery and beyond may well be linked to less formal care use by African American PWDs and their African American caregivers.

African American Culture

African American culture has interwoven beliefs and ideas from Africa as well as from the historical context within the United States. The African American family has been described as having five strengths: strong kinship bonds, strong work orientation, adaptability of family roles, high achievement orientation and religious orientation (Hill, 2003). Of these strengths, three seem more closely linked to the African American dementia dyad. First, strong kinship bonds describe the ease of taking relatives into one's homes to provide care (Hill, 2003). The decision to rely on informal networks— those related by common ancestry, marriage, fictive kin, friends and/or neighbors— over formal care may be a more comfortable decision for African American dementia dyads. Second, the adaptability of family roles is seen in African American families (Hill, 2003). Decisions and responsibilities are shared within African American families (Kane, 2000). Thus, the lower reports of burden by African American family members to take on the role of caregiver to African American PWDs may illustrate this strength (Dilworth-Anderson et al., 2002; Pinquart & Sorensen, 2005). Third, religious orientation is important to the well-being of African Americans and has been considered a survival mechanism since slavery (Hill, 2003). The respect given African American older adults (within the culture of the African American family) may be related to the strengths of the African American family, a perspective not previously seen in African American dementia research. Including this cultural view in understanding African American dementia dyads warrant study regarding decision-making involvement of African American PWDs within the dyads.

Decision-Making Involvement

Decision-making involvement is defined in this Dissertation as the amount of verbal and non-verbal communication provided by the PWD and/or their caregiver regarding everyday decisions and formal care decisions. Multiple decisions are made on a day-to-day basis regarding the everyday care of the African American PWD. Caregiving dementia research has often relied on the caregiver's decision regarding medical choices (Braun et al., 2009). Yet, including the PWD in everyday decision-making in the early stages of diagnosis is at the core of personhood (Kitwood, 1997) and can decrease ethical dilemmas for caregivers and clinicians (L. M. Miller, Whitlatch, & Lyons, 2016). Additionally, when PWDs were more involved with everyday decision-making, they reported better QOL (Menne et al., 2009; Menne & Whitlatch, 2007) as do caregivers who also reported lower depression and less negative relationship strain (Menne et al., 2008).

Everyday decision-making involvement of PWDs has not been previously studied in African American dementia dyads. Considering the culture of the African American family, African American older adults' perspectives are respected in the family (Lindauer et al., 2016) and everyday decisions are often shared (Kane, 2000). Thus, this research supports the need to examine African American PWDs decision-making involvement from the perspectives of both members of the dyad. Whether examining factors associated with QOL of each member of the dyad or examining the dyads' perceptions of decision-making involvement of African American PWDs, addressing either or both research questions may generate new knowledge regarding factors, which could influence the QOL of both members of the dyad's caregiving process.

Quality of Life

QOL is a global perception of overall well-being—including social, psychological and physical domains. QOL has been described by four main sectors: 1) behavioral competence, which includes cognition and ADLs/IADLs, 2) perceived QOL regarding health and relationships, 3) objective environment, which consists of geographic location and social networks and 4) psychosocial well-being that includes mental health and positive and negative feelings (Lawton, 1991). Over the past few decades, QOL of dementia caregivers has been well studied, though not specifically focused on African American caregivers. In the studies with African American caregivers, African American caregivers reported higher levels of QOL or lower levels of psychological distress than non-Hispanic White caregivers (Dilworth-Anderson et al., 2002). Similarly, one study with an entirely African American sample of caregivers (N= 187), found the majority (83%, n= 156) reported no psychological distress (Dilworth-Anderson, Williams, & Cooper, 1999). Better QOL in African American caregivers was often attributed to the strengths of African American culture (e.g., religion and greater family support). Yet, not all African American caregivers have these strengths which may account for the greater distress in the remaining African American caregivers in the study (Dilworth-Anderson et al., 1999). Clearly, there is variability within African American families and dyads that needs to be examined.

Persons with mild-to-moderate dementia reliably report their perceived QOL (Brod, Stewart, Sands, & Walton, 1999). Although, only a few studies have examined the QOL of PWDs or the dementia dyad, Menne et al. (2009) found African American PWDs reported lower QOL than non-Hispanic White PWDs. Given the contrary reports of QOL by the African American PWDs compared to their African American caregivers, there is a need to study both members of the dyad together. Previous research that examined QOL in dementia dyads primarily focused on the congruence between the PWD and their caregiver regarding QOL of the PWD (Moon et al., 2016; Moon et al., 2017; Sousa et al., 2013). Findings suggested that caregivers often underestimate QOL of PWDs, possibly related to caregivers’ bias towards the dementia trajectory (Moon et al., 2016; Moon et al., 2017; Sousa et al., 2013).

Throughout the dementia trajectory, perceptions of both members of the dyads can influence their QOL. Similar appraisal of perceptions between PWDs and their caregivers has been associated with better QOL for both members of the dyad (Moon et al., 2017). Given the importance of family in African American culture and the movement towards examining the dyad as a unit of care (Northouse, Katapodi, Schafenacker, & Weiss, 2012), it is important to include both perceptions of the dyad's when examining their QOL. Despite what is known regarding dementia dyads, there are no studies that have focused specifically on factors that influence the QOL of African American dementia dyads.

Dyadic Research

Dyadic research includes the examination of both the African American PWD and the African American caregiver as a unit, considering how they function together. Including both members in dyadic research is aligned with African American cultural norms. Dyadic research with African American PWDs and African American caregivers is needed to add to our understanding of how both members are involved in the caregiving process (Lyons et al., 2002; Martire, Schulz, Helgeson, Small, & Saghafi, 2010). Aligning with African American culture and the importance of family, investigating the contribution of each member of the African American dementia dyad regarding formal care use and decision-making involvement is an important consideration. There is a misconception that aging within the African American dementia community is the same (Brown et al., 2014). This misconception hinders our ability to create clinically relevant interventions tailored to African American dementia dyads. Given the cultural, historical context and lack of research on the African American family, it is important to examine the potential heterogeneity within African American dyads during the dementia caregiving process.

Heterogeneity

Heterogeneity is present in African American dementia dyads, dementia caregiving and treatment. There is great variability regarding cognitive impairment and dementia-related symptoms (e.g., aggression, apathy, hallucinations and personality changes) across ethnic and racial groups, with evidence suggesting minority groups as more cognitively impaired with greater dementia-related symptoms (Sayegh & Knight, 2013). In addition, nuances within African American dementia dyads vary based on acculturation, cultural beliefs and practices (Hill, 2003; S. E. Williams, 1992), creating vast differences within the customs and culture of the African American population. One seminal conceptual framework, the Negro Family as a Social System, focused on highlighting the variability within African American families (Billingsley, 1968). African American families are described by the structure of the family, roles within the family, their socioeconomic status and geographic location (Billingsley, 1968), suggesting the racial label of “African American” encompasses much heterogeneity. Examining a group of African Americans together in a sample without considering the inherent variability is missing the individuality of each participant or dyad in the study. Thus, an examination of the preferences of formal care use and perceptions of decision-making involvement of the African PWDs should consider the heterogeneity that may exist across African American dementia dyads. By identifying patterns of heterogeneity, we will better understand and represent the experiences of African American dyads, moving us closer to tailored interventions.

Pattern identification specifically embraces heterogeneity by going beyond the “average” of a sample to identify subgroups. Most traditional analytic approaches focus on the average participant or dyad; however, it is possible to identify patterns based on variability within a given sample. Pattern identification within dyads has been done previously in persons with dementia

(L. M. Miller, Whitlatch, Lee, & Caserta, 2018) and heart failure (Lee, Mudd, et al., 2015; Lee, Vellone, et al., 2015). Identifying separate naturally occurring patterns can allow us to determine the unique characteristics that distinguish between the subgroups, creating a way to tailor interventions. No study has specifically focused on pattern identification in African American dementia dyads.

Theoretical Framework

The Negro Family as a Social System (Billingsley, 1968) is the conceptual framework used to guide the research presented in this Dissertation. Dr. Andrew Billingsley, a sociologist with expertise in African American families originally proposed the Negro Family as a Social System in 1968 (Billingsley, 1968), which was later merged with other conceptual frameworks to form the Black Family Socio-Ecological Context Model. The Negro Family as a Social System conceptual framework emphasizes the importance of identifying the heterogeneity in African American families (Billingsley, 1968). Culturally relevant conceptual frameworks have traditionally been missing in the study of African American individuals (Dilworth-Anderson et al., 2002), limiting the ability to gain appropriate context and understand nuance unfamiliar to traditional Western worldviews.

The Negro Family as a Social System posits three main interrelated social networks including the *Negro family*, *Negro community* and *Wider society* (Billingsley, 1968). The *Negro family* consists of dyadic relationships such as mother-daughter and husband-wife. The *Negro community*, a racial subsociety, which captures the duality of the African American population—shared historical and cultural similarities and the heterogeneity in geographic location and social class—includes churches, neighborhood associations and small businesses such as barbershops and salons. The *Wider society* describes the health care, economic and political systems. The

Negro Family as a Social System emphasizes “both the interdependence of these families with other levels of society and the variability among African American families” (Billingsley, 1988, p.4).

In addition, Dr. Billingsley (Billingsley, 1968) adapted the work of Drs. Talcott Parsons and Robert Bales (Parsons & Bales, 1955) to describe the instrumental role and expressive role functions of the African American family. Instrumental role functions are mainly related to economic function, including the responsibilities of obtaining education, making decisions and maintaining health (Billingsley, 1968). African American families are expected to prepare the members to meet their needs of food, clothing and shelter (Billingsley, 1968). Decision-making involvement, caregiver’s socioeconomic status or educational level and the cognitive status of African American PWDs were operationalized as instrumental role functions in this Dissertation. Expressive role functions include providing companionship, creating an atmosphere that fosters a sense of belonging, self-respect and self-esteem including feelings (Billingsley, 1968). In this Dissertation, dyadic relationship quality is operationalized as an expressive role function. Dyadic relationship quality describes the appraisal of dyadic strain and positive interaction experienced by both members of the dyad during the caregiving process (Sebern & Whitlatch, 2007). QOL of both members of the dyad and formal care use will be examined considering the family structure, instrumental role and expressive role functions, geographic region and formal care use of African American dementia dyads.

Dissertation Purpose and Aims

The overall purpose of this Dissertation is to contribute new knowledge regarding the influence of formal care use and decision-making involvement on QOL of African American dementia dyads considering the role of African American culture. African American culture supports an emphasis on African American PWDs coupled with the Negro Family as a Social Systems, which includes a focus on family, heterogeneity and interdependence between social systems. This Dissertation supports these concepts by including both African American PWDs and African American caregivers, considering the family structure and role functions (instrumental and expressive) unique to each dyad and relying on the *Negro community* and *Wider society* in understanding decision-making involvement and formal care use.

Limited research has focused on barriers and facilitators of formal care use in African American dementia dyads. The use of formal care is the only way for African American older adults to receive a formal diagnosis of Alzheimer's disease or related dementias. With a diagnosis, African American PWDs can have improved access to treatments and resources that are used to slow the progression of the disease trajectory. Coupled with the opportunity to better understand formal care use by African American dementia dyads, this body of works will increase our knowledge of the caregiving process of African American dementia dyads by specifically focusing on decision-making involvement of African American PWDs. Given the unique and often leadership role within the family, African American older adults decision-making involvement may hold promise when identifying tailored interventions for improving QOL in African American dementia dyads. Refer to Figure 1 for Dissertation aims and Figure 2 for the operational model.

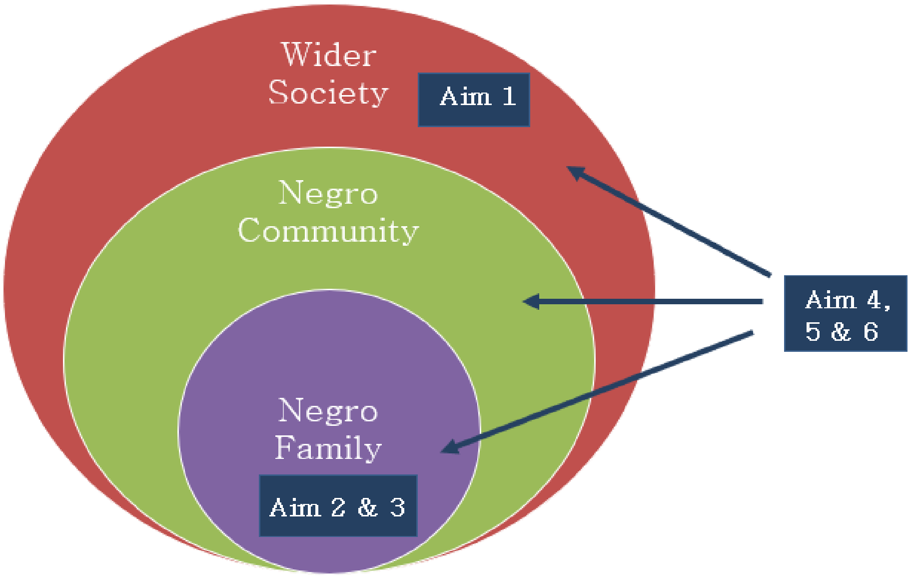

Figure 1. *The Negro Family as a Social System, Billingsley (1968) & Dissertation Aims*

Chapters and Chapter Aims

Table 1

Dissertation Chapters and Aims

	Dissertation Chapters	Chapter Aims
Formal Care Use	**Chapter 2**: Formal Care Use by African American Persons with Dementia and Their Caregivers: An Integrative Review	Aim 1: Identify the state of what is known regarding African American PWDs and their caregivers and formal care use to guide future research and interventions.
Quality of Life	**Chapter 3:** Factors Influencing Quality of Life in African American Dementia Dyads	Aim 2: Describe the covariation between QOL of African American PWDs and their African American caregivers. *Hypothesis 2: There will be a significant covariation between QOL of African American PWDs and their African American caregivers.*

		Aim 3: Describe the association between family structure, instrumental and expressive role functions and QOL of African American dementia dyads. *Hypothesis 3: Family structure, instrumental and/or expressive role functions will be associated with QOL of both members of African American dementia dyads.*
Decision-Making Involvement	**Chapter 4:** Patterns of Dyadic Appraisal of African American Persons with Dementia Decision-Making Involvement and Quality of Life	Aim 4: Identify and characterize patterns of dyadic appraisal regarding decision-making involvement (an instrumental role function) by PWDs in African American dementia dyads. Aim 5: Examine the association of the observed patterns with other subsystems of the Negro Family as a Social System. *Hypothesis 5: Patterns of dyadic appraisal of African American PWD decision-making involvement in African American dementia dyads will be associated with the other subsystems of the Negro Family as a Social System (family structure, expressive role functions, African American community and the wider society) and QOL.* Aim 6: Examine the association between membership of observed patterns and the dyad's QOL. *Hypothesis 6: An observed pattern of dyadic appraisal of higher decision-making involvement by African American PWDs and more congruence will have better QOL.*

Aim One. Based on the Negro Family as a Social System, the first aim focuses on the *Wider society*, specifically formal care use. The first aim was completed by an integrative review (Whittemore & Knafl, 2005) of current English-language research published regarding African American PWDs and/or African American caregivers use of formal care. The review provided a synthesis of the relationships between formal care use by African American PWDs and their caregivers to offer recommendations for future research and practice. This aim, in part, serves as a foundation for the studies that will be reported in later Dissertation chapters by determining what is known regarding formal care use by African American PWDs and their caregivers and what facilitators and barriers were identified in formal care use, which may later improve QOL of African American dementia dyads.

Aim Two and Three. The second and third aims focus on the social system of the *Negro Family*. The *Negro Family* allows for a deeper examination of family structure and expressive and instrumental role functions including the importance of decision-making within the family (a facilitator identified from Aim One). These aims were accomplished by using a cross-sectional, secondary data analysis to investigate the family structure, instrumental and expressive role functions associated with QOL of African American dementia dyads. The findings provided insights on 1) whether there is a covariation between QOL of African American PWDs and African American caregivers and 2) how family structure, instrumental and expressive role functions are associated with QOL of both members of African American dementia dyads. These aims elucidated the need for dyadic analysis in African American dementia dyads and highlighted factors of the *Negro Family* associated with QOL of each member of African American dementia dyads.

Aims Four, Five and Six. The fourth, fifth and sixth aims focus on all three social systems: *Negro Family, Negro Community* and *Wider Society*. The fourth aim allowed for a deeper examination of decision-making involvement of African American PWDs (an instrumental role function). Through this aim, we identify and characterize naturally occurring patterns of dyadic appraisal of PWDs decision-making involvement in African American dementia dyads. The fifth aim examines the association of the observed patterns to other subsystems of the Negro Family as a Social System (i.e., family structure, expressive role functions, African American community and wider society). This aim facilitates a deeper understanding of how the concepts of the Negro Family as a Social System influence pattern membership. The final aim of this Dissertation examines the association of the observed patterns with QOL of each member of the African American dementia dyads, highlighting which pattern of dyadic appraisal of the African American PWD decision-making involvement has significantly better QOL. To address these aims, the study was conducted as a secondary data analysis of African American dementia dyads. This study increased our understanding of QOL of both members of African American dementia dyads considering the heterogeneity of African American PWDs decision-making involvement within African American dementia dyads. This study was the first to identify pattern membership of how dyads appraise the decision-making involvement of the PWD among African American dementia dyads.

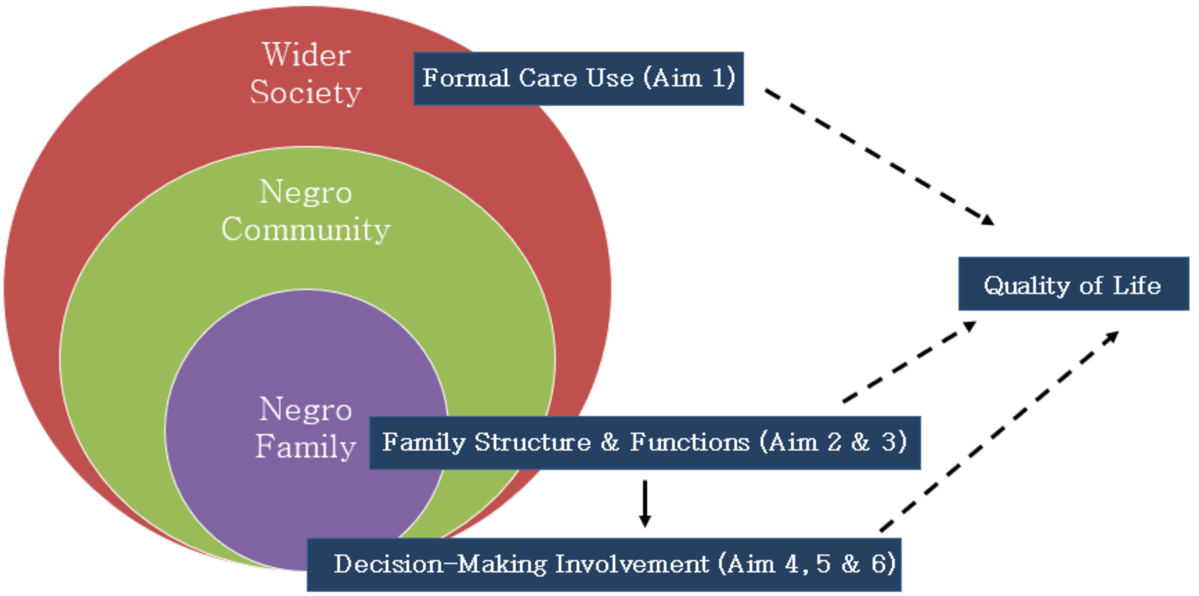

Figure 2. *Operational Model with Conceptual Framework and Dissertation Aims*

Implications for Nursing Science

The proposed Dissertation has important implications for nursing professionals, clinicians and researchers focused on gaps in our knowledge of African American dementia dyads. The Dissertation uses a conceptual framework created to understand African American families in the context of interdependent social systems to examine two gaps in our knowledge on QOL— the role of formal care use and the dyad's appraisal of the PWD decision-making involvement on the dyad's QOL. As the incidence of dementia is projected to increase, this is a pivotal time to examine how decision-making involvement and formal care use are associated with QOL of African American dementia dyads.

Nurses and nurse professionals are often the frontline of treatment with formal care use. Understanding the African American PWD decision-making involvement within the African American dementia dyad and how similar the members of the dyad appraise that involvement may highlight how to conduct formal care visits that optimize health outcomes for the African American dementia dyad. In addition, considering African American culture and heterogeneity when caring for African American dementia dyads supports there is no "one size fits all" approach and could underscore instrumental and expressive role functions that influence QOL.

Pattern identification of African American dementia dyads supports the belief that much heterogeneity is present within African American families. Identification of patterns of dyadic appraisal of African American PWD decision-making involvement can provide new lines of inquiry for the creation of tailored interventions. Thus, broadening and deepening our understanding of African American dementia dyads regarding the relationship of formal care use and decision-making involvement of African American PWDs on QOL to effectively improve health outcomes and elucidate future research.

Summary

Dementia is a degenerative brain disorder that has the potential to negatively impact every aspect of the older adult’s life. Despite advances in dementia research, limited work has focused specifically on the African American dementia dyad. Through these chapters, a more complete understanding of African American dementia dyads regarding formal care use and decision-making involvement of African American PWDs will be examined with a focus on how these variables contribute to African American dementia dyads’ QOL.

CHAPTER II

Formal Service Use by African American Individuals with Dementia and Their Caregivers: An Integrative Review

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Abstract

Dementia is a predominant problem in older adults, affecting African Americans individuals at higher rates than other ethnic groups; yet, African American older adults use fewer formal services. To identify factors influencing formal service use by African American individuals with dementia and their caregiver, an integrative review of the literature was performed using four databases from 1990 to July 2017. Fourteen articles (nine quantitative and five qualitative) describing formal service use were included in the review. Three main themes were identified: *Formal Service Need*, *Expectations of Formal Service Providers* and *Formal Service Use*. Recommendations to improve formal service use are suggested.

Keywords: formal service need, expectations, caregiving dyads

Introduction

Of the total African American population, individuals 65 years and older are expected to increase from approximately 9% in 2012 to 18% in 2050 (Ortman et al., 2014). African American individuals are twice as likely as non-Hispanic White individuals to develop Alzheimer’s disease and other dementias but less likely to be diagnosed (Alzheimer's Association, 2016) or use formal services, depending more on informal networks for care (Chin et al., 2011; Dilworth-Anderson et al., 2002; Mukadam et al., 2013).

The increased risk of Alzheimer’s disease and other dementias is believed to be associated with health conditions such as cardiovascular disease and diabetes, which are more prevalent in African American individuals (Glymour & Manly, 2008; Lines & Wiener, 2014). In addition, African American individuals are less likely than non-Hispanic White individuals to have adequate health insurance and have fewer quality health care services related to residential segregation (Institute of Medicine, 2003). Inability to use health care services results in limited treatment options (Zuckerman et al., 2008) and poorer outcomes (Chin et al., 2011; Mukadam et al., 2013; Sayegh & Knight, 2013), resulting in increased burden on the family and the economy. A sample of African American caregivers described their initial formal service use only occurring after a crisis event involving an emergency room department visit and inpatient stay (Hinton et al., 2004). This study suggests substantial delays in receipt of a diagnosis until a severe behavioral disturbance occurs (Hinton et al., 2004). Such delays result in substantial economic costs and limit options for treatment. Yet, little is known about formal service use by African American individuals with dementia and their caregivers.

The purpose of the current integrative review (Whittemore & Knafl, 2005) is to identify the state of what is known regarding African American individuals with dementia and their caregivers and formal service use to guide future research and interventions.

Method

A review was conducted of original research articles reporting data published through July 2017. The search included the following databases: MEDLINE, CINAHL, Scopus, and PsycINFO. Search terms included *African American*, *dementia*, *health care*, *access*, *help seeking, utilization*, *relationship, dyad, resources*, *formal resources*, *formal services, challenges*, *obstacles*, *factors* and *barriers*. *African American* and *dementia* were used in every search with a combination of one word from up to two synonym groups (i.e. health care, access, utilization, help seeking or resources, formal resources, formal services or relationship, dyad or challenges, obstacles, factors, barriers) totaling no more than four search terms in each inquiry. The following MeSH terms—*African American, dementia, health services accessibility, health services accessibility/utilization, delivery of health care, caregivers, health knowledge, attitudes and practice, health resource utilization, health service needs and demand, health care delivery, health care services, treatment barriers, health care utilization*—were also used to increase sensitivity and specificity of results. Reference lists were hand-searched. Eligibility criteria comprised articles with original data written in English regarding formal service use that included African American participants only or African American individuals as a subset of the sample. Due to the paucity of literature, no time limit was applied.

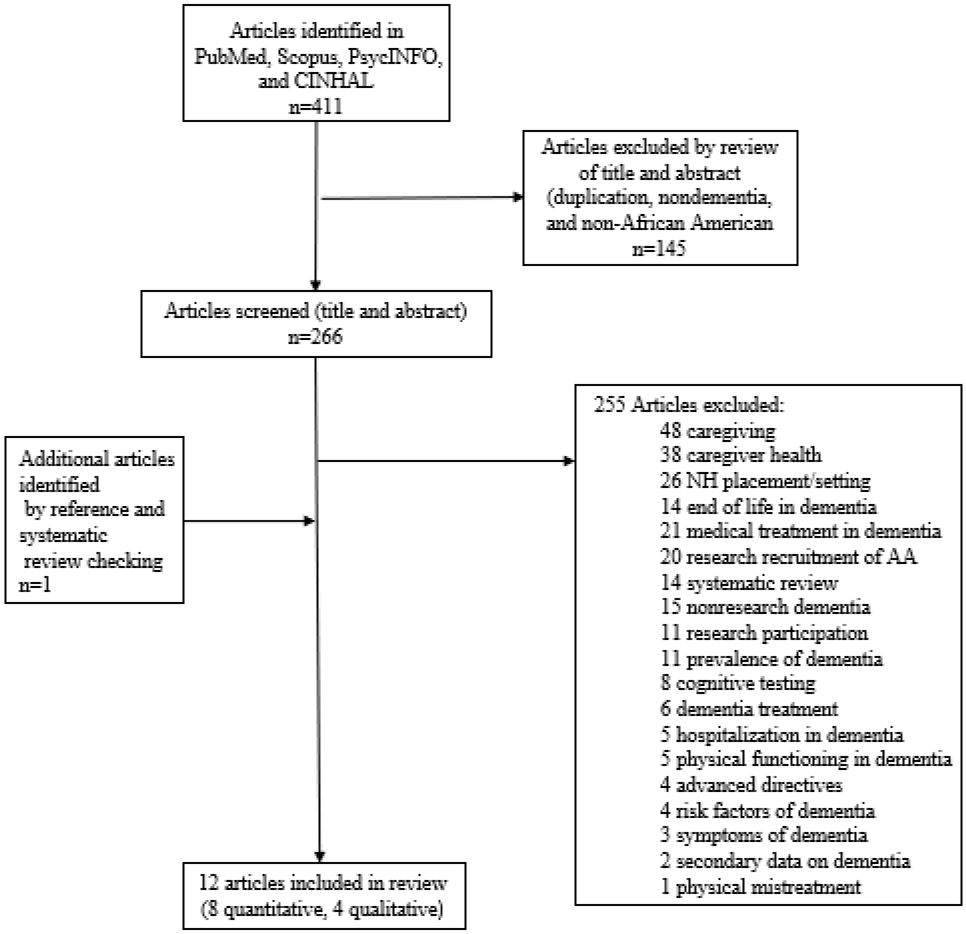

Figure. Systematic literature search using Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Guidelines.

Fourteen articles were chosen for the final review (**Figure**), including nine quantitative and five qualitative studies. Studies are alphabetized with additional characteristics in **Table A** (available in the online version of this article). Quality assessment of the quantitative studies was performed by both authors separately, using the Newcastle-Ottawa Quality Assessment Scale adapted for cross-sectional studies (Modesti et al., 2016). The Newcastle-Ottawa Quality Assessment Scale was used to assess the research design, representativeness of the sample, sample size, response rate, validity of measurement tool, objectivity of outcome, and statistical analysis. When differences occurred in four study quality scores, the authors discussed the areas of disagreement, reached consensus, and rescored the studies. The level of evidence in the quantitative articles were reviewed and graded by both authors using the evidence grading by Harbour and Miller (2001), ranging from level A to D. The level of evidence of all quantitative studies was non-analytic and classified as level D. Quality assessment of qualitative studies were graded by both authors guided by the Critical Appraisal Skills Programme (CASP) criteria. Statement of study aims, methodology, design, recruitment, data collection, data analysis, and findings were considered appropriate in all qualitative studies in the review (**Table B**, available in the online version of this article).

Definitions

Formal services were defined as inpatient and outpatient health care service visits, adult day care, respite care, and paid assistance with activities of daily living (ADL) or instrumental ADL. Informal network included family members—those related by common ancestry, marriage, and fictive kin— friends, and/or neighbors who provide direct care to the individual with dementia. *Fictive kin* are defined as individuals who are not related by blood lineage or marriage but are considered members of the family.

Measurement

The measures used to assess formal service use varied greatly. Most studies used checklists of formal services (Cox & Monk, 1990; Kosloski, Montgomery, & Karner, 1999; B. Miller & Mukherjee, 1999), questionnaires specific to the study (Ho, Weitzman, Cui, & Levkoff, 2000; Kosloski et al., 2002), or asked open-ended questions through interviews (Gerdner & Simpson, 2009; Lampley-Dallas, Mold, & Flori, 2001, 2005; Levkoff et al., 1999; Scharlach et al., 2006). Three studies used an established measure, the Duke Older Americans Resources and Services, Part B, (Edwards & Morris, 2007; Hinrichsen & Ramirez, 1992).

Unit of Analysis

The unit of analysis comprised of the individual with dementia, caregiver or caregiving unit, differentiated by racial or ethnic characteristics. Most of the studies used the caregiver as the unit of analysis to describe formal service use of the individual with dementia. Two studies identified a caregiving unit including the individual with dementia and caregiver (Hinrichsen & Ramirez, 1992; Li, Edwards, & Morrow-Howell, 2004). Edwards and Morris (2007) examined the individual with dementia only. In addition, in most of the studies, the African American individuals with dementia and African American caregivers were subsets of the sample compared to non-Hispanic Whites individuals (Hinrichsen & Ramirez, 1992; B. Miller & Mukherjee, 1999), non-Hispanic White individuals and another minority group (Ho et al., 2000; Kosloski et al., 1999; Kosloski et al., 2002) or at least one other minority group only (Cox & Monk, 1990; Levkoff et al., 1999; Scharlach et al., 2006). The remaining six articles exclusively investigated African American participants (Desin et al., 2016; Edwards & Morris, 2007; Gerdner & Simpson, 2009; Lampley-Dallas et al., 2001, 2005; Li et al., 2004).

Results

Three main themes were found among the articles included in the current integrative review: *Formal Service Need*, *Expectations of Formal Service Providers*, and *Formal Service Use*. The main themes were identified by the first author (K.B.) with concurrent agreement from the second author (K. S. L.). First, articles were organized by the main topic (i.e., formal service use). Second, articles were divided into subtopics. Third, common themes were identified across studies. What is known regarding these three themes in relation to African American individuals with dementia and their caregiver is addressed.

Formal Service Need

Formal service needs were identified across four articles in the review (Desin et al., 2016; Gerdner & Simpson, 2009; Hinrichsen & Ramirez, 1992; Ho et al., 2000). African American caregivers endorsed a greater need for formal services in three articles. Caregivers expressed a need for more formal services for older adults in their geographic region (Gerdner & Simpson, 2009). In addition, African American caregivers reported needs for formal services for case management (36.7%), homemaker services (36.7%), and caregiver training (30%) (Desin et al., 2016). When formal service needs were compared between African American caregivers and non-Hispanic White caregivers, African American caregivers endorsed significantly more needs in three areas: nursing care (39.4% vs. 12%, $p < .001$), physical therapy (36.4% vs. 17.2%, $p < .05$), and completion of a comprehensive examination (57.6% vs. 33.3%, $p < .05$) (Hinrichsen & Ramirez, 1992). Conversely, in the study by Ho et al. (2000), African American caregivers reported significantly less unmet medical needs than both Chinese American and Latino caregivers (Ho et al., 2000). Ho et al. (2000) pointed out African American caregivers in the sample had slightly higher incomes, although the difference was not statistically significant. However, better financial status can decrease medical needs, which may have confounded the results. Across the studies, African American caregivers acknowledge formal service needs. Yet, the needs of African American caregivers may not be adequately conveyed to formal service providers.

Expectations of Formal Service Providers

Expectations of formal service providers was another identified theme among four articles (Gerdner & Simpson, 2009; Kosloski et al., 2002; Lampley-Dallas et al., 2001, 2005). African American caregivers expected physicians to be the initial contact for older adults in obtaining a dementia diagnosis (Gerdner & Simpson, 2009; Lampley-Dallas et al., 2005). Physicians were expected to possess knowledge to provide guidance in care decisions to caregivers and recognize the disease progression (Lampley-Dallas et al., 2005). Other health care professionals, not including physicians, were expected to facilitate a connection between the physician and formal services for African American caregivers (Lampley-Dallas et al., 2001). Interestingly, African American caregivers were significantly more likely to expect the government to have a responsibility to assist caregivers financially when compared with non-Hispanic White and Latino caregivers (Kosloski et al., 2002). Thus, African American caregivers appear to favor a stronger role of the primary care provider and government assistance and support. Although this may appear to contradict the lower use of formal services by African American caregivers, it may also reflect opportunity for ways to engage African American caregivers within the health care and formal service systems through supporting greater communication of their expectations and needs.

Formal Service Use

Formal service use was an important theme across seven articles (Cox & Monk, 1990; Edwards & Morris, 2007; Kosloski et al., 1999; Levkoff et al., 1999; Li et al., 2004; B. Miller & Mukherjee, 1999; Scharlach et al., 2006). Levkoff et al. (1999) found African American caregivers reported a desire to have greater family involvement when making decisions regarding formal service use for the African American individual with dementia. Decisions to use formal services were negatively associated with how confident the African American caregiver felt in their role as caregiver (odds ratio= 0.53, 95% confidence interval [0.29-0.96]) (Li et al., 2004). Similarly, B. Miller and Mukherjee (1999) found greater acceptance of formal service use was associated with lower caregiver mastery, being female, and being an African

American caregiver versus non-Hispanic white caregiver, whereas Kosloski et al. (1999) found older African American caregivers and those who worked full-time were more likely to use formal services. Thus, formal service use is greatly impacted by the characteristics of the African American caregiver and the level of support from family.

Several characteristics of African American individuals with dementia were associated with formal service use. African American individuals with dementia living alone with Medicaid certification were more likely to use formal services (Edwards & Morris, 2007). Increased and decreased impairment with ADLs in African American individuals with dementia were significantly associated with formal service use ($p < .05$) (Cox & Monk, 1990; Kosloski et al., 1999). More research is needed that focuses on both members of the dyad simultaneously (i.e., caregiver and individual with dementia).

Several barriers to formal service use were described by African American caregivers across studies. African American caregivers reported frustration regarding the lack of understanding and consideration of African American cultural needs in formal services as a barrier to use (Levkoff et al., 1999). Likewise, African American caregivers voiced concerns regarding the notion their cultural concerns were different from the dominant culture, negatively impacting formal service use (Scharlach et al., 2006). Given the historical oppression experienced by African American individuals, there needs to be greater recognition and understanding of the important cultural needs and concerns of African American individuals with dementia and their caregivers to ensure their greater engagement in and receipt of necessary help and support.

Discussion

Despite the projected prevalence of dementia in the African American population, research seems to be no closer to determining the best ways to engage African American individuals with dementia and their caregiver in the use of formal services. To address this gap, a review of published literature was conducted. The current review found several key themes and identified important limitations that have led to recommendations for future research and clinical implications.

The most compelling finding of the current review is that African American caregivers acknowledge a need for formal services. This reported need seems contradictory with the lack of formal services used by African American dementia dyads (Chin et al., 2011; Dilworth-Anderson et al., 2002). Although, previous research has suggested potential reasons for low use—for example, caregivers interpreting cognitive changes in the African American older adult as normal aging (Chin et al., 2011; Sayegh & Knight, 2013) and stigma related to the diagnosis of dementia (Mukadam et al., 2013; Sayegh & Knight, 2013)— the current review suggests expectations of providers and cultural concerns may be important barriers in need of further investigation. Moreover, research that examines whether formal services match the actual needs of African American caregivers and individual with dementia rather than assumptions of their needs is warranted.

An important theme and area for further examination regards the specific role and influence formal service providers have on African American individuals with dementia and their caregivers. The African American patient-provider relationship is fraught with historical oppression and health care inequalities resulting in clinical uncertainty, bias, and stereotypes (Institute of Medicine, 2003). A sample of African American caregivers reported frustration with navigating the health care system, especially with disappointment in their physician's dismissal of memory and/or behavioral concerns of their family member (Hughes, Tyler, Danner, & Carter, 2009). Mistrust in health care providers has been associated with a lack of formal service use by African American individuals with dementia and their caregivers (Chin et al., 2011). Albeit, once continuity of care is established—whether appropriate or not—African American caregivers expect a great deal from their formal service providers when it comes to managing and treating African American individuals with dementia that needs to be better understood. Effectively diagnosing and treating individuals with dementia in the primary health care setting has been linked with more comprehensive approaches—multidisciplinary teams of providers, care coordinators, social workers, and community outreach (Stewart et al., 2014), as providers may be unaware of the resources available to African American older adults and their caregivers. Better alignment between providers and the needs of the African American dementia dyad is necessary to increase engagement in and use of formal services, that will ultimately lead to better outcomes for both members of the African American dementia dyad.

Limitations and Research Implications

Despite the strengths of this review in presenting the state of the science in this area, there were several limitations across studies and this body of work that can inform recommendations for future research. Namely, little research has been done in this area and few studies explicitly focused on African American caregivers or African American individuals with dementia. Many studies included small sample sizes, cross-sectional designs, and focused on the African American caregiver instead of the dyad. Based on the limitations, there are several recommendations for moving this research forward.

First, research needs to focus explicitly on the African American population. Available research has been limited by small sample sizes due to the lack of research participation by African American individuals (Chin et al., 2011). Only two studies had African American participants as the entire sample with a sample size of ≥ 200 (Edwards & Morris, 2007; Li et al., 2004), limiting knowledge and generalizability. Both studies recruited from a program that was specifically created to provide outreach and medical services to minority and low-income families. Other studies have identified the importance of recruiting from programs specifically focused on African American individuals and pillars in the African American community such as churches and barber shops (Bonner et al., 2017; Danner, Smith, Jessa, & Hudson, 2008; A. B. Murphy et al., 2017). In addition, a greater effort is required to have representative samples that at least match national and/or state averages. More importantly, studies are needed to explicitly focus on the African American dyad’s experience from conceptualization through analysis to maximize our ability to understand how and why African American individuals with dementia and African American caregivers use services and inform strategies to better meet their needs.

Second, longitudinal research is vital to understanding how formal service needs and use change over the course of the dementia experience for the African American dementia dyads. The current review highlights how little has changed in this research over the 27-year timeframe covered by the studies. All but one study—conducted over 10 years ago—used a cross-sectional design. Given the large time period across studies, it is unclear what impact changes in health care have had on inconsistencies between studies. For example, African American caregivers reported less medical needs compared with Chinese-American and Latino caregivers (Ho et al., 2000), but African American caregivers reported significantly greater needs for medical care compared with non-Hispanic White caregivers (Hinrichsen & Ramirez, 1992). Are the results of the more recent study due to the design of the study or changes that have occurred in providing care for African American individuals with dementia over the years? Without longitudinal work in this area, and more current studies, ecologically sound strategies for supporting African American dementia dyads cannot be developed.

Third, research needs to focus on the African American dementia dyad as a unit of analysis; most studies in the current review focused predominantly at the level of the caregiver. Much has changed in the understanding of the ability of individuals with dementia to participate in research over the past two decades, with empirical evidence strongly suggesting individuals with mild-to-moderate dementia can and should be included in research (Kitwood, 1997) and are capable of providing reliable answers of health status on self-assessments (Brod et al., 1999) and articulating feelings and preferences (P. A. Clark, Tucke, & Whitlatch, 2008). In addition, methodologies that examine dyads as units of analysis have become far more pervasive in the past decade since many of the studies in this review were completed. Considering the close family ties in African American culture, inclusion of perspectives of both members of the dyad may provide insight not previously discovered. Yet, only one article examined both the African American individual with dementia and the African American caregiver (Li et al., 2004). Culturally, decisions made about an African American older adult are often considered by caregivers and the informal network (Dilworth-Anderson et al., 2002). Using a dyadic approach in the relationship of African American individuals with dementia and their African American caregivers is essential. Investigating both members of the dyad may offer vital information in the use of formal services by African American individuals with dementia.

Nursing Implications

The current review has several implications for nursing practice—to educate and advocate. First, nurses have a unique opportunity to understand the needs of the African American dementia dyad for formal service needs and potential barriers to use, even if not specifically spoken. Nurses often spend greater amounts of time with African American individuals with dementia and their caregivers. The time spent assessing African American individuals with dementia may provide an opportunity for African American dementia dyads to express concerns or feelings that can result in a conversation regarding available formal services and match with the dyad’s needs. Nurses can provide education on formal services that benefit African American individuals with dementia and African American caregivers. Without education from nursing staff, African American dyads may be unaware of services to meet their current and future needs.

Second, if nurses understand the expectations and needs of African American dyads, they can better advocate for meeting those needs. Nurses can be the liaison for formal service providers for dyads and communicate the needs and expectations to other providers who interact with members of the dyad. Providing formal service information during the appointment may improve communication between African American dementia dyads and formal care providers. In addition, acknowledging the important role other family members play in decision making by inviting those family members to appointments may be particularly important, given the important role of the broader family within African American culture.

Summary

The current review is an important addition to the literature on formal service need, formal service use and expectations of formal service providers and African American individuals with dementia and African American caregivers. Formal services are still not consistently used by African American individuals with dementia and their caregivers, despite improvements in the health and well-being of those who use services. To address this problem, a more consistent and culturally sensitive approach is essential in improving the health outcomes of African American individuals with dementia.

Table A

Characteristics of Articles Included in the Integrative Review of Formal Service Use by African American (AA) Individuals with Dementia (IWD) and Their Caregivers (CG)

Author (Year)	Sample	Dementia Measure	Study Design	Results	Quality Score[a]
Cox & Monk (1990)	N=50 CGs 31-AA 19-Hispanic	Not provided	Descriptive, longitudinal (Quantitative)	Increased impairment in ADL scores (but not mental impairment) was related to increased use of formal supports (p< .05) by AA CGs' impairment.	5
Desin et al. (2016)	N=30 AA CGs	Caregiver report	Descriptive, cross-sectional (Quantitative)	AA CGs endorsed unmet need regarding care provided during the day (40%), managing the older adult's	2

				memory loss (37%) and handling behaviors (33%).	
Edwards & Morris (2007)	N=343 AA individuals with dementia 179-lived alone 164-lived with CG	CDR	Descriptive, cross-sectional (Quantitative)	Predictors of formal service use: Medicaid certification, presence of a caseworker, living alone, and mild dementia	7
Gerdner & Simpson (2009)	N=15 AA CGs	Formal diagnosis, Caregiver report	Ethnographic, cross-sectional (Qualitative)	All 15 AA CGs indicated a physician should be the initial contact for treatment--"God… gave us doctors and nurses...”	N/A

Hinrichsen & Ramirez (1992)	N=152 Caregiving Units 33 AA (3 also Hispanic) 119-white	Medical diagnosis, MMSE	Descriptive cross-sectional (Quantitative)	Medicaid recipients were significantly more likely to have more needs met by the formal care network (p< .001).	7
Ho et al. (2000)	N=117 CGs 29-AA 32-Euro-American 25-Chinese 31-Latino	CDR, MMSE	Descriptive, cross-sectional (Quantitative)	AA CGs reported significantly less unmet medical service needs compared to all other CGs (p< .01).	7
Kosloski et al. (1999)	N=2,947 CGs 703-AA 758-Hispanic 1,486-Non-Hispanic white	Caregiver report	Descriptive, cross-sectional (Quantitative)	AA CGs working full-time had increased likelihood of formal service	6

				use (p< .05) and fewer ADL impairments were associated with formal service use (p<.05).	
Kosloski et al. (2002)	N=315 CGs 121-AA 46-Latino 148-white	Not provided	Descriptive, cross-sectional (Quantitative)	AAs CGs had the highest belief the government had a responsibility to assist CGs financially.	6
Lampley-Dallas et al. (2001)	N=13 AA CGs	Caregiver report	Exploratory, cross-sectional (Qualitative)	CGs expected physicians to have a working knowledge of dementia and diagnose dementia accurately.	N/A

Lampley-Dallas et al. (2005)	N=13 AA CGs	Caregiver report	Exploratory, cross-sectional (Qualitative)	CGs expected physicians to provide information about formal services, be knowledgeable about the dementia process, and to be supportive as CGs made decisions.	N/A
Levkoff et al. (1999)	N=40 CGs 10-AA 10-Chinese American 10-Irish American 10-Puerto Rican	Caregiver report	Retrospective, cross-sectional (Qualitative)	AA CGs endorsed the need to include family in the decision to use formal services and difficult experiences had negatively impacted the use	N/A

				of formal services.	
Li et al. (2004)	N=200 urban AA Caregiving units	CDR, MMSE	Descriptive, cross-sectional (Quantitative)	PWDs who were Medicaid recipients (p<.0001), with an annual income equal to or higher than $10,000 (p< .05), and with fewer ADL/IADL impairments (p= .05), were more likely to use formal services.	6
Miller & Mukherjee (1999)	N= 215 Spouse CGs 77-AA 138- white	Not provided	Descriptive, cross-sectional (Quantitative)	CGs who were women, AA, current formal service users, and who had lower levels of	6

				caregiving mastery scores had a greater likelihood of accepting government and community formal services.	
Scharlach et al. (2006)	N=76 CGs 12-AA 8-Chinese 9-Filipino 9-Korean 11-Native American 6-Hispanic 9-Russian 12-Vietnamese	Not provided	Prospective, cross-sectional (Qualitative)	AA CGs expressed the concerns that the needs of the dominant culture were different from minority culture, resulting in a barrier to formal service use.	N/A

Note: AA= African American, CG= caregiver, CDR= Clinical Dementia Rating Scale, MMSE= Mini Mental State Exam, ADL= activities of daily living, IADL=instrumental activities of daily living. ^{a}Quality score determined by using the Newcastle-Ottawa Quality Assessment Scale adapted for cross-sectional studies. Scores range from 0 (low quality) to 10 (high quality).

Table B

Quality Assessment for Qualitative Articles in Integrative Review

Author	Stated Aims?	Qualitative Method?	Design?	Recruitment Strategy?	Data Collection?	Researcher and Participants Relationship?	Ethical Issues?	Data Analysis?	Stated Findings?	Research Valuable?
Gerdner & Simpson (2009)	Yes	Yes	Yes (in-depth interview, interview guide)	Yes (convenience sampling, community liaisons)	Yes (one interview audiotaped, transcribed verbatim, no mention of saturation)	Can't Tell (use of field notes)	Yes	Yes	Yes	Yes
Lampley-Dallas et al. (2001)	Yes	Yes	Yes (focus groups, interview guide)	Yes (convenience sampling)	Yes (audiotaped, transcribed verbatim, saturation after second focus group)	No	Yes	Yes	Yes	Yes

Lampley-Dallas et al. (2005)	Yes	Yes	Yes (focus groups, interview guide)	Yes (convenience sampling)	Yes (audiotaped, transcribed verbatim, saturation after second focus group)	No	Yes	Yes	Yes	Yes
Levkoff et al. (1999)	Yes	Yes	Yes (in-depth interview, two interview guide)	Yes (convenience sampling)	Yes (audiotaped, transcribed verbatim, translated to English, if necessary)	Can’t Tell (field notes of setting and nonverbal aspects)	Can’t Tell (no mention of IRB or consent)	Yes	Yes	Yes
Scharlach et al. (2006)	Yes	Yes	Yes (racial- and ethnic-specific focus	Yes (convenience sampling)	Yes (audiotaped, note take at each session)	Can’t Tell (discussion after each session, written summary of impressions)	Can’t Tell (no mention of IRB or consent)	Yes	Yes	Yes

			groups, interview guide)							

CHAPTER III

Factors Influencing Quality of Life in African American Dementia Dyads

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Abstract

Objective: Both caregivers and the older adults they care for can experience declines in quality of life (QOL) over the course of the dementia trajectory. Yet, little research has examined QOL in African American caregivers and even less in African American persons with dementia (PWDs), making it difficult to identify factors associated with QOL.

Method: Guided by the Negro Family as a Social System framework, a secondary data analysis was used to examine the influence of family structure (i.e., type of caregiver), instrumental (i.e., decision-making involvement of PWDs, caregivers' educational level and PWDs' cognitive status) and expressive (i.e., dyadic relationship quality) role functions on QOL in a sample of 62 African American dementia dyads (i.e., African American PWDs and their African American caregivers). Dyadic data were analyzed using multilevel modeling to control for the interdependent nature of the data.

Results: On average, African American PWDs reported significantly worse QOL than African American caregivers. Within African American dementia dyads, QOL covaried. African American PWDs experienced significantly worse QOL when their caregiver was a non-spouse and they themselves perceived less involvement in decision-making. In addition, African American caregivers experienced significantly worse QOL when they reported greater dyadic strain with the African American PWD and were non-spouses of African American PWDs.

Conclusion: Findings emphasize the importance of the dyadic relationship, family structure and role functions in predicting QOL of African American dementia dyads. Findings suggest understanding the interpersonal characteristics of dyads may hold promise for improving their QOL.

Keywords: multilevel modeling, caregiver, decision-making involvement, dyadic strain

Introduction

The population of African American older adults in the United States is continuing to increase, with an estimated increase from 3.8 million in 2012 to 10.3 million by the year 2050 (Ortman et al., 2014). In addition to the increased number of African American older adults, research suggests an increased incidence of Alzheimer’s disease and other dementias in African American older adults compared to non-Hispanic White and Hispanic older adults (Alzheimer's Association, 2018). This incidence is associated with greater rates of diabetes, hypertension and stroke in the African American population (Alzheimer's Association, 2018). Despite the suggested risk of Alzheimer’s and other dementias in African American older adults, limited research exists that examines the African American person with dementia (PWD) and even less research that investigates both African American PWDs and their African American caregivers. Previous research supports PWDs providing their own responses to health assessments (Brod et al., 1999), consistently and reliably over time (P. A. Clark et al., 2008). In addition, the inclusion of African American PWDs in research aligns with African American culture. African American families tend to share the responsibility of decision-making (Kane, 2000). African American PWDs are valued, and their opinions respected within the African American family (Lindauer et al., 2016).

Decision-Making Involvement and QOL

Caregiving is an inherently dyadic process that involves the interactions and relationship of both the PWD and their caregiver (Lyons et al., 2002; Martire et al., 2010). Caregiving consists of multiple decisions made throughout the day, often by PWDs or on their behalf. Previous research that includes the PWD and their caregiver provides insight on how dyads (i.e., PWDs and caregivers) function during caregiving (Coeling, Biordi, & Theis, 2003; Lyons &

Lee, 2018; Menne et al., 2008; L. M. Miller, Lee, Whitlatch, & Lyons, 2017; L. M. Miller et al., 2016). Previous research highlighted that decision-making involvement (e.g., verbal and/or nonverbal communication) could be shared between both members of dementia dyads (Menne et al., 2008). When PWDs perceived greater decision-making involvement, both members of dyads experienced significantly better QOL (Menne et al., 2008). On the other hand, negative experiences in caregiving such as increased dyadic relationship strain have been associated with less decision-making involvement by PWDs (L. M. Miller, Lee, et al., 2017). Previous research has also found adverse effects of the caregiving process on caregivers' QOL (Schulz & Beach, 1999; Schulz & Martire, 2004). Yet, to our knowledge no study has examined decision-making involvement of PWDs in a sample of entirely African American dementia dyads.

QOL in African American Dementia Dyads

The majority of QOL research has included only small numbers of African American caregivers (if any), limiting generalizability to African American dementia dyads. Studies that have examined African American caregivers have found that these caregivers reported less psychological distress (Dilworth-Anderson & Gibson, 2002) and greater positive aspects from caregiving (Haley et al., 2004) when compared with non-Hispanic White caregivers. African American PWDs have been studied far less, resulting in a scarcity of research focused on QOL of African American PWDs. Menne et al. (2009) noted one factor that was associated with worse QOL of PWDs was being African American. In this study, African American PWDs were compared to non-Hispanic White PWDs with little consideration to the cultural differences within and among these two racial groups. Given both the paucity of research and conceptual frameworks focused on African American dementia dyads, there is a strong need to examine and understand dyads through a more culturally relevant theoretical lens.

Proposed Conceptual Framework

The Negro Family as a Social System is a conceptual framework originally proposed by Dr. Andrew Billingsley in 1968 and later reprinted in 1988. The Negro Family as a Social System consists of a network of three social systems—the Negro family, the Negro community and the Wider society (Billingsley, 1968). Centrally located in the original model is the *Negro family*, highlighting the importance of dyadic relationships such as mother-daughter, father-son, or mother-father.

Components of the *Negro family* include family structure and two role functions. Family structure is described based on the family composition (e.g., two-parent, single-parent or blended families) (Billingsley, 1968). In this study, family structure is adapted to describe the type of caregiver (i.e., spouse vs. non-spouse) of African American dementia dyads. The two role functions are instrumental and expressive (Billingsley, 1968; Walsh, 2003). Instrumental role functions are characterized by maintaining the physical and social integrity of the family unit including decision-making (e.g., decision-making involvement of PWD), educational obtainment (e.g., educational level of caregiver), economic provision and maintaining health (e.g., cognitive status of PWD) (Billingsley, 1968; Walsh, 2003). Expressive role functions are characterized as maintaining social and emotional relationships among the family unit including positive and negative feelings (e.g., dyadic relationship quality), self-worth and belonging (Billingsley, 1968; Walsh, 2003). The *Negro community*, which should be viewed as a racial subsociety consisting of the dual nature of the African American population—a group of people often characterized as monolithic but with great variability in conditions, personality and behaviors (Billingsley, 1968). The *Negro community* includes geographic regions, social class as well as businesses such as local barbershops or beauty salons. The *Wider society* consists of the health care, educational and political system, for example.

The model proposes that African American families are embedded in a network of larger social systems (i.e., *Negro community* and *Wider society*) that influence outcomes of these African American family members (Billingsley, 1968, 1992). QOL is an important outcome to consider. QOL can be defined as health related or a broader description encompassing mental, physical, social and role functions and health perceptions (Ware & Sherbourne, 1992). Lawton (1991), further, described QOL as a multidimensional concept, which incorporates four main sectors—behavioral competence (e.g., activities of daily living and cognition), perceived QOL (e.g., relationships and health), objective environment (e.g., neighborhood and social networks) and psychosocial well-being (e.g., mental health and positive and negative emotions). Therefore, given the global nature of QOL, the examination of African American dementia dyads should take into consideration some, if not all, of these broader influences. For example, African American families have not had equal access to health care and education when compared to other ethnic and/or racial groups (Billingsley, 1968; Institute of Medicine, 2003). Thus, the health and well-being of African American families could be negatively affected by the disproportionate access and not only being African American. As a result, examining the QOL of African American dementia dyads allows for recognition of the variability across dyads. Family structure, instrumental and expressive role functions were examined in this current paper as predictors of QOL of African American dementia dyads (**Figure 1)**.

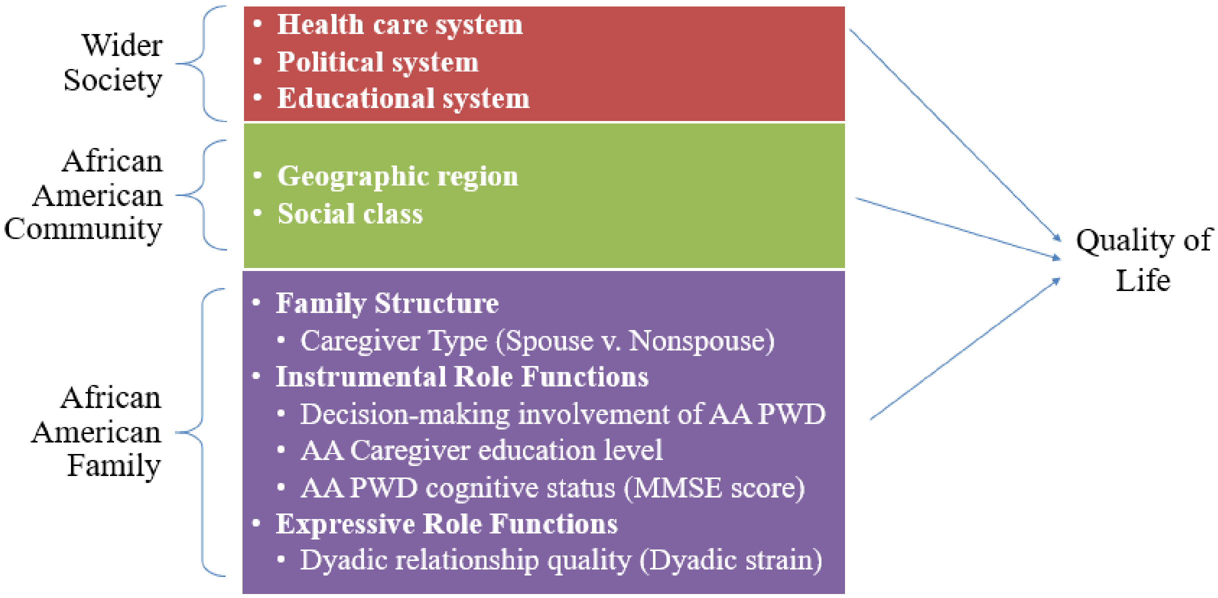

Figure 1. Proposed model adapted from the Negro Family as a Social System (Billingsley, 1968). Each bracket on the left represents a network of interdependent relationships. The rectangles in the middle describe the subsystems represented in each relationship (bolded text) and how these subsystems were operationalized as study variables. The arrows on the right represent the relationships between the network of relationships and subsystems associated with QOL. AA=African American PWD=person with dementia

The current study is the first known study to examine family structure and role functions associated with QOL of both members of African American dementia dyads. Using the Negro Family as a Social System, our research questions are: 1) Will there be a covariation between QOL of African American PWDs and their African American caregivers? and 2) Are family structure types of caregivers and instrumental and expressive role functions associated with QOL of African American dementia dyads?

Method

Participants and Procedures

The study is a secondary analysis of data collected from a study examining the caregiving process of both PWDs and their caregivers (Powers & Whitlatch, 2016). In the original study, inclusion criteria consisted of the following: 1) PWDs had a confirmed diagnosis of dementia (coded as yes/no) or a Mini Mental State Examination (MMSE) score between 13 and 26, 2) PWD was community-dwelling and 3) PWD had a primary, informal caregiver—person who provided the most caregiving (Powers & Whitlatch, 2016). In total, 202 community dwelling PWDs and their caregivers (131 non-Hispanic White dyads and 71 African American dyads) were recruited from Cleveland, OH and San Francisco Bay Area, CA. Additional recruitment information is provided elsewhere (Feinberg & Whitlatch, 2001). For the current study, both members of the dyad were required to be African American and have complete data on study predictors (i.e., type of caregiver, decision-making involvement, caregiver's educational level, PWD's cognitive status and dyadic relationship quality) and outcome variable (i.e., QOL). This resulted in a sample of 62 dyads, which is similar to other samples (Lyons et al., 2002; L. M. Miller, Lee, et al., 2017). For the original study, informed consent was obtained from all participants. Ethical approval for the current secondary analysis of de-identified data was obtained by the IRB at Oregon Health & Science University after being determined exempt from human subject review.

Outcome Measure

QOL of the PWD and their caregiver was measured using equivalent versions of the Quality of Life-Alzheimer's Disease measure (QOL-AD) (R. G. Logsdon, Gibbons, McCurry, & Teri, 1999; R. G. Logsdon, Gibbons, L. E., McCurry, S. M., & Teri, L., 2002). The QOL-AD was created based on Lawton's conceptual domains of QOL (R. G. Logsdon, Gibbons, L. E., McCurry, S. M., & Teri, L., 2002). The QOL-AD was developed to examine QOL in persons with mild-to-moderate dementia symptoms and has been used in previous studies to rate the QOL of both the PWD and their caregiver (R. G. Logsdon et al., 1999; Moon et al., 2017). The scale consists of 13 items; the reliability in this study was Cronbach's alpha = 0.82 for African American PWDs and Cronbach's alpha = 0.89 for their caregivers. An example of the items on the scale is: "When you think about your whole life, and all the different things about you, would you say it's….?". Each item was rated by African American PWDs and their caregivers based on their perceptions of different aspects of their own lives on a 4-point Likert scale: 1= poor, 2= fair, 3= good and 4= excellent. Items are summed to a total score ranging from 12-48, with higher scores indicating better QOL.

Predictors

Family Structure. Family structure of African American dementia dyads was identified based on the type of caregiver of each dyad. The type of caregiver was reported by the caregiver and coded as spouse or non-spouse caregiver. Type of caregiver of the African American dementia dyads was examined as a predictor of QOL.

Instrumental Role Functions. Decision-making involvement by African American PWDs was examined using the Decision-Making Involvement Scale (DMI) (Menne & Whitlatch, 2007) which has been used in previous studies to examine the perceived decision-making involvement of PWDs (Menne et al., 2008; L. M. Miller, Lee, et al., 2017). The DMI was created to allow PWDs to report on their perceived decision-making regarding day-to-day decisions supporting autonomy and independence of the PWD (Menne et al., 2008). The DMI is a 15-item scale, and the reliability in this study was Cronbach's alpha = 0.86. A sample item from the scale is "How involved are you in decisions about what to do in your spare time?" Responses are answered based on a 4-point scale of 0= not at all involved, 1= a little involved, 2= fairly involved and 3= very involved. The total score is a mean of the scale, ranging from 0-3;

higher scores indicate greater perception of decision-making involvement by African American PWDs.

Other instrumental role functions included in the model were the educational level of African American caregivers and cognitive status of African American PWDs. The educational level of African American caregivers reported by the caregiver was a proxy for socioeconomic status (Galobardes, Shaw, Lawlor, Lynch, & Davey Smith, 2006). In addition to using the MMSE as a screening tool, we used it to reflect the cognitive status of African American PWDs. The MMSE is an 11-item scale; the reliability of the MMSE in our study was Cronbach's alpha = 0.54. The MMSE ranges from 0-30 with higher scores indicating better cognitive status (Folstein, Folstein, & McHugh, 1975).

Expressive Role Function. The dyadic relationship quality was examined by the Dyadic Strain subscale of the Dyadic Relationship Scale (DRS) (Sebern & Whitlatch, 2007). The Dyadic Strain subscale was included in the analysis to examine dyadic relationship quality based on the perceived strain in the relationship reported by the African American PWD and their caregiver (Menne et al., 2009; L. M. Miller, Whitlatch, Lee, & Lyons, 2017). The Dyadic Strain subscale is a 4-item measure for PWDs and a 5-item measure for caregivers; with a reliability of Cronbach's alpha = 0.70 for African American PWDs and Cronbach's alpha = 0.77 for African American caregivers in this study. A sample question: "Because of my health, I felt resentful toward my caregiver" (PWD version) or "Because of helping my relative, I felt resentful toward him/her" (caregiver version). A 4-point option response includes: 0= strongly disagree, 1= disagree, 2= agree and 3= strongly agree. The total score is a mean of the scale ranging from 0-3; higher scores indicate greater perceived relationship strain.

Analysis Plan

Multilevel modeling was used to analyze data at the level of the dyads while controlling for the interdependence in the data (Lyons et al., 2002; Sayer & Klute, 2005). The multivariate outcomes model simultaneously estimates the latent scores for both the African American PWD and the African American caregiver. The multilevel models were tested using Hierarchical Linear Modeling software, version 7.03 (Raudenbush, 2017). Predictors (type of caregiver, decision-making involvement of African American PWDs, educational level of African American caregivers, cognitive status of African American PWDs, dyadic strain by African American PWDs and their African American caregivers) were added to a conditional Level 2 model (between-dyad) to determine their association with QOL. The first model or Level 1 unconditional model (i.e. no predictors) examines QOL of the African American dementia dyad. The Level 1 unconditional model (within-dyad) represents the QOL score (*Y*) for both the African American PWD and the African American caregiver, the sum of a latent true score (β_1 for the PWD and β_2 for the caregiver), plus *r*, a residual term, that denotes measurement error. The equation is specified as follows:

$$\mathrm{Y}_{ij} = \beta_{1j}\,(\text{PERSON WITH DEMENTIA}_{ij}) + \beta_{2j}\,(\text{CAREGIVER}_{ij}) + r$$

where Y_{ij} depicts the QOL score *i* in dementia dyad *j*. PERSON WITH DEMENTIA is a dummy variable or indicator variable with a value of 1 if the response was obtained by the African American PWD and a value of 0 if it was obtained by the African American caregiver. CAREGIVER is a dummy variable or indicator variable taking on the value of 1 if the response is obtained by the African American caregiver and a value of 0 if by the African American PWD. The β_{1j} and β_{2j} depict the PWD's and caregiver's latent QOL scores, respectively. In addition, the Level 1 unconditional model provides a tau correlation, capturing the covariation of QOL of the African American PWDs and their caregivers.

The Level 2 model (between-dyad) comprises simultaneous regression equations with β_{1j} and β_{2j} operating as dependent variables. The model can be specified as the following:

$$\beta_{1j} = \gamma_{10} + [\gamma_{11}\text{Predictor}_1 + \gamma_{1n}\text{Predictor}_n] + u_{1j}$$

$$\beta_{2j} = \gamma_{20} + [\gamma_{21}\text{Predictor}_1 + \gamma_{2n}\text{Predictor}_n] + u_{2j}$$

with γ_{10} and γ_{20} as the Level 2 intercepts, depicting average values of QOL for the African American PWD and African American caregiver, respectively, adjusting for the predictors in each equation. This model included family structure (i.e., type of caregiver), instrumental role functions (i.e., decision-making involvement of the African American PWD, African American caregivers' educational level, African American PWDs' cognitive status) and expressive role functions (i.e., dyadic strain of African American PWDs and their African American caregivers) as predictors of QOL for both members of the African American dementia dyad.

Parallel Scales

To provide adequate information to estimate measurement error variances for both the African American PWD and the African American caregiver, parallel scales of the outcome measure QOL-AD were created for both members of the dyad (Barnett, Marshall, Raudenbush, & Brennan, 1993; L. M. Miller, Lee, et al., 2017; Sayer & Klute, 2005). Items from the QOL-AD were matched into pairs based on the closeness of their standard deviations to create six pairs with one item from each pair assigned to one of the two scales (for a total of 12 items). As a result, the process yielded two scales with equal variance and reliability for each member of the dyad (i.e., a total of four scores for each dyad).

Results

Sample Characteristics

Background characteristics are provided in **Table 1** for the 62 African American dementia dyads. The majority of PWDs and their caregivers were female (PWD = 68%, caregiver = 81%). Most caregivers had attended high school or more (56%). Seventy-six percent of African American PWDs had a diagnosis of dementia from a health care provider and a MMSE score of 21.08 (SD ± 3.94). On average, African American PWDs perceived their decision-making involvement as “fairly involved” (on a range of “not at all involved” to “very involved”). Overall, African American caregivers when compared to African American PWDs were significantly younger, predominantly daughters/daughters-in-law and had significantly better QOL. Additionally, there was a large effect size for ages of African American PWDs compared to their caregivers and a medium effect for African American caregivers’ QOL compared to QOL of African American PWDs. There was no significant difference between African American PWDs and their caregivers in perceived dyadic relationship strain but there was a small-medium effect size.

Table 1

Sample Demographics and Measure Descriptives (N= 62 Dyads)

	AA PWD	AA CG	Effect Size
Age in years, (mean ± SD)	76.55 ± 7.84	60.49 ± 13.35***	1.52
Women (%)	42 (68%)	50 (81%)	-----
Spouse CG (%)	-----	19 (30.6%)	-----
Non-spouse CG			
Daughter/daughter-in-law (%)	-----	27 (43.5%)	
Son/son-in-law (%)	-----	5 (8.1%)	-----
Other relative (%)	-----	11 (17.7%)	-----
PWD lives with CG or someone else (%)	24 (39%)	-----	-----
Years of Care (in months), (mean ± SD)	-----	39.07 ± 39.38	-----
Greater than high school (%)	29 (47%)	35 (56%)	-----
Dementia diagnosis by provider (%)	47 (76%)	-----	-----
MMSE score, (mean ± SD)	21.08 ± 3.94	-----	-----
Dyadic Strain, (mean ± SD)	0.84 ± 0.57	1.01 ± 0.47	0.32
Decision-Making Involvement, (mean ± SD)	2.27 ± 0.66	-----	-----
Quality of Life, (mean ± SD)	31.5 ± 5.49	34.39 ± 5.95**	0.50

Note: AA= African American; PWD= person with dementia; CG= caregiver; SD= standard deviation; MMSE= Mini-Mental State Examination. ** $p < 0.01$. *** $p < 0.001$, indicates significant difference between the two groups. Effect size= Cohen's d (difference between two means)= 0.20 (small), 0.50 (medium), 0.80 (large).

Quality of Life

Results of the unconditional (within-dyad) model (**Table 2**) show that PWDs and their caregivers reported moderate QOL. African American caregivers reported significantly better QOL than African American PWDs. Moreover, QOL within dyads covaried (tau correlation =

0.26), responding to our first research question and reinforcing the use of multilevel modeling. In addition, there was significant variability around the average scores of both African American PWDs ($\chi^2 = 287.14$, $p < .001$) and caregivers ($\chi^2 = 331.73$, $p < .001$), indicating significant heterogeneity in QOL across dyads.

Predicting Dyadic Quality of Life

QOL of African American PWDs was significantly associated with their perceived decision-making involvement, $t(2.85) = 2.72$, $p < .01$), and type of caregiver, $t(4.11) = 5.23$, $p < .001$). There was a medium effect size for both decision-making involvement

Table 2

Multilevel Models Predicting African American Persons with Dementia and Their Caregivers Quality of Life (N=62 Dyads)

	AA PWD			AA Caregiver		
	β (SE)	t	Effect size (r)	β (SE)	t	Effect size (r)
Fixed effects						
Unconditional Model						
Intercept	31.5 (0.69)***	45.54		34.39 (0.75)***	45.54	
Conditional Model						
Intercept	29.37 (0.96)***	30.50		33.02 (1.09)***	30.31	
PWD MMSE score	-0.02 (0.17)	-0.14	.00	-0.17 (0.19)	-0.92	.02
PWD decision-making involvement	2.72 (0.95)**	2.85	.36	0.95 (1.06)	0.89	.12
Caregiver educational status	0.93 (1.17)	0.80	.01	1.00 (1.34)	0.75	.01
Caregiver dyadic strain	-1.24 (1.23)	-1.01	.13	-6.19 (1.39)***	-4.44	.51
PWD dyadic strain	0.57 (1.03)	0.56	.08	0.39 (1.17)	0.33	.04
Caregiver type (non-spouse)[a]	5.23 (1.27)***	4.11	.48	2.87 (1.43)*	2.01	.26
Random effects	Variance component	χ^2	df	Variance component	χ^2	df
AA PWD	23.27	287.14***	2	13.32	182.19***	8

AA Caregiver	28.37	331.73***	2	18.10	233.58***	8
Model comparison[b] χ^2 (df)		43.93 (24)**				

Note: [a] Non-spouse is the referent. [b]Deviance statistics used to compare conditional model (i.e., with covariates) to unconditional (i.e., no covariates) model. AA= African American; PWD= person with dementia. β = unstandardized coefficient; MMSE= Mini Mental State Examination; SE= standard error; effect size r (correlation coefficient)= $\sqrt{t^2/(t^2+df)}$ = .10 (small), .30 (medium), .50 (large). * $p < .05$; ** $p < .01$; *** $p < .001$.

(*r* = .36) and type of caregiver (*r* = .48). African American PWDs who reported less decision-making involvement and whose caregivers were non-spouses were significantly more likely to have worse QOL. Similarly, QOL of African American caregivers was associated with the caregiver type, *t*(2.01) = 2.87, *p* < .05), and caregiver reported dyadic strain, *t*(-4.44) = -6.19, *p* < .001). There was a small effect size for caregiver type (*r* = .26) and a large effect size for dyadic strain (*r* = .51). African American caregivers experienced significantly worse QOL when they were non-spouses of the PWD and when they reported greater dyadic relationship strain with the PWD. Thus, these findings respond to our second research question.

Discussion

Little is known about what influences QOL in African American dementia dyads. Specifically, it is unknown what family structures and role functions are associated with QOL within the context of African American dementia dyads. Using the Negro Family as a Social System as a conceptual model, we were able to examine variables that are culturally relevant to African American dementia dyads. The results support the use of the Negro Family as Social System as a model by emphasizing the interdependence and heterogeneity within African American dementia dyads' QOL. Several findings are important. First, QOL of African American PWDs and their caregivers covaried, implying the interdependent nature of the dementia caregiving process. Second, African American PWDs reported significantly worse QOL than their African American caregivers. Lastly, African American PWDs who perceived less decision-making involvement and had non-spouse caregivers experienced worse QOL; whereas, African American caregivers who reported greater dyadic relationship strain and were non-spouse caregivers experienced worse QOL.

The current study builds on the previous research that has examined QOL of PWDs and their caregivers using a dyadic approach (Moon et al., 2016; Moon et al., 2017). In the current study's findings, African American PWDs, on average, reported significantly worse QOL than African American caregivers, which has been previously found (Moon et al., 2017). Although, the finding regarding African American PWDs QOL is not a surprising finding. This study is one of the first to examine the covariation of QOL within African American dementia dyads, which has been supported in dementia caregiving research (Moon et al., 2017) as well as more broad illness caregiving literature (Lyons & Lee, 2018). QOL was low-moderately correlated within dyads, suggesting the importance of focusing on QOL at the dyadic level to better understand the interpersonal factors associated with dyads most at risk for worse QOL.

We found three interpersonal factors associated with QOL of African American dementia dyads—type of caregiver, decision-making involvement of African American PWDs and dyadic strain reported by African American caregivers. Regarding QOL of both members of African American dementia dyads, type of caregiver or family structure was significantly associated with worse QOL for both PWDs and their caregivers. In both cases being a non-spouse caregiver (predominantly daughters and daughters-in-law) was significantly associated with worse QOL. Our results suggest being a spouse caregiver has a protective effect on QOL for that caregiver and the PWD for whom they provide care. Divergent to our findings, Pinquart and Sorensen (2011) found spouse caregivers reported greater psychological distress in caregiving when compared to both adult children and adult children-in-law caregivers. The distress experienced by spouse caregivers were associated with several sociodemographic characteristics including greater amounts of caregiving, their own perceived poorer physical health and depressive symptoms (Pinquart & Sorensen, 2011). Those findings suggest being a spouse caregiver had a negative effect on their QOL. Given these contrary results, future research is warranted. Our analysis did not explicitly examine daughter/daughter-in-law caregivers, but they were the majority of our non-spouse caregivers. When caregivers were examined further by relationship, Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, and Lopez-Pousa (2010) found daughter caregivers’ perception of PWDs’ QOL was significantly related to more negative reports of depressive symptoms, social burden and feelings of guilt experienced by these daughter caregivers. Among non-spouse caregivers in two studies, the burden experienced by daughter caregivers was significantly more than male non-spouse caregivers (e.g., sons) (Conde-Sala et al., 2010) or (e.g., [grand]sons) (Laporte Uribe et al., 2017). Their perception of burden could result from the internalization of psychological distress experienced by daughter caregivers. Daughter caregivers often have multiple family demands while caring for their parent with dementia. Yet, Laporte Uribe et al. (2017) also found female caregivers reported significantly greater personal development related to caregiving. Similarly, positive attributes of caregiving have been found in studies of African American caregivers (Dilworth-Anderson et al., 2002). The experiences of daughter/daughter-in-law caregivers cannot be examined in isolation. Within these dyads with predominantly daughter/daughter-in-law caregivers, post hoc analysis revealed the majority of the African American PWDs were widowed. The death of the PWDs’ spouses could result in an inability to meet certain responsibilities (and/or unexpected new responsibilities) placed on the family (particularly on African American non-spouse caregivers) by the wider society (Billingsley, 1968), which may have contributed to their dyadic strain.

The level of dyadic strain reported by African American caregivers played a significant role in predicting their QOL. Closer examination of the DRS items reveal African American caregivers reported greater dyadic strain, anger and depressive symptoms regarding caregiving for African American PWDs. Based on the Negro Family as a Social System, healthy family functioning is measured by the ability of African American dementia dyads to meet the instrumental and expressive role functions of the family (Billingsley, 1968). Our study findings suggest African American caregivers are more overwhelmed and experience greater dyadic strain within the dyadic relationship than previously identified in dementia caregiving literature (Haley et al., 2004). The interpersonal relationship between African American caregivers and African American PWDs is significant in determining their QOL. Thus, interventions to improve QOL of African American caregivers will need to take into consideration the dynamics of the relationship within African American dementia dyads. Because the increased strain or stress reported by African American caregivers (while controlling for the strain of African American PWDs) does not seem to translate the same way to the African American PWD. The quality of the relationship is more protective for the African American caregivers; whereas, being more involved with decision-making appears to be more protective for the African American PWDs.

African American PWDs who perceived less decision-making involvement were found to have significantly worse QOL (Menne et al., 2009). Our findings highlight the importance of including African American PWDs in everyday decision making. Over the last few decades, research focused on the values and preferences of PWDs has supported the involvement of PWDs in everyday decision-making (Menne et al., 2008; Menne & Whitlatch, 2007). The current study strongly reinforces the need to involve African American PWDs in decision-making during the mild-to-moderate disease trajectory. The lack of decision-making involvement may be especially difficult for African American older adults given their previous respected, leadership role in many African American families and the African American community. Decision-making involvement in dementia dyads has been described as evolving from supported to substitute decision-making during the disease trajectory (Samsi & Manthorpe, 2013). Yet, future research with larger studies is needed to determine if decision-making involvement within African American dementia dyads follows this same evolution.

Limitations

The study had several limitations. The size of the sample was relatively small, limiting the number of variables included in the model. Although not statistically significant in the current study, the moderate effect sizes of perceived decision-making involvement of African American PWDs by their African American caregivers and dyadic strain of African American caregivers by the African American PWDs suggest further examination of these interpersonal factors in larger African American samples is warranted. The study was cross sectional; therefore, no causal inferences can be made or examination of changes in QOL over time. Future studies should include longitudinal designs that allow African American dementia dyads to be their own control without relying or comparing to other racial or ethnic groups and for complete examination of the conceptual framework of the Negro Family as a Social System. In addition, examining biobehavioral variables may add a more objective component to the subjective QOL data gained through surveys.

Strengths and Implications

Despite the limitations, there are several notable strengths in the current study. The current study findings point to taking a broader view when looking at QOL in African American dementia dyads. The study highlights the need for African American dyadic research and examining the interpersonal factors within African American dementia dyads. Findings suggest the importance of the type of caregiver, decision-making involvement of African American

PWDs and dyadic relationship strain reported by African American caregivers on QOL of African American dementia dyads.

Our findings elucidate the complexity of caregiving and the gaps in our understanding regarding a subgroup of African American caregivers with limited research—African American non-spouse caregivers (who were predominantly daughters/daughters-in-law). Sixty percent of caregivers are female and 20% (5.6 million) are African American (National Alliance for Caregiving and AARP, 2015). Our study sample is consistent with both African American female caregivers and African American daughter caregivers being the majority. Kim et al. (2018) found African American caregivers with multiple caregiving roles experienced worse self-rated health when compared to caregivers with only one caregiving role, possibly related to limited opportunities to care for their own health. Well-meaning providers cannot overlook the critical role and potential fragile nature of African American non-spouse caregivers when they attend appointments with African American PWDs. These visits may be one of the few points of contact for African American non-spouse caregivers with providers and their risk of worse QOL should be addressed.

In the clinical setting, factors that influence QOL of both members of African American dementia dyads should be addressed. For example, encouraging the inclusion of African American PWDs in decision-making during the early stages of the disease trajectory preserves their position in the family and respect instilled by African American culture. In addition, it is important to evaluate the QOL of both African American PWDs and their African American caregivers. Relying solely on secondary proxy report rather than on the responses of African American PWDs or not probing African American caregivers to better understand their situation, clinicians may miss key factors that would highlight their risk of worse QOL. Future research should continue to identify African American dementia dyads at risk for worse QOL through the examination of decision-making involvement of both African American PWDs and their African American caregivers.

This novel study elucidates the need to examine the African American PWD and their African American caregiver through a dyadic lens that is supported by our findings and the interdependence in African American culture. Greater attention is needed to investigate the African American dementia dyad as a unit, understanding cultural nuance and identifying other dyadic characteristics (e.g., sex of the caregiver) that put African American PWDs and their caregivers at greater risk for worse QOL. These discoveries will foster strategies to best support African American dementia dyads in both research and clinical practice.

CHAPTER IV

Patterns of Dyadic Appraisal of African American Persons with Dementia Decision-Making Involvement

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Abstract

Background and Objectives: Everyday decision-making involvement by persons with dementia (PWD) and similar appraisal of perceptions of dementia dyads (i.e., PWDs and their caregivers) has been associated with better quality of life (QOL) for both members of these dyads. However, no study has examined decision-making involvement in an African American population and how PWDs' decision-making involvement was associated with QOL of both member of African American dementia dyads. As a first step to develop tailored intervention to optimize QOL of dementia dyads, the purpose of this study was to identify patterns of dyadic appraisal of decision-making involvement of PWDs in African American dementia dyads.

Research Design and Methods: A secondary analysis of cross-sectional data from 62 African American dementia dyads was conducted. Multilevel and mixture modeling were used to generate incongruence and dyadic averages in African American dementia dyads appraisal of decision-making involvement of African American PWDs and identify distinct patterns.

Results: Three distinct patterns of dyadic appraisal were observed. 19.4% of dyads were labeled as "*Incongruent, PWD Poorly Involved*"; 53.2% were labeled as "*Incongruent, PWD Moderately Involved*"; and 27.4% were labeled as "*Congruent, PWD Very Involved*". The *Congruent, PWD Very Involved* pattern consisted of African American PWDs who were significantly younger and had less cognitive impairment. African American PWDs in the *Incongruent, PWD Moderately Involved* pattern had significantly better QOL than African American PWDs in the *Incongruent, PWD Poorly Involved* pattern but did not significantly differ from African American PWDs in the *Congruent, PWD Very Involved* pattern.

Discussion and Implications: Findings highlight the need to tailor strategies to optimize QOL in African American dementia dyads. While improving everyday decision-making for those

African American PWDs in the *Incongruent, PWD Poorly Involved* pattern may hold promise, other strategies are needed to improve QOL for African American PWDs in the remaining patterns.

Keywords: informal caregiving, culturally sensitive

Introduction

In the United States, African American older adults are twice as likely to develop Alzheimer’s disease and other dementias compared to non-Hispanic White older adults (Alzheimer's Association, 2016; Ortman et al., 2014). African American older adults are also diagnosed at later stages of dementia, resulting in greater morbidity (Chin et al., 2011). Despite the disproportionately high risk of dementia in African American older adults, little is known about how African American dementia dyads (i.e., African American persons with dementia [PWD] and their African American caregivers) manage the caregiving process, such as everyday decision-making and its impact on quality of life (QOL). Many everyday decisions are made by PWDs or on their behalf, such as what to eat, what clothes to wear, what time to get up or go to bed (Menne et al., 2008; Menne & Whitlatch, 2007). Understanding how involved they are in these everyday decisions and the level of (in)congruence regarding this involvement within the dyads can provide greater insight into dementia caregiving.

For more than a decade, dementia research has begun to focus on the dementia dyad – moving away from sole reliance on proxy reports of caregivers alone (Braun et al., 2009; Lyons et al., 2002; Martire et al., 2010). Expanding research efforts to include the PWD acknowledges the dual nature of the caregiving process (Kitwood, 1997). This shift toward a dyadic perspective is timely, in that African American decision-making is often family based (Kane, 2000). To date, decision-making involvement (e.g., verbal and nonverbal communication) has not been explicitly studied within African American dementia dyads. Lindauer et al. (2016) found African American caregivers intentionally kept African American PWDs involved in daily activities out of honor and respect for their prior role in the family.

To date, we know that PWDs desire greater involvement in everyday activities (P. A. Clark et al., 2008) and treatment decision-making (Hirschman, Joyce, James, Xie, & Karlawish, 2005) but have been prematurely removed from involvement in both types of decisions (L. M. Miller et al., 2016). The PWD's removal or exclusion could be related to the body of research that has focused on decision-making capacity, which has overshadowed research on their decision-making involvement (L. M. Miller et al., 2016). Yet, moving beyond decision-making capacity to decision-making involvement may prove beneficial for both members of dementia dyads, particularly as it is a more strength-based approach and aligns more strongly with person-centered care. Indeed, decision-making involvement by PWDs has been associated with improved quality of life (QOL) for PWDs (Menne et al., 2009; Menne & Whitlatch, 2007) and their caregivers (Menne et al., 2008). Further, caregivers who reported greater decision-making involvement by PWDs also reported less strain in the dyadic relationship (L. M. Miller, Lee, et al., 2017).

Along these lines, similar appraisal of perceptions between dyads—either dementia dyads or couples—have been positively associated with the well-being of the members of these dyads. Moon et al. (2017) found when dementia dyad members had similar appraisal regarding the care values of PWDs both PWDs and their caregivers experienced significantly better QOL. When spouses/partners of persons with prostate cancer had similar appraisal of the characteristics of prostate cancer, this congruence was significantly associated with better health related QOL for those couples (Merz et al., 2011). Taking this body of literature further, Lyons and Lee (2018) theorized that the health and well-being of dyads is based on the appraisal of both members of the dyad and how these dyads manage the illness. While no study has explicitly examined the (in)congruence of PWDs decision-making involvement, appraisal of decision-making and the amount of (in)congruence are associated with QOL. It is important to examine African American dementia dyads using the family-centered culture of African Americans.

The current study is informed by the Negro Family as a Social System conceptual framework (Billingsley, 1968) to optimize QOL for both members of African American dementia dyads. According to this conceptual framework, better outcomes and well-being are associated with factors of the family or dyad, their local environment and more global systems of healthcare. Research supports examining the characteristics of dyads to better understand caregiving processes (Lyons & Lee, 2018). Dyads do not function in isolation and the environment in which they live has the potential to influence their health and well-being. Having an attachment to the environment—both immediate and surrounding was associated with better QOL of PWDs (O'Rourke, Duggleby, Fraser, & Jerke, 2015). Whereas the resources and formal care provided in the environment were associated with QOL for dementia caregivers (Oliveira, Zarit, & Orrell, 2019). Thus, greater decision-making involvement by African American PWDs, more congruent appraisal between dyads, more socioeconomic stability in the neighborhood or geographic location and use of formal care can result in better well-being for African American dementia dyads.

Family structure considers the dyadic relationship of members of the family (e.g., mother-daughter, father-son), in this case the type of dementia dyad (i.e., spousal dyads or non-spousal dyads). *Instrumental role functions* are described by managing the family affairs through obtaining education, economic resources, making decisions and maintaining health (i.e., caregiver’s educational status, PWD decision-making involvement and PWD cognitive status). *Expressive role functions* include a sense of belonging, emotional support and feelings (i.e., dyadic relationship quality). In addition, the African American family should be considered as a social system embedded within other larger social systems of the *African American community*, a subsociety, consisting of resources and businesses (e.g., geographic region) and the *Wider society* described as health care, political and economic systems (i.e., formal care use of respite and adult day care) (Billingsley, 1968). The quality of the family structure and the extent to which needs are met based on the instrumental and expressive role functions can impact the outcomes of African American dementia dyads differently (i.e., QOL) (Billingsley, 1968). Thus, our research supports examining the African American dementia dyad as a unit to identify patterns of dyadic appraisal of decision-making involvement of African American PWDs to optimize QOL of both African American PWDs and their African American caregivers.

Pattern identification within and across dyads has been identified in PWDs (L. M. Miller et al., 2018) and persons diagnosed with heart failure (Lee et al., 2017; Lee, Vellone, et al., 2015). Identifying patterns of African American dementia dyads with different decision-making involvement can lead to the creation of tailored interventions to improve health outcomes and foster family-centered care. Given the importance of decision-making involvement of PWDs and the interdependent nature of African American families, understanding patterns at greater risk for worse QOL can highlight strategies to improve decision-making for care planning as well as begin to understand the (in)congruence within African American dementia dyads.

The purpose of this study was to: 1) identify and characterize patterns of dyadic appraisal regarding decision-making involvement (instrumental role function) by PWDs within African American dementia dyads, 2) examine whether the observed patterns are associated with other subsystems of the Negro Family as a Social System and 3) explore whether membership in the observed patterns is associated with the dyad’s QOL. We hypothesized at least two distinct patterns of appraisal of African American PWDs decision-making involvement would be identified at the level of decision-making involvement and/or the amount of (in)congruence. Second, we hypothesized that membership in an observed pattern of PWD decision-making involvement would be associated with other subsystems of the Negro Family as a Social System (family structure, expressive role functions, African American community and wider society). Third, we hypothesized that dyads in a pattern with greater African American PWD involvement and more congruent decision-making involvement would have better QOL. Through this analysis, we will elucidate the heterogeneity within and across African American dementia dyads and observed patterns based on a culturally sensitive conceptual framework to identify patterns at risk for worse QOL.

Design and Methods

A secondary data analysis of 62 African American dementia dyads was conducted using cross-sectional data from a prior study examining caregiving of 202 dementia dyads (71 African American dyads and 131 non-Hispanic White dyads) (Powers & Whitlatch, 2016). Dyads were recruited from Cleveland, OH and San Francisco, CA. Participants in Cleveland were recruited through the Eldercare Services Institute at the Benjamin Rose Institute on Aging and the former University Memory and Aging Center. Participants in San Francisco, CA were recruited through the Family Caregiver Alliance client lists. Dyads in the original study were eligible for participation if both members of the dyad: 1) lived in the community and not a residential facility, 2) caregivers were primarily responsible for caregiving for the PWD and 3) PWDs had a formal diagnosis of dementia or scored 13 to 26 on the Mini Mental State Examination (MMSE). More in-depth recruitment details are presented elsewhere (Feinberg & Whitlatch, 2001). In our current study, PWDs and their caregivers were required to be African American and have no missing data on the outcome measure and study variables. Informed consent was obtained by each member of the dyad in the original study. The study was approved by the Oregon Health & Science University's institutional review board.

Outcome Measures

Quality of Life. QOL of African American PWDs and their caregivers was measured using the Quality of Life-Alzheimer's Disease Scale (QOL-AD) developed for persons with mild-to-moderate dementia (R. G. Logsdon et al., 1999). The QOL-AD 13-item scale is scored using a four-point Likert scale. Both African American PWDs and African American caregivers rated their perception of their own QOL (G. Logsdon et al., 1999; Moon et al., 2017). A sample question is "How do you feel about your energy level? Do you think it is poor-excellent?" Responses are from 1 (Poor) to 4 (Excellent). Responses are summed resulting in a total score between 13-52, with higher scores indicating better QOL. The measure has demonstrated excellent inter-item reliability in a dementia dyad study (Bowling et al., 2015), including the current sample (PWD $\alpha = 0.82$; Caregiver $\alpha = 0.89$).

Decision-Making Involvement. Decision-making involvement of the African American PWD was measured using the Decision-Making Involvement Scale (DMI) developed for persons with mild-to-moderate dementia (Menne et al., 2008). The DMI is a 15-item scale, scored using a four-point Likert scale of 0 (Not Involved at all) to 3 (Very Involved). A sample item is "How involved are you in decisions about what to spend your money on?" (PWD version) or "How involved is your relative in decision about what to spend his/her money on?" (Caregiver version). Responses are averaged resulting in a mean score between 0-3, with higher scores indicating greater decision-making involvement. The measure had good inter-item reliability using Cronbach's alpha in another dementia dyad study (L. M. Miller, Lee, et al., 2017) and in the current sample (PWD $\alpha = 0.86$; Caregiver $\alpha = 0.94$).

Independent Variables

Demographic Characteristics. Demographic characteristics were examined by a survey created by the original investigators at baseline. The characteristics that were available across studies and fit within the conceptual framework are the following: age, sex, marital status, educational level, annual household income and formal diagnosis of dementia (yes/no).

Cognitive Impairment. Cognitive impairment of the African American PWD was measured using the MMSE. The MMSE is an 11-item questionnaire used to evaluate cognitive impairment spanning aspects of working memory, orientation, language, attention and delayed recall (Folstein et al., 1975). The total score ranges from 0-30, with a lower score signifying greater cognitive impairment. The scale demonstrated fair inter-item reliability in our sample ($\alpha = 0.54$).

Measures of Other Subsystems of the Negro Family as a Social System. These subsystems include family structure (type of caregiver), expressive role functions (dyadic relationship quality), the African American community (geographic region) and wider society (formal care use).

Family Structure. Family structure was examined based on the self-report at baseline of African American caregivers' types of caregiver. Caregivers were identified as spouses or non-spouses.

Expressive Role Functions. Expressive role functions were examined using the Dyadic Relationship Scale (DRS) (Sebern & Whitlatch, 2007). The DRS was used to measure both the strain and positive interaction of the dyadic relationship quality by both the African American PWD and African American caregiver. The DRS has two subscales—Dyadic Strain and Positive

Interaction. For the PWD, the Dyadic Strain subscale is a 4-item measure and a 5-item measure for the caregiver. An example item is: “Because of my memory problems, I felt depressed when I had problems with my relationship with my caregiver” (PWD version) or “Because of helping the PWD, I felt depressed because of my relationship with her/him” (Caregiver version). The responses are rated from 0 (Strongly Disagree) to 3 (Strongly Agree). Responses are averaged resulting in a mean score between 0-3, with higher scores indicating greater strain within the dyad. The subscale has demonstrated good inter-item reliability (Menne et al., 2009), including our sample (PWD, α = 0.70; Caregiver, α = 0.78).

The six-item positive interaction subscale of the DRS (Sebern & Whitlatch, 2007) was used to measure positive interaction of the dyadic relationship quality by both African American PWDs and African American caregivers. An example item is: “Because of my memory problems, I felt closer to him/her than I have in a while” (PWD version) or “Because of helping the PWD, I felt closer to her/him than I have in a while” (Caregiver version). The responses are rated from 0 (Strongly Disagree) to 3 (Strongly Agree). Responses are averaged resulting in a mean score between 0-3, with higher scores indicating greater positive interaction. The subscale has demonstrated good inter-item reliability (Menne et al., 2009), including our sample (PWD, α = 0.68; Caregiver, α = 0.84).

African American Community. The African American community was described by the geographic region in which both members of the dyad lived. Two geographic regions were identified in this study. Dyads either lived in Cleveland, OH or San Francisco, CA.

Wider Society. The wider society was examined with a survey of formal care use of the dyad designed by the researchers of the original study and administered during the baseline interviews with African American caregivers. The Formal Support: Preferences and Use is a 10-

item survey using a dichotomous “yes’ or “no” response. A sample item is “Are you currently using service providers to help your relative with…?” Two items were included in our analysis regarding formal care use of respite and adult day care.

Analytic Approach

Multilevel Modeling. Dyadic data were analyzed using multilevel modeling resulting in empirical Bayes estimates of incongruence and dyadic averages in the software program Hierarchical Linear Modeling (HLM), version 7 (Raudenbush, Bryk, & Congdon, 2011). Multilevel modeling (MLM) is a comprehensive approach used to identify incongruence and dyadic averages while controlling for measurement error and the interdependence within the dyad (Lyons et al., 2002). MLM has been used to analyze incongruence between the PWD and their caregiver in previous studies (Lyons et al., 2002; L. M. Miller, Whitlatch, et al., 2017; Reamy et al., 2011).

First, within-dyad variation will be modeled with the following unconditional Level 2 model equation: $Y_{ij} = \beta_{0j} + \beta_{1j}(\text{Dyad}_{ij}) + r_{ij}$. This unconditional Level 2 model will be used to estimate: 1) the incongruence (or gaps) between dyadic appraisals by African American PWDs and African American caregivers regarding the decision-making involvement of African American PWDs and 2) the dyadic average (or level) of African American PWDs’ decision-making involvement (β_{0j}). Second, using the scores from the DMI (β_{1j}), we coded the African American PWD as -0.5 and the African American caregiver as 0.5 in the dyad (Dyad_{ij}), plus measurement error (r_{ij}) (Lyons et al., 2002; L. M. Miller, Whitlatch, et al., 2017). The HLM program not only estimated both across dyads but also generated empirical Bayes estimates for each dyad. Lastly, the incongruence and dyadic averages of the DMI were used to identify potential patterns.

Latent Class Mixture Modeling. Distinct naturally occurring patterns were identified using latent class analysis, specifically, latent class mixture modeling in Mplus version 8 (Los Angeles, CA, USA). Latent class mixture modeling uncovers unidentified heterogeneity among dyads, resulting in classifications or patterns. Incongruence and dyadic averages of the African American dementia dyads were included in our analysis (Lee, Vellone, et al., 2015). Model convergence (entropy near 1.0), the size of observed classifications (5% or greater of the sample), posterior probabilities (average near 1.0), the parametric bootstrap likelihood ratio (PBLRT) and the Lo-Mendell-Rubin adjusted likelihood ratio test (Lo, Mendell, & Rubin, 2001) were used to examine the performance of other classifications (e.g. two latent classes vs. three) (Lee, Vellone, et al., 2015; Ram & Grimm, 2009).

Descriptive (mean, standard deviation and frequency) and comparative (analysis of variance [ANOVA] and χ^2) statistics were conducted using the software package StataIC, version 14 (Statacorp, 2017). We compared observed patterns using ANOVA, χ^2 and calculated effect size comparisons using eta-squared and Cramer’s V, respectively.

Results

African American PWDs in the study were on average 77 ± 8 years old, with the majority having received a dementia diagnosis from a provider (76%), an MMSE score of 21 ± 4 (reflecting mild dementia symptoms), widowed (48%) and were predominantly female (68%). Whereas, on average, African American caregivers were 61 ± 13 years old, were predominantly female (81%), married (60%), mostly non-spouse caregivers (69%) and half (50%) had annual household incomes of greater than or equal to $30,000. Refer to **Table 1** for additional sample characteristics.

Table 1

Overall Sample Characteristics and Measures (N= 62 Dyads)

	AA PWD	AA CG
Age in years, mean (± SD)	76.55 ± 7.84	60.50 ± 13.35
Female (%)	42 (68%)	50 (81%)
Marital status, married/partnered (%)	21 (34%)	37 (60%)
Geographic region, OH (%)	56 (90%)	56 (90%)
Greater than high school (%)	14 (23%)	35 (56%)
Dementia diagnosis, yes (%)	47 (76%)	-----
MMSE score, mean (± SD)	21.08 ± 3.94	-----
Household income, ≥ $30K/year (%)	-----	31 (50%)
Caregiver type, spouse/partner (%)	-----	19 (31%)
Dyadic Strain, mean (± SD)	0.84 ± 0.57	1.01 ± 0.47
Positive Interaction, mean (± SD)	2.14 ± 0.52	1.88 ± 0.54
Adult Day Care use (%)	25 (41%)	-----
Respite use (%)	30 (48%)	-----
Quality of life, mean (± SD)	34.34 ± 5.80	37.41 ± 6.34

Note: Annual household income divided by frequency of sample. AA= African American; PWD= person with dementia; CG= caregiver; SD= standard deviation; MMSE= Mini-Mental State Examination.

Dyadic Appraisal of Decision-Making Involvement

In this sample of African American dementia dyads, there was significant variability in the amount of incongruence ($\beta = -0.56$, $p < 0.001$) and the dyadic averages ($\beta = 1.95.$, $p < 0.001$) across African American dementia dyads regarding decision-making involvement of African American PWDs. On average, African American PWDs rated their decision-making involvement higher than their African American caregivers.

Patterns of Decision-Making Involvement of African American PWDs

Three distinct patterns of dyadic appraisal of decision-making involvement by African American PWDs were identified. The model convergence (entropy = 0.954), size of observed patterns (greater than 5% of sample), posterior probabilities (> 0.980), PBLRT (-135.683, $p < 0.001$) and Lo-Mendell-Rubin adjusted likelihood ratio test (16.95, $p = 0.031$) all represented good model fit. **Table 2** provides the differences in dyadic appraisal by patterns; **Figure 1** visually illustrates the differences.

Patterns were labeled based on dominant characteristics of dyadic appraisal. 19.4% of dyads were labeled as "*Incongruent, PWD Poorly Involved*" because African American PWDs and their African American caregivers reported significant incongruence and lower dyadic averages of decision-making by African American PWDs. 53.2% of dyads were labeled as "*Incongruent, PWD Moderately Involved*" because African American PWDs and their caregivers reported significant incongruence and midlevel dyadic averages. Lastly, 27.4% of dyads were labeled as "*Congruent, PWD Very Involved*" because of statistically non-significant incongruence and significantly higher dyadic averages. Unadjusted characteristics based on family structure, expressive role functions, the African American community and the wider society are provided by each observed pattern and presented in **Table 3**.

Pattern membership was significantly associated ($p < 0.05$) with the age of the African American PWD, the MMSE score of the African American PWD and marital status of both African American PWDs and their African American caregivers, not supporting our first hypothesis. Older African American PWDs were significantly more likely to be in the *Incongruent, PWD Poorly Involved* or *Incongruent, PWD Moderately Involved* patterns. African American PWDs and African American caregivers were significantly more likely to be married/partnered in the *Incongruent, PWD Moderately Involved* pattern. African American PWDs in the *Congruent, PWD Very Involved* were more likely to have higher MMSE scores. Additionally, there was a small effect size for the age of African American PWDs (eta-squared = 0.12), a moderate effect size for the MMSE score of African American PWDs (eta-squared = 0.24) and a large effect size for marital status of African American PWDs (eta squared = 0.29) and African American caregivers (eta squared = 0.37). There was a significant difference and a small effect size for the QOL (eta squared = 0.10) experienced by African American PWDs. African American PWDs in the *Incongruent, PWD Moderately Involved* pattern experienced significantly better QOL compared to the African American PWDs in the *Incongruent, PWD Poorly Involved* pattern. African American PWDs in the *Congruent, PWD Very Involved* pattern did not significantly differ from African American PWDs in either the *Incongruent, PWD Moderately Involved* pattern or the *Incongruent, PWD Poorly Involved* pattern. There was no significant difference experienced in QOL of African American caregivers by pattern membership, which did not support our second hypothesis.

Table 2

Differences of Patterns Appraisal of Decision-Making Involvement by the African American PWD

Decision-Making Involvement	*Incongruent, PWD* *Poorly Involved* (n=12)	*Incongruent, PWD* *Moderately Involved* (n=33)	*Congruent, PWD* *Very Involved* (n=17)	Effect size
Incongruence	-0.75 ± 0.31[a]	-0.77 ± 0.15[a]	-0.03 ± 0.10[b]	0.15**
Dyadic Average	0.98 ± 0.07[a]	1.87 ± 0.04[b]	2.81 ± 0.05[c]	0.90***

Note: Incongruence and average scores are empirical Bayes estimates from multilevel modeling which controls for the interdependent nature of the data and corrects measurement error. Negative incongruence scores signify AA PWDs rated their decision-making involvement higher than their caregivers. Positive incongruence scores signify AA PWDs rated their decision-making involvement lower than their caregivers. A score of 0 indicates congruence or no incongruence. Effect size = eta squared; PWD= person with dementia. [a,b,c]Pair t-test showed a statistically significant difference between in incongruence between *Incongruent, PWD Poorly Involved* and *Congruent, PWD Very Involved* patterns and *Incongruent, PWD Moderately Involved* and *Congruent, PWD Very Involved* patterns $^{**}p < 0.01$ $^{***}p < 0.001$

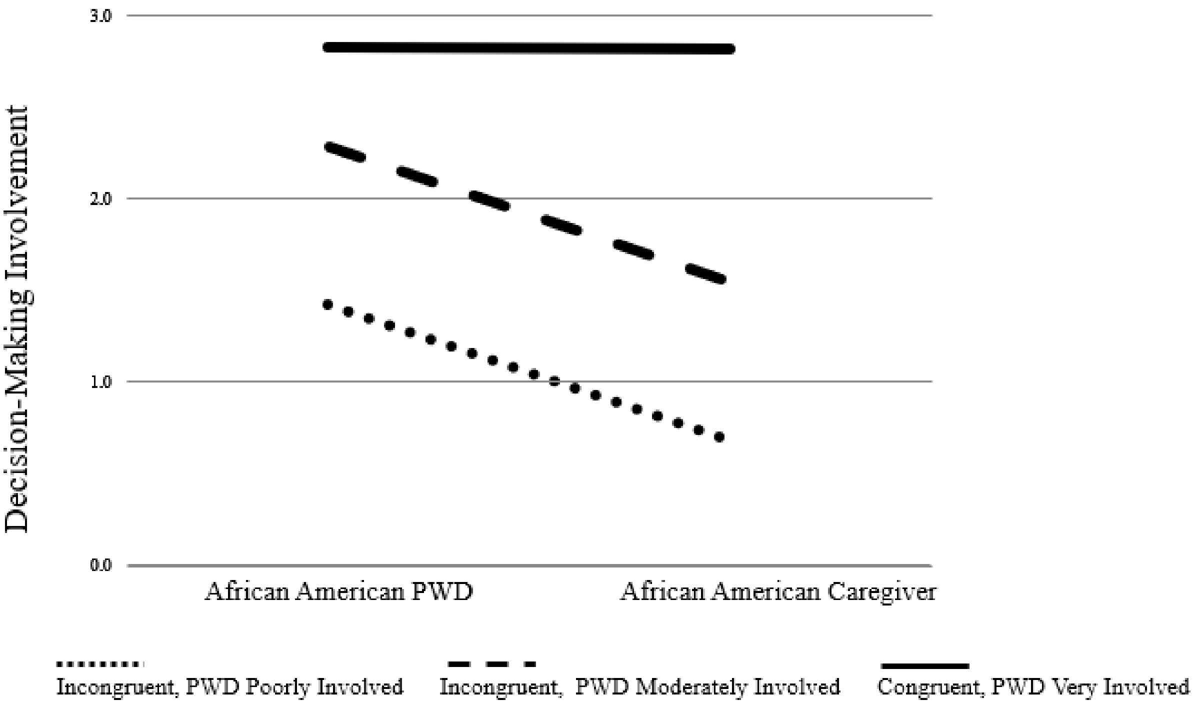

Figure 1. Distinct Patterns of Dyadic Appraisal of Decision-Making Involvement by the AA PWDs. The level illustrates the average decision-making involvement of African American PWDs by African American PWDs' and their African American caregivers' overall appraisal of decision-making involvement by African American PWDs. The incongruence or slope of each line illustrates the differences of the appraisals of decision-making involvement between both members of African American dementia dyads.

Table 3

Unadjusted Differences in Sample Characteristics Among Patterns (ANOVA, χ^2)

Characteristics (mean ± SD or %)	*Incongruent,* *PWD Poorly* *Involved* (n=12)	*Incongruent,* *PWD Moderately* *Involved* (n=33)	*Congruent,* *PWD Very* *Involved* (n=17)	Effect size
PWD age in years	78.75 ± 8.08[a]	77.85 ± 6.81[a]	71.93 ± 8.43[b]	0.12*
CG age in years	56.83 ± 8.72	62.79 ± 12.82	58.64 ± 16.57	0.04
PWD Female	9 (75%)	19 (58%)	14 (82%)	0.24
CG Female	11 (92%)	27 (82%)	12 (71%)	0.18
PWD Married/Partnered	1 (8%)	17 (52%)	3 (18%)	0.29*
CG Married/Partnered	3 (25%)	26 (79%)	8 (47%)	0.37**
Family Structure				
CG type, spouse[d]	1 (8%)	14 (42%)	4 (24%)	0.30
Instrumental Role Functions				
PWD Greater than HS	1 (8%)	9 (27%)	4 (24%)	0.16
CG Greater than HS	5 (42%)	21 (64%)	9 (53%)	0.17
PWD MMSE score	18.33 ± 3.21[a]	20.65 ± 3.74[a]	23.86 ± 3.16[b]	0.24***
Income[e], ≥ \$30K/year	4 (33%)	21 (64%)	6 (35%)	0.26
Expressive Role Functions				
PWD Dyadic Strain	0.92 ± 0.46	0.84 ± 0.65	0.79 ± 0.51	0.01
CG Dyadic Strain	1.15 ± 0.39	1.04 ± 0.55	0.87 ± 0.33	0.04
PWD Pos Interaction	2.06 ± 0.62	2.17 ± 0.56	2.15 ± 0.40	0.01
CG Pos Interaction	1.71 ± 0.38	1.95 ± 0.62	1.88 ± 0.49	0.03
AA Community				
Geographic location, OH	11 (92%)	28 (85%)	17 (100%)	0.22
Wider Society				

Adult day care use	7 (58%)	10 (30%)	8 (47%)	0.22
Respite use	7 (58%)	14 (42%)	9 (53%)	0.13
Outcome				
PWD QOL	31.25 ± 4.71[a]	35.94 ± 6.33[b]	33.41 ± 4.42	0.10[*]
CG QOL	35.33 ± 6.88	38.73 ± 6.17	36.25 ± 6.04	0.05

Note: [a,b,c]Post-hoc analysis (Paired t-test) showed that there was significant difference between patterns. [d]Spouse is the referent. [e]Household income. PWD= person with dementia; HS= high school; MMSE= Mini Mental State Examination; POS= positive; SD= standard deviation. Effect size= eta-squared and Cramer's V. **p* < 0.05, ***p* < 0.01, ****p* <0.001

Discussion

This study examined the dyadic appraisal of decision-making involvement of PWDs in 62 African American dementia dyads. To our knowledge, this is the first study that has identified patterns of decision-making involvement among African American dementia dyads and has examined the association between distinct patterns of decision-making involvement with other variables. There is important knowledge gained from this study. We identified three patterns of dyadic appraisal of decision-making involvement of African American PWDs. Over half of the sample was described as the *Incongruent, PWD Moderately Involved* pattern, which tended to have PWDs with lower MMSE scores and better QOL than PWDs in the *Incongruent, PWD Poorly Involved* pattern. In addition, both African American PWDs and their caregivers were more likely to be married in the *Incongruent, PWD Moderately Involved* pattern than the other patterns. About one third of the dyads were described as the *Congruent, PWD Very Involved* pattern with the youngest PWDs, lower MMSE scores who experienced QOL not significantly different from PWDs in the *Incongruent, PWD Moderately Involved* pattern or *Incongruent, PWD Poorly Involved* pattern. The least frequent pattern, *Incongruent, PWD Poorly Involved,* consisted of dyads, which were similar in age to the other incongruent group, with lower MMSE scores than PWDs in the *Congruent, PWD Very Involved* pattern who experienced worse QOL than PWDs in the *Incongruent, PWD Moderately Involved* pattern.

There are important clinical implications from the current study findings. Pattern membership was significantly associated with QOL of African American PWDs. African American PWDs in the *Incongruent, PWD Poorly Involved* pattern experienced worse QOL than PWDs in the *Incongruent, PWD Moderately Involved* pattern. African American PWDs in this pattern may be experiencing greater dementia symptoms compared to PWDs in the other patterns due to the lower MMSE scores. As a result, the involvement in decision-making is significantly lower than decision-making involvement across patterns. African American PWDs in this pattern will benefit from increased decision-making involvement as greater decision-making involvement has been linked with better QOL for PWDs (Menne et al., 2009). To facilitate the increase in everyday decision-making by African American PWDs, we recommend allowing African American PWDs to be involved with decisions that are of more importance to them. While the quantity of decision-making involvement may be reduced as a result of the dementia illness trajectory, decision-making should be focused on activities of enjoyment (Trigg, Watts, Jones, & Tod, 2011). For example, if an African American PWD was the primary homemaker for his/her family. Decisions around what to eat and foods to buy may be of greater importance. The goal of the intervention is to tailor decision-making involvement to the African American PWDs' specific needs to optimize their QOL.

Across patterns, African American PWDs in the *Incongruent, PWD Moderately Involved* pattern experienced better QOL and a significant amount of incongruence within the dyad. African American PWDs in the *Incongruent, PWD Moderately Involved* pattern have slightly higher MMSE scores but do not statistically differ from the MMSE scores of African American

PWDs in the *Incongruent, PWD Poorly Involved* pattern. An intervention to improve their decision-making involvement is not warranted, and it is unclear whether an intervention to decrease the incongruence is needed. Research supports the notion that members of dyads should be on the same page (less incongruence) to facilitate working as a team to meet the needs of both members of the dyad to improve their well-being (Lyons & Lee, 2018; Merz et al., 2011; Orsulic-Jeras, Whitlatch, Szabo, Shelton, & Johnson, 2016). Yet, L. M. Miller et al. (2018) found in dyadic patterns of the importance of care values of PWDs some level of incongruence was present in dyads and may not be feasible to completely eliminate. Based on the QOL experienced by African American PWDs in the *Incongruent, PWD Moderately Involved* pattern, we are inclined to agree that some level of incongruence may be expected, given the uncertainty in the dementia disease trajectory. In addition, African American PWDs were more likely to be married in this pattern, which may have positively influenced the QOL of African American PWDs (Bonds, 2019). Future research with larger samples of African American dementia dyads are needed to better understand the role of incongruence in these dyads.

Lastly, African American PWDs in the *Congruent, PWD Very Involved* pattern did not experienced statistically different QOL from African American PWDs in either of the previous patterns described. Dyads in this pattern have similar appraisals of the involvement of African American PWDs and, on average, these PWDs are very involved in everyday decisions. Improving decision-making involvement of African American PWDs as a clinical intervention for QOL is not warranted. The identification of patterns revealed that the use of decision-making involvement to optimize QOL for all African American PWDs is not an effective intervention for all three patterns.

Dementia research has begun to acknowledge the importance of heterogeneity when examining health outcomes among different ethnic/racial groups (Chin et al., 2011). But, one area of heterogeneity that has been examined less is the variability within a particular ethnic/racial group. The identification of three patterns based on African American PWDs' decision-making involvement highlights this heterogeneity, even in this sample of 62 dyads. Understanding the heterogeneity within and across African American dementia dyads, may hold promise in clinical and research settings to determine ways to intervene. Our analysis suggests that providers should begin to consider heterogeneity when engaging with African American dementia dyads and incorporate this concept into their counseling regarding decision-making when applicable. Similarly, for gerontologists and other investigators, the same study design or intervention may not be effective for all samples of African American PWDs and their African American caregivers. There is a need to begin to understand the heterogeneity within dyads, which is suggested with the direction of precision medicine with tailored interventions.

The identification of patterns and associated variables were based on the tenants of the Negro Family as a Social System. Using this conceptual framework to guide the analysis created the opportunity to look at variables that are culturally sensitive to African American families. This approach fosters analysis that considers the ability of dyads to meet their needs as well as the demands placed on the dyads from outside influences (Hill, 2003). As a result, the heterogeneity in the instrumental role function of decision-making involvement was elucidated. This variable may have been missed in another conceptual framework. Although not significant in this sample, there are a few other variables based on the Negro Family as a Social System that may be of importance in a larger sample—family structure or type of caregiver, expressive role functions or caregiver dyadic strain, *Negro community* or geographic region and the *Wider society* or formal use of adult day care. The use of culturally sensitive conceptual frameworks and theories like the Negro Family as a Social System are necessary when examining underrepresented populations to determine the variables to include in analysis.

Our findings highlight some variables that were not significantly different between the three patterns. First, African American caregivers did not experience significantly different QOL across patterns. Moon et al. (2017) found incongruence in decision-making involvement was not significantly associated with QOL in PWDs or caregivers. While our findings for African American caregivers are similar, the findings are divergent for African American PWDs. Lindauer et al. (2016) found African American caregivers worked to keep African American PWDs present in activities. This present focus by African American caregivers could be an attempt at keeping African American PWDs involved in everyday decision-making. As a result, when African American caregivers are unable to uphold the decision-making involvement of African American PWDs' QOL is negatively affected.

African American caregivers' dyadic relationship quality was not associated with pattern membership or their QOL. L. M. Miller et al. (2018) found caregivers reported dyadic strain was significantly associated with pattern membership. In addition, caregivers who experienced greater dyadic strain perceived less decision-making involvement by PWDs (Menne & Whitlatch, 2007; L. M. Miller, Lee, et al., 2017). Our contrary finding may be two-fold. First, African American dyads may be more protected from disagreements within the dyad. Epps (2014) found African American caregivers positively viewed the caregiving experience to a greater extent than non-Hispanic White caregivers, which is related to strong beliefs of family obligation. This finding is similar to previous research (Dilworth-Anderson et al., 2002; Powers & Whitlatch, 2016). Second, the phrase "dyadic strain" may not resonate with African American caregivers. Epps, Rose, and Lopez (2019) found familism, a strong sense of obligation to family, may describe the duality of African American caregivers' positive and negative perceptions of caregiving. We speculate that given this familism, African American caregivers may have difficulty answering measures negatively regarding caregiving. Future work should focus on teasing out these positive and negative perceptions.

Limitations

There are a few limitations. First, the sample size is relatively small since we were identifying latent classes or patterns. Identification of more specific characteristics of each pattern would be better suited for larger samples of African American dementia dyads. Second, the association between the three patterns and the independent variables may be attenuated. The latent classes are not known classes, yet, it is assumed in the analysis. Third, the study used a cross-sectional design limiting our ability to see if pattern membership changes over time. Larger, longitudinal studies are warranted to improve our analysis with this line of inquiry.

Strengths

There are several strengths noted in this study. This study is the first to examine the dyadic appraisal of decision-making involvement in entirely African American dementia dyads. The analysis is novel by identifying patterns of dyadic appraisal of decision-making involvement of African American PWDs and associating the patterns with QOL. Our study elucidates clinical implications and the importance of tailoring interventions to meet the needs of each member of African American dementia dyads. Thus, our findings *suggest the need for more than just one approach in assessing and treating African American dementia dyads*. As a result, decision-making involvement can be tailored to the dyads in each pattern. In addition, the inclusion of both perspectives of African American PWDs and their African American caregivers was another strength. Caregiving is at least a dyadic process (Lyons et al., 2002), if not a family process within the African American population (Epps et al., 2019), in which including at least two perspectives is necessary.

Decision-making within African American families tends to be a shared experience. Although, our study only highlights the significance of decision-making involvement by African American PWDs. Future research should focus on the shared decision-making involvement, including both African American PWDs and their African American caregivers. In addition, future work is needed to tease out the potential differences in everyday decision-making involvement in African American dementia dyads compared to decision-making involvement that directly influences formal care, specifically focused on the formal caregiver and provider relationships. By understanding how and with which decisions (e.g., everyday and/or formal) members of African American dementia dyads are involved, we can tailor interventions to meet their needs. Interventions may include increasing the everyday decision-making of African American PWDs as we have seen here, decreasing the level of incongruence within the dyad regarding decision-making, or determining how decisions are made within dyads to model that in clinical and research settings. Decision-making involvement is modifiable and may provide a way to intervene to improve health outcomes and treatment options for both members of African American dementia dyads.

CHAPTER V

Discussion, Summary and Implications

The overall aim of my Dissertation was to examine the heterogeneity of the caregiving process—specifically decision-making involvement and formal care use—of African American dementia dyads and how this process influences their quality of life (QOL) from a culturally sensitive approach. The overall aim was addressed by: 1) understanding formal care use by African American dementia dyads, 2) assessing the associations of variable factors within the family with QOL of both members of the dyad and 3) examining the associations between decision-making, formal care use and QOL of African American dementia dyads. Three manuscripts were included in this Dissertation, which each focused on one of these Dissertation aims. The manuscripts consist of one literature review (**Chapter 2** [**Aim 1**]) and two data-based manuscripts (**Chapter 3** and **4** [**Aims 2-6**]). Various methodological approaches and statistical analyses were used in these manuscripts.

Overview of Findings

Taken together, these three manuscripts promote the scholarly consideration regarding heterogeneity in African American dementia dyads related to formal care use, decision-making involvement and QOL (see **Table 1**), with specific focus on the decision-making involvement of African American persons with dementia (PWD). The findings are supported by a culturally sensitive conceptual framework, the Negro Family as a Social System (described in **Chapter 1**). This framework includes different networks or social systems—the *Negro family*, *Negro community* and *Wider society*. This chapter will provide a synthesis of the main findings, theoretical, practical and research implications and strengths and limitations of this work.

Table 1

Chapter Aims and Findings

	Aims	Findings
Formal Care Use	Aim 1: Identify the state of what is known regarding African American PWDs and their caregivers and formal care use to guide future research and interventions.	1. Of published studies, three themes emerged: *Formal Care Need, Expectations of Formal Care Providers,* and *Formal Care Use.* 2. African American caregivers report a need for more formal care in their geographic region, especially regarding nursing care, physical therapy, case management and receiving a comprehensive examination for African American PWDs. 3. African American caregivers expected formal care providers, specifically, physicians to be the point of contact for diagnosing dementia and with assisting the caregivers in making care decisions. Other health care professionals were expected to facilitate connections with physicians and formal care. 4. African American caregivers desired formal care use. Facilitators of formal care included the following: African American caregivers having family involvement in decision-making, being female caregivers, being older caregivers, caregivers with full-time employment, African American PWDs living alone with Medicaid coverage and both increased and decreased impairment in ADLs by the African American PWD. Barriers to using formal care by African American caregivers was reporting greater confidence in their caregiving role and experiencing a lack of cultural understanding in formal care use.
Quality of Life	Aim 2: Describe the correlation between QOL of African American PWDs and their African American caregivers. Aim 3: Describe the association between African American dementia dyads and QOL regarding family structure, instrumental and expressive role functions.	1. African American PWDs reported significantly worse QOL than African American caregivers. QOL within dyads covaried among African American caregivers and African American PWDs. There was significant heterogeneity regarding QOL across dyads. 2. African American PWDs had significantly worse QOL when they reported less decision-making involvement and had caregivers who were non-spouses. African American caregivers had significantly worse QOL when they reported greater dyadic strain in the relationship and were non-spouses.

Decision-Making Involvement	Aim 4: Identify and characterize patterns of dyadic appraisal regarding decision-making involvement (instrumental role function proxy) by the PWD in African American dementia dyads. Aim 5: Examine the association of the observed patterns with other subsystems of the Negro Family as a Social System. Aim 6: Examine the association of the observed patterns with the dyad's QOL.	1. Three distinct patterns of decision-making involvement of African American PWDs were identified: *Incongruent, PWD Poorly Involved; Incongruent, PWD Moderately Involved* and *Congruent, PWD Very Involved.* 2. African American PWDs in the *Incongruent, PWD Poorly Involved* pattern reported the significantly worse QOL than African American PWDs in the *Incongruent, PWD Moderately Involved* pattern. African American PWDs in the *Congruent, PWD Very Involved* pattern experienced no significant difference in QOL compared to the African American PWDs in the *Incongruent, PWD Poorly Involved* pattern or the *Incongruent, PWD Moderately Involved* pattern. 3. African American PWDs in the *Congruent, PWD Very Involved* pattern were significantly younger with significantly higher MMSE scores than African American PWDs in the two other patterns. The subsystem of instrumental role functions (i.e., decision-making involvement and MMSE scores of PWDs) of the Negro Family as a Social System was significantly associated with the observed pattern but no other subsystem.

Discussion

To optimize QOL of African American dementia dyads, this Dissertation takes into consideration African American culture from previous literature and includes culturally relevant variables in the analysis. Given the increased risk of developing Alzheimer's disease and related dementias, African American dementia dyads need research focused on understanding their caregiving process and working to ensure their well-being during the dementia illness trajectory. This Dissertation identified two main areas of focus—decision-making involvement and contextual characteristics.

Decision-Making Involvement. Decision-making involvement is a central focus of this Dissertation. In this Dissertation, we operationalized decision-making involvement as everyday decisions, such as what time to get up or what clothes to wear or as formal care decisions, which include decisions about health care (L. M. Miller et al., 2016). The findings in this Dissertation build on previous research regarding the importance of decision-making within African American families (Kane, 2000). In our literature review (**Chapter 2**), decision-making involvement within the family was a vital facilitator to using formal care for African American caregivers. Similar to our findings, African American caregivers of African American older adults who reported greater family support were associated with greater use of formal care for either African American PWDs or their caregivers (S. W. Williams & Dilworth-Anderson, 2002). Ward and Ashaye (2008) found formal care use was associated with better QOL for PWDs. We included decision-making involvement of African American PWDs as a predictor in **Chapter 3** to identify other factors associated with QOL of both members of African American dementia dyads. Given the interdependent nature of the caregiving process within each specific dyad, there was a need to examine QOL considering both members of the dyad. Multilevel modeling was used to control for the interdependent nature of the data. The approach elucidated similar findings as well as findings that have not been identified within prior samples of African American dementia dyads. Decision-making involvement of African American PWDs was examined because of the important role most African American older adults have within African American culture. In **Chapter 4**, everyday decision-making involvement was not a predictor but an outcome variable, which we used to identify heterogeneity within and across the sample of 62 African American dementia dyads. In this chapter, we examined the appraisal of decision-making involvement of African American PWDs from the perspectives of both members of the dyad. This approach allowed for the examination of (in)congruence within the dyads. Three distinct patterns of decision-making involvement of African American PWDs were identified using latent class mixture modeling.

The majority of the dyads was labeled as the *Incongruent, PWD Moderately Involved* pattern. The second largest was labeled as the *Congruent, PWD Very Involved* pattern. With the smallest labeled as the *Incongruent, PWD Poorly Involved* pattern. These patterns were identified based on two metrics: 1) gaps of in(congruence) between the reports of African American PWDs and their African American caregivers and 2) dyadic averages of the level of decision-making involvement of African American PWDs. The identification of three distinct patterns indicates the heterogeneity within this small sample of African American dementia dyads. Thus, findings suggest we cannot assume that every African American PWD within African American dementia dyads has similar decision-making involvement in their caregiving process.

The appraisal of decision-making involvement of African American PWDs has a role in determining the use of formal care and was significantly associated with their QOL of African American PWDs. Yet, the appraisal of decision-making involvement regarding QOL seems to be more important for PWDs in certain African American dementia dyads. Findings from **Chapter 4** highlight the association between three patterns of dyadic appraisal of decision-making involvement of PWDs in African American dementia dyads and their QOL. These findings suggest the importance of pattern membership with the association of QOL of African American PWDs. African American PWDs in the *Incongruent, PWD Moderately Involved* pattern showed significantly better QOL than African American PWDs in the *Incongruent, PWD Poorly Involved* pattern. Similarly, greater decision-making involvement of PWDs was associated with better QOL of the PWDs (Menne et al., 2009), supporting that everyday decision-making involvement is important for QOL of African American PWDs. African American PWDs in the

Congruent, PWD Very Involved pattern were significantly younger with higher MMSE scores than the two other patterns. Yet, African American PWDs in the *Congruent, PWD Very Involved* pattern had no significant difference in their QOL compared to African American PWDs in the *Incongruent, PWD Poorly Involved* pattern or *Incongruent, PWD Moderately Involved* pattern. Dyadic research supports the notion that less incongruence is better for caregiving (Lyons & Lee, 2018; Orsulic-Jeras et al., 2016). Interestingly, our finding was contrary to these previous studies because we found greater decision-making involvement and less incongruence in this pattern was not associated with better QOL for African American PWDs. One explanation of this discrepancy might be regarding how examining decision-making involvement by both members of the dyad may result in two very distinct modes of decision-making. Trigg et al. (2011) suggested the discrepancy between QOL rating of PWDs and caregivers was based on two modes of QOL assessment based on *feeling* and *observation* by PWDs and caregivers, respectively. We speculate African American PWDs rated their decision-making involvement based on how involved they *feel* in making decisions. Whereas, African American caregivers rated the decision-making involvement of African American PWDs by their *observation*. Understanding modes of decision-making may result in interventions that focus on both modes of decision-making involvement—*feeling* and *observation.* To address this mismatch of QOL assessments, future research is warranted to qualitatively assess how each member's views the domains of decision-making involvement and explore underlying mechanisms of difference in their reports.

Contextual Characteristics. While decision-making involvement was more focused on the African American PWDs, there were important contextual characteristics identified in this Dissertation. Findings from the literature review (**Chapter 2**) identified characteristics of African

American caregivers that were either facilitators or barriers to using formal care. Research has suggested African American caregivers are less likely to use formal care (Alzheimer's Association, 2016; Cooper et al., 2010). Yet, our literature review findings highlight African American caregivers report a need for formal care and one facilitator of formal care use was self-identifying as a female. This characteristic is of interests because the majority of our sample of caregivers in the data-based manuscripts are female (81%). Future research should focus on the formal care needs of African American female caregivers who seem interested in using formal care to assist with their care of African American PWDs. Thus, studies that focus on the formal care needs of African American female caregivers are needed.

The type of caregiver (i.e., spouse vs. non-spouse) was also associated with QOL. Whereas, non-spouse caregivers (predominantly daughters/daughters-in-law) experienced worse QOL for themselves and their African American PWDs. African American caregivers who reported greater dyadic strain experienced worse QOL. Contrary to our findings, caregivers who reported worse dyadic strain were associated with worse QOL for PWDs (L. M. Miller et al., 2019). Whereas in this Dissertation, factors associated with QOL for African American PWDs and caregivers did not influence the QOL of the other member of the dyad. Dyadic strain reported by African American caregivers influenced their own QOL and decision-making involvement was associated with their own QOL (**Chapter 3**)**.** These findings highlight the two role functions described in the Negro Family as a Social System conceptual framework. The instrumental role function of decision-making involvement and the expressive role function of dyadic strain. While it was beyond the findings of this Dissertation to completely understand the association between instrumental and expressive role functions, it is worth further investigation in larger studies as we try to better understand the roles of these two functions on QOL in African American dyads utilizing the conceptual framework.

Theoretical Implications. The findings of this Dissertation align with the tenant of the Negro Family as a Social System. The tenant supports examining QOL while considering the *Negro family* or dyad, the *Negro community* and *Wider society*. Findings from **Chapter 3** highlight the importance of the concepts of the African American family—family structure, instrumental and expressive role functions—when examining QOL. In **Chapter 4**, predictors from the *Negro community* were analyzed in the unadjusted model. We considered the geographic region of the dyads (i.e., Cleveland, OH or San Francisco Bay Area, CA), although not significantly associated with QOL in the unadjusted model in **Chapter 4**. The African American community may warrant further examination of geographic, regional and/or neighborhood difference in larger samples, especially when considering formal care access. The wider society was examined in both **Chapters 2** and **4**. The literature review suggests the desire of African American caregivers to have their formal care needs met by formal care providers, who African American caregivers feel are integral in assisting African American PWDs with obtaining a dementia diagnosis and assisting with making other formal care decisions. In **Chapter 4**, variables describing formal care use were entered in unadjusted models associated with QOL. The wider society variable of formal care use of adult day care might be of interest in a larger study, though not significant in our findings.

In considering the tenant of the Negro Family as a Social System, this Dissertation analyzed African American dementia dyads using a culturally sensitive theoretical framework, which is often missing when examining underrepresented minority samples (Dilworth-Anderson et al., 2002). Findings in **Chapter 2** highlight an interesting finding that despite previous research regarding a lack of formal care use, African American caregivers reported formal care needs. The formal care needs and expectations of formal care provides can create a hinderance to formal care use of African American dementia dyads. African American caregivers wanted their physician and provider to make the dementia diagnosis and connect them to formal care. Yet, the referral process for diagnosing dementia and the limited time during visits with physicians and providers may negatively influence this expectation. Thus, we have two recommendations. First, allocating time to identify the formal care needs of African American dementia dyads during their scheduled visits would be important. Second, physicians and providers should provide adequate information regarding the disease, progression and management (e.g., referrals) to ensure African American caregivers' expectations are met. The remaining studies in this Dissertation (**Chapters 3 and 4**) started to elucidate the unique characteristics and cultural relevance of decision-making involvement of PWDs within African American dementia dyads compared to predominantly non-Hispanic White dementia dyads to improve the gap in our understanding of the dementia caregiving process. As a result, findings in **Chapters 3** and **4** were contrary to previous findings in other data-based studies of dementia dyads. For example, in **Chapter 3**, the type of caregiver of African American dementia dyads was significantly associated with QOL of both African American PWDs and their African American caregivers. Whereas, non-spouse (predominantly daughters/daughters-in-law) were associated with worse QOL for both members of the dyad. In **Chapter 4**, African American PWDs in the *Incongruent, PWD Moderately Involved* pattern—not the pattern with the most congruence and decision-making involvement—were associated with better QOL. These findings reinforce the importance of examining African American dementia dyads to determine the unique characteristics and nuances compared to non-Hispanic White dementia dyads to understand the dementia caregiving process of African American dementia dyads.

Using this conceptual framework, we examined variables with cultural importance and highlighted the use of the Negro Family as a Social System, which can guide future work in African American dementia dyads, especially related to health outcomes. Based on this conceptual framework, health of African American dementia dyads in this Dissertation cannot be examined without taking into consideration the social systems in which the dyads interact. This conceptual framework focuses on the family, the community and the health care system. Thus, health outcomes (such as QOL) are examined by beginning to understand how each of these interdependent social systems contribute to the well-being of African American dementia dyads. This Dissertation examined QOL while focusing on these three social systems. One limitation of this conceptual framework is related to the health outcomes that can be examined. While there are several health outcomes that may be influenced by these social systems, one could argue that not all health outcomes will fit in this conceptual framework.

Practical Implications. Based on the findings from **Chapter 2**, main themes were identified. Nurse practitioners and other providers should have more of a responsibility to assess formal care needs and convey the availability of formal care resources to African American dementia dyads. The health care system is not set up for lengthy visits with providers. Thus, nurses (through various conversations that occur during formal care visits) play a pivotal role in listening to the concerns of African American dementia dyads to facilitate improving their formal care use through meeting their formal care needs.

Chapter 3 identifies the importance of three factors that are associated with worse QOL for either the African American PWD or their African American caregiver. First, nurses and nurse practitioners should focus on assessing decision-making involvement by PWDs in African American dementia dyads. Since dementia is a degenerative disease, decision-making involvement by African American PWDs in the earlier stages of the disease trajectory may be more important and provide a sense of autonomy despite the uncertainty experienced during the caregiving process. Second, nurse practitioners and other providers should assess the dyadic strain potentially experienced by African American caregivers. It is unclear if the dyadic strain is completely related to the caregiving process or if the strain reported was within the dyad prior to the dementia diagnosis. What is apparent is the need for providers to assess for dyadic strain, which negatively influences QOL of these African American caregivers. Third, while caregivers cannot change whether they are a spouse or non-spouse caregiver, nurse practitioners and nurses should be aware of the increased risk for non-spouse caregivers and their African American PWDs to experience worse QOL. There should be special attention provided to this subgroup of dyads to inquire about their caregiving process to identify other modifiable ways to intervene.

Chapter 4 identified three patterns of dyadic appraisal of decision-making involvement of African American PWDs. Pattern membership was associated with QOL. Two clinical implications were identified for nurses and nurse practitioners. First, nurse practitioners and nurses should pay attention to the heterogeneity within and across African American dementia dyads related to the PWD's decision-making involvement. This assessment will provide insight into whether a decision-making intervention is warranted as only one pattern—*Incongruent, PWD Poorly Involved* pattern—in our study would benefit from such an intervention. Second, pattern membership for African American PWDs was significantly associated with QOL in two of the three patterns. While assessing the decision-making involvement of African American PWDs, providers should assess the QOL of both members of African American dementia dyads.

The overall Dissertation findings elucidate one salient theme—interpersonal factors. In examining African American dementia dyads, the significance of interpersonal factors is revealed. For example, appraisal of PWDs' decision-making involvement, dyadic strain, type of caregiver and incongruence each highlight the importance of the relationship between African American PWDs and their African American caregivers. The perception of decision-making involvement relies on the accounts of both members of the dyad. The reports of either the caregiver or PWD can be influenced by how the individual is feeling during the caregiving process or by how much dyadic strain is reported, which can influence the perceptions of incongruence (L. M. Miller et al., 2019). The type of caregiver is related more to the relationship between the members of African American dementia dyads. The dynamics—either good or bad—of these relationships can be from before the diagnosis of dementia or after and contribute to the well-being of the dyad.

In order to address the importance of these interpersonal factors and provide optimal care, nurse practitioners and other health care providers may assess when/where greater decision-making involvement can occur from both members of the dyad. For example, which decisions are most important to African American PWDs and which decisions are African American caregivers willing to allow more involvement from African American PWDs? To address dyadic strain reported by African American caregivers, nurse practitioners, nurses and other providers may assess the amount and intensity of caregiving tasks performed by African American caregivers and determine if some of these tasks can be provided by other sources (e.g., formal care use). Further, if appropriate, nurse practitioners and other health care providers could utilize a dyadic counseling intervention to assist with care planning needs of PWDs (Orsulic-Jeras et al., 2016) or suggesting the use of adult day services for African American PWDs (Parker, Gaugler, Samus, & Gitlin, 2019), which allowed socialization for African American PWDs with older adults as well as respite for African American caregivers for self-care (Parker et al., 2019).

Research Implications. The overall goal of this Dissertation was to begin to understand how to improve QOL of African American dementia dyads through appraisal of African American PWDs' decision-making involvement and formal care use guided by a culturally sensitive theoretical framework. Based on the findings in this Dissertation, future research will focus on four lines of inquiry: 1) formal care use and QOL, 2) shared decision-making involvement in everyday decisions, 3) the networks of the Negro Family as a Social System and 4) African American daughter caregivers of African American PWDs. First, we will focus on assessing formal care use of African American dementia dyads and their QOL through qualitative analysis. Through dyadic interviews, findings will explore decision-making involvement of formal care use by African American dementia dyads and describe how formal care use influences QOL. The goal is to create a tool that can be used within formal care settings (e.g., pre-visit) to identify caregivers and their formal care needs to improve their QOL. Second, further research is needed to assess the appraisal of decision-making involvement of African American caregivers more extensively. This Dissertation focused on the appraisal of African American PWDs decision-making involvement from both members of the dyad. The appraisal only provides half the information regarding decision-making involvement of African American dementia dyads. The goal of this line of inquiry is to understand if decision-making involvement of African American caregivers has a similar significant role within African American dementia dyads as decision-making involvement of African American PWDs. Third, due to our small sample size all the networks of the Negro Family as a Social System were not examined in this Dissertation. To better understand how these concepts influence QOL, we will examine all networks of the Negro Family as a Social System with larger samples of African American dementia dyads. While we found significant implications with the instrumental role functions and caregiver type (**Chapter 3** and **4**), we do not know how the other subsystems will collectively influence QOL. Lastly, our finding regarding non-spouse African American caregivers was surprising. A greater understanding of African American culture in the context of dementia caregiving is needed, especially with a focus on dyadic strain in African American non-spouse caregivers (predominantly daughters/daughters-in-law caregivers) of African American PWDs. Previous research has supported the notion that, on average, African American caregivers report lower levels of strain (Dilworth-Anderson et al., 2002). Given our findings, we want to focus on African American daughter caregivers who may not be doing as well with caregiving as previously thought. Understanding the origin of the dyadic strain (e.g., dyadic relationship, caregiving associated with dementia), may elucidate strategies for intervention.

Strengths and Limitations. In this section, we focus on strengths and limitations across all three manuscripts. First, the manuscripts in this Dissertation are the first to examine formal care, QOL and pattern membership in an entirely African American sample of PWDs and African American caregivers. As a result, the manuscripts highlight the variability within and across African American PWDs and their African American caregivers, suggesting the need for future research that focuses specifically on underrepresented minority samples. Second, the two data-based manuscripts explicitly studied African American dementia dyads. Using a dyadic approach in these manuscripts elucidated new insights and findings specific to African American dementia dyads. Lastly, the use of a culturally sensitive theoretical framework to guide the manuscripts in this Dissertation added cultural sensitivity to the variables included in each manuscript.

Despite these strengths, there were several limitations. First, we had relatively small sample sizes in each manuscript. Both **Chapters 3** and **4** consisted of 62 dementia dyads. Second, the data-based manuscripts (**Chapters 3** and **4**) were secondary data analyses, which in combination with the small sample sizes limited the ability to test all of variable in the Negro Family as a Social System. Third, there is limited generalizability since data (used in **Chapters 3** and **4**) were collected in Cleveland, OH and San Francisco Bay Area, CA.

In sum, the manuscripts in this Dissertation suggest another strategy to analyze QOL in African American dementia dyads. We should consider the broader social context, in which African American dementia dyads are embedded. This social context should include the unique characteristics of the African American dementia dyad, the community and resources (or lack thereof) that surround the African American dementia dyad and the wider society of formal care, based on the Negro Family as a Social System. African American dementia dyads are not monolithic but have heterogeneity that should be better understood to facilitate the tailoring of interventions to improve QOL of both members of African American dementia dyads.

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