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# A Systematic Literature Review of Effective Interventions For African-American and Hispanic Alzheimer's Caregivers

by

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M.S.W. Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, MN
In partial fulfillment of the requirements for the degree of

Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publically present the findings of the study. This project is neither a Master's thesis nor a dissertation.

#### Abstract

In this systematic review, an investigation of research on effective social work interventions for African-American and Hispanic caregivers of loved ones with Alzheimer's disease (AD) was conducted. Through a comprehensive literature search, twelve articles met the set inclusion criteria. Peer-reviewed journal articles on quantitative or qualitative research studies on African-American and Hispanic AD caregivers served as the data source. The review found three categories of interventions: in-home programs, Cognitive Behavior Therapy (CBT) focused small groups, and support groups. The majority of the studies included a demonstrated effort to culturally tailor each intervention. The results of the review demonstrate an overall improvement in depression, diminished sense of burden, and other measures of healthy caregiver coping. The majority of the interventions demonstrated little difference between racial or ethnic groups, indicating that cultural tailoring is advantageous to creating effective AD caregiver interventions. Based on the findings, further research is needed to explore CBT's efficacy for African-American caregivers and to assess interventions that address caregiver anxiety. Furthermore, this project indicates the ongoing need for social work practitioners to act with cultural sensitivity, curiosity, and responsiveness as a means for effective cross-cultural interventions.

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# A Systematic Literature Review of Effective Interventions For African-American and Hispanic Alzheimer's Caregivers

Alzheimer's disease (AD) and other forms of dementia have created overwhelming economic, emotional, and familial burdens. As a larger segment of the population ages so does the number of individuals and families who are impacted by Alzheimer's. Degenerative cognitive loss is not considered an inherent part of growing older, yet the risk of developing AD and other forms of dementia increases with age (National Institute on Aging, 2013a; World Health Organization, 2012). Between 60-80% of individuals dealing with cognitive loss receive a diagnosis of Alzheimer's disease (Alzheimer's Association, 2014a). The corresponding 20-40% are diagnosed with vascular dementia, dementia with Lewy bodies, frontotemporal lobar degeneration, Parkinson's disease dementia, Creutzfeldt-Jakob disease, normal pressure hydrocephalus, or mixed dementia (Alzheimer's Association, 2014a; National Institute of Neurological Disorders and Stroke, 2014). Even though the various forms of dementia have distinct symptoms, they share a spectrum of similar behavioral changes and cognitive decline with AD.

## Caregiving

The act of caregiving for a loved one with Alzheimer's, no matter the race or ethnicity of the caregiver, impacts the lives of the individuals providing care in a variety of ways. The evaluation of formal economic costs for AD, which include institutionalized care, Medicare, and calculable out-of-pocket expenditures, was estimated at \$109 billion in 2010 (National Institute on Aging, 2013b). However, when factoring in unpaid caregiving, this estimate nearly doubles to over \$215 billion in 2010 and to \$220.3 billion in 2013 (Alzheimer's Association, 2014a; National Institute on Aging, 2013b). These

dollar amounts suggest a sense of the impact that AD has upon the loved ones whom contribute to the care of an AD-affected individual. They also put a monetary value on the amount of time, energy, and sacrifice that caregivers contribute on behalf of their spouse or partner, parent or friend with cognitive loss. Caregivers are a critical element of this growing public health issue. In 2013, 15.5 million people gave 17.7 billion hours of unpaid care (Alzheimer's Association, 2014b).

**Aspects of caregiving.** Providing care for an AD-affected individual includes a variety of instrumental activities of daily living (IADL) such as household chores, meal preparation, overseeing finances, and making medical appointments. Activities of daily living (ADL), another facet of caregiving, consist of various basic personal needs of selfcare such as toileting, getting dressed, bathing, transferring from chair to bed, and feeding. Providing care for an individual with Alzheimer's involves meeting a multitude of needs as the cognitive degeneration progresses. In the early stages of the disease, caregiving involves assisting with creating directive lists and instructions for daily tasks that alleviate the need for abstract thought (Richardson & Barusch, 2006). In the second stage of the disease, an AD-affected individual may wander, encounter disorientation, lose recognition of family and friends, and physically deteriorate (McInnis-Dittrich, 2014). In the third and final stage of Alzheimer's, the caregiving becomes even more encompassing when continence, mobility, and verbal ability to communicate have dissipated (McInnis-Dittrich, 2014). Studies put forth that caregiving creates an objective burden of providing physical care, guiding behavior, offering ongoing emotional support, and managing the medical system all while responding to the subjective hardship of a loved one's progressive loss (Sussman & Regehr, 2009; Vitaliano, Young, & Russo,

1991). In other words, caregiving calls for an output of external and internal energy, all while navigating and defining loss, anticipatory grief, and a progressive disease.

Caregiving may manifest in diminished physical health, economic uncertainty, loss of social supports, and an increased risk of depression (Liu & Gallagher-Thompson, 2009). Role captivity, the sense of being trapped or with few options, is a possible consequence that results in caregiver overload and strain. Spouses, partners, and adult children who are caregivers often encounter stress from the change of reciprocity in relationship with their loved one and social isolation as cognitive loss progresses (McInnis-Dittrich, 2014; National Alliance for Caregiving, 2009).

## Rates of Alzheimer's Disease in African-American and Hispanic Communities

In 2014, an estimated 5.2 million people in America had Alzheimer's disease (Alzheimer's Association, 2014a). Even though the majority of Americans with AD at present are Caucasian, "older African-Americans and Hispanics are proportionately more likely than older whites to have Alzheimer's disease and other dementias" (Alzheimer's Association, 2013). The cause for these rates are linked to increased occurrence of diabetes and high blood pressure within both African-American and Hispanic populations (Alzheimer's Association, 2014a). Due to genetic and environmental factors, "the prevalence, incidence, and cumulative risk of Alzheimer's disease appears to be much higher in African-Americans than in non-Hispanic whites" (Alzheimer's Association, 2002). Other issues such as late diagnosis, culturally biased assessments, and underreporting of cognitive decline add to the disparity of care of AD within the African-American community (Alzheimer's Association, 2002). By 2050, the number of elder Hispanics with AD is projected to increase from less than 200,000 in 2004 to more than

1.3 million in 2050 (Alzheimer's Association, 2004). Hispanic Americans encounter cultural biases in medical evaluations, yet also deal with limited access to the healthcare system due to language barriers, leading to an later diagnosis rate that limits therapeutic interventions (Alzheimer's Association, 2004). This paper will use, for the most part, the term "Hispanic," following the lead of the majority of research using that descriptor in reference to Latin Americans.

The global and culturally specific incidence rates of Alzheimer's disease, both at present and projected, are striking. They reveal a pervasive and growing issue for families who are providing care for AD-affected loved ones. These families are in need of services, education, and effective interventions to facilitate sustainable caregiving. This issue is a significant opportunity and an urgent need for social work to address.

# Perceptions of African-American and Hispanic Caregiving

Research demonstrates not only the growing incidence of AD, but also emphasizes the implicit challenges of caregiving (Alzheimer's Association, 2002; Alzheimer's Association, 2004; Alzheimer's Association, 2014a; Liu & Gallagher-Thompson, 2009; Vitaliano et al., 1991). However, not all families equally perceive providing caregiving as negative or intrusive, nor do they express the burden of caregiving in the same way. While strengths exist in every culture, African-American and Hispanic communities demonstrate particular familial connections that contribute to and define caregiving. A focus on cultural strengths in these communities is not intended to negate the systemic injustices that contribute to inadequate and biased dementia assessments, increased vascular disease and diabetes, and delayed diagnoses that may hinder early stage medical interventions (Alzheimer's Association, 2014). However, the

perception of responsibilities, community supports, familial, and kin commitment is crucial in the discussion of caregiving.

African-Americans report a strong support system that consists of not only relatives but also neighbors and friends as a source of social ties for the primary caregiver of a frail elder (Smerglia, Deimling, & Barresi, 1988). Perhaps due in part to a strong network of support, African-Americans perceive caregiving for an AD-affected loved one as an honored family responsibility, rather than a burden to be eased, and are therefore less likely to seek help (Alzheimer's Association, n.d.). Hispanic Americans share a strong sense of loyalty, putting family needs before individual needs (Alzheimer's Association, 2004; McInnis-Dittrich, 2014). In Hispanic culture, dementia is often viewed as part of the aging process as is the responsibility of caring for elders a part of serving the family (Alzheimer's Association, 2004).

Much research has been devoted to the impact of caregiving for AD-affected loved ones. It covers a breadth of topics such as: caregiver burden, mental and physical health, grief, use of community supports, and effect of institutionalized care. However, the vast majority of research is based on Caucasian caregivers that may incorrectly create a normative sense of the caregiving experience. Although caregiving has inherent challenges that are shared among cultures and races, differences exist. In addition to differences of perceptions of the caregiving relationship, willingness and ability to utilize community supports and social work services can vary across racial and ethnic lines.

Thus, this paper will review research on African American and Hispanic caregivers in an attempt to gather the most effective social work interventions as reported by these distinct communities. The initial literature review provides a background for the systematic

review that follows. By first examining research on caregiving, caregiver burden, social work interventions, and cross-cultural social work, a foundation for the systematic review of research is created. In order to identify differences, an understanding of the majority of research must be established.

African American and Hispanic caregivers' wisdom, resilience, and commitment in the face of challenge offer social workers a deeper understanding for practice, especially those who serve cross-culturally. The intent of this project is to broaden social work knowledge in this area that is often unjustly devoted to Caucasian sample populations. The best social work practice is one that is informed and changed by learning from the experiences of all individuals. Focusing on the research on interventions with African American and Hispanic caregivers offers greater insight to social workers to serve with more cultural sensitivity and understanding.

#### **Literature Review**

#### Caregiver Burden

Caregiver burden is a well-documented concept in research literature, yet as stated above presents a bias with a lack of diversity within sample populations. Even though the challenges of caregiving can be perceived in a variety of ways, it remains a significant issue within the Alzheimer's community. Burden is considered a 'subjective filter' or intervening measure through which the tasks of caregiving and characteristics of the care recipient flow, influencing the more or less objective changes in the lives of caregivers (Walker & Pomeroy, 1996). In light of this definition, caring for a loved one with cognitive and memory issues creates palpable strain and hardship if it is perceived through such a filter of stress or a positive source of meaning if perceived through a filter

of familial respect. However, even an honorable role can create strain and hardship.

Research demonstrates differences based on ethnic and racial variations of role appraisal,

offering a diversity of responses to the caregiving experience.

Caucasian caregiver burden perspective. The following research articles present an overwhelmingly disproportionate perspective, with Caucasians making up between 84%-99% in groups. In the sampled Caucasian populations, depression, anxiety, somatic complaints, and illnesses may result from the role in which caregivers become the "silent clients" (Bartfay & Bartfay, 2013). Cumulative stress and the highly uncertain course of dementia, although predictably degenerative, add to the isolating role of providing care for an individual with AD. Thus, the progressive nature of Alzheimer's contributes to the burden of caregiving. Those who are responsible for the majority of care experience an increase in burden as their loved one's cognition decreases (Gaugler et al., 2003; Smyth & Milidonis, 1999). Likewise, in comparison to those in long-term care, community-based caregiving for AD-affected individuals develops a greater level of burden for caregivers no matter the stage of Alzheimer's (Bell, Araki, & Neumann, 2001). As dementia and needs grow, the greater the burden upon the caregiver. As AD behaviors become more demanding, intrusive, or unmanageable, the challenge of consistent yet responsive care increases. Correspondingly, challenging behavior that results from AD was significantly associated with an increase in caregiver burden (Kramer, 1993; Sussman & Regehr, 2009).

One aspect of caregiving is the strain from familial relationships. Caregiver's concern for the opinion of family members is associated with emotional burden, role captivity, and role overload (Smyth & Milidonis, 1999). The burdens of restricted and

overwhelmed feelings tend to increase with lack of familial foundation support and reliance. In one study, Caucasian caregivers reported a lack of consistent help from family and friends and wanted more support (Sussman & Regehr, 2009). Notably, there was no reported association between emotional support from family and friends and caregiver's burden in that study. Yet, apart from family opinion or support, Smyth & Milidonis (1999) suggest that the burden of caregiving is influenced by foundational beliefs about the caregiver role. Correspondingly, normative beliefs of caregiving shape the experience of the role, how burden is characterized, and how resources are utilized, if at all (Smyth & Milidonis, 1999).

Ethnic variations in report of caregiver burden. African-American caregivers reported lower burden than their Caucasian counterparts (Haley et al., 1996; Heo & Koeske, 2013; Knight et al., 2002). Correspondingly, appraisals of negative emotion declined in time for caregiving African-Americans whereas it increased for Caucasian (Skarupski, McCann, Bienias, & Evans, 2009). Furthermore, African-American caregivers of loved ones with AD scored higher on the Positive Aspects of Caregiving assessment (PAC) than Caucasians (Roff et al., 2004). The significant correlation between PAC and race is partly explained by measures of socioeconomic (SES) status, troubling behavior by their AD-affected family member, anxiety, and religion. African-Americans reported lower SES, fewer bothersome behaviors, less anxiety, and a higher rate of religiosity (Roff et al., 2004). In contrast, both groups reported similar levels of depression and social supports (Roff et al., 2004). Measures of depressive symptoms can vary when religion is used as means of caregiver coping. African-Americans

cognitions, or behaviors) and a lower appraisal of burden and depression in comparison to both Caucasian and Hispanic groups (Heo & Koeske, 2013). On the contrary, whereas religious attendance is associated with lower measures of depressive symptoms (Heo & Koeske, 2013), another study reflected no difference in utilizing both prayer and church for well being for African-American and Caucasian caregivers (Haley et al., 1996). Yet, both studies reflect a similar belief by African-Americans that the hardship of caregiving for an AD-affected relative was not considered unfair, but just a part of life (Haley et al., 1996; Heo & Koeske, 2013). In like manner, an "adaptive advantage" may exist for African-Americans, contributing to an ability to re-frame and sustain ongoing caregiving relationships in midst of adversity (Skarupski et al., 2009).

Continuing, Hispanic caregivers of AD-affected loved ones report significantly higher rates of personal strain and role stress than African-Americans (Cox & Monk, 1996). Yet the younger ages of the former caregivers in comparison to the latter may contribute to the high reports of burden (Cox & Monk, 1996). Providing care for younger children and older relatives with AD concurrently present a complicated and taxing role for a caregiver. Having older or adult children relieves some of the burden that a member of the proverbial "sandwich generation" may experience when tending to both the demanding needs of young and old. At the same time, familism is shown to be associated with high sense of Hispanic cultural identity and a lower sense of caregiver burden but not depression (Knight et al., 2002). In comparison to Caucasian caregivers, Hispanic caregivers reported a high level of self-efficacy in managing challenging behaviors and upsetting thoughts that were associated with less burden (Montoro-Rodriguez & Gallagher-Thompson, 2009). Likewise, Hispanics reported lower burden and more

religious coping than Caucasians (Heo & Koeske, 2013). Yet, both Hispanic and Caucasian caregivers demonstrate that as the number of challenging AD-related behaviors increase, so does caregiver burden (Montoro-Rodriguez & Gallagher-Thompson, 2009).

#### **Social Work Interventions**

The National Association of Social Workers (NASW) Code of Ethics (2008) states that "Social workers engage people as partners in the helping process and seek to strengthen relationships among people to promote well being at all levels" (Ethical Principles section, para. 5). Social work practice within the AD community follows the NASW Code of Ethics by offering a spectrum of interventions for the clients with cognitive loss, primary caregivers, and family. Interventions must take into account and balance the competing needs and perspectives of the entire family system, facilitating communication to make decisions, maintain relationships, and protect the welfare of the AD-affected individual. Initially, a social work mental health assessment for depression or anxiety could lead to an identification of early stage dementia, initiating a medical evaluation and a broader interdisciplinary intervention. Through case management, social workers connect to such interdisciplinary resources to equip a safe home, navigate the community, and utilize Medicaid or Medicare. Social workers can also complete a functional assessment of ADLs and IADLs, allowing for a greater understanding of needs and strengths.

Families may access social workers following a crisis such as an incident of wandering or escalating behavioral challenges. Psychotherapy offers assistance for both individuals with Alzheimer's and their caregivers to accept the diagnosis, deal with the

transitions involved, address grief, and identify inherent strengths. Support groups serve as a social work intervention for early to middle stage patients and caregivers for the entire length of the disease. Adult day health programs can act as a means of community for the AD-affected individual while providing respite for caregivers. Social workers serve as a constant source of support for persons with Alzheimer's, creatively assisting other therapies to effectively address behavioral issues rather than solely relying on psychotropic medications to calm distress and anxiety (McInnis-Dittrich, 2014; Richardson & Barusch, 2006).

Advocacy & clinical work. Social work tailors interventions to not only help caregivers cope, but also to derive meaning in their efforts and support from their surrounding communities. The existing literature explores a variety of forms that social work interventions can take. As an advocate, social workers are seen as crucial in an interdisciplinary team for the newly diagnosed AD patient and their family, offering resources, education, and support (Berman & Rappaport, 1984). Furthermore, this advocacy can promote a caregiver and their family's ability to cope with the new reality of AD and with the inevitable future challenges of the disease (Cummings, Long, Peterson-Hazan, & Harrison, 1998). Correspondingly, as time and the disease progresses, the social work intervention may evolve into a therapeutic relationship, dealing with the emotional stresses and grief that develop when caring for a loved one with degenerative cognitive disease (Berman & Rappaport, 1984; Sanders, Marwit, Meuser, & Harrington, 2007). The need for social workers to directly question and discuss the intimate and overwhelming challenges of caregiving without avoidance of grief, loss, or depression are shown as imperative for interventions (Ross, Holliman, & Dixon, 2003; Sanders et

al., 2007; Walker & Pomeroy, 1996). Likewise, interventions must include factoring in the thought process that occurs between a caregiving situation or challenge and the reaction of the caregiver (Morano, 2003).

Caregivers often develop clinical depression, yet it may be more situational and transient than other depressive disorders (Walker & Pomeroy, 1996). Therefore, Morano (2003) determined since the experience of caregiving for an AD-affected individual can be so unique that social workers focus on "...how caregivers appraise their situation, both in terms of burden and satisfaction, as well as coping skills, particularly emotion-focused coping, could help empower caregivers, while improving their psychological well-being" (p. 127).

Group work. Another social work intervention that can involve psychoeducation, support, or skills training often takes place in groups (Barusch & Spaid, 1991; Cummings et al., 1998; Gendron, Poitras, Dastoor, & Perodeau, 1996; Walker, Pomeroy, McNeil, & Franklin, 1994). Caregivers report high satisfaction with taking part in a group, yet often depression and perceived burden rates reportedly increase with group participation (Barusch & Spaid, 1991; Gendron et al., 1996; Walker et al., 1994). Groups can give members a window into their future for their loved ones, which affirms the reality of dementia's progressive nature and certain course of decline in spite of its unpredictable nature. The need for homogeneous groups have been suggested conceptually to deal with increase of depression, however, the ability to actually gather individuals who are all experiencing the same level of grief, stage of AD, and determination of burden may prove to be clinically problematic and unrealistic (Walker et al., 1994). On the other hand, non-homogenous and cognitive-behavioral focused groups can also lead to a

stronger sense of assertiveness, requests for assistance, and utilization of available services (Gendron et al., 1996). Short-term skills training also leads to increased coping effectiveness and taking on problematic situations with a decrease in situations that had previously felt overwhelming (Barusch & Spaid, 1991).

**Fostering resilience.** Some caregivers reflected resilience in spite of emotional and physical demands, loss and grief, uncertainty and loss of control (Ross et al., 2003). Characteristics of caregivers that demonstrate such resilience offer social workers insight as to how to thrive in the midst of providing constant care and increasingly more demanding care. Shared characteristics of resilient caregivers include a long duration in identifying one as a caregiver, time away from the caregiving role, participating in exercise and hobbies, cultivating emotional support, practicing a form of religion, maintaining a philosophical outlook of acceptance, and a sense of humor (Ross et al., 2003). According to Kramer (1993), "Understanding which coping strategies predict caregiving satisfaction is an important line of inquiry that could assist family service providers to target and develop strategies for enhancing the positive experiences of caregivers" (p. 385). Yet, even caregivers identified as "resilient" report the difficulties of their role, such as being incapable of talking with others who do not understand or even want to hear about caregiving (Ross et al., 2003). Resilient caregivers who manage to cope, respond from strength, and find meaning in the challenges of Alzheimer's disease, inform social work interventions. It is imperative to curiously consider how caregivers maintain resilience in the midst of progressive and profound adaptations in a significant relationship.

#### **Cross-Cultural Social Work**

Human dignity is a foundational part of social work as evidenced in the NASW *Code of Ethics* (2008): "Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity" (Ethical Principles section, para. 4). In addition, social workers are to maintain a perspective of solidarity, working from an ethic of social justice. Through this lens, social workers seek justice for those who are oppressed and strive for cultural and ethnic sensitivity (National Association of Social Workers, 2008). Recognition of differences is explicitly put forth, yet difficult to achieve not only theoretically, but also in clinical practice. Therefore, the reality of working cross-culturally while embodying respect of ethnic and racial diversity is complex and deserving of critical reflection.

To understand the dynamics involved in cross-cultural social work, semantics must be explored. Cross-cultural social work practice is generally understood as occurring when the participants represent different cultures, races, ethnicities, or lifestyles (Yan & Wong, 2005). In light of supporting ethical cross-cultural practice, NASW (2007) defines cultural competence as "the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognizes, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each" (p. 12).

#### Critique of Cross-Cultural Social Work & Cultural Competence

The literature on cross-cultural social work lies on a spectrum addressing how the dominant culture permeates social work theory and practice (Lee, E. & Bhuyan, R., 2013;

M. Y. Lee, 2003) to how cultural competence could possibly help or harm building a therapeutic relationship (Furlong & Wight, 2011; E. Lee, 2010; Yan, 2005; Yan & Wong, 2005). The term "cultural competence" has also come under scrutiny, questioning if this is a skill or educational standard that can possibly be acquired (Furlong & Wight, 2011). Cultural competence is surmised to be cross-cultural social work's foundation as well as a "technical solution" for the complexities of racially and ethnically diverse practice (Yan & Wong, 2005). According to E. Lee (2010), even though the idea of cultural competence may have "good intentions, it tends to foster 'culture-specific, rather than client-specific' interventions within the cross-cultural therapeutic exchange" (p. 275).

These critiques have led the way to new terms and explorations of cultural competence as a means of further challenging the notion that adequate understanding of different cultures, races, or ethnicities can be mastered. One response is the strengths-based concept that focuses on attitude rather than knowledge about a unique people group. M.Y. Lee (2003) points out that "clinicians operating from a strengths perspective should be curious about and appreciative of the cultural strengths in clients" (p. 387). This approach also acknowledges the dynamic of power or race or ethnicity that can negatively impact a clinical relationship (Dover, 2009; Lee, E. & Bhuyan, R., 2013; M. Y. Lee, 2003).

Cultural sensitivity. Acknowledging not only the power differential, but also the cultural differences between a client and a social worker are integral in fostering "cultural awareness" (Yan, 2005). This awareness includes a practitioner's ethnic or racial identity, in addition to their organizational and professional culture (Yan, 2005). Furthermore, this awareness is built from a foundation of self-awareness and reflection (Furlong & Wight,

2011; Yan, 2005; Yan, 2008). Recognition of how culture affects and influences worldview, relationships, and experiences, can prevent social workers from perpetuating the dominant culture's expectations or their own values on a client (Yan, 2005). Self-awareness corresponds with critical reflexivity that includes the professional context and a larger understanding of history and political context (Dover, 2009; Furlong & Wight, 2011; Lee, E. & Bhuyan, R., 2013; Yan, 2008). Inclusion of racism, economic injustice, immigration or refugee stories, and indigenous perspectives all must be taken into account for greater empathic responsiveness and intervention.

Correspondingly, this acknowledgment, self-awareness, and critical reflection can lead to internal conflicts for social workers that are members of the dominant culture. Furlong & Wight (2011) state that "of its nature, this dialogue is likely to be, at least from time-to-time, uncomfortable because such a review de-centres broader cultural biases and privilege" (p. 50). Discomfort can stem from admission of bias or prejudiced beliefs and the necessity of challenging a worker's "own vulnerabilities" to protect and serve their clients (Lee, E. & Bhuyan, R., 2013). In addition, an attitude and acceptance of "not knowing" allows for greater interaction and collaboration with the client, rather than a prescribed understanding from the dominant worldview (M. Y. Lee, 2003). In like manner to "not knowing," the emphasis on empathy rather than on building rapport may offer a means to develop a clinical cross-cultural relationship that is respectful of the client's dignity and culture (Dover, 2009). According to Dover (2009), since rapport is difficult to develop cross-culturally, focusing on "empathic communication may be the key to achieving practice effectiveness across cultural boundaries, even when full rapport

is difficult due to compatibility-inhibiting cultural unfamiliarity on the part of either worker or client" (p. 27).

The call for curiosity. Working cross-culturally allows for inclusion of experience and education. Furlong & Wight (2011) clarify this point by stating that "each non indigenous person can repurpose encounters with indigenous difference, asking: 'What do I know?' 'What can I learn?'" (p. 52). This does not mean making stereotypical cultural assumptions. Rather, a perspective of informed awareness creates a "starting point" for curiosity about another's life and experience (Furlong & Wight, 2011). Yet, these generalizations should not be considered universal descriptions of a particular group, but only as a point for a willing practitioner to begin learning about another individual from their unique perspective. M.Y. Lee (2003) clarifies the point by stating "the clinician who holds a 'not knowing' stance is free to enter into the client's subjective experiences of her life situations and collaboratively engage in a solution-building process that is viable and responsive to her cultural context" (p. 388). The discovery of unique meaning for a client's experience or interaction in light of his or her culture is part of the challenge of cross-cultural social work (Yan & Wong, 2005). Thus, cultural competence, as put forth in the NASW Standards for Cultural Competence, is not an easily created mode of practice. Its complexity is multi-faceted and challenged by perceptions of awareness and reflection.

The literature on caregiving, social work interventions, and culture reveal a variety of considerations for practice. Research with overwhelmingly Caucasian samples does not establish a normative view. Equally important, there is a disparity within literature that reflects African-American and Hispanic perspectives as caregivers for AD-

affected individuals. Thus, the purpose of this project is to explore the effective interventions used for African-American and Hispanic caregivers of loved ones with Alzheimer's disease. Their collective experiences from a variety of interventions gathered through research, need to be listened to with the intent for more respectful and responsive social work service. The goal is to glean from current research articles pertinent insights that will enable cross-cultural social work relationships to acknowledge and work from the unique perspectives and insights of caregivers and their loved ones with dementia within the African-American and Hispanic communities. The aim is not to further stereotypes, but to identify interventions and explore their impact on caregivers. The literature is lacking, therefore, the purpose is to describe effective interventions for African-American and Hispanic caregivers.

# **Conceptual Framework**

Working with individuals and families who provide care for a loved one with a progressive and incurable disease calls for a realistic point of view. Ignoring the eventual outcome of deepening dementia and death is not respectful of the dignity of the entire family system affected by Alzheimer's disease. Yet this realism is open to interpretation and expression, allowing for caregivers' perceptions of strengths to intersect and impact the perspective that shape a social worker's interventions.

Strengths perspective. A perspective that takes a prudent account of AD and caregiving while maintaining a focus on the strengths of the caregiver is not only possible but also beneficial. Social work does not need to downplay the difficulties of AD to utilize resilience, nor negate loss while celebrating the individual in the midst of progressive change. The strengths perspective counters the medical or pathological view

that emphasizes diagnoses, problems, and the expertise of clinical practitioners (Saleebey, 1996). Instead, the strengths perspective creates an opportunity for social workers to see capabilities, knowledge, hopes, beliefs, and options in spite of circumstances that may have altered such gifts (Saleebey, 1996). Furthermore, Peacock et al. (2010) claims "individuals should be viewed in light of and defined by their values, strengths, hope, aspirations, and capacities regardless of the stressful or burdensome nature of the situation around them" (p. 642). The strengths perspective provides social work a framework that strives for balance, acknowledging a client's reality while concurrently recognizing and supporting their courage, resiliency, and insight. Thus, this research project is guided by this conceptual understanding of strength. By approaching literature on African American and Hispanic caregivers with the perspective that they are the experts who have profound insights directs this project to discover this expertise that can best inform and improve social work interventions.

It is imperative for social workers that serve older adults to take into account the vast array of strengths that are inherent with age. Growing older means navigating difficulties of life and finding ways to cope and survive. For elders within the African-American and Hispanic communities, resilience is a fundamental characteristic that must be acknowledged within the social work relationship. These particular elders have seen and experienced pervasive oppression and racism, and often reflect the consequences of unjust social systems with poorer health and lower economic status. The experience of ageism, added to a lifetime of dealing with overt and covert injustice, creates further need for resilience and tenacity. The strengths perspective does not discount oppression nor pathologically conceptualize aging, but takes a generative approach that assumes

potential and capability while seeking to capitalize on the unique resiliency of each individual (Chapin & Cox, 2008; Langer, 2004). Thus, it is a fitting framework for this research in that strengths perspective views the client as the expert. This research will depend upon data that came forth from the experiences of African-American and Hispanic caregivers of AD-affected loved ones. The strengths perspective is open to different appraisals of meaning with a non-judgmental stance, taking into account implications of faith and spiritual resources for caregiving.

In addition to recognizing the unique competencies of individuals, the strengths perspective also integrates culture as it is viewed as a source of meaning and fortitude. The personal and family narratives shaped by culture are sources of strength and "may provide a source for the revival and renewal of energies and possibilities" (Saleebey, 1996). Culture impacts how caregivers of those with AD define and speak about their work as "a burden," "a family responsibility," or "my turn to give back." These descriptions connote different meaning, offering an important point of distinction for the social worker to understand. While caring for an individual with progressive and debilitating dementia definitely changes a relationship, the strengths perspective relies on the caregiver to name the challenges, define what is stressful, and determine the meaning of providing such care. A task of caregiving may be problematic for one caregiver and not another. A framework of strengths makes room for the caregiver, not the social worker, to define what is an issue and what is not. This research has an intrinsic lens of strength in that the literature reviewed will be perceived as coming from the experts, the African-American and Hispanic caregivers, that will inform and shape social work practice.

#### Method

This study used a systematic review as a method of collecting and analyzing data to identify effective interventions for African-American and Hispanic caregivers from selected research articles. This method of research involves identifying and analyzing existing studies to contribute to a collection of knowledge. Petticrew & Roberts (2006) describe systematic literature reviews as "a method of making sense of large bodies of information, and a means of contributing to the answers to questions about what works and what does not" (p. 2). This type of research also allows for a broader sample than could be procured through a small solo quantitative or qualitative study.

A systematic literature review was chosen for this study because it allows for a focus on a particular question and community while giving the opportunity to explore a larger set of existing data. The majority of the research on caregiving for AD-affected loved ones lack cultural, ethnic, and racial diversity in their sample populations. The extent of existing literature puts forth a normative understanding of the best social work interventions yet often lack ethnic diversity. Systematic literature reviews seek to test an explicit hypothesis or to answer a question, instead of creating a summary compiling "all there is to know" about a distinct subject (Petticrew & Roberts, 2006). Thus, this study's sample will come from completed research that has focused on African-American and Hispanic caregivers of loved ones with Alzheimer's disease. Through analyzing peer-reviewed quantitative and qualitative studies consisting of these two minority samples, this project will attempt to identify the best social work practices and interventions that were reported as effective within these specific caregiving communities.

#### **Data Collection & Sampling**

In addition to focusing only on qualitative and quantitative research, several parameters were created to select articles for inclusion in this systematic literature review. The study limited articles to English-written, peer-reviewed and published studies conducted within the U.S. and Canada. Articles published from January 1995 to January 2015. Dissertations were excluded due to lack of peer-review, as were case studies because of small sample sizes. Studies that consisted of other racial and ethnic groups in addition to African Americans and Hispanics in the sample populations were included if they met the search terms of this project. However, African-Americans and/or Hispanics had to be represented by at least 30% of the sample population to be included in the systematic review.

Pub Med, psycINFO, SocINDEX with Full Text, and Social Work Abstracts were utilized to locate pertinent literature for review on February 19, 2015. As shown in Table 1 (see Appendix), search terms used were "social work," "Alzheimer's," "caregiver," and "intervention," "strategy," and "action" all truncated to extend the search for articles. In addition, "African-Americans", "Black," "Hispanic," and "Latino" were utilized as a means to identify the greatest number of articles that referenced these particular communities of color. Participants in all the studies self-identified their race, ethnicity, or culture, yet not all broke the categories down to such a degree. This study chose to exclude a study that consisted only of Cuban Americans in the sample population because most of that research was geographically limited to Miami, FL with unique economy and history. Thus, the Hispanic groups represented in this review were self-identified as born in the U.S., Mexico, Central or South American countries.

As shown in Figure 1 (see Appendix), after accounting for duplicates resulting from the database search, 22 articles remained. Through analysis, 18 were eliminated due to 29% or fewer of African-Americans or Hispanics in sample populations, lack of quantitative or qualitative design, marketing focus of research, international source, or lack of testing on an AD caregiver intervention. Of the remaining four, one study (Gonyea, Lopez, & Velasquez, 2014) cited a systematic review (Napoles, Chadiha, Eversley, & Moreno-John, 2010) that analyzed 18 studies on culturally sensitive interventions for AD caregivers. These 18 studies were then analyzed for inclusion in this review. Of those articles, ten were excluded with eight articles integrated into the initial four studies identified through PubMed, SocINDEX with Full Text, Social Work Abstracts, and PsychINFO. This established a final count of twelve articles for this systematic literature review (see Table 2 in Appendix). The remaining articles were then categorized into the different intervention strategies that emerged from the research and reviewed.

# **Data Analysis**

After the 12 articles were identified, they were read and categorized into three groups:

- In-Home Programs (4 articles)
- Cognitive Behavior Therapy (CBT) Groups (4 articles)
- Support Groups (4 articles)

The categories of in-home programs, Cognitive Behavior Therapy (CBT) groups, and other support groups were identified through reading for re-occurring terms, ideas, themes, and/or methods. The first reading included completing an analysis (see Figure 2

in Appendix) for each article to gather notes on each specific research question, sample, design, results/findings, and areas for discussion. In addition, more themes were identified to highlight points of distinction and connection to other data in the review. Once the three categories emerged from the data, the articles were read again, with further notes recorded within a notebook to clarify and narrow the interventions and measures of each study (see Figure 3 in Appendix).

This second reading also identified a fourth category of cultural tailoring of caregiver interventions. The term "cultural tailoring" came from the systematic review by Napoles, Chadiha, Eversley, & Mareno-John (2010) that introduced more data into this study. They defined cultural tailoring as "the development of interventions, strategies, messages and materials to conform with specific cultural characteristics" and "can include incorporation of themes, messages and graphics found to be consistent with the values and beliefs shared by subgroups, e.g., African Americans" (p. 2). The theme of cultural tailoring of interventions emerged through the frequent use of the term within each of the articles that demonstrated its impact on the data. This step in the procedures within the systematic review helped to refine the exploration for clear interventions for African-American and Hispanic caregivers. The third reading of each article was intended to catch discrepancies between the data and notes, highlight findings, and add further information that was previously missed into the article analysis worksheets (see Figure 2) and notes (see Figure 3). Once these three readings were completed, work began on the findings section, using the two sets of notes and the articles to report the data.

#### **Strengths & Limitations of Systematic Literature Review**

One of the limitations of this review was that 75% of the articles had sample sizes of twenty or fewer. Although the findings from these smaller populations contribute to social work knowledge and suggest implications for practice, larger sample groups add strength to the results. Even though CBT interventions demonstrated effectiveness with caregivers, the four articles were only comprised of Hispanic and Caucasian participants. In the first group of 22 articles analyzed for review, only four actually tested an intervention. The majority of articles that were excluded explored appraisal of AD caregiving within the African-American and Hispanic communities. That body of research is valuable as it informs practice, but indicates that direct research on AD caregiver interventions on communities of color is narrow. Thus, the number of articles that fit the parameters of this review was limited. Table 1 (see Appendix) demonstrates the difference of the amount of articles that specify African-American and Hispanic caregivers and those that do not. Another limitation of this review is the lack of overt direction on cross-cultural social work practice. Since five of the articles noted the importance of bicultural and bilingual staff, it creates questions and profound challenge for social workers that seek cross-cultural practice. Issues of cultural competency, awareness, and sensitivity are ones that need to shape social work practice within the AD community.

This project demonstrated strength in the systematic nature of the review.

Although there is a limit to find and include every piece of peer-reviewed published research, this review followed a strict set of parameters to locate articles to expand the collection of knowledge about effective AD interventions for African-American and

Hispanic caregivers. Another strength is that it identified the need to culturally tailor any intervention to bolster its effectiveness and impact. These challenges can serve as a strength in that they direct curiosity, prevent status quo responses, and motivate the social worker to continually listen to client needs, background, and experience as informed by race, ethnicity, and culture. The lack of clear definitive cross-cultural direction acts as an enticement to work with cultural sensitivity and remain active learners given the caregivers' expertise.

# **Findings**

# **In-Home Programs**

The in-home interventions reported varied in design and intent, but all four articles in this category (Table 3) concentrated on caregiver skill training within the environment of the home shared by the primary caregiver and care recipient. Each of the articles emphasized the real-life context of the home and possible modifications that could be implemented to improve the caregiving experience.

Table 3. *In Home Programs* 

Authors	Title	Sample	Intervention	Measures
Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher- Thompson, D., (2006).	Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial.	212 Hispanic or Latino, 219 Caucasian, & 211 African- American caregivers	6-month multi- component intervention: (12) in home & telephone sessions for psychoeducation & problem solving skills vs. (2) minimal	variables of risk, depression, burden, self care, social support, and caregiver recipient problem behaviors
Burgio, L., Stevens, A., Guy, D., Roth, D. L., & Haley, W. E. (2003)	Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia.	48 African- American & 70 Caucasian caregivers	telephone check-ins 12-month skills training consisting of group then (16) in-home sessions vs. minimal suppport group	care recipient problem behavior, behavior bother, satisfaction in enjoyable activities/leisure, depression, anxiety

Elliott, A. F.,	Enhancing	166 African-	6-month program of (9)	health, mood,
Burgio, L. D., &	caregiver health:	American, 169	in-home & (3)	physical
DeCoster, J.	Findings from the	Hispanic, 160	telephone sessions vs.	improvement,
(2010).	resources for	Caucasian	(2) minimal telephone	sleep, burden,
	enhancing	caregivers	check-ins	bother, depression
	Alzheimer's			
	caregiver health II			
	intervention.			
Gitlin, L. N.,	Effects of the home	100 African-	12-month home	caregiver well-
Winter, L.,	environmental	American, 85	environmental skill	being, objective &
Corcoran, M.,	skill-building	Caucasian, 5	building program of (5)	subjective burden,
Dennis, M. P.,	program on the	other	home visits and (1)	caregiver recipient
Schinfeld, S., &	caregiver-care	caregivers	telephone conversation	problem behaviors
Hauck, W. W.	recipient dyad: 6-		vs. caregiving as usual	
(2003).	month outcomes			
	from the			
	Philadelphia			
	REACH initiative.			

**Description of interventions.** The interventions used in these four articles shared an educational aim, despite utilizing different methods. Meeting in caregivers' homes fostered an individualized and personal approach, allowing the intervention to be uniquely constructed for the particular needs and situation of each caregiver and care recipient. Burgio et al. (2003) and Belle et al. (2006) both found that one-on-one support in the client's home allowed for the development of a therapeutic alliance in addition to encouraging caregiver's self-efficacy.

Burgio et al. (2003) tested a skills training intervention that focused on management of AD behaviors, problem-solving abilities, expanding social support and leisure activities, and re-framing challenging situations. In like manner, Gitlin et al. (2003) analyzed the impact of providing education on home environment, management of AD behaviors, and expanding problem-solving abilities. However, they also included an OT assessment of needed adaptive equipment to assist in caregiving within a home setting. Although both interventions integrated some of the same educational means, the intention for Gitlin et al. (20013) was to lower the objective stressors of caregiving,

whereas Burgio et al. (2003), "worked to develop short-term psychosocial interventions" for the benefit of caregiver well-being (p. 569).

Elliott et al. (2010) and Belle et al. (2006) both analyzed the impact of providing education on caregiver emotional well-being, safety, stress, self-care, social support, community resources, and managing AD behaviors. Belle et al. (2006) reported that the interventional education was not just informative in nature, but also instructive in that it helped clients through role-playing, problem-solving, and brainstorming possible actions for situations unique to each caregiver. Other intervention strategies used in these two studies included teaching stress management techniques, cognitive methods for reframing negative responses, and approaches for enhancing health. Belle et al. (2003) reported emphasizing social support through use of "resource notebooks with educational material and telephones with display screens linked to a computer-integrated telephone system to provide information and facilitate group support conference calling" (p. 730). Although the intervention was in-home, both studies sought to offer strategies for caregivers to reach out and connect while uniquely strengthening their caregiving skills. Belle et al. (2006) and Elliot et al. (2010) both collected risk profiles at baseline, allowing for even greater individualization for each caregiver intervention, although no cultural tailoring beyond translation of materials into Spanish was integrated. Gitlin et al. (2003) did not report any cultural adaptations, whereas Burgio et al. (2003) reported using several in its intervention. Interactive educational materials were created for different learning styles in addition to an ethnically diverse staff trained in cultural sensitivity. Burgio et al. (2003) also reported using reported using advocacy training to address the racism that African-American caregivers experience within the medical community.

**Reported outcomes.** Even though the majority interventions in this category lacked expansive cultural tailoring, these four articles demonstrate some effectiveness and variance. When looking at the effect on caregiver depressive symptoms, Burgio et al. (2003) reported no change in both ethnic groups (African-American and Caucasian) within their sample over the 12-month period. Belle et al. (2006) and Elliott et al. (2010) reported that all groups (African-American, Hispanic, and Caucasian) demonstrated a reduction in depressive symptoms, with depression inventory scores lowering from 'at risk' range to 'normative' range in their 12-month intervention span. In comparison, the control group in Belle et al. (2006) that lacked the in-home intervention demonstrated a statistically significant increase in depressive symptoms. When compared to the control group within that study, Hispanics demonstrated statistically significant improvement in all areas of measurement; depression, burden, self-care, social support, and AD problem behaviors, whereas African-Americans did not. Altogether, both Belle et al. (2006) and Elliott et al. (2010) showed that the in-home intervention benefitted all ethnic and racial groups, but not to the degree of improvement experienced by Hispanics caregivers.

The in-home skills training as reported by Burgio et al. (2003) showed that both African-American and Caucasian caregivers experienced a decrease in AD challenging behavior and bother from that behavior, in addition to an increase in satisfaction from leisure activities. Likewise, Gitlin et al. (2003) reported decreased upset with memory-related behavior problems along with improved emotion from caregiver skill training. However, according to Gitlin et al. (2003) "no statistical intervention effects were found for race or for any measures of care recipient functioning" (p. 540). Although the intervention lacked statistical significance, Gitlin et al. (2003) reported improvement in

objective burden with caregivers reporting fewer days of assistance needed from family and friends. In Burgio et al. (2003), skills training interventions impacted African-American caregivers with a significant gain in positive facets of caregiving over time, while Caucasian caregivers demonstrated no improvement. Yet, the African-American caregivers who participated in the Burgio et al. (2003) study experienced a decrease in satisfaction and approval with social support, with their Caucasian counterparts remaining stable in this area. In contrast to Burgio et al.'s findings, Belle et al. (2006) reported, "a clinical meaningful effect favoring the intervention for social support" for all racial groups (p. 735). Even though Hispanics and Caucasians demonstrated statistically significant improvements in quality of life and African-Americans did not, both Belle et al. (2006) and Elliott et al. (2010) reported that all caregiver groups benefitted from the interventions. According to Belle et al. (2006),

Caregivers in the intervention group reported that study participation helped them feel more confident in dealing with the care recipient, made life easier for them, improved their ability to care for the care recipient, improved the care recipient's life, and helped them keep the care recipient at home (p. 737).

As can be seen, in-home interventions indicate an overall effectiveness and benefit in varying degrees for African-American and Hispanic caregivers.

## **CBT Group Programs**

The four articles in this category (Table 4) report the findings of CBT-focused psychoeducational small groups with Hispanic and/or Caucasian caregivers as sample populations.

Table 4. *CBT Group Programs* 

Authors	Title	Sample	Intervention	Measures
Gallagher- Thompson, D., Gray, H. L., Dupart, T., Jimenez, D., & Thompson, L. W. (2008).	Effectiveness of Cognitive/Behavioral small group intervention for reduction of depression and stress in non- Hispanic white and Hispanic/Latino women dementia family caregivers: Outcomes and mediators of change.	89 Hispanic & 95 Non-Hispanic White caregivers	4-month CBT- based small groups vs. marginal telephone support	perceived stress, bother, depression, learned skill utilization
Gallagher- Thompson, D., Coon, D. W., Solano, N., Ambler, C., Rabinowitz, Y., & Thompson, L. W. (2003).	Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: Site-specific results from the REACH national collaborative study.	91 Latino & 122 Caucasian female caregivers	10-week small group ("Coping With Caregiving") consisting of psychoeducation vs. traditional listening based support group	self-care, depression, coping, social support, burden, & bother
Gallagher- Thompson, D., Thompson, L., Rivera, P., & Arean, P. (2001).	A psychoeducational intervention to reduce distress in Hispanic family caregivers: Results of a pilot study.	70 Hispanic caregivers	8-week psychoed. group ("Coping With Frustration Class") vs. waitlist control group	depression, contolling anger, burden
Gonyea, J. G., Lopez, L. M., & Velasquez, E. H. (2014).	The effectiveness of a culturally sensitive cognitive behavioral group intervention for Latino Alzheimer's caregivers.	67 Hispanic caregivers	5 weekly 90- minute CBT small group vs. psychoeducation small group	caregiver distress, self- efficiency, and depression

Cultural tailoring was reported in every CBT intervention. Examples include translating materials into Spanish, having bicultural and bilingual staff, and creating written documents that supported didactic education for group participants. Gallagher-Thompson et al. (2003) and Gonyea et al. (2014) reported using groups that integrated a social component within interactive teaching sessions, time for informal conversations with refreshments, celebrations at completion with a graduation-type ceremony, and participation certificates. The CBT groups had an intervention goal to lower the stigma of

AD and other dementias by using an educational instead of a therapeutic approach, similar to the in-home programs. Gonyea et al. (2014) utilized the words "education" instead of "therapy" and "memory problems" instead of "dementia" in their outreach and recruitment for the intervention. The group names reflected the educational focus such as; "Circulo de Cuidado" (Circle of Life), "Coping With Frustration Class," and "Coping With Caregiving." According to Goyea et al. (2014) "an important beginning point in the intervention was a discussion on the etiology of Alzheimer's, the disease stages and associated behavioral changes, and caregivers' reactions to the diagnosis and behavioral changes" (p. 4). The education aimed to de-stigmatize AD's cognitive loss and behavioral changes.

Description of interventions. The CBT interventions continued this destignatization of AD in both the control and experimental groups. The four articles reported on the comparisons between group interventions based on CBT principles and traditional emotional-based psychoeducational support groups or telephone support. The "Coping With Caregiving" class, reported by Gallagher-Thompson et al. (2003), emphasized an educational focus with a curriculum based on skills-training in a group setting that allowed for practice and personal integration of caregiving information. The goals of the class, explained by Gallagher-Thompson (2003), reflected cognitive and behavioral perspectives "essentially through a reduction of negative thoughts and attitudes and through an increase in positive reinforcement by use of more adaptive social behaviors" (p. 582). Following a standard group 'check-in,' both Gallagher-Thompson et al. (2003) and Gonyea et al. (2014) interventions consisted of the class participants learning relaxation techniques, appraising challenging AD behaviors realistically, and

communicating with confidence. The connection between cognitions and behavior was emphasized, as was integrating pleasurable activities into daily life and rewarding achievements in the caregiving relationship. The "Coping With Frustration" class, as reported by Gallagher-Thompson et al. (2001), also utilized CBT interventions such as identification and challenge of distressing thoughts, relaxation, and assertiveness to manage emotions that can develop from the role of caregiving. Even though CBT provided an interventional structure to AD caregiving, the groups allowed an individualized approach as well. According to Gonyea et al. (2014), "the particular behavior focus was individualized or tailored to the specific concerns of each caregiver" (p. 5). Gallagher-Thompson et al. (2003) fostered this approach as well with social time allowed for breaks, but also for leaders to meet with participants individually to problemsolve, strategize, and offer feedback. At home assignments created a means to try out modifications of caregiving, track responses to challenging situations, and record questions for following classes. Although all the interventions included a didactic approach, time for practicing caregiving techniques and review of homework was an integral aspect of the groups. Gallagher-Thompson et al. (2008) and Gallagher-Thompson et al. (2001) reported that this time reflected the CBT emphasis of increasing confidence and positive cognitions through gaining mastery of new skills.

Reported outcomes. Gallagher-Thompson et al. (2008) and Gallagher-Thompson et al. (2003) reported that results from CBT group interventions were similar between Hispanic and Caucasian participants, no matter the level of education attained. In particular, the measure of depression was impacted by the CBT approach. All four articles in this category treatment groups reported the greatest results on this particular

variable, with all interventions showing a statistically significant reduction of depressive symptoms in comparison to the control groups. Additionally, Gonyea et al. (2014) demonstrated that the improvement in depression was sustained, revealing a consistent measure three months post intervention. However, Gallagher-Thompson et al. (2001) reported that although the intervention was effective on lowering depressive symptoms and demonstrating "meaningful change," the scores remained in the "mild-to-moderately depressed range" (p. 28). Despite the noted effect on depression, anxiety was only measured in Gonyea et al. (2014) that demonstrated no change between the experimental CBT group and control psychoeducational group.

"Caregiver bother", a measure of caregiver distress over their loved one's cognition and behavior challenges, showed significant reduction in comparison to the control groups in Gallagher-Thompson et al. (2008) and Gallagher-Thompson et al. (2003). Gonyea et al. (2014) reported a measure of neuropsychiatric distress related to AD symptoms demonstrated a significant decrease of distress upon completion of the "Circulo de Cuidado" class that remained at the three-month post-test. In like manner, Gallagher-Thompson et al. (2003) showed a significant effect from the CBT interventions in the measure of both adaptive and negative caregiver coping. Positive coping strategies also increased after the "Coping With Caregiving" class that corresponded with a decrease in negative coping strategies. Continuing, Gallagher-Thompson et al. (2008) reported an increase in effective use of skills assertiveness, relaxation, tracking mood and behaviors, and caregiver planning that was shown to positively impact the measure of depression and caregiver distress.

Only one group measured the intervention's effectiveness on caregivers' measure of anger in a variety of ways. Gallagher-Thompson et al. (2001) analyzed caregivers' present experience of anger, patterns of anger expression, and its management and control. The "Coping With Frustration" class participants demonstrated an impact on this emotion with a trend in the direction of significant mediation in caregivers' capability to control their anger. In spite of this trend, no other measures of anger within the Gallagher-Thompson (2001) study demonstrated significant change.

In light of the overall reported benefits of CBT interventions, Gallagher-Thompson et al. (2003) reported that caregiver perceptions of positive social support demonstrated no significant effects or difference between racial groups or the experimental and control groups. Positive social support was defined as assistance with transportation, emotional encouragement, and tangible provisions of care. Instead, Gallagher-Thompson et al. (2003) reported a minimal positive effect was indicated by the CBT group on managing negative social interactions such as criticism or judgment. Despite the lack of significant impact on social interactions, CBT demonstrated an overall effective benefit for Hispanic AD caregivers.

# **Support Groups**

The articles in this category (Table 5) consist of caregiver interventions that were classified as support groups. Authors identified using more a variety of approaches to caregiver support including psychoeducation, skill-development, yoga, meditation, spirituality, and prayer.

Table 5. Support Groups

Authors	Title	Sample	Intervention	Measures
Kally, Z., Cote, S. D., Gonzalez, J., Villarruel, M., Cherry, D. L., Howland, S., Hepburn, K. (2014).	The savvy caregiver program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers.	149 Hispanic, 91 African- American, & 79 Asian caregivers	"Savvy Caregiver Program:" 6-week program of 2-hour sessions that included education, skills, and attitudes to enhance caregiver role	caregiver mastery, competence, depression, responses to problem behaviors, management of meaning, & management of
Morano, C. L. &. B., M. (2002).	A psychoeducational model for Hispanic Alzheimer's disease caregivers.	20 Hispanic caregivers	5-day, 20-hour psychoeducational program	situation.  caregiver knowledge, coping skills, resource knowledge, communication
Sistler, A., & Washington, K. S. (1999)	Serenity for African American caregivers	7 African- American daughter caregivers	8-week group ("Serenity for African- American Caregivers") focused on problem- solving skills and education	competence, knowledge, situation control, happiness
Waelde, L. C., Thompson, L., & Gallagher- Thompson, D. (2004).	A pilot study of a yoga and meditation intervention for dementia caregiver stress.	8 Hispanic & 4 Caucasian female caregivers	6-session yoga & mediation program ("Inner Resources")	self-efficacy, anxiety, self-rated improvement, & adherence to program

Each article reflected the researchers making a degree of cultural tailoring for the caregiver intervention. Even though the research on Kally et al.'s (2014) Savvy Caregiver Program (SCP) was designed to study the intervention's effect on non-Caucasian caregivers, no cultural variations were implemented into the program. Both Waelde et al. (2004) and Morano & Bravo (2002) incorporated translation for all written materials, in addition to bilingual and bicultural staff members leading didactic and group sessions in Spanish. Sistler & Washington's (1999) intervention was developed to address African-American caregiver "perceptions of not feeling understood and a perceived lack of competence in the caregiving role" (p. 51). Thus, this particular support group was tailored to increase education, confidence, and support by enhancing a sense of control

and problem-solving skills in an informal setting for African-American caregiving daughters.

**Description of interventions.** The four articles in this category presented interventions that all share the same goal of increasing a caregiver's capabilities and support network, while decreasing the isolation of the caregiving role. Yet their approaches differed, incorporating a variety of means to create community and enhance knowledge. Sistler & Washington (1999) reported that the support group that focused on caregiver spirituality used "The Serenity Prayer" from Alcoholics Anonymous as a theme for the intervention. It developed a foundation for discussing a caregiver's sense of control; how it had been challenged, lost, or altered in caring for a loved one with AD. "The Serenity Prayer" created a spiritual approach for the support group in which to talk about the negative and positive experiences of caregiving. Sistler & Washington (1999) also reported on the incorporation of a theme of problem solving with the "DAD" method that was described as "defining the problem, assessing the options, and doing something about the decision" (p. 55). Spiritual aspects permeated the support group's curriculum on problem solving as well as the educational components of AD, and the challenges of self-care, communication, and behavior problems. Waelde et al. (2004) also focused on a spiritual approach but with utilizing a program of meditation and yoga. Instead of a focus on acceptance, enhancing control, and increasing problem-solving skills, the "Inner Resources" intervention focused on stress reduction. According to Waelde et al. (2004), a distinct emphasis was "placed on the meditative practice of surrender as an affect management technique to address the depression and anxiety associated with the stresses of caregiving" (p. 679). Participants were also given a log to record in-home sessions and

a manual to guide their yoga practice away from the group. Waelde et al. (2004) reported that the weekly sessions consisted of a period of meditation, a teaching time on yoga and mediation practices, and then discussion of how to apply these methods into daily life of AD-caregiving.

In comparison, Kally et al. (2014) and Morano & Bravo (2002) reported greater psychoeducational intent, with more formal times for education to instruct on AD progression, behaviors, community supports, and coping. Kally et al. (2014) sought to provide "family and informal caregivers with the basic knowledge, skills, and attitudes needed to carry out their role in caring for a family member with Alzheimer's disease, and to effectively manage the increasing stress involved in this role over time" (p. 683). The psychoeducational model described by Morano & Bravo (2002) was similar to SCP but with inclusion of an elder law attorney, a representative from the Alzheimer's Association, and discussion of assistance programs and institutionalization options. However, Morano & Bravo's (2002) intervention was unique in its compacted presentation over five consecutive days. They reported that the last day and the impending end of the short-lived group served as a catalyst to discuss grief and loss, and the importance of creating and strengthening a caregiver's support system. Although the four articles in this category varied in approach, all demonstrated effective interventional impact on both African-American and Hispanic caregivers.

**Reported Outcomes.** Kally et al. (2014) and Waelde et al. (2004) reported a statistically significant decrease of depressive symptoms. No difference was reported between the participants in the yoga/meditation and SCP groups in the measures of depression. In addition, Kally et al. (2014) reported that the SCP results were sustained

by both African-American and Hispanic group members one year after the intervention. Waelde et al. (2004) reported a significant reduction in anxiety within a month of the completion of the yoga and meditation program. Sistler & Washington (1999) demonstrated an increase in happiness following participation in the caregiver support group.

Kally et al. (2014) and Sistler & Washington (1999) reported a statistically significant increase in caregiver competence in all ethnic and racial groups. Morano & Bravo (2002) reported that caregiver knowledge increased in understanding and management of AD. A similar finding of improvement was demonstrated in measures of self-efficacy in the caregiving role in Waelde et al.'s (2004) research, reflecting competency in dealing with distressing events and negative thoughts in caregiving. In spite of this finding by Waelde et al. (2004), caregiver burden was unaffected by the intervention. However, according to Waelde et al. (2004), over 70% of participants "reported feeling 'somewhat better' or 'much better' than before the study in terms of activity level, physical pain, sleep problems, depression, frustration, energy level, and overall well-being" one month following the intervention (p. 683). Continuing, Waelde et al. (2004) reported that over 90% indicated all the yoga, breathing, and meditation interventions with the exception of the taped yoga for use at home as "moderately" or more helpful. Morano & Bravo (2002) utilized an exit interview that demonstrated satisfaction with the psychoeducational program, with a fulfillment of personal needs from the five-day intervention. In addition, the participants in Morano & Bravo (2002) "indicated that the program design of including formal presentation, group discussions,

and time for informal discussions among the caregivers was particularly helpful and informative" (p. 125).

Kally et al. (2014) reported two measurements unique to the SCP intervention. Management of meaning and management of situation demonstrated statistically significant improvement in African-American and Hispanic experimental groups. These measures indicated use of positive re-framing, reducing expectations, and management of the care recipient's needs and behaviors. In addition, Kally et al. (2014) reported that both management of meaning and management of situation demonstrated maintenance of results from six to 12 months post intervention. Overall, the psychoeducational and support group interventions showed effective and beneficial impacts for the caregiver participants.

# **Cultural Tailoring of Interventions**

Cultural tailoring, the intention to develop interventions that integrate and accommodate cultural characteristics, was reported as used in ten out of the twelve articles within this systematic review. Cultural tailoring was integrated by Burgio et al. (2003) following clinical observation that found specifically identified in-home interventions as more beneficial to African-Americans than group-based. Burgio et al. (2003) reported shaping their program in response to that observation. Sistler & Washington's (1999) research also reflected this experience and reported a lack of and resistance to support group participation by African-American caregivers. They responded by limiting their small group intervention to African-American daughters who were caregivers for an AD-affected parent. Sistler & Washinton's (1999) role-defined

and racially homogeneous group allowed for the caregivers to share in the honor of their role, yet also receive assistance and support in a safe environment.

**Informal vs. formal programs.** Morano & Bravo (2002) reported that the original cultural tailoring for their psychoeducational intervention did not adequately meet the desires of their Hispanic participants. At the initial session of the psychoeducational program, the researchers found that adhering to a tight schedule for speakers, formally lead discussion, and presentations was problematic. Instead, group participants sought out and valued the informal times for connection through socialization. Morano & Bravo (2002) described their observations; "the socialization time was as important to the caregivers as the educational time; therefore, adequate socialization time had to be built into each day" (p. 125). In an attempt to improve attrition rates in both condition groups, Gonyea et al. (2014) designed the groups to be "small, informal, and highly interactive, involving a great deal of chatting" (p. 4). In addition, the leaders were intentional to arrive early and remain late after each weekly session, allowing unstructured time for conversation and support. This was reported as an attempt to convey authentic warmth and concern, staff characteristics that were not discussed in the rest of the reviewed articles. Gallagher & Thompson et al. (2003) reported opening each group with informal conversation and including a graduation celebration at the end of the intervention.

**Bilingual & bicultural staff.** The use of bilingual and bicultural staff were reported by Belle et al. (2006), Burgio et al. (2003), Gallagher-Thompson et al. (2001), Gallagher-Thompson et al. (2003), Gallagher-Thompson et al. (2008), and Waelde et al. (2004). Gonyea et al. (2014) also demonstrated this use of bilingual and bicultural staff

in addition to creating a "culturally sensitive framework." They reported that by incorporating beliefs, values, and life experiences of Hispanic families, the intervention was tailored to address relevant issues that affected the AD-caregiver role. Because Hispanic families often encountered frustration with waiting lists and disrespect from community agencies, Gonyea et al. (2014) also designed their research so that all participants, whether in the experimental or control group, engaged in some form of a psychoeducational intervention. This was reported to serve as a means of valuing all participants. Belle et al. (2006) utilized staff training for both cultural sensitivity and dealing with racism within the medical community to better advocate for their African-American group participants.

#### Discussion

This systematic literature review described research that focuses on AfricanAmerican and Hispanic AD caregivers in order to identify the most effective
interventions as reported by these distinct communities. The twelve articles that were
used as data in this study reveal three categories of effective interventions: In-home,
CBT-based, and support group interventions. Cultural tailoring was integrated in the
majority of the articles, thus creating a fourth category of findings pertinent to this study.
The data show similarities as well as differences, and suggest implications for policy,
research, and practice. Some of the most pertinent findings were the observations
concerning cultural tailoring of the caregiver interventions.

Culturally modifying caregiver interventions were incorporated into 10 out of the twelve articles reviewed. The two that did not accommodate for race, ethnicity, or culture still reported a beneficial effect similar to the others that designed research with a distinct

community in mind (Elliott et al., 2010; Gitlin et al., 2003). Cultural tailoring varied along a spectrum from basic language translation of program and presentation materials, to intentional and expansive modifications. Inclusion of informal times of conversation, celebrations, and specific needs of African-American and Hispanic families were also addressed. Some went even further, using ethnic or racial group characteristics as part of developing the intervention. Generally, the reviewed articles demonstrated that cultural tailoring was advisable, yet did not address the complex issues of cross-cultural practice, language constraints, and the attributes of a culturally sensitive staff. However, the cultural adaptations reflected the strength-based approach of cross-cultural practice; serving from a perspective of respect and curiosity about the strengths and resilience of another culture. Since the in-home, CBT, and support group interventions indicated an overall benefit for the African-American and Hispanic caregivers, social workers should integrate these practices along with cultural tailoring. Responding with cultural sensitivity and awareness, empathy and a willingness to alter programs as needed creates an effective caregiver intervention.

The findings reveal that listening and responding to participant feedback was beneficial to a program's outcomes. Flexibility in approach and design allows for the needed aspects of the intervention, as perceived by the participants, to evolve and create impact. A social worker's willingness and intent to utilize caregiver insight to shape and affect a program increases efficacy and benefit. Overall, the findings indicate a need for informal social support that can be facilitated through formal settings, whether through interventions of structured in-home sessions or group education and support.

With the emphasis on culturally tailoring interventions, it was striking to see an overall lack of difference between ethnic and racial groups responses to the different interventions. The research articles indicated that with efforts to accommodate, appreciate, and respond to race and ethnicity, beneficial outcomes generally result. It leads to a question that if the research lacked cultural tailoring, would the results have been as consistent between African-American, Hispanic, and other groups? What about barriers to group participation such as lack of caregiver time, transportation issues, or respite care for the AD-affected individual? What efforts can be made to make support not only culturally sensitive but also accessible with the demands of caregiving? According to Gallagher-Thompson (2008), "there was minimal evidence of an ethnicity or ethnicity by treatment effect, indicating that there was little justification for evaluating the two ethnic groups separately when testing the primary hypotheses" (p. 292). Yet, racial and ethnic differences remain in values, needs, and appraisal of caregiving. Even though caregiving interventions may look different and range in focus, they share similar intentions for beneficial outcomes.

Another similarity emerged from the data, yet was not overtly identified. The importance of normalization for AD-caregivers was never clearly pointed out, but was implicit in the education about AD, its resulting behaviors, and inherent caregiving challenges. Since normalization may reduce the sense of isolation in the role of caregiving and lessen the emotional burden, it is a powerful tool for intervention. By educating on the typical emotional and behavioral responses that can develop from ongoing, unpredictable, and stressful demands of providing AD care, the power of such emotions can be reframed and lessened. Through normalization, healthy expectations of

the role can be established, needs for help and respite acknowledged, and connections to others within the caregiving community may be formed. The groups and in-home interventions all challenged the isolation that caregivers can feel when dealing with an all-encompassing role. For African-American and Hispanic caregivers, there was an apparent benefit to normalizing interventions that approached them individually, in their unique situations, appraisal of challenge, and context, whether in the home or community setting.

The overall lack of literature on culturally diverse caregivers points to a bias within research on aging adults. An incorrect assumption seems to exist that aging lessens the impact of race, ethnicity, and culture. Integrating an individual's unique source of resilience is an integral part of social work practice, thus incorporating cultural origins of strength, wisdom, and connection should not be ignored as an aspect of research. Age does not diminish race and ethnicity, but instead refines their value and meaning. Social work practice and research need to emphasize cultural diversity, especially in areas such as caregiving where strength and resilience are demonstrated.

### **Implications for Policy**

This study suggests a need for increased funding for research and interventions in diverse communities. This need is apparent by the lack of research literature (Table 1.) in comparison to those who do not include communities of color in their sample populations. The lack of research on African-American and Hispanic AD caregiver interventions contributes to a narrow field of resources for cross-cultural social work practice. With greater funding for research within racially and culturally diverse AD communities, further analysis of effective interventions would be possible, expanding

possibilities for community and home-based programs. More funding would allow for continuing the current research on African-American and Hispanic AD caregivers, focusing on cultural differences and similarities within an ethnic group. In addition, a further exploration of adult children and spouses or partners providing care is called for within communities of color.

The difficulties of AD caregiving in and of itself prevents caregivers from utilizing support resources that could assist or alleviate some burdens of the role. The needs of caregivers vary, depending on the relationship with the care recipient. The challenges of an older spouse or partner providing care will differ from an adult child who is the work force and raising children of their own. Yet for both types of caregivers, economic and job stability affects caregiving abilities. Policy implications that emerge from this study address the need to increase the economic stability for caregivers of ADaffected loved ones. Individuals in the workplace should not be punished for caregiving, yet job insecurity, lost wages due time away from work, and lack of eligibility for FMLA (Family Medical Leave Act) benefits create additional stress to an already burdensome role. First, adult children who are providing care for a parent should have expanded social security coverage. The Social Security Caregiver Credit Act (H.R. 5024) would create greater economic security for a caregiver's retirement years by crediting up to five years of work when providing unpaid care for a relative (Library of Congress, 2014). Creating such a credit recognizes the value of caregiving and the economic sacrifices that families endure. It would even benefit lower-income families to a greater degree due to an income-based sliding scale that would enable proportionately larger credits to caregivers who earn less.

## **Implications for Future Research**

This research was influenced by the racial disparity within AD caregiver research. Thus, implications for future research are plentiful due to the ongoing need for social work to seek effective interventions that cross culture, race, and ethnicity. Yet, other implications also emerged from the findings. For example, the majority of the articles measured depression, with only two reporting on the impact of the intervention on anxiety. One showed no intervention effect on anxiety between the experimental and control group (Goyea et al., 2014) and the other measured a significant reduction with practice of yoga and meditation (Waelde et al., 2004). Depression and anxiety, even not at clinical levels, can often concurrently present in AD caregivers. Apprehensive expectation and worry can easily define a caregiver of an AD-affected loved one as they deal with pervasive and progressive decline. Anxiety may provide a caregiver a false sense of security in an attempt to reign in disorder or created structure in the midst of change. Thus, further research that specifically analyzes the impact of various caregiver interventions on anxiety could broaden the options of social work practice. Even though Roff et al. (2004) noted that African-American caregivers report less anxiety in comparison to other groups, this review's lack of findings on the condition calls for further inquiry for all racial and ethnic groups.

Correspondingly, research on CBT interventions with African-American caregivers of AD-affected loved ones was completely lacking in this review. Since the findings demonstrate benefits from for the Hispanic and Caucasian caregiving communities, a study with African-American participants in a CBT intervention is warranted. With cultural tailoring, this type of study could offer a comparison of an

approach that has shown effectiveness and give an alternative intervention for caregivers of color. Comparing CBT within an in-home program and a small group community based group could offer an even greater indication of effectiveness and best modes of practice for social work clinicians. Would CBT group interventions paired with an individualized at-home program allow for even greater benefit? Further exploration on the impact of culturally tailoring caregiver interventions could also offer better insight into how to best practice cross-culturally.

The paucity of research on communities of color creates vast opportunities for future research to expand the body of knowledge for social work. Studies on cross-cultural practice within geriatric social work are needed as a larger and increasingly diverse segment of the U.S. population ages. The findings of this review offer tangible ideas of how to culturally tailor a caregiver intervention for African-American and Hispanic AD caregivers, yet more research, education, and discussion is called for within cross-cultural practice. Is cultural sensitivity enough to facilitate beneficial outcomes when working cross-culturally? When are homogenous groups necessary and what fosters heterogeneous group cohesion?

### **Implications for Practice**

The effective demonstration of CBT in Hispanic groups suggests that social workers are able to utilize a wide range of interventions within this approach. CBT offers an evidence-based practice across many conditions, with this review indicating beneficial outcomes for AD caregivers in both in-home and group settings. The cognitive and behavioral approach can be offered to different racial and ethnic groups with an

educational focus to downplay the therapeutic aspect so as to avoid the stigma of psychotherapy.

Although CBT was a substantial and obvious finding within this review, one implication for practice was notably absent in the literature. None of the articles in the review identified elder abuse or neglect as a possible issue with caregiving of ADaffected individuals. This is an issue that is often overlooked out of discomfort, fear, shame, or denial, so calls for acknowledgement to bring it to light. Caregiver interventions do not need to discuss elder abuse and neglect in an accusatory manner, but framed with options for community supports, connections, and skills to manage AD behaviors. Normalizing the complex and all-encompassing challenges of caregiving, and the possible anger, depression, or despair that can result need to be paired with tangible interventions that offer hope, concrete resources, and connections for ongoing support. Barriers to services for communities of color need to be addressed within these interventions, making them as culturally accessible as possible. Adult Day Health and other respite programs, in-home care, housekeeping services, and caregiver skill training are all methods to bolster caregiving and prevent abuse. The lack of reference to the issue of elder abuse or neglect in the reviewed articles serves as a catalyst to social work practice. Elder abuse and neglect exists, thus social work must not overlook this issue out of fear of upsetting caregivers only to perpetuate the silence around this troubling reality. Social work practice can work with families to further strengthen and support goals to honor and protect elders with AD.

The use of cultural tailoring in the majority of the research studies in this review offer significant implications for practice. Seeking cultural inclusion into social work

practice only strengthens interventions and responds to AD caregivers' actual needs, not those perhaps perceived from a different cultural perspective. The implications for cultural sensitivity pervade all of social work practice and extend beyond learning from and serving African-American and Hispanic caregivers. Utilizing faith communities and Interprofessional organizations allow for possible bicultural and bilingual staff to benefit caregivers, their AD-affected loved ones, families, and friends. Expanding cross-cultural social work practice, as indicated by this review, involves creatively responding to the responses of caregivers, altering interventions for maximum effectiveness.

Social workers, especially those working cross-culturally, need to take risks creating interventions for African-Americans and Hispanic AD caregivers and other ethnic and racial communities. Working from a willingness to learn and adapt in order to build an effective intervention is paramount. Cultural tailoring calls for such a willingness and perspective. It takes courage to listen to the proverbial "language of the heart" that is culturally based and deep with meaning. For AD caregivers, the opportunity to not only learn within the context of their unique values, experiences, and traditions, but to have these shape the intervention itself has the potential to build an effective and powerful means of support. Social workers must be responsive and daring, advocating for a homogeneous group if necessary, acting from respectful curiosity to ask questions, and maintain a flexible and strengths-based attitude to be open to wisdom and insight.

Serving from a reflective informed awareness allows social workers to realize what they know and what they need to learn, empowering them to offer the most effective and respectful intervention.

As rates of Alzheimer's disease increase, so do the numbers of caregivers. Social workers need to be prepared to cross-culturally support caregivers, despite the racial and ethnic disparities of research on effective interventions. Cross-cultural practice can be enhanced by informed and responsive tailoring of interventions specific to a unique group of caregivers. Through offering formal educational opportunities, informal social connections can be fostered and developed. With this systematic review's identification of effective interventions with African-American and Hispanic caregivers, social workers are more equipped to foster and facilitate support in a variety of ways. By offering culturally sensitive interventions, caregivers are honored, empowered, affirmed, and equipped to continue in a role that is challenging yet of inordinate value and worth.

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# Appendix

Literature Search Terms and Number of Identified Articles

Table 1.

	Search Engines/Data Bases & Number of Articles Identified			
Search Terms Alzheim* & caregiv*	PubMed 4219	EBSCO: Social Work Abstracts & Soc Index Full Text 755	PsycINFO 1795	
Alzheim* & caregiv* & African American or Black or Hispanic or Latino	162	95	121	
Alzheim* & caregiv* & social work & intervention* or strategy* or action*	61	49	45	
Alzheim* & caregiv* & social work & intervention* or strategy* or action* & African American or Black or Hispanic or Latino	11	14	10	

<sup>\*=</sup>Truncated to broaden search

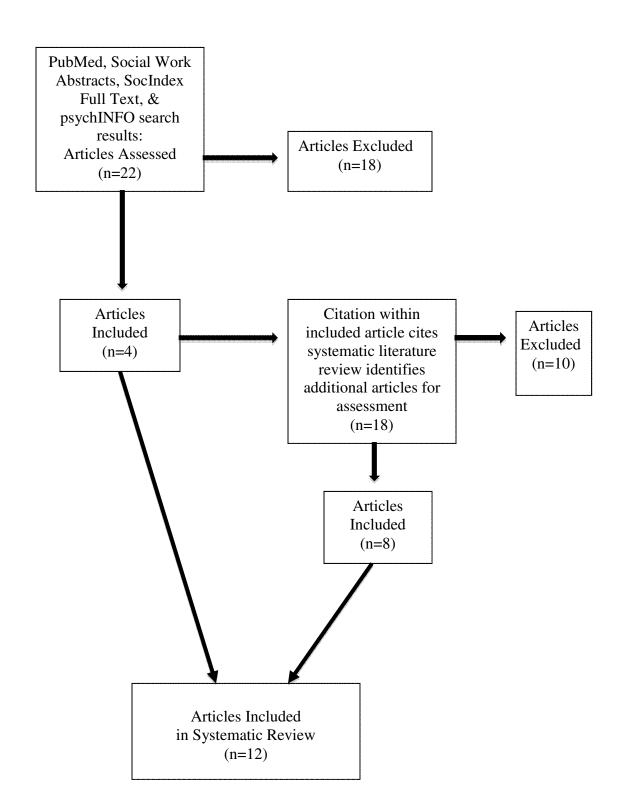


Figure 1. Flow Chart of Article Inclusion

#### Table 2.

## Systematic Literature Review Reference List

Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., . . . (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. Annals of Internal Medicine, 145(10), 727-738. doi:145/10/727 [pii]

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Kally, Z., Cote, S. D., Gonzalez, J., Villarruel, M., Cherry, D. L., Howland, S., . . . Hepburn, K. (2014). The savvy caregiver program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. Journal of Gerontological Social Work, 57(6-7), 681-693. doi:10.1080/01634372.2013.850584

Morano, C. L. & B., M. (2002). A psychoeducational model for Hispanic Alzheimer's disease caregivers. The Gerontologist, 42(1), 122-126.

Sistler, A., & Washington, K. S. (1999). Serenity for African American caregivers. Social Work with Groups, 22(1), 49-62.

Waelde, L. C., Thompson, L., & Gallagher-Thompson, D. (2004). A pilot study of a yoga and meditation intervention for dementia caregiver stress. Journal of Clinical Psychology, 60(6), 677-687. doi:10.1002/jclp.10259 [doi]

Author/ Article	Population/ Sample	Research Question	Concepts/ Variables	Research Design	Data Analysis	Results/ Findings	Discussion/ Implications	
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Figure 2. Article Analysis Example

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Figure 3. Second Reading Notes