A Critical Examination of Diversity in Caregiving: Care Provision for African Americans with Dementia

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Abstract

Many African-Americans affected by Alzheimer's disease, a common neurodegenerative form of dementia, lack access to Speech-Language Pathologists despite the higher incidence of 14% to nearly 100% in this underserved population (Alzheimer's Association, 2003). The aforementioned issue is reflective in Communication Disorders literature about caregiving for dementia patients because the research tends to focus exclusively on Caucasian Americans. To investigate how African-Americans receive care for Alzheimer's disease, this study considers four major factors: sociocultural demographics of these patients, socioeconomic and cultural background of caregivers, contexts and methods of caregiving, as well as medical knowledge about the nature of dementia and effective caregiving approaches. This article suggests that through the work of Speech-Language Pathologists and other health practitioners, careful clinical considerations of cultural differences and further research focusing solely on African-Americans, can combat the differential access to services and treatment.

Introduction

Alzheimer's disease is the most common form of dementia and is expected to dramatically increase over the next half century (Alzheimer's Association, 2003; Cloutterbuck & Mahoney, 2003; Waites, 2009; Gaskin et. al, 2013). Although Speech-Language Pathologists play a major role in rehabilitating these patients, many populations lack access to these caregivers. Consequently, few studies about underserved populations affected by Alzheimer's disease exist in the field of Communication Disorders. In particular, older African-Americans are on fixed incomes, which creates many barriers to even basic medical care, and especially specialty services such as speech therapy. Given that census projections indicate the aging population of African-Americans approximately quadrupling by 2050, their access to treatment options should be more closely examined by health practitioners. This demographic will be susceptible to developing Alzheimer's due to a number of biological, social, economic, and environmental factors (Dilworth-Anderson et. al, 2002; Rovner et. al, 2012/2013). Therefore, this study will investigate family caregiving practices for African-Americans with Alzheimer's disease, emphasize the social and economic issues in caregiving for African-Americans, and offer suggestions to improve the caregiving services for this underserved population.

Significance of Study

In the US, African Americans are two to three times more likely to develop Alzheimer's disease than those from Non-Hispanic Caucasian backgrounds. As of last year, more than 20% of African-Americans were identified as living with the disorder (Gaskin et. al, 2013), and 13% of the care was being provided in the family home context (apa.org/pi/about/publications/caregivers/faq/statistics.aspx). Clinical Speech-Language Pathologists are vital members in the healthcare team for patients with dementia since their services can include creating interventions and memory tools to retain cognition for a longer period (Sander et. al, 2007), 'communication training' to reduce miscommunication in the caregiving relationship (Mason-Baughman & Lander, 2012; Watson et al., 2013), and rehabilitating feeding and swallowing once these functions are impaired during end-stage of the disease. However, most of Speech-Language Pathologists' care provision will be provided in an institutional setting for older adults. This unknowingly excludes cultural groups, like African-Americans, who are already faced with other social and economic inequalities from receiving appropriate restorative care (Gaskin et. al, 2013).

Few studies examine the caregiving dynamics in the African-American population with Alzheimer's disease, unless it is a comparative study with Caucasian-Americans or other ethnic minority groups (Lawton et. al, 1992) – (e.g., Ripich et. al, 1997; Hinton et. al, 2005; Belle et. al, 2006). This could be solely due to the lack of African-Americans participating in dementia research or an inherent longstanding racial bias in medical care (Ballard et. al, 1993; Weitzman & Levkoff, 2000; Cloutterback & Mahoney, 2003). Of those studies, there had been consideration given to cultural differences and values, but not much afterthought for incorporating this scholarship into the reformation of healthcare with an interdisciplinary framework. Since there are limited studies actually discussing the ethnography in care practices for African-American patients with Alzheimer's, this becomes a call for concern and must be understood with "social, medical, and political" perspectives to better understand the equivocal underpinnings at work (Naue & Kroll, 2008).

Research Questions

The intent of this research article is to provide answers to the following questions: 1) How do African-Americans in urban areas receive care for Alzheimer's disease? 2) What are African American caregiver and care recipients' understanding of dementia? 3) How does power and knowledge influence caregiving practices for African-Americans with Alzheimer's disease? It is hypothesized that first, African-Americans receive inadequate medical services thus making caregiving resources limited; secondly, African-Americans' interpretation of dementia is misinformed due to health illiteracy, lack of proper insurance, and socioeconomic status; and lastly that medical and allied health discourse has the power to determine 'appropriate' care practices.

Theoretical Framework

"*Caregiving is one of the fundamental building stones in our world but it is frequently camouflaged*" says Dr. Arthur Kleinman, a psychiatrist at Harvard University, in an interview discussing his experience as a caregiver for his wife with dementia. Due to the nature of dementia (i.e., memory loss, issues with daily living, cognitive decline) and symptoms of

Alzheimer's disease in particular, individuals with dementia will require assistance from a caregiver. Caregiving, as Kleinman defines more in-depth, is "a foundational component of moral experience… envisioned as an existential quality of what it is to be a human being. We give care as part of the flow of everyday lived values and emotions that make up moral experience" (Kleinman, 2010). He proposes prominent ways to shape the culture of caregiving and views cultural systems as an impact on the treatment of bodies, which thus influence the perceptions of health and wellness and human conceptions of medical normality, in both the practitioner and the patient (Kleinman, 1976; Kleinman & van der Geest, 2009; Kleinman, 2010). Kleinman draws upon social logician Michael Foucault's conception of biopower, the interaction of knowledge and power, to keep the systematic nature of society in place through discourse. Foucault argues that, in this society, life has two aspects, population regulation and disciplining individuals (White, 2009). Essentially, individual bodies need to be controlled on the inside and outwardly characterized, which requires the social inaction of "disease" categories (White, 2009). Therefore, the staple of medical discourse and understanding regarding caregiving will mirror the fundamental conventions of the society that yields it (White, 2009). Kleinman has contributed ample medical anthropological literature drawing from these concepts to provide a new outlook and thought process for medical professionals. Overall, his views on caregiving are much more humanistic in nature and less discriminatory than the current U.S. medicalization of caregiving (Kleinman, 1976), and could be a great resource for the African-American culture given their often strong ties to religion, limited health care access, and resistance to specialized medical services.

Literature Review

Barriers to Dementia Research for African-Americans

Recruitment efforts for African-Americans with Alzheimer's disease to join research studies have been extremely difficult over the years (Ballard et. al, 1993; Weitzman & Levkoff, 2000). There is a lack of adequate research on how dementia and Alzheimer's disease impacts African-American patients singularly, despite the fact that this disease is much more prevalent in African-Americans than it is in Caucasian-Americans (Rovner et. al, 2013). The 1993 CERAD study utilized different efforts, such as simple educational brochures and posing a call for more minority caregivers in medical facilities, to help combat the main barriers that often leave African-Americans without proper treatment of the disorder. These main barriers included difficulties with transportation, educational level, economic / financial constraints, perception of inaccessibility, and lack of rapport or cultural ties to the clinical staff. Also, physician referral was a big determinant in African-American patients actually receiving specialized care for dementia (Ballard et. al, 1993). Over twenty years later, and these same issues face the African-American community of dementia patients today (Ballard et. al, 1993).

Socio-Anthropological Views on Dementia

When an individual is diagnosed with dementia, it naturally changes that person's character, not only in their self-image, but also in the eyes of others. The identity change that occurs once diagnosed is permanent, and is frankly incomparable to the expected changes of identity over the lifespan (Naue & Kroll, 2008). So, family caregivers will begin using a medicalized outlook to scrutinize the person with dementia. In turn, this impacts the relationship between the individual deemed as 'demented' and the able-bodied because the caregiver will

better conceptualize the ups and downs that ensues as the disease progresses, but as a tradeoff, aid in the loss of the functional thought and independence of the individual (Naue & Kroll, 2008). Therefore, the medicalization and notion of disease have a strong influence on 'demented' individuals since it governs "interventions for and communication with demented persons" (Naue & Kroll, 2008).

African-Americans live in the culture of 'commonsense' as explanations for illness and disease, as do many other Americans (White, 2009). In short, these are socially constructed ideas, or ideologies, that disguise its true objective to marginalize groups in the 'minority' role (Naue & Kroll, 2008). This structural inequality continues to keep the aging bodied African-Americans in a position that they have been kept in for most of their life. Medical knowledge and practices are social endeavors, the result of conflicting groups defining the environment and its contents, and not the expected product of science or natural surroundings (White, 2009). Other social factors that shape medical practice are the actual doctor-patient relationship. White explains that doctors treat patients in ways that reflect the social standing of the patients. Therefore those of a lower class or status are seen for much shorter periods of time, than those of high social status. The social status of some older African-Americans inherently falls into these categories, their elder and minority statuses, in addition to a 'demented' status (Naue & Kroll, 2008). A sociological perspective is that prevailing social conditions have to be in place before one's ailment transforms into a serious disease; consequently, good social environments would harvest populations that are in good health, much further than medicalization of care would (White, 2009, p.39).

Power Relations in Caregiving for Dementia

Acknowledging the individual with dementia's decline in competence can be an extremely difficult task for the family caregiver, but it is one that is best supplemented with intervention (Dunham & Cannon, 2008; Watson et al., 2013). For example, burdens in the relationship can stem from problematic or resistant behavior to instructions on behalf of the care recipient (Watson et al., 2013). Proper medical knowledge about competence versus incompetence in dementia can provide family caregivers with a boost of confidence in taking overall control and making care decisions (Dunham & Cannon, 2008). Dunham and Cannon (2008) found that the caregiver's idea of power and control proceeded as the disease did. Thus it would be a struggle to capture a balance between control and preserving dignity of the patient (Dunham & Cannon, 2008).

Personhood and citizenship are two social lenses that consider humans in similar ways. When applied to dementia research, these lenses either examine dementia at an individual level (micro) or at a broader level (macro), but not specifically how the individual cases influence dementia in society (Bartlett & O'Connor, 2006). The application of personhood and citizenship in caregiving practices has the potential to increase the dementia patient's agency in socially constructed structures (Bartlett & O'Connor, 2006). The examination of these critical lenses together would expand dementia practice and research, as well as challenge healthcare professionals to reevaluate current practices, adopt innovative methods for better care services for the patients, and offer comfort for family caregivers (Bartlett & O'Connor, 2006; Chenoweth & Spencer, 1986).

Ethnic Minorities and Family Caregiving

A small number of research studies have reported that African-Americans and other minorities tend to standardize serious illnesses, like dementia, instead of acknowledging its severity (Hinton et. al, 2005). According to Hinton et. al (2005) expert clinical care acknowledges a patient and their family's understanding of a medical illness, including its source and nature (Kleinman, 1976; Hinton et. al, 2005). Hinton (2005) examined three different typologies (or explanatory models) used by family caregivers of ethnic minority origins to explain dementia, which are folk, biomedical, or mixed model. In brief, a folk model uses language to explain sickness through largely cultural and traditional experiences, whereas a biomedical model uses language to explain biological behaviors and functions as a disease (Kleinman, 1976; Hinton et. al, 2005). The latter is commonly used by medical professionals (Kleinman, 1976; Hinton et. al, 2005). The sample in Hinton's study revealed that 54% of caregivers believe that dementia [and particularly Alzheimer's disease] is the result of psychosocial stress or natural maturation processes (Hinton et. al, 2005). This belief exemplifies a mixed explanatory model, consisting of biomedical and folk components, despite the fact that older minority adults are not as accustomed to the biomedical model (Hinton et. al, 2005). Even further, these researchers found that minority caregivers and those with lower education held such mixed models of dementia more likely than Anglo-European Americans. These models strongly influence the type of care that the individual with dementia receives, since the family caregiver becomes the sole proprietor in this relationship.

The relationship between family caregiver and care recipient is usually one of significance, since family caregivers across all ethnicities tend to be female family members living with the ill (Lawton et. al, 1992; Hinton et. al, 2005; Dunham & Cannon, 2008; Bookman and Kimbrel, 2011). Dilworth-Anderson et. al (2002) found in their narrative of 59 peer-reviewed articles issued during 1980-2000, that African-American family caregivers conveyed stronger values of familial obligation when compared to Caucasian American family caregivers (Cloutterback & Mahoney, 2003). This fact attributes to why institutional placements and formal assistive care for minority adults occur at lesser rates than Caucasian Americans (Dilworth-Anderson et. al, 2002). In some cases, compliance with formal practices of medical care is viewed as a form of dehumanization of the care recipient (Dunham & Cannon, 2008).

Methods

To investigate the caregiving practices for African-Americans with Alzheimer's disease, this critical examination analyzed more than 20 articles and sources across various disciplines, which included gerontology, medical anthropology, nursing, communication disorders, sociology, and psychiatry. The scholarly search criteria entailed publishing dates that spanned across the last two decades, 1993 – 2013, and the following key terms - African-Americans, African-Americans and Alzheimer's disease, African-American caregivers, caregiving, dementia, dementia caregiving, biopower, biomedicine, explanatory models, and intergenerational relationships. Following the review of literature, reoccurring themes in the discourse regarding caregiving for African-Americans with Alzheimer's disease were considered and included demographics, socioeconomic status, sociocultural values of patients and caregivers, context of caregiving, and medical knowledge. These main considerations aligned with the earlier proposed research questions of this study.

Findings

African-Americans with Dementia:

The Demographic

In the United States, the percentage of African-Americans aged 65 years and older, has increased steadily since 1980 (Waites, 2009). Subsequently, this population is expected to reach 6.9 million by year 2030, and 8.6 million by year 2050 (Alzheimer's Association, 2003; Waites, 2009). When compared to non-Hispanic Whites, the occurrence, rate, and accumulative risk have all been deemed higher in African-American adults (Alzheimer's Association, 2003). For that reason, older African Americans are two to three times more likely to have Alzheimer's disease, with more than 20% of African-Americans currently living with the disorder (Gaskin et. al, 2013). What's more, African-Americans elders are living extensive lifespans, potentially aging across four or more generation of family members (Waites, 2009). African-Americans tend to be diagnosed at a later stage of Alzheimer's disease — limiting the effectiveness of treatments that depend upon early intervention (Alzheimer's Association, 2003).

Socioeconomic Status

Reports from the U.S. Administration on Aging show that African-Americans aged 65 years and older, who served as leaders of their households, held a median income of $35,025 in 2008 (Administration on Aging, 2010). Older African-Americans living on such low and fixed incomes typically have access to governmentally funded services, such as social security (SSI), pensions, and Medicare (Bookman and Kimbrel, 2011). This form of economic support, although beneficial to many lives, faces prominent financial deficits (Bookman and Kimbrel, 2011). For this reason, African-American elders in this demographic are not permitted access to services which allow them to age in their homes comfortably or exclusively in institutional care (Bookman and Kimbrel, 2011).

African-American Caregivers for Dementia:

Who Cares? : Intergenerational Relationships

According to the American Psychological Association (apa.org/pi/about/publications/ caregivers/faq/statistics.aspx), 65.7 million people serve as family caregivers. Of that population, 13% are African-American. Family caregivers provide assistance in many phases of dementia care, including emotional support, medication management, as well as aid with activities of daily living, such as toileting, bathing, or eating (Gallagher-Thompson, 2013)**.** In addition, these caregivers are not only providing care for the individual with dementia but they are also balancing care for younger generations, careers, and other personal relationships (Bookman and Kimbrel, 2011).   Despite the multitude of responsibilities, African-American caregivers take pride in the opportunity to care for the demented, because caregiving is seen as a "rewarding traditional family value" (Cloutterback & Mahoney, 2003; Gallagher-Thompson, 2013).

Furthermore, the familial responsibility of caring for the ill family member is not only the sole responsibility of the primary caregiver, but a shared duty of "extended" family members and close friends (Dilworth-Anderson et. al, 2002; Cloutterback & Mahoney, 2003; Bookman and Kimbrel, 2011). This reflects the intergenerational social networks of "kinship" formulated

throughout many years, amongst elder African-Americans and their strong ties to blood-relatives and trusted non-members of their family (Waites, 2009).

Contexts of Caregiving:

Urban Areas

Family caregiving in the home context is not limited to African-Americans as a minority group, but it has played a longstanding role in their culture of care (Weitzman & Levkoff, 2000; Rovner et. al, 2013). One African American caregiver in Levkoff's study (1993) remarked "black people don't put their old people in homes" which demonstrates the relationship between culture and home care provision (Weitzman & Levkoff, 2000). One article reports that the delivery of health care for African-Americans is substandard, even after extraneous factors like socioeconomic status and health insurance brand were controlled for (Briggs, 2005).

Sociocultural Values: Religion and Health

Other informal forms of support for family caregiving characterized in the African-American culture are religious prayer and faith in "God's Will", or God's power to determine life's outcomes (Dilworth-Anderson et. al, 2002; Waites, 2009; Rovner et. al, 2013). Rovner et. al (2013) found that African-Americans commonly associate religion and spirituality to their opinions about wellness and disease (Waites, 2009). Older African-Americans will especially opt to use religion as a resource to supplement the psychosocial health issues that they have acquired from the mistrust of the U.S. healthcare system (e.g., Tuskegee Airmen experiments) (Weitzman & Levkoff, 2000). Haley (2013) states that elderly African-Americans are less likely to refuse "life-sustaining treatment" even when quality of life is meager during end-stage. To a greater extent, the social stigma associated with dementia has even kept some older African-Americans from disclosing their dementia status to fellow church members (Weitzman & Levkoff, 2000).

Discussion

Dementia is discussed across a number of academic disciplines ranging from nursing to communication disorders to political science to medical anthropology. However, search results do not yield a formal discussion about the caregiving practices of African-Americans exclusively, and/or in the family context when dealing with dementia. The findings of this study show that older African-Americans living with Alzheimer's disease make up 20% of the United States population; their family caregivers subsequently account for 13% of the population. In other words, the majority of care being provided to African-American adults with dementia, ages 65 and older, are being provided by a member of their family and in a household. The power of "family" and "kinship" is so influential in the African-American community that it is alarming that more academic disciplines continue to overlook its role and construct. Researchers agree that African-Americans and their families are the most affected group by Alzheimer's disease within the United States, so the urgency to help delineate this disorder in this population is crucial. The limitations of this study focused on the lives of elders in lower-income, urban areas rather than rural areas. These findings are not subjective across all African-Americans since this cultural group varies across education level, literacy, and socioeconomic status.

Future Research

Since the home is usually a context for dementia care, it would be beneficial to see if there are ways to improve the household beginning with the family, before outside care providers (e.g. home health aides, geriatric nurses, and speech language pathologists) are brought in. Such incorporation may improve the type of care that these professionals will have to provide, the relationship of the family caregiver-care recipient, and the character of the ill throughout their disease progression (Kleinman, 1976). Accordingly, careful considerations should be given to gender roles in caregiving since research reflects a common caregiver profile, which is a female unwed daughter. This commonality could possibly influence the care for the individual with dementia depending on the prior relationship – a mother-daughter versus father-daughter relationship. So exploring these family roles can be useful in examining if caregiving associations, like burden or uplifts, are increased or decreased depending on the gender roles in the caregiving relationship. Also, the support to the primary caregiver should be examined further, because it can show what type of support is ideal in the home arena for African-Americans with dementia.

Moreover, general clinical measurements would be ideal across cultures for the sake of time efficiency, but the quality of services would present itself not useful if cultural differences are not recognized. The literature shows that caregiving is a traditional value in the African-American community which demonstrates respect and service to the elder kin, who is an important figure. African-Americans either due to socioeconomic status, belief systems, or misdiagnosis are still less likely to seek general medical treatment. Rather, the elders that are deemed demented or display these characteristics are assisted by family members and close friends who have developed a bond that goes beyond that of a professional.

Finally, communication styles of the African-American caregiver-care recipient relationship are important for clinicians to understand. African-Americans have many verbal / non-verbal cues, phrases, and gestures that signify meaningful ideas within their cultural group, communities, and homes. An outsider should first ask these things rather than assume what is normal or abnormal for a dementia patient, out of respect for the patient and their family. General signs are true, but the comorbidity of other health issues, social and environmental factors, often play a major role in the lives of these patients and even their caregivers. Therefore, suggestions for future research include empirical and ethnographic studies based on this critical interpretation.

Conclusion

African-Americans adults, aged 65 years and older, are at higher risks for developing Alzheimer's disease and other related dementia illnesses. In the African-American home context, family caregiving provides an intergenerational and multigenerational support system of caregivers that is an aid in the patient's health care team. Clinicians need to encourage cultural competence by respecting the nature of such intertwined communities.

The lack of research that focuses on this population hinders future professionals and experts alike from truly understanding the importance in difference. Difference does not equate to wrong, but it does require a different way of doing things to ensure the best care possible to all human beings. Starting with the facts, more recruitment efforts, and raising awareness can all be starting points to help this group better understand the disease, how to handle it, what living with

the disorder entails, the prevalence, prevention efforts, and what resources, services, and strategies are available to help them through such a treacherous process.

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